The Experiences of Fathers in a Family Integrated Care (FICare) Program

By

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ABSTRACT

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OBJECTIVE: To describe the experiences of fathers of infants born at 32⁰⁷ to 34⁶⁷ weeks’ gestational age admitted to a Level II neonatal intensive care unit (NICU) and enrolled in a randomized controlled trial evaluating the Alberta Family Integrated Care (FiCare) program.

METHODS: A descriptive phenomenology study using semi-structured interviews with 13 fathers and 24 father-written journal entries.

FINDINGS: Fifteen themes were generated by triangulating data from interviews and journals: mental preparation, fear of the unknown, reassurance of medical care, level of communication, identifying the fathers role, parenting with supervision, effect of medical staff, effective communication, physical environment, perceived health of infant, balancing life, teamwork through adversity, preparing for discharge home, post-NICU medical care, and relationship to child.

CONCLUSIONS: Fathers enrolled in the Alberta FiCare program attributed their level of confidence and positive NICU experience that continued post-discharge to the attention and the care they received at the bedside.
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# TABLE OF CONTENTS

<table>
<thead>
<tr>
<th>Section</th>
<th>Page Number</th>
</tr>
</thead>
<tbody>
<tr>
<td>ABSTRACT</td>
<td>ii</td>
</tr>
<tr>
<td>ACKNOWLEDGEMENTS</td>
<td>iii</td>
</tr>
<tr>
<td>TABLE OF CONTENTS</td>
<td>iv</td>
</tr>
<tr>
<td>LIST OF TABLES</td>
<td>vi</td>
</tr>
<tr>
<td>LIST OF FIGURES</td>
<td>vii</td>
</tr>
<tr>
<td>LIST OF APPENDICES</td>
<td>viii</td>
</tr>
<tr>
<td><strong>A. INTRODUCTION</strong></td>
<td></td>
</tr>
<tr>
<td>A1. The transition to fatherhood</td>
<td>1</td>
</tr>
<tr>
<td>A2. Fathers’ relationship with their children</td>
<td>3</td>
</tr>
<tr>
<td>A3. Effect of parenthood on partner relationships</td>
<td>5</td>
</tr>
<tr>
<td>A4. Fathers’ experience of normal and traumatic childbirth</td>
<td>7</td>
</tr>
<tr>
<td>A5. The Neonatal Intensive Care Unit: The disruption of the normal transition to fatherhood</td>
<td>10</td>
</tr>
<tr>
<td>A6. Experiences of fathers post-discharge from the Neonatal Intensive Care Unit</td>
<td>11</td>
</tr>
<tr>
<td>A7. Interventions for fathers in the Neonatal Intensive Care Unit</td>
<td>12</td>
</tr>
<tr>
<td>A8. Family Integrated Care Programs in the Neonatal Intensive Care Unit</td>
<td>15</td>
</tr>
<tr>
<td><strong>B. RESEARCH QUESTION AND OBJECTIVES</strong></td>
<td>16</td>
</tr>
<tr>
<td><strong>C. RESEARCH DESIGN AND METHODS</strong></td>
<td>17</td>
</tr>
<tr>
<td>C1. Setting</td>
<td>17</td>
</tr>
</tbody>
</table>
C2. Participants 18
C3. Research procedure 20
C4. Data analysis 20
C5. Rigor 21
C6. Ethics 22
C7. Consent 22

D. FINDINGS 22
D1. Characteristics of participants 22
D2. Thematic Analysis 23

E. DISCUSSION 51

F. CONCLUSIONS 60

G. REFERENCES 62

H. APPENDICES 76
LIST OF TABLES

TABLE 1: Demographics of fathers who completed a semi-structured interview (N = 13)
LIST OF FIGURES

FIGURE 1: Example of the triangulation process of the semi-structured interviews with the journal entries

FIGURE 2: Thematic ‘map’ of analysis of the Pre-NICU experience for interviewed fathers

FIGURE 3: Thematic ‘map’ analysis of the Pre-NICU experience for journal entry fathers

FIGURE 4: Thematic ‘map’ analysis of the NICU experience for interviewed fathers

FIGURE 5: Thematic ‘map’ analysis of the NICU experience for journal entry fathers

FIGURE 6: Thematic ‘map’ analysis of the post-discharge from NICU experience for interviewed fathers

FIGURE 7: Thematic ‘map’ analysis of the post-discharge from the NICU experience for journal entry fathers
LIST OF APPENDICES

APPENDIX I: Demographic Data collection form

APPENDIX II: Interview Guide for Fathers of Moderate and Late Preterm Infants

APPENDIX III: Consolidated Criteria for Reporting Qualitative Studies (COREQ)

APPENDIX IV: Research Ethics Board Approval Documents

APPENDIX V: Consent Forms for Participants

APPENDIX VI: Tables of the Thematic Analysis of Fathers’ Experiences
A. INTRODUCTION

A1. The transition to fatherhood

The transition into family life occurs in developmental stages that begins during pregnancy and peaks during the first year of life. New roles must be learned, partner relationships change, and new relationships begin. Interviews of fathers in the antenatal period described their fear, excitement, and joy that began with the news of the pregnancy. In studies reviewing fathers’ antenatal experiences in relation to the care and to the support they received, many fathers described a lack of involvement in antenatal health care provision, of preparation received for the postnatal period and infant care, and of support beyond what was received by their partners. In particular, fathers felt excluded from antenatal classes and appointments because these were mother focused. Fathers were given little guidance about their role, and limited practical information, such as clinic phone numbers, and the timing of classes and appointments made fathers feel punished for working. Thus, fathers are disadvantaged even prior to the birth of their child.

Dissociating fathers from the antenatal experience can have profound effects postnatally. In a systematic review of qualitative studies from 1974 to 2016 that pertained to father-infant bonding and interventions that promoted father-infant bonding with infants younger than a year of age, 28 articles met the inclusion criteria. In these studies, fathers entered parenthood with the expectation of establishing an immediate bond with their newborns, but when they were not equipped with the skills to effectively bond, or lacked guidance during labor and birth, they developed feelings of frustration, resentment, and alienation. Fathers described a delayed onset of bonding to their infants from 6 weeks to 2 months postpartum as a result of their lack of
knowledge on child care. This lack of skill decreased their confidence and subsequently decreased the quality and the quantity of time spent with their infants. Fathers’ desire to be involved in child rearing and their gradual achievement of parenting skills as compared to mothers was demonstrated in other qualitative studies examining the experiences of fathers after childbirth. In a study of 44 couples in the United States surveys were used to examine self-efficacy at 4, 8, 12, and 16 weeks of age of a first child. Fathers reported significantly lower infant care self-efficacy than mothers and had delayed parental satisfaction. The reasons for this delay in parental satisfaction and achievement of parenting skills was attributed to the lack of opportunity and encouragement as many fathers returned to work 7 days after birth. Additionally, maternal satisfaction with birth outcomes and perception of spousal competence dictated fathers’ access to their infant with mothers seen as gatekeepers to their children. Fathers want to be involved with their infants from birth but lack the skills and knowledge to do so, which has limited their self-confidence and their parental satisfaction.

Interviews of first time fathers in the first year of their child’s life described the transition into fatherhood as overwhelming. Fathers had difficulties placing the baby in the center, struggled with the responsibility of balancing work and home, and had problems managing the changing relationship with their partner. This transition can have a profound impact on fathers’ mental health and well-being. Baldwin et al, 2018 synthesized 351 studies in a systematic review of fathers’ mental health and well-being in the first year after birth. In this review, fathers worried about being a ‘good father’. They often felt helpless and pushed out of their relationship with their partner struggling to find a role. The subsequent changes in their role increased their stress which manifested as tiredness, irritability, and frustration. Fathers felt unsupported and in search of father-friendly resources and services to support their mental health.
and wellbeing. Overall, a positive aspect of new fatherhood was the rewarding experience that came from being involved with their child and bonding with them; those who recognized the need to change and worked with their partners adjusted better to their new role. Understanding the struggles of fathers in this new role is paramount as it forms the basis for appreciating the difficulties that fathers face when placed in circumstances that disrupt the normal transition to parenthood such as the birth of a preterm infant. Complete consideration of the fathers’ experience beginning in the antenatal period and continuing postnatally is required in order to improve fathers’ transition to fatherhood.

A2. Fathers’ relationship with their children

Unsurprisingly, fathers have very different relationships and roles with their infants than mothers. Paternal involvement is the direct result of their accessibility to their children, their engagement in child care, and their demonstration of responsibility by providing for both the material and emotional needs of their children. Attachment develops in early infancy when there is a positive interaction between father and child. Fathers develop a heightened, arousing, and playful relationship with their infants, which complements the more quiet activities favored by mothers. This type of play has long-term implications for infant attachment and psychological security. Sarkadi et al, 2008 conducted a systematic review of 24 studies of paternal involvement on developmental outcomes in children. The authors concluded that regular engagement, involvement, or cohabitation by a father with his child resulted in positive outcomes including enhanced cognitive development and decreased behavioral and psychological problems. The studies included in this review were limited by not explicitly defining ‘paternal involvement or engagement,’ making them irreproducible and therefore they
did not provide clear guidelines on how to optimize fathers’ engagement in order to enhance their child’s development.

Defining ‘paternal involvement’ is important when considering its impact on infant development. In a large longitudinal prospective study of 10,440 children living in southwest England between 1991 to 1992, paternal involvement was measured on three factors: (1) fathers’ emotional response to their child, (2) their involvement in domestic, and childcare activities, and (3) their feelings of security in their role as a parent and partner.13 Fathers, interviewed at 8 weeks and 8 months, who were responsive to their child and felt secure in their role were more likely to have children with a lower adjusted odds of behavioral problems, as measured by the Strengths and Difficulties Questionnaire, at ages 9 and 11 years.13 These results were adjusted for parental age, level of education, socio-economic status (SES), employment status, and child’s age and gender.13 In a similar example of the effect of paternal involvement, a cohort study, using data from the Early Childhood Longitudinal Study, measured the motor and mental ability at 10 months and 2 years in 6,000 children with fathers who were involved during pregnancy and at the time of birth, as measured by eight father-reported items.17 Fathers’ involvement during pregnancy and childbirth more so than during infancy had a greater positive effect on the neurodevelopmental outcomes specifically of infants with medical risk such as prematurity and low birth weight.17 The strength of these two studies was that they showed a clear link between paternal involvement and its positive effect on the behavioral and developmental outcomes of children. Studies in the area of paternal involvement and infant development are limited by their lack of definition of ‘paternal involvement’ and by their datedness, because contemporary fathers are increasingly more involved in the care of their children. As well, the majority of studies involved primarily fathers of term infants and did not explore the effect of paternal involvement
in the preterm population.\textsuperscript{18} Future studies should be conducted to evaluate and to explore paternal involvement and its effects on the development of infants especially infants at high risk of adverse neurodevelopmental outcomes. With this knowledge future interventions could be developed to support fathers in their desire to engage with their child.

**A3. Effect of parenthood on partner relationships**

The birth of a child brings about many changes and, in particular, affects the relationship between the partners caring for that child. In general, couples experience increased conflict, spend less time together, and have decreased intimacy.\textsuperscript{19} In a longitudinal study of 218 couples and their self-reports of their relationships’ functioning following the birth of their first born child, parents showed a sudden deterioration of marital satisfaction, which persisted throughout the remaining 8 years of the study; whereas in couples without children, the deterioration occurred more gradually.\textsuperscript{20} These negative relationships risk affecting the parent-child relationship and the child long-term in their own relationships in what is called the spillover hypothesis: ‘the transfer of mood, affect, or behavior from one setting to the next’.\textsuperscript{21} The spillover hypothesis was examined in a cohort of 203 families with mothers and fathers of children between the ages of 8 and 16 years who completed daily diaries in regards to relationship quality, depressive symptoms, marital satisfaction, and parenting.\textsuperscript{21} Mothers and fathers who reported positive ratings of their marital quality were more likely to have higher ratings of parent-child relationship quality.\textsuperscript{21} An important moderator of marital satisfaction was the effect of parental depressive symptoms on marital quality and on parent-child relationship.\textsuperscript{21} Fathers reported poorer marital quality and father-child relationship quality when impacted by maternal depressive symptoms.\textsuperscript{21} Limitations to these studies, and an important area for future
research, are the mechanisms involved in these spillover relations and the modifiable risk factors that increase the risk for marriage deterioration and reduce the quality of the father-child relationship.

Supportive co-parenting moderates marital quality and marital conflict. Supportive co-parenting is the process by which each parent acknowledges the value and the contribution that the other parent provides to child-rearing and to the relationship. Supportive co-parenting is thought to reduce the impact of stress on a couple’s relationship and thereby improve marital quality and parent-child relationships. From the Fragile Families Child Well Being Study, 5,000 families were recruited between the years of 1998 and 2000 and interviewed across cities in the United States at birth, 1, 3, 5, and 9 years of age. A sample of 848 couples from this study were included if they were married/cohabiting, if they lived together for the first three years of their infants’ life, and their infant was their first child. They were evaluated across the first 3 years of parenthood for their relationship quality, parental stress, and supportive co-parenting as measured via self-report data and questionnaires. Fathers who were considered to be a supportive co-parent as assessed by the mother based on a validated questionnaire, significantly buffered the effects of parental stress and resulted in a higher relationship quality. These reports were supported by observations and questionnaires of marital satisfaction of 120 couples during pregnancy, 4 months, and 18 months post-birth of a first-born child. In these couples, mothers’ higher marital satisfaction at every time point was associated with higher family functioning at 18 months. These studies indicate that when fathers were considered to be successful co-parents by mothers and were trusted to take good care of their children and were well supported, the dyadic mother – father relationship furthered the parent-child relationship. The available research on marital quality and its resultant effect on parental-child quality were
limited to healthy term infants and cannot be generalized to families of preterm infants. The effect of the NICU experience on the partner relationship is not well elucidated with few studies that have explored this phenomenon. In the NICU, parents experience anxiety, stress, and role strain in addition to lack of privacy, and limited communication between each other. Unresolved parenting and spousal problems that develop in the NICU can continue beyond the NICU. Further inquiry into the effect of the NICU on the family unit and how that differs from families in which there is no disruption at birth, is necessary to elucidate their needs. Supporting fathers early in the perinatal and postnatal period may help mitigate the effects of deteriorating marital satisfaction and subsequently improve overall family functioning.

A4. Fathers’ experience of normal and traumatic childbirth

The attendance of fathers during childbirth was only encouraged since the 1970s and with the entrance of the father in the delivery room came the expectation of fathers as the support person to the woman giving birth and not as part of a couple delivering a child. In a qualitative study of 8 first-time fathers who experienced a normal uncomplicated delivery (unassisted by forceps, vacuum extraction, and caesarean section and mother and infant with no complications affecting their health) the major theme that emerged was that “delivery was a transformative experience”. Their expectations of delivery were different than reality, and as a result they felt vulnerable in a new situation, inadequate in their role as support person, powerless, and fearful. However, they welcomed involvement and information on how to best support their partners. Fathers reflected positively when they described their first encounter with their child as the greatest event in their life. The experience of fathers involved in an
uncomplicated delivery was positive; however, fathers struggled immediately with their new role, identifying their need for support.

Providing support to fathers requires an understanding of their needs. In a questionnaire of 72 fathers evaluating their desires during the birth process, fathers needed information about the procedures of birth, the medical/technical equipment involved in the birth process, and their involvement in labor and childbirth. Fathers with previous children, of higher SES, and who were married were less likely to express needs than first-time fathers, of lower educational level, or who were cohabiting with their partners. The reasons for these differences may be that fathers of higher education and SES were more likely to search for health information independently. Fathers might not have expressed needing emotional support as they felt that they should suppress their feelings and support their partners’ emotions. In a separate study from Sweden, 14 fathers were interviewed regarding the needs and the characteristics of professional support received during pregnancy. Fathers described wanting (1) pedagogically mediated communication and illustrations to help absorb information, (2) details on how to support women during childbirth including techniques to help with the process, and (3) practical information about parenthood including parental leave, insurance, and infant-related items they needed to purchase. They also described wanting access to other expectant parents to discuss their experiences, and perceived their increased importance and involvement when they received professional support. An understanding of these needs in normal childbirth is essential for understanding how these needs evolve in a complicated childbirth in order to better provide and evaluate support for fathers during pregnancy and delivery.

A normal childbirth provides a life-changing experience for fathers; however, when events surrounding a delivery change dramatically from the expected and routine plan, fathers
experience additional challenges. Etheridge et al, 2017 conducted qualitative interviews of 11 fathers who reported finding childbirth traumatic by describing the birth with either ‘fear, helplessness, or horror’. The complications experienced by fathers included and were not limited to assisted-deliveries/caesarean sections, hemorrhage, and prematurity. Fathers described a ‘rollercoaster of emotion’ because of the speed and the unexpectedness of events. They feared death of their partner or infant while helplessly watching the catastrophe unfold. They bore abandonment by staff, as they were given no explanation for the events. They had the positive experiences of birth disrupted by not being able to share with their partner and they felt torn amongst moving between mom and baby. The impact of this experience was profound as fathers felt disconnected for months post-birth, ruminating over the birth events, feeling more emotional than before, which impacted their work. Many fathers felt it was not right to feel as negatively affected as they did because the experience did not happen to them but to their partners and their children, often using avoidance to resolve these difficulties. Research in this area looking at the needs of fathers in both normal and complicated childbirth has highlighted that fathers require anticipatory guidance, preparation, communication, and support in their own right. There was limited research in fathers’ experience of normal and complicated childbirth and studies had reduced transferability, as fathers were either recruited from countries where social support was heavily available or were specific to fathers who sought help for their birth trauma experience. The studies were also not specific to fathers experiencing preterm birth. Further study in the area of fathers’ involvement in normal and traumatic childbirth can help develop strategies to improve their experience and ultimately shape their subsequent encounters with the health care system, their partners, and their infants.
A5. The Neonatal Intensive Care Unit: The disruption of the normal transition to fatherhood

Parents of infants who require critical care at birth are rarely prepared for the shock and anxiety that comes with an admission to the neonatal intensive care unit (NICU). Provenzi and Santoro 2015 conducted a systematic review of 14 qualitative studies concerned with fathers’ experiences of preterm infants, born < 370/7 weeks gestational age (GA). In this review, the following themes emerged: emotional roller-coaster, paternal needs, coping strategies, self-representation, and caregiving engagement. Fathers reported a general sense of lack of control in the NICU. They defined their role within the family structure as overseers, protectors, and earners and would often prioritize their needs lower than those of the mother and the newborn child. Many fathers coped by hiding their feelings and returning to work. However, they also felt the lack of physical contact with their infant delayed their transition into fatherhood. Fathers reported using information gathering and regular communication with members of the health care team as a method to help regain their sense of control and be provided with support. Sisson et al, 2015 conducted a systematic review of 24 studies of fathers of preterm infants, ≤ 376/7 weeks GA, and their experiences in the NICU. Additional themes identified from this review included: (1) being unable to exercise their parental autonomy as a result of their internal fears and hesitations around the medical equipment, (2) feeling that the lack of information received was exclusive to them, and (3) isolation, as the needs of mother took precedence with the sense of them being on the sideline. In summary, the fathers’ experience in the NICU was described as one with the potential to cause significant anxiety, distress, and disruption to the parenthood experience. Limitations of these studies included small sample sizes of less than 10 participants,
lack of generalizability of the findings as paternity leave varies by jurisdiction, and inability to differentiate outcomes by gestational age. Further study is required to determine if an intervention directed at increasing fathers’ involvement with their child and giving them control back would improve their NICU experience.

A6. Experiences of fathers post-discharge from the Neonatal Intensive Care Unit

The experience of fathering a preterm infant who required neonatal intensive care continues after discharge from hospital. Aydon et al, 2018 interviewed parents of preterm infants born 28\(^{0/7}\) to 32\(^{6/7}\) weeks GA, in Western Australia, in regard to their experiences of being discharged from the NICU. Parents described being prepared by medical staff in the care of their infant, but feeling rushed on the actual discharge day, and wanting more notice and a better plan from staff. Some parents were uncertain about their mental and their physical preparation for taking care of their infant while at home. Some parents felt more comfortable and in control and others expressed anxiety about taking their infant home without the constant monitoring and support from nursing. In qualitative interviews after discharge with fathers of preterm infants, born between 25\(^{0/7}\) to 34\(^{6/7}\) weeks GA, several themes of their experiences emerged. Fathers’ described a major life adjustment from having an infant cared for in the hospital to having the full responsibility for round the clock care of their infant at home. Although fathers were prepared for discharge from the NICU they were not prepared for what discharge meant or the intensified exhaustion that ensued. The adjustment created a strain and a threat to the couple’s relationship as they felt that they did not have the time or energy to support each other. Fathers also worried about their infant’s future development and would compare them with that of
infants of the same age.45 Fathers underwent a period of strain and adjustment as they settled into a new routine at home.

Fathers felt that as they established a normal family routine, with a normal social life they felt encouraged that they would be able to manage their life as before. Most fathers described feeling stronger having gone through this experience.45 Similarly, in interviews of 8 fathers of preterm infants < 36⁰⁷ weeks GA discharged from the NICU, participants described that it took time for them to feel like a real father, to get to know their infant, and to become more confident.35 They also described gaining from this situation by having their relationship with their partner strengthened from the strain, changing and adapting as a person.35 Their feelings of attachment increased over time and they felt that they had a stronger bond with their infants than friends with term babies.35 In contrast, in a study using self-reports of parental competence in first time fathers, 25 fathers with preterm infants born < 37⁰⁷ weeks GA were compared to 24 fathers of term infants born ≥ 37⁰⁷ weeks GA.46 Fathers of full term infants had an overall higher sense of parenting competence, satisfaction, and parental efficacy than fathers of preterm infants.46 In observations of 54 term and 49 preterm born at 30⁰⁷ to 36⁰⁷ weeks GA, mothers and fathers of preterm infants had lower interaction scores than those of term infants at 3 and 12 months of age.47 In particular, fathers of both term and preterm infants had lower interaction scores than mothers.47 What is currently unknown from these studies is the effect of a NICU intervention targeted at improving fathers’ comfort level with their preterm infant, specifically moderate to late preterm infants, 32⁰⁷ to 34⁶⁷ weeks GA, on their parenting ability, confidence, and satisfaction on transition home.

A7. Interventions for fathers in the Neonatal Intensive Care Unit
Several interventions were created to target improving the various aspects of the parental experience while in the NICU. In a systematic review of randomized controlled trials involving early interventions for preterm infants < 37\(^{0/7}\) weeks GA and their parents that included a community component, 18 studies met the inclusion criteria.\(^{48}\) A major gap in this reviewed literature was that relatively few studied interventions targeted fathers. Of the 18 studies that were reviewed, only 5 studies included fathers in the interventions and of those 5 studies, only two studies reported outcomes for fathers.\(^{48}\) In one study, Melnyk et al, 2006 evaluated the effect of an educational intervention on stress and depression in parents in the NICU and only 47.7% of fathers participated in 54.7% of the activities.\(^{49}\) Similarly in Kaarelsen et al, 2006, fathers participated in only 6 of the 12 intervention sessions aimed at reducing parental stress in the NICU.\(^{50}\) Most interventions involved primarily mothers and included psychosocial support, parental education, and interventions targeting infant development.\(^{48}\) These interventions showed positive effects on maternal anxiety, depression, and self-efficacy.\(^{48}\) Some interventions directed at both parents only showed benefit in mothers and not fathers. Interventions involving infant massage or tactile stimulation had conflicting results with only mothers who received benefit;\(^{51}\) whereas, in other studies fathers’ level of attachment increased with physical contact.\(^{52}\) In qualitative interviews of 20 fathers surrounding their experience of skin-to-skin contact with their preterm infants between 25\(^{0/7}\) to 35\(^{6/7}\) weeks GA, fathers described the experience as heart-warming, rewarding, giving them a role and improving their self-esteem, and seeing it as a way to regain control, to bond with their infant, and to provide them with benefit.\(^{53}\) Fathers felt more included and as equivalent in importance to mothers, helping them achieve more equal parenthood.\(^{53}\) Fathers who engaged in skin-to-skin contact while in the NICU were more aware of their parenting role and transition into parenthood.\(^{32,35}\) Other studies that involved fathers
primarily focused on education around the NICU and their preterm infants. In a randomized control trial involving fathers of preterm infants, < 37\(^{0/7}\) weeks GA, fathers in the intervention group were given booklets with information about their infant and what they can do for themselves and their infant. The outcomes obtained were: (1) paternal stress as measured by the Parental Stressor Scale, (2) perceptions of nursing support as measured by the Nurse-Parent support tool, and (3) fathering ability based on a self-reported questionnaire.\(^5\) Fathers in the intervention group had significantly higher fathering ability, perceived nursing support, and reduction in paternal stress as compared to the control group.\(^5\) A methodological critique of this study is that ‘fathering ability’ was not well described. In Melbourne, Australia, a program was developed that allowed fathers with an infant admitted to the NICU to attend a weekly focus group facilitated by neonatologists and an infant mental health psychologist. Fathers who attended this group described the difficulties in transitioning into parenthood and with infant bonding but gave positive feedback about the peer support gained from attending the weekly group.\(^5\) Another study of 47 fathers with infants (average GA of 35\(^{6/7}\) weeks) in the NICU reported a reduction in stress, as assessed by the Parental Stressor Scale: Neonatal Intensive Care Unit, following their visit to the NICU.\(^5\) This study demonstrated the importance of fathers’ presence in the NICU for their wellbeing.\(^5\) To date, there are no studied interventions that integrate all components that have shown to be beneficial for fathers including physical contact, caregiving, and education surrounding the NICU and preterm infants. Moreover, the majority of the studies that looked at interventions in the NICU did not target fathers and those studies that did had small samples, focused on a narrow area of intervention, or did not explore the fathers’ experiences within the intervention to understand their overall benefits. As a result, no one
intervention targeted the many aspects of fathers’ experience in the NICU nor did they explore their experiences in the NICU following the intervention.

**A8. Family Integrated Care Programs in the Neonatal Intensive Care Unit**

More recently, there has been a greater focus on interventions directed at families during their NICU admission including family integrated care (FICare) in which parents, most often mothers, are supported to provide the majority of care while their infant is still admitted to the NICU. In 1979, a specialized mother-infant unit was established in Tallinn, Estonia for preterm infants and unwell full-term infants. Mothers were taught and expected to provide all the infant’s care until discharge with assistance from nurses and hospital staff as necessary. Mothers kept notes of their infant’s state of health, massaged their infants daily, often used skin-to-skin for physical contact, and the vast majority breastfed or provided breast milk to their infants. This model of care was recently adapted to Canada as a Family Integrated Care (FICare) for use in level III NICUs. The four-pillar model of FICare for Level III NICUs consisted of: (1) staff education and support, (2) parent education, (3) NICU environment, and (4) psychosocial support. In the pilot study by O’Brien et al, 2013, a primary caregiver was asked to spend ≥ 8 hours per day in the NICU providing care for their infants between 7 am and 8 pm, to include daily medical rounds, and a daily education session for a 21 day period. The pilot study included 42 mothers with their infants and found a steeper weight gain trajectory and breastfeeding at discharge in the FICare group compared to a matched comparison group. Parental stress as measured by the Parent Stress Scale - NICU was lower at discharge as compared to the time of enrollment. In a subsequent multicenter, cluster-randomized control trial of 25 tertiary NICUs with eligible infants born at ≤ 33 weeks’ gestation, infants in the
FICare intervention sites showed steeper weight gain trajectories, greater incidence of high-frequency breastmilk feeding at discharge, and lower mean stress scores in parents as compared to standard care. The Alberta Level II NICU model of FICare was modified from the Level III model as preterm infants admitted to a Level II NICU have a shorter length of stay and in Alberta the provincial health services are delivered by two providers (Alberta Health Services and Covenant Health). The modified Alberta FICare program involved three main pillars: (1) information sharing (one-to-one communication and bedside rounds), (2) parent education (one-to-one and group education), and (3) parental support from professionals and veteran parents (parents with previous experience in the Level II NICU). The effect of FICare or similar family centered interventions on fathers is unknown. Based on what is known in the literature on fathers’ experiences in the NICU and their important role within the family unit, FICare may change parental experiences, and in particular fathers’ experiences in the NICU. The purpose of this study was to elucidate the experiences of fathers of moderate to late preterm infants, 32\(^{0/7}\) to 34\(^{6/7}\) weeks GA, in the Alberta FICare program in hopes of understanding their perceptions of (1) their NICU experience from admission to discharge, and (2) their relationships with their partners and child to better create recommendations for future program developments.

**B. RESEARCH QUESTION AND OBJECTIVES**

What are the experiences of fathers of preterm infants born at 32\(^{0/7}\) to 34\(^{6/7}\) weeks GA admitted to a Level II NICU and enrolled in a randomized controlled trial evaluating Alberta FICare?

**Objective I:** To describe the experiences of fathers enrolled in the Alberta FICare program.
Objective II: To compare the experiences of fathers enrolled in the Alberta FICare program to those in the standard care group.

C. RESEARCH DESIGN AND METHODS

To answer the proposed research question, a qualitative study was undertaken using the qualitative research methodology of descriptive phenomenology as described by Husserl. Phenomenology examines subjective human experience. Descriptive phenomenology is based on having no preconceived notions on the human experience of interest, which requires description of the experiences without interpretation, and relies on the fact that there will be features to the experience that are common to all persons in a similar situation. This methodology was chosen because there was no known literature on the subject of the experiences of fathers of moderate and late preterm infants in a FICare program. Hence the goal of this study was to describe the fathers’ experience in the Alberta FICare program in the NICU. The experiences of fathers’ in the standard care group were included to reflect on the contrasting experiences to those fathers in the FICare program.

C1. Setting

This was a sub-study of a multi-center prospective cluster randomized controlled trial design of FICare for caregivers of moderate and late preterm infants in 10 Level II NICU sites across Alberta. These sites were randomized into one of two groups: FICare (intervention) or standard care (control). Mothers were recruited into the study within 72 hours of admission to the NICU. Preterm infants were typically discharged around 36\(^{0/7}\) weeks corrected GA (CGA) if
they were healthy and gaining weight. To ensure at least a one-week exposure to the FICare program, we included only mothers of infants born between 32\(^{0/7}\) to 34\(^{6/7}\) weeks GA. Mothers enrolled at the FICare intervention sites agreed to be present in the NICU at least 6 hours/day (approximately equivalent to three feedings). The 6 hours could be divided and/or shared with fathers or other designated kin caregivers. Mothers received individualized or group education and support from nurses according to the FICare study protocol as described previously.\(^{59,62}\)

C2. Participants

Inclusion and Exclusion criteria:

We included fathers if they (1) were the biological father of an infant(s) born between 32\(^{0/7}\) to 34\(^{6/7}\) weeks GA whose mother was enrolled in the Alberta FICare study, and (2) spoke English well enough to conduct a video-conferencing or telephone interview. We chose biological fathers, as their experiences were likely to be different than that of non-traditional parental units.

We excluded fathers of infants requiring palliative care, infants with severe congenital or chromosomal anomalies, or those infants apprehended by child protective services as these were the exclusion criteria of the main study. Fathers of infants with these various circumstances were likely to have a different experience than fathers of the majority of moderate and late preterm infants.

Study 1: Semi-structured interview Sample

We recruited a purposive sample of fathers of moderate and late preterm infants in the FICare study from August 2018 to March 2019. At the time of the 2-month follow-up, consent
was obtained from mothers to be contacted for future research. For those mothers who consented, we inquired whether the father of the preterm infant(s) might be interested in sharing his experiences. Fathers were also recruited through a FICare newsletter and online announcements that were sent to all FICare participants. Mothers were given the study investigator’s (AS) contact information to be forwarded to the father. When a father contacted AS, she provided information about the study, answered questions, and obtained informed electronic consent via Qualtrics™, an online data collection platform, according to the ethics approved protocol for the cluster randomized control trial.

Purposive sampling, a form of non-probability sampling whereby participants are chosen based on a particular characteristic (or characteristics) that maximally contributes to the research question(s) as opposed to random or convenience sampling from a population was used in keeping with qualitative methodologies. We used maximum variation sampling to identify fathers with a broad range of key characteristics including variations in age, race, socio-economic status, level of education, as well as GA.

Study 2: Parent Journal Sample

As part of the Alberta FICare study, all mothers were given a journal with slight differences for FICare and standard care groups. Both groups were asked to record daily out-of-pocket costs in the journal. In addition to costs, mothers in the FICare group were asked to record information about the infant’s progress and questions for the multi-disciplinary health care team. In the FICare group, mothers were invited to write “My thoughts for the day…” Approximately 10% of fathers wrote in a journal on their own accord. These journals provided additional data on fathers’ experiences during their infants stay in the NICU.
C3. Research Procedure

Demographic information was collected via Qualtrics™ and included: age, marital status, number of children, number of and GAs of prior and current children, employment status, household income, and ethnic background (Appendix I). Fathers were interviewed by video-conferencing using Skype™ at a time mutually agreeable to the researcher and participant. Video-conferencing was chosen as the primary mode of communication in order to better engage with the participant and to capture their non-verbal cues. If video-conferencing was not available to the participant, a telephone interview was conducted. The interviews were conducted using a semi-structured interview guide and were 45 min to 1 hour long (Appendix II). Participants were first introduced to the researcher (AS), her background, qualifications, and motivations for the study. They were then asked questions in regards to their experiences during labour and delivery, during the NICU admission, with the Alberta FICare program, with discharge, and post-discharge from the NICU. Inquiries were also made of their relationship with their child and their partner, as well as their parenting experiences (Appendix II). Interviews were digitally audio-recorded. The first three interviews were transcribed verbatim by AS and the subsequent interviews were transcribed by a transcriptionist (CW). Field notes were made during and after the interviews. Transcriptions were reviewed by AS and verified for accuracy. The transcriptionist had conducted previous transcriptions for this study.

C4. Data Analysis

The demographic information was analyzed first to describe the sample characteristics and contextualize findings. Demographic data were presented as mean and standard deviation
(SD) or as number and percentage (%) as appropriate. Identifying personal information was removed from the interview data, prior to the analysis of the interview transcripts. A thematic analysis was conducted according to Boyatzis 1998 method.\textsuperscript{65} Thematic analysis occurred in 6 stages. Stage 1: AS underwent an immersive reading of the data and initial ideas were noted. Stage II: Initial codes were generated in a systematic fashion across the entire data set. Members of the committee, KB, RA, VS, and TS reviewed initial codes to ensure consistency with the data. Stage III: Themes were created by collating codes into potential themes. Stage IV: The themes were reviewed and a thematic ‘map’ of the analysis was generated. Stage V: The themes were defined and named in order to develop refined themes with clear definitions. Questions that arose from analysis of initial interviews were explored in subsequent interviews. The same analysis approach was used for the parent journal data. Data from the transcribed interviews and the journal entries were coded separately and themes were triangulated from both these sources of data.\textsuperscript{66} Stage VI: The final stage involved relating the analysis back to the original research question and literature.\textsuperscript{65,67}

\textbf{C5. Rigor}

The rigor of the study was addressed through verification strategies such as checking and confirming the data through the use of field notes, digital recorders, and peer review by the committee.\textsuperscript{68} Purposive sampling allowed for the generation of common themes to gain greater insights into the phenomenon in question. Sampling both from interviews and from journal entries at different time points provided detailed data as representative of the fathers’ experiences as possible.\textsuperscript{66,68} An audit trail ensured that processes, decisions, and procedures of the study were documented and justified. Member checking was achieved by submitting a summary of the
findings for participants to comment on their perceived accuracy. This thesis followed the consolidated criteria for reporting qualitative research (COREQ) guidelines (Appendix III).

C6. Ethics

Ethical approval for this study was obtained from the University of Toronto Research Ethics Board (Human Protocol Number 35244) and the Conjoint Health Research Ethics Board (CHREB) in Calgary (REB17-1422_REN1). The ethics applications submitted to the CHREB in Calgary was submitted and linked to the Health Research Ethics Board (HREB) at the University of Alberta and Covenant Health. The Ethics application complied with the principles as laid out by the Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans. The ethics approvals are included in Appendix IV.

C7. Consent

The consent form was emailed to the interested participants, who were asked to sign and to return it via Qualtrics™, an online tool that can receive and store securely the consent forms. Any printed consent forms were stored separately from any data in locked drawers in the locked research office, which was located in a secure Nursing Research Office, University of Calgary research office (Professional Faculties Building 2250A). The consent forms are shown in Appendix V.

D. FINDINGS

D1. Characteristics of Participants
All mothers who had participated in the Alberta FICare study (n = 654) were provided with the study information. Thirteen fathers were interviewed, 11 interviews were conducted via video-conferencing while two were conducted over the telephone. The baseline characteristics of the participants were presented in Table 1. Four of the 13 fathers were from a standard care site in the FICare Level II study and the remaining 9 fathers were from a FICare site. The average age of the fathers was 37.1 (SD = 7.2) years. Eleven of the fathers were married, one was in a common-law relationship, and one was divorced. Eleven fathers were employed with an household income of > $80,000 per year. All fathers were Canadian with North American, British Isles, or European ancestry. Four were first time fathers while the others had previously 1 or 2 children. The average GA of their child admitted to the NICU was 33.7 weeks (SD = 0.9). There were two fathers who had twins, and two fathers with a previous preterm infant (< 37\(^0/7\) weeks) with 1 each requiring or not requiring admission to the NICU. Characteristics of fathers in the FICare and standard care groups were similar, though fathers in the standard care group did not have representation from a divorced father, or father of three children, or fathers in a lower household income bracket of 60-80,000$ per year.

Of the 24 fathers who recorded journal entries, one was from a standard care site and the remaining 23 were from FICare sites. The average GA of infants was 33.4 (SD = 0.8) weeks, with an average birth weight of 1948 (SD = 353) grams, and an average length of stay of 20 (SD = 7) days. There were four fathers with twins.

D2. Thematic analysis

The experiences of fathers of moderate or late preterm infants were divided into three separate time periods: (a) pre-NICU, (b) NICU, and (c) post-discharge from the NICU. These
time periods were developed naturally from how the fathers compartmentalized their NICU experience. All fathers were represented in each time point. The most poignant quotations that provided evidence for each theme were collated and a description of the thematic analysis of the interviews and the journals over all three time periods was presented in Appendix VI. A figure outlining the process of triangulation was described in Figure 1.

Pre-NICU experience

The thematic ‘maps’ of analysis of the interviews and of the journal entries for this time period are shown in Figure 2 and Figure 3 respectively. Eight themes from the interviews were generated regarding the fathers’ experiences of the pre-NICU period with four themes triangulated from the journal entries.

Mental preparation affects the emotional experience of early delivery

Learning that your child will be delivered preterm is an emotionally distressing experience. The temporal association between learning that your child will be born preterm and the timing of delivery impacts the magnitude of the emotional experience. Fathers who expected an early delivery were more mentally prepared at the time of delivery and were more likely to perceive the situation in a calm and controlled manner:

We were kind of told that they might come out early. So, it wasn’t a shock… The few days leading up, I think [my wife] kind of felt like it was coming, so … our bags were ready and you know, we already had a kid, so mentally we were ready to go. (Interview 9, FlCare)

For fathers who had the opportunity to see the NICU prior to their admission, this was reflected on positively:
It was around 28 weeks that my wife went for a regular check-up and they noticed very high blood pressure … one good thing is that … they kind of prepared us for potentially having a 28 week old baby. We did get an opportunity to tour around the NICU, which was really good, it definitely made the experience when we did go there at 32 weeks a lot less overwhelming just because we had seen it. (Interview 4, standard care)

When the delivery of their preterm infant occurred suddenly, there was a lack of mental preparation and as a result fathers were more likely to experience fear and anxiety:

It was kind of a bit of a shock for us. … we got a call from [the hospital] saying to my spouse that we need to come in and clarify some bloodwork … We were totally blindsided … when the … obstetrician came in and said ‘he needs to come out.’ We were just like [showing face of shock and surprise]. (Interview 3, standard care)

Scary…We had no plans for baby to come out so early and didn’t even know anything was wrong with [the] pregnancy until an ultrasound early in the afternoon yesterday sent us to the hospital. …Baby 1st official day started off with a lot of commotion, fear, anxiety, and joy. It truly is a strange mix of emotions I have never felt before. (Journal 638, FICare)

The amount of preparation a father received prior to the delivery of their preterm infant impacted the emotional experience of delivery from one of terror and stress to that of a more calm and relaxed approach. Preparation came in the form of a temporal gap from being told their infant will be born preterm to when they actually delivered, which was mediated by the visual and verbal education fathers received surrounding having a preterm infant and the expected NICU stay.

**Perception of a rushed environment regardless of preparation**

Uniformly fathers felt that at the time of delivery the environment in the labour room was fast-paced with many individuals around and many activities happening at once with fathers at the center watching the scene unfold as a bystander.

It was all pretty go, go, go. (Interview 6, standard care)
It was a lot going on. And so my wife was on her own and then all of a sudden, now. Now it’s coming, and I’m basically following. (Interview 7, FICare)

It was surprising and nerve wracking to find out that mother went into early labour. I did not know what would … happen to the baby. Everything happened so fast there was no time to react or even come up with a plan or an explanation. (Journal 563, FICare)

Fathers depicted a scene of controlled chaos with many individuals around, many activities happening at once, with fathers following the crowd without a complete appreciation of the events that were taking place.

Reassurance of medical care led to reduced anxiety in the face of an otherwise difficult experience

The medical care received was uniformly seen as positive, calming, and reassuring to all fathers. Fathers experienced comfort in knowing their child was well taken care of by skilled hands despite the relative unknowns of their infant’s outcome:

I found it to be very scary but the staff was very reassuring and very comfortable and you could tell that they knew their skill sets in and out and they knew what they were doing. It was very calming in that aspect. (Interview 5, FICare)

At just over 2 lbs he looked so tiny on the warmer and with the … of nurses assisting there were moments where he completely disappeared behind their hands. The only real comfort that can be felt comes from watching those skilled hands and knowing the he is in the best place with the most talented people we could ever ask for looking out for him. (Interview 638, FICare)

Fathers either expressed fear for their child and/or their partner. This fear was lessened by the reassurance they gained from watching the medical care team and their expertise at work or they had no concern at all because of their faith in the medical care provided. Fathers experienced an immediate amount of trust in the medical team early on their hospital journey.

Fear of the unknown leads to an emotionally terrifying experience
The birth of their preterm infant created a certain amount of uncertainty in outcome and fathers experienced anxiety and fear for their child and the end result:

He was in there for so long, but still a lot of complications that we knew could happen and the concern was always I guess nagging about what could or you know, could not happen. (Interview 10, FICare)

This period of anxiety was followed by a sense of relief when their infant was found to have a positive outcome:

I mean it’s scary, right, cause you don’t know, you kind of expect the worst, but luckily um, she was bigger than they thought, she was breathing on her own just fine, so she was, she did really well, but it’s the unknown right, you don’t know. (Interview 11, FICare)

For fathers with written accounts of their experience, there was greater imagery regarding the physical manifestation of medical interference such as the medical equipment and how that was perceived as fearful, making it difficult to believe their infant was in fact in good health:

As soon as she was born we were instantly worried about baby. She was healthy enough to spend an hour with us. It was rather scary seeing her with all the tubes, IV’s and sensors attached to her tiny body. While all the hospital staff was reassuring us that everything seemed okay, we had a hard time believing since we never encountered anything like this before. We would [be] by her side and patiently observed every minute of her first day or the remainder of. (Journal 563, FICare)

The medical care received by an infant, although seen as a positive brought forth the concerning reality that their infant was potentially unwell and had higher needs than that of an infant born from a routine delivery and this had the potential to create fear and anxiety surrounding the potential outcomes.

**Determining one’s role in the physical environment**

Fathers often described this existential experience in which they did not know where they should be, what they should be doing, or who they should be with:
You want to stay with your wife, but you also wanna be with your kids, and if you go with your new kids because you have to, you worry about how your wife’s doing … There’s definitely about a 30 minute period where it’s like really unclear. And you’re going to the NICU unit where you haven’t been before. So it’s not familiar, so it was a bit of a strange period. ...I wasn’t sure who I really wanted to be with at that moment. (Interview 9, FICare)

Fathers were physically and emotionally divided into two causing confusion in the immediate post-natal period about their role. They felt unsure if they should be with their partner or their infant. Their partner was being taken care of from a medical perspective but might have required emotional support. On the other hand, their infant was undergoing immediate medical management, but fathers felt as though their physical presence was unnecessary to establishing the health and wellbeing of their infant:

Because you know they’re trying to do their job. They’re trying to get everything done. And you just kind of want to see. ...last thing they need is me fumbling around in their way, right? So I kind of stood off to the side and watched best I could. It’s one of those times you feel quite useless as a person. Because there’s not much I can do, right? (Interview 6, standard care)

Some fathers reflected that they were encouraged to be involved with their infant at the bedside but often they would choose to stand aside from the medical care workers so as to not interfere with the care of their infant. In this initial period post-birth of their preterm infant and initial admission to the NICU, fathers were immediately searching for their best served role in the physical environment.

Supporting fathers for early involvement had a positive effect on initial experience

Fathers who had the opportunity to physically touch or hold their infant soon after delivery experienced an early connection to their infant, and reflected on the opportunity positively:
It was actually pretty positive … I got to take him and hold him … for a little bit. Honestly I don’t know how long it was because you’re just enjoying the moment. (Interview 10, FICare)

Early skin-to-skin contact helped fathers when faced with the anxiety of having an infant brought to the NICU:

They were very encouraging to get that connection. … the skin to skin right away, which … definitely helped (Interview 7, FICare)

Fathers who had the opportunity for skin-to-skin contact perceived it as a task that only they could fulfill as their partner was not available and this opportunity gave them a sense of purpose in the postnatal environment.

**NICU preparation involves a holistic approach of both mental preparation around infant medical care and the routine processes of the NICU**

For many fathers there was little to no preparation in regards to what to expect upon admission to the NICU until the arrival to the NICU, expressed simply by one father:

I had no idea what to expect or even what the NICU was, at that point. (Interview 8, FICare)

The orientation to the NICU was perceived to be primarily surrounding the day-to-day physical workings of the NICU environment and teaching parents basic navigation through the unit:

It was a lot of this is how you get in and out and this is what you need to do, so we understood that you know, you’ve gotta wash your hands at the sink before you go in, you buzz to get in and different things like that. Check in at the desk. … you know, there’s a fridge here for the breast milk so that mom knows where to put her breast milk when she comes in and how to get it labeled. (Interview 8, FICare)
Many fathers expressed needing more practical knowledge for a prolonged NICU admission and in particular, they wanted financial and logistical information that would affect fathers returning to work:

I think that at some point if someone could give you some details about what that might entail, that would be beneficial, because like, I don’t know, like if it comes at 32 weeks, you might be in the hospital for 4-5 weeks … I don’t know if I would’ve been able to take 4-5 weeks off work, like that, financially, that could really strap you. Like, I think people need to be better prepared, like, hey don’t take your vacation this year, you might want to save it for this time. (Interview 9, FICare)

Although fathers were prepared for an admission to the NICU because their infant would require ongoing medical care, there was less preparation in regard to what that would technically entail including requiring prolonged time off work of uncertain duration or the daily cost of parking and the resources available for reduced fees for prolonged admissions. Fathers appreciated communication around the logistical aspects of day-to-day life in the NICU and wanted to receive this information directly.

Level of communication helps ease uncertainty and increases assurance by medical care

Effective communication between fathers and the medical team was a critical determinant to the initial perceived experience in the peripartum period. When fathers received effective communication, they felt confident, less anxious, and reassured by the process:

And then, because he was earlier, there was extra people in there. I knew that they were basically explaining what they were doing. And they were good at that. Explaining everything that was gonna go, we’re gonna get to do this, and then we’ll take him there. (Interview 7, FICare)

Reflecting back now I can’t believe that even with everything going on, time was still made for dad to cut the cord as well as to have continuous communication on what was happening and why. Somehow it was extremely calming and reassuring. (Journal 638, FICare)
For fathers who had limited communication there was a heightened sense of fear and frustration:

So it got quite bad very quickly … The doctors aren’t really sure what happened but there they suspect that the placenta abrupted while she was in labor and both kids and her crashed while they had the monitors on them and all of a sudden it was ‘c-section stat’ and they were gone. And I didn’t see anything. I didn’t know what was happening for about 45 mins. About a half an hour to 45 min. So um and none of the nurses or doctors or anybody that I had access to would communicate. Or had any information about what was going on. (Interview 2, standard care)

Communicating with fathers during the peripartum period was a crucial opportunity to inform and reassure. Negative experiences were unanimously had if fathers were not given appropriate, effective, and timely information.

The NICU experience

The thematic ‘maps’ of analysis of the interviewed and journal entry fathers’ NICU experience are shown in Figures 4 and 5 respectively. There were nine themes equally shared between the interviewed and journal entry fathers.

*Fathers searching for and identifying their role in the NICU, wanting more involvement and equal support to their partners*

Fathers experienced a new world when entering the NICU environment, one in which it was not initially obvious as to what their role should be and what they should be doing. They could see that many aspects of care for both their wife and their child were being taken over by the medical care team, which could create the feeling of being superfluous and unnecessary.

You definitely feel helpless … And you take a backseat. … you do feel a little helpless when it comes to… what your role should be. For my first, I was there to support my wife with whatever she needed and help take care of my daughter.
And with the second it was the doctors were there for her, and I was just kind of sitting off on the sidelines. (Interview 8, FICare)

Fathers desired involvement in any way possible. For fathers it was a challenge to not immediately feel needed:

When I couldn’t fill that void, it, for me, not being relied upon … so you’re kind of standing there going, well I can’t, I can’t pump her, and I can’t you know, there’s really nothing I can do to aid, so my only role here is to strictly support. And for me, it’s tough, it’s tough. You know, just being, never, me not really being relied upon or being, you know, needed in any capacity, … so you’re literally standing there going, what do I do with my hands. (Interview 13, FICare)

Fathers often spoke of their supportive role to their wives. Some fathers felt as though they might not have been as directly involved as their wives, but they could still contribute in a supportive way:

You’re going into a survival mode where its sort of you kind of just lock yourself down as much as you can and get as much sleep as much as you can and support your wife as much as you can. (Interview 1, FICare)

Likewise, fathers in the standard care group expressed that the father’s role more often indirectly impacted their child in the form of support:

I knew my role. … I’m a stay busy type of person right so like that’s why I was the chief bottle washer … Cause there’s certain things that I think that bond between a child and his mom is different than the dad and his mom and the child right so um I knew the importance of her having skin to skin and you know the feeding and all that stuff … my job was to try and ease that burden. That’s how I came in it, I was like I was the go boy. Just sweep the car off, warm the car up anything I could to help out. Um I would’ve probably mopped the floors honestly like I would’ve done anything there just to kind of stay busy. (Interview 3, standard care)

Fathers in both the standard care and the FICare group discussed a degree of taking a backseat to the mother who was still perceived as the primary caregiver:

When you introduce a third member to your family … like the dad’s number 3 all of a sudden so. That’s going to be in the book I write on being a father its called ‘you’re number 3’ … Mom’s were treated kind of as the primary and um you
know it was the way they kind of they didn’t really speak to you as a family they speak to mom type of deal in that sense. (Interview 3, standard care)

Fathers generally did not want to take a backseat and wanted to be directly involved as a caregiver and to be treated equally including getting information directly from the source:

There was a lot of focus on like [my child] and his mom. … But I think a little bit more, I guess, focus on notes or something for the dad. Just to make it kind of a little bit easier to try to relay the information to the dad a little bit more directly. … just to not get the information like you know, the doctor to the mom and then the mom to the dad. Like kind of just have a little bit more of a direct link or something, some kind of avenue to get the information a little bit more direct so things aren’t lost in translation. (Interview 10, FICare)

The more information we can have the better … I mean FICare, still even FICare was it’s all about mom. You know, my cell phone was the one that we gave when we were there, and you know, every time FICare calls, it’s for my wife. Maybe from a FICare standpoint, there’s more of an opportunity to have, you know, an even distribution of contact to both parents. (Interview 8, FICare)

Upon triangulation of the data from the parent journals, fathers similarly echoed the sentiment of uncertainty as to what their role should be, identifying that their needs and identity were different from that of the mothers but at the same time they wanted to be involved:

I love seeing baby and spending as much time with him as possible but am I supposed to sit there and watch him? I am so unsure of everything. All I know is how much love I have for my son and I really want what’s best for him. Spent some on the internet while with baby tonight trying to find answers, found a couple books that might help and read a lot about other dad’s feeling the exact same way so I am definitely not alone but no answers. (Journal 638, FICare)

Fathers wanted to be seen and to be treated as equal parents to their partners and although some fathers felt there was no difference in how they were treated or how much they were involved as compared to their partners, there continued to be some disparity between the father’s and mother’s role either perceived by fathers or realized in the NICU environment.

*Fathers support and benefit from parenting with supervision in a positive NICU environment that encourages parental independence*
For fathers in the FICare program there was a feeling that the nurses were giving them and their child extra attention and were encouraging of paternal participation:

I got the sense that the nurses are aware that, they must be obviously, cause you do things differently with FICare, so they try to push you to do more of those things as well. (Interview 11, FICare)

The ability that we had [to] be a little bit closer with a couple of the nurses. Because they would come and you know, check on him specifically and take more of a … interest … because of the FICare program. They wanted to follow up and different things like that. So, umm, given that – if we were in the same situation again, for sure we would absolutely sign up again. (Interview 8, FICare)

I have started to hold baby more and more during feeding from tube. Nurses have been great. (Journal 680, FICare)

Fathers in the FICare program emphasized the importance of being involved to help gain confidence and get past the fear of physically handling a preterm infant in order to get closer to their infant:

When they’re premature …you’re worried about they’re fragile as newborns and afterwards there’s a feeding tube and all that kind of stuff. So, yeah, it’s still a lot different. … the biggest thing, was just to do it, right. And the support of not just the FICare program, but the nurses in the NICU as well. (Interview 11, FICare)

We are starting to get comfortable picking the twins up now without relying on the nurses to pass them off to us. This was a big step since we were hesitant. (Journal 609, FICare)

Even without direct acknowledgement of the FICare program, fathers in the FICare group spoke often of being supervised parents, being taught at the bedside by nurses to help transition for discharge home and to help increase paternal involvement, which was viewed as a positive:

My nurses were just, they were all up front with everything that it was. If we needed something, we’d go get it. If you need this, you go get it….It helped speed up. It, it was good…We were basically parenting, with supervision. For, nine days, while we got ready to go home. (Interview 7, FICare)

All the nurses and stuff were really good as far as you know, you take the first bath for example, … this is how you do this, cause this is different in the NICU
than it is at home or even her first bath. … they kind of almost give you jobs to do, you’re going to hold baby like this, this is how you do it, … And I think the other thing too that you know, probably helps you feel more involved as a dad in the NICU. (Interview 11, FICare)

I rushed through my chores to come see him. I am so tired! Its ok he is worth it. He has been reacting to my voice a lot and even smiled. He looks really good. He pooped a couple times so I get to practice diaper changes. (Journal 662, FICare)

The extensive supervision was viewed negatively by some fathers who experienced a barrier between the medical team and their ability to care for their child, often having to ask for permission to parent their child:

… They’ve got lots of things going on and you do very much wait on it. I mean, as far as they’ll warm the bottle up and it will be sitting on the bottle warmer, ready to go, and you’ve got him on you, but you can’t do that extra step of going and getting it and start feeding him. … you have to ask for permission to, you know, dress him in clothes that you’ve brought in for him and things like that. … you needed to rely on somebody else to kind of help you through things that you knew how to do and were confident doing on your own type thing. …you do feel that you’re almost having to ask permission to … parent your child at times. … Cause, you know, you’re the parent. Especially being the dad, you’re the protector … And you just want to jump in. (Interview 8, FICare)

For fathers in the standard care group there was still a general sentiment that if they felt included and received teaching around the care of their infant, they were more involved and better prepared for discharge home:

They were great if we had to ask questions, they were there. Uh, you know, scheduling time to do the first bath, scheduling time to do the first diaper change. Like they made sure that we were there for everything, to kind of, be included. … I felt like they did a really good job of kind of including us and making sure we were involved and you know, to really kind of get our feet underneath us. So, when we got home, it was more of the same, just all the time. (Interview 6, standard care)

Fathers in the standard care group were more likely to report experiences in which they did not always feel welcome to care for their child or did not feel they had a purpose:

That first little bit was a little bit tough to kind of find what the proper routine should be. Cause at the same time we want to be there but there’s also you know
when he was feeding on the feeding tube all the time there’s not, other than holding him there’s not much we can do. And some of the nurses kind of made it seem like it was an inconvenience for them to bring him out of the isolette to allow us to hold him. Other nurses were a lot more easy about it and definitely encouraged it. So we were trying to balance out. Are we interfering with them. I know they have a busy schedule and lots of babies to look after versus wanting the care and be there for our child. (Interview 4, standard care)

Fathers in the standard care group experienced not having a role until either parent was able to do something that only they could do such as breastfeeding. Prior to the initiation of breastfeeding, the role of caring for the child fell primarily onto the medical team:

I mean it also changed a bit once he started breastfeeding a little bit. Then we felt more of a purpose to be around or for my wife to be there. (Interview 4, standard care)

In general, fathers benefited from a welcoming environment that involved teaching and bedside attention, which promoted their independence with taking care of their preterm infant while preparing them for discharge home.

**Effect of medical staff**

Overwhelmingly, all fathers regardless of the study group experienced the effect of the medical team on their overall experience. Having a positive interaction with a physician or a nurse carried through to their overall impression of the NICU and their experience during the NICU:

There was a certain level of comfort there … and the physician came and you know he came and checked on him which was huge put his arm around me right like there was a comforting thing there … I admired the gentleman. … He had [a] phenomenal bedside manner like all of those things like the power of touch and all of those things were like a certain comforting aspect so I felt like it was I was in the right place. I never doubted that for a second and …I knew that’s where we needed to be. (Interview 3, standard care)
Fathers felt positively about the medical staff if they felt the bedside staff was knowledgeable, kind, or a good communicator:

I found the staff to be extremely friendly. Extremely knowledgeable and even with it being our third child we still had questions. (Interview 5, FiCare)

The nurses have been wonderful at helping us understand the processes and procedures. (Journal 616, FiCare)

I expected to feel worse honestly and scared for the babies but the nurses assured us that what the babies are going through is quite standard for their age (Journal 252, FiCare)

The NICU experience could be affected negatively by the perceived treatment received at the bedside:

I think the nurses really make or break the experience. … if we had you know a good nurse just attentive you know and on the ball and kind of really patient with us … the experience was great. (Interview 1, FiCare)

We struggled with the overnight nurse … the unit seemed short-handed. Mother was called from her hospital room to the NICU to help out and was treated poorly. The nurse was very rude to my wife and I had to speak to her and tell her that what she did was wrong. I will talk to our head nurse tomorrow. We should not be treated this way. (Journal 609, FiCare)

The bedside medical staff could have a profound effect on the NICU experience for fathers. Having knowledgeable, helpful, and consistent bedside support led to a more positive experience.

*Importance of effective communication with fathers as the information gatherers*

As fathers established their roles in the NICU a key feature was their role as information gatherers. A part of their responsibility as fathers was to be present to receive the information around the care of their child and their current status so that they can be better informed themselves but also help disseminate information to their partner who they felt required support with communicating with the medical team:
Some of the nurses were fantastic. Being available for rounds and being encouraged to be there when the doctors were doing the rounds was very helpful and everyone was very open and candid and answered any questions um so we tried to make sure that we were always there everyday when they came around to do rounds. And that was great. (Interview 4, standard care)

I think number 1 would be how the information is delivered. So when we were admitted we kind of got like a folder I can’t remember or a binder and it had lots of this sort of stuff that looked like it had been photocopied a hundred thousand times and it was nothing like and even just having something like ‘here’s your NICU manual. … I feel like my role became sort of the I’m the gatherer and the cultivar of the information and I am the one getting the most sleep because my wife is there she’s feeding every three hours so the more information that I have that I can reference for both of them is useful. (Interview 1, FICare)

I’ve been told things 2 and 3 times, which I actually appreciate. The staff here know their stuff but it’s nice hearing the same info from different sources at different times. (Journal 757, FICare)

When communication was sparse or ill-received this was a point of frustration for fathers who appreciated transparency and a plan:

You don’t want to rock the boat because you’re depending on these people. So early on there’s like that little chart that’s in all the rooms … and these all have to be green before your baby can go home and so the first couple of days I’m like ‘ok so the sheets with the information basically said we’re going to update this everyday’ uh but it was really quickly found out that they didn’t update it everyday and I found that they didn’t update it…I don’t think they updated it almost until she went home. …we kind of just realized that we have to grin and bear it. (Interview 1, FICare)

Throughout the NICU admission fathers continuously wanted up-to-date information about the status of their infant. They desired information that was clear and provided a strong visual care plan for their child.

**Impact of physical environment**

The physical environment impacted the experience of fathers in the NICU. Fathers spoke of the space constrictions that affected them personally and made them feel like a burden:
I would say as a father sometimes a place to sit…a place that’s more welcoming…where there’s room for you where its comfortable where you’re not just like grabbing a spare chair from the corner and trying to shove it in the room and join in so kind of makes you feel like you’re a little bit of a burden or like in the way more. (Interview 4, standard care)

Hard to get comfortable when you constantly feel in the way while annoying I understand that it is what it is with such a small unit. (Journal 563, FICare)

Sharing a space with other visitors was a challenge as it was felt that not all families were respectful of the NICU environment, which became a concern for the effect the disruptive environment had on their infant’s health:

You have to be very clean going in there, so as parents, you wash up and you’re very clean and you’re quiet and respectful when you go in …you know, people were coming in and like in their jackets and bringing strollers and they would have to be told not to come in and then, that was the only really annoying thing, was the amount of traffic, you know, and people not following the rules to a T. (Interview 9, FICare)

NICU is getting a lot of visitors. It feels very crowded with constant stream of people coming in and out with all the new baby arrivals … Last thing I want is to see my preemie baby sick. (Journal 563, FICare)

For some fathers the open concept model in the NICU was seen as a positive because it increased engagement between parents:

It was kind of neat because … I got an appreciation of other parents and you can see them role modeling behavior which was kind of the nice thing about the open concept where you see you know you see dads really active and engaged and doing ‘hey that’s skin to skin, I want to try that’ right so I think that’s nice to see some positive role models is really good thing too. (Interview 3, standard care)

Other positives to the physical environment included the impact of the medical staff personalizing the space for each infant, and normalizing the NICU environment to make the space feel more like a home environment:

The nurses were pretty helpful … they made up little, like you know, little name tag identifiers for all the babies there. … They tried to personalize the area kind of as much as they could. Um, and that was really helpful just to kind of make it feel a little less like a hospital. (Interview 10, FICare)
It is crazy to me how anything can almost become normal. After two weeks, I find myself spending more time thinking about stupid little things with baby care than I do about his health and if he is going to make it. I am concerned about … About how to decorate his room at the hospital, worried about why he doesn’t have a fancy decorative name badge like some of the other kids. (Journal 638, FICare)

The physical environment of the NICU impacted the comfort and the perception of feeling welcomed at the bedside by fathers. The physical environment was also an opportunity to normalize the space while ensuring the best protection for the infant.

**Perceived health of infant**

The experience in the NICU was shaped by the health state of the infant. In particular, the initial introduction to the NICU and the medical care received by the infant even if considered overall “well” could have been a jarring and terrifying experience for fathers. The appearance of the medical equipment and the monitoring could have created an appearance of an unwell infant, which was difficult for fathers to cope with:

I remember I was coming home from the hospital and this was day 3 or 4 so really early days and stuff like that she’s got feeding tubes and they are having problems finding places to put her IV and stuff like that kind of like had to block myself off emotionally and just to say ‘you know what. Whatever happens is going to happen.’ I can’t keep coming home from the hospital crying everyday because I’m scared…I feel like maybe if had she been a normal baby maybe you don’t really go through that. You get to sort of welcome and have all the joy and the excitement as opposed to saying oh for me to get through this I actually just have to wall myself off a little bit…that started to come down I think as we saw that she was making progression and also seeing that her against the other babies. (Interview 1, FICare)

In particular, the sounds of the monitors and the alarms were very difficult to handle emotionally by some fathers during their NICU stay. A new infant who visibly appeared to need extra treatment created a scary image of an unwell child:
The monitors and the beeping and the alarms would go off a lot and you know, every time they would go off, the nurses would come in and reset it. But the alarms going off I think probably the most, like, it was really hard. That part was really hard. The alarms would go off, like his heart rate would slow or his oxygen would slow, or drop, and that would happen throughout the whole time. Um, and I know everyone said it was normal, it was ok, but it was just like, that part, that experience in the NICU, that was probably the worst part of it actually. (Interview 10, FICare)

I think I ran off adrenaline today. It was very hard to sleep overnight with having a new baby. There were so many cords and wires and machines everywhere. It was kind of unnerving. They would make noises that were stressful, but the nurses explained everything. (Journal 662, FICare)

Fathers described the emotional difficulty in managing ones fear and remaining strong when their infant was actually unwell:

She had two events today, she came out on her own, but its still very nerve wracking, I hope they stop completely soon. Still have panic attacks every time she sneezes, hiccups, or coughs. It is hard to be strong sometimes. (Journal 563, FICare)

Watching our daughter get intubated was the most difficult thing to witness. Felt helpless and scared. The staff is incredible and baby is much stronger than her dad. (Journal 400, FICare)

For the majority of fathers at some point, they saw their child as healthy, especially when compared to other children in the NICU. This realization that their child was doing well occurred as they acclimatized to the medical environment of the NICU and created a positive experience:

I mean, it was really good, because she did quite well, you know, like she was on track the whole time, there was you know, no setbacks, so it was fairly easy from that perspective, because there was no bad news. I might have a different, it’s not the doctor’s fault obviously, but, if there was kind of bad news at some point, it would’ve been stressful for sure. (Interview 11, FICare)

The initial period of having an infant in the NICU caused significant stress for some fathers as they witnessed their child undergo medical treatment that an infant who was born at term and healthy would not otherwise endure and this impacted the initial experience in a
negative manner. However, for most fathers the NICU experience remained positive as their infant remained in good health and they adapted to the NICU environment.

**Balancing home, work, and hospital life**

A major challenge for most fathers was the reality of being the caregiver who was likely to go back to work and/or likely to have the responsibility of taking care of the home. Their tasks might have included housekeeping or child-care responsibilities for the other children, a role which would have been normally shared with their partner, which now fell solely to them:

> Well, you know, especially on top of the fact that you work often. You get up in the morning, drop number one off at daycare, go to work all day, pick them up, grab the food for them, go for a visit, come back, it’s just like by the time you get home, it’s 10 o clock at night and you’re just dead on your feet again, right? (Interview 6, standard care)

Fathers expressed how the effect of all the tasks that need completion ultimately led to less time spent with their infant:

> Realizing everything I have to do in a day is stressful. Between work, cleaning, walking our dog, cooking, and traveling to the hospital, my time with baby is limited. (Journal 662, FICare)

The conflict between responsibilities of the home with the desire to being with their infant resulted in sadness felt on part of the father because they could not be more directly involved in the care of their child:

> I am worried about going home tonight. I do not want to be away. But I need to take care of our pets so mother can be available for feedings. The thought of leaving is upsetting. My wife said I could take some of the time I was going to use when he comes home now, but I think I will regret not being at home with him. (Journal 662, FICare)
Fathers discussed the importance of having external support and reflected on how their experience in the NICU could have been different without the help. The support they received from their work helped balance their life between hospital and home.

I wasn’t working… I got extra time while he was there. Might’ve been a day or so at the end, but, umm… it was pretty simple getting time. it makes a big difference if you have to go back to work, it’s a different situation. And not all dads have that opportunity. (Interview 7, FICare)

Going on 23 days with minimal sleep and trying to balance everything is too hard. Work needs me as we started out involuntary period today. They have been amazingly supportive. (Journal 638, FICare)

When there was a lack of external support, fathers’ found the NICU experience much more trying and isolating:

My mother-in-law came out for the first month which was great. But then, she left and um, we don’t have any family around, so it’s, that’s been the hardest part, doing all of it without any real family support. (Interview 9, FICare)

Having an unsupportive work environment created additional anxiety and worry:

Work starting to be a concern. They are being understanding but I feel that their patience is running a bit thin. (Journal 563, FICare)

For many fathers an important facet to a positive NICU experience involved achieving the home life balance through establishing a daily routine:

I think for us honestly we reflect on that as a really positive experience right that like from the initial fear of ‘he needs to come out tomorrow or today’ to you know settling into a routine which it was still a great routine that we got up everyday made our coffee, went to the NICU did our feed went downstairs played cards all those kind of things right so I think I don’t know its uh I wouldn’t change anything. (Interview 3, standard care)

The daily routine was an important theme that affected the NICU experience depending on how supported fathers were external to the NICU environment and how great their responsibilities were elsewhere. For fathers who had the opportunity to take time off work and
had minimal external concerns, the NICU was a positive opportunity to spend time with their partner and their infant. For fathers with heavier demands outside of the hospital, the experience was an exhausting challenge trying to balance their multiple responsibilities.

**Teamwork through adversity**

Fathers spoke of the challenges that occurred between them and their partner in the NICU environment that ultimately brought them closer together:

It’s a stressful environment, there was just some frustrations. And once again, it was just I think fatigue, fatigue played a major part of it...I mean my wife and I were always very close, we were, but it definitely didn’t separate us. And I think it did make us a little bit stronger. … because we realized that the team work is going to make the dream work here. We’re either going to live by the sword or die by the sword, but we can’t be two separate entities. (Interview 13, FICare)

Times have been tough but its moments like this that remind me, we can do it, we are going to make it. We will be a family again soon and this is just another challenge that we won’t let tear us apart. (Journal 638, FICare)

Often a challenge for couples was that they were physically separated from each other throughout the entire NICU stay:

I think we worked really well as a team most of the time. Umm, you know, we didn’t get to see each other much during it. Especially the second time, we were kind of passing off, you know. The ships in the night. She was there, I was there, we were back and forth. (Interview 6, standard care)

For a father in the FICare program, their relationship with their partner did not change as they were able to communicate via the parent journal:

I think the journal helped a lot because we were able to understand each other’s feelings going through the process. So when we got home, we were able to consciously make decisions to not feel like that again, right. To not, to not get each other to feel like that. We were able to share a little bit more. So … no, I would say that it’s, you know, normal. No major changes on that side. (Interview 8, FICare)
Fathers expressed the difficult nature of having an infant in the NICU on their relationship with their partners with most stressors being attributed to fatigue and their growing responsibilities. Regardless of these challenges, they often described working through these problems together and coming together as a family.

Post-discharge from NICU experience

There were four themes amongst the interviewed fathers as shown in Figure 6 and three triangulated themes from the fathers’ journal entries as shown in Figure 7.

Preparation for discharge home

Towards the end of the NICU stay, fathers felt prepared to go home. Fathers described the benefit of having a period of time where their infant was normalized, removing all medical equipment from the daily care to better emulate the home environment:

She kind of went through the whole stage of you know, one bed to the next, they kind of graduate them up, and then, yeah for the last probably 5 days I want to say, she was kind of in a separate room … and she was off monitors and stuff by then. …It’s nice to not have to worry about you know the feeding tube and the monitor cables and all that, it’s more normal, like a normal human. (Interview 11, FICare)

In particular, fathers in the FICare program more often attributed their comfort with returning home secondary to the training they received in the NICU in the cares required for their preterm infant:

But once we got home … the transition was natural. … because of the, you know the encouragement for kangaroo care and feeding and changing and doing regular things with him, he didn’t feel like a stranger by any means when we got home. You know, and he was our son, so I think there was a lot of positive stuff that happened at the NICU that helped with that transition. (Interview 8, FICare)

Looking forward to take our babies home. We are feeling a lot more comfortable with managing time and the demands of the babies. (Journal 609, FICare)
A part of the preparation to going home involved communication around timing of discharge, which was experienced by some fathers as being relatively unclear or not exact:

Being that it was not our first child … we felt a lot more prepared. If it would’ve been our first it would’ve been a lot more overwhelming um but being our second it was definitely easier. … we saw with the other babies around us you don’t know exactly when you’re going to go home. … I think the day he had a little setback and he wasn’t [ready to go]. so you get a little disappointed then all of a sudden its like ‘no now it is today.’ … Yeah and they kind of warned us. The nurse practitioner said ‘we’ll tell you to aim, to plan for the due date original date that they go home but chances are we will tell you the day before that this is the day that you’re going home.’ And that’s [kind of what happened]. (Interview 4, standard care)

Fathers were eager and ready to go home, which was felt more often by fathers in the FICare program as they were prepared to regain control of their home life. They had good communication surrounding the goals that needed to be reached prior to discharge and appreciated the effect of removing the various medical interventions in a staged process before going home. However, the date of discharge was relatively unknown until the day of discharge, which led to a lack of preparation, though fathers accepted any setbacks when the timing did not go as planned.

Post-NICU medical care and support

Although the appearance of the monitors and the medical equipment in the NICU was initially daunting, fathers eventually acclimatized to the medical monitoring and the 24/7 care:

It was kind of comforting. Cause you know he’s breathing. You can see his breathing rate. You can see his pulse. So it was. It was more comforting to see it. It was probably harder knowing that we were bringing him home and we would not have that…. I think it was just the last day or maybe the day he came home off all the leads um even kind of leading up to the day before or so uh one of the nurses just shut them monitor off so we couldn’t just watch it while we were feeding him and changing him and that was a good little test. (Interview 4, standard care)
Stress levels even higher as now no monitor, no sensors, and no hospital soon. It is really hard to trust oneself that the baby is doing as fine as she is. I hope that the doctors/nurses are right. I really want her to do well. (Journal 563, FICare)

At discharge, the realization was daunting and stressful that there would be a lack of medical oversight and that as fathers they were now completely responsible for their children:

We were well prepared to go home as best you can be but that drive that drive taking the kids out of the hospital and putting them in the van on that first drive home was the most nervous experience of my life. …well you got these two lives now that are totally dependent on you right and um they’d never been in a car before and all that other stuff so its like ‘oh my God we’re not committed right? We don’t have all this help’ (Interview 2, standard care)

Despite preparation for discharge home, the physical removal of medical supports and the realization of the lack of continuous access to medical care was a major stressor for fathers.

Adding to the discharge experience, fathers felt more confident going home if they felt that they were well supported when it was time to leave the NICU so that they did not feel alone to fend for themselves:

We felt very prepared to leave. And we all felt very comfortable to go home because they were very upfront with us and they gave us phone numbers to make sure that we do have any kind of issues or questions that we have the resources available to us. So leaving there we felt very comfortable. (Interview 5, FICare)

Other fathers found help in their paediatrician and other medical care providers after discharge from the NICU:

I found the paediatrician to be a big help. I think at the start [we] were going to see her like once every two weeks or once a month, and then now we don’t see her at all. …We actually found a family doctor around the corner from us that’s amazing, like she’s the best doctor we’ve ever had. And she asked the right questions, and she talked to us too, and if we had questions we would actually call her and she would help us, or go see her. …it really helped us to reassure us that everything was going good, you know. (Interview 9, FICare)
For others if their experience did not include adequate post-discharge follow-up, the lack thereof did not go unnoticed and generally had a negative effect on their post-discharge from the NICU experience:

I guess if I had one thing … that would help improve for after, … if there was … follow-up of some kind maybe. Just from the release from the ICU, just like, that first … 24-48 hours, … like a phone call or something. …I can imagine there’s going to be at least some other parents who are probably as neurotic as I am about everything that’s going on and just not sure. … Maybe feel a little bit better from that reassurance that … as long as he’s doing all these things, then it’s just fine. And it stopped really, it stopped abruptly. (Interview 10, FICare)

Like having a FICare liaison to say ‘now that you’re out we’re going to we still have all the things you can access …We’re going to hook you up with the breastfeeding clinic to have that stuff done automatically so kind of not trying to figure out what to do so that she’s getting the best care. (Interview 1, FICare)

Having post-discharge follow-up was identified as a key piece in supporting fathers’ comfort level post-discharge from the NICU.

**Recalibrating the care and establishing a new routine**

Once discharged home, fathers experienced a transition in which they had to restart and recreate a post-hospital routine trying to manage the demands of their children at home, their work, and their needs to create a new normalcy:

I think it was more just all of our routines and everything settling out between the three kids and just having to live life and me going back to work and our lives went slowly back up to where it normally is. Just figuring out how the new puzzle works better. (Interview 4, standard care)

Fathers in the standard care group expressed more often a period of recalibrating the care, as they were previously daytime parents to having to switch to full-time parents:

The funny part was you know you’re kind of always wanting to get home but then you realize that when you have all the help and care at the hospital coming home is a little bit tougher um because it was kind of more like a 9 to 5 thing so my wife
would go in every morning and stay until 5. Then we’d go home its 24 hours. But just kind of adjusting to that. (Interview 4, standard care)

Other fathers in the standard care group described not having the complete confidence in caring for their infant, which took time to obtain:

So it was probably like about a month and we kind of got into a good rhythm. Its like all those things like. Double checking car seats. Just not having the confidence yet like lets feel the bath water right. (Interview 3, standard care)

All fathers felt going home was an overall positive to their quality of life as they had access to more comforts at home than at the hospital:

It was more comfortable because we were actually sleeping in our bed, as opposed to on some of the hospital, uh, chairs, chair cots, or benches that they have there. (Interview 7, FICare)

The transition to home even though embraced by fathers required a period of recreating and re-establishing a new routine that took time to fully institute.

**Relationship to child**

Fathers spoke of bonding with their infant. Establishing a connection with their infant required early involvement and accountability by fathers. For fathers who were involved in their child’s care from the moment they arrived in the NICU, they immediately felt bonded to their child:

I wouldn’t say there was any delay in the bonding just because … we made a point of, of going there and being there for every feeding, and just kind of immersing ourselves into [my child’s] life. (Interview 13, FICare)

Other fathers felt that the bonding occurred later when they were completely in control of the care of their child such as this experience of a standard care group father:

I would suggest it probably felt like a delay because I think the rubber hits the road when its you. Its your place its you’re in your space you’re accountable 24/7
so … that was certainly a bit of a harder thing for sure. (Interview 3, standard care)

As fathers bonded to their infants, their concern for their infant’s health and wellbeing increased following discharge from the NICU:

I’ve often felt like there’s a little bit of PTSD associated with it um just because of those first couple of days where your daughter is going to the NICU and its like she might not make it right[…]. I kind of feel like the experience left us a little uh a little more I don’t know how to say this maybe a little more tense, a little more wound up when it comes to our daughter as far as her health is concerned. (Interview 1, FICare)

For some fathers this concern continued on beyond infancy as more thoughts occurred around their child’s growth and development:

He’s 2 and a half years old now, and still, … where should he be in his development? Where should he be in his size? … so, we’re still looking at, still feeling the side effects, I guess you could say, from his birth. He’s having trouble with his eyesight, but everything else is developed well. So it’s just a matter now, of making things as normal as possible, right? But you still have those thoughts, even today, 2 and a half years later, of the side effects that come with having such a premature child. (Interview 8, FICare)

Regardless of their concerns around their child’s growth and development, all fathers held a positive view of their child and any concerns were reconciled with the awe they held for their child:

Oh she’s amazing. She’s really big. … we have a picture that basically shows how big she was when she was born. It looks like a little drawing like a scale and its like we can’t fathom it anymore. She’s crawling. She’s bumping into stuff. She’s making us laugh. You’d never know right. Yeah so its kind of amazing that she’s done really well. You would not know even looking at her [that her]charts that say she was born 7 weeks early. (Interview 1, FICare)

It seems every challenge you put in front of him he takes it like a champ. (Journal 638, FICare)

All fathers developed a connection with their infant at some point and for some fathers, the medical concern of having a preterm infant continued after discharge from the hospital.
Regardless of any anxieties, fathers were amazed by the capabilities and growth potential of their preterm infants.

**E. DISCUSSION**

In this qualitative research study, the phenomenon of fathers’ experience in Alberta FICare was explored. Using data-driven inductive analysis, fathers enrolled in Alberta FICare had a positive NICU experience if they received effective communication, bedside attention, and training on how to care for their preterm infants. Compared to the fathers in the standard care group, fathers in the Alberta FICare program were more likely to articulate the attention and the teaching they received at the bedside and attributed that learning to the increase in confidence they gained with their preterm infants that continued on post-discharge from the NICU. Fathers in the Alberta FICare program who wrote journal entries about their experience in the NICU corroborated these findings.

The pre-NICU admission experience provided an opportunity to analyze the sampled population’s experience to that of what was known in the literature. The developed themes of mental preparation around early delivery, perception of a rushed environment, and fear of the unknown were found in similar qualitative research of fathers and their experiences at complicated deliveries of both preterm and term infants. The impending birth of a child is a time for increased stressors for fathers. In a systematic review of 18 studies examining stress in fathers in the perinatal period, which included pregnancy to the end of the first year of life, it was found that fathers experienced heightened stress that increased from the antenatal period to the time of birth and decreased thereafter. This stress is likely a cumulative effect of the environment and the anticipation around the birth of their child.
At the time of delivery and soon after, fathers in the current study identified themes of feeling reassured by the medical care, while feeling lost and uncertain in their environment and their role, and needing good communication for assurance and to ease uncertainty. These themes were supported by a literature review of 10 articles, which included 929 expectant fathers who described their experiences of unpredictable complications during childbirth including shoulder dystocia, post-partum hemorrhage, fetal asphyxia, vacuum extractions, and emergency caesarean sections. Fathers in these studies emphasized the importance of medical professional to father communication and the negative effect of not being supported, leaving them with feelings of anger, fear, and helplessness. They also described the effect of the physical environment if separated from their infant and their partner with limited access to information on their health and wellbeing. Fathers in the current study had an overwhelmingly positive experience when they had the opportunity to do skin-to-skin contact with their infant. In a study of 49 fathers of preterm infants < 33\(^{0/7}\) weeks GA the effect of early skin-to-skin contact on the stress responses of fathers measured using blood pressure and salivary cortisol was evaluated before and after the intervention. A statistically significant reduction in blood pressure measurements and cortisol levels were noted 75 minutes after skin-to-skin contact. In the pre-NICU period it was evident that fathers experienced heightened amount of stress around the time of delivery and the strategies identified that could improve their experience included (1) adequate communication and preparation by medical professionals, (2) father-specific support in the form of a designated guide to help fathers navigate the immediate postnatal period, (3) giving them a role and opportunity to be involved, and (4) allowing for immediate physical involvement with their child.
The effect of FICare on the experiences of fathers in the NICU and post-discharge from the NICU is not reported in the literature. In our study, fathers routinely were searching for their role that was unique to that of their partners who were often seen as having a more obvious role of feeding and direct caregiving. In studies of fathers’ experiences in the NICU, fathers were described as searching for their role separate from their partners. In a phenomenological study, Logan and Dormire 2018 described the experiences of 7 fathers of infants born between 25\(^{0/7}\) to 27\(^{6/7}\) weeks GA in the NICU. Fathers described navigating a foreign land that was woman/mother focused, found perseverance in working and staying strong for the family, described using holding to bond with their infant, and had renewed faith by fitting in as a different kind of father, “a father of a preterm infant”. In our study, all fathers benefited from extra bedside attention and teaching; however, fathers in the FICare program specifically noted that their involvement in FICare enabled them access to more support and teaching from the bedside nurse, and to additional resources, which lead to a positive experience for them. It was the fathers’ experience that they were overwhelmingly supported and benefited from a NICU environment that encouraged their independence.

Negative experiences were associated with a lack of independence. This theme was supported by Russell et al, 2014 who conducted a qualitative analysis of 7 fathers of preterm infants, < 32\(^{0/7}\) weeks GA, who discussed the importance of being allowed to care for their infant including cleaning, diaper changing, touching, and holding. Parents in the current study discussed the negative feelings they had when they were not allowed to help with personal care for their infant versus the appreciation they felt when they were shown how to do tasks by neonatal staff or when they were allowed to be present during their occurrence. In a study of 111 fathers of very low birth weight infants (< 1500 grams), fathers reported missing non-bedside
interventions such as father-specific infant care courses, seminars, chatrooms etc.\textsuperscript{42} Findings from the current study suggests that if fathers are provided with the opportunity to be part of the FICare program targeting both partners and not just mothers, it may lead to a more positive NICU experience by increasing their involvement and reducing their anxiety around their preterm infant.

An important facet of a successful NICU experience and FICare program was the involvement of healthcare professionals (physicians, nurses) and their communication between fathers. Unsurprisingly, fathers were more likely to describe a positive experience if their caregivers were knowledgeable, supportive, and good communicators. Fathers found it important to be engaged and this was achieved by attending daily morning rounds to gain information on their infant and to have their questions addressed. Similar results were found in other studies describing the fathers’ experience in the NICU.\textsuperscript{36,42,78} In a synthesis of 24 studies on the fathers’ experiences in the NICU, fathers routinely reported a lack of communication as a contributor to a negative experience and some felt the issue was exclusive to them as information was not always adapted to their lifestyle as they may be working or driving to and from work.\textsuperscript{43} In the current study, fathers were able to identify facets to their NICU experience that were potentially out of the control of the NICU itself but had an impact on their experience. These factors included the physical environment, the health of their infant, and the balance of their home, work, and hospital life. Similarly, fathers have previously reported vulnerability when their child was unwell and felt that they must be placed in a role of being the strong family member who was there to protect the family.\textsuperscript{43} A theme of ‘perseverance’ was reported by Logan and Dormire, 2018, in which fathers were expected to care for everyone and everything while balancing the demands of work and needing to stay strong for the family.\textsuperscript{77} This issue brings to light the needs
of fathers whose experience in the NICU is shaped by their external demands, the health of their infant, and the perceived support and communication they receive from the medical team.

An emerging theme discussed amongst fathers was the strengthening of their relationship with their partner during the NICU stay despite the stressors and the fatigue of having an infant in the NICU. When infants were first admitted to the NICU, fathers were known to prioritize their partner’s needs over their own. Following the admission to NICU and the discharge home, the relationship between father and partner became strained. This strain was reported in a long-term prospective study of 20 parents of extremely low birth weight infants after the first year of life in which 58% of parents reported tension in the husband-wife relationship. Although the relationship pressure noted in other studies was not identified in the present study, health care professionals should question and discuss the health of the partner relationship following discharge from the NICU and make appropriate referrals for couples to receive ongoing relationship support.

Alberta FICare had a profound effect on the pre- and post-discharge experiences of fathers. A literature review of 50 studies that explored the phenomenon of transitioning home from hospital of parents of preterm infants, < 370/7 weeks GA, identified themes that included: disruption of the parental role development, psychological consequences of preterm birth such as post-traumatic stress disorder, and learning caregiving and parenting. In the current study, fathers in both the standard care and Alberta FICare groups felt prepared to go home at discharge. However, fathers in the Alberta FICare program were more confident and prepared. They attributed this confidence to their involvement with their child and to the teaching they received while in the NICU. They described the transition to home as being easy as it continued to be more of the same routine but at home. Though fathers in the standard care group discussed
feeling prepared to go home, they were more aware of the resulting shift in care when they transitioned to being full time parents. The experiences of fathers in the Alberta FICare program were different to that recounted in an analysis of 13 fathers’ lived experiences in the first 3 years following their child’s very preterm birth.\textsuperscript{45} In this study, a theme of ‘struggling to endure’ was generated, which described the physical and mental exhaustion fathers experienced when transitioning to full-time day-to-day care.\textsuperscript{45} Alberta FICare may be beneficial to fathers in easing the initial transition home as they have become experienced with the demands of their baby.

Despite the preparedness to go home and the involvement they had in the NICU, fathers had the concern however brief or insignificant, of the sudden lack of medical oversight after discharge. In a descriptive qualitative study of the experiences of 20 couples of preterm infants, 28\textsuperscript{0/7} to 32\textsuperscript{6/7} weeks GA, pre- and post- discharge from the NICU, parents felt prepared to go home because of the teaching they received while in the NICU; however, at the time of going home they continued to express anxiety about taking their infant home without the constant monitoring and support from nursing and medical staff.\textsuperscript{44} Fathers in the current study expressed that having a period of post-NICU follow-up at home would be beneficial to help with this anxiety. Neonatal home care (NHC) is a model of care that allows parents to care for their infants at home with supportive care that is provided by paediatric nurse specialists following their initial stay in the NICU.\textsuperscript{81} In this model, the infants are physiologically stable but still have medical needs. In Sweden, 22 parents in this home care setting were interviewed and they found that the NHC linked the trust and the reliance from the NICU and established it in the home. The NHC provided opportunities for telephone availability and home visits, which reinforced the feeling to parents that they were not abandoned post-discharge from the NICU.\textsuperscript{81} Considering the findings from the present study, fathers desired an intervention to bridge the gap between NICU
care to home life and models such as the NHC was a good example of an intervention that could fulfill this need. Regardless of their perceived support by the NICU following discharge home, all fathers in both the FICare and standard care group had a period of adjustment when bringing home their infant. The FICare program helped ready fathers for discharge and reduced their delay into parenthood. The program also had the potential if expanded in the future to provide post-discharge follow-up, which was an expressed need by fathers.

Fathers expressed that the bonding they experienced with their child correlated directly to the relative amount of involvement they had with their child. Scism and Cobb, 2017 analyzed 28 studies in an integrative review of interventions that promoted father-infant bonding. Interventions that promoted bonding including opportunities for physical contact such as skin-to-skin contact, umbilical cord cutting, and involvement during birth were considered the most effective by fathers. In a descriptive study of 20 interviewed fathers regarding their feelings about skin-to-skin contact, fathers overall felt the experience was both gratifying and challenging, as they might have provided skin-to-skin contact while exhausted or in an uncomfortable position but it allowed them to feel more included. In this study, fathers in the Alberta FICare program were more likely to express that they felt bonded early with their infant as they were physically more involved in the care of their infant early on compared to the standard care group. Despite the level of bonding achieved, in both groups, there continued to exist some anxiety over the health and wellbeing of their child post-NICU stay. This mostly manifested as a brief stress in the initial post-NICU discharge period until their infant grew to the size and achieved milestones like that of other infants their age. For others, the anxiety continued for the years following discharge from the NICU. Regardless, all fathers shared a positive view of their child. This sense of relief over their child’s positive development and the overarching
pride fathers have for their children has been reported elsewhere. Fathers want and need to feel bonded to their children. Early physical involvement and continuous reassurance over their infant’s health and wellbeing is necessary to facilitate their transition to parenthood.

This study of fathers in Alberta FICare and their NICU experiences had many strengths. To our knowledge, this was the first study attempting to explore the unknown phenomenon of the fathers’ experience in a FICare program moving beyond what was previously known about the fathers’ experience in the NICU. As qualitative research, the study drew strengths from exploring all aspects of the fathers’ experience as expressed by fathers in self-reflection but also confirmed by the detailed live accounts of these fathers during their NICU admission in their journal entries. The study drew rigor from having a detailed audit trail, analysis done by external reviewers, and member checking. All fathers were given the developed themes to reflect on their own personal experience and their replies were consistent with the presented results.

There were a few limitations to this study. As this study was qualitative, by its very nature was subjective and could be biased by the researchers’ interpretation of the data. In particular, the researcher AS who conducted the interviews and did the primary analysis is a female neonatologist with minimal experience in the area of qualitative research and also risked bias based on gender and occupation. The other contributors to the analysis include KB, RA, TS, and VS, all university affiliated researchers, with varying experience in qualitative research, and background knowledge in the area of fathers’ experiences in the NICU. This limitation was circumvented by checking themes and sub-themes of fathers in previous studies for associations, by creating an audit trail with self-reflection, by external review of developed codes and themes throughout the analysis process, and by member checking with the fathers to confirm or disaffirm theme development of their experiences. The explored outcomes were restricted as
themes were generated solely from fathers’ recollection of experiences versus in the moment lived experience at the time of admission and during hospital stay. This limitation was supported by having journal entries with detailed accounts of the father experience as it occurred. The FICare program in the Level II NICUs was directed at mothers and fathers were indirectly involved through their partners. This difference in recruitment proved not to be a disadvantage as fathers of whose partners were involved in Alberta FICare described feeling more involved but they also described wanting more independence and support that was specifically targeted to them and not just their partners. This need can be addressed in future interventions targeting parents. Lastly, the fathers recruited in this study were of similar ethnicity and income levels, which was not reflective of the diverse population of families in the NICU.

The burden of preterm birth is great. Globally, 15 million infants per year are born preterm, < 37\(^0/7\) weeks gestation, and approximately 80% of these infants are born between 32\(^0/7\) – 36\(^6/7\) weeks GA.\(^{82,83}\) Historically, these infants have been cared for in specialized care nurseries by health care professionals with minimal involvement of parents.\(^{84}\) It was not until the 1990s, that family centered care became a priority for hospitals and health care professionals.\(^{85}\) With this culture change, came the knowledge surrounding parental experiences in the NICU including increased stress, anxiety, and decreased self-efficacy for caring for their infants.\(^{32,41,47,86,87}\) This NICU experience disrupted the normal transition into parenthood. Over the years, the focus has been on the maternal experience and interventions targeted at improving their experiences.\(^{48,51,88}\) However, it is known that fathers have a profound role and impact on their partner’s experiences, their infant’s outcomes, and are themselves significantly impacted by the NICU experience.\(^{36}\) FICare was developed to target all aspects of the NICU experience for families by empowering parents to care for their child while in the NICU, as soon as they were
able after admission. Fathers of preterm infants enrolled in Alberta FICare benefitted from a positive and supportive environment that increased their independence and involvement, which carried through into the post-discharge NICU period and beyond.

There are many future areas of research for improving the fathers experience in the NICU following this study. Future research in this area should include piloting and evaluating father-specific programs, from pre-admission to post-discharge, directly aimed at improving the stress and anxiety in fathers, their involvement with the care and well-being of their infants, and their level of communication with health professionals. Fathers have unique needs compared to their partners and interventions should include (1) a designated support person during labor and delivery and through the initial NICU admission to help guide fathers through the process and facilitate their early involvement with their infants (2) a supportive environment that increases paternal involvement and independence when caring for their infants and (3) a post-NICU follow-up process that helps fathers navigate the transition home and the challenges they face. Focusing on fathers in the future will not only lead to improved experiences for families but may impact the long-term outcomes of their infant and their family.

F. CONCLUSIONS

Fathers of preterm infants born between 32\(^{0/7}\) to 34\(^{6/7}\) weeks GA enter the NICU with heightened levels of stress, uncertainty, and fear with little expectation of the NICU environment. Through their stay in the NICU they gained confidence in the care of their preterm infant when they felt supported, involved, and received adequate communication from the healthcare professional team. This positive experience has a “carry over” effect post-discharge when parents are well prepared for discharge home. Fathers enrolled in Alberta FICare attributed
their level of confidence and positive NICU experience that continued post-discharge to the level of attention and care they received at the bedside. FICare has the potential to support fathers in the NICU, enriching their NICU experience, and ultimately improving family outcomes.
G. REFERENCES


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68. Tuckett AG. Part II. Rigour in qualitative research: complexities and solutions: Anthony G Tuckett outlines the strategies and operational techniques he used to attain rigour in a qualitative research study through relying on Guba and Lincoln’s trustworthiness criterion. Research strategies such as use of personal journals, audio recording and transcript auditing, and operational techniques including triangulation strategies and peer review, are examined. Nurse researcher. 2005;13(1):29-42.


Table 1: Demographics of fathers who completed a semi-structure interview (N = 13)

<table>
<thead>
<tr>
<th></th>
<th>Intervention group (N = 9)</th>
<th>Standard care alone (N = 4)</th>
</tr>
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<tbody>
<tr>
<td><strong>Age, mean (SD)</strong></td>
<td>35.2 (3.5)</td>
<td>41.5 (11.7)</td>
</tr>
<tr>
<td><strong>Marital Status</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Married, n (%)</td>
<td>8 (89)</td>
<td>3 (75)</td>
</tr>
<tr>
<td>Common-Law, n (%)</td>
<td>0 (0)</td>
<td>1 (25)</td>
</tr>
<tr>
<td>Divorced, n (%)</td>
<td>1 (11)</td>
<td>0 (0)</td>
</tr>
<tr>
<td><strong>Number of children</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>1, n (%)</td>
<td>3 (33)</td>
<td>1 (25)</td>
</tr>
<tr>
<td>2, n (%)</td>
<td>4 (44)</td>
<td>3 (75)</td>
</tr>
<tr>
<td>3, n (%)</td>
<td>2 (22)</td>
<td>0 (0)</td>
</tr>
<tr>
<td><strong>Gestational age, mean (SD)</strong></td>
<td>34.0 (0.9)</td>
<td>33.1 (0.8)</td>
</tr>
<tr>
<td><strong>Employed, n (%)</strong></td>
<td>9 (100)</td>
<td>4 (100)</td>
</tr>
<tr>
<td><strong>Income</strong></td>
<td></td>
<td></td>
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<tr>
<td>60-80,000, n (%)</td>
<td>2 (22.2)</td>
<td>0 (0)</td>
</tr>
<tr>
<td>&gt;80,000, n (%)</td>
<td>7 (77.8)</td>
<td>4 (100)</td>
</tr>
<tr>
<td><strong>Nationality</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Canadian, n (%)</td>
<td>9 (100)</td>
<td>4 (100)</td>
</tr>
<tr>
<td><strong>Ethnicity</strong></td>
<td></td>
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<td>North American, n (%)</td>
<td>4 (44)</td>
<td>1 (25)</td>
</tr>
<tr>
<td>European, n (%)</td>
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</tr>
<tr>
<td>British Isles, n (%)</td>
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<td>3 (75)</td>
</tr>
<tr>
<td><strong>Language</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>English, n (%)</td>
<td>9 (100)</td>
<td>4 (100)</td>
</tr>
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</table>
Figure 1: Example of the triangulation process of the semi-structured interviews with the journal entries

- Semi-structured interviews
  - Expected early delivery lead to greater preparation
  - Unexpected early delivery lead to surprise and fear

- Journal entry
  - Unexpected early delivery
  - Quick delivery
  - Fear and anxiety

Mental preparation affects the emotional experience of early delivery
Figure 2: Thematic ‘map’ of analysis of the Pre-NICU experience for interviewed fathers

- Expected early delivery lead to greater preparation
- Unexpected early delivery lead to surprise and fear
- Overwhelming and rushed environment
- Many activities occurring at once
- Many individuals in the birthing environment
- Reassurance in care received
- Uncertainty and the fear of the unknown
- Perception of being in the way
- Feeling lost and out of place
- Positive effect of holding
- Support for early involvement
- NICU preparation around infant expectations
- Logistical onboarding
- Communication around medical care a positive experience
- Lack of communication creates a negative experience
- Mental preparation affects the emotional experience of early delivery
- Perception of a rushed environment regardless of preparation
- Reassurance of medical care led to reduced anxiety in the face of an otherwise difficult experience
- Fear of the unknown leads to an emotionally terrifying experience
- Determining one’s role in the physical environment
- Supporting fathers for early involvement had a positive effect on initial experience
- NICU preparation involves a holistic approach of both mental preparation around infant medical care and the routine processes of the NICU
- Level of communication helps ease uncertainty and increases assurance by medical care
Figure 3: Thematic ‘map’ analysis of the pre-NICU experience for journal entry fathers

- Unexpected, early delivery
- Quick delivery
- Fear and anxiety
- Uncertainty
- Fear of the unknown
- Medical involvement
- Reassured by medical team
- Concern for infant
- Reassurance by medical team
- Communication

Mental preparation affects the emotional experience of early delivery
Fear of the unknown leads to an emotionally terrifying experience
Reassurance of medical care led to reduced anxiety in the face of an otherwise difficult experience
Level of communication helps ease uncertainty and increases assurance by medical care
Figure 4: Thematic ‘map’ analysis of the NICU experience for interviewed fathers

- Identifying and establishing role
- Dad as secondary parent
- Support role
- Wanting involvement
- Information gatherers
- Father-specific support

- Encouraged involvement as a positive
- Supported independence increased comfort and reduced anxiety
- Inclusive environment and nursing attention
- Needing permission to parent and wanting more independence

- Knowledgeable
- Personal touch and attention
- Supportive
- Reassurance

- Fathers searching for and identifying their role in the NICU, wanting more involvement, and equal support to their partners
- Fathers support and benefit from parenting with supervision in a positive NICU environment that encourages parental independence
- Effect of medical staff
<table>
<thead>
<tr>
<th>Communication and explanation</th>
<th>Importance of effective communication with fathers as the information gatherers</th>
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<tr>
<td>Engagement</td>
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<td>Information gathering</td>
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<tr>
<td>A welcoming environment</td>
<td>Impact of physical environment</td>
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<tr>
<td>Rule following</td>
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<tr>
<td>Effect of space</td>
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<td>Noise level</td>
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<td>Role modeling</td>
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<td>Uncomplicated NICU stay</td>
<td>Perceived health of infant</td>
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<td>Medical complications</td>
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<td>Medical realities of prematurity</td>
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<td>Impact of external support</td>
<td>Balancing home, work, and hospital life</td>
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<td>Competing demands between home and hospital</td>
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<td>Establishing a routine</td>
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<tr>
<td>Working through the challenges of stress and fatigue</td>
<td>Teamwork through adversity</td>
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<td>Relationship strengthening</td>
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<tr>
<td>Physical separation</td>
<td></td>
</tr>
<tr>
<td>Communication</td>
<td></td>
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</tbody>
</table>
Figure 5: Thematic ‘map’ analysis of the NICU experience for journal entry fathers

- Searching for a role
- Love for child
- Seeking support
- Physical involvement
- Supportive environment
- Reassurance by medical staff
- Effective communication
- Perceived mistreatment
- Information gathering
- Multiple sourced information
- Effect of space
- Lack of control over others
- Creating a home environment
- Medical realities of a preterm infant
- Medical complications
- Establishing a routine
- Competing external demands
- NICU a challenge to family
- Fathers searching for and identifying their role in the NICU, wanting more involvement, and equal support to their partners
- Fathers support and benefit from parenting with supervision in a positive NICU environment that encourages parental independence
- Effect of medical staff
- Importance of effective communication with fathers as the information gatherers
- Impact of physical environment
- Perceived health of infant affects experience
- Balancing home, work and hospital life
- Teamwork through adversity
Figure 6: Thematic ‘map’ analysis of the post-discharge from NICU experience for interviewed fathers

- NICU involvement
- Determination of discharge and communication
- Support from medical staff

- Stressful awareness of the lack of medical oversight
- Post-discharge follow-up

- Starting over
- Gaining confidence
- Adjusting to 24/7 care

- Positive view of the child irrespective of prematurity
- Bonding correlated to level of involvement
- Anxiety over health and wellbeing of child post-NICU

- Preparation for discharge home
- Post-NICU medical care and support
- Recalibrating the care and establishing a new routine
- Relationship to child
Figure 7: Thematic ‘map’ analysis of the post-discharge from the NICU experience for journal entry fathers

- Readiness for discharge
- Gaining confidence
- Faith in child's achievements

- Stressful awareness of lack of medical oversight

- Positive view of the child irrespective of prematurity
- Strength through adversity

- Preparing for discharge home
- Post-NICU medical care and support
- Relationship to child
APPENDIX I: Demographic Data Collection Form

To give us a better idea of who is participating in our study, please tell us a bit about yourself.

Please tell us your age: _______ yrs

What is your marital status?

☐ Single
☐ Married
☐ Common-law
☐ Live in partner
☐ Divorced
☐ Separated
☐ Widowed
☐ Don't know
☐ Prefer not to answer

How many CHILDREN under the age of 18 years live in your household (related to you or not)? ______

Have you had a previous preterm infant born < 37 weeks gestational age?

☐ Yes
☐ No

If you answered yes to the previous question, did your infant require admission to the neonatal intensive care unit?

☐ Yes
☐ No

What was the gestational age of your previous preterm infant? ______

What is your present employment status?

☐ Employed full time (30 or more hours/week)
☐ Employed part time (less than 30 hours/week)
☐ Unemployed (but LOOKING for work)
☐ Not in the labor force (NOT LOOKING for work)
☐ Student employed part-time or full-time
☐ Student not employed
☐ Retired
☐ Homemaker
☐ Paternity leave
☐ On disability
☐ Other (please specify) ______
☐ Don't know
☐ Prefer not to answer
What is the TOTAL income of ALL members of your household for the past year, BEFORE taxes and deductions?

- Less than $20,000
- $20,000 to $39,999
- $40,000 to $59,999
- $60,000 to $79,999
- More than $80,000
- Don't know
- Prefer not to answer

Were you born in Canada?

- Yes
- No
- Prefer not to answer

17. a) If no, where were you born?
____________________________________________

17. b) How long have you lived in Canada?

- Less than 1 year
- 1-5 years
- 6-10 years
- More than 10 years

People living in Canada come from many different ethnic origins as defined by Statistics Canada (Please select only one). What were the ethnic or cultural origins of your ancestors?

- North American (e.g. American, Canadian, including French Canadian)
- Aboriginal (e.g., First Nations, Inuit, or Metis)
- British Isles (e.g. English, Irish, Scottish, Welsh)
- French (e.g. French, Acadian)
- European
- African (e.g. Congolese, East African, Ethiopian, Kenyan)
- Arab (e.g. Egyptian, Lebanese, Moroccan, Palestinian, Tunisian)
- South Asian (e.g., East Indian, Pakistani, Sri Lankan)
- East and Southeast Asian (e.g., Vietnamese, Cambodian, Malaysian, Laotian)
- West Asian (e.g., Iranian, Israeli, Afghan, Armenian)
- Latin, Central, and South American (e.g. Mexican, Colombian)
- Caribbean origins (e.g. Cuban, Dominican, Haitian, Puerto Rican)
- Oceania (e.g. Australian, New Zealander, Hawaiian, Samoan)
- Other: Please specify_________________
- Prefer not to answer

What language do you speak most often at home?

- English
- French
☐ Other (please specify) ______________________
☐ Prefer not to answer
APPENDIX II: Interview Guide for Fathers of Moderate and Late Preterm Infants

1. Can we start with what was it like to hear the news that your child was about to be born? What was the childbirth and delivery experience like? What did you expect upon learning your baby would be born preterm? What was your expectation of the NICU?

2. Tell me about your NICU experience
Prompts: What were your expectations or concerns upon admission? How were these expectations/concerns realized? What was helpful during your NICU admission? What were the challenges you faced during your baby’s NICU admission?
Probe: Consider experiences with staff, other parents, visitors, other needs

3. Tell me about your involvement in the Family Integrated Care Program
Prompts: How did you hear about the program? Why did you get involved in the program? How was the program beneficial to you? What aspects of the program do you think should be improved? How do you think the program could be changed to support fathers during their NICU stay?

4. Can you describe your experience of being discharged from the NICU?
Prompts: What were your feelings about discharge? What did you expect? How were you prepared for discharged? Did you feel prepared to go home? What would be beneficial to you to help with the transition to home?

5. Describe your transition into parenthood? What was your experience in becoming a father?
Prompt: How did the admission to the NICU affect your transition to parenthood?
Probe: Consider the emotional, psychosocial, mental aspect
Prompt: What would be helpful in the transition to parenthood while in the NICU? What have you found helpful in parenting your child?
Probe: Consider support groups, peer groups, online resources, partner, family, friends

6. How would you describe your relationship with your child?
Prompts: How would you describe your child? Happy? Playful? Difficult? How has your relationship with your child changed with time?

7. How would you describe your relationship with your partner? How has your relationship changed over time?

Concluding questions:
8. Finally, thank you for your time. Are there any other questions I should ask you that will shed light on your NICU experience? On your FICare experience?
9. Are there any other things that you would like to share about your experience as a father?
10. Do you have anything else to tell me about how the NICU could do a better job for transitioning fathers into parenthood of a preterm infant?
11. Do you have any questions that you would like to ask of me?
APPENDIX III: Consolidated Criteria for Reporting Qualitative Studies (COREQ)

<table>
<thead>
<tr>
<th>No.</th>
<th>Item</th>
<th>Guide questions:description</th>
<th>Reported on Page #</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td><strong>Domain 1: Research team and reflexivity</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td><strong>Personal Characteristics</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>1.</td>
<td>Interviewer/facilitator</td>
<td>Which author/s conducted the interview or focus group?</td>
<td>20</td>
</tr>
<tr>
<td>2.</td>
<td>Credentials</td>
<td>What were the researcher’s credentials? E.g. PhD, MD</td>
<td>58</td>
</tr>
<tr>
<td>3.</td>
<td>Occupation</td>
<td>What was their occupation at the time of the study?</td>
<td>58</td>
</tr>
<tr>
<td>4.</td>
<td>Gender</td>
<td>Was the researcher male or female?</td>
<td>58</td>
</tr>
<tr>
<td>5.</td>
<td>Experience and training</td>
<td>What experience or training did the researcher have?</td>
<td>58</td>
</tr>
<tr>
<td></td>
<td><strong>Relationship with participants</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>6.</td>
<td>Relationship established</td>
<td>Was a relationship established prior to study commencement?</td>
<td>20</td>
</tr>
<tr>
<td>7.</td>
<td>Participant knowledge of the interviewer</td>
<td>What did the participants know about the researcher? e.g. personal goals, reasons for doing the research</td>
<td>20</td>
</tr>
<tr>
<td>8.</td>
<td>Interviewer characteristics</td>
<td>What characteristics were reported about the interviewer/facilitator? e.g. Bias, assumptions, reasons and interests in the research topic</td>
<td>59</td>
</tr>
<tr>
<td></td>
<td><strong>Domain 2: study design</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td><strong>Theoretical framework</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>9.</td>
<td>Methodological orientation and Theory</td>
<td>What methodological orientation was stated to underpin the study? e.g. grounded theory, discourse analysis, ethnography, phenomenology, content analysis</td>
<td>17</td>
</tr>
<tr>
<td></td>
<td><strong>Participant selection</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>10.</td>
<td>Sampling</td>
<td>How were participants selected? e.g. purposive, convenience, consecutive, snowball</td>
<td>19</td>
</tr>
<tr>
<td>11.</td>
<td>Method of approach</td>
<td>How were participants approached? e.g. face-to-face, telephone, mail, email</td>
<td>19</td>
</tr>
<tr>
<td>12.</td>
<td>Sample size</td>
<td>How many participants were in the study?</td>
<td>23</td>
</tr>
<tr>
<td>13.</td>
<td>Non-participation</td>
<td>How many people refused to participate or dropped out? Reasons?</td>
<td>23</td>
</tr>
<tr>
<td></td>
<td><strong>Setting</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>14.</td>
<td>Setting of data collection</td>
<td>Where was the data collected? e.g. home, clinic, workplace</td>
<td>20</td>
</tr>
<tr>
<td>Question</td>
<td>Description</td>
<td>Rating</td>
<td></td>
</tr>
<tr>
<td>-------------------------------------------------------------------------</td>
<td>----------------------------------------------------------------------------</td>
<td>--------</td>
<td></td>
</tr>
<tr>
<td>15. Presence of non-participants</td>
<td>Was anyone else present besides the participants and researchers?</td>
<td>23</td>
<td></td>
</tr>
<tr>
<td>16. Description of sample</td>
<td>What are the important characteristics of the sample? e.g. demographic data, date</td>
<td>23</td>
<td></td>
</tr>
</tbody>
</table>

**Data collection**

<table>
<thead>
<tr>
<th>Question</th>
<th>Description</th>
<th>Rating</th>
</tr>
</thead>
<tbody>
<tr>
<td>17. Interview guide</td>
<td>Were questions, prompts, guides provided by the authors? Was it pilot tested?</td>
<td>20</td>
</tr>
<tr>
<td>18. Repeat interviews</td>
<td>Were repeat interviews carried out? If yes, how many?</td>
<td>N/A</td>
</tr>
<tr>
<td>19. Audio/visual recording</td>
<td>Did the research use audio or visual recording to collect the data?</td>
<td>20</td>
</tr>
<tr>
<td>20. Field notes</td>
<td>Were field notes made during and/or after the interview or focus group?</td>
<td>20</td>
</tr>
<tr>
<td>21. Duration</td>
<td>What was the duration of the interviews or focus group?</td>
<td>20</td>
</tr>
<tr>
<td>22. Data saturation</td>
<td>Was data saturation discussed?</td>
<td>21</td>
</tr>
<tr>
<td>23. Transcripts returned</td>
<td>Were transcripts returned to participants for comment and/or correction?</td>
<td>N/A</td>
</tr>
</tbody>
</table>

**Domain 3: analysis and findings**

**Data analysis**

<table>
<thead>
<tr>
<th>Question</th>
<th>Description</th>
<th>Rating</th>
</tr>
</thead>
<tbody>
<tr>
<td>24. Number of data coders</td>
<td>How many data coders coded the data?</td>
<td>21</td>
</tr>
<tr>
<td>25. Description of the coding tree</td>
<td>Did authors provide a description of the coding tree?</td>
<td>21</td>
</tr>
<tr>
<td>26. Derivation of themes</td>
<td>Were themes identified in advance or derived from the data?</td>
<td>21</td>
</tr>
<tr>
<td>27. Software</td>
<td>What software, if applicable, was used to manage the data?</td>
<td>N/A</td>
</tr>
<tr>
<td>28. Participant checking</td>
<td>Did participants provide feedback on the findings?</td>
<td>21</td>
</tr>
</tbody>
</table>

**Reporting**

<table>
<thead>
<tr>
<th>Question</th>
<th>Description</th>
<th>Rating</th>
</tr>
</thead>
<tbody>
<tr>
<td>29. Quotations presented</td>
<td>Were participant quotations presented to illustrate the themes/findings? Was each quotation identified? e.g. participant number</td>
<td>24-51</td>
</tr>
<tr>
<td>30. Data and findings consistent</td>
<td>Was there consistency between the data presented and the findings?</td>
<td>24-51</td>
</tr>
<tr>
<td>31. Clarity of major themes</td>
<td>Were major themes clearly presented in the findings?</td>
<td>24</td>
</tr>
<tr>
<td>32. Clarity of minor themes</td>
<td>Is there a description of diverse cases or discussion of minor themes?</td>
<td>24-51</td>
</tr>
</tbody>
</table>
APPENDIX IV: Research Ethics Board Approval Documents

RIS Protocol Number: 35244
Approval Date: 4-Oct-18
PI Name: Dr Vibhuti Shah
Division Name:

Dear Dr Vibhuti Shah:

Re: Your research protocol application entitled, “Experiences of fathers of preterm infants in a family integrated care program: A qualitative study”

The Health Sciences REB has conducted a Delegated review of your application and has granted approval to the attached protocol for the period 2018-10-04 to 2019-10-04.

Please note that this approval only applies to the use of human participants. Other approvals may be needed.

Please be reminded of the following points:

- **An Amendment** must be submitted to the REB for any proposed changes to the approved protocol. The amended protocol must be reviewed and approved by the REB prior to implementation of the changes.

- **An annual Renewal** must be submitted for ongoing research. You may submit up to 6 renewals for a maximum total span of 7 years. Renewals should be submitted between 15 and 30 days prior to the current expiry date.

- **A Protocol Deviation Report** (PDR) should be submitted when there is any departure from the REB-approved ethics review application form that has occurred without prior approval from the REB (e.g., changes to the study procedures, consent process, data protection measures). The submission of this form does not necessarily indicate wrong-doing; however follow-up procedures may be required.

- **An Adverse Events Report (AER)** must be submitted when adverse or unanticipated events occur to participants in the course of the research process.

- **A Protocol Completion Report** (PCR) is required when research using the protocol has been completed. For ongoing research, a PCR on the protocol will be required after 7 years, (Original and 6 Renewals). A continuation of work beyond 7 years will require the creation of a new protocol.

- If your research is funded by a third party, please contact the assigned Research Funding Officer in Research Services to ensure that your funds are released.

Best wishes for the successful completion of your research.
CERTIFICATION OF INSTITUTIONAL ETHICS APPROVAL

Ethics approval for the following research has been renewed by the Conjoint Health Research Ethics Board (CHREB) at the University of Calgary. The CHREB is constituted and operates in compliance with the *Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans* (TCPS 2); Health Canada Food and Drug Regulations Division 5, Part C; ICH Guidance E6: Good Clinical Practice and the provisions and regulations of the Health Information Act, RSA 2000 c H-5.

**Ethics ID:** REB17-1422_REN1

**Principal Investigator:** Karen Marie Benzies

**Co-Investigator(s):** Amy Shafey
Thomas Stelfox

**Student Co-Investigator(s):** Catherine Ringham

**Study Title:** Experiences of Fathers of Preterm Infants in a Family Integrated Care Program: A Qualitative Study

**Sponsor:**

**Effective:** Saturday, September 22, 2018  
**Expires:** Sunday, September 22, 2019

**Restrictions:**

This Certification is subject to the following conditions:

1. Approval is granted only for the research and purposes described in the application.
2. Any modification to the approved research must be submitted to the CHREB for approval.
3. An annual application for renewal of ethics certification must be submitted and approved by the above expiry date.
4. A closure request must be sent to the CHREB when the research is complete or terminated.

**Approved By:**  
Stacey A. Page, PhD, Chair, CHREB

**Date:**  
Thursday, August 23, 2018
APPENDIX V: Consent Forms for Participants

CONSENT FORM

TITLE: Experiences of Fathers of Preterm Infants in a Family Integrated Care Program: A Qualitative Study

INVESTIGATORS:
Principal investigator: Dr. Karen Benzies
Co-investigators:
Dr. Amy Shafey
Dr. Vibhuti Shah
Dr. Tom Stelfox
Dr. Reshma Amin

Main contact phone number: Dr. Karen Benzies (403) 220-2294

This consent form is only part of the process of informed consent. It should give you the basic idea of what the research is about and what your participation will involve. If you would like more detail about something mentioned here, or information not included here, please ask. Take the time to read this carefully and to understand any accompanying information. You will receive a copy of this form.

BACKGROUND

Globally, 15 million infants are born preterm (defined as a baby born at < 37 weeks gestational age). Approximately 80% of these infants are born moderate to late preterm (32⁰⁶⁷/₇ – 36⁶⁷/₇ weeks gestational age). In the past few years, research around parental experiences in the neonatal intensive care unit has shown that fathers are significantly impacted by the neonatal intensive care unit (NICU) experience. The Family Integrated Care (FICare) Program was created to target all aspects of the NICU experience for families by empowering them to care for their child while in the NICU. However, there is no information to-date about fathers’ experiences with this program and whether their involvement has improved their NICU experiences.

This qualitative study is part of a larger multi-center, randomized controlled trial of FICare for caregivers of moderate and late preterm infants (32⁰⁶⁷/₇-34⁶⁷/₇ weeks GA) across Alberta. This portion of the study involves video-conferencing interviews with fathers of moderate and late preterm infants who were enrolled in the FICare study. Approximately 30 fathers will be asked to participate in the study.

WHAT IS THE PURPOSE OF THE STUDY?
This study aims to describe the experiences of fathers of moderate and late preterm infants in a FICare Program to improve fathers’ NICU experience and develop father-specific NICU programs. You are being invited to participate in this study because your family was enrolled in the main FICare study.

WHAT WOULD I HAVE TO DO?

- Complete a questionnaire that provides information about yourself
- Participate in one video-conferencing interview via Skype™ using your personal computerized device when your child is approximately 2 months corrected gestational age
- The interview will be audio-recorded only and not video-recorded
- The interview will occur at a time mutually agreeable to yourself and the researcher.
- The interview will be approximately 45 mins to 1 hour in duration
- You will be asked to answer the questions surrounding your experiences in the NICU, in the FICare program, your transition to parenthood, and your experiences parenting
- You will receive a summary via email of the initial results for your feedback, which is not mandatory for participation in this study

WHAT ARE THE RISKS?

The birth of a child born preterm is known to be a source of stress and distress for the parents. Interviews carry the risk of reliving that stress. If you feel during or following the interview that you are emotionally stressed, disturbed, or upset, please let the research investigator know, the interview may be paused or stopped at any time, and support resources will be made available to you. Also, you are free to skip any questions that you do not wish to answer.

WILL I BENEFIT IF I TAKE PART?

If you agree to participate in this study there may or may not be a direct benefit to you. The information we get from this study may help us to provide better support in the future for fathers of moderate to late preterm infants.

DO I HAVE TO PARTICIPATE?

Participation in this research study is strictly voluntary and you may withdraw from the study at any time. If you wish to withdraw from the study during or after the interview please let the research investigator know. Following your withdrawal, all data collected from your participation will be removed. The exception where it will not be possible to withdraw data will be when the data has been presented or published.

WILL I BE PAID FOR PARTICIPATING, OR DO I HAVE TO PAY FOR ANYTHING?

Your participation in this study is strictly voluntary. You will not be paid for participation and you will not have to pay to participate.
WILL MY RECORDS BE KEPT PRIVATE?

- Interviews will be digitally audio-recorded and transcribed verbatim. All digitally audio-recorded files will be deleted at the time of study completion when the data is presented or published.
- Access to the interview transcript will be limited to Dr. Amy Shafey and the co-investigators as listed on this form. The transcript of the interviews will be analyzed by Dr. Amy Shafey as a research investigator and will be reviewed by the other co-investigators listed on this form.
- Any summary interview content, or direct quotations from the interview, that are made available through academic publication or other academic outlets will be anonymized so that you cannot be identified, and care will be taken to ensure that other information in the interview that could identify you is not revealed.

SIGNATURES

Your signature on this form indicates that you have understood to your satisfaction the information regarding your participation in the research project and agree to participate as a participant. In no way does this waive your legal rights nor release the investigators or involved institutions from their legal and professional responsibilities. You are free to withdraw from the study at any time without jeopardizing your health care. If you have further questions concerning matters related to this research, please contact:

Dr. Karen Benzies (403) 220-2294
Or
Dr. Amy Shafey (403) 944-3359

If you have any questions concerning your rights as a possible participant in this research, please contact the Chair, Conjoint Health Research Ethics Board, University of Calgary at 403-220-7990.

Participant’s Name

Signature and Date

Investigator/Delegate’s Name

Signature and Date

Witness’ Name

Signature and Date
The University of Calgary Conjoint Health Research Ethics Board has approved this research study.

A signed copy of this consent form has been given to you to keep for your records and reference.

RESOURCES

Listed below are resources accessible to you if you should feel distressed at any point in time during or after the telephone interview:

HEALTH LINK 811#

Distress Centre Calgary Helpline – 403.266.HELP (4357)
### APPENDIX VI: Tables of the Thematic Analysis of Fathers’ Experiences

#### APPENDIX VIa: Semi-structured interviews: Pre-NICU Experience

<table>
<thead>
<tr>
<th>Interview #</th>
<th>Meaning unit</th>
<th>Code</th>
<th>Sub-Theme</th>
<th>Theme</th>
</tr>
</thead>
<tbody>
<tr>
<td>9</td>
<td>We were kind of told that they might come out early. So, it wasn’t a shock… The few days leading up, I think [my wife] kind of felt like it was coming, so … our bags were ready and you know, we already had a kid, so mentally we were ready to go.</td>
<td>Expected early delivery</td>
<td>Mental preparation</td>
<td>Expected early delivery lead to greater preparation</td>
</tr>
<tr>
<td>2</td>
<td>Yeah I can’t imagine anyone going in, any father anyways, going into a multiple birth without taking all this training and it’s just be mind boggling you know cause we had a completely uneventful pregnancy. If I had gone in … without knowing what a twin multiples pregnancy could turn into I would’ve lost it right there</td>
<td>Mental preparation</td>
<td>Training</td>
<td>Mental preparation affects the emotional experience of early delivery</td>
</tr>
<tr>
<td>4</td>
<td>It was around 28 weeks that my wife went for a regular check-up and they noticed very high blood pressure … one good thing is that … they kind of prepared us for potentially having a 28 week old baby. We did get an opportunity to tour around the NICU, which was really good, it definitely made the experience when we did go there at 32 weeks a lot less overwhelming just because we had seen it.</td>
<td>Expected early delivery</td>
<td>Preparation</td>
<td>Reduced anxiety</td>
</tr>
<tr>
<td>9</td>
<td>I was a little bit worried. I mean truthfully, uh, we</td>
<td>Unexpected</td>
<td>Worry and fear</td>
<td>Unexpected delivery lead to</td>
</tr>
</tbody>
</table>
woke up at 3, 2 or 3 in the morning and her water, she was bleeding, so that was scary … we didn’t know if it was her water bursting … but it was really just gushing blood, so we panicked to the hospital, 

| 8 | I still thought … he’s at least another 4-5 weeks out before we can even think about delivering him anyways. So maybe she’ll be in the hospital, maybe she’ll be on bed rest, whatever. So I took my daughter to my parents place and dropped her off … and when I got back, uh, they were saying ok, it’s time to deliver. So very scary for us obviously. | Unexpected  
Worry and fear |

| 3 | It was kind of a bit of a shock for us. … we got a call from [the hospital] saying to my spouse that we need to come in and clarify some bloodwork … We were totally blindsided … when the … obstetrician came in and said ‘he needs to come out.’ We were just like [showing face of shock and surprise]. | Unexpected  
Shock |

| 6 | It was all pretty go, go, go. | Quick delivery  
Overwhelming  
Rushed |

| 7 | It was a lot going on. And so my wife was on her own and then all of a sudden, now. Now it’s coming, and I’m basically following. | Fast-paced  
environment  
Many activities occurring at once  
Perception of rushed environment regardless of preparation |

| 3 | We were just kind of sitting around and the doctor’s like ok uh he’s coming out now and so it was all of a sudden … I was taking her toenail polish off there was like 4 or 5 | Fast-paced  
environment  
Many activities occurring at once  
Many activities occurring at once |
<table>
<thead>
<tr>
<th>5</th>
<th>5 people in the room right and the anesthesiologist comes in and says when did you have breakfast and she had a big breakfast and he’s like ok we need to hold off so it was like it was like ‘rush, rush, rush, rush, rush hard stop.’ … I wore out a pair of shoes walking up and down the hall … long story short that was kind of … the environment I guess.</th>
<th>Worry and fear</th>
<th>Intimidation by medical team</th>
<th>Many individuals in the birthing environment</th>
<th>Reassurance of medical care led to reduced anxiety in the face of an otherwise difficult experience.</th>
</tr>
</thead>
<tbody>
<tr>
<td>4</td>
<td>Hearing the little cry was uh a good relief. And I mean … even though its intimidating because there’s so many people in the room it’s also comforting that you know that they are going to get very good care and they are gonna do everything possible.</td>
<td>Worry and fear</td>
<td>Intimidation by medical team</td>
<td>Many individuals in the birthing environment</td>
<td>Reassurance of medical care led to reduced anxiety in the face of an otherwise difficult experience.</td>
</tr>
<tr>
<td>9</td>
<td>I felt super comfortable. …they prepped us … if we’re going to be anywhere right now, this is exactly where you wanna be. On an operating table in a room with like 10 super skilled people. Like, you’re in the perfect place, it doesn’t get any better. So, uh, we weren’t worried at all.</td>
<td>Preparation</td>
<td>Reassured by medical care</td>
<td>Reduced anxiety</td>
<td>Reassurance in care received</td>
</tr>
<tr>
<td>5</td>
<td>I found it to be very scary but the staff was very reassuring and very comfortable and you could tell that they knew their skill sets in and out and they knew what they were doing. It was very calming in that aspect.</td>
<td>Worry and fear</td>
<td>Reassured by medical care</td>
<td>Calming</td>
<td></td>
</tr>
<tr>
<td>9</td>
<td>I was a bit worried cause they’re gonna be premature and how are they gonna do</td>
<td>Uncertainty</td>
<td>Anxiety</td>
<td>Uncertainty and the fear of the unknown</td>
<td>Fear of the unknown leads to an</td>
</tr>
<tr>
<td></td>
<td>Those first couple of days were really rough because you weren’t really sure what was going to happen and then you sort of at that point have [to be] like we’re going to take it a day at a time and whatever happens sort of happens sort of thing.</td>
<td>Uncertainty Anxiety One day at a time</td>
<td>emotionally terrifying experience</td>
<td></td>
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<tr>
<td>11</td>
<td>I mean it’s scary, right, cause you don’t know, you kind of expect the worst, but luckily um, she was bigger than they thought, she was breathing on her own just fine, so she was, she did really well, but it’s the unknown right, you don’t know.</td>
<td>Uncertainty Fear of complications Reassured by good health</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>10</td>
<td>He was in there for so long, but still a lot of complications that we knew could happen and the concern was always I guess nagging about what could or you know, could not happen.</td>
<td>Uncertainty Fear of complications</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2</td>
<td>I think looking back and saying ‘nothing at work um would even bother me again.’ It’s like relative to how bad of an experience.</td>
<td>Worry and fear</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>9</td>
<td>You want to stay with your wife, but you also wanna be with your kids, and if you go with your new kids because you have to, you worry about how your wife’s doing … There’s definitely about a 30 minute period where it’s like really unclear. And you’re going to the NICU unit where you haven’t been before. So it’s not familiar, so it was a bit of a strange period. ...I wasn’t sure who I really wanted to be with at</td>
<td>Unsure of place Going back and forth Aimless wandering</td>
<td>Feeling lost and out of place Determining one’s role in the physical environment</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Page</td>
<td>Text</td>
<td>Positive effect/fathers for early involvement</td>
<td>Perception of being in the way</td>
<td>Perception of being in the way</td>
<td></td>
</tr>
<tr>
<td>------</td>
<td>-----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------</td>
<td>-----------------------------------------------</td>
<td>---------------------------------</td>
<td>---------------------------------</td>
<td></td>
</tr>
<tr>
<td>4</td>
<td>I was just kind of aimlessly wandering kind of back and forth between where she was going to be back to the recovery room, back to the NICU. Not sure what to do.</td>
<td>Positive effect of holding</td>
<td>Having involvement</td>
<td>Feeling useless</td>
<td></td>
</tr>
<tr>
<td>4</td>
<td>It’s your baby and you want to be there but also there’s a lot of people and I didn’t. You know even ‘where do I stand where I’m not in people’s way’</td>
<td>Perception of being in the way</td>
<td>Wanting involvement</td>
<td>Physically removing oneself</td>
<td></td>
</tr>
<tr>
<td>6</td>
<td>Because you know they’re trying to do their job. They’re trying to get everything done. And you just kind of want to see. Last thing they need is me fumbling around in their way, right? So I kind of stood off to the side and watched best I could. It’s one of those times you feel quite useless as a person. Because there’s not much I can do, right?</td>
<td>Perception of being in the way</td>
<td>Feeling useless</td>
<td>Physically removing oneself</td>
<td></td>
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<td>8</td>
<td>They were busy working on him and, uh, doing what they needed to do. So I just tried to stay out of the way… they were very inviting to bring me over, but uh, it was just me trying to stay out of the way basically at that point, as much as possible. And let them do their job, right…you just want to let them have their time to do their work</td>
<td>Perception of being in the way</td>
<td>Physically removing oneself</td>
<td>Avoiding involvement</td>
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<tr>
<td>13</td>
<td>Well and that’s just it. This is our first child that we’ve fought so hard to get her there. And … so I went back</td>
<td>Positive effect of holding</td>
<td>Positive effect of holding</td>
<td>Supporting fathers for early involvement had a positive</td>
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<tr>
<td>Page</td>
<td>Text</td>
<td>Effect on initial experience</td>
<td>Supporting comments</td>
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<td>10</td>
<td>It was actually pretty positive … I got to take him and hold him … for a little bit. Honestly, I don’t know how long it was because you’re just enjoying the moment. Positive effect of holding.</td>
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<td>12</td>
<td>So, there was a doctor … who actually gave me sh*t because… well, when she was born right, she was in an incubator, but he … said ‘get in here and start taking pictures, it won’t come again.’ I was trying to let them work. Physically removing oneself Perception of being in the way Supported early involvement.</td>
<td></td>
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<td>7</td>
<td>They were very encouraging to get that connection… the skin to skin right away, which … definitely helped Supported early involvement Positive experience.</td>
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<td>8</td>
<td>I had no idea what to expect or even what the NICU was, at that point. No expectation of the NICU. NICU preparation around infant expectations.</td>
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<td>4</td>
<td>Neonatologist who did come yes. And he was the one who arranged us to then do a tour with one of the nurses. Yeah, we kind of knew where we go in. What the room looks like. They actually did let us take a look at a 28 week old baby… and that was definitely shocking at first to see how small they are … and then when our baby was born it wasn’t shocking because we kind of knew what to expect. Told directly about NICU expectation Greater preparation.</td>
<td></td>
<td>NICU preparation involves a holistic approach of both mental preparation around infant medical care and the routine processes of the NICU.</td>
<td></td>
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<tr>
<td>8</td>
<td>It was a lot of this is how you get in and out and this is what you need to do, so we understood that you know, you’ve gotta wash your hands at the sink before you. Logistical onboarding NICU daily life.</td>
<td></td>
<td>Logistical onboarding.</td>
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</table>
go in, you buzz to get in and different things like that. Check in at the desk… you know, there’s a fridge here for the breast milk so that mom knows where to put her breast milk when she comes in and how to get it labeled.

| 3 | We kind of found it just through overhearing around some of the mechanics of just the logistics of being there. You know you can sign up for a parking pass right. So we’ve spent the daily parking amount everyday for like ten days before we just happened to overhear that um that you know you just go up there and say you’re in the NICU the parking pass is like 10 bucks for the rest of the month. Those kind of tiny components that maybe ease the burden a little bit ……so again I think that onboarding, orientation type

| 9 | I think that at some point if someone could give you some details about what that might entail, that would be beneficial, because like, I don’t know, like if it comes at 32 weeks, you might be in the hospital for 4-5 weeks … I don’t know if I would’ve been able to take 4-5 weeks off work, like that, financially, that could really strap you. Like, I think people need to be better prepared, like, hey don’t take your vacation this year, you might want to save it for this time.

|   | Logistical onboarding
Financial concerns

|   | Need for greater preparation

|   | Logistical

|   | onboarding

|   | Financial

|   | concerns
<table>
<thead>
<tr>
<th>7</th>
<th>And then, because he was earlier, there was extra people in there. I knew that they were basically explaining what they were doing. And they were good at that. Explaining everything that was gonna go, we’re gonna get to do this, and then we’ll take him there.</th>
<th>Communication Assured by medical care</th>
<th>Communication around medical care a positive</th>
<th>Level of communication helps ease uncertainty and increases assurance by medical care</th>
</tr>
</thead>
<tbody>
<tr>
<td>2</td>
<td>So, it got quite bad very quickly … The doctors aren’t really sure what happened but there they suspect that the placenta abruptly while she was in labor and both kids and her crashed while they had the monitors on them and all of a sudden it was ‘c-section stat’ and they were gone. And I didn’t see anything. I didn’t know what was happening for about 45 min. About a half an hour to 45 min…and none of the nurses or doctors or anybody that I had access to would communicate. Or had any information about what was going on.</td>
<td>Lack of communication</td>
<td>Negative experience</td>
<td>Uncertainty Emergency delivery</td>
</tr>
<tr>
<td>10</td>
<td>So, the experience itself was very like, I didn’t know what was going to happen, right… So there was a lot of doctors, there were a lot of people in there. They’d mentioned too, that they had to prepare for a c-section which, they didn’t, they didn’t specify that it was someone else’s c-section, but they had said they had to prepare for a c-</td>
<td>Lack of communication</td>
<td>Uncertainty</td>
<td>Emergency delivery</td>
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</tbody>
</table>
section, so I was thinking they had meant her. Like that she would be going.

APPENDIX VIb: Semi structured interviews: NICU experience

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<thead>
<tr>
<th>Interview #</th>
<th>Meaning unit</th>
<th>Code</th>
<th>Sub-Theme</th>
<th>Theme</th>
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</thead>
<tbody>
<tr>
<td>8</td>
<td>You definitely feel helpless … And you take a backseat. … you do feel a little helpless when it comes to… what your role should be. For my first, I was there to support my wife with whatever she needed and help take care of my daughter. And with the second it was the doctors were there for her, and I was just kind of sitting off on the sidelines</td>
<td>Helpless Searching for a role Perception of being in the way Not having a purpose</td>
<td>Identifying and establishing role</td>
<td>Fathers searching for and identifying their role in the NICU, wanting more involvement, and equal support to their partners</td>
</tr>
<tr>
<td>3</td>
<td>Like I think there’s a bit of floundering around on when we got there like I wanted to be active I didn’t really understand what my role was right so like so if you think about like the boundaries within the facility I didn’t know</td>
<td>Searching for a role</td>
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<td>13</td>
<td>When I couldn’t fill that void, it, for me, not being relied upon … so you’re kind of standing there going, well I can’t, I can’t pump her, and I can’t you know, there’s really nothing I can do to aid, so my only role here is to strictly support. And for me, it’s tough, it’s tough. You know, just being, never, me not really being relied upon or being, you know, needed in any</td>
<td>Searching for a role Support role Helpless</td>
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<td>3</td>
<td>When you introduce a third member to your family … like the dad’s number 3 all of a sudden so. That’s going to be in the book I write on being a father it’s called ‘you’re number 3’ … Moms were treated kind of as the primary and … you know it was the way they kind of they didn’t really speak to you as a family they speak to mom type of deal in that sense.</td>
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<td>10</td>
<td>There was a lot of focus on like [my child] and his mom. … But I think a little bit more, I guess, focus or notes or something for the dad. Just to make it kind of a little bit easier to try to relay the information to the dad a little bit more directly. … just to not get the information like you know, the doctor to the mom and then the mom to the dad. Like kind of just have a little bit more of a direct link or something, some kind of avenue to get the information a little bit more direct so things aren’t lost in translation</td>
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<td>8</td>
<td>You can definitely see the difference when it was all of us together. It was all about mom and baby. And it was me on the sidelines. But obviously when I was there by myself, they were</td>
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Mom and child focused
Dad has lesser role

Mom and child focused
Dad has lesser role

Mom and child focused
Dad has lesser role

Wanting direct involvement

Wanting direct involvement

Mom and child focused
Dad has lesser role
<p>| | | |</p>
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<td>very, it was all about me at that point.</td>
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<tr>
<td>3</td>
<td>You know it was the way they kind of they didn’t really speak to you as a family they speak to mom type of deal in that sense</td>
<td>Dad has lesser role</td>
</tr>
<tr>
<td>8</td>
<td>The more information we can have the better … I mean FICare, still even FICare was it’s all about mom. You know, my cell phone was the one that we gave when we were there, and you know, every time FICare calls, it’s for my wife. Maybe from a FICare standpoint, there’s more of an opportunity to have, you know, an even distribution of contact to both parents.</td>
<td>Information gathering Mom focused Dad has lesser role</td>
</tr>
<tr>
<td>1</td>
<td>Having maybe a counselor ... saying ‘hey do you want to. Are you ok? Do you want to have a chat?’ maybe approach both the mom and the dad. And be like ‘I can come by whenever you want, and I can have a chat in the room or whatever.’ Just be available to kind of talk about these experiences…a NICU fatherhood coach or something like that</td>
<td>Father focused support Father specific support</td>
</tr>
<tr>
<td>1</td>
<td>You’re going into a survival mode where it’s sort of you kind of just lock yourself down as much as you can and get as much sleep as much as you can and support your wife as much as you can</td>
<td>Support role</td>
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<td>13</td>
<td>You need to keep, you need to get it out here and</td>
<td>Support role</td>
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go in there and just be strong and be strong for her.

| 3 | I knew my role … I’m a stay busy type of person right so like that’s why I was the chief bottle washer … Cause there’s certain things that I think that bond between a child and his mom is different than the dad and his mom and the child right so um I knew the importance of her having skin to skin and you know the feeding and all that stuff … my job was to try and ease that burden. That’s how I came in it, I was like I was the go boy. Just sweep the car off, warm the car up anything I could to help out… I would’ve probably mopped the floors honestly like I would’ve done anything there just to kind of stay busy. | Identifying a role
Support role
Dad has different purpose
Wanting involvement | Wanting involvement |

| 11 | I got the sense that the nurses are aware that, they must be obviously, cause you do things differently with FICare, so they try to push you to do more of those things as well | Supportive environment | Encouraged involvement as a positive |

<p>| 6 | They were always pretty inclusive. Allowed me to kind of come in and do a bottle feeding, do anything else like that. Generally, be in their way even though I know at night they’re probably busy and trying to run around and do things | Supportive environment | Fathers support and benefit from parenting with supervision in a positive NICU environment that encourages parental independence |
| 8 | So, near the end of it, I was able to go and get the blankets myself out of the warming oven and kind of not have to wait so much on the nurses. | Supported independence |  |
| 7 | It’s weird to say you rave about it, the NICU. But it’s just the care that you had, and the attention you got from the nurses...We weren’t limited to the connection or the availability of him because of, becoming, being a premature baby. | Supportive environment Nursing attention Not limited to connection | Inclusive environment and nursing attention |
| 11 | All the nurses and stuff were really good as far as you know, you take the first bath for example, … this is how you do this, cause this is different in the NICU than it is at home or even her first bath … they kind of almost give you jobs to do, you’re going to hold baby like this, this is how you do it, … And I think the other thing too that you know, probably helps you feel more involved as a dad in the NICU. | Supportive environment Nursing attention |  |
| 8 | The ability that we had [to] be a little bit closer with a couple of the nurses. Because they would come and you know, check on him specifically and take more of a … interest … because of the FICare program. They wanted to follow up and different things like that. So … given that – if we were in the same situation again, | Nursing attention |  |</p>
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<tbody>
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<td>1</td>
<td>Being able to do things like change her diaper and get things for her incubator and her crib and doing like the tummy time ... I do think sort of being able to be involved even just on that little bit was awesome. Because you know your baby is in a box and you’re not sure what’s going to happen. Yeah so even like changing the diaper that sort of stuff was pretty cool</td>
<td>Being involved as a positive Reduces anxiety of being in the NICU</td>
<td>Supported independence increased comfort and reduced anxiety</td>
</tr>
<tr>
<td>6</td>
<td>They were great if we had to ask questions, they were there. Uh, you know, scheduling time to do the first bath, scheduling time to do the first diaper change. Like they made sure that we were there for everything, to kind of, be included. … I felt like they did a really good job of kind of including us and making sure we were involved, and you know, to really kind of get our feet underneath us. So, when we got home, it was more of the same, just all the time.</td>
<td>Supportive environment Preparing for discharge home</td>
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<td>7</td>
<td>My nurses were just, they were all up front with everything that it was. If we needed something, we’d go get it. If you need this, you go get it...It helped speed up. It, it was good...We were basically parenting, with supervision. For, nine</td>
<td>Supported independence Parenting with supervision Preparing for discharge home</td>
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days, while we got ready to go home.

3  We almost got parenting kind of coaching throughout the process which like I think we were really beneficiary of having that time with them and they taught us a ton where [it] wasn’t us trying to be worried about ‘what’s the proper bath temperature’ all those kinds of things. All those kind of little things that were phenomenally important to us that they really mentored us to be parents

Parenting with supervision Preparing for discharge home

11  When they’re premature …you’re worried about they’re fragile as newborns and afterwards there’s a feeding tube and all that kind of stuff. So, yeah, it’s still a lot different. … the biggest thing was just to do it, right. And the support of not just the FICare program, but the nurses in the NICU as well

Supported independence Nursing attention

1  We don’t want to piss anyone off because we don’t want you know if the baby is awake and needs food and the timer is going off, we’re going to wait until the nurse gets to us because we don’t want to be that THAT patient that we pay for it later on

Limitations of medical care Perception of being in the way Affecting care of child Wanting more independence Permission to parent

4  That first little bit was a little bit tough to kind of find what the proper routine should be. Cause at the same time we want to

Lack of supported involvement Perception of being in the way Needing permission to parent and wanting more independence
be there but there’s also you know when he was feeding on the feeding tube all the time there’s not, other than holding him there’s not much we can do. And some of the nurses’ kind of made it seem like it was an inconvenience for them to bring him out of the isolette to allow us to hold him. Other nurses were a lot more easy about it and definitely encouraged it. So, we were trying to balance out. Are we interfering with them? I know they have a busy schedule and lots of babies to look after versus wanting the care and be there for our child.

| 8 | … They’ve got lots of things going on and you do very much wait on it. I mean, as far as they’ll warm the bottle up and it will be sitting on the bottle warmer, ready to go, and you’ve got him on you, but you can’t do that extra step of going and getting it and start feeding him. … you have to ask for permission to, you know, dress him in clothes that you’ve brought in for him and things like that. … you needed to rely on somebody else to kind of help you through things that you knew how to do and were confident doing on your own type thing. …you do feel that you’re almost having to ask | Affecting care of child  
Permission to parent  
Wanting more independence  
Permission to parent  
Parenting with supervision |
<table>
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<th>permission to … parent your child at times… Cause, you know, you’re the parent. Especially being the dad, you’re the protector … And you just want to jump in.</th>
<th></th>
<th>Parenting with supervision Wanting more independence</th>
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<tbody>
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<td>8</td>
<td>The toughest part was needing the nurses to come in and take him out of his enclosure … But taking him out of his enclosure and the deal with all the wires that we could get him on. It would be nice to be able to go in and just pick him up yourself, but we needed help with that. Getting him on and off every time. So … you were pretty dependent on the people there. I mean, they were great, but … I don’t know if there’s anything that can be done to make it more independent.</td>
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<td>4</td>
<td>I mean it also changed a bit once he started breastfeeding a little bit. Then we felt more of a purpose to be around or for my wife to be there.</td>
<td>Lack of supported involvement</td>
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<td>9</td>
<td>Everyone there was professional, it was clean, they were organized. I mean, we left there and felt bad for leaving our babies, but then knew that, met the women and the nurses and knew that they were in great hands. And I mean, it is very comforting. You know, it wasn’t easy to leave every night and leave your babies in the hospital,</td>
<td>Professional Reassured by medical care</td>
<td>Reassurance</td>
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<td>Effect of medical staff</td>
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<td>but we did it, and they were amazing.</td>
<td>Power of touch Reassured by medical care</td>
<td>Personal touch and attention</td>
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<td>There was a certain level of comfort there … and the physician came, and you know he came and checked on him which was huge, put his arm around me right like there was a comforting thing there … I admired the gentleman… He had [a] phenomenal bedside manner like all of those things like the power of touch and all of those things were like a certain comforting aspect so I felt like … I was in the right place. I never doubted that for a second and...I knew that’s where we needed to be</td>
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<td>1</td>
<td>I think the nurses really make or break the experience... if we had you know a good nurse just attentive you know and on the ball and kind of really patient with us … the experience was great.</td>
<td>Nursing attention</td>
<td></td>
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<td>5</td>
<td>I found the staff to be extremely friendly. Extremely knowledgeable and even with it being our third child we still had questions.</td>
<td>Knowledgeable</td>
<td>Knowledgeable</td>
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<tr>
<td>3</td>
<td>It meant a lot to us to be there and like kind of like relish the experience and cause they taught us a ton too that was a big positive was they were like you know first bath ‘Dad get in here ...[My wife] was having trouble with ...with ...hand expressing and so</td>
<td>Supportive staff Helpful</td>
<td>Supportive</td>
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<td>like the nurse was like kay I’ll come with you back to your room cause I was trying to describe what was going on ...So she’s like ‘let me come back with you, I’ll show you’ those were kind of the memories where like ‘wow that was phenomenal that somebody did that for us right’</td>
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| 4 | Some of the nurses were fantastic. Being available for rounds and being encouraged to be there when the doctors were doing the rounds was very helpful and everyone was very open and candid and answered any questions um so we tried to make sure that we were always there everyday when they came around to do rounds. And that was great. |
| Communication and explanation |
| Communication and explanation | Importance of effective communication with fathers as the information gatherers |

| 8 | We got all of our information, really from the nurses, not from the doctors themselves for the most part. The doctors would come in and do their tests and their things and their rounds and fill out all our paperwork and we would just kind of stay out of the way and the nurses would come back later and kind of explain, ok, here’s what they found, here’s what’s happening. Our communication really was more with the nurses than it was with the doctors themselves |
| Information gathering |
| Information gathering | Communication |

<p>| 106 |</p>
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<th></th>
<th>You don’t want to rock the boat because you’re depending on these people. So early on there’s like that little chart that’s in all the rooms … and these all have to be green before your baby can go home and so the first couple of days I’m like ‘ok so the sheets with the information basically said we’re going to update this everyday’ uh but it was really quickly found out that they didn’t update it everyday and I found that they didn’t update it…I don’t think they updated it almost until she went home…we kind of just realized that we have to grin and bear it.</th>
<th>Failures of communication Visual communication Information delivery</th>
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</thead>
<tbody>
<tr>
<td>9</td>
<td>I loved them. Loved them. Like we missed one, one day and I was [disappointed], everyday I had to be there for rounds. Like, cause that’s when you get engaged with the doctors and you hear about how they’re doing. You know, you hear snippets throughout the day, but we made rounds everyday and it was the best thing of the stay</td>
<td>Rounds Information gathering Engagement</td>
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<td>1</td>
<td>I think number 1 would be how the information is delivered. So when we were admitted we kind of got like a folder I can’t remember or a binder and it had lots of this sort of stuff that looked like it had been photocopied a hundred thousand times</td>
<td>Information delivery Failures of communication Information gathering</td>
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and it was nothing like and
even just having something
like ‘here’s your NICU
manual… I feel like my
role became sort of the I’m
the gatherer and the
cultivar of the information
and I am the one getting
the most sleep because my
wife is there she’s feeding
every three hours so the
more information that I
have that I can reference
for both of them is useful

|   | I would say as a father
sometimes a place to sit.
…a place that’s more
welcoming … where
there’s room for you where
its comfortable where
you’re not just like
grabbing a spare chair
from the corner and trying
to shove it in the room and
join in so kind of makes
you feel like you’re a little
bit of a burden or like in
the way more. |
|---|---|
| 4 | A place to sit
Feeling
welcome
Lack of comfort
Feeling less like
a burden |
|   | A welcoming
environment |
|   | Impact of
physical
environment |

|   | The nurses were pretty
helpful … they made up
little, like you know, little
name tag identifiers for all
the babies there. … They
tried to personalize the
area kind of as much as
they could … and that was
really helpful just to kind
of make it feel a little less
like a hospital. |
|---|---|
| 10 | Personalizing
the space
Less like a
hospital |

|   | You have to be very clean
going in there, so as
parents, you wash up and
you’re very clean and
you’re quiet and respectful
when you go in …you
know, people were coming |
| 9 | Rule following
Traffic |
|   | Rule following |
in and like in their jackets and bringing strollers and they would have to be told not to come in and then, that was the only really annoying thing, was the amount of traffic, you know, and people not following the rules to a T

| 11 | I mean it is quite tight. You know, they try to get as many in as possible, and you have your own little space, but it’s fairly small. You know, once baby is breast feeding, you kind of put up some little partition walls, but there really isn’t room for two of you in there | Lack of space No room for two people Lack of comfort Feeling welcome | Effect of space |
| 12 | They gotta stick something in there for parents to sleep on | Place to sleep Lack of comfort | |
| 5  | Sometimes it was a noisier environment with some due to other adults. Thankfully when it became quiet hours it was just that, quiet. So, it was again nothing that the NICU could really … do in the background. They don’t have the time and resources to be chasing people around asking them to be quiet constantly. They can’t control other people | Noisy environment Rule following Cannot control others | Noise level |
| 3  | It was kind of neat because … I got an appreciation of other parents and you can see them role modeling behavior which was kind of the nice thing about the open concept where you see you know you see dads | Role modeling behavior | Role modeling |
really active and engaged and doing ‘hey that’s skin to skin, I want to try that’ right so I think that’s nice to see some positive role models is [a] really good thing too.

<table>
<thead>
<tr>
<th></th>
<th>One of the sad takeaways when you’re in the NICU is that you start to see how your baby is doing in the NICU as compared to some of the other babies and so like you know there were babies who were born around [Child]’s age and they were you know still having episodes and their alarms going off all the time and … after a little while we [thought]…[Child’s name] is doing really well she just needs to be gaining weight and that’s going to take some time.</th>
<th>Comparing infant to others Well child</th>
<th>Uncomplicated NICU stay</th>
<th>Perceived health of infant</th>
</tr>
</thead>
<tbody>
<tr>
<td>11</td>
<td>I mean, it was really good, because she did quite well, you know, like she was on track the whole time, there was you know, no setbacks, so it was fairly easy from that perspective, because there was no bad news. I might have a different, it’s not the doctor’s fault obviously, but, if there was kind of bad news at some point, it would’ve been stressful for sure</td>
<td>Well child Positive experience</td>
<td></td>
<td></td>
</tr>
<tr>
<td>1</td>
<td>I remember I was coming home from the hospital and this was day 3 or 4 so really early days and stuff like that she’s got feeding</td>
<td>Fear Medical involvement Medical realities of a preterm</td>
<td>Medical complications</td>
<td></td>
</tr>
</tbody>
</table>
| 9 | I think one time in the NICU unit, we had a couple rough days with our daughter, and she was, you know, they didn’t know what was going on with her, her temperature was up and down, she couldn’t hold temp, she wasn’t eating, she had to have a spinal tap, she, they had a bunch of things on her blood work, it was crazy. | Fear
Unwell child
Medical involvement |
| 8 | The first week that he was in NICU …you hear all the monitors beeping and buzzing away and the alarms going off. It was, it was all very surreal and all | Comparing infant to others
Impact of space
Worry and fear
Monitor anxiety |
| 111 | tubes and they are having problems finding places to put her IV and stuff like that kind of like had to block myself off emotionally and just to say ‘you know what. Whatever happens is going to happen.’ I can’t keep coming home from the hospital crying everyday because I’m scared…I feel like maybe if had she been a normal baby maybe you don’t really go through that. You get to sort of welcome and have all the joy and the excitement as opposed to saying oh for me to get through this I actually just have to wall myself off a little bit…that started to come down I think as we saw that she was making progression and also seeing that her against the other babies. | infant
Having to physically and emotionally remove oneself |
very terrifying, or scary, terrifying at the same time. And then later on, when he got moved into his own room … You only hear his monitor, you only hear his alarm, it was a lot easier to kind of just sit there with him, you know, on your chest and just be together, right? … it was more the just being around everybody… you heard everybody and all the commotion and all the alarms from all the other beds. And it, it just, it was very, you’re just waiting for your turn, for them to have to rush into your baby and, it was, a little unsettling.

| 10 | The monitors and the beeping and the alarms would go off a lot and you know, every time they would go off, the nurses would come in and reset it. But the alarms going off I think probably the most, like, it was really hard. That part was really hard. The alarms would go off, like his heart rate would slow or his oxygen would slow, or drop, and that would happen throughout the whole time … and I know everyone said it was normal, it was ok, but it was just like, that part, that experience in the NICU, that was probably the worst part of it actually.

| 3 | You’re trying to wrestle with … the health of the Monitor anxiety Medical involvement Medical realities of preterm infant Worry and fear

<p>|  | Isolation Lack of family Impact of external support Balancing home, work, |</p>
<table>
<thead>
<tr>
<th></th>
<th>baby and the health of mom … we don’t have any direct family down here so there was a certain component of being isolated</th>
<th>Trying to cope without support</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>9</td>
<td>My mother-in-law came out for the first month which was great. But then, she left and um, we don’t have any family around, so it’s, that’s been the hardest part, doing all of it without any real family support.</td>
<td>Trying to cope without support</td>
<td></td>
</tr>
</tbody>
</table>
| 7 | I wasn’t working… I got extra time while he was there. Might’ve been a day or so at the end … it was pretty simple getting time. it makes a big difference if you have to go back to work, it’s a different situation. And not all dads have that opportunity. | Support from work  
Coping with external support |   |
| 6 | My mom was out for a bit at the start. So, we had the extra set of hands. Then … my wife’s parents came over shortly after that. So, same thing. So we had a lot of set of hands around here. There wasn’t … we didn’t feel like it was too overwhelming. | Coping with external support |   |
| 12 | Because I was in Fort Mac for a week and then … we have an older teenager at home, so I was, she was ok, but I don’t know, I was running back and forth to see her and then running to the hospital to see [my partner], then back to see the teenager, and then back to work. It was not that much fun | Going back and forth  
External demands from NICU | Competing demands between home and hospital |
<table>
<thead>
<tr>
<th></th>
<th>Well, you know, especially on top of the fact that you work often. You get up in the morning, drop number one off at daycare, go to work all day, pick them up, grab the food for them, go for a visit, come back, it’s just like by the time you get home, it’s 10 o clock at night and you’re just dead on your feet again, right?</th>
<th>Going back and forth External demands from NICU</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>3</td>
<td>I think for us honestly we reflect on that as a really positive experience right that like from the initial fear of ‘he needs to come out tomorrow or today’ to you know settling into a routine which it was still a great routine that we got up everyday made our coffee, went to the NICU did our feed went downstairs played cards all those kind of things right so I think I don’t know … I wouldn’t change anything</td>
<td>Routine Positive experience</td>
<td>Establishing a routine</td>
</tr>
<tr>
<td>3</td>
<td>We worked through it together right and … yeah we really needed each other through that whole process right?… it was even just the dynamic with our family as well right how that support mechanism [worked]</td>
<td>Teamwork Support mechanism</td>
<td>Working through the challenges of stress and fatigue</td>
</tr>
<tr>
<td>13</td>
<td>It’s a stressful environment, there was just some frustrations. And once again, it was just I think fatigue, fatigue played a major part of it…I mean my wife and I were always very close, we</td>
<td>Stressful environment Fatigue Strength in adversity Team work</td>
<td>Relationship strengthening</td>
</tr>
</tbody>
</table>
were, but it definitely didn’t separate us. And I think it did make us a little bit stronger. … because we realized that the team work is going to make the dream work here. We’re either going to live by the sword or die by the sword, but we can’t be two separate entities.

|   | I think we worked really well as a team most of the time…you know, we didn’t get to see each other much during it. Especially the second time, we were kind of passing off, you know. The ships in the night. She was there, I was there, we were back and forth. | Teamwork  
Lack of communication  
Lack of physical contact | Physical separation |
|---|---|---|---|
| 8 | I think the journal helped a lot because we were able to understand each other’s feelings going through the process. So when we got home, we were able to consciously make decisions to not feel like that again, right. To not, to not get each other to feel like that. We were able to share a little bit more. So … no, I would say that it’s, you know, normal. No major changes on that side. | Communication  
Impact of journal  
Sharing | Communication |
APPENDIX VIc: Semi-structured interviews: Post-discharge from NICU experience

<table>
<thead>
<tr>
<th>Interview #</th>
<th>Meaning unit</th>
<th>Code</th>
<th>Sub-Theme</th>
<th>Theme</th>
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<tbody>
<tr>
<td>11</td>
<td>She kind of went through the whole stage of you know, one bed to the next, they kind of graduate them up, and then, yeah for the last probably 5 days I want to say, she was kind of in a separate room … and she was off monitors and stuff by then…It’s nice to not have to worry about you know the feeding tube and the monitor cables and all that, it’s more normal, like a normal human.</td>
<td>Steps towards discharge Normalizing infant</td>
<td>Determination of discharge and communication</td>
<td>Preparation for discharge home</td>
</tr>
<tr>
<td>7</td>
<td>They kept showing on a chart that everyday it was, this is where it’s at, this is where he needs to be, in order to … go home and be comfortable so that you’re… you’re not worrying.</td>
<td>Communication</td>
<td>Preparation for discharge</td>
<td>Reduce anxiety</td>
</tr>
<tr>
<td>4</td>
<td>Being that it was not our first child … we felt a lot more prepared. If it would’ve been our first it would’ve been a lot more overwhelming … but being our second it was definitely easier… we saw with the other babies around us you don’t know exactly when you’re going to go home… I think the day he had a little setback and he wasn’t [ready to go]. so you get a little disappointed then all of a sudden its like ‘no now it is today’… Yeah and they kind of warned us. The nurse practitioner said ‘we’ll tell you to aim, to plan for the due date original date that they go home but chances are we will</td>
<td>Second child preparation Setback with disappointment Unknown timing</td>
<td>Communication</td>
<td></td>
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</tbody>
</table>
tell you the day before that
this is the day that you’re
going home.’ And that’s [kind
of what happened].

<p>| 12 | Being discharged was fine. Yeah, it took a little while, but the nurses made sure the car seat was appropriate and she was in there correctly. Yep, it was ok. Yeah. I mean I was concerned that she was under the 5 pound mark ...Well then I also trusted the doctors and nurses. I think it was fine, cause she was off the monitors and everyone else was satisfied that she could do all this stuff, then I was too. | Steps towards discharge  Communication Assured by medical staff |
| 8  | So finally the day came that he weighed enough then when he was told that yes he could go home that day, then it just seemed like it wouldn’t come fast enough. So, ok, here, we’re gonna give him a bath, we’re gonna show you how to bathe him. Like, no, I just want to take him home. Let’s just go! | Prepared for discharge  Anxious to get home |
| 13 | Because they had [my child] so regimented at that point, it was actually pretty easy. I mean, we were tired, we were exhausted, and all that stuff, but you know, she had the 3 hour sleep cycles and then you know, the, she was already breast feeding at the hospital, you know, it was a really easy transition, in my opinion. I mean obviously, as I said, we were tired, as I think every parent is, but as far as the transition from that, you know when we were | Routine established  NICU involvement  Prepared for transition home  Natural transition  NICU involvement |</p>
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<th>Text</th>
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<tbody>
<tr>
<td>11</td>
<td>Yeah, that’s definitely the way I felt it. Because you know, we did so much in the NICU. We did you know, diaper changes and feedings and before and after breastfeeding, everything top to bottom, right. So you don’t feel a big adjustment coming home.</td>
<td>NICU involvement Prepared for transition home Natural transition</td>
</tr>
<tr>
<td>8</td>
<td>But once we got home … the transition was natural… because of the, you know the encouragement for kangaroo care and feeding and changing and doing regular things with him, he didn’t feel like a stranger by any means when we got home. You know, and he was our son, so I think there was a lot of positive stuff that happened at the NICU that helped with that transition.</td>
<td>NICU involvement Natural transition</td>
</tr>
<tr>
<td>5</td>
<td>We felt very prepared to leave. And we all felt very comfortable to go home because they were very upfront with us and they gave us phone numbers to make sure that we do have any kind of issues or questions that we have the resources available to us. So leaving there we felt very comfortable.</td>
<td>Prepared for discharge home Post-discharge support Support from medical staff</td>
</tr>
<tr>
<td>2</td>
<td>We were well prepared to go home as best you can be but that drive that drive taking the kids out of the hospital and</td>
<td>Prepared for discharge Worry and fear Full Stressful awareness of the lack of medical Post-NICU medical care and support</td>
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<td></td>
<td>putting them in the van on that first drive home was the most nervous experience of my life...well you got these two lives now that are totally dependent on you right and … they’d never been in a car before and all that other stuff so its like ‘oh my God we’re not committed right? We don’t have all this help’</td>
<td>responsibility Lack of medical oversight</td>
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<tr>
<td>8</td>
<td>You know, we, we took turns staying up awake with him a lot, because we just didn’t, you know, sit there and watch him sleep. Because you’re not sure, he doesn’t have any of the monitors now. He doesn’t have any of the stuff. It’s happening, so you keep looking out, you keep watching out for him. But ...the transition was really good. ...We had everything we needed at home. ...We were his parents again at home, I guess you could say.</td>
<td>Lack of medical oversight Full responsibility</td>
</tr>
<tr>
<td>4</td>
<td>It was kind of comforting. Cause you know he’s breathing. You can see his breathing rate. You can see his pulse. So it was. It was more comforting to see it. It was probably harder knowing that we were bringing him home and we would not have that…. I think it was just the last day or maybe the day he came home off all the leads um even kind of leading up to the day before or so uh one of the nurses just shut them monitor off so we couldn’t just watch it while we were feeding him and changing him and that was a good little test</td>
<td>Lack of medical oversight Normalizing infant Prepared for transition home</td>
</tr>
<tr>
<td>9</td>
<td>I found the paediatrician to be a big help. I think at the start [we] were going to see her like once every two weeks or once a month, and then now we don’t see her at all. …We actually found a family doctor around the corner from us that’s amazing, like she’s the best doctor we’ve ever had. And she asked the right questions, and she talked to us too, and if we had questions we would actually call her and she would help us, or go see her. …it really helped us to reassure us that everything was going good, you know.</td>
<td>Medical support post-discharge Reassurance post-NICU</td>
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<td>10</td>
<td>I guess if I had one thing … that would help improve for after, … if there was … follow-up of some kind maybe. Just from the release from the ICU, just like, that first … 24-48 hours, … like a phone call or something. …I can imagine there’s going to be at least some other parents who are probably as neurotic as I am about everything that’s going on and just not sure. … Maybe feel a little bit better from that reassurance that … as long as he’s doing all these things, then it’s just fine. And it stopped really, it stopped abruptly.</td>
<td>Lack of medical support post-discharge Reassurance Availability</td>
</tr>
<tr>
<td>1</td>
<td>Like having a FICare liaison to say ‘now that you’re out we’re going to we still have all the things you can access …We’re going to hook you up with the breastfeeding clinic to have that stuff done automatically so kind of not trying to figure out what to do</td>
<td>Lack of medical support post-discharge Availability</td>
</tr>
<tr>
<td>Page</td>
<td>Text</td>
<td>Medical support post-discharge</td>
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<tr>
<td>5</td>
<td>We had a lot of support. The only thing that we had a little bit of issues with again [my wife] breastfeeding and the car accident. But they ...continued support with her via phone and email as far as I know.</td>
<td></td>
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<td>3</td>
<td>So it was probably like about a month and we kind of got into a good rhythm. Its like all those things like. Double checking car seats. Just not having the confidence yet like lets feel the bath water right.</td>
<td></td>
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<tr>
<td>11</td>
<td>I definitely found almost like and extended newborn period. All the night waking lasted longer, for a period of time, you know, all those kind of things, and then by about, I want to say 6 months, she kind of started to catch up to where, non-adjusted kind of. All those kind of developmental stuff. But definitely an extended newborn period. Like it was definitely a lot longer of the night wakings.</td>
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<td>4</td>
<td>The funny part was you know you’re kind of always wanting to get home but then you realize that when you have all the help and care at the hospital coming home is a little bit tougher um because it was kind of more like a 9 to 5 thing so my wife would go in every morning and stay until 5. Then we’d go home its 24 hours. But just kind of adjusting to that.</td>
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<td>7</td>
<td>It was more comfortable</td>
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<tr>
<td>1</td>
<td>because we were actually sleeping in our bed, as opposed to on some of the hospital … chairs, chair cots, or benches that they have there.</td>
<td>home</td>
</tr>
<tr>
<td>2</td>
<td>It’s hard ... when you don’t outnumber the kids anymore… Because you’re constantly kind of, one’s taking care of one and one’s taking care of the other … so that was tough. I felt like, you know, with the first one you can kind of get breaks.</td>
<td>outnumbered New normal</td>
</tr>
<tr>
<td>3</td>
<td>When we got home ... you’re already very fatigued. As it was. But you’re a different kind of fatigued … because you have all this build up for what home is like and then you get home and its kind of that narrative starts from page 1 again right because its completely different now.</td>
<td>Fatigue Starting over</td>
</tr>
<tr>
<td>4</td>
<td>I think it was more just all of our routines and everything settling out between the three kids and just having to live life and me going back to work and our lives went slowly back up to where it normally is. Just figuring out how the new puzzle works better.</td>
<td>Settling out multiple routines Starting over Going back to work Figuring out the puzzle</td>
</tr>
<tr>
<td>5</td>
<td>We definitely treated her differently… I found it to be a lot more thought into uh ‘oh my God she’s doing this.’ And you end up going into Dr. Google and you start thinking the world is ending because she was a preemie but it turns out not so much. Once they are through that initial I’d say about 3-6</td>
<td>Treated her differently Resilience with time Effect of size on perception of child</td>
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<td>Text</td>
<td>Keywords</td>
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<td>8</td>
<td>He’s 2 and a half years old now, and still, … where should he be in his development? Where should he be in his size? … so, we’re still looking at, still feeling the side effects, I guess you could say, from his birth. He’s having trouble with his eyesight, but everything else is developed well. So it’s just a matter now, of making things as normal as possible, right? But you still have those thoughts, even today, 2 and a half years later, of the side effects that come with having such a premature child.</td>
<td>Ongoing anxiety over development Effect of prematurity</td>
</tr>
<tr>
<td>1</td>
<td>I’ve often felt like there’s a little bit of PTSD associated with … just because of those first couple of days where your daughter is going to the NICU and it’s like she might not make it right … I kind of feel like the experience left us a little uh a little more I don’t know how to say this maybe a little more tense, a little more wound up when it comes to our daughter as far as her health is concerned.</td>
<td>Ongoing anxiety over health Effect of prematurity</td>
</tr>
<tr>
<td>1</td>
<td>Oh she’s amazing. She’s really big. … we have a picture that basically shows how big she was when she was born. It looks like a little drawing like a scale and its like we can’t fathom it anymore. She’s crawling. She’s bumping into stuff. She’s making us laugh. You’d never know right. Yeah so its</td>
<td>Positive view of the child irrespective of prematurity Effect of size on perception of child Unknown that was premature</td>
</tr>
<tr>
<td></td>
<td>kind of amazing that she’s done really well. You would not know even looking at her [that her]charts that say she was born 7 weeks early.</td>
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<td>9</td>
<td>I think for the first couple months when they were really small, you know, definitely, 100 percent. But as they, as they … passed their natural birth date and as their weight got up to like a normal baby. I remember going when they got to like 6, 8, 9, 10 pounds, they started to look and feel like a normal baby. I didn’t look at them at all as premature anymore.</td>
<td>Effect of size on perception of child</td>
</tr>
<tr>
<td>3</td>
<td>I think if anything we just. I don’t know I as a father kind of lookin’ and just seein’ like all the steps … he was kind of fighting to get to the next level of working hard and stuff I just see it different … I just have that much more admiration about who he is as a person and you can kind of wait.</td>
<td>Admiration Positive descriptors</td>
</tr>
<tr>
<td>10</td>
<td>He’s just such an incredible little boy. Like he, he’s so smart. For 2 and a half, he’s just so, like he has the, his vocabulary is amazing. He can put together like 10 word, 12 word sentences. He can count to you know, 20. He points out all the different numbers. He knows, he can recognize numbers, letters, everything. He’s just, he’s just so, so smart</td>
<td>Positive view of the child irrespective of prematurity</td>
</tr>
<tr>
<td>13</td>
<td>I wouldn’t say there was any delay in the bonding just because … we made a point of, of going there and being</td>
<td>No delay in bonding Involved from the beginning</td>
</tr>
<tr>
<td></td>
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<td>Bonding correlated to level of involvement</td>
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there for every feeding, and just kind of immersing ourselves into [my child’s] life.

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<thead>
<tr>
<th>Study #</th>
<th>Meaning unit</th>
<th>Code</th>
<th>Theme</th>
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<tbody>
<tr>
<td>3</td>
<td>I would suggest it probably felt like a delay because I think the rubber hits the road when its you. Its your place its you’re in your space you’re accountable 24/7 so … that was certainly a bit of a harder thing for sure</td>
<td>Delay in bonding Accountability</td>
<td>Delay in bonding Accountability</td>
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APPENDIX VIId: Journal entry fathers’ experience

<table>
<thead>
<tr>
<th>Study #</th>
<th>Meaning unit</th>
<th>Code</th>
<th>Theme</th>
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</thead>
<tbody>
<tr>
<td>563</td>
<td>It was surprising and nerve wracking to find out that mother went into early labour. I did not know what would … happen to the baby. Everything happened so fast there was no time to react or even come up with a plan or an explanation.</td>
<td>Unexpected early delivery Quick delivery</td>
<td>Mental preparation affects the emotional experience of early delivery</td>
</tr>
<tr>
<td>638</td>
<td>Scary…We had no plans for baby to come out so early and didn’t even know anything was wrong with [the] pregnancy until an ultrasound early in the afternoon yesterday sent us to the hospital. …Baby 1st official day started off with a lot of commotion, fear, anxiety, and joy. It truly is a strange mix of emotions I have never felt before.</td>
<td>Unexpected early delivery Quick delivery Fear and anxiety</td>
<td></td>
</tr>
<tr>
<td>563</td>
<td>As soon as she was born, we were instantly worried about baby. She was healthy enough to spend an hour with us. It was rather scary seeing her with all the tubes, IV’s and sensors attached to her tiny body. While all the hospital staff was reassuring us that everything seemed okay, we had a hard time</td>
<td>Fear of the unknown Uncertainty Medical involvement</td>
<td>Fear of the unknown leads to an emotionally terrifying experience</td>
</tr>
</tbody>
</table>
believing since we never encountered anything like this before. We would [be] by her side and patiently observed every minute of her first day or the remainder of.

| 609 | Day 1 was rough. Lots of unknowns. And worrying about whether my wife and the babies would be ok. My mind took me to places wondering how I would deal with it if something happened. A moment that was both magical but frightening at the same time. | Fear of the unknown |
| 638 | At just over 2 lbs he looked so tiny on the warmer and with the … of nurses assisting there were moments where he completely disappeared behind their hands. The only real comfort that can be felt comes from watching those skilled hands and knowing the he is in the best place with the most talented people we could ever ask for looking out for him. | Concern for infant Reassured by medical team |
| 638 | Reflecting back now I can’t believe that even with everything going on, time was still made for dad to cut the cord as well as to have continuous communication on what was happening and why. Somehow it was extremely calming and reassuring. | Supported to be involved early Communication Reassured by medical team |
| 638 | I love seeing baby and spending as much time with him as possible but am I supposed to sit there and watch him? I am so unsure of everything. All I know is how much love I have for my son and I really want what’s best for him. Spent some on the internet while with baby tonight trying to find answers, found a couple books that might help and read a lot about other dad’s | Searching for a role Love for child Seeking support |

Fathers searching for and identifying their role in the NICU, wanting more involvement, and equal support to their partners.
<table>
<thead>
<tr>
<th>ID</th>
<th>Text</th>
<th>Physical involvement</th>
<th>Supported involvement</th>
<th>Comments</th>
</tr>
</thead>
<tbody>
<tr>
<td>589</td>
<td>I was really excited to finally have some skin on skin time with my daughter which didn’t seem like a big thing till I got that time, made me very happy.</td>
<td>Physical involvement</td>
<td>Supported involvement</td>
<td>Fathers support and benefit from parenting with supervision in a positive NICU environment that encourages parental independence</td>
</tr>
<tr>
<td>662</td>
<td>I rushed through my chores to come see him. I am so tired! Its ok he is worth it. He has been reacting to my voice a lot and even smiled. He looks really good. He pooped a couple times so I get to practice diaper changes.</td>
<td>Physical involvement</td>
<td>Supported involvement</td>
<td></td>
</tr>
<tr>
<td>680</td>
<td>I have started to hold baby more and more during feeding from tube. Nurses have been great.</td>
<td>Physical involvement</td>
<td>Supportive involvement</td>
<td>Nurse attention</td>
</tr>
<tr>
<td>609</td>
<td>We are starting to get comfortable picking the twins up now without relying on the nurses to pass them off to us. This was a big step since we were hesitant.</td>
<td>Improved comfort</td>
<td>Gaining confidence</td>
<td></td>
</tr>
<tr>
<td>400</td>
<td>We ask for help from nursing on tips for feeding</td>
<td>Nursing attention</td>
<td>Teaching</td>
<td></td>
</tr>
<tr>
<td>743</td>
<td>I was enjoying my time with baby. I was able to hold her in my arms today and she is showing me signs that she knows me.</td>
<td>Physical involvement</td>
<td></td>
<td></td>
</tr>
<tr>
<td>616</td>
<td>We are feeling more comfortable with all the sounds and alarms of the equipment.</td>
<td>Habituating to NICU environment</td>
<td></td>
<td></td>
</tr>
<tr>
<td>252</td>
<td>I expected to feel worse honestly and scared for the babies, but the nurses assured us that what the babies are going through is quite standard for their age</td>
<td>Reassurance by medical staff</td>
<td></td>
<td>Effect of medical staff</td>
</tr>
<tr>
<td>252</td>
<td>Overwhelmed a little. Scared for babies but felt good about the care they are receiving</td>
<td>Reassurance by medical staff</td>
<td></td>
<td></td>
</tr>
<tr>
<td>616</td>
<td>The nurses have been wonderful at helping us understand the processes and procedures.</td>
<td>Effective communication</td>
<td></td>
<td></td>
</tr>
<tr>
<td>609</td>
<td>We struggled with the overnight nurse … the unit seemed short-</td>
<td>Perceived mistreatment</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
handed. Mother was called from her hospital room to the NICU to help out and was treated poorly. The nurse was very rude to my wife and I had to speak to her and tell her that what she did was wrong. I will talk to our head nurse tomorrow. We should not be treated this way.

Bedside rounds really gives you great feedback and plan

I’ve been told things 2 and 3 times, which I actually appreciate. The staff here know their stuff but it’s nice hearing the same info from different sources at different times.

NICU is getting a lot of visitors. It feels very crowded with constant stream of people coming in and out with all the new baby arrivals … Last thing I want is to see my preemie baby sick

Hard to get comfortable when you constantly feel in the way while annoying I understand that it is what it is with such a small unit.

The little bit of extra space and the openness the window provides made it feel a little bit more comfortable and a little closer to home.

It is crazy to me how anything can almost become normal. After two weeks, I find myself spending more time thinking about stupid little things with baby care than I do about his health and if he is going to make it. I am concerned about … About how to decorate his room at the hospital, worried about why he doesn’t have a fancy decorative name badge like some of the other kids.

It was Baby’s first full day at the
<table>
<thead>
<tr>
<th>ID</th>
<th>Text</th>
<th>Categories</th>
<th>Notes</th>
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</thead>
</table>
| 129 | NICU, she is so small, and all the tubes and wires are really intimidating. We could barely touch her. She looked so weak and fragile. ...We were able to touch her. It was such a good feeling. After spending most of the day at the hospital we were accustomed to all the beeps and alerts. The alarms were much less scary after a while. | Worry and fear  
Physical involvement  
Impact of medical oversight  
Medical realities of a preterm infant | infant |
| 662 | I think I ran off adrenaline today. It was very hard to sleep overnight with having a new baby. There were so many cords and wires and machines everywhere. It was kind of unnerving. They would make noises that were stressful, but the nurses explained everything. | Medical involvement  
Worry and fear  
Medical realities of a preterm infant | |
| 563 | She had two events today, she came out on her own, but its still very nerve wracking, I hope they stop completely soon. Still have panic attacks every time she sneezes, hiccups, or coughs. It is hard to be strong sometimes. | Worry and fear  
Medical complications | |
| 400 | Watching our daughter get intubated was the most difficult thing to witness. Felt helpless and scared. The staff is incredible, and baby is much stronger than her dad. | Medical involvement  
Worry and fear  
Positive view of the child irrespective of prematurity  
Medical complications | |
| 563 | Life coming back to normal, established a routine between home, hospital, and everything else. | Establishing a routine  
Balancing home, work, and hospital life | |
| 676 | Very glad to be in a routine. Nurses extremely helpful and ...of the stressors of being in NICU. Mother and I return home to sleep for a few hours every night, which is good for feeling better, however, we feel terrible about leaving baby at the hospital even though we know he is in good | Nursing support  
Feeling guilt  
Establishing a routine  
Balancing home and hospital life | |
<table>
<thead>
<tr>
<th>Page</th>
<th>Text</th>
<th>Coding</th>
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</thead>
<tbody>
<tr>
<td>662</td>
<td>I am worried about going home tonight. I do not want to be away. But I need to take care of our pets so mother can be available for feedings. The thought of leaving is upsetting. My wife said I could take some of the time I was going to use when he comes home now, but I think I will regret not being at home with him.</td>
<td>Feeling guilt Balancing home and hospital life</td>
</tr>
<tr>
<td>662</td>
<td>Realizing everything I have to do in a day is stressful. Between work, cleaning, walking our dog, cooking, and traveling to the hospital, my time with baby is limited.</td>
<td>Feeling guilt Balancing home and hospital life</td>
</tr>
<tr>
<td>676</td>
<td>Making multiple trips a day from home to hospital. Getting lots of advice from all staff which is very helpful however overwhelming at times.</td>
<td>Multiple daily trips Balancing home and hospital life</td>
</tr>
<tr>
<td>563</td>
<td>Work starting to be a concern. They are being understanding but I feel that their patience is running a bit thin.</td>
<td>External pressures Balancing home and hospital life</td>
</tr>
<tr>
<td>638</td>
<td>Going on 23 days with minimal sleep and trying to balance everything is too hard. Work needs me as we started out involuntary period today. They have been amazingly supportive</td>
<td>Fatigue External support Balancing home and hospital life</td>
</tr>
<tr>
<td>638</td>
<td>I go back to work tomorrow and terrified about how to juggle everything[...]</td>
<td>Balancing work and hospital</td>
</tr>
<tr>
<td>638</td>
<td>Times have been tough but its moments like this that remind me, we can do it, we are going to make it. We will be a family again soon and this is just another challenge that we won’t let tear us apart.</td>
<td>NICU a challenge Strength Teamwork through adversity</td>
</tr>
<tr>
<td>609</td>
<td>Looking forward to take our babies home. We are feeling a lot more comfortable with managing time and the demands of the</td>
<td>Readiness for discharge Gaining confidence Preparing for discharge home</td>
</tr>
<tr>
<td>Babies</td>
<td>Readiness for discharge</td>
<td>Preparing for discharge</td>
</tr>
<tr>
<td>--------</td>
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</tr>
<tr>
<td>563</td>
<td>She is doing good. We see a positive turn bit by bit. She is still gaining weight and very active. I think we ...most of the criteria for discharge so we are getting closer and closer to discharge which would be awesome. ...She is doing exactly what she is supposed to do!</td>
<td>Readiness for discharge</td>
</tr>
<tr>
<td>638</td>
<td>The NICU has been excellent however I can’t wait to have my family together and to be able to take full control.</td>
<td>Preparing for discharge</td>
</tr>
<tr>
<td>563</td>
<td>Stress levels even higher as now no monitor, no sensors, and no hospital soon. It is really hard to trust one self that the baby is doing as fine as she is. I hope that the doctors/nurses are right. I really want her to do well.</td>
<td>Stressful awareness of the lack of medical oversight</td>
</tr>
<tr>
<td>633</td>
<td>I’m impressed with how strong he is and how tolerant he is with being handled</td>
<td>Positive view of the child irrespective of prematurity</td>
</tr>
<tr>
<td>638</td>
<td>It seems every challenge you put in front of him he takes it like a champ.</td>
<td>Positive view of the child irrespective of prematurity</td>
</tr>
</tbody>
</table>