Mother’s Lived Experience During Repair of Long-gap Esophageal Atresia: A Phenomenological Inquiry

A dissertation presented by Patricia Catherine Fleck to The Bouve’ College of Health Sciences, School of Nursing in partial fulfillment of the requirements for the degree of Doctor of Philosophy in the subject of Nursing Northeastern University Boston, Massachusetts

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Dedication

My career as a nurse has been immensely satisfying to me. It is part of who I am. As a child, I wanted to be a nurse and loved adventure. These two facets of my life define me. I have been very fortunate to have met and married a wonderful man who has always fully supported every decision I have made to continue to move my personal and professional goals forward, many of which have involved nursing and adventure.

My husband Gregory and I were blessed to have four healthy children, who are now grown. We have three beautiful and healthy grandchildren. Over the years I have had the privilege to care for literally thousands of new babies as they entered the world to join their families. Many of these babies were born prematurely or started life out with life threatening illness. My compassion for them and their families has deepened with time, and has grown to a new level since undertaking this journey.

I am deeply indebted to the mothers who have shared their stories with me. Without them, this would not have been possible. Words cannot express the gratitude I have for these women and their families. I dedicate my work to my family and to families everywhere.
Acknowledgments

My studies at Northeastern University have spanned four decades. As a brand new diploma student at the New England Deaconess Hospital School of Nursing I walked along the verdant Fenway, past the Isabelle Stewart Gardner and Museum of Fine Arts to the campus of Northeastern to study Chemistry, Anatomy and Physiology and Anthropology as I began my nursing career. When I returned to complete my baccalaureate degree, Professors Nancy Walden and Paula Fellows, both of whom who have passed away, left an everlasting impression on me and encouraged my professional growth.

In 1992 when the Neonatal Nurse Practitioner program debuted, I felt like it had been designed for me. It has made a tremendous difference in my career. I am deeply indebted to Dr. Elizabeth Howard who brought both the Neonatal Nurse Practitioner Program and the PhD Program to Northeastern and encouraged me to pursue my dreams.

I never would have imagined that I would be walking these same paths, 40 years later, on my way to receiving a doctoral degree. I have seen many changes in my field of neonatal nursing. I have been most fortunate to have as my chair, an expert mentor and world-renowned leader in neonatal nursing, Dr. Carole Kenner. Thank you for your unwavering support and guidance.

I would like to acknowledge Dr. Rhonda Board for her sedulous assistance in development of my research proposal. This proposal has grown from the early quantitative aims to the full and rich phenomenological inquiry that it is today. And finally, thank you to Dr. Sandra Mott who has been with me for each step of my qualitative proposal and research for her steadfast assistance navigating the intricacies’ of the Nursing Research Council and Review Board at Boston Children’s Hospital. You have been a wonderful mentor to me.
Abstract

Infants born with Long-Gap Esophageal Atresia (LGEA) pose unique physiologic risks in the newborn period. Prolonged hospitalization and multiple procedures impact the mother’s experience of birth and subsequent maternal response to interacting with and nurturing her infant. The aims of the study were: 1) better understand the mother’s perception and interpretation of the diagnosis, treatment and recovery trajectory for her infant, and 2) advance the nursing science of caring for these mothers and their infants. A hermeneutical phenomenological design was used to guide this inquiry. A purposeful, heterogeneous sample of three mothers was interviewed on three separate occasions. The analysis phase utilized the existential framework to bring voice in the form of a written narrative to reveal the essence of each mothers’ experience. The central organizing theme was identified as Making Connections: Day-by-Day. The Phases of Time, The Long and Winding Road; My New Purpose: A New Me; and A New Community were identified as themes that conveyed the essence of the experience. The results contribute to nursing’s knowledge and understanding of a mother’s experience of having an infant with LGEA. This knowledge provides clinicians with a greater understanding of the mother’s perspectives, concerns, and the need for individualized interventions to support mothers whose infant’s undergo this process. Future directions for research with this unique population of infant’s includes further examination of physical growth and development, achievements over time, techniques to support positive feeding practices and interventions to facilitate the emotional health of infants and their mothers.
Chapter One: Introduction

Mother’s Experience During Repair of Long-Gap Esophageal Atresia: A Phenomenological Inquiry

Patricia Fleck, MSN, NNP-BC

Northeastern University
Mother’s Experience During Repair of Long-Gap Esophageal Atresia: A Phenomenological Inquiry

Infants born with Long-Gap Esophageal Atresia (LGEA) are born with an esophagus that is not intact, posing unique physiologic risks in the immediate newborn period. This congenital anomaly requires an extended hospitalization and multiple procedures with analgesia, sedation and paralysis that impact the mother’s experience of pregnancy, birth and subsequent maternal attachment and ability to nurture her infant. The purpose of this study was to understand the essence of the experience of being a mother of an infant with LGEA.

A hermeneutical phenomenological approach guided this inquiry. Multiple probing interviews with each participant provided data that contributed to a better understanding of the meaning these mothers ascribed to the interrupted and limited opportunities they had to learn and interact with their newborn. Each experience was portrayed through the mother’s situated context. The process of understanding each mother’s experience involved immersion in the reality of her life worlds. Only then did the data have meaning. It was through sharing in their reflections that I understood how they interpreted and gave meaning to their experiences. It is this understanding that provides nurses with insight to modify care, identify resources, and offer individualized support. Qualitative research was chosen for this study because it has the potential to enhance understanding of a phenomenon and challenge the existing practice guidelines with evidence (Leeman & Sandelowski, 2012).

This chapter presents the evolution of the qualitative research presented and the stance of the researcher. The process of this research is detailed in three separate manuscripts that describe
the harmonious and logical progression of inquiry. Finally, the manuscript dissemination plan is described.

Formulating the Question

Evolution of the study

My current role as a Neonatal Nurse Practitioner (NNP) in the NICU at a large academic quaternary children’s hospital that has a program focused on the complex needs of infants born with Long Gap Esophageal Atresia has given me a special lens from which to view the experience of mothers and their infants as they proceed through the process of esophageal growth induction for a delayed primary anastomosis. I had witnessed the quiet solitude, anxiety and apparent frustration of mothers’ as they maintained a vigil by their infant’s bedside while their infant was undergoing multiple medical and surgical procedures. There were also mothers who were not able to be with their infants because of conflicting family needs, financial demands or distance. The separation and challenges to maternal care giving coupled with the infant’s compromised relational abilities necessitated by the treatment protocols further interfered with the development of a natural synchrony that is present in a healthy mother-infant relationship (Renya & Pickler, 2009). This research proposal developed as a result of my impressions of these challenging experiences I saw in both the infants and their mothers as they journeyed together through the process of “growing the esophagus” in the NICU.

My naturalistic qualities as a thoughtful, caring and inquisitive nurse practitioner brought me to the method of phenomenology to answer the research questions. vanManen (1990) describes a turning to the phenomenon, a reawakening of basic experiences in the world. I found myself being there, Dasein, turning to these mothers and their infants and felt a desire to pursue
the reality of the lived experience of the mothers who were undergoing this alteration in their mothering role. As an advanced practice nurse, my moral imperative to continue to advance knowledge development for nursing science and mentor nurses caring for these high risk infants, became the stimulus for evaluating the current practice guidelines and provision of care (Leeman & Sandelowski, 2012).

What is Known

Mothers whose infants are born with LGEA experience psychological stress related to the anatomic defect. Being a witness to their infant’s physiologic distress while undergoing the surgical procedure, enduring separation, and not being able to hold and naturally care for her infant during this time adds to their anxiety (Bystrova, et al, 2009; Faugli, Aamodt, Bjorland, Emblam & Diseth, 2005).

The experiences of being present with the infant in the NICU, yet limited in their opportunities to participate in the infant’s care, have the potential to influence the maternal representation of her infant, the attachment process, and the emotional health and well being of both mother and infant. The profundity of maternal responses in this unique population has not been described in the literature and represents a gap in the nursing science in maternal-infant attachment in surgical infants. Nursing’s ability to understand and respond to mothers needs may strengthen the mothers’ feelings of competence and facilitate positive experiences for this high-risk dyad.

Understanding early experiences can contribute to the maternal infant interactions in high-risk populations and positively influence their health and wellbeing (Ainsworth,1979; Als & Lawhorn, 2004; Holditch-Davis et al.,1999). Positive mother-infant interaction facilitates
Research Study

The purpose of this study was to understand the meaning of the lived experience of being a mother of an infant born with LGEA. Although these mothers were physically present with their infants, their opportunities for interactions were diminished through the sedation and paralysis protocols required throughout the phased surgical process of growing the esophagus so the two ends could be connected and made functional. There were two specific aims:

Aim 1) better understand the mother’s perception and interpretation of the diagnosis, treatment and recovery trajectory for her infant, and

Aim 2) advance the nursing science of caring for these mothers and their infants.

Dissemination Plan

The results of this research are presented in three separate manuscripts. The manuscript sequence and dissemination plan is outlined in this section.

Manuscript One

The first manuscript is an integrated review of the literature presented as described by Whittemore and Knafl (2005). The purpose of this integrative review was to synthesize the available literature related to the health outcomes of infants with LGEA and its impact on the maternal infant interaction. Specifically, the problem formulated for this integrative review was as follows: What are the health outcomes in terms of the mother-infant interaction with their social competency and secure attachment for later social, language and cognitive development (Mantymaa et al., 2006). Since understanding and mediating the parental response becomes essential for improved outcomes, a qualitative study was undertaken to explore the maternal experiences and meaning of having an infant with LGEA.
LGEA infants during and following their delayed primary anastomosis? The results of the integrated review revealed three specific outcome domains: 1) physical health 2) neurodevelopmental outcomes, and 3) socio-emotional outcomes including mother-infant interaction.

Discussion includes a synthesis of the literature and the themes and relationships revealed, as the data related to the infant with LGEA and the evolving mother-infant interaction. The synthesis allowed for a reconceptualization of the topic and portrayed a deeper and more comprehensive understanding of this multifaceted phenomenon (Whittemore & Knafl, 2005). The target journal for the manuscript, *Infants with Long-Gap Esophageal Atresia: An Integrative Review* is the *Journal of Pediatric Nursing*.

**Manuscript Two**

This clinical paper describes the impact of interrupted attachment on growth and development of infants that experience surgery in the neonatal period. The purpose of this paper is to inform clinical nursing practice about caring for high-risk infants and their mothers. Current evidence suggests that surgical procedures in the neonatal period include physiological and behavioral risks (Aite et al, 2014; Bevilacqua, et al 2014a; Bevilacqua et al, 2014b; Gischler et al, 2009; Maheshwari, Trivedi, Walker & Holland, 2013; Walker, Halliday, Badawi, Stewart, & Holland, 2103). Some of the risks interfere with the normal process of attachment due to alterations in the infant’s physiological functioning and innate capabilities as well as the surgical process and requisite anesthesia and analgesia. In addition these changes may alter maternal responses and subsequent competency caring for her infant. Nurses have the dual responsibility of supporting the physiologic needs of the infant while facilitating attachment behaviors in their
fearful, anxious mothers. To support this introduction and foster interaction, it is imperative for nurses to understand both infant and maternal characteristics and behaviors.

The principals of maternal-infant attachment are reviewed to assist nurses as they focus on identifying the infant’s individual physical, emotional and developmental strengths while promoting maternal attachment behaviors between the infant and mother dyad. The paper also discusses the emerging infant temperament and how the infant, as a distinct human, influences the mother’s responses thus forming the basis of a synchronous relationship. The relational process of feeding is also considered on the developing mother-infant relationship when the infant is unable to feed orally. Implications for nursing practice are identified. The target journal for the manuscript, *Interrupted Attachment in the Surgical Newborn* is *The American Journal of Maternal Child Nursing.*

**Manuscript Three**

The third manuscript reports the results of the research study. The research format follows Munhall’s (2012) method for hermeneutical phenomenological inquiry. The proposal development, implementation and contextual processing were completed with the assistance of my dissertation committee and mentors, Dr. Sandra Mott, a leading qualitative researcher and pediatric nurse scientist at the children’s medical center, Dr. Carole Kenner, expert neonatal nurse scientist and dissertation committee chair, and Dr. Rhonda Board, pediatric nurse scientist and academic faculty. An extensive audit trail chronicles the research process from proposal development to the written textual expressions of the results. Concurrent confirmability and authenticity validate the truthfulness of the interviews and transcriptions, field notes, and reflexive journaling. The analysis phase utilized the existential framework and integration of the
life worlds to give voice in a written narrative of the meaning of each mothers’ experience of being of mother to an infant with LGEA. The written narrative illustrates the answers given to the research question. Subsequent interviews allowed for probing and collaborative interpretation to interpret the meaning and unveil the essence of the mothers’ lived experience in relation to their journey of learning their infant and the specialized care required.

The findings are discussed in relation to what is known, i.e. that which is described in the literature and evaluated by current research supporting successful mother-infant attachment in infants with life threatening conditions (vanManen 2012). Interpretive theory acknowledges multiple realities and the importance of the human experience when addressing the health needs of specific populations. The study findings will endeavor to suggest a holistic approach that can be used to individualize assessment and understanding of a mother’s personal perspective when her infant is born with LGEA. This understanding will support mothers to optimize situations that enable them to understand and learn their unique newborns and to improve the overall health and outcome for their infants.

Implications for nursing practice are discussed. This study contributes to nursing science by informing nursing practice in caring for infants born with LGEA and their mothers. The target journal for the manuscript, *Mother’s Lived Experience During Repair of Long-gap Esophageal Atresia: A Phenomenological Inquiry* is *Advances in Neonatal Care.*
Contribution to Nursing Science

The new knowledge gained from this study has potential to improve delivery of family centered individualized care to this high-risk dyad that has not previously been described. The results of this study will contribute to neonatal nurses’ knowledge and understanding of the experiences of being a mother of an infant with LGEA.

This knowledge will provide clinicians a greater understanding of a mother’s perspectives, concerns, and needs, ultimately guiding the design and implementation of interventions to support women in their roles as mothers and advocates for their infant. Providing individualized family focused developmentally supportive care that focuses on the identified needs of infants with LGEA can lead to improved physical, neurodevelopmental and emotional outcomes. The emphasis on empowering mothers to know and understand their infant will enable them to participate fully in the care of their infant.
References


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Chapter Two

Infants with Long-Gap Esophageal Atresia: An Integrated Review of the Literature

Patricia Fleck

Northeastern University
Infants with Long-Gap Esophageal Atresia: An Integrated Review of the Literature

Esophageal Atresia (EA) is a rare congenital anomaly that results in the incomplete formation of the esophagus with both structural and physiologic effects of both the esophagus and trachea. The prevalence rate is approximately 1 in 4000 births (Nassar et al, 2012; Pederson, Calzolari, Husby, Garne, & EUROCAT Working Group, 2011). There are several types of EA and true Long-Gap Esophageal Atresia (LGEA) presents in 3% to 10% of infants with EA. Long gap esophageal atresia is characterized by an esophagus that ends in a blind pouch in the upper thorax, with or without a tracheoesophageal fistula (TEF) and a distal esophageal segment emanating upward from the stomach, with the gap spanning the distance of three to greater than five vertebral bodies. Fifty percent of infants with EA will also have additional congenital anomalies (CA) or chromosomal abnormalities, the most common being congenital heart defects. Prenatal detection of EA by ultrasound ranges from 9% to 56% (Brantberg, Blaas, Haugen & Eik-Nes, 2007; deJong et al, 2010) and is often made late in gestation with little time for physical or emotional preparation prior to delivery. Abnormal findings on prenatal screening ultrasounds for fetal anomalies have been demonstrated to alter mother-infant interaction during pregnancy and then continue into the neonatal period (Viaux-Savelon et al, 2012).

Because a traditional surgical primary anastomosis is not possible in this form of EA (El-Gohary, Gittes, & Tovar, 2010; Spitz 2007; Zani et al, 2014), surgical management of LGEA continues to be a global challenge. Currently the preferred surgical intervention requires a delayed primary anastomosis with an overall survival rate of greater than 90% (El-Gohary, et al, 2010; Zani et al, 2014). Since 2000, the number of infants surviving repair of EA has increased dramatically, therefore, current research on this population has switched to neurodevelopmental
outcomes and quality of life (Aite et al, 2014). These infants are at considerable risk for physiologic disorganization related to suboptimal functioning of autonomic, motor, and behavioral states during the neonatal period from repeated medical and surgical procedures, as well as mechanical ventilation with obligatory anesthesia and sedation. In addition, infants with LGEA experience stress related to early maternal separation, delay in establishing oral feedings and negative oral experiences (Caplan, 2013; Hawley, 2001; Ho & Mok, 2006).

Having an infant with life threatening anomalies requiring major surgery in the neonatal period can be a source of stress for a new mother (van Manen, 2012) and have a negative effect on maternal-infant interaction (Viaux-Savelon et al, 2012). While hospitalized in the Neonatal Intensive Care Unit (NICU) the sedation and paralysis protocols for LGEA repair reduce the mother’s ability to provide care for her infant, thus compromising her ability to naturally experience and learn about her infant and respond to the newborn’s needs (Feldman, Magori-Cohen, Galili, Singer, & Louzoun, 2011). Researchers have found that stress, depression and anxiety are associated with having an infant hospitalized in the NICU (Pinelli et al, 2008; Segre, McCabe, Chuffo-Siewart & O’Hara, 2014). Together, the infant’s inability to reach a physiological organized, self-regulated state and the maternal psychological response to having a critically ill infant appear to negatively impact infant health and development and the maternal-infant interaction.

The purpose of this integrative review was to synthesize the available literature related to the health outcomes of infants with LGEA and the impact of those outcomes on the maternal-infant interaction. The research question formulated for this integrative review was what is the
impact of health outcomes of infants with LGEA on the mother-infant interaction following a delayed primary anastomosis?

**Method**

**Design**

This integrative review follows the 5-step framework for enhancing rigor described by Whittemore and Knafl (2005) and was chosen to best summarize the broad array of available literature pertaining to infants with LGEA. Step one was to identify a problem and state the purpose of the review. Specific variables were selected for inclusion and exclusion to focus the review. The second step was a comprehensive literature search followed by the third step, data evaluation in which quality of the existing research studies was assessed. The fourth step of data analysis occurred as the data from each primary source were extracted and categorized. In the fifth step the data were displayed in a table format that allowed for deduction and comparison with the goal of synthesizing the information to create a holistic understanding of what was known about infants with EA and LGEA.

**Literature Search**

The literature search was performed between September 2014 and January 2015. Cumulative Index for Nursing and Allied Health Literature (CINAHL) and PubMed databases were used to conduct the search with the terms *esophageal atresia, long-gap esophageal atresia, newborn, infant, feeding, outcomes, psychosocial and maternal-infant interaction*. Terms were used separately and in combination to search titles and abstracts of published reports for an exhaustive selection of pertinent articles. Bibliographies and reference tables were also used to garner more studies.
**Inclusion criteria.** Articles written since 2001 in English that were related to health outcomes and management of infants with EA under the age of one year were selected. Due to the paucity of literature related specifically to infants with LGEA, articles with types of EA were included.

**Exclusion criteria.** Articles excluded were isolated case reports or series reports from regional centers that focused primarily on generalized surgical approaches with center-specific data, articles exclusively on surgical techniques, and research that focused on children older than one year. Textbooks, editorials, dissertations and abstracts of unpublished articles were also excluded.

**Search Results and Data Evaluation**

One hundred and seventy articles were identified with the search terms. Article reference lists were also reviewed, resulting in 36 additional studies for possible inclusion. Eliminated were thirty-four duplicates and two that were not available in English. Remaining articles were reviewed for eligibility criteria and appraised for quality and informational value. The final review yielded 16 articles: 13 research studies and three clinical reviews (Figure 1).

A formal quality appraisal form was not created to assess the studies in the final selection for the review due to the diversity of research designs that were used. Rather, conventional rules of research rigor were used to critique the selected studies according to the study design (Whittemore & Knafl, 2005). This approach included assessing methodological quality and informational value related to infants with EA.
Figure 1

Data Analysis

As each article was reviewed, data were extracted and organized by author, year and country; study purpose and design; sample; variables and data collection; study findings; and limitations (Table 1). The primary sources and extracted data were presented in the table in alphabetical order by the first author. There were three groups of authors with sequentially published articles that demonstrated a progressive program of research pertaining to infants with EA, a specific criterion recommended by Whittemore and Knafl (2005) to establish rigor. The purpose of using these organizing constructs was to compare and identify patterns and analyze
relationships among the studies to differentiate the health outcomes of infants with LGEA and the impact if any, on maternal-infant attachment. The limitations of each study are included in Table 1.

**Results**

**Study Characteristics**

The study designs in this review included one experimental design and twelve non-experimental designs and three clinical reviews. There were no qualitative designs or theoretical papers that provided a framework for evaluating the health and maternal-infant interaction of infants with EA. As data were extracted, common terms, variables and topics of interest were identified leading to the development of categories that were considered for review.

Only two studies specifically addressed the health issues of infants with LGEA. Friedmacher and Puri (2012) conducted a systematic review of complications and outcomes and Maheshwari, Trivedi, Walker and Holland (2013) published a retrospective chart review examining short term results, growth and neurodevelopmental outcomes (NDO) with LGEA infants. Eight additional studies focused on infants with EA/TEF, while three focused on surgical infants that included those with EA as participants in the study. Of the three clinical reviews, one focused on the surgical outcomes for infants with EA, another examined the feeding difficulties experienced by infants with EA, and the third review explored the psychological impact of EA. One study was performed in the United States while the rest of the research was conducted internationally.
Synthesis of the Findings

The review of the literature revealed infants with EA and LGEA have multiple areas of concern that revolve around three major categories. The categories that emerged based on these findings were: 1) physical health, 2) neurodevelopmental health and 3) psychosocial health of infants with EA or LGEA.

Physical health. The reports that included physical health in their discussion focused on the respiratory and gastrointestinal systems, both of which contribute to feeding difficulties. Friedmacher and Puri, (2012) and Maheshwari et al. (2013) focused on the physical health and demands on the infant with either EA or LGEA. These demands were in the form of enduring multiple surgeries over a period of months, delayed growth velocity, and risks of aspiration and pneumonia. A Delayed Primary Anastomosis (DPA) is the preferred method of surgical management of infants with LGEA, as it allows the infant to grow into adulthood with a natural esophagus and has better long-term outcomes than replacement alternatives (Friedmacher & Puri, 2012). However, this usually means an extended length of hospitalization. While there have been occasional reports of infants being discharged home while awaiting DPA, the majority of infants remain hospitalized until after the repair. Decreased growth velocity has been noted in infants with LGEA which then increases waiting time for a DPA and adds to the infant’s hospital length of stay (Maheshwari et al., 2013).

a. Respiratory issues. The reports of Castilloux, Noble and Faure, (2010), Friedmacher and Puri, (2012), Kovesi and Rubin (2004), and Maheshwari and colleagues, and Mortellaro and colleagues (2011) found the respiratory comorbidities typically associated with EA which include chronic respiratory insufficiency, TEF, tracheomalacia (15% - 60% of infants with EA),
LGEA: INTEGRATED REVIEW OF THE LITERATURE

and vocal cord paralysis. Chronic respiratory symptoms requiring supplemental oxygen or ventilation support add to the physiologic demands of the infant, compromising growth and challenging the development of oral feeding (Castilloux et al., 2010). Tracheomalacia results in respiratory distress and cyanosis (Castilloux et al., 2010; Maheshwari et al., 2013). This distress may be due to an intermittent collapse of the trachea and is treated with an aortopexy, which in turn, compounds the number of surgical procedures, exposure to anesthesia and add to the infant’s LOS (Friedmacher & Puri, 2012).

Respiratory complications following surgical repair of EA include wheezing, diminished pulmonary function, bronchial reactivity, cough, recurrent pneumonia and chest wall deformities from repeated surgical interventions. Recurrent TEF may lead to aspiration that can further compromise the infant’s respiratory status. Surgical technique, tension on the anastomosis site, anastomotic leak and most commonly, gastro-esophageal reflux disease (GERD) are factors that increase the risk of recurrent TEF and strictures (Castilloux et al., 2010; Friedmacher & Puri, 2012, Maheshwari et al., 2013). None of these reports however, link the respiratory problems and their impact on the maternal-infant interaction.

Vocal cord paralysis (VCP) is a finding that may appear after birth or in the post-operative period when the infant has stridor, aphonia or is unable to be extubated (Mortellaro et al, 2011). Clinically stable infants with unilateral VCP may be managed expectantly while bilateral VCP may be an indication for tracheotomy for airway protection and management.

b. Gastrointestinal issues. The reports that discussed gastrointestinal issues as the central theme primarily focused on dysphagia and multiple forms of feeding disorders (Castilloux et al, 2010, Friedmacher and Puri, 2012, and Maheshwari et al, 2013. Dysphagia is co-morbidity for
all survivors of repaired EA due to the dyskinetic lower esophageal segment. Feeding difficulties commonly include oral aversion, un-coordinated suck-swallow, esophageal dysmotility, recurrent strictures, GERD, aspiration and recurrent respiratory illnesses that interfere with the development of oral feeding skills (Castilloux et al., 2010). Although the majority of patients who have a primary anastomosis eat normally, the incidence of dysphagia increases with GERD, strictures, requiring repeated dilations and LGEA (Friedmacher & Puri, 2012). While most esophageal strictures respond to dilations, resections or re-anastomosis may become necessary, adding to the number of surgical procedures and exposure to anesthesia. In addition to GERD, other post-operative complications include anastomotic leaks, strictures, esophagitis, oral aversion and growth failure that can place additional burden on the infant’s ability to grow, orally feed and increase mother’s stress during feeding (Maheshwari et al., 2013).

Because of the prevalence of GERD with infants after surgical repair for EA, two studies focused on decreasing its effects. Hagander et al. (2012) examined the impact of initiating a proton pump inhibitor (PPI) to treat GERD following surgery for EA. There was however, no correlation between the initiation of therapy and development of strictures. Friedmacher & Puri, (2013) found that 30% of infants with recalcitrant GERD, fundoplication was performed thus adding to the number of surgeries, resulting in increased LOS and increased feeding difficulties.

Whereas healthy newborns establish a responsive feeding cycle with their mothers in the first days of life, infants with EA are denied this experience. Instead they experience multiple oral adverse events that place them at risk for establishing oral feeding. Feeding difficulties are associated with respiratory distress, recurrent strictures that require repeated dilations, GERD, and esophageal dysmotility and are commonly manifested by oral aversion, un-coordinated suck-
Infants with EA and LGEA, especially those with associated congenital anomalies experience a long LOS because of multiple surgical procedures, increased ventilator support and the use of medical feeding devices (Bevilacqua et al. 2014b; Gischler et al., 2009). Gastrostomy tube feeding and parenteral nutrition are essential for optimal nutrition for growth in infants having a DPA (Friedmacher & Puri, 2012; Maheshwari et al, 2013). Forty-nine percent of infants with EA experience significant clinical morbidity in the first year of life, while more than half of those continue to experience significant physical morbidity after one year of age (Castilloux et al., 2010).

The issues with feeding and prolonged LOS have been associated with additional burdens on the family (Castilloux et al., 2010; Gischler, 2009). Feeding difficulties were viewed as a significant source of stress that had a negative impact on how the mother viewed her parenting abilities (Caplan, 2013; Ramsey & Birnbaum, 2013). Education for parents regarding their infant’s complex medical issues and care needs have been identified as a means to ameliorate continued stress and to normalize their experience.

2. Neurodevelopmental outcomes. The second category to emerge was neurodevelopmental outcomes (Aite et al., 2014; Bevilacqua et al., 2014a; Bevilacqua et al., 2014b; Gischler, et al., 2009; and Walker, Halliday, Badawi, Stewart & Holland, 2013). There have been conflicting results in measuring the NDO outcomes of infants requiring surgery for congenital anomalies (CA) in the neonatal period. Infants with CA who are operated on after
birth have an increased incidence of delays in growth and development that correspond to complexity and severity of illness, number of surgical procedures, and hospital LOS (Gischler, et al 2009). In particular, infants with EA were noted to have below normal growth velocity that was attributed in part to respiratory compromise, making the infants more likely to be dependent on medical devices for feeding altering normal feeding behaviors. Infants with EA also were identified as having the highest scores for complexity of care and number of procedures compared to infants with other types of CA, adding to their exposure to anesthesia and LOS, factors that have been identified as having a negative impact on NDO (Gischler et al 2009),

In one of the first NDO studies specific to EA, the infants were noted to have concern for moderate delay in development of the expressive language domain (Walker, Halliday, Badawi, Stewart & Holland, 2013). In addition, there were mild delays in cognitive, receptive language, fine motor skills, and particularly in the gross motor skill domain found at one year of age compared to healthy control infants.

However, Bevilacqua et al (2014a; 2014b) more recently demonstrated that infants with CA who required surgery after birth were on average more likely to have normal NDO as measured by the Bayley’s Infant Scales of Development 3rd Edition (BSID III). Similar findings were found in a study that focused solely on infants with EA (Aite et al., 2014). But it is important to note that the ranges of cognitive scores at six months of age were lower than the normal distribution and repeated evaluations at 12 and 24 months demonstrated improvements into the normal range in both groups. These suggest that the child’s early traumatic experiences associated with surgery and hospitalization may have impacted early cognitive and motor development. Both Aite et al, (2014) and Bevilacqua et al. (2014a) hypothesized that the
improvement in scores by 12 months of age was related to traumatic stress during the infant’s early hospitalization course and further suggested that the relationship between feeding difficulties and the stress it imposes on the infants’ developing socio-emotional relationships including the maternal-infant interaction and may influence cognitive function.

The risk factors associated with lower scores for both cognitive and motor scales were the complexity of congenital anomalies requiring surgery, the number of surgical procedures performed, the number of medical devices required by the infant such as gastrostomy or tracheotomy tubes, and most significantly, and the length of ventilation assistance that the infant required (Bevilacqua et al., 2014a; Bevilacqua et al., 2014b). Additional risk factors identified by Aite and colleagues (2014) for lower cognitive scores were body weight less than the fifth percentile, GERD and post-traumatic oral aversion. Lower scores on motor scales were related to the mother’s employment status and the number of surgeries performed thus potentially limiting maternal-infant interaction. Interestingly, infant’s whose initial hospital LOS was longer demonstrated greater improvements in gross motor scores that were attributed to early initiation of physical therapy (Bevilacqua et al., 2014b).

Infants with LGEA frequently present prematurely, on average 35 weeks gestation. Prematurity in itself has been associated with a range of developmental delays (Maheshwari et al., 2013). Decreased growth velocity and lack of oral feeding skills at discharge are identified as risks associated with poorer NDO (Maheshwari et al., 2013). The presence of additional congenital anomalies, physical health issues, number of surgeries and post-operative complications were correlated with significant delays in gross motor skills on standard
evaluations with BSID III at 12 months of age (Maheshwari et al., 2013), and was the first study to specifically address the NDO of infants with LGEA.

In summary, these studies signal an increased risk for delay in cognitive development, especially in the expressive language domain (Walker et al, 2013) and for motor development in infants who undergo surgical correction for EA (Aite et al, 2014; Bevilacqua et al, 2014a; Bevilacqua et al, 2014b; Gischler et al, 2009). These cognitive and motor developmental delays proceed to within the normal range by one year of age, demonstrating a period of “catch up.” This suggests that the initial hospitalization period is a stressful event that may have an impact on the infant’s early cognitive development (Aite et al., 2014; Bevilacqua et al 2014a; Bevilacqua et al 2014 b).

3. Psychosocial outcomes. The third category that emerged was the psychosocial outcomes of the mother and infant. Mothers of infants with EA exhibit behaviors of depression, anxiety and post-traumatic stress (Faugli, Aamodt, Bjornland, Emblem & Diseth, 20015; Faugli, Emblem, Veenstra, Bjornland & Diseth, 2008; Faugli, Emblem, Bjornland & Diseth, 2009). Emotional states play a role in maternal-infant interactions and may manifest as reduced sensitivity and altered maternal affect towards the infant (Faugli et al., 2005).

Maternal wellbeing is an important factor in developing a relationship with a newborn. The responsiveness, reciprocal behaviors and experiences over time influence the healthy development of maternal-infant interaction (Caplan, 2013; Faugli, et al., 2005). Maternal stress associated with feeding impacts the mother-infant relationship in the context of reciprocal responsivity and socio-emotional behavior (Faugli et al., 2005; Faugli et al., 2008). Maternal
anxiety is heightened during infant feeding following EA repair that is primarily related to the infants’ distress from physical compromise (Faugli et al., 2008).

Mother-infant relationships develop from the mothers’ and infants’ experiences and responses to one another during feeding. Recognizing that maternal-infant interaction is predominated by feeding behaviors, Faugli et al (2005) described the clinical challenges of infants’ with EA that impose significant stress on the feeding experience. They showed that the determination of each mother to succeed in her task of nurturing her infant resulted in intrusive behaviors, such as continually prompting her infant to feed, on the part of the mother. Although this study was limited by a small sample size, Faugli et al. (2005) suggested that mothers of infants with EA may benefit from anticipatory guidance to promote positive experiences around the feeding relationship as it contributes to the infant’s emotional and neurodevelopment. Furthermore, Faugli et al. (2008) found that the quality of the mother-infant interaction was influenced by the act of feeding, and that mother’s feeling of competence was compromised when feeding her infant with EA. On the other hand, mothers demonstrated strength in other aspects of care during the mother-infant interaction, indicating there are many components in the adjustment of maternal attitudes and adaptation to the infant’s complex condition. The nature of the relationship of competence to maternal-infant interactive behavior has not yet been explored and is an area that was identified for further study.

Chronic illness in infancy can jeopardize the infant’s mental health and negatively influence maternal-infant attachment. Prognostic factors that contribute to infant mental health disorders, identified in infants with EA at one year of age include mechanical ventilation, multiple surgeries, post-traumatic stress symptoms reported by the mother, and moderate to
severe family strain, (Faugli et al., 2009). It is interesting to note that many of these are the same factors that impact NDO in this high-risk population. Post-traumatic stress experienced by infants during their initial hospitalization has been described in infants experiencing NICU care and has been posited to influence the infant’s ability to respond to stress and thus perceived by the mother as a more vulnerable infant (Caplan, 2013; Faugli et al., 2005). Maternal positive affect provides an organizing function for the infant, which the infant depends upon to regulate it’s own affect. Feeding relationships that occur in the context of a positive, responsive manner form the basis for a reciprocal exchange between mothers and their infants that promotes interaction, allowing for the infant to explore his environment and promote brain development (Faugli et al., 2005; Faugli et al., 2008; Ramsey & Birnbaum, 2013). There is a paucity of data related to the psychosocial outcomes of infants with EA and very few of the infants in these studies were identified as having LGEA.

**Discussion**

The purpose of this integrative review was to synthesize the available literature related to the health outcomes of infants with LGEA and the impact of those outcomes on the maternal-infant interaction. The research question formulated for this integrative review was what is the impact of health outcomes of infants with LGEA on the mother-infant interaction following a delayed primary anastomosis?

The treatment and management of EA/LGEA has the potential to affect the infants’ immediate and long-term health outcomes in the areas of physical, neurodevelopmental, and psychosocial growth and development. The advantage of having a natural esophagus for life makes DPA the preferred method of repair for LGEA. But because the average repair occurs at 3
months of age, co-morbidities of EA, the physical problems associated with the surgical procedure, and post-operative complications, there is an increase incidence for NDO delays and added stress on the emerging mother-infant relationship. However, published studies are focused primarily on the physical problems and medical treatment and not on the maternal-infant interaction. Furthermore, the presence of additional congenital anomalies, severity of illness, frequency of painful procedures with limitations of physical movement all compound the health risks for the infant undergoing surgery in the newborn period (Gischler et al., 2009). Although the burden to the family is discussed as a collateral difficulty related to the infants’ complex care, the correlation to the development of the mother-infant interaction has not been studied.

Respiratory issues may cause considerable concern to a mother caring for and learning to feed her infant (Caplan, 2013). These oral experiences can negatively influence the post-operative transition to oral feedings and may magnify maternal stress (Faugli et al., 2005; Ramsay & Birnbaum, 2013). Witnessing her infant’s physiologic distress is traumatic and contributes to a mother’s responses to her infant and feelings of competence caring for her infant (Caplan, 2013; Faugli et al., 2009). The experiences may set the stage for maladaptive behaviors by infants and their mothers that directly impact mother-infant interaction.

Ideally, the mother should be the person initiating and responding to the infant with her expressed milk for oral care and non-nutritive sucking to promote oral skills and improve the infant’s self-regulatory behaviors (Caplan, 2013; Faugli et al, 2009). Engaging the infant with pleasant oral experiences is essential to the natural exploratory behaviors the infant uses to learn about the world. Normal newborn behavior includes oral feeding and explorations of the environment that are necessary for orienting themselves in space, learning the characteristics of
objects, and forming the basis of social skills. The physical contact of feeding promotes motor
skill development while the face-to-face interaction and reciprocal nature of the feeding
relationship influence the infant’s physiologic organization and expressive responses. It is clear
that developing feeding relationships and reducing maternal anxiety associated with feeding of
infants following EA repair is an area for concern that speaks directly to the relational abilities of
mothers to feed and interact in a competent, enthusiastic and caring manner with their infants
(Faugli et al., 2008).

Dysphagia is a primary focus in the literature related to the outcomes of infants with
EA/LGEA. Infants who require long-term gastrostomy feedings may lose interest in oral feeding
at a critical time when it is essential to maintain sucking and oral feeding skills (Ramsay &
Birnbaum, 2013). Dependence on a medical device such as a gastrostomy tube is a reminder to
the mother that her child has special needs, which may reinforce uncertainty and negatively
influence maternal identity (Wilken, 2012). The reciprocal cue based relationship necessary for
mother-infant interaction can also be affected by the use of gastrostomy tube feedings at
scheduled times without regard to hunger or feeding cues that don’t allow the infant to
establishes a cycle of hunger and satiation associated with the responsiveness of his mother
(Caplan, 2013; Ramsay & Birnbaum, 2013). Mothers should be supported while the infant
practices feeding skills as growth and feeding issues present a greater risk for cognitive and
motor delays and influence mother-infant interaction (Aite et al, 2014; Ramsay & Birnbaum,
2013). Medical complexity, the use of medical devices, decreased normal exploratory behaviors
and a prolonged hospital LOS impose additional risks on the developing infant’s behavior as
well as the maternal responses to her infant (Bevilacqua et al., 2014a; Bevilacqua et al., 2014b; Gischler et al., 2009).

Of most concern however, are the results of studies that describe an association between lower ranges in cognitive and motor scores on BSID III and psychological trauma and stress in the neonatal period (Aite et al, 2014; Bevilacqua 2014a; Bevilacqua 2014b; Gischler, 2009; Maheshwari et al 2013; Walker et al 2013). The physiological stress experienced by the infant influences the mother’s ability to respond to and care for her infant as she normally would (Faugli et al 2009) and an inability to feed further diminishes the infant’s ability to discover and explore his environment, behaviors that are associated with social integration and relational health (Caplan, 2103; Faugli et al, 2009). Education and building maternal competence, especially in the feeding domain, are key elements for improving the emotional health of mothers that influences the outcome in infants with EA/LGEA (Faugli et al., 2008). The results of these studies become more concerning as emerging evidence reveals that early NDO may predict later outcomes of infants who have surgery for CA (Laing, Walker, Ungerer, Badawi, & Spence, 2011; Mazer, Gischler, Van der Cammen-Van Zijp, et al., 2010).

The mother may perceive the infant as vulnerable during the first year of life especially in the presence of delayed cognitive and motor development. This can have long term implications for child development and family stress. Targeting the critical period during which a mother comes to learn and respond to her infant with maternal support and education may serve to decrease the stress associated with early mothering behaviors. Being aware of the stress imposed on the infant with repeated painful medical and surgical procedures may reduce stress responses experienced by the infant. Incorporating maternal care giving activities has potential to facilitate
relational competence and influence the infant’s responses to treatment and recovery and ultimately shape the overall health and NDO of the infant.

Maternal responses are influenced by the mother’s personal experiences, levels of stress and anxiety as she forms a relationship with her infant. Many mothers experience post-traumatic stress from having a prenatal diagnosis of an infant with EA which is compounded by prolonged LOS, repeated surgeries, delays in oral feeding and diminished synchrony that feeding brings to the mother-infant relationship (Faugli, et al., 2009). Providing insight into the infant’s regulation and emerging temperament can enlighten a mother’s awareness of her infants unique personality. This can then help guide her responses to the infant to optimize their mutual responses so she can recognize the goodness of fit between them (Seifer et al., 2014). The mother’s personal experience of caring for her infant born with LGEA constitutes a gap in the literature for understanding the factors involved in caring for this high-risk population.

Limitations

There are few studies that address the specific needs of infants with LGEA. Information related to infants with EA/LGEA represents a broad array of epigenetic etiologies, surgical reports and series reports of outcomes that contribute additional detail to the information found in the selected studies. Limiting the studies to infants less than one year of age served to identify the early needs of infants with EA/LGEA in relationship to their emerging socio-emotional development and maternal-infant interaction but may have left out information related to infant development and long-term outcomes that were reported in studies of older children. The researchers who specifically addressed infants with LGEA recognized the limitations of their small sample sizes (Maheshwari, et al, 2013) and the range of years that comprised the
systematic review of a delayed primary repair (Friedmacher & Puri, 2012), during a time of rapid technological advancements. In the three available studies that specifically examined mother-infant interaction, a very small percentage of infants with EA actually had LGEA.

**Clinical Implications**

Suggested nursing interventions focus on establishing a normal growth promoting environment and routine. Providing non-nutritive sucking can assist the infant to achieve self-regulation during times of stress thus promoting physical organization and stability. Maintaining oral sucking reflexes until the infant can begin oral feedings is essential to successful transition to oral feedings. Physical closeness, maternal touch and recreating the physical activities normally associated with feeding behaviors while the infant is fed through a gastrostomy tube may be important factors that influence the early period of infant motor development, expressive language and mother-infant interaction that have the potential to influence the NDO of this high risk population (Faugli et al., 2005). In addition, infants with EA and LGEA may benefit from interdisciplinary and a comprehensive nutritional plan from birth, as poorer NDO is associated with growth failure (Walker et al. 2013).

Occupational therapists Ramsey and Birnbaum (2013) advocate for an interdisciplinary approach that begins upon admission to optimize the infant’s physical development and to promote positive experiences with oral development for feeding and language acquisition. Early intervention should be considered for all infants with EA especially those with congenital heart defects or VACTERL and CHARGE associations, or syndromic EA, who present with higher risk of delayed development. Early enrollment in occupational and physical therapy has been shown to improve motor abilities and have the potential to improve oral feeding interest and
skills for both the infant and the mother that can improve the NDO and psychosocial outcomes of infants with EA (Bevilacqua et al., 2014b; Ramsay & Birnbaum, 2013). Mothers should be supported when caring for and learning to feed her infant in order to fully understand the physical needs of her infant, and the importance of her responses and behavior on her infant’s behaviors and NDO.

**Research Implications**

Although improvements in NDO became evident at a year of age in most infants, this review did not include whether or not the improvement continued. Furthermore, there was no information in these studies that showed the impact of anesthesia or long-term exposure to opiates and sedatives on the emerging developmental capacities of infants with EA. Current and future studies should focus on acquiring a better understanding of how experiences during the first six months of life alter development, targeting ones that most need addressed, and on what can be done to reduce the infant’s stress and maximize the relational capacity before, during and following surgery to optimize developmental potential.

Maternal competence and its effect on infant feeding behavior require further examination. Maternal presence and influence on alternative oral motor stimulation to facilitate oral feeding skills is an area that has not been studied to date but could generate valuable knowledge on the mother-infant relationship. In addition, studies examining the relationship among feeding, cognitive and motor development on the mother-infant interaction should also be considered. There are no published studies that examine a mother’s experience with feeding her LGEA infant or the actual feeding experiences of these infants. The relationship of mother-infant interaction to
the NDO of infants with LGEA has yet to be fully explored and further examination of the personal experiences of these mothers may help inform practice and guide future inquiry.

Conclusions

This integrative review identified factors that influence the outcomes of infants with EA/LGEA and provides further insight into the multiple dimensions of their care. These studies represent the current knowledge regarding the health and well being of infants born with EA/LGEA and their emerging relationships with their mothers. EA and specifically LGEA present a myriad of physiologic demands in the neonatal period that cause significant stress for both infants and mothers. These findings can guide evidence-based care and inform nurses as they enter into and facilitate the fragile dynamics of beginning relationships between these high-risk infants and their mothers.


<table>
<thead>
<tr>
<th>Author(s), Year &amp; Country</th>
<th>Study Purpose &amp; Design</th>
<th>Sample</th>
<th>Variables and Data Collection</th>
<th>Main Study Findings</th>
<th>Limitations</th>
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</thead>
<tbody>
<tr>
<td>Aite et al. (2014) Italy</td>
<td>To investigate if EA is a disease specific risk factor for neurodevelopmental outcome (NDO) in the first year of life. Observational prospective longitudinal study</td>
<td>N = 35 infants met criteria. 30 children completed follow up.</td>
<td>Variables Bayley Scales of Development 3rd Edition (BSID III) to assess motor and cognitive development; ANOVA to assess differences in BSID III by gender, gestational age, hospital length of stay (LOS), number of surgeries, number of esophageal dilations, and days of mechanical ventilation. Weight at follow up, number of post-operative surgeries or dilations, parental age, educational level</td>
<td>This study addressed the neurodevelopmental health of infants with low risk EA. No associations found between motor and cognitive scores 6 months of age and clinical and socio-demographic variables. At 12 months, cognitive delay correlated with weight at &lt; 5% all of whom had GERD and oral aversion. Infants with unemployed mothers at 12 months of age scored lower on the motor function.</td>
<td>None listed. Report identified as the first to address Neurodevelopmental outcomes (NDO) in a disease specific (low risk EA) population in the first year of life. The study has a small sample size, gestational age at birth &gt; 32 weeks, no LGEA, no confounding congenital anomalies or genetic syndromes that influence NDO.</td>
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<tr>
<td>Study</td>
<td>Objective</td>
<td>Design</td>
<td>Groups</td>
<td>Variables</td>
<td>Data Collection</td>
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<td>Bevilacqua et al. (2014a). Italy</td>
<td>To describe short-term NDO of infants operated on for congenital anomalies (CA) and assess impact of CA on outcome. Cross sectional follow up design.</td>
<td>Group A-Infant’s at 6 months of age (N =150) Group B- Infants at 12 months, (N =156) Group C – Infants at 24 months (N =84) 5 subsets in all groups: 1) EA 2) CDH 3) mid-gut anomaly 4) abdominal wall defect 5) colo-rectal malformation</td>
<td>Variables Bayley Scales of Development 3rd Edition. ANOVA, chi square to assess differences in clinical and socio-demographic variables among groups and between cognitive and motor development and to verify the impact of type of CA.</td>
<td>Data Collection Repeated measures at 6, 12 and 24 months of age</td>
<td>This study addressed the neurodevelopmental health of infants with gastrointestinal anomalies that require surgery. Short-term NDO of infants with gastrointestinal anomalies in normal range regardless of type of malformation. Risk for poorer NDO related to number of surgeries. Range of cognitive scores improved to range of norms as infants matured.</td>
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<tr>
<td>Bevilacqua et al (2014b)</td>
<td>To identify clinical and socio-</td>
<td>N =150 total children with</td>
<td>Variables BSID III Cognitive</td>
<td>This study addressed the</td>
<td>The role of pharmacological</td>
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<td>Country</td>
<td>Study Object</td>
<td>Sample Description</td>
<td>Outcome Measures</td>
<td>Methodology</td>
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<td>Italy</td>
<td>Describe short-term NDO in children operated on for abdominal and thoracic CA</td>
<td>Prospective cohort observational study for non-cardiac major CA. Thoracic and abdominal surgical issues: 1) EA N = 41, 2) CDH N = 42, 3) Mid-gut anomaly N = 34, 4) Abdominal wall defect N = 18, 5) Colo-rectal malformation N = 20</td>
<td>Thoracic and abdominal surgical issues: 1) EA N = 41, 2) CDH N = 42, 3) Mid-gut anomaly N = 34, 4) Abdominal wall defect N = 18, 5) Colo-rectal malformation N = 20</td>
<td>Data Collection: Repeated measures at 6 and 12 months of age.</td>
<td>Motor and Motor and Scales; Univariate linear regression was conducted to analyze the clinical and socio-demographic variables on NDO. Multivariate regression was utilized on variables that reached significance. Data Collection: Repeated measures at 6 and 12 months of age.</td>
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<td>Canada</td>
<td>Describe short (first year of age) and long-term (after 1 year) outcome in patients with EA and identify early predictive factors of morbidity in the first month that are predictive of global outcome.</td>
<td>Retrospective chart N = 134 patients, 49% female, mean birth weight 2.580 kg, mean gestational age 38 weeks, 6% twin gestation, 34% VACTERL and 19% LGEA</td>
<td>Variables: 1) Complicated vs uncomplicated evolution detailing incidence of complications in each group. Data Collection: Retrospective chart review from 1990-2005</td>
<td></td>
<td>This study addressed the physical health of infants with EA. 49% had complicated course in first year of life. Factors associated with morbidity: birth weight, LGEA, respiratory complications, agents or type of anesthesia has not been fully determined, or the relationship to sedation for ventilation in this population. NDO may be related to the complex nature of the anomaly and also the complex nature of the treatment.</td>
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<td>Castilloux, Noble &amp; Faure (2010).</td>
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<tr>
<td>Study Authors and Year</td>
<td>Objective</td>
<td>Sample Size and Description</td>
<td>Variables/Methods</td>
<td>Findings</td>
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<td>Faugli et al. (2005). Norway</td>
<td>To assess the quality of parent-child interactions and relationships in children with EA using the Parent-Child Early Relational Assessment (PCERA) Observational non-experimental.</td>
<td>N =15 one-year-old infants and their mothers.</td>
<td>Variables: Videotaped sessions Infants and mothers playing and feeding were assessed Data Collection Videotaped sessions via PCERA</td>
<td>This study addressed the socio-emotional health of infants with EA. PCERA reveal stressors affecting the parent-infant relationship.</td>
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<tr>
<td>Faugli et al. (2009) Norway</td>
<td>To assess mental health and to find prognostic factors for mental health among infants with EA. Retrospective, Non-experimental, Comparative analysis</td>
<td>N - 39 children born with EA, and their mothers</td>
<td>Variables/Data Collection Infant mental health was assessed by Diagnostic classification 0-3 (Zero to Three, 1994), Development was assessed with BSID II. Maternal anxiety and distress</td>
<td>This study addressed the socio-emotional health of infants with EA. Children with EA are vulnerable to mental health disorders; predictive factors are posttraumatic stress reported by mother,</td>
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<tr>
<td>Study</td>
<td>Purpose</td>
<td>Sample</td>
<td>Variables</td>
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<tr>
<td>Faugli et al, (2008). Norway</td>
<td>To assess the quality of the mother-infant interaction in children with EA compared to other hospitalized children with no feeding difficulties and to search for possible predictors of impaired interaction. Retrospective Non-experimental case – controlled comparative analysis</td>
<td>N = 37 infants with EA and a control group of 10 infants with urologic surgical issues</td>
<td>Infants in play and feeding situations, and mother psychological distress and anxiety. Data Collection The PCERA, a General Health Questionnaire, State Trait Anxiety Inventory</td>
<td>This study addresses the socio-emotional health of infants with EA. Positive finding of range of strength in mother-infant interaction, higher trait anxiety than control mothers. Challenges in feeding for the mother related to feelings of competence.</td>
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<td>Friedmacher &amp; Puri (2012). Ireland</td>
<td>To investigate the complications and long-term outcome in patients with LGEA managed by Delayed Primary</td>
<td>N = 44 articles included from 1981 to 2010 included in a quantitative synthesis. Overall number of study</td>
<td>Data extracted included patient characteristics, with primary outcomes being complication</td>
<td>This study addressed the physical health of infants with LGEA. TEF was divided when gastrostomy.</td>
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None reported by authors. Aside from recurrent aspiration, other respiratory co-morbidities mentioned in other
Anastomosis (DPA) based on a meta-analysis of the published literature. Systematic literature review subjects was 451, ranging from 1 to 74 infants in reviewed studies. Rates. 43% pure LGEA, of those, 55.9% distal TEF and 1.1% proximal TEF. Mean gap 3.6 cm (range 1.9 to 7 cm). DPA performed at mean of 11.9 weeks (range 0.5-54 weeks).

Data Collection

Meta-analysis

tube placed. Optimal timing of DPA 12 weeks. Complications: anastomotic leaks, strictures, symptomatic GER, esophagitis, dysphagia, recurrent fistula, recurrent aspiration pneumonia, growth restriction, and Barrett’s metaplasia. Strictures were more common following anastomotic leak or symptomatic GERD. Symptomatic GERD leads to esophagitis. Strictures and GERD lead to dysphagia. Fundoplication occurred 30% for GERD.

Gischler et al. To determine the N = Of 142 eligible Variables This study studies were not addressed.
<table>
<thead>
<tr>
<th>Year</th>
<th>Country</th>
<th>Study Description</th>
<th>Sample</th>
<th>Variables</th>
<th>Findings</th>
<th>Study Type</th>
</tr>
</thead>
<tbody>
<tr>
<td>2009</td>
<td>Netherlands</td>
<td>To conduct a pre and post intervention study and analyze the physical, mental, and psychomotor development up to 24 months; and to examine diagnostic group differences and how co-variables influence outcomes. Observational, prospective, longitudinal cohort study.</td>
<td>101 patients born with major congenital anomalies (CA), (17 of whom had EA).</td>
<td>Severity of illness, neurologic examination, sociodemographic variables including parental age, marital status, ethnicity and socioeconomic status.</td>
<td>This study addressed the neurodevelopmental health of infants with surgically treated congenital anomalies, including EA. Infants with EA had the maximum number of associated anomalies, highest number of surgical interventions and were notable for delayed growth. Neurologic outcome was also below normal and correlated with number of CA, LOS, severity of illness, number of surgical interventions, and need for home medical equipment.</td>
<td>Retrospective study with historical controls did not show a decrease in</td>
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<tr>
<td>2009</td>
<td>Hagander, Muszynska, Arnbjornsson, &amp; Sandgren</td>
<td></td>
<td>N = Study group of 39 infants; control group of N = 63 infants treated in the</td>
<td>Variables</td>
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- **Data Collection**: The Therapeutic Intervention Scoring System, Touwen neurologic examination, the Dutch version of BSID. ANOVA and random regression models utilized for analysis.
<table>
<thead>
<tr>
<th>Year</th>
<th>Country</th>
<th>Study Design</th>
<th>Objective</th>
<th>Study Population</th>
<th>Data Collection</th>
<th>Results</th>
</tr>
</thead>
<tbody>
<tr>
<td>2012</td>
<td>Sweden</td>
<td>To review the short-term results including survival, length of stay, post-operative complications, growth and neurodevelopmental assessment of a cohort of LGEA infants. Retrospective record review, specific patient cohort.</td>
<td>To review the short-term results including survival, length of stay, post-operative complications, growth and neurodevelopmental assessment of a cohort of LGEA infants. Retrospective record review, specific patient cohort.</td>
<td>N = 15 patients with LGEA</td>
<td>Clinical data, demographic and clinical variables including neurodevelopmental outcomes. Chart Review</td>
<td>This study addressed the physical health of infants with LGEA. Small sample size, n=15, 60% had other congenital anomalies. 80% had prenatal diagnosis. Overall survival was 80%. Median LOS 83 days. Complications included: strictures (62%), GERD (39%), anastomotic strictures in infants treated with PPI’s. Dilations were performed earlier in hospital course based on clinical experience compared to the control group. Treatment duration and dose were not evaluated.</td>
</tr>
<tr>
<td>Mortellaro, Pettiford, St. Peter, Fraser, Ho, &amp; Wel (2011). United States</td>
<td>To describe the prevalence of vocal fold immobility in the EA/TEF population. Retrospective review</td>
<td>N = 150 patients with EA/TEF. Median age at repair was 12 days +/- 33 days. LGEA accounted for 6% of cohort. Mean gestational age 36 weeks with 86% of infants being males.</td>
<td>Variables Patient characteristics and procedural variables related to repair of EA/TEF. Number of consults made to otolaryngology for post-op issues constituted postoperative respiratory issues.</td>
<td>This study addressed the physical health of infants with EA. 3 percent of this cohort of AE/TEF patients presented with vocal fold immobility after EA repair. The etiology is difficult to assess, as bronchoscopy was not performed pre-operatively.</td>
<td>Technical limitation noted; availability of recurrent laryngeal nerve injury via endotracheal tubes not available in infant sized tubes.</td>
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<tr>
<td>Walker, Halliday, Badawi, Stewart, &amp; Holland (2013). Australia</td>
<td>To describe survival and developmental outcome of infants with EA +/- TEF who had operations</td>
<td>N = 31 infants of 34 eligible infants enrolled, compared with 62 age matched healthy</td>
<td>Variables Infant development including cognitive scores, receptive and expressive</td>
<td>This study addressed the neurodevelopmental health of infants with EA. The</td>
<td>Small sample size owing to the rarity of the disease. Clued Recognized need to include prospective</td>
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</table>
Discovering that the fetus/infant has EA is a traumatic event for parents. Surgery, NICU care, complicated course, and associated anomalies compound stress for both parents and infants. Parental PTSD affects parental responses to infant and impacts infant psychological and social development.

Ramsay & Birnbaum (2013). Canada

Feeding difficulties in children with esophageal atresia: treatment by a multidisciplinary team

EA poses immediate challenges in the newborn period with regard to feeding. With a focus on minimizing effects of surgeries and post-operative complications,
emphasis is placed on assisting mothers to maintain relational feeding behaviors, and providing guidance for challenges of feeding related issues.
Chapter Three

The Impact of Interrupted Attachment in the Surgical Newborn

Patricia Fleck

Northeastern University
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Nurses caring for high-risk infants have the responsibility of supporting fragile infants. Understanding and addressing the needs of a mother whose newborn requires surgery after birth is an important step to knowing her infant, one in which joy can be coupled with uncertainty. Similar to mothers of infants born prematurely, infants born with congenital anomalies requiring surgery after birth present a biological risk to the process of attachment. Like premature infants, infants who have surgery in the newborn period have also been shown to be at risk for delayed neurodevelopmental outcomes, which in turn influences the process of mother-infant interaction and attachment (Bevilacqua et al., 2014; Gischler et al., 2009). To facilitate this introduction and foster interaction when the infant is compromised, it is important for nurses to understand both maternal and infant behavior that involve mother-infant interaction and successful attachment.

Mothers and their infants speak to one another in a unique and continual dynamic from the time of conception throughout the life cycle. This language develops through a continuous interplay of sensory cues; some visual, some tactile, and some perceptions which only the mother or infant can sense. A mother’s role in the interaction is to be attentive to the behavioral cues of her infant, to respond to and prompt her infant. The infant’s responses and ability to engage and regulate behavior are important initial steps that shape future interactions (Ainsworth, 1979).

Risks for impaired maternal-infant interaction may arise during pregnancy when a mother learns her fetus has a congenital anomaly or her infant is born with anomalies and may include anxiety and depression of the mother leading to maladaptive behaviors (Viaux-Savelon et al, 2012). Infants who are born with congenital anomalies that require surgery after birth experience stress and physiologic dysfunction that interferes with the natural maternal-infant attachment.
process. They are separated from their mothers at birth by necessity for life saving treatments. Then the surgical experience is accompanied by analgesia and sedation that further diminishes their ability to interact, thus affecting the infant’s ability to be an active participant in the maternal-infant relationship. Because positive mother-infant interaction facilitates the development of an infant’s social competency and secure attachment for later social, language and cognitive development, these experiences can play a role in the infant’s evolving temperament as the infant continues to be cared for in the Neonatal Intensive Care Unit (NICU) (Mantymaa, Puura, Luoma, Salmelin & Tamminen, 2006). In turn, the emotional responsiveness of a stressed and anxious mother can have a significant emotional impact on her response to her newborn with resulting insensitivity to the infant’s needs (Shin, Park, Ryu & Seomun, 2008). Therefore, mediating the maternal response becomes essential for improved outcomes in this high-risk dyad.

The purpose of this paper is to inform bedside nurses about the experiences of mothers with surgical infants in the neonatal period and the impact that may have on maternal responses affecting the maternal-infant interaction and attachment process. This paper will begin by reviewing literature that supports the natural process of healthy mother-infant attachment, and then examine the impact of illness and surgical stress on the infant’s capability to be an active participant in the emerging relationship. Evidenced based practices are explored that will strengthen neonatal nurses understanding of their role in supporting and providing care to mothers and infants that will foster the process of attachment for this high risk dyad.
The Natural Process of Attachment

Maternal-infant interaction is part of the complex process of human growth and development that is influenced by maternal identity and the experience of becoming a mother. Mothers begin developing attachment as the pregnancy is discovered and progresses and the fetus becomes a part of them (Lothian, 1999; Mercer, 1995). When an infant is born, the immediate physical contact with their infant is a strong emotional, biochemically-mediated and anticipated event. The natural release of oxytocin promotes the maternal instinct for keeping the infant in close proximity and heightens the maternal responsiveness to the needs of her infant (Johnson, 2013). Often after birth, the mother experiences a feeling of euphoria, tranquility and love that emanates from the satisfaction of the actual birth experience. While bonding is described as the emotional tie that occurs between a mother and her infant (Klaus & Kennell, 1976), attachment is the development of the relationship that grows from this emotional connection of the infant to its mother or significant person that has life-long implications for healthy infant development (Ainsworth, 1979).

Often the mother is the most prevalent adult with whom the infant interacts, but relationships may include the father and family members. Mothers have an innate need to share their childbirth experiences and introduce their infant to its new family (Mercer, 1995). Attachment is also influenced by family values, cultures and the social context in which the behavior occurs. The infant emerges as part of a family and is recognized as an active participant in the relationship from the moment of birth with recognizable strengths and characteristics (Brazelton & Nugent, 2011).
Maternal attachment is an integral component of infants’ physical and emotional development. Maternal sensitivity to her infant is an attribute of attachment that relates to her recognition of her infant’s cues and needs. The mothers and infants responses to one another form the basis of interaction and the development of attachment behaviors. Ainsworth (1979) describes four types of parent-infant attachment: three organized types- secure, anxious and resistant, and one type of disorganized attachment- insecure attachment. The sensitivity of the mother’s responses influences the infant’s behavioral responses.

A mother’s ability to perceive and interpret her infant’s cues contributes to the reciprocal nature of interaction. Her sensitivity behaviors are a result of her maternal identity and wellbeing, previous experiences with her infant and the changeable nature of the infant’s status. Simultaneously, the infant learns to anticipate predictable maternal behaviors elicited in response to his/her needs and behaves according to the mother’s contingent response. Infants who receive consistent, sensitive and responsive care and attention respond with an organized secure attachment. Infants experiencing less sensitive attention or experience rejection can also develop an organized fashion of responding to their caregiver but may develop avoidance behaviors and express less distress to avoid interaction with the insensitive caregiver, resulting in an insecure avoidant attachment. Thus, inconsistent and insensitive qualities of care giving may result in an organized but resistant and insecure attachment, while disorganized attachment is typically preceded by inconsistent and maladaptive maternal responses. The latter types of attachment set the stage for socio-emotional insecurity and interfere with normal development of the infant. The quality and sensitivity of the interactions are the key determinants of the type of attachment that develops (Benoit, 2004; Shin et al., 2008).
Maternal Sensitivity

Ainsworth (1979) defined maternal sensitivity as a mother’s ability to consistently recognize and interpret her infant’s efforts at communication and suitably respond. This concept has evolved to encompass a broader range of maternal behaviors including warmth and soothing responsiveness, negotiating conflict, creating opportunities for engagement and providing positive affective interactions (Shin et al., 2008). A concept of maternal sensitivity described by Shin et al. (2008) predicts attachment and influences on infant development that include the maternal attributes of ability, reciprocity, contingency of the infant’s behaviors, and the quality of the mother’s behaviors. Contextual factors that affect the process have been identified as positive social support, maternal-fetal attachment and self-esteem while maternal anxiety, depression and stress, separation, and risk of death and disability, were seen as negative affecting factors.

Maternal responsiveness is related to sensitivity and is dependent on the mother’s emotional availability and her ability to comfort and soothe her infant. Acknowledging the infant’s positive responses to a mother’s attention reinforces feelings of confidence, promotes reciprocal vocalizations and a dialogue between a mother and her infant.

Synchrony

Synchrony has been described as essential to the interaction of mothers and infants. Reyna and Pickler (2009) explored the meaning of mother-infant synchrony within the theoretical framework of attachment and described several methods for its measurement. The harmonious rhythmic attention withdrawal pattern is evident in observations of mother’s interactions with their infants. The intensity as well as the frequency of interactions appears to
have significance as the relationship evolves. Specific mention is made of the contributions the infant has on maternal response, and the models of maternal behavior as they influence the interaction. A mother’s working model of care giving for her infant involves thinking about care, reflecting on her infant’s response, and engaging her infant and determining feeding behaviors.

Baker and McGrath (2011) conceptualize maternal-infant synchrony as beginning in pregnancy, when the mother perceives her infant as being a part of her changing image and being. A novel definition of maternal-infant synchrony that evolved as a result of an integrative review by Baker and McGrath (2011) is a “dynamic relationship that is mutually engaging, temporally coordinated, and includes an element of contingency” (p.3). The concepts of maternal sensitivity, responsiveness and maternal wellbeing are key factors that influence and shape the development of a synchronous relationship.

Supporting the natural process of healthy mother-infant attachment when there is an interruption in the relational experience of birth and attachment can be a challenge to nurses caring for mothers and their surgical infants in the neonatal period. Encouraging mothers to focus on identifying the infant’s individual physical, emotional and developmental strengths can help promote satisfying maternal attachment behaviors and promotes the development of a synchronous relationship (Renya & Pickler, 2009). The contextual factors that influence synchrony in the emerging mother-infant relationship are unique to each individual and include social support, marital satisfaction, prenatal expectations, previous parenting experiences and a mother’s own experiences as a child. Prenatal expectations of a healthy infant may have been disrupted during a prenatal discovery of a congenital anomaly or at the time of delivery when the
infant presents in distress. Thus, the availability of social supports and care from the health care team are essential to help manage stress associated with her infant being cared for in the NICU.

**Attachment in the Context of Feeding**

Feeding is an essential behavior for survival. Providing nourishment is a natural mothering behavior resulting in a continuous and reciprocal repertoire of interactive behavior that provides a foundation for maternal-infant interaction and the attachment process. Feeding choices are made by mothers and are an integral component of early maternal identity. Maternal feeding behaviors are sensitive and responsive to the infant’s cues, protective, nurturing and comforting. As much of the natural attachment process occurs in the context of feeding and nourishing the infant, consideration must be given to the absence of the reciprocal and contingent behavioral patterns that are missing from the mother-infant relationship when the infant is unable to feed orally.

Infants develop feeding skills based on neuro-developmenta l maturity, state of arousal at feeding time and biophysical challenges associated with illness or immaturity. Examining the mutuality of complex behaviors that comprise maternal and infant responses during feedings is challenging, as the process is dynamic and influenced by multitude factors including the setting, the capabilities of the infant, maternal sensitivity and motivation (Reyna & Pickler, 2009). It becomes evident when an infant cannot feed orally as a result of a congenital anomaly or surgical procedure that an interruption of the maternal-infant interaction occurs. Nursing care that supports sensitive mothering behaviors focusing on providing pleasant oral experiences for their infant is paramount to recognizing the infant’s needs for oral stimulation and gratification as a necessary component of infant well being.
The Surgical Infant

When infants are born with life threatening complications, the process of attachment may be altered resulting in the development of long-term negative behavioral patterns for the infant. The surgical infant may have limited ability to interact due to the anomaly and physiologic instability. Stabilization of the newborn in the delivery room is a priority for health care providers. Infants may require surgery in the immediate or newborn period that further impedes contact and meaningful interaction. The surgical process, anesthesia and analgesia can further reduce the infant’s relational abilities and impose significant stress for a mother.

Supporting the infant’s self-regulation and state organization

Surgery in the neonatal period brings about physiologic disruption in the integration of autonomic, motoric, state organization and attention-interaction systems of the infant resulting in an inability to interact with his mother or environment (Als, 1982). Supporting and stabilizing the infant’s physiologic demands and providing developmental support for his needs allows the infant to come to an alert, interactive state where he can explore his surroundings and co-regulate his behavior with his mother (Evans & Porter, 2009; Feldman, Magori-Cohen, Galili, Singer, & Louzoun, 2011).

However, infants with physiologic instability, motor or sensory deficits have a disadvantage, as response to the infant’s behaviors may be unpredictable and difficult for a mother to recognize and interpret (Shin et al, 2008). Management of the infant’s neurobehavioral state is challenging for both the nurse and the mother as the infant is in a state of sedation during the surgical experience. Effective post-operative management often includes the concurrent use of opiates and sedatives that are titrated to provide pain relief and maintain the infants’ state.
behavior scale (SBS) in the suggested range (Aranda, 2005; Hawley, 2001). The infant’s autonomic responses to touch, maternal voice and ambient light and noise, as well as painful procedures, need to be acknowledged and medications adjusted to maintain comfort and physiologic stability. Infants physiologic organization can be supported and often respond with decreased heart rate and blood pressure when their mother comforts them during this time (Evans & Porter, 2009; Feldman, et al, 2011).

As the infant begins to recover, the nurse can help the mother identify her infant’s behavior patterns and promote the infants’ transition from sleep to awake states. This transition is referred to as state organization (Als & Lawhorn, 2004; VandenBerg, 2007). The infant may experience periods of crying or restlessness where the mother can intervene with supportive measures, such as non-nutritive sucking (Medoff-Cooper, & Ray, 1995) and touch and positioning, to allow the infant to achieve a more regulated state and engage in social behavior to the extent that they are able (VandenBerg, 2007). Mothers can also be engaged in protection of the infant’s sleep, for this is essential to state organization of the recovering infant (Altimier, 2011). Infants whose mothers demonstrated sensitivity to their needs had improved physiologic regulation (Reyna & Pickler, 2009) thus, showing that maternal behaviors can have an important influence in the infant achieving regulatory functions. The infant’s ability to self-regulate improves over time with physical recovery, medication weaning, maturity, experience and the contingent responses of the caregiver. Early experiences shape future behavior and development, thus it is important to provide consistency and sensitive responses from the caregiver as the infant recovers and seeks relational experiences.
Infant Temperament

Infant temperament has been correlated with stable integration of the subsystems and autonomic stability along with the infant’s response to stimulation as the infant develops (Zhu, 2007). The infant’s temperament is defined by the infant’s behavior and is manifested by activity, adaptability, approach and withdrawal behaviors, mood and rhythmicity and is an important component of the infants’ personality. The infant’s temperament influences the mother’s response to her infant and guides early mother-infant interaction with contingent responses from one another (Hughes, Shults, McGrath & Medoff-Cooper, 2002).

Three temperament constellations described by Hughes et al, (2002), are easy, difficult and slow to warm up. Surgical infants may be at increased risk for difficult temperament due to the physiologic stress associated with their anatomical defect, autonomic instability, anesthesia, periods of mechanical ventilation, repeated number of invasive procedures, sedation and a delay in establishing interactive behavior and oral feedings. Temperament has been described in infants with congenital heart disease, with more difficult temperament being associated with more complex physiology (Torowicz, Irving, Hanlon, Sumpter, & Medoff-Cooper, 2010). In addition, parental perceptions of the child’s temperament may have notable effects on development. Mother’s who experience depression, anxiety and stress are more likely to perceive their infant has having a more difficult temperament (McGrath, Records & Rice, 2007). A difficult temperament has been found to correlate with emotional neglect of the infant and continued conflicts that may lead to maternal coercive or intrusive behavioral characteristics (Mantymaa et al., 2006).
Newborn Feeding Difficulties

Infants with an impaired ability to orally feed or who experience dysphagia diminish the reciprocity that impacts the attachment process. Surgical infants with gastrointestinal malformations such as esophageal atresia (EA) are unable to feed orally in the immediate newborn period, and often have delays of two to three months before a primary anastomosis can be performed (Zani et al, 2014). Infants with EA have been shown to diminished communication and visual contact with their mother, while the mothers demonstrated less physical contact and vocalization with their infant during feeding (Faugli, Aamodt, Bjorland, Emblam, & Diseth, 2005).

Feeding difficulties are associated with infants who have had prolonged hospital courses that are frequently complicated by mechanical ventilation and chronic lung disease, as well as infants who experience necrotizing enterocolitis with subsequent feeding intolerance and those with congenital heart disease (CHD). Physiologic stability is required before an infant can be held and offered non-nutritive suckling to prepare for oral feeding. Unlike preterm infants whose sucking patterns improve with maturity, infants that have surgery for CHD, demonstrate a disorganized feeding pattern that typically improves as the infant recovers (Medoff-Cooper & Irving, 2009). The infant may not be able to transition easily to an awake, alert state, or provide cues that he/she is hungry due to the effects of surgery and medications. Mothers of infants with CHD report that feeding is often the most difficult component of care giving. Harrison (2009) examined the effect of maternal behavior during feeding on infants with transposition of the great arteries, a common CHD. In spite of the mother’s attention to the infant’s special needs during feedings, the infants continued to demonstrate impaired physiologic regulation during
feedings. These findings suggest that more attention needs to be focused on supporting maternal sensitivity by recognizing the infant’s cues and supporting physiologic stability and state changes with interventions such as skin-to-skin care and non-nutritive suckling.

Emphasis is often placed on successful acquisition of oral feeding skills in the premature infant population and in the convalescing term infant as a task that must be mastered for discharge rather than the process of responding to the infant’s individual needs and maternal competence during feeding (Swift & Scholten, 2009). Mothers of surgical infants with feeding difficulties reported significant stress, anxiety, and demonstrate insensitivity and inconsistency during feeding. They have also been shown to have intrusive behavior patterns while feeding their infants (Faugli, Emblem, Veenstra, Bjorland, & Diseth, 2008). Measures that enhance maternal sensitivity to her infant’s behaviors and cues might serve to improve maternal-infant interaction in this high-risk dyad.

For infants who depend on medical devices for feeding, the role of the mother as a source of nourishment changes from a close physical contact and intimate exchange to a technical, scheduled event, regardless of hunger cues, especially when somatic growth is challenged. A recent meta-analysis was done examining the role of oral feeding on establishing the role of the mother and her emotional state (Wilken, 2012). Surgical infants with dysphagia who rely on gastrostomy tube feedings may lose interest in sucking and oral feedings and fail to achieve oral feeding goals. In addition to feeding, other pre and postnatal environmental and social risk factors, such as maternal education, literacy, socio-economic status, and access to health care may also contribute to less than optimal growth and development. These may further impact the infant’s ability to achieve normal behavioral milestones and influence mother-infant interaction.
Maternal Stress

Mothers may begin to experience anxiety and stress well before the birth of their infant when a congenital anomaly is suspected (Viaux-Savelon, 2012). The worry about the type of condition and how that may impact her infant and her family’s quality of life can touch the heart of maternal responsibility and ethical responsivity of being a mother. Seeing her newborn infant with disabling anomalies and being filled with a sense of anxiety for what the future may bring can elicit a sense of being overwhelmed (vanManen, 2012). Maternal depression has been associated with the perception of her infant having a difficult or demanding temperament that may serve to compound her feelings of helplessness and isolation (McGrath, et al., 2007). In addition, other individual contextual factors such as self-esteem, depression, and perceived support influence the dynamic of this initial and subsequent encounter with her infant and contribute to the mother’s ability to relate to her critically ill newborn (Lothian, 1999; Reis, Rempel, Scott, Brady-Fryer, & Van Aerde, 2010; Upham & Medoff-Cooper, 2005). Surgical infants who require gastrostomy tube feedings may negatively impact a mothers stress level and lead to her altered maternal identity and possible post-traumatic stress disorder in both mothers and infants (Wilken, 2012). Negative emotionality has been described as an emotional state that includes stress, anxiety, panic and trauma symptoms in mothers of NICU infants that increases with a maternal history of depression, degree of prematurity and infant health complications. Negative emotionality can leave a mother feeling vulnerable and less able to interact with her infant (Serge, McCabe, Chuffo-Siewert & O’Hara, 2014) thus having a considerable negative effect on her already compromised newborn.
Separation

Separation after delivery or an infant’s transfer to a tertiary care center for advanced treatment impacts the mother’s feelings of closeness to her infant in the postpartum period that can last for several months (Hillan, 1992). Early skin-to-skin contact and early suckling have been found to positively affect the mother-infant interaction (Bystrova, 2009) however, surgical infants may spend less time in physical proximity with their mothers or may not be able to suckle. Advocating for direct maternal-infant contact after stabilization is imperative to promote interactive behaviors prior to the surgical procedure. In spite of the anxiety associated with holding their newly born infant connected to monitors and medical devices, time spent pre-operatively may provide a critical opportunity for early bonding experiences. Infants who undergo complex or repeated surgical interventions may have limitations on skin-to-skin holding for days or even weeks at a crucial time for maternal relational development (Karl, Beal, O’Hare, & Rissmiller, 2006; Kearvell, 2009). Encouraging physical touch and providing essential cares including mouth care, diapering and range of motion can provide mothers with alternative methods of eliciting contingent responses and reciprocal behaviors from their infants as well as reinforcing their working models of caring for their infant.

Perception of the Vulnerable Infant

In this era of improved survival of infants with long, complex courses in the NICU, premature and critically ill infants have been identified as being at risk for developmental delays. Early neurodevelopmental delays in one year old infants that is related to neonatal surgery has been shown to be predictive of developmental outcomes a five years of age (Liang, McMahon, Ungerer, Taylor, Badawi & Spence, 2010). Maternal stress and parenting of medically complex
infants in the NICU influences the maternal perception of her infant and subsequent interaction (Holditch-Davis, Tesh, Miles, & Burchinal, 1999). Interactions between mothers and infants with chronic medical conditions are dynamic and change as the infant matures. Medically fragile infants and their mothers demonstrate developmental progression in their interactive behavior over time, similar to healthy mothers and infants (Holditch-Davis et al., 1999) thus demonstrating adaptability over time.

Infants with physical challenges that interfered with feeding, such as uncoordinated suck and swallow, improved as the infant became more stable and mature (Holditch-Davis et al., 1999). Their mothers adapted their contingent responses and minimized stimulation, such as talking, that might distract the infant to promote feeding success. The mothers might have been so concerned for survival and medical status of the infant, that any neurologic compromise had only minor effects on interactions (Holditch-Davis et al., 1999). For example, infants with cleft lip and palate are at risk for impairments in maternal-infant interaction due to the mother’s response to her infant’s appearance and frustration with feeding challenges (Murray, 2008). Timing of repair has been implicated as a factor that influences mother-infant interactions as well as cognitive development of the infant. Later repairs were negatively correlated with infants’ scores on standardized measures of cognitive and motor skills (Murray, 2008).

**Overcoming Challenges for Successful Attachment**

Nurses have a pivotal role in observing the mother-infant interaction, and pointing out the infant’s capabilities. Mothers often surprise themselves by realizing how much they already know about their infant. Synchrony develops as the infant and mother learn from one another, which empowers them and provides feelings of satisfaction and competence (Karl et al., 2006).
Mothers have physical and emotional needs that must be met in order to be emotionally available for their infant. Mothers who feel supported by family members who share care and feeding responsibilities have an improved sense of competence than mother’s who feel the full weight of responsibility for their infant (Pridham, Melby, Brown & Clark, 2010). Anticipation of the mother’s need for support with guided participation in care may enhance the infants’ regulatory abilities while improving the mother’s feeling of competence allowing for synchrony to develop in the dyad (White-Traut & Norr 2009).

**Mother- Nurse Relationship**

Mothers need to establish relationships with nurses and health care providers in the NICU who provide psychosocial support. Mother-nurse interaction is a recognized factor in minimizing anxiety and improving competence in care giving with high-risk infants (Kearvell & Grant, 2009). Creating opportunities to listen to a mother’s needs and concerns when her infant is in the NICU can provide information and reduce anxiety from uncertainty. Normal mothering activities like bathing, feeding, are interlaced with monitoring, suctioning, positioning and painful medical procedures. NICU nurses must provide education and support, but also listen and encourage mothers to learn about their infant with relationally framed questions that to allow mothers to be emotionally available to their infants as they progress through the stages of surgery (Karl et al., 2006; Reis et al., 2010). Parents report that nurses are the most important person providing care for their infant. Increased parental satisfaction with their role as parents was associated with nursing presence, anticipation of their needs and continued guidance as their infant progressed in the NICU (Reis et al., 2010). Mothers and nurses develop relationships that support mother-
infant interaction allowing by mothers to be emotionally available to their infants and fulfill their role as a mother.

**Mothers’ Strengths**

Mothers adapt over time to the challenges presented to their role as a mother (Faugli et al., 2008; Gardner, 2014). First time mothers whose infants were hospitalized in the NICU described initial feelings of grief and loss, separation and distress as they observed their infants undergo painful procedures. Normalization of their experience occurred as they become adept at integrated mothering behaviors with care-giving activities as they learned how to care for their infants. Experience, time and organization proved to be valuable components to learning their infants needs and structuring their activities, providing mothers with a sense of responsibility and competence, essential for mother-infant attachment (Gardner, 2014). The mothers’ feelings of accomplishment were a positive factor identified in preparation for their infant’s discharge in this medically complex population. In addition, mothers who are guided to learn about their infant’s individual behaviors are more likely to have a positive impression of the infant’s temperament and demonstrate synchrony and “goodness of fit” for one another (McGrath et al., 2007).

**Mindfulness and Attachment**

Promoting positive emotionality and availability has been associated with developing a secure and healthy mother-infant attachment. An approach to improving mothers’ negative emotionality is the practice of mindfulness. Mindfulness is a process where individuals pay particular attention to the present moment, placing past experiences and worry about future unknowns at bay so that the experience can be enjoyed and experienced at its fullest (Synder, Shapiro & Treleaven, 2012). Mindfulness includes the attributes of intention, attention and
attitude. When these attributes are present in nurses and mothers who share responsibility in caring for their infant, a sense of mutuality ensues that promotes positive emotions and being in the moment. Nurses provide a caring, holistic attitude with the intention of promoting health and wellbeing. Encouraging mothers to live in the moment, giving their infant their undivided attention and experience each new moment as it unfolds with their infant provides memorable moments that create a special bond and also help the infant achieve an organized physiologic state (Evans & Porter, 2009; Feldman et al., 2011). Engaging in mindfulness while holding their infant skin-to-skin can create intimate moments that has the power to help the infant regulate autonomic functioning and promote physiologic stability, promote synchrony, influence a mother’s perception of her infant and allow the infant to be a full participant in the mother-infant relationship.

Conclusions

Nurses caring for infants undergoing surgery are ideally positioned to promote the initial emotional bonds for mothers and infants, setting the stage for successful mother-infant attachment. Infants who are compromised in their ability to be an active participant in the maternal-infant interaction inhibit the essential needs of a mother to physically respond and connect with that infant. Nurses caring for surgical infants have an opportunity to share their observations and knowledge of the infant, providing information about their infant’s individual characteristics to acquaint the mothers with her infant and to help diminish her anxiety.

A responsive parent has the ability to shape the development of her infant’s future capabilities. Each encounter is a complex process that is dynamic, temporal and influenced by the contributions of the infant, mother, family, clinical staff and the environment where the
encounters take place. Nurses must recognize the unique needs and stressors of each mother and respond in a caring, relational and personal manner that respects the intentions of each mother.

Encouraging mothers to “be in the moment” and include the practice of mindfulness in their care can improve mother’s emotional availability, opening their hearts and minds to their infant.

While supporting the infant’s self-regulatory function and enabling the mother to be sensitive and responsive to her infant’s unique needs remains a challenge to those caring for this high-risk dyad, nurses can identify opportunities to utilize the theoretical underpinnings of attachment to provide personalized interventions in the immediate newborn period. Traditional maternal-child nursing has been built on the nurse-mother relationship that: (1) guides the new mother in adapting to her role as a mother, (2) assists in identifying unique behavioral characteristics of her newborn and (3) reinforces the infant’s reciprocal responses to her attention. Capitalizing on the natural biochemical responses, promoting skin-to-skin care, optimizing the environment for intimacy, practicing mindfulness and promoting maternal-infant attachment are all within the scope of practice for the maternal-child and neonatal nurse.
References


Chapter Four

Mother’s Lived Experience During Repair of Long-Gap Esophageal Atresia: A Phenomenological Inquiry

Patricia Fleck
Northeastern University
Boston Children’s Hospital

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Mother’s Lived Experience During Repair of Long-Gap Esophageal Atresia: A Phenomenological Inquiry

Becoming a mother is a major event in the life of a woman. Maternal identity is associated with the desire for an infant and attachment behaviors begin when the pregnancy is realized (Johnson, 2010). Physical and biochemical changes occur that influence maternal behaviors and help a woman prepare for the delivery of her infant. The diagnosis of a potential fetal anomaly occurs when a surveillance ultrasound reveals abnormal findings. Confirmation of actual anomalies often does not occur until delivery; however the unsettling information may cause anxiety and depression to dominate a mother’s emotional responses in preparation for delivery and even into the neonatal period (Viaux-Saveion et al, 2012). When an anomaly is known or suspected, specialized care of the infant at delivery often necessitates delivery at a high-risk perinatal center, potentially adding to the stress and anxiety of being separated from family and existing supports. Becoming mother to an infant with a congenital anomaly alters the normal trajectory for delivery, feeding choices, and maternal-infant interaction that may influence the health and emotional wellbeing of the mother and the infant’s development.

Esophageal Atresia (EA) and in particular, Long Gap Esophageal Atresia (LGEA) is a congenital anomaly that requires surgical intervention and specialized care for the infant.

**Background and Significance**

Long Gap Esophageal Atresia is a rare congenital anomaly that results in the incomplete formation of the esophagus and has both structural and physiologic effects such as the frequently associated defects in the trachea. Esophageal Atresia occurs in approximately 1 in 4000 births and is categorized by the anatomical defect (Nassar, 2012). True LGEA is present in 3% to 10% of infants with EA and is characterized by an esophagus that ends in a blind pouch in the upper
The thorax, with or without a tracheoesophageal fistula (TEF) and a distal esophageal segment poking upward from the underdeveloped stomach, with the gap spanning the distance of three to five or more vertebral bodies (El-Gohary, Gittes & Tovar, 2010).

The preferred surgical intervention requires a staged primary anastomosis and has an overall survival rate of over 90%. Increased morbidity and mortality are correlated with decreased gestational age and birth weight along with the presence and severity of associated anomalies (Hansen & Puder, 2003; El-Gohary et al, 2010; Spitz, 2007; Zani et al, 2014). This surgical procedure involves post-operative protocols of ventilation, sedation and paralysis to avoid undue tension or strain on the anastomosis site (Foker, Kendall-Krosch, Catton, Munro & Khan, 2009). Infant sedation and paralysis limit a mother’s ability to care for or interact with their infant during this time in the Neonatal Intensive Care Unit (NICU). In addition, the recovery time for each stage of the procedure may vary as co-morbidities and surgical complications may compound the treatment plan and recovery process (Hansen & Puder, 2009; Spitz, 2007).

Maternal-infant interaction influences the development of a healthy synchronous relationship (Reyna & Picker, 2009). The normal mother-infant relationship is continually shaped by the mutual responsivity to one another and occurs naturally in the context of feeding her infant. During the surgical process, the mother’s ability to naturally experience her infant, develop a synchronous relationship and respond to her newborn’s needs are affected by the infant’s course and how it is experienced by the mother (Feldman, Magori-Cohen, Galili, Singer & Louzan, 2011; Lefaiver et al, 2009). Infants with EA are unable to feed by mouth until the esophagus is repaired, and then feedings may be complicated by dysphagia, gastrointestinal and respiratory difficulties (Hawley, 2001). The development of maternal competency may be
negatively influenced by her infant’s condition resulting in negative effect on the infant’s cognitive and socio-emotional development (Pridham, Melby, Brown & Clark, 2010).

The complexity and technological environment of the Neonatal Intensive Care Unit (NICU) is an intimidating arena for the mother to learn her infant and actively participate in decision-making (Heermann, Wilson, & Wilhelm, 2005; Kenner & Lott, 2014; van Manen, 2012).

Infants’ with EA have been found to be at risk for altered neurodevelopmental outcomes (NDO) and maternal-infant interactions. Researchers have found that infant’s who have undergone gastrointestinal and abdominal surgeries in the neonatal period, including infants with EA, have shown significant delays in cognitive and motor development at 6 and 12 months. These delays are associated with length of time on a ventilator, number of surgeries, decreased growth, and hospital length of stay (Aite et al, 2014; Bevilacqua et al, 2014a; Bevilacqua et al 2014b; Gischler et al, 2009; Walker, Halliday, Badawi, Stewart & Holland, 2013). Infants with LGEA have been found to have a decrease in growth velocity, a delay in achieving oral feeding skills and delays in gross motor skills according to Bayley’s Scores of Infant Development (3rd edition) at 12 months of age (Maheshwari, Trivedi, Walker, & Holland, 2013). These studies suggest that the complexity of the infants’ anomalies, associated with mechanical ventilation and repeated surgical procedures, may be a source of maternal and infant stress and influence the infant’s socio-emotional development and subsequent cognitive development in the first months of life.

Esophageal Atresia has been demonstrated as a risk factor that contributes to stress in early interactions between a mother and her infant. In studies examining mothers and infants with EA, mothers exhibit less enthusiasm, positive affect and sensitivity towards their infant, especially with regard to mutual interactions during feedings (Faugli, Aamodt, Bjorland,
Emblam, & Diseth, 2005). Faugli and colleagues (Faugli, Emblem, Veenstra, Bjorland, & Diseth, 2008) utilized the Parent Child Early Relational Assessment to examine maternal interactive behavior and found that maternal sensitivity and responsiveness in the feeding relationship as well as mother’s feelings of competence, were more concerning in mothers whose infants had EA compared to dyads whose infants had undergone urological surgical procedures.

As a neonatal nurse practitioner (NNP), I observed the challenges that mothers of infants with LGEA have had as they underwent the long and arduous process of surgical repair and learning to care for and feed their infants. The experience of the mothers’ of infants with LGEA was a phenomenon of interest that resonated with me as I practiced in the NICU. Given the paucity of literature pertaining to care of the infant with LGEA, this naturalistic inquiry was motivated by the moral imperative for advancing nursing science by gaining a greater understanding of the mother’s experience and conceptualizing the evidence to inform clinical practice for this vulnerable population (Leeman & Sandelowski, 2012; Tobin & Begley, 2004).

Understanding the meaning mothers give to the early experiences of limited care and interaction with their infant and the effects of stress during the surgical experience may provide valuable information for the health care team to enhance the relational abilities of mothers and infants and positively influence the health and wellbeing of the dyad (Mantymaa, Puura, Luoma, Samelin, & Tamminen, 2006).

The purpose of this study was to understand the meaning of the lived experience of being a mother of an infant born with LGEA. The aims of the study were: 1) better understand the mother’s perception and interpretation of the diagnosis, treatment and recovery trajectory for her infant, and 2) advance the nursing science of caring for these mothers and their infants.
Methods

Design

A hermeneutical phenomenological approach was used to guide this study. This method enables the researcher to explore and interpret with the mother, her experience of the phenomenon and ultimately learn its essence. According to Munhall (2012), the philosophy of Heidegger denotes a relational perspective of individuals, and implies that individuals are actively engaged in their life world. Individuals are influenced by cultural, societal and historical norms that shape their behaviors. Each conscious being is motivated by personal background and experiences. Situational awareness is connected to the mind, or consciousness, and the action one takes in the moment is in accordance with the individual’s beliefs. Personal perception of the situation motivates actions and language and occurs in a continuum over time. Individual expression takes multiple forms and is unique for each person. Munhall (2012) emphasizes a respect for the subjective, self-determined, self-described realities of persons. Inquiry driven from the phenomenological perspective provides a lens to discover and understand the unique meaning mothers ascribe to experiences with their infants.

Phenomenology is a study of the lived experience. The experience is viewed through non-verbal communication as well as the spoken words that encompass the mind-body connection in a lived time and space. Language is the primary expression that defines the thoughts, feelings and emotions of a person. Observations of semiotic expressions in the setting of the experience provide insight into the meanings attached to one’s situated context, adding personal dimension. The information shared by those who are the focus of interest generates knowledge through the intersection of understanding and interpretation of the lived experience of the participants (Creswell, 2007).
Recording the dialogue and describing the details surrounding the experience transform the lived experience into a “textual expression of essence” (vanManen, 1990, p.36) that can be used for discourse. The research questions provided a platform for inquiry to explore and interpret meaning using the rich textual description of the experience. The fundamental existential life worlds that describe human experiences became the organizing constructs for describing and interpreting the experiences (Munhall 2012; vanManen, 1990).

Ontology is the phenomenology of being (vanManen, 1990). Being in the world is a process of living in a unified and connected sphere of existential life worlds that consider temporality, spatiality, corporeality and communality. The time and space in which a person lives in the world provides a situated context for experiential living. How each person experiences time or space in relation to their experience differs based on contingencies that arise. Theses experiences and personal interpretations influence the body, shape the mind and give rise to intentionality and relational experiences. Each individual assigns meanings to these experiences that drive their actions and beliefs.

The existential life worlds (Table 1) provided a rubric for the process of probing and interpreting the thoughts and experiences expressed by the mothers to reveal the essence of the phenomenon.

**Table 1 Existential Life Worlds**

<table>
<thead>
<tr>
<th>Life World</th>
<th>Experience as Lived</th>
</tr>
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<tbody>
<tr>
<td>Temporality</td>
<td>The passage of time from diagnosis to recovery and preparation for discharge.</td>
</tr>
<tr>
<td>Spatiality</td>
<td>The children’s hospital, initially the NICU and then an in-patient unit.</td>
</tr>
<tr>
<td>Corporeality</td>
<td>The mother of an infant with LGEA acknowledging her mind-body connection.</td>
</tr>
</tbody>
</table>
The relationships that the mother establishes with the nurses and others responsible for the care of her infant during the process.

The hermeneutic method proposed for this study delves into the early experiences of mother’s of infants with LGEA. Hermeneutic phenomenological inquiry enables researchers to interpret the subjective meaning mothers give to their experience (Munhall, 2012). Discovering the meaning of the experiences that these mothers describe will enable nurses to come to a greater understanding of the focus of this phenomenon that can be used to generate evidence on which to base care. A series of interviews were conducted to generate a respectful, thoughtful, insightful interpretation of the experiences that ultimately gave meaning to and revealed the essence of this phenomenon.

Setting and Sample

The setting for the study was a quaternary children’s hospital in New England that is a regional referral center caring for infants with LGEA. The 24-bed NICU admits approximately ten infants per year with this diagnosis. The infants are transferred to an inpatient surgical unit once recovered from the Foker anastomosis procedure; for the infant and mother to continue to convalesce, learn to feed and prepare for discharge.

Recruitment began after approval by the designated Institutional Review Boards. Given the rarity of the disease, a purposeful, convenience sample came from the population of mothers whose infants had been admitted to the NICU with a diagnosis of LGEA and who underwent the Foker anastomosis procedure. The research team consisted of myself as the primary researcher, an experienced pediatric nurse scientist who is a qualitative methodologist, and two expert neonatal and pediatric nurse scientists.
The inclusion criteria were mothers of infants diagnosed with LGEA that had undergone the Foker procedure, regardless of gestational age at birth, gender or birth order or presence of associated anomalies or chromosomal abnormalities. Mothers who did not speak English were excluded as I am English speaking only and the use of translator may have inhibited revelation of the true meaning of the experience for these mothers.

A brochure was developed to inform potential participants of the study (Appendix A.). Mothers were approached by the EA nurse practitioner after the infant recovered from the second stage of the Foker procedure and were considered medically stable, either before or after transfer to the inpatient acute care unit. The mothers were informed of the study and given a copy of the brochure. I followed up with each mother, answered any questions and obtained written consent for study participation if she was interested. The sample was dependent on the patient population of infants recovering from the Foker procedure during this time, with a goal of enrolling mothers until data saturation occurred.

**Procedure**

The interviews were held in a location of the mother’s choosing, wherever the mother felt most comfortable engaging in conversation. Some interviews were held in infant’s room and some in the hospital garden. Throughout each interview, my focus was on hearing her words and understanding the meaning of her experience. Prior to each interview I reminded myself to set aside all prior knowledge and experience and to remain open to everything each mother had to say and not offer any personal opinions (Munhall, 2012). Although I practiced as an NNP in the NICU during the time of the study, I had no clinical responsibility for the care of any infant admitted for treatment of LGEA, thus maintaining a neutral stance as researcher and eliminating potential bias or coercion.
The interviews were audio recorded and I transcribed them verbatim, removing all personal identifiers in the process. Data were collected for the purpose of the study and files were kept in a secure locked file cabinet with access limited to only the three-member research team. The audiotapes were destroyed after they were transcribed and the transcription validated.

The methodologist and I read the transcripts independently while listening to the audio tape recordings to ensure accuracy and completeness of the transcript. The first readings of each transcript led to formulating initial impressions and identifying statements that needed further elaboration or clarification. The beginnings of interpretations and follow up questions were created to stimulate discussion and dialogue during the next interview. The process of interviews and probing more deeply into each mother's experience continued until the true essence was revealed in the lens of her life worlds.

Cultural beliefs and value systems influence the natural expression of each mother’s identity and are incorporated into her life world, making her a unique individual. These factors influence perception and understanding of the meaning of the experience and can account for variation among mothers participating in the study (vanManen, 1990). Since a mother’s comments are influenced by her nature, it was critical that probing dialogue continue until essence was elicited and data saturated.

**Data Collection**

Each mother was interviewed multiple times using open-ended inquiry. The initial questions were similar for everyone (Table 2) and individual follow-up probes sought clarification or additional information.

**Table 2 Interview Questions**

| Please tell me, in your own words, what it is like for you, to be a mother of an infant with LGEA? |
Describe your experience, from your heart, of what it has been like to get to know your baby.

Give me an example of what you have learned.

How has this contributed to your role as a mother?

Give a specific instance when you felt a bond between you.

What stands out as a difficult moment for you?

Subsequent interview questions were prompted from the prior interview, and interviews continued until no new information emerged and the essence of the experience was revealed.

New participants were enrolled and interviewed until data saturation was achieved, that is, no new data were shared and there was agreement about the essence of the phenomenon of interest.

The final sample was comprised of a total of three mothers. Table 3 provides a biosketch, using pseudonyms that describe each mother and personalizes her situation.

### Table 3 Biosketch of the participants

<table>
<thead>
<tr>
<th>Mother</th>
<th>Delivery</th>
<th>Infant</th>
</tr>
</thead>
<tbody>
<tr>
<td>Eva 24 year old single African American woman, first living infant</td>
<td>Delivered by emergent caesarean for placental abruption in her community hospital, infant transferred to tertiary care for initial care, then transferred from out of state at 2 months to LGEA center.</td>
<td>34-week gestation female, isolated LGEA, gastrostomy placed at 3 days of age.</td>
</tr>
<tr>
<td>Heather 27 year old married white woman, first infant</td>
<td>Transferred from out of state for delivery at a high-risk perinatal center linked to the to LGEA center. Caesarean delivery for failure to progress in labor.</td>
<td>33-week gestation female, Isolated LGEA. TEF repaired and Gastrostomy placed at 3 days of age.</td>
</tr>
<tr>
<td>Alison 32 year old married white woman, second infant</td>
<td>Caesarean delivery in a high-risk perinatal center for known anomalies and non-reassuring</td>
<td>38-week large for gestational age male infant, multiple congenital anomalies. Treated</td>
</tr>
</tbody>
</table>
fetal heart tracing. Initially treated for perinatal depression, transferred from out of state at 2 months to LGEA center.

for perinatal depression. Gastrostomy placed at 2 weeks of age.

In addition to the recorded audiotapes, field notes about each mother’s body language and behavioral responses during the interview were recorded. The mothers’ conduct including speech, touch or guarding towards the infant was observed to understand the corporeality of her experience. Pictures, prayer cards, and other symbolic objects placed near the infant were noted as they had meaning for the mother and were addressed in the context of the life worlds. This information and the texts generated from the transcribed interviews resulted in an abundance of data that reflected on the meaning of the participants’ lived experiences. Consensus among the research team following review of the transcripts, field notes and reflexive journals determined that saturation was achieved.

Each interview was directed towards learning the mother’s experience and the information gained was compared to prior and subsequent interviews. Immersion in and contemplation of the data revealed the core meaning of the experience. The reflective recollections as expressed in each mother’s thoughts, emotions, motives and insights made clear the meaning of this lived experience (Munhall, 2012).

Data Analysis

Data collection and analysis occurred concurrently as the study evolved. Each interview transcript was read, reflected upon and the emerging experiential expressions noted prior to the next interview. It was through reflection, rewriting of significant statements, and further probing of the mother’s perceptions that the essence of her experiences was revealed.
Reflecting on each mother’s words and gaining an understanding of the significance each mother attached to her experiences allowed me to gain insight into the meaning in the context of her personal situation. The participants contributed their subjective, self-described experiences, and by means of reflection and the use of a heightened phenomenological consciousness on my part, we were able to interpret the essence of the experience. The analysis of data was guided by existential life worlds in each mother’s situated world (Munhall, 2012; vanManen, 1990). The authenticity of the dialogue captured the essence of the experience for each mother and was thoughtfully reviewed in a relational manner that considered the hermeneutical existential life worlds including the environment, the physical embodiment of the experience as well as the temporal relationship of the encounter, providing a deeper understanding of each woman being a mother of an infant with LGEA.

Although every mother had an infant with LGEA, each was unique and had her own awareness of her situation that was acknowledged and respected during the interviews. The mothers shared intimate experiences that enriched the interconnectedness and intersubjectivity between the mother and myself (Munhall, 2012). As data were further analyzed, there appeared to be consistencies as well as differences in the subjective interpretation of their collective experiences. When the information gleaned from the participants became familiar and additional conversation failed to reveal new information, an integration of the narrative with the life worlds was produced. The existential experiential expressions gave rise to an interpretive interaction that provided an understanding of the contingencies of each mother’s life worlds. From this, the phenomenological meaning of the essence of the mothers’ experiences was developed (Munhall, 2012).
Rigor. Rigor in a qualitative study relates to establishing trustworthiness. Trustworthiness validates the confidence of the findings produced in the context of the study (Morse, Barrett, Mayan, Olson & Spiers, 2002). Trustworthiness is evaluated with the criteria of credibility, transferability, confirmability and dependability. Trustworthiness was established by reflecting on the narratives with each participant (Creswell, 2007; Munhall 2012). Conventional member checking occurred as each participant was given printed copies of the transcripts for review following each interview to establish credibility of the data. The mothers identified with the content and stated that it was true to their experience and communicated what they wanted to convey. The prior transcript was used as the foundation for the next interview as the mothers elaborated on what they had said or added new thoughts based on what happened between interviews.

Transferability refers to how well the results of this study can be transferred or applied to similar settings. This study’s results should be considered when caring for mothers and their infants who experience the Foker procedure for a delayed primary anastomosis. Confirmability was ensured through continual consultation with the methodology expert. The logical progression of dialogue and inquiry was driven by the participants’ behaviors and responses, which were reviewed by the participants themselves, myself, the methodologist and the neonatal expert on the research team for confirmability (Munhall, 2012; Morse et al, 2002; Tobin & Begley, 2004). Likewise, confirmability was demonstrated in the process of coding. Initially the methodologist and I coded the data independently. My familiarity and past experience with the population supported an insightful conceptualization of the data as I combined my interpretation with the significance of the phenomenon of interest. When we met to compare codes, the differences were not significant and we easily reached agreement.
Throughout the study I maintained a reflexive journal to construct a means of reflection, and interpretation to provide evidence of the hermeneutical process that occurred. These journals along with my field notes provided depth and richness to the transcribed texts. They also authenticated the findings while establishing an audit trail to ensure dependability (Munhall, 2012; Morse et al, 2002; Tobin & Begley, 2004; van Manen, 1990). Peer debriefing occurred in the manner of sharing all written transcripts, reflexive journals and field notes with the members of the research team.

**Results**

Reflecting on the mother’s words and understanding their experiences allowed for assigning meaning in the context of their situation. The authenticity of the dialogue captured the essence of the experience for each mother. There are many similarities in the experiences as well as some differences. The differences are helpful to understand the scope of realities for mothers during this experience specifically as it relates to each mother’s situated context, her horizon and the physical embodiment of the experience. The existential life worlds overlap in many examples with an interconnectedness that provides a greater understanding of each woman’s experience of being a mother of an infant with LGEA (Munhall, 2012).

Phenomenological existential life worlds provide the structure and form to portray our understanding of the experience (van Manen, 1990). The experiences are personified by examples that illustrate the mother’s lived experiences for our discovery, understanding and interpretation.

The essence that conceptualized the study was “Making Connections: Day-by-Day” (Figure 1). The essence was revealed through themes that emerged in relation to the existentials. They are described and interpreted as: a) the many phases; b) the long and winding road; c) a new me, my purpose; d) our new community. Each theme is comprised of multiple subthemes
and together they contribute essential elements to a greater understanding of the meaning constructed by these mothers of their experience being a mother of an infant born with LGEA.

**Figure 1 Essence of the Experience**

![Diagram of the Many Phases](image)

**The Many Phases**

This theme refers to the passage of time from diagnosis to recovery and preparation for discharge home. Each participant described common phases that took place throughout the experience. The various phases occurred along a continuum from the initial prenatal diagnosis to the transition to home. Many of the events were interconnected with temporality, such as, “the unknowns were to become known,” which happened many times over, as the infant was delivered, the diagnostic evaluation revealed or dismissed the presence of additional anomalies, the surgery was performed, an esophogram was performed to determine when the esophagus was
in continuity, the infant learned to feed, the infant weaned from the narcotics and sedatives, and finally after numerous dilations, it was time to return home. Reflecting on these experiences validated the experiential expression of the many phases that permeated the lived experience.

Heather related,

It’s about having patience and not projecting too far forward...taking each day for what it is, going through whatever emotions and what is going on with the baby. It’s not up to us. Once you give up the idea that you can control (events)...letting go of expectations, you aren’t disappointed anymore. Each day is different and you have to roll with it. We hope to look back at this time as just a small piece of her life.

**Waiting and the gift of time.** One of the subthemes depicting the temporal experience of each mother was waiting. Initially, time weighed heavy on their minds. “That’s the biggest struggle with the entire process. You go through so many phases.” Waiting was expressed in many of the phases of the journey. Waiting to deliver, waiting to go see my baby in the NICU. Waiting for my milk to come in. Waiting for the doctors to round for information. Waiting for surgery. Waiting for the esophagus to grow. Waiting for my baby to “wake up”. Waiting for the esophagus to heal and be able to feed. Waiting to go to the inpatient unit so we can have our own space together again. Waiting for my baby to learn to feed. Waiting to go home. Waiting for the unexpected. Time was expressed as exhausting, with uncertainty weighing heavy on the minds of each mother.

In hindsight, waiting was seen as a gift of time that they were given as they waited with their infant’s surgery. In spite of feelings of frustration related to all the waiting expressed by the participants, the mothers universally described the time waiting for surgery as a gift. For some the time before surgery, typically 6 to 8 weeks, was used to get to know their infant and to spend
time holding and enjoying the experience of skin to skin contact, which is an intimate experience.

As soon as I saw her for the first time, we did skin-to-skin and she just melts on you. Like now, I can’t imagine now… not being able to hold her for a whole month… it may have affected our bonding… I can tell she is really connected to me… at first you think, oh six weeks, that’s such a long time to wait (for surgery), but it turned out to be the best thing.

One infant was large for gestational age and had co-morbidities. Allison described his initial course as being very scary, with a guarded prognosis and protocols that didn’t allow her to hold him. Although she regretted earlier time lost, she delighted in the later concentrated time of recovery. She descried the time spent together during the convalescent phase,

I wish I hadn’t had to go back to work (when he was in the NICU). I thought that I would have more time when he came home. I just don’t remember when he was little, little… I feel like the time we have now is making up for the lost time in the beginning. … the other great thing is watching him perform things… each first is a really big deal… I feel like, my God, we are so lucky, he’s doing it.”

Eva shared her experiences of adaptability and resilience dealing with challenges as she related her feelings to me,

I was hoping we would be home before now. She will be five months old next week.

When I got here, I realized there is a little more to it… maybe a few more weeks… now it’s a few more… but its just more time for me and her to hang out together. I’ll be so relieved to get home and say Thank you God.

**Surgery.** Surgery was the time that was the most difficult for each of the mothers, but also the most exciting. “That is why you are here. You feel helpless, it’s bittersweet in many
ways and you don’t get to hold your baby for a month. But she will come out [of] this with her own esophagus.” Each mother was very grateful that they had come to this center for the procedure. “It was the right thing to do for the baby. I can’t imagine it any other way. It was worth putting our life on hold.” But, even so it was difficult. Heather related,

She is paralyzed and doesn’t look anything like what you remember. But at the same time, it’s this unbelievable miracle; they are growing her esophagus...being paralyzed is very difficult to see as her mother. In my mind, I thought she would be heavily sedated, sleepy and not be able to move, but that was not the case. She was more or less trapped in her little body. At times a tear would come out, and the nurse would say she’s agitated, and I’m like she’s agitated? That was hard, there were times when I wanted to say, let’s just stop this now.

While some mothers felt a sense of responsibility to be there during the paralysis, “she struggled to open her eyes and we locked just eyes, she knew we were there,” one mother had to return home to work during the time of paralysis. Although she had daily updates by the surgical fellow, “who became my best friend and kept me cued into when his next surgery would be...those were the longest two weeks...he went past the average of 14 days and at that point I was having ...panic attacks.”

**The cadence of time.** The time passed differently during each of the phases. The passage of time varied, as each mother became more active participants in their infants care; as they assumed more responsibility as some of the unknowns became known. The waiting was deemed long, in particular during the surgical process, when mothers were less able to interact with their infant. Later, time spent engaged with staff learning about their infant and being an active
participant was time that passed more quickly. “Some days go by so fast, you don’t want to miss anything… really enjoy those moments, moments you never get back.”

**The Long and Winding Road**

The mother’s experiences occurred in a variety of settings. The long and winding road conveys the journey that the mothers described during their experiences. “We are on this road and really not really knowing what we would be dealing with. I feel like everything we get past…I hold my breath a little…I don’t know where the road can bend and turn…. We’ve come so far and we still don’t know what lies ahead.”

**Leaving home.** Moving to the medical center was an experience common to all of the mothers.

I never thought about whether I could…or should do this, I had to. When we made the decision to come to, we hit the ground running. This was our number one responsibility…however we were going to take care of it…the rest would work itself out.

And it has. I know without a doubt her story would be completely different.

Allison related the initial reluctance for her infant to be transferred for surgery. “I had to go back to work as we waited to decide whether to do surgery or not. They said he might not have a good quality of life and to have surgery was a big deal…and to have to travel for it. It was horrible.”

**Home away from home.** Heather and her husband lived in housing provided by the hospital in a community setting a short walk from the hospital. Coming to the hospital each day was now their routine. Arriving in the NICU each day, being given an update by the nurses and being present for rounds with the Esophageal Atresia Team had significance. “The NICU became our new normal. We live at the Parent House, it’s close and we have a routine. We talk things out, we are always part of the conversation.”
Allison and her daughter walked from the Parent House each day and settled into their daily routine. “It just works. It’s nice to have a routine, it really helps with all the things he has going on and his timing fits in with what we do. He sleeps at night so it’s OK to leave him and go back to ‘our place’.” A secondary gain for Allison and her daughter was to be together 24/7 while her brother was in the hospital. If they had been at home she would have been in preschool/daycare while her mother was at work. “They have really bonded as siblings. This time has been great for their relationship. He just loves her and watches everything she does.”

Going home. Home was always on the horizon for each mother. That was a universally motivating factor, to take responsibility and learn to care for their infant. Achieving a sense of normalcy was very prevalent among the mothers. “You get back to your everyday things…with the hope that your everyday sense of normal will be getting home.”

It’s time and patience and not planning on going anywhere for a while…it’s been four months and we’re still in the process… it keeps you motivated. That’s the whole goal, to provide her with a normal life. To see that she will have that opportunity…everyday we sat in the hospital…it’s so inspiring…to see that we have gotten this far with the decisions we have made.”

Eva asked if there comes a time when you don’t need the Esophageal Atresia Program (EAP) any longer. “I mean, I appreciate everything they’re doing for her, but I just want to get home.” Allison stated she had lived in the hospital during this process longer than she had been in her home after a recent move before her son was born. She too was eager to restore a normal home routine as her son approached time for discharge.

When we get home…we will have time to spend to help him learn to eat…and settle into a new routine, so it’s good. I feel that everything happens for a reason…It’s too bad the
insurance company won’t pay me to be his care provider instead of the home care nurses that can’t disconnect his monitors, take him out in the yard and do “normal” things.”

Heather was introspective as she imagined her life at home with her newborn,

In a way, as you get closer to leaving, it’s like we have just had a newborn. Even though we have had her for 3 months, now we get to live all the experiences, as it was meant to be, as it should have been. We’ve made a conscious decision that’s it’s all on us now. We are preparing for going “into the wild”, that’s what we call being out on our own.

A New Me: My Purpose

Corporeality was expressed in the existential experiences of the mind body connection that was described by each mother as they related to their infant. It is human nature to assign meaning to experiences and relate to them. Emotions that occur in response to contingencies, interactions and relationships can be either very positive or negative,

Grief. A distinct boundary formed between the times of discovering the pregnancy to discovering that there was an abnormal finding on ultrasound. Heather and Eva each described a profound sense of denial. Eva said, “No, this can’t be. And then you’re like, why me? This baby will need to have an operation as soon as she is born.” Heather grieved…

It felt like you had lost someone; of real grieving…I would not have been able to have this conversation then. You never forget that moment when you’re given the news, and then boom, we didn’t know then how much our life was going to change, forever.” A picture hanging at her infant’s bedside shows a happy couple, being pregnant, excited about the future. She stated, “That was before, now I look at that picture differently, it’s kind of bittersweet.”
Each mother acknowledged the anxiety that permeated her mind each day until her infant was delivered. “We were worried that she would have other birth defects, things that go along with this, like VACTERL syndrome. When she was born, my husband kept going back to the NICU to check if she really had an anus, that’s sounds so silly but we needed to know.”

Delivery came early for Eva and Heather, as is common with EA. The premature contractions that Heather experienced disappeared after she travelled 3000 miles to the high-risk perinatal center to receive her care. The anxiety of making the big move was behind her and she could move on to the next phase.

Allison was distraught as each ultrasound showed changes that were concerning to her doctors. She was advised to transfer her care to a high-risk center in an adjacent state, because they can handle that. “But I wondered, how could I handle it? It was very stressful.”

This existential experience of the infant growing within, with unknown features and unknown future expectations provoked feelings of inadequacy, anxiety and fear of the unknown. The ultrasound had the effect of challenging the concept of “knowing her baby” before birth, expecting, as the term is used, may not be what she was expecting at all. How does one prepare for that? When her infant was born he was resuscitated and was placed in therapeutic hypothermia for neuro-protection but did not respond as expected to being warmed causing concern.

He did not move for 3 days even after he was warmed. He had been sedated, but it should have worn off, and he still didn’t move or breathe on his own. No one knew if he would make it or not or ever be able to do anything. The day we decided to move ahead with a gastrostomy feeding tube, he opened his eyes and looked right at my husband. It
was like he was saying, “thanks Dad.” His condition continued to change over time. Look at him today. He does better after every operation, better than anyone ever expected.

**Separation.** At delivery, each mother was separated from her infant, missing out on the initial experience of the first hours with her newborn. Heather was being cared for at an adjacent hospital that was physically connected but she felt “miles from my baby.” Allison felt sadness that she could not be with her infant because she had a cesarean delivery and her infant was undergoing hypothermia and could not be held. Eva was able to see her baby for a short time before they transferred her infant to the tertiary center several hours away. “I didn’t know if she would ever remember me with all those other nurses in her face.”

Each mother experienced separation but each did so in a different way based on her personal situation. Being separated from their newly born infant produced anxiety and stress. In essence, no matter what the distance, separation was the source of their distress. Each mother had a prenatal diagnosis with a concerning ultrasound finding that was confirmed when the infant was born. However, the diagnosis and treatment decisions were just the beginning of getting to know their infant. They did not have the luxury of privacy as they learned their infant’s unique features and personality. The learning opportunities had frequent interruptions and barriers that added stress to the experience of mothering. “The NICU was like a bubble, you are right out there.”

**Coming together again.** Being reconnected with their infant when the paralysis was lifted was jubilant for the mothers. Heather related, “she just opened her eyes the slightest, she was trying. She had four pounds of water on her. And then she closed them, but she was like, hey Mom and Dad, I am with ya! That was really special.” Eva expressed her surprise when her
daughter was awakened earlier than she anticipated. “It was the 4th of July and she truly had her independence.”

Recalling her infant awakening after the paralysis was lifted, Heather used the expression “we locked eyes” as she had when they met after birth, and again when her infant was experiencing withdrawal and again while she learning to feed. “It’s important how you project yourself to her when she needs you, to be there for her.” It was her way of knowing they had made a connection.

Eva was grateful to move to the inpatient unit where she and her infant were able to room in together. They had had a period of several weeks in their referral hospital while the infant gained sufficient weight to meet the criterion for the Foker procedure. Once she came for the procedure, the sleeping accommodations were in another building. When they were transferred to the patient surgical unit they were able to room together again. “She feels more like my child, I know she is, but we’ve been confined to a room, which is weird. Now I can put her in the stroller and go outside. The closer we get to home, the more excited I get. I think about what she’s going to be like when we get home.”

**Responsibility.** During pregnancy and early in the infant’s course feelings of personal responsibility for their infant’s condition were expressed. What did I do wrong to cause this? The nurses explained to me that this happens and nothing I did caused it. “Heather relented, “It was 3 months later when I sat down with the surgeon and he said nothing you did or didn’t do caused this, that I could finally get it out of my head.”

While some mothers expressed guilt, each began to share feelings of hope and optimism. Allison related,

For us, we thought we had to do the best thing for him. You’re not going to regret taking
him to the best hospital in the country and having a bad outcome but you would regret
not taking him and having a bad outcome. Ultimately, he’s doing great and he’s eating
and that’s why we came here.

When asked what she had learned as a mother, Allison replied,

Most of all, that you still get to be happy, that awesome things still happen and your baby
is amazing. All the things I worried about when I found out I was pregnant. We would
have him no matter what... We wonder how he will do...looking ahead...but he is an
awesome little person. There is still hope with tons of love and happiness; there is still
hope.

Being satisfied with the decisions made as a parent in the best interest of their child drew
reflection that carried a great deal of emotion.

It was so heavy. It’s a lot of responsibility. You are making decisions, some of which
were beyond what I could even understand. You are put in this position, it was never
questioned. I never thought whether I could do this. I have to. It’s so much… it changes
your life in so many ways. What does it really mean for our life and our child’s life?

Intuition came with confidence as they grew to know their infants. With regard to feeding her
infant, Heather shared, “I try and stay calm… I feel like she reads our cues and if I am
tense…she is looking to me to show her this is OK, so I relax and go slow. I talk sweetly to
her…coming up with a routine and practicing.” She referred to this feeling as her “Mummy gut”
as she expressed the faith she had in her own intuition.

It’s amazing to be so in tune with your instincts. One day she had a fever and was
withdrawning; I knew it from the last time. They said, it could be infection, so we have to
draw her blood and start antibiotics. It was awful to put her through that for nothing. I
tried to explain it… to my husband, but it’s not the same.

Allison spoke about knowing that she had to speak up for her son when something wasn’t quite right,

I should have been more assertive, he had gradually developed a stricture and everyone thought it was the flu that they said I gave him. I knew it was a stricture and no one listened to me. Finally, one of the surgical residents came and couldn’t pass the tube. He had dilation performed the next morning. I knew what it was. It took a few days for me to have normal feelings again.

Each mother described the feelings of their purpose for being here with their infant and the inner strength that kept them going. Eva revealed her feelings of being a mother as her new purpose in life. Eva was proud of her ability to care for her infant, “God gave her to me in this condition for a reason: she is perfect for me. This is my life path.”

And Heather shared,

It changes your life and the mommy instinct in you just takes over. The biggest lesson for me was to give up, not control, but just the idea of what I expected of my baby, what I thought having my baby would be like… This is what it is and we’re going to get through it. It has made me look at my life differently. Taking it day by day.

Providing for their infant was an important point that was revealed by each of the mothers. All of the mothers pumped breast milk. “The breast milk has helped her in so many ways, she grew so well, she had her surgery weeks ahead of …expected.” Pumping milk added a sense of purpose to the mother’s experiences. “It’s like I have to be on her schedule, I would be up feeding her if she were with me. Plus, then it’s not all on the nurses. She is my responsibility.” Feeding their baby was a way of connecting that had been long awaited and produced feelings of
anxiety and joy. The first oral feedings were by bottle, but each of the mothers was eager to breastfeed too, which was encouraged. “With all she has gone through, it’s the least I can do for her. Feeding was such billed as a big deal, now she has this new esophagus so lets use it!”

Mother’s looked to the nurses and feeding team experts to guide the early experiences. Mothers and infants developed their own rhythm for feedings; one infant would not feed if others were watching, but she would “go to town” if she and her mother were alone. Another mother would “zen out” so her infant would not feel her anxiety as she put her to breast.

A New Community

A multiplicity of relationships were described that each mother established with the nurses and others responsible for the care of her infant during the process. A new community emerged as each mother acclimated to her new environment. Over time, they realized that the nurses, the Esophageal Atresia Program (EAP) staff and the other families they met who were going through the same thing had become their new community. Each mother used social media to learn about their infant’s condition, connect with other mother’s who had an infant with LGEA, and to share their experiences.

Support. Each mother had a dedicated support person with her during the initial phase of the surgery. The relationship of the support person was different for each mother. Heather had her husband with her, Allison, her young daughter, who also needed to stay with her mother as her father was at work in a distant state. Eva was a single mother who was accompanied by her mother for the initial surgery. Eva was surprised at how emotional her own mother was when her infant returned from surgery, ventilated and paralyzed. Each day, the infant was more edematous and by the end of the week, Eva could hardly bear to see her daughters changing appearance. In addition, her mother was crying in response to her personal distress. “I was supporting her and I
Nursing. Nurses are the first contact a parent has when approaching their infant’s bedside. In the challenging environment of the NICU, the nurses made mothering behaviors possible. They demonstrated care by modeling for the mothers how to hold and care for their infant in spite of the technology that was a major component of the infant’s care. The nurses read the mothers’ cues and assisted them in reading and interpreting their infants’ cues thus facilitating parental involvement in caring. Heather acknowledged that at times, she too, needed care.

They made the day normal; we had a routine. Seeing the nurses, asking how she was doing, they understood. The nurses made it bearable. I was amazed by their knowledge and how gentle they were, yet strong. The nurses knew that I needed care too and were very supportive, asking what I needed, how they could help. That day, I really needed that.

The mothers perceived the role of the nurse differently depending on the day and circumstances. As her infant developed a fever, Eva became frustrated that she couldn’t care for her daughter the way she wanted. The nurse kept taking the blankets off to help her fever come down. “Are those chill bumps on her arms? She’s making me cold looking at her. She needs her blanket.” Negotiating roles and responsibilities between nurses and mother became easier over time as the mother’s gained experience with the equipment and understanding of their infant’s needs.

The esophageal atresia program. Each mother found herself coming to the medical center with her infant for treatment through a different path. Heather found the program online and contacted parent whose child had undergone the procedure. “This was the biggest game changer for us. I would probably still be crying.” Allison pressed her physician to seek an alternative to the “wait and see” approach that was offered to them. And Eva was very grateful
that her physician said, “You are going (to this institution) for her surgery, that’s what I would do if it were my child.” Each mother expressed a great deal of trust in the surgeons and other care providers. Allison recollected,

He was having a fundoplication, but it wasn’t going well. The doctor came out and said we could try this… it was little more difficult and not a very common procedure. So, we really just had to take his word for it…. And we said go for it. It was the right decision, he’s doing great.

The EAP has a holistic interdisciplinary team approach to care for infants with LGEA. The EA nurse practitioner, social worker, child life, feeding and lactation specialists play an integral part in normalizing the experience for the mothers.

It was good to meet other mother’s in the support group. You can see them in the NICU, but you can’t just say oh, does your baby have EA? So now we all know each other and even though we are at different stages, it helps to talk. Sometimes we talk about regular things. Not just EA.

Allison’s young daughter loves meeting in the group and asks, “Are we going to the party?” Eva was hesitant as she spoke of attending the support groups. “It’s good sometimes. I’m kind of like…I’m the only African-American mom there and I feel kind of like not out of place but well how often does that happen. But the last group, one mom was Hispanic so that was good. We have each other don’t we?” she says as she squeezes her baby close to her.

**Art, literature and social media.** Art and literature are expressions of our individual and collective existence that are shared through the experience of our community and society. Recollecting experiences expressed through art, poetry, and Internet journalism are timeless, contemporary and readily available for those interested in the phenomenon. Reaching out to the
Internet as a resource is normative for the millennia generation. They routinely use it for information gathering and sharing. All of the participants interviewed utilized the Internet and “Dr. Google” for information related to their experience, and acknowledged the benefit they received from information found online. These mothers were virtual pioneers as mothers of infants with LGEA. In addition to using Facebook© to communicate with family and friends at home, Heather produced a blog to chronicle their journey through the experience of growing a new esophagus and giving her daughter an opportunity for a “normal life”. In her reflections Heather provided an accurate, informative conveyance of truths that brought to the reader the essence of her being a mother to her daughter. It included pictures, friends’ and family members’ comments as well as the parents’ perspective of the journey. This mother wanted to, give back to others walking in her shoes and tell a good story about an infant with LGEA who could be treated successfully. A lot of what you read online can be negative with people searching for answers. I want to share our positive experience with others to give others hope when they need it most. We wouldn’t have been here without hearing someone else’s story.

Sharing positive stories provides a powerful means of support to others making the decision or who are in the early phases of recovery after the surgery. http://littleeverly.worldpress.com

Metaphors are a way of using language to express and depict the essence of one’s experience. Metaphors often serve as a phenomenological description of using language to express thinking and being in the world (vanManen, 1990). The Marathon, a novel by a mother of an infant with LGEA compares her journey of having an infant with LGEA to her husband’s running of the marathon as a member of the hospital’s fund raising team. In her novel, she relates the shocking and traumatic prenatal diagnosis, a premature delivery, and the extended wait for a
delayed primary repair and multiple other surgeries for co-morbidities. Her husband, who has the major responsibility for running things at home, decides to train for the marathon. As he competes, he runs the course with the support from his family and friends, and is buoyed by the cheering crowds and the joyful reunion at the finish line, paralleling the hospital course he and his family endured and conquered in their run with LGEA.

Anxiety, depression, and exhaustion deepen a mothers feeling of helplessness just as the countless hours of exhausting training discourage and frustrate a runner. A myriad of extended supports gave her strength and fortitude to both. Both are resilient, committed to a goal, and determined to preserve knowing they will succeed and conquer any and all obstacles. similar to the marathon runner.

**Discussion**

The purpose of this study was to understand the meaning of the lived experience of being a mother of an infant born with LGEA. The specific aims of the study were 1) to better understand the mother’s perception and interpretation of the diagnosis, treatment and recovery trajectory for her infant, and 2) to advance the nursing science of caring for these mothers and their infants.

The first aim was addressed by coming to a shared interpretation with each mother and her experience of having an infant with LGEA. The essence that conceptualized the experience was given the metaphorical title “Making Connections: Day-by-Day.” It was a journey marked by developing relationships with their infant, the nurses and health care providers as well as personally as a mother during the many phases of diagnosis, treatment; and recovery trajectory for each infant.

Previous research has shown that mothers who approach delivery with abnormal prenatal
ultrasound findings have an increased risk of anxiety, depression and a negative impact on maternal-infant interactions (Viaux-Savelon, 2012; Wigert et al., 2006). Each mother had been diagnosed prenatally and had feelings of anxiety, stress and of being overwhelmed prior to their infant’s birth. In addition, each mother shared the circumstances of their infants’ birth via emergency cesarean delivery, all with differing medical indications. One mother had a previous pregnancy loss that added to her feelings of inadequacy. A past history of depression or an infant with health complications increases the vulnerability of a mother to experience depression and anxiety while their infant is in the NICU (Serge, McCabe, Chuffio-Siewart, & O’Hara, 2014). These mothers whose infants were in the NICU were recovering physically and emotionally themselves after delivery. As the mothers recovered and increased participation and physical proximity in care, they become increasingly engaged with their infants, a phenomenon described previously by Obeidat and colleagues (Obeidat, Bond & Callister, 2009). As noted by Wigert, Johansson, Berg & Hellstrom, (2006) each mother benefited from caring by the nurses and health care team members to feel that they were included and valued as the infant’s mother. The mother’s feelings of trust in the health care providers were enhanced by timely communication, caring and acknowledgement of their concerns and the desire to participate in decision-making and care of their infant, as found in previous studies (Heerman, Wilson & Wilhelm, 2005; Wigert et al., 2006).

During the treatment phases, the participants shared a range of experiences in the physical spaces of the hospital and the providers they interacted with over time. The challenging environment of the NICU gave way to open space of recognizable sights and sounds and people who brought familiarity and reassurance. However, the lack of privacy and care practices that had to be negotiated with nurses also brought about challenges for some of the mothers. These
challenges were similar to findings by Heerman et al., (2005), who identified the phases that mothers experience as they shift their focus on the NICU environment to their infant, and finally to their role as a mother. Their experiences were influenced by the health status of the infant, each mother’s own experience and the culture of the NICU. The mothers in this study who had traveled so far from home for their infant’s care were surrounded by other complex, critically ill infants, and were faced with the many challenges that accompanied a staged esophageal repair. Separation from their infant was an inevitable consequence of care in the NICU, and the rare nature of the condition imposed many unknowns that compounded the feeling of time going by slowly. As each mother became more knowledgeable and engaged, the cadence of time quickened, as if they were reawakened to their commitment of being a mother once again, an attribute noted by Johnson (2008) that represents an important connection in the mother-infant relationship.

In this study, being present with their infant when the infant was undergoing the surgical procedure and was ventilated, sedated and paralyzed was overwhelming for the mothers. Giving up control and watching the infant endure possible pain and suffering, and fear of the unknown was a source of distress. Lack of control over the infant’s hospital course was also a common thread in the discussion. Being able to accept the infant’s condition and deal with fear and frustration was mediated by being close to their infant, feeling included in their daily care and having honest, caring communication. The mothers in this study validated findings from previous research (Gardner, 2014; Obeidat et al., 2009; Wigert et al., 2006) that information, involvement in care, affirmation of themselves and their infants as unique individuals were important behaviors that gave meaning to their role as mother.

One very powerful theme that resonated with participants was the sense of purpose that
their lives had taken on with the birth of this infant. A parental pedagogical paradigm offered by vanManen (2012) reveals that this is a common ethical response to having an infant born that requires intensive care and medical or surgical interventions for survival. Each participant was willing to relocate and sacrifice their career, social supports, and let go of preconceived expectations about parenting in order to do the best thing for their child. This type of emotional and behavioral responses were life changing and brought about a new sense of purpose as a mother and for some mothers, a renewed faith in a higher power.

The focus on feeding was omnipresent. These mothers yearned to nourish their infant and pumped their milk from day one to provide for their child. The milk was used for oral care introducing the infant to the taste, smell and a positive oral experience that was provided by the mother. This gave the mother an opportunity to see her infant’s response to her breast milk. Waiting for the two weeks following anastomosis for an esophogram to be done was a very important time as then, finally the infant could be offered oral feedings. It took patience and practice on the part of the infant, and the mother for this process to be smooth and satisfying. These mothers showed determination, inner strength and a will to succeed and to nourish their infant in these special cases. Each mother found her own strength and sense of competency as she became increasingly sensitive to her infant’s unique needs (Gardner, 2014; Obeidat et al., 2009).

Building maternal competence especially with regard to feeding and facilitating interactive and reciprocal behavior of infants with LGEA is an area that can serve to enhance the mother’s experience (Faugli, Emblem, Veenstra, Bjorland, and Diseth, 2008). Development of maternal competency is a process that nurses can facilitate with an understanding of each mother feeding choices and care giving practices. In addition, by engaging the mother in the learning
and knowing of the infant’s changing capabilities and personality dimensions, nurses support the mothers sense of security and competence. The process of acknowledging each mother’s accomplishments encourages physical closeness, helps the mother to identify her infants’ abilities, and promotes attachment. Using expressed milk for oral care and pleasure with face to face interaction serves to reinforce a mother’s developing sensitivity for satisfying her infant’s oral needs, well before the infant begins to feed orally. The experiences reiterated given by these mothers illuminate the need for providing positive early relational experiences while being sensitive to their infant’s changing and often challenging needs.

Nurses can reinforce the day-to-day presence and developing relationship of a mother and her infant as a significant antecedent to developing healthy attachment (Ainsworth, 1978). Physical proximity promotes autonomic co-regulation during skin-to-skin holding, recognizing their infant’s needs and responding with care and love are essential for developing positive mother-infant interactions during the phases of surgery (Feldman et al., 2011; Renya & Pickler, 2009). Time spent learning their infant’s prior to surgery served as an invaluable resource to the mother’s in the stressful pot-operative period when their infant was emotionally and physically unavailable to them. Mother’s had developed confidence and the beginnings of a synchronous relationship prior to their infant’s difficult surgery that buoyed their sense of confidence and enabled them to adapt and respond to their infants changing needs.

The transition to the inpatient unit for convalescence brought about new opportunities for relationships, recognition and negotiation. The mothers wanted their voices and their needs acknowledged. The mothers were becoming the experts about their infant, understanding his or her needs and idiosyncrasies. The mothers knew their infant better than anyone else. Similar to mothers of NICU infants described by Heerman et al., (2005) and Obeidat et al., (2009) each
mother expressed the need to be challenged and trusted at the same time to prove to themselves that they were now responsible for their child and were partners in care giving. Becoming the expert on their infant was a necessary component for discharge, or in the words of one mother, going “into the wild”, a term she referred to for being discharged and out on their own. And like the mothers infants examined by Faugli et al (2008), the mothers in this sample showed commitment and capacity for adaptation and coping throughout the challenging start to their role as a mother of an infant with EA.

The participants in this study were at times very emotional during the interviews especially when reflecting on their experiences when they learned the abnormal ultrasound results and the potential for the infant requiring surgery after birth. All of the participants experienced being separated with feelings that ranged from anxiety and anger to hopelessness and despair. They were also emotional when recounting the experience of the surgical procedures often described as the most difficult period. Their optimism and behaviors toward their infants may have been mediated by their personal attributes and the specific attention given to their emotional needs through family and nurse support and with the anticipatory guidance provided by the Esophageal Atresia Treatment Program members. Each participant shared with me that she was grateful to have an opportunity to discuss her experience during the course of the study, a secondary gain that has been noted in other qualitative studies that helps normalize their experience and validate their emotions (Munhall, 2012).

Metaphors are a way of expressing experiences to depict through language, the essence of one’s experience, a phenomenological description using language to express thinking and being in the world (vanManen, 1990).
Limitations

This study provided a beginning understanding of the essence of being a mother of an infant with LGEA. Due to the nature of qualitative methodology, this was a small sample that included only English speaking mothers, thus limiting the generalizability of the results. In addition, this study did not directly address mothers’ feelings of depression or anxiety, factors that have been associated with alterations in maternal-infant interaction.

Clinical Implications

Understanding the experiences that helped the mothers achieve her individual maternal identity while under duress has the potential to inform neonatal and pediatric nurses. Nurses are positioned to support basic mothering behaviors and promote sensitivity to their infant’s special and often compromised communication and relational abilities. Holistic strategies that promote family centered care that emphasize the infant’s unique strengths can maximize maternal responsiveness and strengthen the emerging maternal-infant interaction. The essence of the mother’s experiences revealed here suggests nurses convey knowledge, empathy and compassion in their practice to advance the nursing science of caring for this high-risk dyad.

Generating practice based evidence from examining current care practices with qualitative methods can lead to designing interventions that can have significance for the ones receiving the care (Leeman & Sandelowski, 2012). Because contextual factors cannot always be controlled in practice, understanding and interpreting the essence of these examples may serve as evidence that can further refine our knowledge of evidence based care delivery by validating or challenging the technical protocols as experienced by the participants. Use of the interpretive paradigm is essential to understand the experiences of mothers as they navigate the complex processes when their infant requires surgery in the neonatal period for a life threatening
condition. Phenomenology gives voice to the mother’s experiences and describes previously unidentified needs and information to the members of the health care team so they can improve overall patient experience and lead to improved outcomes.

The results of the study may be applicable to future mothers who have an infant with LGEA or other congenial anomaly. The subjective nature of each participant’s responses must be taken into consideration in the context of providing family centered individualized care in the NICU. This knowledge can provide clinicians with a greater understanding of a mother’s perspectives, concerns, and need for individualized interventions for support. Nurses can optimize the opportunities that promote early, positive, reciprocal and sustained mother-infant interaction. Nurses also must provide clear and timely information and support that enables each mother to own the concept of being a knowledgeable mother, the expert in reading the infant’s cues, and the confidence to trust her intuition and act on this knowledge (Heerman et al., 2005; Obeidat et al., 2009).

**Research Implications**

The experience of the health care providers caring for these infants needs to be explored to determine the contextual factors within the health care system that influence care delivery. Creating negotiated partnerships with families can be a fulfilling component of nursing practice, but can also bring challenges when the afore mentioned contextual factors come into play. The role of fathers and extended families needs further study to maximize our understanding of the family dynamics that these conditions impose on family functioning. Physical and neurodevelopmental outcomes need further investigation with contextual variables such as analgesia and anesthesia exposure with repeated procedures that influence both short and long-term outcomes in this population. And finally, a descriptive study that includes a larger sample
size and a longitudinal design would add profundity to the mother’s role development and illustrate the development of working models of being a mother of a high-risk infant.
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Chapter Five: Conclusions and Implications

Mothers Experience During Repair of Long-Gap Esophageal Atresia

Patricia Fleck

Northeastern University
Mothers Experience During Repair of Long-Gap Esophageal Atresia

The experience of having an infant born with Long-Gap Esophageal Atresia (LGEA) is a multifaceted journey that begins in pregnancy when the mother discovers her fetus may have a birth defect that represents a serious health risk at birth and beyond. Stress and depression may affect the mother’s acceptance of her pregnancy and influence the mother-infant interaction at birth and into the neonatal period (Viaux-Saveion et al, 2012). Some mothers are separated from their family and social supports to deliver their infant in a high-risk perinatal center to ensure availability of an interdisciplinary team that can provide lifesaving and comprehensive care. Other mothers experience separation from their infant after birth when it becomes apparent that the infant has LGEA. Separation following delivery has been demonstrated to influence the emerging maternal-infant relationship and subsequent attachment behaviors of mothers and infants (Bystrova, 2009). The preferred surgical repair for LGEA is a delayed primary repair that consists of a staged surgical procedure with multiple exposures to the requisite anesthesia, analgesia, sedation and paralysis with mechanical ventilation in the post-operative period (Friedmacher & Puri, 2012).

Since the early 2000’s, the survival rate of infants with esophageal atresia (EA) and LGEA has improved to over 90% (Friedmacher & Puri, 2012; Zani, 2014). Subsequently, as the focus of research has shifted to quality outcomes for these infants, researchers have found evidence of neurodevelopmental delay in the first year of life (Aite et al., 2014; Friedmacher & Puri, 2012; Maheshwari, Trivedi, Holland & Walker, 2013). Infants with EA in general, and LGEA in particular, are even more at risk for neurodevelopmental delays related due to the increase in number of operations and duration of mechanical ventilation with concurrent analgesia and sedation. In addition, prolonged sedation compromises mother-infant interactions.
with the potential for long-term implications on the emotional and social growth and
development of the infant (Faugli, Emblem, Bjorland, & Diseth, 2009; Faugli, Emblem,
Veenstra, Bjornland, & Diseth, 2008; Maheshwari et al., 2013).

Mothers of infants with LGEA endure a host of challenging experiences as they anticipate, observe, and learn to care for their newborn. A greater understanding of the mother’s experiences can inform nursing practice and advance interventions that address the unique care needs for this population of infants and their mothers (Leeman & Sandelowski, 2102). Phenomenology, the study of the lived experience, was chosen as the best method to answer the research question; namely, what is the experience of being a mother during repair of long-gap esophageal atresia (Munhall, 2012; van Manen, 1990).

**Review of the Literature Findings**

An integrated review of the literature was done to assess the current state of knowledge concerning surgical outcomes of infants with LGEA. The five-step procedure developed by Whittemore and Knafl (2005) was used to ensure rigor in the review process. Due to the paucity of literature available related to infants with LGEA, studies that included infants with EA were also incorporated in the review.

The results of the integrated review revealed that infants with EA and LGEA have three categories of concern that are important for care. The categories that emerged were 1) physical health, 2) neurodevelopmental health and 3) psychosocial health. Data from each category was synthesized to provide an overview of the issues and the impact on the emerging mother-infant relationship. Moreover, 50% of these infants have co-existing congenital anomalies (CA), and more than half of the infants with EA have a complicated hospital course (Castilloux, Noble, & Faure, 2010; El-Gohary, Gittes, & Tovar, 2010).
The inability of the infant to swallow and feed naturally is a significant issue that is later complicated by gastro-esophageal reflux. Feeding is a fundamental behavior that is essential for survival and much of the relational experience of a mother and her infant occurs in the context of feeding. The long delay in oral feeding has an effect on the infant’s physical, neurological and socioemotional development. The infant may also experience respiratory distress due to their inability to swallow secretions, which puts the infant at risk for aspiration. In addition, the trachea is malformed and may collapse upon exhalation or during crying, compounding the infant’s distress. Respiratory issues further complicate the challenges of learning to feed following the surgical repair. Mothers are fearful of their ability to care for and feed their infant because of the respiratory and feeding challenges that are posed by their infants (Caplan, 2013), placing anxiety and stress on the mother-infant interaction.

The infant’s severity of illness, presence of additional CA, prolonged hospitalization, number of surgical and medical procedures, medications, immobility and limited physical contact with mother inhibits the normal neurological development of the infant (Aite et al., 2014; Bevilacqua et al., 2014a, Bevilacqua et al, 2014b; Gischler et al., 2009; Maheshwari et al., 2013; Walker, Halliday, Badawi, Stewart, & Holand, 2013). The infant’s limited ability to explore the environment may result in low cognitive and motor scores as measured by standard developmental metrics. There was some evidence that the low scores seen in the first six months of age improved into the normal range by one year of age, suggesting that the stress associated with hospitalization and surgery were influenced the infant’s neurodevelopmental outcomes (NDO) (Aite et al., 2014; Bevilacqua et al., 2014a, Bevilacqua et al., 2014b). Infants perceived as being developmentally delayed that require medical devices for feeding, and whose
hospital courses are complicated by co-morbidities, impose additional strain on maternal perception of her infant and subsequent mother-infant interaction.

The psychosocial outcomes of infants were concerning as delays in expressive language and diminished reciprocal behaviors had a negative impact on mother-infant interaction. The challenges associated with feeding were shown by Faugli, Emblem, Veenstra, Bjornland, & Diseth (2008) to negatively influence the reciprocal responsivity of mothers to their infants, demonstrated by diminished pleasure and intrusive behaviors by the mothers. Continued investigations by Faugli, Emblem, Bjorland, & Diseth, (2009) revealed that many of the same factors that impact the NDO and subsequent emotional health of the infant. Following repair of EA, mothers and infants experience much stress while learning to feed and that interferes with their ability to respond positively to one another.

Although there is limited research that examines the effects of EA and LGEA on mother-infant interaction, there is sufficient evidence to believe that stress and anxiety in combination with the physical demands present a risk for healthy mother-infant attachment.

The Impact of Interrupted Attachment in Surgical Newborn

The purpose of this clinical paper is to inform nurses about the experiences of mothers whose infant requires surgery in the newborn period and the impact that may have on maternal-infant interaction and the attachment process. The stress associated with surgery in the newborn period poses significant risk on the physiologic organization of the infant. Mothers also experience depression, anxiety and repetitive stress that affect their imagined role as a mother and influences their sensitivity and reciprocity toward her infant (Serge, McCabe, Chuffo-Siewart, & O’Hara, 2014). The basic theory of attachment was reviewed to familiarize maternal-child and neonatal nurses with key elements denoting secure mother-infant attachment when this
fundamental experience may be at risk (Ainsworth, 1979). Supportive nursing interventions include encouraging mothers to recognize the infants’ unique characteristics and discover and assist the mother in developing a sense of confidence and becoming more sensitive to her infant’s needs and emerging temperament.

The surgical newborn’s temperament may be affected by the physiologic disruptions and disorganization related to the anomaly and respective surgery. The physiologic disorganization interferes with the ability for them to be alert and interactive (Als, 1982). The technical environment of the newborn intensive care unit (NICU) and the alterations of the infants’ state of arousal caused by sleep interruptions, noise, and scheduled enteral tube feedings further diminish the infants’ ability to be an active participant in the mother-infant relationship (Brazelton & Nugent, 2011). Nursing interventions include guiding mothers in ways to protect the infant’s physical environment and improve physiologic organization through touch and a gentle approach. The organized infant is better able to interact with his/her mother and environment (Altimier, 2011).

Surgical infants who experience dyspagia or the absence of oral feeding due to their complex disease may be denied basic oral stimulation and exploration of their environment. They therefore have less ability to experience the physical activity that naturally occurs during the feeding experience further limiting their NDO and interactions with their mother (Caplan 2013; Faugli et al., 2008).

Synchrony is the development of a healthy, reciprocal and mutually engaging relationship between a mother and her infant (Reyna, & Pickler, 2009). The development of a synchronous relationship is an essential element of healthy attachment which can be altered by a mother’s negative emotionality (Baker & McGrath, 2011). Maternal stress is an important factor that can
have a significant impact on a mother’s responsivity to her newborn (Serge et al., 2014), while depression has been linked to a mother’s negative perception of her infant’s emerging temperament (McGrath, Records, & Rice, 2007).

Nurses are instrumental in assisting a mother to overcome the challenges for successful attachment. Knowledgable nurses can guide care by providing mothers with information and opportunities to learn about their infant. Encouraging direct physical contact with skin-to-skin care, oral-motor stimulation and being present in the moment have potential to positively influence the developing relationship that was interrupted for surgical newborns and their mothers. A genuine and caring nurse-mother relationship that is sensitive to each mother’s needs drives successful development of a mother’s trust and confidence to care for her infant (Reis, Rempel, Scott, Brady-Fryer, & Van Aerde, 2010; Snyder, Shapiro, & Treleaven, 2012).

Factors that occur as a result of surgery such as separation, intubation and ventilation, anesthesia, pain and sedation, and feeding difficulties in the neonatal period may have a negative impact on the infant’s ability to self-regulate and organize behaviors that allow reciprocal interaction with their mother. Engaging in the practice of mindfulness can reduce stress and refocus a mother’s attention to the present, increasing her sensitivity and emotional responsiveness to her infant’s needs thus promoting secure attachment in the neonatal period and beyond.

A Phenomenological Inquiry: Mothers Experience During Repair of Long-Gap Esophageal Atresia

Infants with LGEA are born with an esophagus that is not connected and may often accompanied by an abnormal connection between the esophagus and the trachea called a tracheoesophageal fistula. The preferred surgical correction is a delayed primary repair of the
esophagus and trachea (Zani et al., 2014). In the meanwhile, the infant cannot orally feed and is separated from his/her mother for lifesaving management. In about half of the cases of LGEA, a prenatal diagnosis may have been suspected from abnormal prenatal ultrasound. Often maternal polyhydramnios is present as the fetus is unable to swallow and absorb amniotic fluid in normal amounts. Excess amniotic fluid has the potential to cause premature delivery (Friedmacher & Puri, 2012). These factors may alter a woman’s maternal identity and may lead to depression and anxiety that can negatively influence the bonding experience with her newly born infant and threaten healthy attachment (Viaux-Saveion, 2012).

The experience of a mother whose infant is having a delayed primary repair of LGEA is not described in the literature. Understanding the meaning mothers give to the early experiences of limited care and interaction with their infant and the effects of stress during the surgical experience may provide valuable information to the health care team to enhance the relational abilities of mothers and infants and ultimately influence the health and wellbeing of the dyad (Mantymaa, Puura, Luoma, Samelin, & Tamminen, 2006).

The purpose of this study was to understand the meaning of the lived experience of being a mother of an infant born with LGEA. The aims of the study were: 1) better understand the mother’s perception and interpretation of the diagnosis, treatment and recovery trajectory for her infant, and 2) advance the nursing science of caring for these mothers and their infants.

A hermeneutical phenomenological method was used to answer the research question. Examining the lived experience through a phenomenological lens supports discovery and understanding of the meaning mother’s ascribe to experiences with their infants. Having a greater understanding from a shared interpretation of the mothers’ experience generated knowledge to advance the science (Munhall, 2012). The existential life worlds guided the
analysis and revealed the essence of each mother’s experience. The life worlds consisted of the
temporality (time) and spatiality (location/space) of the experience, while the corporeality (mind-
body connection) and communality (relationships that grew from interactions) that defined the

The research team consisted of myself, a qualitative methodologist and expert pediatric
nurse scientist, Dr. Sandra Mott, as well as a neonatal nurse expert and a pediatric nurse expert.
The setting for this inquiry was a major children’s academic medical center in the Northeast with
an interdisciplinary program that provides specialized care to infants and children with
congenital anomalies and diseases of the esophagus. After obtaining the necessary approvals
from the respective Institutional Board Reviews, a sample of three mothers was consented to
participate. We met in a location of their choosing at the hospital, when their infant was in the
convalescent stage of their course, to allow the mother to reflect upon her experiences. The
interviews began with a set of probing questions that changed for subsequent interviews, as new
information was unveiled during the discourse.

Rigor was maintained by addressing authenticity and trustworthiness. I kept a journal to
record strategic decisions and the course of data collection as it unfolded to authenticate the
process. In addition, I maintained a reflexive journal to document my reflections about each
interview and record the mother’s non-verbal behaviors and other symbolic gestures and objects
that contributed to the experience. Trustworthiness was evaluated with the criteria of credibility,
transferability, confirmability and dependability (Tobin & Begley, 2004).

The essence that conceptualized the study was: “Making Connections: Day by Day.”
Four themes emerged in relation to the existential lifeworlds that revealed the core meaning that
mothers gave to the experience. They are: a) the many phases, b) the long and winding road, c) a
new me: my purpose, and d) a new community. Each theme was comprised of subthemes that provided insight into the experience thus allowing for a greater understanding of the meaning constructed by the mothers of infants born with LGEA. Similarities and differences between the mothers were compared. In final evaluation it was determined that they were minor and did not interfere with transferability of the findings, thus enhancing our understanding of the phenomenon (Munhall, 2012).

The Many Phases was depicted by many circumstances that involved waiting. Waiting was initially experienced as an imposition, however, as time went on, each mother conveyed that time was in fact a gift, that allowed them an opportunity to get to know their infant before the operation. Surgery and the Cadence of Time captured the temporal element of this existential.

The Long and Winding Road mapped out the journey and the many stops along the way. Each mother packed up their life as they knew it and moved to the Esophageal Treatment Program for treatment of their infant. This resulted a separation from family and known social supports. The hospital and the members of the team became their new home away from home that helped to normalize their experience. And finally, preparing to return home completed the circle for the mothers as they prepared for going home with their infant.

My New Purpose: A New Me was a powerful theme that emerged as the mothers shared their intimate feelings about their responsibilities to their infants. Each described the stages of grief they experienced as they learned of their fetal diagnosis. Grief turned to further loss as each relinquished the anticipated role of mother to one of shared care while their infant was being cared for in the NICU prior to surgery. The hiatus that was superimposed during sedation and paralysis in the immediate post-operative period was deemed the most difficult portion of their journey. Their energy eventually turned into advocacy as the mothers gained confidence and
assumed full responsibility for their infants. They each described how their life had been
changed in a positive manner, that they had a new purpose and had found a source of inner
strength they did not realize the possessed.

Nurses formed the backbone of the New Community as they navigated the experience of
being the mother of an infant requiring delayed esophageal repair. Nurses created opportunities
to get to know and participate in skin-to-skin care and decision making about providing care.
Frustration was expressed when their expectations did not match those of the health care team.
Each mother had her own individual significant partners or other family members that she relied
on for support. The Esophageal Atresia Program was another major source of support as it
brought mothers together who shared similar experiences, resources and supports. Their new
community extended into the virtual realm with online social media sites such Facebook© pages,
blogs, and the world-wide-web, used by all of the mothers as a source of information and
communication.

A greater understanding of the mother’s perception and understanding of the experience
of prenatal and postnatal diagnosis, the treatment and recovery trajectory for her infant and
modified role as mother was gained through the time spent in close communication and shared
interpretation with these mothers. This new insight has the potential to inform neonatal nurses
caring for this high-risk dyad. There were several limitations noted. However, the study provides
a beginning understanding of the essence of being a mother of an infant with LGEA. Through
consecutive open-ended interviews the mothers shared what was important and meaningful to
them during this experience. They were equally interested in communicating with future parents
with a child with LGEA as well as the healthcare community about what they perceived as
critical elements of care.
Implications and Future Research

Nurses are ideally positioned to help mothers fulfill their ideals of being mother. The findings allow for a greater understanding of the essence of these mothers’ distinctive experiences. Nurses must convey knowledge, empathy and compassion for each mother while simultaneously providing care for their fragile infant. Nurses can suggest holistic interventions to promote physical touch, encourage mothers to be in the moment with their infant as they learn their unique attributes and revel in the hope that each new life brings. Generating practice through evidence by examining current care practices can lead to novel interventions that have significance for the intended population (Leeman & Sandelowski, 2012). Personal experiences can customize protocols to refine our knowledge of a particular population. Each person’s personal context and experiences motivates one to behave in certain ways. Ontology is the phenomenology of being (vanManen, 1990). Being in the world as a mother of an infant with LGEA is a multifaceted journey that we now have a greater understanding of and can strive to improve the health outcomes of infants with this rare disease.

Future research should be directed at understanding the contributions of family functioning on the mother’s experience of having an infant with LGEA. Designing interventions to promote successful feeding and measuring the effect on mother-infant interaction and their relationship to NDO is essential to understanding the effect of feeding on mother-infant interaction and how that shapes growth and development. And finally, understanding the contextual factors within the health care system that influence care delivery and utilization, and the impact of social media on access and follow up care is a concept worthy of future investigation.
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