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Exploring the Experience of Foster Parents as they care for children who are making the Transition from the Hospital into the Foster Home

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EXPLORING THE EXPERIENCE OF FOSTER PARENTS AS THEY CARE

FOR CHILDREN WHO ARE MAKING THE TRANSITION FROM THE

HOSPITAL INTO THE FOSTER HOME

BY

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DISSERTATION

Submitted in Partial Fulfillment of the
Requirements for the Degree of

Doctor of Philosophy

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DEDICATION

This research is dedicated to all of the foster parents, past, present and future, who dedicate indescribable amounts of physical and emotional energy towards caring for the most vulnerable members of our society: children with significant health issues who, for whatever reason, do not have a biological parent available to care for them. These vital members of our community are rarely recognized for the work that they do or for the sacrifices they make. They often must endure frequent and challenging situations and struggles that are often due to the complex nature of our child welfare, legal and health care systems. Yet so many of them toil away, working hard to ensure that these unique children are safe and well cared for.

In an era where the attrition rates of qualified foster parents continue to decline, it is hoped that this research will be a part of a growing understanding of what this group of individuals and families are dealing with so that all of those involved in caring for foster children can continue to work together to provide the best care and caring environment for these vulnerable children.

ACKNOWLEDGMENTS

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ABSTRACT

This study explored the perceptions foster parents have about their work as caregivers of foster children who are hospitalized and then discharged from the hospital into a foster home. The numbers of children in foster care nationwide has decreased over the past 25 years, yet the proportion of children in foster care who have significant health conditions has increased dramatically (Wang, Edelstein, Waldinger, Lee & Bath, 2011). There has also been significant attrition of qualified foster parents who are able to care for foster children with significant health needs (Pecora, Whittaker, Maluccio, Barth & DePanfilis, 2009; Vig, Chinitz & Shulman, 2005). The experience of working with these children often begins while the child is hospitalized, yet virtually nothing is known about the experience these foster parents go through in caring for children making the transition.

Eighteen licensed or formerly licensed foster parents in a northwestern state and who had experience caring for a foster child who had been discharged directly from a hospital into their care were interviewed about their experience. Interpretive Description (Thorne, 2008) was used to conceptualize and frame the data elicited from the participants in the study. Following data analysis, thirteen themes and multiple sub-themes emerged within the three basic research questions. There are several important elements to understand about the perceived experience of foster caregivers of hospitalized children: a) they are often motivated by deeply set beliefs, often but not always spiritual, in the sacredness of children and the importance of all children being cared for; b) as much knowledge about any and all conditions, situations, policies etc…is extremely important to the foster parent in making them feel empowered and competent in caring for these children; c) positive communication with key persons such as caseworkers, health care workers and biological parents is a major factor in whether the foster parent perceives this experience as being a positive experience or a negative experience; d) the ability to advocate for the needs of the child in their care is a crucial element to being a successful foster parent of a child who has been hospitalized.

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INTRODUCTION

Currently in the United States, there are approximately 415,000 children in foster care (Administration on Children and Families, 2012). While this is about 25% less than the number of children in foster care 25 years ago, the challenges and demands of caring for children in foster care have increased (Wang, Edelstein, Waldinger, Lee & Bath, 2011). A growing segment of foster children are those children with significant chronic health issues, more often defined as children with special health care needs (CSHCN) (Chernoff, Combs-Orme, Risley-Curtiss, & Heisler, 1994). Children with special health care needs have one or more multiple chronic medical conditions that require higher levels of care and greater coordination between the various health care and child welfare systems that foster children are involved. These children also require higher levels of training and knowledge from their foster parents (Pecora, Whittaker, Maluccio, Barth & DePanfilis, 2009; Heller, Smyke & Boris, 2002; Vig, Chinitz & Shulman, 2005). For many foster parents who work with children with significant health issues, the hospital is the setting where they first meet the child and they are tasked with providing care when they make the transition out of the hospital into the foster home. It is not uncommon for a child with special health needs to come in contact with the Child Welfare System during a hospital admission. Thus, for many foster parents who opt to work with children with significant health needs, they often meet the child for the first time during an inpatient stay.

Researchers have studied foster parents to better understand their needs and experiences (Marcellus, 2004; 2008). While there is increasing research on the needs of

parents who work with foster children with significant medical conditions, there is a gap in knowledge related to the experiences of foster parents who are caring for a child during the transition from hospital to home. This study has been done in an attempt to increase the scant amount of knowledge related to foster parents who work with hospitalized children.

Background/Significance

Health Status of Foster Children

Studies examining the health status of young children (ages 1 to 3 years) entering foster care have documented high rates of both acute and chronic medical problems. In one study, investigators found that 82% of the children entering foster care had at least one, and nearly 29% had three or more chronic medical conditions (Halfon, Mendonca, & Berkowitz, 1995). In another study, more than 90% of children entering foster care had an abnormality in at least one body system (Chernoff, Combs-Orme, Risley-Curtiss, & Heisler, 1994). In a study of over 6000 children entering foster care in one state, Steele and Buchi (2008) found that 54% had at least one acute or chronic health condition when they first came into foster care.

Placement into Foster Care

An important component of any foster placement is the initial period when a child comes into the custody of the child protection system and a foster parent or foster family is recruited to take care of that child for some period of time. In most cases, child protection workers or law enforcement officers are given responsibility for identifying a safe home with competent, licensed foster parents who are able to meet the needs of the foster child (Pecora, Whittaker, Maluccio, Barth & DePanfilis, 2009). If a child has been

admitted to the hospital for care following reports of significant abuse or neglect, or if there are concerns about the ability of the birth parent to care for a newborn infant upon discharge from the hospital, child protection workers are required to investigate. Ultimately it is usually the caseworker who must ensure that the child is safe and will remain safe after s/he is discharged from the hospital. Often this investigation leads to the removal of the child from the custody of their birth parents due to concerns that the parent is the perpetrator of the abuse, has allowed the neglect to occur, or will be unable to care for the child in their home upon discharge from the hospital (Heller, Smyke, & Boris, 2002; Hornor, 2013).

Child Maltreatment

When discussing child abuse or child neglect, the most accepted term is "child maltreatment" (Pecora, Whittaker, Maluccio, Barth, & DePanfilis, 2009). Although each state is responsible for determining the exact legal definition of child maltreatment, the most accepted national definition is: "Any recent act or failure to act on the part of a parent or caretaker which results in death, serious physical or emotional harm, sexual abuse or exploitation; or an act or failure to act which presents an imminent risk of serious harm" (Child Welfare Information Gateway, 2012). In 2010, 81.2 % of perpetrators of child maltreatment were the biological parents of the victim (Sedlak et al., 2011).

It is difficult to accurately quantify the number of children experiencing maltreatment. The most commonly accepted measure of maltreatment is the numbers of referrals local child welfare agencies receive (Pecora, Whittaker, Maluccio, Barth & DePanfilis, 2009). Referrals to local or state agencies regarding concerns about child

maltreatment are usually initiated by family members, teachers, concerned neighbors, as well as nurses, physicians and other health care workers. In 2010, there were approximately 3.3 million referrals to child protection agencies for incidents of child maltreatment (Administration on Children and Families, 2012). Of this number, it was estimated that 2.9 million were actually victims of neglect or abuse (Sedlak, et al.., 2010). This represents about 1 in every 25 children in the United States. Of these victims, 1545 children died as a result of the maltreatment they suffered (Administration for Children and Families, 2012).

Child maltreatment is often the result of problems experienced by their birth parents, including substance abuse, mental health issues, social isolation and domestic violence (Shaffer, Huston, & Egeland, 2008). Adverse environmental conditions such as lack of employment, financial stress, and especially a caregiver being a victim of violence are also risk factors for maltreatment of children (Vig, Chinitz, & Shulman, 2005). Children with disabilities are also vulnerable to maltreatment, both abuse and neglect (Verdugo, Bermejo, & Fuertes, 1995). Despite declines in many types of violence and abuse directed at children and teenagers in the last decade, physical abuse and neglect from adult-instigated victimization (maltreatment) towards children actually increased by 0.8% (abuse) and 0.2% (neglect) between 2003 and 2008 (Finkelhor, Truner, Ormrod, & Hamby, 2010).

While child fatality rate data are available, there are no data on the numbers of children who survive yet need to be hospitalized due to maltreatment. There are data showing that survival rates for children who are involved in any type of trauma,

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accidental or non-accidental, are increasing due to advances in medical technology and improved health care (Johnson & Kastner, 2005; Wang & Barnard, 2004).

When a child is unable to leave the hospital in the custody of his/her birth parents, child welfare personnel must identify foster parents who are willing to care for the child in their home upon discharge. Once recruited, the foster parents often meet the child during the hospitalization. They may have some input into the process or timing of the transition from hospital to their home, but there is scant research devoted to this process. Almost nothing is known about what this experience is like for the foster parent(s).

Neonatal Intensive Care Unit.

Approximately 40% of children in foster care are born prematurely or have low birth weight (Halfon, Mendonca, & Berkowitz, 1995). The potential complications of prematurity are many, including respiratory, neurologic, visual and auditory problems, as well as conditions that lead to poor growth (Vig, Chinitz, & Shulman, 2005). Developmental delays are much more common in infants that are born prematurely.

Premature newborns may be exposed to both legal and illegal substances prenatally that can affect their health. Infants exposed to substances such as methamphetamine, marijuana, barbiturates, and high amounts of alcohol are at a greater risk for premature birth or low-birth weight (Chasnoff, Griffith, Freier, & Murray, 1992). Prenatal substance exposure (PSE) is the preferred term for newborns that test positive for any of these substances (Vig, Chinitz, & Shulman, 2005).

Issues Specific to Foster Children's Health

It is well documented that children who enter foster care have high rates of unmet health needs (Halfon, Mendoza, & Berkowitz, 1995; Simms, Dubowitz & Szilagyi, 2000;

Takayama, Wolfe, & Coulter, 1998). Yet there is also strong evidence that even though

they are placed in foster care, as a group, their health needs continue to be unmet. One

study shows that 32% of children placed in foster care continued to have at least one

unmet health need after 6 months (Halfon, Mendonca, & Berkowitz, 1995). Vig, Chinitz

and Shulman (2005) suggest that one reason for this problem is due to the large number

of medically/developmentally complex children in care. Caseworkers with large

caseloads are unable to keep up with the needs of the children in their custody and may

be delegating more responsibilities to the foster parents. Foster parents may not have the

training or knowledge to effectively work within the systems of care for children with

SHCN. It has also been pointed out that usually, biological parents who have a child that

is born with a significant congenital health issue or acquires a major medical condition

usually have the benefit of a gradual education by nurses or specialized health care

workers (Vig, Chinitz, & Shulman, 2005). Foster parents rarely have that opportunity

when they take a child into their home. These same authors also point out that foster

parents often have little information about the health of the children in their care as

availability of medical records may be difficult for foster parents to obtain.

     Children who are maltreated, whether due to abuse, neglect, or congenital health

conditions following birth, often have significant health needs that require extensive

parent education and specialized medical care (Halfon, Mendoza, & Berkowitz, 1995;

Simms, Dubowitz & Szilagyi, 2000; Takayama, Wolfe, & Coulter, 1998). When these

children are ready to transition from the hospital but are still in the custody of child

welfare agencies, they usually go to live with a foster family until a more permanent

arrangement such as reunification with the biological family or termination of the

biological parents' rights so that a legal adoption can be pursued. Due to the nature of the child's health status, these foster parents assume the roles of case-manager, caregiver, and parent for a period of a few days to several months or longer (Brown & Rodger, 2009; Lauver, 2008; Vig, Chinitz & Shulman, 2005).

Child welfare systems are reporting a loss of competent foster parents at a critical time: when there are more children with complex care needs entering the system. The problem of recruiting and retaining foster parents is significant because there are growing numbers of children who must remain hospitalized longer than previously, sometimes several months, due to the fact that local agencies cannot find suitable placements for these children (DeWitt, Jansen, Davidson, Ward & Keens, 1993; Wang & Barnard, 2004). Not only is this a burden on the financial resources of the health care system, it also adds to the strain on caseworkers working within the child welfare system (Alliance for Children and Families, 2001). High levels of caseworker turnover have been linked to negative outcomes in children involved with the child welfare system, including decreased school performance and higher levels of juvenile incarceration (Wagner, Johnson & Healy, 2009).

Discharge (Transition) to the Foster Home

In recent years, there has been research devoted to foster parents who care for children with SHCN (Blythe, Wilkes & Halcomb, 2013, Brown & Rodger, 2009; Lauver, 2008; Schneiderman, Smith, & Palinkas, 2012). However, the specific challenges of taking a child from the hospital into the foster home and understanding the issues and challenges that present has received scant attention from nurse researchers. According to the Joint Commission, all patients who are discharged from the hospital must undergo

some type of organized discharge planning (The Joint Commission, 2010). Discharge planning has been noted as the primary strategy that nurses utilize to ensure that a patient's needs will be met after leaving the hospital (Coleman & Berenson, 2004). Most hospital based nurses prepare their patients and families for the transition from hospital to home on a daily basis. Yet despite this regular routine, patients and families are often discharged home with unmet home care needs or inadequate education that may often lead to complications or hospital readmissions (Titler & Pettit, 1995; Weiss et al., 2007).

The process of transition from hospital to home is a critical step in the care of a child, yet only a scant amount of previous research has focused on this process as experienced by foster parents. In a time when there is an increase in foster parent attrition, a better understanding of foster parent perceptions of this experience is critical for nurses to be able to meet their needs.

Purpose of the Study

The purpose of this study was to identify and explore the common issues that foster parents encounter as they care for children making the transition from the acute care setting to the foster home. The specific aims were:

1. To describe the experiences that foster parents encounter, such as communication with health care workers and/or caseworkers; navigating child welfare and health care systems; ability to access support services or obtain needed referrals for health care; or changes within their own biological family, as they care for the foster child making the transition from being a patient in a hospital to being a child living in the foster home.

2. To describe experiences that the foster parent considers having a positive effect on their ability to care for the child during this transition.

3. To describe experiences that the foster parent considers having a negative effect on their ability to care for the child during this transition.

Research Questions

The specific research questions for this study were:

1. What are the common experiences encountered by foster parents when caring for a child who is making the transition from the acute care setting to the foster home?

2. What experiences do foster parents consider having a positive effect on their ability to meet the care needs of the child and why?

3. What experiences do foster parents consider having a negative effect on their ability to meet the care needs of the child and why?

Definition of Terms

Children with Special Health Care Needs (CSHCN)

Children who have or are at increased risk for a chronic physical, developmental, behavioral, or emotional condition and who also require health and related services of a type or amount beyond that required by children generally (McPherson, et al., 1998)

Child Welfare

Child welfare is a continuum of services designed to ensure that children are safe and that families have the necessary support to care for their children successfully. Child welfare agencies are often engaged in services that are aimed at preventing child abuse and neglect, investigating reports of possible child abuse and neglect, arranging for children to live with relatives or unrelated foster parents to ensure the safety of children, and

working with families to help reunify the children with biological parents or move ahead with adoption of children (Pecora, Whittaker, Maluccio, Barth & DePanfilis, 2009).

Caseworker

A caseworker is a type of social worker who is employed by a government agency, non-profit organization, or other group to take on the cases of individuals and provide them with advocacy, information or other services. In child welfare agencies, most foster children are assigned a specific caseworker who is tasked with ensuring the safe care of children in state custody (Pecora, Whittaker, Maluccio, Barth & DePanfilis, 2009).

Foster Care

Foster care is a system in which a minor has been placed into a ward, group home, or private home of a state-certified caregiver referred to as a "foster parent". The placement of the child is normally arranged through a government or a social-service agency (Pecora, Whittaker, Maluccio, Barth & DePanfilis, 2009).

Foster Child

A child who has been placed in the legal custody of the state, most often under the auspices of county or state child welfare agency guidelines. This placement is usually done to fulfill a court order or due to some concern for the child's safety (Pecora, Whittaker, Maluccio, Barth & DePanfilis, 2009).

Foster Parent

A person who acts as the primary caregiver for a child placed in foster care. This person is either related to the foster child (kinship) or not biologically related. Most foster parents must go through some sort of training to be licensed by the state, pass a criminal background check, and their home must pass a basic safety inspection. Foster parents are

usually paid a standard monthly fee set by the state to compensate for the child's basic needs such as food (Pecora, Whittaker, Maluccio, Barth & DePanfilis, 2009).

Kinship Placement

The placement of a child with biological relatives, members of their tribe, godparents, stepparents, or other adults who have a family relationship to a child prior to their being placed in foster care (Pecora, Whittaker, Maluccio, Barth & DePanfilis, 2009).

Respite Care

Planned or emergency care provided to a child or adult with special needs in order to provide temporary relief to the family members who are caring for that child or adult (Pecora, Whittaker, Maluccio, Barth & DePanfilis, 2009).

Child Maltreatment

Child maltreatment includes physical, sexual, or emotional abuse, in addition to neglect (where neglect refers to the failure of a parent to provide for a child's development when in a financial position to do so). (Child Welfare Information Gateway, 2012) Federal law defines child abuse and neglect as any recent act, or failure to act, on the part of a parent or caretaker that results in death, serious physical or emotional harm, sexual abuse or exploitation, or an act or failure to act that presents an imminent risk of serious harm to a child. (Child Welfare Information Gateway, 2012)

Prenatal Substance Abuse (PSE)

Prenatal substance exposure occurs when a pregnant woman uses illicit drugs during pregnancy. PSE has potentially deleterious and even long-term effects on exposed children, although the full extent of the harm is not fully understood. Women who take illicit drugs while pregnant are likely to experience other negative factors such as

nutritional deficits, lack of prenatal care, neglect or abuse, and other socioeconomic conditions which make it difficult to determine the direct impact of prenatal drug use on a baby (Kim & Krall, 2006).

Neonatal Intensive Care Unit (NICU)

An intensive-care unit specializing in the care of ill or premature newborn infants. A NICU is typically directed by one or more neonatologists and staffed by nurses, nurse practitioners, pharmacists, physician assistants, resident physicians, and respiratory therapists. (Philip, 2005).

Pediatric Intensive Care Unit (PICU)

An intensive-care unit specializing in the care of critically ill infants, children, and teenagers. A PICU is typically directed by one or more pediatric intensivists or PICU consultants and staffed by doctors, nurses, and respiratory therapists who are specially trained and experienced in pediatric intensive care. The ratio of professionals to patients is generally higher than in other areas of the hospital, reflecting the acuity of PICU patients and the risk of life-threatening complications (Rosenberg & Moss, 2004).

Congenital Health Issue

The word congenital refers to diseases or problems with the body that are present at birth. Congenital problems are commonly referred to as "birth defects". These problems may be genetic, caused by difficulties during pregnancy or the cause may not be known. Congenital problems can range from very minor to severe and life-threatening (Jee, Barth, Szilagyi, & Szilagyi, 2006).

Prematurity

A premature birth is one that occurs before the start of the 37th week of pregnancy. Normally, a pregnancy usually lasts about 40 weeks. Premature babies, especially those born earliest, often have complicated medical problems (Cunningham et al., 2013).

Placement Stability

Placement stability is a measure of how many times a child, usually a foster child, is removed from one foster home (placement) and transferred to another. Placement stability is important for children to develop healthy secure relationships (Leathers, 2002) and serves to reduce the potential stressors that arise from being displaced multiple times. Frequent placement moves not only compounds the issue of being separated from one's parents, but can also result in separation from siblings, relocating to a new geographical area, and experiencing a sense of not belonging; all of which can lead to distress and have a profound negative emotional impact. There is a wealth of research attesting to the importance of sustaining placement stability because experiencing multiple placement changes can have important ramifications for children's development (Leathers, 2002).

Reunification

The process of reuniting the foster child with its biological parent. Most child welfare agencies have policies in place that makes this the primary goal of the child welfare agency when working with foster children. These agencies have many strategies to help achieve this goal, such as family engagement, maintaining family and cultural connections, connecting families to evidence-based services, regular and frequent visits among family members and with the worker, and parent education (Pecora, Whittaker, Maluccio, Barth & DePanfilis, 2009).

Termination of Parental Rights

This is a legal process where the child welfare agency works within the legal system to take away the biological parents legal rights concerning the foster child. This process is usually implemented following a certain period of time where the reunification process has not been successful. Termination of parental rights is often done so that the foster child can be legally adopted by someone other than the biological parent (Pecora, Whittaker, Maluccio, Barth & DePanfilis, 2009).

Chapter 2

LITERATURE REVIEW

This chapter begins with a brief history of the evolution of foster care and several

significant historical milestones. It is followed by a discussion of the research regarding

foster parents and what is currently known about foster parenting with regards to

motivation, retention, and attrition. A third section discusses the current research devoted

specifically towards foster parents who work with children with significant health issues.

The chapter concludes with a discussion of research involving families dealing with the

transition from the hospital to the home environment.

Brief History of Foster Care

Foster care in the United States has roots that begin in the early colonial times.

Based on English Poor Laws that were still followed by early American colonists in the

late 1600s, children who were impoverished or neglected were usually ordered into

indentured servitude to some sort of craftsman or businessman until they were 21 years

old (Everett, 1997). Although this was sometimes referred to as "substitute care," this

was more of a system of indentured servitude, or slavery. In this era, biological parents

would offer their children into this system due to their poverty or inability to care for

their own children (Hasci, 1995). There was no organized system of monitoring the care

of any of these children and abuse and neglect was rampant and widespread.

The social acceptance of giving up children to others who might provide food and

shelter made for conditions that allowed the development of almshouses. Almshouses

were homes or institutions that housed most orphaned children as well as mentally ill

persons, prisoners, and the impoverished (Hasci, 1995). The majority of the orphaned

children of this era were still enslaved in some type of indentured servitude, and the conditions of the almshouses varied tremendously. Most agree that the children living in these places were "warehoused" in conditions that were fraught with hunger, physical and sexual abuse, and almost no state or federal guidelines advocating for any type of standard that focused on the needs of the children (Hasci, 1995).

In the early 1830s, the development of orphanages began to take place, mostly in the eastern U.S. (Everett, 1997). These orphanages would accept children who had conditions such as blindness, deafness, or being homeless after running away from their biological parents. Most orphanages still participated in some form of indentured servitude, but this type of system was beginning to be criticized by organizations that advocated for children. One of these critics was Charles Brace who, at the time, was a leading advocate for children's rights in New York and the founder of the New York Children's Aid Society (Hasci, 1995). Many still consider Brace to be the "father" of the modern foster care system in that he advocated for children who needed care to be placed in homes, not housed in large buildings with many other children and adults with little or no nurturing and individual attention. He and others are credited for effectively ending the orphanage system in the United States. Although many consider this a positive step in the evolution of the foster care system, it should be noted that for many reasons, including a lack of families willing to take in these children, Brace also initiated the first organized system of "placing" orphaned children with families in other states, mostly in the midwest, west and southern United States. This was the start of what would eventually be known as the "orphan trains" and it became a source of free labor for many farmers and ranchers in the mid-west and western areas of the United States (Hasci,

1995). Eventually there became such a demand for this labor force that children's organizations, including Brace's own Aid Society, would hire agents to "sweep" urban streets looking for poor children who would not be missed by their parents or use their extreme poverty to justify to local police how better off these children's lives might be if they were working on a farm. These children would be picked up at the train stations along the routes and families would take the children they needed. There was rarely any effort to screen families who might abuse children and no organized effort to try to keep siblings together (Hasci, 1995).

Eventually, in the early to mid-1900s, critics of this system began to influence change in how society cared for children who needed care outside of their biological families. A primary driver of change came about with the publication of the book *Children in Need of Parents* by Mass and Engler in 1959. They described the national foster care system at the time as a "holding tank," with little or no regard for the needs of the child. They described a system that was based mostly on the whims of the current moral and religious demands of the local community and the lack of standards or basis for policy that was directed at improving the lives of the children being served (Everett, 1997). This exposé of the foster system became a driving force for change at the federal level. Policies in states began to change as well with an increased focus on the safety and protection of the child. There was also an increase in the development of permanency plans. The plans were developed with the goal of having the child reunified with their biological parents or removal of necessary barriers to the adoption process so that children could be placed with adoptive parents who had to meet established standards to be candidates (Everett, 1997).

Among the most important policy changes during this period was the passage of the Aid to Families with Dependent Children (P.L. 87-31, 1935) act. This law was the first federal legislation that established criteria for what was required to remove children from biological homes (Allen & Bissell, 2004). The law also established a federal payment system for foster home care, which quickly led individual states to establish definitions of foster care/homes and criteria for receiving these payments (licensing). Another important piece of legislation in the development of the current foster system was the Child Abuse Prevention and Treatment Act (P.L. 93-247, 1974). This law requires professionals, mostly those who work with children, to report suspected child abuse and neglect. This led to increases in reports of abuse and neglect, with minimum standards established in states for safety and providing care for children (Allen & Bissell, 2004).

One other important piece of legislation was the Adoption Assistance and Child Welfare Act (P.L. 96-272) of 1980. In addition to ensuring continued funding for foster parent programs nationwide, this law also established priorities for child welfare agencies to make good faith efforts to keep families together (Everett, 1997). If child welfare agencies needed to remove children, the new law established safeguards for the types of placements that child welfare agencies must adhere to; foster homes must be the least restrictive environment possible. This virtually eliminated orphanages from the U.S. and significantly reduced the number of children who were placed in institutions.

Foster Care Today

Today's foster care system has evolved from one that treats foster children as the property of adults with almost no rights into a system that gives them many local

protections. The goal is to give children substitute care in a family setting whenever their own families are unable or unwilling to provide the care needed (Crosson-Tower, 2003). Foster care provides: (1) emergency care for a child on a temporary basis; (2) temporary help for a parent who needs it due to stress; (3) the necessary time, within reason, for a parent to solve problems due to lack of housing, addiction, mental illness, poverty, and so on; (4) protection for a child until an institutional placement becomes available; and (5) care until a child can be placed in a permanent situation, such as adoption, or the child becomes an adult (Crosson-Tower, 2003). While there are instances where parents voluntarily give up their children to local agencies, the vast majority of foster placements are initiated by child welfare workers when allegations of abuse or neglect arise and an investigation has revealed that the safety of the child or children is in question (Martin, 2000). This includes medical neglect. Children with serious health issues and a need for skilled care require foster care when their biological parents are unable or unwilling to meet the medical and health needs of their child. Although difficult to determine due to incomplete data sets and differing state standards, there is a growing consensus that the number of children coming into foster care solely due to health issues not being met is growing nationwide (Jee, Barth, Szilagyi, & Szilagyi, 2006; Steele and Buchi, 2008; Vig, Chinitz & Shulman, 2005; Wang, 2004).

The average length of placement for a child in foster care is 30 months (Administration for Children and Families, 2012). There is rarely, if ever a "typical" foster placement as multiple factors affect the length of stay for children. One of the most important is the availability of a quality foster home. Because of the nature of child welfare investigations of abuse or neglect, children often go into foster care without any

forewarning to the system. Therefore, child welfare workers often need to identify a

foster home quickly to serve as a temporary crisis home, also defined as a shelter home

(Pecora, Whittaker, Maluccio, Barth & DePanfilis, 2009). Foster parents who agree to

provide this type of "on-call" care usually agree to shelter and care for children for a

short period of time; perhaps 24 to 72 hours until the child welfare worker can find a

long-term foster home. This longer term foster home might be a relative (kinship)

placement with biological relatives that need to be screened for licensing purposes or

close friends of the biological family. Kinship placements or placements involving adults

known to the children in care are almost always the preferred choice for child welfare

agencies when possible (Martin, 2000). If this type of placement is unavailable, children

are usually placed in a "traditional" foster home, that is, a home with a licensed foster

parent or parents who have met state requirements to care for children. This often

involves some type of pre-service training prior to caring for children, but there are

currently no national standards for this (Pecora, Whittaker, Maluccio, Barth &

DePanfilis, 2009). If needed, foster placements may occur in some type of group home

or institution. Although not as desirable, these placements are sometimes necessary due

to limited availability of foster homes or lack of foster parents who are willing or able to

address the specific behavioral, mental, or physical needs of the child (Pecora, Whittaker,

Maluccio, Barth & DePanfilis, 2009). This is especially true of children with serious

mental health issues. Nationwide, about 9% of foster children reside in these types of

placements (Martin, 2000).

Foster Parenting

Foster parenting in the U.S. has been described as a mostly volunteer effort (Pecora, Whittaker, Maluccio, Barth & DePanfilis, 2009). While most states have systems in place to reimburse foster parents for expenses incurred and many have regular financial payments in place to distribute to parents while they care for foster children, these dollar amounts very rarely cover the true financial burden foster parents incur. Rarely do states offer payments at levels that would make foster parenting economically feasible. Interviews of foster parents reveal that lack of adequate reimbursement is a major contributor to foster parent attrition (Barth, 2001; Chipungu & Bent-Goodley, 2004). Most foster parents decide to take on this responsibility because they want to help children have a safe home (Isomaki, 2002). Other reasons for fostering include altruistic motivators like empathy, love, generosity and a "sense of duty" often based in religious beliefs or spirituality (Farmer, Lipscombe, & Moyers, 2005; MacGregor, Rodger, Cummings, & Leschied, 2006).

The reasons foster parents end their service as caregivers fall into two categories: natural and unnatural (Fees et al., 1998). Natural reasons include age, poor health, adoption, birth of new children into the home, divorce, or relocating to a new area. Unnatural reasons are things such as dissatisfaction with the role of a foster parent, conflicts with the local child welfare agency, feelings of being unable to adequately care for foster children, and feeling unsupported in the role of a foster parent. The following paragraphs discuss these issues.

Role. There are notable challenges to recruiting foster parents. In addition to limited financial resources available to potential foster families, additional factors such as

a greater number of women working outside of the home than in the past, higher housing costs, and a negative public image of foster parenting have been noted as contributors to a smaller pool of foster families (Barth, 2001; Chipungu & Bent-Goodley, 2004; Martin, 2000). There has been some discussion in the literature about the role of foster parents and how to increase the number of available homes. Studies indicate that foster parents are conflicted in defining their role and either identify themselves as professional caregivers or as parents to the children they care for (Broady, Stoyles, McMullan, Caputi & Crittenden, 2010; Hudson & Lavasseur, 2002; Kirton, 2001).

In a series of interviews of 20 experienced foster parents, Kirton (2001) explored the motivations of these caregivers in terms of professional versus parent. One of the main themes expressed by participants was a strong correlation between length of time caring for foster children and identification as a parent versus a professional. In other words, the longer a foster parent worked with an individual child, there becomes less of a concern about reimbursement and financial issues and more of a concern about the child's developmental and educational needs. Kirton (2001) found that intrinsic parenting motivators become stronger when foster parents reported placement durations of 12 months or longer. This same correlation has been noted by others (Broady, Stoyles, McMullan, Caputi & Crittenden, 2010).

Other studies have shown that individual foster parents continue to struggle with their role being either a "transitory parental role" or more of a professional caregiver who is simply assisting the local child welfare caseworker (Picken, Brunsden & Hill, 2011). The feelings of being a parent or a professional were personal to each individual. Motivations for fostering children such as their sense of duty to their community,

religious motivators, and financial status were factors that played into the individual's role perception. It is important to note that regardless of the perceived role that a foster parent has, a lack of acknowledgement from caseworkers regarding the foster parent's perceived role has an impact on the foster parents' self-esteem and emotional well-being (Broady, Stoyles, McMullan, Caputi & Crittenden, 2010).

Personal Characteristics. Foster parents are a diverse group of individuals and families and generally reflect the demographics of their local communities (Pecora, Whittaker, Maluccio, Barth & DePanfilis, 2009). Although there are concerns about the number of minorities being available as foster parents, demographic characteristics of foster parents are often an accurate representation of the local community. Research has shown a link between personal attributes such as love, understanding, and patience and positive child outcomes such as increased placement stability of foster children (Buehler, Cox, & Cuddeback, 2003; MacGregor, Rodger, Cummings, & Leschied, 2006). Having a strong altruistic nature and motivators that are intrinsically personal were noted in interviews with foster parents in Tennessee (Buehler, Cox & Cuddeback, 2003). This was especially important in the decision to continue to foster when stressful events or challenging situations presented themselves.

The ability to identify some sort of personal support system, through family and friends, has also been identified as an important personal characteristic of foster parents. Interviews with experienced foster parents have shown that, when asked specifically about personality characteristics, being able to utilize or organize support systems to help with stressful situations is second only to parenting experience in ranking important attributes (Brown & Calder, 2000; Farmer, 2005; Samrai, Beinart, & Harper, 2011). The

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composition of these networks of support is also important. A study of 304 foster parents

in 39 states revealed that foster parents who relied solely on biological family members

for support while fostering children were more likely to have significantly shorter tenure

as foster parents when compared to foster parents who incorporated friends and other

members of the community, such as church leaders, into their support network (Orme,

Cherry, Rhodes, 2006).

Another important self-identified personal characteristic of foster parents is an

ability to work within complex systems. Buehler, Cox and Cuddeback (2003) found that

when foster parents were asked to identify important personal factors of success in

fostering, both flexibility (*n =13;* 59%) and being organized (*n* = 11; 51%) were ranked

as important. Further exploration through a series of focus groups found that most foster

parents interviewed felt this combination of traits was important in regards to being able

to navigate the various child welfare and legal systems that foster parents deal with as

well as providing safe, consistent care for children who are affected by these systems.

Other studies have also demonstrated this theme of "flexibility within organized

structure" as an important characteristic of a quality foster parent (Brown & Calder,

2000; Brown & Rodger, 2009; Lauver, 2008).

Foster Parents in the Foster Care System

Working within the foster care system itself has been identified by foster parents

as being, at times, more stressful than caring for the child (Buehler, Cox & Cuddeback,

2003). Foster parents have described many stressors associated with working within

child welfare systems, including conflicts with caseworkers, placement changes outside

the control of the foster parents, difficulty with financial reimbursement, and lack of

services, especially support services. In a series of focus group interviews followed by individual interviews with foster parents, Broady et al. (2010) found that the relationship a foster parent perceived with his or her caseworker was central to their feelings of satisfaction with the experience and a major determinant as to whether they planned to continue fostering children in the future. This group of 12 foster parents felt that when they lacked trust or confidence in their caseworker, problems (as perceived by participants) would generally ensue. They also expressed a need to rely on their support networks or personal stress relief methods when they felt that they could not trust their caseworker or that there were "problems within the system" that would affect them. These problems included high turnover of caseworkers, miscommunication about available support or obligations of the foster parents, and issues that affected the stability of the system for the foster parents.

Hudson and Lavasseur (2002) found that a lack of respect from caseworkers and members of the child welfare system was a major source of stress.   Foster parents who answered an extensive questionnaire about their perceptions of support from the agencies they worked with expressed extreme dissatisfaction from things such as not being included in important decisions about the care of the foster child, not having phone calls returned promptly, or being blamed for something that was out of their control. More experienced or "veteran" parents seemed to rank this perceived dissatisfaction at a lower level of importance than less experienced or younger foster parents (Hudson & Lavasseur, 2002). In their discussion, it was postulated that there might be an inherent trait in the veterans that allowed for higher tolerance of system instability or dysfunction. Perhaps this personal trait was a factor in why they persisted as foster parents.

A series of focus groups comprised of 54 experienced foster parents found that a lack of organized support from local child welfare agencies and miscommunication with caseworkers were the strongest sources of dissatisfaction with the foster care experience (Brown & Rodger, 2009). These foster parents described feeling supported by local child welfare agencies when they had a positive relationship with caseworkers, which were described in terms such as honest communication, respect (example: prompt return of phone calls), and being solicited for opinions regarding important decisions related to the children in care. A negative relationship was described as feeling disrespected or poor communication. Participants also noted that high turnover of staff was a consistent source of stress. Most participants felt that it takes time to build trust with a caseworker and new workers need time to build relationships with foster parents. This group of foster parents also felt that their confidence in the system could be eroded when they were not informed about the condition of the child or even intentionally mislead by caseworkers when agreeing to foster certain children. This was described as a very important factor in deciding to continue to foster (Brown & Rodger, 2009). Other studies also indicate that high turnover of caseworkers can affect the feelings of support or confidence in the system as perceived by foster parents (Murray, Tarren-Sweeney, & France, 2011; Samrai, Beinart, Harper, 2011).

Foster Parenting Children with Health Issues

Numbers

Advances in health care procedures and technology are allowing more children with congenital or acquired health issues to survive long stays in the hospital. Between 1980 and 2011, death rates for children ages one to four dropped from 64 per 100,000 to

26 per 100,000 (DeVooght, Child Trends, & Blazey, 2013). However, this decrease in

mortality has increased the number of children living with chronic health issues (Perrin,

Bloom, & Gortmaker, 2007). The National Survey of Children with Special Health Care

Needs (2009/10) survey found that 27.1% of U.S. children have a health condition that

consistently affects their daily activity. The families of these children reported that the

condition caused financial problems (21.6%) and that they had to cut back hours or stop

working (25%).

Foster children have traditionally had much higher rates of chronic health issues

than children who are not in care (Halfon, Mendoza, & Berkowitz, 1995; Simms,

Dubowitz & Szilagyi, 2000; Takayama, Wolfe, & Coulter, 1998). When foster children

come into the system, between 35% to 45% have at least one chronic health condition;

10% have at least one complex condition that requires medication or frequent follow-up

care from a specialist (Szilagyi, 2012). Conditions range from significant developmental

delays to major mental health issues. Foster children with chronic health conditions

requiring specialized treatments, medications, and coordination of home health care

givers to come to the foster home for care such as specialized feedings or complicated

respiratory therapy have also been noted in about 8% of children (Kools & Kennedy,

2003; Steele & Buchi, 2008; Szilagyi, 1998). Central to the health and safety of these

foster children is the knowledge of the foster parent but there is limited research specific

to their needs with respect to dealing with these health issues.

Placement Stability

Placement stability has been described in the literature as an important measure of

a quality outcome in the child welfare system (Pecora, Whittaker, Maluccio, Barth &

DePanfilis, 2009). Children are much more likely to have their developmental needs met

and have better outcomes related to behavior management and school attendance when

they stay in one foster home versus move to several. Rosenberg and Robinson (2004)

examined data from over 105,000 children in 47 states using the Adoption and Foster

Care Analysis and Reporting System (AFCARS) database. This study revealed that

children with at least one chronic health issue were 22% more likely to have more than

one foster placement during their time in foster care when compared to foster children

who had no health issues.

Challenges

In breaking down the specific health issues and referral needs of 149 children

coming in to foster care, Hochstadt, Jaudes, Zimo and Schachter (1987) noted a

correlation between foster children having increased levels of needed follow-up care and

the experience levels of foster parents. Foster children who were placed with foster

parents with previous experience were more likely to keep appointments with

subspecialists when compared to children placed with relatively new foster parents.

Foster parents have described negative experiences in working with children with

SHCN. These include feelings of frustration and incompetence in dealing with specific

tasks involving medical needs, stress in dealing with the child's behavior, and frustration

with both the health care and child welfare systems (Brown & Rodger, 2009; Lauver,

2008; 2009). The concept of "being committed" to caring for and meeting the health

needs of a child in foster care was identified as an important factor when choosing to

work with children with SHCN (Lauver, 2008). Participants in this qualitative study

expressed how important the level of commitment was to be able to do this type of work.

This was important when challenges such as time management, meeting the needs of their own biological children, and dealing with various system issues such as miscommunication with caseworkers or health care providers caused stress and anxiety (Lauver, 2008).

Health Care Access

A study of 77 children who were adopted after spending time in foster care noted that these children often had had difficulty obtaining needed health care while in foster care. The results of surveys obtained from child welfare caseworkers noted that getting access to health care was a significant factor in being able to recruit foster parents as well as finding appropriate permanent homes following termination of biological parent's rights leading to a search for a permanent home for the child (Avery, 1999).

A study of 25 foster parents in southern California found that parents were often turned away from physician services due to the fact that the clinic would not accept Medi-Cal, the state's form of Medicaid (Schneiderman, Smith & Palinkas, 2012). The parents expressed similar frustrations with obtaining dental care for these children for the same reason. Even so, this group of parents did not express concern over these barriers to access to health care for the children, which is a different finding than other studies (Lauver, 2008; Pasztor, Hollinger, Inkelas, & Halfon, 2006). However, this particular group did discuss the importance of social support and the authors of the study speculated that the increased awareness and presence of family support as well as an increased level of formal networking amongst the foster parents helped reduce the perception of transportation and access being a barrier (Schneiderman, Smith & Palinkas, 2012).

Lauver (2008) identified the inability to access needed medical services for foster children in their care as one of many sources of frustration in caring for a SHCN child. These parents also identified lack of access as a significant factor in seeking out help from support networks such as friends, family and caseworkers. Further research identified a lack of access to needed medical care as the most common theme expressed by participants ($n = 10$) (Lauver, 2009). These families all resided in rural locations in the northeast and it came as no surprise that lack of transportation to the limited number of available medical providers was also an issue.

A mixed-methods study of child welfare agencies in 11 states revealed that foster parents felt that access to needed health care was a constant struggle (Pasztor, Hollinger, Inkelas & Halfon, 2006). These parents described frustration in being expected to find a doctor or medical services with minimal assistance from caseworkers. They also described strategies to overcome this barrier, such as utilizing all previous relationships with local medical providers. It was noted that foster parents who had a previous relationship with a specialty provider, either because of their own biological children or previous foster children, did not rank access as significant compared to foster parents with little or no previous contact. Another finding was the issue of physicians not being willing to work with foster children with significant medical issues due to the complexity of the cases, lack of Medicaid reimbursement, and fear of having to testify in court (Pasztor, Hollinger, Inkelas, & Halfon, 2006). Both foster parents and caseworkers, in multiple, separate interviews, expressed these concerns when describing the access issues of working with foster children with SHCN. This study also found that a common strategy of obtaining needed services was to simply go to the hospital emergency room in

the hopes of obtaining a referral for services that might otherwise have been obtained

through a primary care visit (Pasztor et al., 2006). This strategy has been identified by

other researchers as well (Lauver, 2008; Schneiderman, McDaniel, Xie, & Clark, 2010).

Training Issues

In an analysis of 313 foster parent responses to a study dealing with pre-service

training, Fees et al. (1998) found that participants ranked the quality of the training as the

most important factor in feeling satisfied with the actual experience of foster parenting.

Other studies have shown that the training, education or preparation of foster parents, or

lack of specific training related to caring for children with health issues has been

identified as a concern.

A study of 120 children in foster care noted that the "limited experience" of foster

mothers was a significant factor in the placement stability of children with health issues

(Horwitz, Owens & Simms, 2000). Risley-Curtis and Kronenfeld (2001) noted that 37%

of the state child welfare systems ($n = 46$) that participated in their study had any content

related to health issues in the required training for becoming licensed foster parents or

homes. None of the agencies surveyed had any requirement for additional training

following the initial phase. Additionally, 52% of these child welfare systems had no

specific delegation requirements for foster parents when coordinating care. In these

systems, caseworkers and foster parents had no policies or standardized procedures to

follow when assigning responsibility for health care related home care, transportation, or

case management of the foster child's health care (Risley-Curtis & Kronenfeld, 2001).

Other studies have noted that foster parents express how critical it is for those

who work with children with SHCNs receive specific training. Foster parents have

described this training as "critical to being able to care for the children" as well as important in being able to "screen out" potential foster parents who do not possess the capacity to work with the foster child with SHCN and also to be able to work within the system(s) of child welfare and health care (Pasztor, Hollinger, Inkelas, & Halfon, 2006, p. 50). Brown and Rodger (2009) found that foster parents "need to know all about the child's health issue(s) to be effective caregivers." (p. 45). The foster parents in their study not only described this knowledge to be important for the care of the child, they also verbalized the importance being able to the biological parents how to care for their child if and when the child was to be able to return to his/her biological home.

Lauver (2008) heard from foster parents about feelings of anxiety and fear when a child with a significant health issue was first placed in the foster home. They expressed that it took time, often many months after an initial placement, before they would feel confident in performing tasks such as tube-feedings or medication administration. The theme of "on-the-job" training, through Internet resources or consults with home health providers was common. Many of these foster parents described feelings of inadequacy in meeting the child's needs and that they would feel much more confident and prepared when they engaged in their second or third placement of a child with a SHCN.

Schneiderman, Smith and Palinkas (2012) found from their foster parent participants that, as a group, they felt that specific training helped, but they learned much more after actually working with the child. They also discussed how much they often learned about pathophysiology from physicians. Of note, foster parents felt that they learned much more from nurses about the child they were caring for when compared to how much they learned from their individual caseworker (Schneiderman et al., 2012).

A qualitative study involving 54 foster parents participating in focus group discussions revealed that even though the vast majority of participants felt that their training was excellent, many felt that there still needed to be more specialized pre-service training involving caring a child with a SCHN (MacGregor, Rodger, Cummings, & Leschied, 2006). Many expressed a desire for other foster parents to provide the actual training, not the caseworkers who "aren't actually dealing with kids." (p. 361). This issue came up as part of the discussion of these foster parents' descriptions of their need for support.

Child Welfare Agency Support

Training opens doors to networking and social support with other foster parents caring for SHCN. In response to a 12-page questionnaire, an analysis of the responses from both foster parents and caseworkers found that many foster parents perceived that their most important sources of support started from the connections that they made with other foster parents during their pre-service training (Hudson & Levasseur, 2002). The most consistent theme of "need for support" involved monetary needs but more than half of the participants ranked "having the support of other foster parents" equally or more important than having additional money from local child welfare agencies (Hudson & Levasseur, 2002). Foster parents report that feeling supported by doctors and nurses while caring for children is equally important as the support they feel from local child welfare agencies (Brown & Rodger, 2009). Lauver (2008) noted that foster parents of children with SHCN frequently rely on their spouse as a significant source of support. Note that the sample in this study consisted of 10 foster mothers and 3 foster fathers and lacked any single (non-married) participants (Lauver, 2008).

Respite Care

Foster parents working with children with SHCN have described the availability of respite care as an important aspect of support. Two studies have documented foster parents describing the importance of taking time to be away from the stress and demands of these children as well as making time to engage with their own biological family (Lauver, 2008; Schneiderman, Smith & Palinkas, 2012).

Lauver (2008) reported that foster parents working with children with a SHCN have frequent concerns about their ability to find qualified respite care workers. These foster parents made it clear that respite care was essential for them to be able to rest and restore themselves, yet they also stated that very often, they (the foster parents) were the ones who were ultimately responsible for finding qualified families who could care for their foster child if needed, not the caseworkers who usually are tasked with this duty. For many of these foster parents, this added to the stress they felt in meeting the foster child's needs. These same foster parents also expressed a similar frustration in being able to find qualified home health nurses. The shortage of nurses and high turnover rate of nursing staff added to the "roller coaster-like" feeling of never knowing what might happen next, due to the unreliability of knowing when any sort of dependable respite care would come (Lauver, 2008, p. 50).

Another qualitative study of foster parents working with children with a SHCN ranked the caseworker, family and friends, and then specialized support groups within the California child welfare system as the primary sources of support (Schneiderman, Smith & Palinkas, 2012). These foster parents described how critical they felt that the relationship between the foster parent and the caseworker is in determining the quality of

the experience. Caseworkers need to be trustworthy with information sharing and available when contacted, as described by the foster parents.   Having access to support groups was described as being an important factor in feeling like they were not alone in caring for the foster child. Foster parents have reported that they rely on support groups such as these for important information related to home health care and referrals more than the actual caseworker (Pasztor, Hollinger, Inkelas & Halfon, 2006; Vig, Chinitz, & Shulman, 2005).

Complexity of Systems

One issue that is seen throughout the literature is the challenge of dealing with complicated health care and child-welfare systems on a daily basis. This has been identified as a significant issue by both caseworkers, foster parents, and nurses (Brown & Rodger, 2009; Lauver, 2008; Lerret, 2009; McCarthy, 2002; Pasztor, Hollinger, Inkelas & Halfon, 2006).

An examination of 73 different child welfare systems in 35 states identified communication breakdowns, delays in obtaining adequate Medicaid coverage, and delays in scheduling needed services as being a direct result of complexities contained within both the child welfare and health care system as well as the "cross system" challenges (McCarthy, 2002). Foster parents and caseworkers involved in this study identified limited resources, high turnover of social workers, inconsistent knowledge of health issues among social workers, and poor communication between social workers and foster parents as significant issues within the child welfare system. This study also identified systemic issues within the health care system that affected foster parents (McCarthy, 2002). These included an insufficient service capacity, low reimbursement rates for

Medicaid providers thus affecting the foster parent's ability to obtain needed services, and a lack of understanding by health care workers about the unique legal and custody issues of foster children. These factors were identified as having a significant impact on foster parents and their role as caregivers of children with SCHNs. The primary issue in the discussion of "cross system" challenges revolved around communication (McCarthy, 2002). This included poor communication between caseworkers and health care providers leading to role confusion amongst foster parents. Confidentiality issues stemming from confusion about legal custody and unclear policies about sharing of medical information were issues that this study identified as affecting foster parents (McCarthy, 2002).

Lauver (2008) identified systemic issues as a constant challenge to foster parents. In addition to the previously mentioned issue of obtaining their own home health care, participants often expressed frustration with communication breakdown within the two systems. Many of these parents found that they were suddenly thrust in the role of case manager for the health care due to the lack of communication or perceived inadequacy of the caseworker to meet the child's needs. Foster parents in this study verbalized a need to "step up" and be assertive or demanding than they had been in the past if the needs of the foster child were to be met. This included obtaining health care services for the child as well as working with the doctors and nurses when services were provided. Interestingly, many of these foster parents discussed the frustration of being "ignored" or "treated as second class" by the health care workers with whom they interacted (Lauver, 2008, p. 91). This phenomenon was also described in other studies (Pasztor, Hollinger, Inkelas & Halfon, 2006; Vig, Chinitz, & Shulman, 2005). Lauver (2008) also learned

from her participants that their perception of the importance of advocating for the child due to systemic complexity was more important in the eyes of those that had been providing foster care for a longer period of time.

Similar themes were noted by Brown and Rodger (2009) in their study of foster parents who work with foster children with disabilities. The participants ($n = 83$) identified the importance of advocating for information from caseworkers or obtaining medical records as part of being a successful foster parent. Parents noted that advocacy is important with statements such as, "you MUST advocate for the child with the medical system, schools and the birth family" or it being necessary to "be a pain in the butt to get health services for your child" (Brown & Rodger, 2009, p. 42).

Schneiderman, Smith, and Palinkas (2012) found that being an advocate for the needs of the foster child with SHCNs was the most important aspect of caring for the child. The participants listed the complexity of the child welfare and the health care systems as the primary reason for the need of such advocacy. According to most of the foster parents, children in their care would not have their medical needs met or might even suffer some type of negative outcome were it not for their ability to navigate complicated systems and deal with or anticipate problems. Examples included being able to circumvent written protocols when needed or having key medical providers offer support in cases of conflict between caseworker and foster parent (Schneiderman et al., 2012). Being able to obtain needed referrals despite not getting them through traditional means, making daily phone calls, and stocking up on supplies or medications were also listed as necessary skills. The ability to master these challenges increased with the experience of the foster parent.

Pasztor et al., (2006) found that foster parents verbalized a need for a previous relationship with health care workers prior to the placement of a foster child with a SHCN. This relationship was vital in being able to obtain needed services that the foster parent felt the foster child needed, yet they often felt that they could not obtain them by going through traditional channels.

Communication with Caseworkers

McCarthy (2002) identified communication between health workers, caseworkers and foster parents as essential in meeting the needs of a foster child with SCHNs. Yet most research identifies communication problems between caseworkers and foster parents as a significant issue. Brown and Rodger (2009) found that foster parents expressed communication problems as both rampant and significant. Many of the 84 participants in this study voiced frustration with the social workers they dealt with in regards to having adequate communication. These participants noted that they often waited many days for a phone call to be returned or caseworkers not discussing important care needs of the child prior to placement. The foster parents often attributed this to "social worker burnout" or a lack of training or resources for the social workers. The participants also identified a need to "pick your battles" with caseworkers regarding communication breakdowns if they were to maintain adequate channels of communication in the best interest of the foster child.

Knowledge of the Child's Condition

There can also be confusion regarding the extent of a child's medical issues prior to accepting a foster parenting assignment. Lauver (2008) found that many foster parents of children with SHCN reported that they felt either unprepared for the extent of the

child's condition or given inaccurate or even deceptive information by caseworkers when discussing the child's health status prior to the assignment. Pasztor et al., (2006) reported similar issues. Participants stated that it was sometimes difficult to differentiate information that the caseworker knew, but did not share with the foster parent versus information that the caseworker did not know. The most glaring example of a lack of communication was a story, related by a participant, of a baby who was dropped off at the foster home by a caseworker, who then left rapidly. The baby was dressed in a snowsuit (it was winter) and when the foster parent undressed the baby, it became immediately apparent that the infant was in a full body cast. This information had not been discussed by the caseworker prior to or during the delivery of the foster child (Pasztor et al., 2006).

Financial Reimbursement

The financial costs of caring for a child with a SHCN has been well documented (Jeffrey & Newacheck, 2006; Kuhlthau, Hill, Yucel & Perrin, 2005; Newacheck, Inkelas, & Kim, 2004). But despite this need for additional financial resources, there is often a "less than adequate" financial reimbursement system in place for these parents which has been described as a disincentive to continue to work with foster children with SHCNs (Avery, 1999). Brown and Rodger (2009) noted that many of the participants described inadequate financial reimbursement as a major factor in deciding whether to continue to foster or not. Participants made note of the fact that there are often additional, unexpected financial needs when caring for children with disabilities or health issues and that reimbursement for these unplanned expenses is frequently delayed or absent. It therefore falls onto the foster family to absorb the expense (Brown & Rodger, 2009).

Pasztor et al., (2006) also described feelings of frustration from foster parents who care for children with SHCNs regarding financial reimbursement. Many participants described "feeling unsupported financially" as a major factor in deciding whether to continue to care for foster children in the future. This group listed expenses such as clothing and shoes as being unreimbursed; however, the primary expense this group of participants noted as the most troubling was having to pay for medications for their foster children.

Transitioning from Hospital to Home

Support

Parents of children who are being discharged from a hospital desire both detailed information about the condition of the child as well as support in dealing with his or her care needs (Snowdon & Kane, 1995). This perception of support is a very individualized variable and not easy to measure (Affleck, Tennen, Rowe, Roscher, & Walker, 1989; Wong, 1991). The level of support a parent requires may not necessarily correlate with the child's level of illness. This means that while a child may have significant medical issues and intense home care needs, the amount of support that is needed is often affected by factors such as the educational level of the parent, the social network or systems that a parent is involved in, and the financial resources a family has access to (Bent, Keeling, & Routson, 1996; Snowden & Kane, 1995; Weiss, Johnson, Malin, Jerofke, Lang, & Sherburne, 2008).

Education and Teaching of Parents

Having adequate knowledge of a child's medical condition and specific care needs has been well established as an important aspect of parents' perceptions of their

ability to adequately care for a child during transition from hospital to home. Studies of parents who take infants with SHCNs from the hospital have documented their concerns about what might happen when they leave. These fears range from not having the ability to meet the child's medical needs (Baker, 1991) to concerns about being competent or prepared adequately to deal with their child's condition (Bent, Keeling, & Routson, 1996).

Bent, Keeling and Routson (1996), through interviews with parents of children recently discharged from the hospital, found that having an adequate knowledge of the child's condition was the most frequently cited primary concern.   Parents who voiced frustration with the discharge process often cited a "lack of time" by the health care staff or not being able to talk to the child's physician at the time of discharge as a significant factor in feeling prepared or confident in being able to meet the care needs of the child once they went home.   Parents also reported a reduction in anxiety about caring for the child immediately after coming home from the hospital when their unique educational needs, such as their schedule, level of education, and teaching specific to the medical condition of the child, are met (Smith & Daugherty, 2000). Research involving children with chronic health conditions has demonstrated that specialized education programs can significantly reduce hospital readmission rates (Sheikh, O'Brien, & McCluskey-Fawcett, 1993; Wesseldine, McCarthy & Silverman, 1999).

Communication

Communication during the discharge process is a major element in determining whether parents feel ready to care for their children's medical needs at home. The quality of the communication between parents and nurses about the child's needs following the

transition to the home has been described as the essential component of determining if it is successful (Anthony & Hudson-Barr, 2004). A study involving 135 parents of hospitalized children found that the parent's perception of the quality of the nurse's discharge teaching was the primary factor in predicting coping difficulty during the first three weeks following discharge (Weiss, Johnson, Malin, Jerofke, Lang, & Sherburne, 2008). This quantitative study used established scales to determine both the parents "readiness" for discharge as well as the quality of the nurse's discharge teaching and preparation of the family for leaving the hospital.

Other studies have also described the importance of quality communication between nurses and parents in determining how confident parents feel about caring for their children after going home from the hospital (Bent, Keeling, & Routson, 1996). Nurses also perceive communication with their patients as being extremely important for successful discharge (Hansen, Bull, & Gross, 1998).

Foster Parents Making the Transition

There is a great deal of research devoted to biological parents' feelings, perceptions, and concerns about the discharge process and how they cope. There is almost no research dealing with this same process as it relates to foster parents. An extensive search of the current literature revealed that, to date, there are only two published studies devoted to the experience of foster parents caring for children making the transition from hospital to home. Both articles were published by Marcellus (2008, 2010) and involved a study of foster parents of neonates who had experienced prenatal substance abuse (PSE) and had been placed in the custody of child welfare agencies for that reason.

The qualitative study involved 11 foster parents and 3 social workers and utilized one-on-one interviews. These interviews were analyzed and the data were eventually used as a structure to identify three phases of the process of taking a PSE infant home from the hospital: preparing to foster, living as a foster family, and ending the fostering role. Each of these phases has their own unique tasks and the three phases were further developed into a model identified as the Infant Foster Family Care Model (Marcellus, 2010). Phase one (preparing) consists of elements such as being recruited, meeting system requirements and working with social workers to gain information about the specific child or how to access available training and/or support systems. Phase two (living) involves the day-to-day activities of caring for the infant as well as other activities involving the self, the biological family and the available support systems. Phase three (ending) involves the transition of having the infant leave, or needing to make the change due to issues such as burnout or lack of desire to continue the work.

This model was developed from the interviews of participants but because of the very small sample, it was decided that no demographic data would be published as participants would be potentially identifiable. The interviews were revealing. Many interviewees discussed their motivations for caring for these types of children. Reasons included an altruistic desire to contribute to a perceived community need, a spiritual calling, or a personal experience in their own childhood. Participants discussed some of the challenges they faced in meeting the certification requirements and the time and effort it took to finally be eligible to become foster parents who would be deemed qualified to work with PSE infants. Many participants described surprise at the disruption of their regular family routine after the placement of the foster child, often much more than they

had anticipated. There were many stories of how foster parents felt challenged to work

with the child welfare system during the time of transition and how these foster parents

were surprised at how difficult it was to get their needs met from the system. Some foster

parents stated that the time and effort spent working with the child welfare system was

greater than the time and effort they spent working with the foster child. In the

discussion of phase three (ending), this frustration was noted as a major contributor to the

decision to end their service as a foster parent (Marcellus, 2008).

Theoretical Framework

The theoretical framework used in this study was the Middle Range Theory of

Transitions (Meleis, 2007). According to this theory, transition is described as "a change

in health condition, roles and relationships, expectations, or abilities" (Meleis, 2007 p.

418). This framework captures the nature of transitions, facilitators and inhibitors,

patterns of response, and nursing therapeutics. The characteristics of transitions include

types, patterns, and properties (Meleis, Sawyer, Im, Messias, & Schumacher, 2000). This

can help identify positive and negative aspects of the experience, important points in the

chronological timeline of the process, and the perceptions of the experience of foster

parents who are making the transition from caring for a child in the hospital to caring for

a child in their home.

Nursing research that involves transitions can be traced back to the work of Dr.

Afaf Ibrahim Meleis. Dr. Meleis first identified transition as a central concern to nursing

in 1975 (Wilkins & Woodgate, 2006). While others have expanded on this theory in

nursing and other areas (Chick & Meleis, 1986; Meleis, Sawyer, Im, Messias, &

Schumacher, 2000; Selder, 1989), Meleis has been credited with identifying and

developing (with others) her mid-range theory of nursing (Meleis, 2007). This theory is

based on the assumptions that: (1) changes in health status trigger a process of transition

in clients; (2) transitions tend to increase clients' vulnerability, which in turn affects their

health; (3) nurses are the primary caregivers of clients in transition; (4) a sense of balance

is achieved in all transitions; and (5) individuals, families, communities, and societies are

accountable for health. This theory emphasizes that transitions are embedded in their

context and trajectories and, therefore, must be viewed contextually over time to reveal

the meaning of the experience (Wilkins & Woodgate, 2006). Although similar, change is

not synonymous with transition. All transitions involve change, but not all changes

involve transition (Meleis & Trangenstein, 1994). Furthermore, transition denotes a

change in identities, roles, relationships, abilities, or behaviors, and requires individuals

to incorporate new knowledge, to alter behavior, and to change the definition of self

(Chick & Meleis, 1986).

Transitions theory currently identifies four types of transitions: developmental,

situational, health-illness, and organizational (Meleis, 2007). Developmental transitions

involve defined roles such as parent or spouse. Situational transitions refer to changes in

a life situation such as homelessness or family caregiving. Using a health-illness

approach to a transition focuses on specific acute and chronic disease states. Finally,

organizational transitions refer to changes in an organization related to the broader social,

political, or economic environment (Meleis, 2007).

Patterns of transitions are single, multiple, sequential, simultaneous, related, and

unrelated (Meleis, 2007). Identifying the transition pattern helps determine the level of

complexity and overlap for a particular individual. When various events that may

contribute to the transition are recognized, exploring the relationship between these events may yield important information in assisting the individual to adjust. Understanding the common patterns or critical points in the transition of foster children from hospital to home, from the foster parent perspective, can greatly increase the nurse's ability to anticipate critical tasks that need to be done or undertake important communication to improve outcomes. It has also been noted that understanding the pattern can assist the caregiver in reaching a positive outcome (Meleis, Sawyer, Im, Messias, & Schumacher, 2000).

Properties of transitions are awareness, engagement, change and difference, transition time span, and critical points (Meleis, 2007). Therefore, preparing for transitions in the caregiving experience necessitates awareness of need by the caregiver. Being prepared for the complex nature of transitions in caregiving may improve outcomes for both the caregiver and care receiver (Meleis & Trangenstein, 1994). Understanding how foster caregivers are prepared for taking children home from the hospital from their perspective can provide a better understanding of this process and how future interventions aimed at improving the process can be developed.

Engagement is the level to which an individual is involved in a process. Searching the Internet for information or modifying activities may reflect engagement in the caregiving process (Meleis & Trangenstein, 1994). Change is an alteration and may cause disequilibrium or alterations in roles. The changing role of the foster parent involved in this transition is not well understood. The role change they are experiencing when experiencing this process can be a challenging time, fraught with emotional highs and lows. Or it could be an emotionally uplifting experience that improves the foster

caregiver's outlook on life and is intrinsically rewarding. There are different perceptions of this experience based on multiple factors. Background factors and caregiving strategies used by foster parents that influence perception of the transition from hospital to home have not been previously identified or explored.

The property of time span indicates the different phases of transitions, which may vary from individual to individual (Meleis, 2007). Critical points are those events in the transition process that offer opportunity and crisis. Recognition of common caregiving critical points such as diagnosis of an illness, initiation of treatment, change in health status, or cessation of treatment assists the caregiver to prepare for possible events in order to potentially improve the outcome (Meleis, 2007). Recognition of common critical points in the transition experience for foster parents includes the initial contact with the caseworker, the first visit with their foster child in the hospital (or lack of), the amount of previous experience or training a foster parent has with children with health issues, or the availability of support for the foster parent at the time of the transition.

Transition facilitators and inhibitors incorporate personal, community, and societal factors (Meleis, Sawyer, Im, Messias, & Schumacher, 2000). The meaning of an event may either facilitate or inhibit the person's adaptation to a transition in care. Foster parents often have unique and complex motivations for fostering (Picken, Brunsden, & Hill, 2011; Samrai, Beinart, & Harper, 2011; Wulczyn, Barth, Yuan, Jones-Harden, & Landsverk, 2005). Exploring motivations or individual perceptions by foster parents of the transition process will reveal ways to improve the process for foster parents and help them to better adjust to their new role as a caregiver.

Patterns of response include process and outcome indicators. Process indicators allow for early identification of those activities that could positively influence the caregiver or put them at risk. These indicators consist of feeling connected, interacting, location and being situated, and developing confidence and coping. Outcome indicators include mastery of skills and behaviors needed for a new situation as well as integration of a new identity (Meleis, Sawyer, Im, Messias, & Schumacher, 2000). By placing a framework around the perceptions of foster parents experiencing this transition, knowledge deficits or resource deficits are identified at any of the phases of this transition. Important communication tasks or teaching content from nursing or other professions will help the foster caregiver increase their perception of being prepared for the transition.

Nursing therapeutics involve elements of nursing practice that support positive responses to transitions. These elements may include assessment, creation of health environments, or mobilization of resources (Meleis, 2007). Nurses are uniquely positioned to assist the foster caregiver who is caring for the child with health issues make the transition from hospital to home. Transitions theory can guide nurses in identifying patterns, properties of factors that improve or inhibit this process as perceived by foster parents. Understanding the uniqueness of the foster parent who engages in this phenomenon will help nurses anticipate the critical points where interventions need to occur. By utilizing the transition framework, the outcomes for the foster parents as well as the foster children may improve.

Chapter 3

METHODOLOGY

This chapter will describe the methodology that was used for the study including an overview of the specific procedures used to guide the data collection and analysis, description of the study, and the setting for the project. The chapter will also discuss the inclusion and exclusion criteria for participation in the study.

Study Design

The method used for this qualitative inquiry was Interpretive Description. Interpretive Description was first developed by Thorne and colleagues in the mid-1990s. (Thorne, Reimer Kirkham, & MacDonald-Emes, 1997). It was developed in response to an expressed need to generate knowledge through alternative research methods (Thorne, 2008). At the time, Thorne and others were struggling with a lack of practical application that most nursing researchers needed. The three traditional qualitative methods that are still predominantly used in nursing are phenomenology, grounded theory, and ethnography (Polit & Beck, 2008). According to Thorne (2008), these traditional methods have evolved from the social sciences: psychology, philosophy, sociology, and anthropology. Because the nature of these social sciences, these traditional research methods address problems of a more basic nature, mostly social group behavior and the core nature of the human experience instead of the practical problems of nursing (Thorne, 2008). Interpretive description is something that is (1) not deeply attached to any particular method (e.g., ethnography, grounded theory, or phenomenology), but is qualitative and exploratory, (2) not bound to traditional, potentially limiting protocols that only the 'purists' support and that adhere to certain procedures because it is

traditional (thereby lacking the dynamic, evolving nature of *any/all* research methods and contexts), (3) a method that 'becomes what it is (they are) in the hands of users' (Sandelowski in Thorne's introduction, p. 12), and (4) "is a strategy for excavating, illuminating, articulating, and disseminating the kind of knowledge that sits somewhere between fact and conjecture, but which is of central importance to the applied disciplines such as education, community development, human geography, and the health professions" (Thorne, p. 15). She advocates interpretive description as a practical approach/strategy for clinical and other applied disciplines; it adheres to the overall perspective of qualitative inquiry, which is a general, descriptive/exploratory strategy for understanding human experience in the varied contexts of life, health and illness.

According to Lincoln and Guba (2005), one of the most important questions in research is, "How can the knower go about obtaining the desired knowledge and understandings"? (p. 202). Identifying the nature of knowledge creation is central to answering this question and requires identifying the paradigm in which the research will be conducted and how the research questions will be answered. For this study, a constructivist paradigm was an essential element.

Constructivism

Philosophically, constructivism is defined as "the view that the subject matter of scientific research is wholly or partly constructed by the background theoretical assumptions of the scientific community and thus is not, as realists claim, largely independent of our thoughts and theoretical commitments" (Boyd, Gasper, & Trout, 1991, p. 775). While scientists and investigators may resist reopening and re-examining a problem thought solved (Kuhn, 1970), Laudan (1977) argued that more recent evidence

in the evolution of ideas supports a perspective of openness, integration of multiple perspectives/disciplines and inclusion of varied kinds of knowledge. Other general philosophical tenets of constructivism include (1) Kant's (1981) idea that our experience represents a merging of internal mind, interaction with the world and our interpretation of meaning; (2) that constructed knowledge is an effort to validate self by integrating personal, intuitive knowledge with knowledge acquired from others (Belenky, Clinchy, Goldberger, & Tarule, 1986); (3) that people in general, research participants and investigators jointly shape a shared reality (Golden-Biddle & Locke, 1997); and (4) that "constructed knowers" (Meleis, 2012, p. 16) see all knowledge as contextual, accessible through multiple ways of thinking-knowing, and constantly subject to change, development and revision.

Therefore, a constructivist understanding of knowledge is one in which knowledge is co-created between participant and researcher (Appleton & King, 2002). The five key principles of constructivism are: (1) reality and its elements, (2) causality, (3) unique contexts resulting in absence of generalization, (4) the relationship between the researcher and the phenomena under study and (5) the impact of values on the inquiry process (Appleton & King, 2002, p. 642).

Elements of reality. A key to the constructivist paradigm is the understanding that while there are basic "structures, mechanisms and causal powers" that have created the world, there are always multiple and intangible realities that exist and are governed by "structures that exist independently of us" (Appleton & King, p. 642). Researchers who participate in interviewing people about events or experiences must acknowledge the differing perspectives exist for different participants and that the experience, while often

a common one, may not be viewed as being a similar event with equal value given to that event. People choose their reality, either consciously or subconsciously and the constructivist paradigm acknowledges this. The ability of researchers to accurately make inferences about a phenomenon or experience has been debated in the literature (Denzin & Lincoln, 2005). Acknowledging the fact that there are different perceptions of reality, it seems important to remember that each person's experiences and the context in which they occur should be considered valid. This is where constructivism differs from other more traditional modes of inquiry where a single or a minimum number of correct viewpoints is sought (Appleton & King, 2002). The researcher should not dismiss or minimize divergent or opposing viewpoints, even if their goal is to gain a consensual view.

Causality. Causality, or causal linkages between events, has been described as an important concept to help explain or predict behaviors (Appleton & King, 2002). In social science research, this proves to be difficult for many reasons, not the least of which is the complexity of human interactions as well as the complexity of the environment where these interactions take place as behaviors are observed. Social systems, complex relationships, and communication among persons and many unknown environmental influences challenge the notion that any behavior by one person actually causes the behavior of others. Constructivists believe that the concept of causality is misleading and too simplistic or out-of-date and that the process of assembling meanings or interpretations by persons should not happen in a linear (cause and effect) fashion (Appleton & King, 2002).

Generalizability. The ability to generalize findings from research within a certain population or situation into other areas with different populations or situations can be a beneficial resource for making changes or interventions to improve aspects of processes, such as patient care. An example might be taking the results of research involving the experience of cancer patients and utilizing those results to change or alter the care of patients with diabetes. The constructivist paradigm, however argues that no two social settings are sufficiently similar to allow simplistic, sweeping generalizations between the two (Appleton & King, 2002). Therefore, it can be stated that this paradigm produces knowledge based on a fact that there are always multiple interpretations of reality that exist in people's minds, which makes it nearly impossible to determine what the ultimate truth or falsity of the constructed concept might be (Polit & Beck, 2008). The challenge then becomes in how findings from research using a constructivist paradigm are based. Because of this lack of generalization about events or situations, it can be difficult (or risky) to act on the findings of any research as there might not be the same sense of authenticity needed for the findings of that research to be applicable to other situations (Lincoln & Guba, 2005). However, Stake (2010) argued that even "a small amount of qualitative research can falsify a generalization" and that "even in the best of sciences, we are unsure about to what populations the findings apply" (p. 197). His point leaves open the value of a constructivist approach in formal inquiry.

Relationships. The constructivist paradigm also assumes that knowledge is maximized when the distance between the inquirer and the participants in the study is minimized (Polit & Beck, 2008). Thus findings from a study using this paradigm become "the creation of the process of interaction" (Denzin & Lincoln, 2005, p. 27). The value of

this process is that a skilled researcher can capitalize on this interactive process by understanding and documenting the multiple views of reality that may exist (Appleton & King, 2002). The most commonly cited criticism of this process is that it relies on the human being as the primary instrument of data collection. Human subjects, while being extremely intelligent and sensitive, are also fallible as instruments of data sources and collection (Appleton & King, 2002, p. 644). It can be difficult to differentiate what may be very important data from the more trivial or the more obvious. The reliability of the data collection process can also be called into question. As an example, there could be a vast difference in the analysis and conclusions of a study using a constructivist paradigm if the same participants are interviewed, but the primary researcher is replaced with a different person.

Values. To add to the challenge of subjectivity, constructivist researchers argue that "facts are both 'value-laden' and 'theory laden' and if theories are value-determined and facts are theory laden, then facts must also be value-determined" (Appleton & King, 2002, p. 645). It can then be inferred that values are seen as essential in knowledge creation. An obvious challenge to that declaration is that not everyone holds the same values. Yet this concept is enmeshed in constructivist inquiry (Lincoln & Guba, 2005). This is stated by four important tenets of the influence of values on constructivist inquiry: (1) the researcher's own beliefs and values influence the area to be investigated; (2) the theoretical paradigm and methodology selected to guide the inquiry process will have roots in both assumptions and value positions; (3) the research will be influenced by the presence of values ingrained in the study setting; and (4) the beliefs of all groups

represented in a study should be recognized as influential and "the knowledge and experience of people" is directly honored and valued (Denzin & Lincoln, 2005, p. 221)

The constructivist paradigm supports the co-creation of knowledge that is derived from both the participant's experience and the researcher's analysis. By using Interpretive Description as the methodology for this study, the experience of the researcher will be a significant component of framing, analyzing, and interpreting the data collected from the foster parent participants. As foster parent participants in the study describe their perceptions of the experience of caring for a child as the child transitions from hospital to home, the individual descriptions will be developed into a structure of themes that can be better understood. This is known as going from "pieces to patterns" (Thorne, 2008, p. 142). Interpretive Description acknowledges that individuals may perceive similar situations or experiences in very different ways, yet the method will be able to capture patterns and themes within these subjective experiences (Thorne, Reimer, Kirkham, & O'Flynn-Magee, 2004; Thorne, 2008).

Interpretive Description

Interpretive description allows the particular experience of the individual (in this case, foster parents caring for children with SHCN making the transition from hospital to foster home) to be located with the "shared reality" of the health care environment and with the experience of the researcher (Sandelowski & Barroso, 2002). In the more traditional qualitative methods, data can be transcribed and interpreted by the researcher from the sole paradigm of the subject (participant) and defined or coded based on categories defined by previous research or another group of participants' unknown to the researcher. Interpretive Description allows the "description" to become interpretive through

"mulling" (Bazeley, 2013, p. 379). Mulling is a process that is a combination of intensive reading, interpretive memoing, coding, summarizing, and exploration of variations in cases that do not fit any preconceived notions. These ideas and understandings are then clustered, sequenced and woven together into an overall account or story that goes beyond thematic reporting (Bazeley, 2013). Thus Interpretive Description includes the circumstances, meaning, intentions, strategies, and motivations of those who are the subject of the description. According to Thorne (2008):

> Interpretive description requires an analytic form that extends beyond taking things apart and putting them back together again. This requires that we learn to see beyond the obvious, rigorously testing out that which we think we see, and taking some ownership over the potential meaning and impact of the visions that we eventually present as our findings. (p. 142)

Interpretive Description is atheoretical because the intention is not to construct a theory or to theorize, but to generate inquiries related to the clinical problems of health and illness that researchers can describe and interpret in terms of patterns of experience, action, or expression (Thorne, 2008). The goal of Interpretive Description is to answer specific questions related to practical aspects of the nursing discipline. The method presumes the availability of theoretical knowledge, a clinical pattern, and scientific reasons for conducting the study (Thorne, 2008). In order for this method to be viable, a critical review of the past and current literature should form the basis for the preliminary framework. This will assist in the sampling, design, and any early analytic decisions prior to initial data collection. The researcher must remain vigilant throughout the analytic process to avoid producing a structure that results in a glorified content analysis

(Thorne, Reimer Kirkham, & O'Flynn-Magee, 2004). The product of the Interpretive Description method should be a coherent conceptual description of common themes and patterns related to the topic of interest, in this case: the experience of foster parents caring for the child with a SHCN making the transition from hospital to foster home; yet also account for any individual variation (Thorne, Reimer Kirkham, O'Flynn-Magee, 2004; Thorne, 2008).

The descriptions that are created are known as "tentative truth" rather than the original and coherent "new truth" of descriptions that come from a traditional qualitative study (Thorne, Reimer Kirkham, O'Flynn-Magee, 2004). This interpretive aspect is an important differentiation of a methodology in the nursing discipline and the pursuit of practical application rather than "free-floating theorizing" (Thorne, Reimer Kirkham, O'Flynn-Magee, 2004). This allows the findings from such studies to assist in the assessment, planning, and intervention strategies that nurses can apply to solve clinical problems.

Because of the nature of Interpretive Description, this methodology will be effective in allowing individual foster parents who have worked with a foster child with SHCN making the transition from hospital to home to be able to describe their experiences of the phenomenon from their own perspective and context. The researcher will also be able to focus on certain themes or ideas as they arise during the data collection process. This flexibility in data collection will be essential in being able to fully understand the experience of each participant, yet allow each component of data to "fit" into the scaffolding of the data as it grows. As the aim of an Interpretive Description study is to "deconstruct the angle of vision upon which prior knowledge has

been erected and to generate new insights that shape new inquiries as well as applications

of evidence to practice" (Thorne, 2008, p. 75), this methodological framework will

maximize the quality of data collected during the study.

Setting

The overwhelming majority of the participants in this study live within one of ten

counties in southwestern Idaho. This area makes up nearly one-third of the entire state,

yet contains over 65% of the population of Idaho. This also holds true for the percentage

of children in foster care in Idaho (K. Moore, personal communication, March 3, 2014).

Contained within this area are the cities of Boise (population 212,300), Meridian

(population 80,380), and Nampa (population 83,900) (United States Census Bureau,

2013). Collectively this area is home to around 616,500 people and represents about 40%

of the population of the state of Idaho (1,595,000) (United States Census Bureau, 2013).

The racial makeup of this area is 89.8% white, 8.9% Hispanic or Latino, 1.4% Asian,

0.8% Native American, 0.5% African American and 0.1% Pacific Islander. The median

income for a household in this area was $36,695 in 2010 and the median income for a

family was $42,196 (United States Census Bureau, 2013). The per capita income in 2010

was $17,041.

In 2014, there were approximately 1138 children in foster care in the state of

Idaho (Administration for Children & Families, July 2015). The average length of stay in

foster care was 19.3 months. The current monthly foster care rate paid to foster parents

in Idaho is $274 per month for a child under 2 years, $300 per month for a child of 2 to 9

years, and $431 per month to care for a child 10 or older (MARC, 2013). This amount

puts Idaho as the forty-eighth lowest reimbursement rate among the 50 states for two-year-olds and forty-ninth out of 50 states for nine year olds.

Inclusion and Exclusion Criteria for Participation

All participants in this study were licensed by the state when they cared for the child who was hospitalized. Additionally, they must have been recruited by a caseworker to care for a child who needed to be in foster care at the time that the child was admitted to an acute care facility. The participant would then be responsible for the child while that foster child made the transition from the facility into their home. All participants needed to be able to speak and read English.

Some potential participants were excluded because, although they wanted to participate, the foster child that they cared for had previously been in their care prior to being hospitalized for a significant health issue. There were also 2 participants who were disqualified from participating due to the fact that they were actually a kinship placement. Based on the research questions for this study, it was determined that the experience of a biological relative foster parent (kinship placement) might differ significantly from the experience of a non-kinship placement, especially in the areas of previous knowledge of the foster child's health condition and the relationship/interactions between the foster family and the biological parents.

<div align="center">Chapter Summary</div>

This chapter presented a discussion of the basic underlying concepts behind the methodology for the study as well as a description of Interpretive Description. It also offered a brief overview of the setting for the study with some of the criteria for

participation. Much more detail about the sample of the foster parents, the foster families

and the data analysis will be described in Chapter 4.

Chapter 4

FINDINGS AND INTERPRETIVE THEMES

This chapter will present a) a discussion of the context of the study and external impacts to the data collection process; b) a description of the recruitment, collection and data analysis processes; c) presentation of the basic demographic characteristics of the sample; and d) the final themes and subthemes that emanated from the collected data. The data collection centered around three research questions and therefore data were organized into three sections based on each question. Each section is further subdivided into themes and subthemes following an interpretive process. A matrix guide was developed during this process and was constantly changed, tweaked and refined as the data were reviewed, analyzed and reanalyzed both during and after the data collection process. Although much of the data are complex and multi-meaningful, the final stage of organization was intended to demonstrate the most meaningful and logical way for professionals who work with foster parents to understand the experience of the foster parents who participated in this project.

Context

The goal of this project was to explore the experience of caring for foster children who are discharged directly from the hospital into foster care from the perspective of the foster parents. As discussed previously, this is a poorly understood phenomenon with almost no published research related to the foster parent perspective. The number of foster parents available to care for children continues to drop (DeWitt, Jansen, Davidson, Ward & Keens, 1993; Wang & Barnard, 2004), and it is not clear why this is happening. A logical conclusion to gain insight into the possible reason for the attrition of these

important caregivers is to simply ask them what they think about fostering and their

perceptions of the experience. In order to better understand the views of these foster

parents, it is important to listen to them and allow them to openly describe their

perceptions and feelings about their experience. This was accomplished by creating a

safe, confidential process for them to openly express their feelings, concerns, frustrations,

etc. about their experience and how it affected them and their family.

Confidentiality

All of the interviews for this study were done in settings where privacy and

confidentiality of the participating foster parent was prioritized. Except for a single

participant who was interviewed by telephone, all consent forms were signed in the same

private area where the interview took place. The foster parent who was interviewed via

telephone signed a consent form that had been emailed to him/her and was signed and

mailed back to the primary researcher.   The majority of interviews occurred either in the

primary researcher's office (N = 10) or the foster parent's private home (N = 6). One

interview occurred at a local clinic that serves foster children and victims of maltreatment

and then there was the one phone interview. Originally it was assumed that few, if any of

the participants would be open to having the interview done at their private home,

however many of the participants who agreed to be interviewed expressed to the primary

researcher how important it was to them to be able to participate in the project after the

project was explained to them over the phone during the initial recruiting process.

Although several participants expressed to the primary researcher that they were not

concerned about confidentiality about their participation, it still seemed important to

maintain an atmosphere of confidentiality not just because of the requirements for good

research, but to keep the confidence of the foster parent in feeling that they could openly express themselves. Many participants became emotional (either tearful or angry) as they discussed the experience and it was felt that much of the important and meaningful themes that were expressed would not have been shared without the participant feeling confident that their identity would not be revealed. Even though several of the participants made it clear that they had no concerns about caseworkers or nurses in the child welfare system discovering what they may have said, many of these same participants agreed that they still hoped to maintain a positive relationship with any child welfare worker they might encounter in the future.

Recruitment and Data Collection

The majority of participants (N = 14) were originally contacted by the primary researcher follow a mass mailing of recruitment letters (see Appendix E). A total of 505 of these letters were sent out to all currently licensed foster parents in a 10-county area in southwestern Idaho. Four additional participants were recruited after original participants contacted them and encouraged them to contact the primary researcher so that they could be interviewed.   Each participant was given a $25-dollar VISA gift card following initial greetings. Then the purpose of the study was explained to each participant with a brief description of what types of questions would be asked during the interview and how the data would be collected and analyzed. The potential participant was then asked if they would be willing to participate in the study and then they signed the consent form (see Appendix B). None of the people who were scheduled for an interview declined to participate.

Each interview consisted of the primary researcher obtaining basic demographic data about the participant, the persons living in the foster home during the time of fostering, and some additional information about the foster child being discussed. This information is outlined on the Demographic Information form (see Appendix D). After the information was obtained, the primary researcher turned on the audio recording device and then asked a series of open-ended questions. Although each interview rarely followed any set script, especially towards the end of the data collection phase of the study, the basic questions that were asked are listed on the Question Template form (see Appendix C). As mentioned previously, most interviews took place in the primary researcher's office or the participant's home, but one interview took place in a special secure facility where the primary researcher works and one interview took place over the phone. For that interview, the participant had mailed the primary researcher their signed consent prior to the interview taking place. The interview was recorded using a phone application called TapeAcall. This application created an mp3 audio file which was downloaded into the same secure folder for the transcriptionist to transcribe into the same document as all of the other interviews.

Data Analysis Procedures

Transcription of Interviews

Following the completion of each interview, the audio file from the portable recorder was uploaded into a secure database through the primary researcher's computer in his office. A copy of this audio file was then placed in a secure shared folder where a transcriptionist could access the file and then transcribe the data into a Word document. This document was then placed in the same folder for the primary researcher to access.

As each transcribed document became available to the primary researcher, he would pour through the document to change all the names of participants, family members, foster children and family members and any caseworkers or health care workers that had been mentioned by name. He also consistently made notes (added to the field notes of the interviews) about any specific things that had occurred during the interview such as emotional moments or occasional interruptions by children if the interview occurred at the participant's home.

It also was important for this initial scanning of the data to occur because it became apparent early on that the primary researcher needed to change/improve his interview methods. While this researcher has extensive experience working as a nurse and nurse practitioner in the health care setting, the type of communication and "interviewing" skills he possesses were not necessarily eliciting the type of responses that were needed. Early on in the analysis process, the chair of the dissertation committee, Dr. Lobo, was able to look over some of the first few transcripts and make the determination that the primary researcher would be better served by improving his interview skills. The goal of interviewing participants in research is to solicit as much information as possible by capturing how those being interviewed view their world and understanding as much as possible how the complexities of their individual perceptions and experiences (Patton, 2015). The primary researcher has experience working with parents and foster parents in the role of the clinician and quite often information that is obtained from parents about children needs to be concise and "to the point". This type of communication and interviewing is much different than gathering information for data collection in a qualitative research study. Thorne refers to this concept as "abandoning

that former self" when new researchers who have experience communicating with people as clinicians begin to obtain subjective data outside of the familiar clinical setting (2008, p. 108-109). After some extensive discussion and the elimination of the transcripts of two initial participants, the interviews became much more productive in obtaining quality data that added to the study.

Throughout the process of looking over each transcribed document, the primary researcher spent time looking over the content of the data in terms of what sort of original impressions he was getting from reading the data as well as remembering the context of certain statements from the recent memory of having been in the room during the interview. This was the beginning of taking many of the pieces of the data being collected and forming the patterns that would eventually lead to the construction of the set of themes presented later in chapter 4. Thorne (2008) describes this process in detail as a phase of analysis where a researcher can often associate selective data with certain, seemingly justifiable emotions that can significantly bias the analysis process. It was during this time that Dr. Lobo was invaluable in aiding the primary researcher to avoid these pitfalls and eliminate as much as possible the "trickster ravens" that defy most researchers conscious control (Thorne, 2008, p. 143).

As transcripts were initially analyzed and themes began to emerge, subsequent interview questions were refined and altered in an effort to obtain higher quality data. This included an increased focus on following up with "probes" after participants began to discuss what the researcher felt was a familiar theme. In interviews that occurred later in the summer or early fall, an answer that a participant gave might be followed up with a statement like "that's interesting that you mention that because I have heard something

similar from other folks in the study" or "you know, other people have told me something similar to what you are saying. Could you give me some more details about that?" This solicitation of additional information added greatly to the process as the quality of data improved from interview to interview.

Details of the Analysis

The analysis of the content of each interview was done at various intervals both throughout the collection phase as well as following the completion of all of the interviews. As the database of participant transcripts grew, the primary researcher, in consultation with the chair of his committee, began to build a basic structure of themes and subthemes through an iterative process of reflection, re-reading the transcript, and further reading of other transcripts and/or discussions with the chair. This process of "pondering, chewing on, and then wrestling with the data" is an important component of Interpretive Description (Beck, 2013). This led to the start of a basic organizational structure of a concept model of themes. Following the completion of the data collection phase, these initial themes as well as a few revised themes were drawn out on several large sheets of paper that were strategically placed in the primary researcher's office. Each transcript was printed out and each of the initial themes were "cut" from the pages of the transcript and taped to color coded sheets of paper that were subsequently pinned to the wall in what appeared to be the correct spot. As each piece of data was read and often reread for clarity and thoughtful analysis, changes to the placement of themes occurred and new themes and especially sub-themes began to emanate from the data. These handmade bits of data were moved around into the various "spots" on the wall until a solid structure of presentation of the themes were in place.

Credibility

To support the interpretations and categorization of data by the primary researcher, outside perspectives were utilized to verify appropriate descriptions of participant data in an effort to maximize the credibility of the study. In addition to Dr. Marie Lobo, a long-time expert on pediatric health issues, Dr. Karen Godard, a member of the clinical faculty at Boise State University was included in the data analysis phase of this study. Dr. Godard is a Pediatric Nurse Practitioner with over 30 years of clinical experience who, like the primary researcher for this study, has extensive experience working with foster children with health issues and the foster parents who care for these children. It seemed important to include others in this process in order to validate the analytic logic the is required by the use of Interpretive Description (Thorne, 2008).

Following an extensive review of the data, a meeting between Dr. Godard and the primary researcher was held. During this meeting, the various themes and sub-themes that resonated from the data were described in detail by the primary researcher and much discussion about meanings and interpretations were debated. At the conclusion of the meeting, several changes were made in how the data were initially described, especially in how the themes were ordered in the final presentation. The input from Dr. Godard was extremely valuable in helping to verify the appropriate thematic structure presented in this study.

Interpretive Authority. Although the primary researcher is ultimately accountable for the credibility in the findings of this study, the consistent advisement and

direction provided by Dr. Lobo during the data analysis process as well as the final

review and evaluation by Dr. Godard following the completion of the data analysis have

given this study a solid amount of Interpretive Authority. The perspectives of these two

qualified and experienced individuals have enhanced the trustworthiness and reduced

whatever amount of subjective bias may have been present in the initial analysis, an

important element of any research study using Interpretive Description (Thorne, 2008).

Demographic Descriptive

The study sample consisted of 18 participants who described their experiences

caring for 19 foster children. Some demographic data are presented in Tables 1-3. Table

1 describes important information about each participant. Table 2 breaks down the

information of each participant to show the age of each foster child, the reported

diagnosis for each, as well as other information about the foster parent participant and

foster child. Table 3 describes some significant information about the rest of the foster

family. Unless otherwise indicated, those data do not reflect that of the interviewed

foster parent and the foster child, just the other members of the family that were residing

in the foster home at the time that the hospitalized foster child came into care.

Table 1 - Demographic Characteristics of Participants in the Study

Characteristics	*N*	*% Totals*
Age Range		
<30	5	28%
31-40	7	39%
41-50	4	22%
50 or >	2	11%
Gender		
Male	2	11%
Female	16	89%
Ethnicity		
White	18	100%
Education		
High School	1	6%
Some College	6	33%
Associates Degree	1	6%
Bachelor's Degree	9	50%
Master's Degree	1	6%
Income		
$15,000-24,999	4	22%
$25,000-49,999	5	28%
$50,000-74,999	5	28%
$75,000-99,999	3	17%
>$100,000	1	6%
Another adult in the home		
Yes	14	78%
No	4	22%
First time Foster Parents?		
Yes	5	28%
No	13	72%
Previous Experience working with CSHCNs?		
Yes	9	50%
No	9	50%

Table 2 - All Participants by Name and Demographics

NAME*	Age at time of fostering	Gender	1st time FP?	Name of Foster Child	Age of Foster Child at time of discharge	Reason for Hospitalization	# of days hospitalized prior to discharge
Alicia	29	Female	yes	Sara	16 m	Abuse/Neglect	3
Deena	62	Female	no	Delilah	16 yrs	Mental Health	30
Carla	36	Female	no	Jake	6 m	Abuse/Neglect	14
Sheila	40	Female	no	Tim	15 m	Prenatal Substance Use	2
Jane	39	Female	no	John	2 m	Abuse/Neglect	5
Becky	30	Female	no	Thomas	6 m	Abuse/Neglect	1
Betsy	25	Female	no	Ally	4 m	Other	5
Courtney	28	Female	yes	Stephanie	13 m	Congenital Issue	370
Vanessa	39	Female	no	Cody	1 m	Prenatal Substance Use	14
Mike	39	Male	no	Cody	1 m	Prenatal Substance Use	14
Roxanne	48	Female	no	Lisa	16 yrs	Mental Health	22
Janet	60	Female	yes	Laura	14 yrs	Mental Health	5
Irene	29	Female	yes	Lynn	4 days	Prenatal Substance Use	14
Jessica	47	Female	no	Casey	7 days	Prenatal Substance Use	9
Michelle	36	Female	no	Adam	1 day	Prenatal Substance Use	9
Jean	49	Female	no	Mary	1 day	Prenatal Substance Use	15
Ann	37	Female	yes	Kate (teen)/ Oscar (infant)	14 yrs/ 4 m	Prematurity of Infant (Oscar)	140
Steve	43	Male	no	Natalie	4 days	Prenatal Substance Use	9

*All names are alias names of participants and the foster children

Table 3 – Characteristics of other members of the foster family

Characteristics	N	% Totals
Health Status of Partner/Spouse		
Excellent	6	43%
Good	8	57%
Fair	0	0%
Poor	0	0%
Partner/Spouse has significant health issue?		
Yes	3	21.4%
No	11	78.6%
Gender of other children in home		
Male	17	45%
Female	21	55%
Biological Children vs Foster Children living in home		
Biological	25	66%
Foster	13	34%
Health Status of other children in home (biological and foster children)		
Excellent	29	76%
Good	4	11%
Fair	3	8%
Poor	2	5%
Significant Health Issues of other children living in the home?		
Yes	4	11%
No	34	89%
Child/Adolescent offers Significant Support to Foster Parent?		
Yes	20	53%
No	18	47%
Reason for Hospitalization of Foster Child		
Congenital Health Issue	1	5%
Prematurity	1	5%
Physical Abuse/Neglect	4	21%
Prenatal Substance Exposure	8	42%
Mental Health Issue	3	16%
Other	2	11%

Sample Size

The ideal sample size for a study using Interpretive Description is often difficult to determine (Beck, 2013). For this study, it was important to weigh the hope of obtaining a large and diverse sample of foster parents who met the criteria for participation against the challenge of limited resources and access to this unique population. Based on the few previous studies involving foster parents who work with CSHCNs, it was determined that a sample of at least 12 participants with potentially up to 30 participants would most likely be adequate in obtaining a sufficient amount of relevant and insightful data about the topic. As data collection and analysis with the generation of themes progressed, it was determined that a sample of 18 total participants would be adequate for this project.

Recruitment Data

For administration purposes, the Idaho Department of Health & Welfare is divided into 7 regions with each region having its own administrative structure of Child Welfare workers. Following approval from the administrative team, two lists of all the current licensed foster parents in Region 3 (N = 242) and Region 4 (N = 263) were generated in self-stick label form. A solicitation letter (see Appendix E) with directions on how to contact the primary researcher was mailed to each address. This initial mailing generated 23 replies via email or a phone message. Each of these potential participants was then contacted with a return email or a return phone call where a face-to-face interview was scheduled at one of the locations previously mentioned. This process resulted in the interviews of 14 of the participants. The vast majority of those potential participants who were contacted expressed seemingly sincere enthusiasm about the study

after it was explained. Of the few persons who were unable to participate because they did not meet the criteria, there was a near universal expression of disappointment at not being able to participate.

The additional 4 participants in the study were interviewed after they contacted the primary researcher independently via a telephone call. All 4 of these participants were friends or colleagues of the original 14 participants and wanted to participate themselves.

Foster Parent Participant Characteristics

Foster Parent participants in this study consisted of 16 (89%) females and 2 (11%) males. The ages of these participants, at the time of initial contact with their foster children, ranged from 25 years to 62 years with a mean age of 41.5 years. The ranges of household income are shown in Table 1. Each participant was asked about the total number of years of formal education they had starting with the 1st grade of elementary school up until any type of graduate education. The number of years ranged from 12 to 22 with a mean number of years being 15.8. Of these participants, 4 (22%) did not have a partner or significant other living with them at the time of the experience. The majority of participants, 13 (72%), had previous experience working as a foster parent prior to being recruited to care for the hospitalized foster child. Three of the participants were registered nurses and one participant was a lay midwife. The group was evenly divided when asked about having had previous experience working with children with special health care needs prior to fostering the child being discussed in this study.

Foster Child Characteristics

The ages of foster children described in this study ranged from newborns to 16 years, with the average age of the children coming in at 2.8 years. The amount of time these children spent in the hospital prior to leaving the hospital ranged from just one day to an extreme of 370 days (just over one year). It should be noted that most of the children were hospitalized for a few days with three outliers/exceptions: One adolescent had spent about a month in an inpatient facility, another young baby had been born with significant prematurity leading to a lengthy 4 and ½ month stay in the NICU and another young child had some extreme congenital health issues which contributed to her stay in both the NICU and PICU of the same hospital for just over 1 year. Table 3 shows the frequencies of the reasons that these children were admitted to the hospital with Prenatal Substance Exposure being the most frequent reason (n = 8, 42%).

Family Demographics

Each participant in the study was asked about other members of the family who were residing in the home at the time of the foster placement. Of the 14 participants who indicated that they had a spouse or partner living with them, 3 participants indicated that their partner had a significant health issue. Participants were also asked to rank the health status of any other members of the family (biological or foster) who were residing in their home at the time. These rankings are listed in Table 3, with the majority, 29 (76%) of the 38 children, having what was described as excellent health at the time. Only 4 (11%) of the 38 children had a significant health issue at the time of the experience.

Support. Each participant was asked about whether they felt that other members of the family offered significant support to them during the experience of caring for the

foster child. All of the participants indicated that their partners offered significant

support to them as they cared for the foster child. Of the 38 children (biological and

foster) who resided in the 18 homes, participants indicated that they felt that 53% (n =

20) had offered support to them during the experience

Presence of Other foster children. Participants in the study were also asked to

identify how many other foster children, if any, were placed with them at the time of the

experience. Of the 18 foster homes and 38 other children living in these homes, 34% (n

= 13) were foster children.

Interpretive Themes

The themes for this study seemed to easily fit into a structure guided by the

original three research questions. Within each of the three questions, themes and

subthemes were organized into a theme matrix (see Figure 1). Each theme and subtheme

evolved primarily based on the transcripts of interviews as well as some of the

observations and field notes of the primary researcher. Organizing the themes and

subthemes of this experience and placing a meaningful label on each was a challenge for

the primary researcher. This was mainly due to the fact that each participant is an

individual foster parent, and with a few exceptions, completely separate from other

participants in the study. So each experience being articulated by each participant

initially seemed to deserve its own category. Yet after careful analysis and reflection,

common threads of similar perspectives on unique experiences began to crystallize as the

transcripts and field notes were carefully read and re-read with constant thoughtful

reflection. This iterative process resembled Patton's (2015) depiction of reflexivity as

integrating the deeper, often common contexts that surround participants, such as the

political, cultural, linguistic and economic dimensions of their daily lives.

Figure 1: Matrix of Themes and Subthemes

Question #1: The Experience of Making the Transition	Question #2: The Positive Aspects of the Experience	Question #3: The Challenging Aspects of the Experience
Themes and Subthemes	Themes and Subthemes	Themes and Subthemes
Motivation to Foster 1. God/Spirituality 2. Making a difference for the children 3. What the experience gives to the foster parent **Advocacy** 1. Have to fight/work around the system 2. I know best **Previous experience as a foster parent is helpful** 1. I'm glad I was a nurse/glad I had experience working with CSHCN **Lessons Learned** 1. Communication is critical 2. Information is critical	**Caseworker is Meeting the needs of the Foster Parent** **Health Care Workers are being supportive** 1. Providing clear communication/needed information **The Effects on the Family (both Foster Family and Biological Family)** 1. Helping biological parents become better parents / assisting them with getting their children back 2. The influence of the child on the foster family 3. Watching the foster children growing and developing	**Communication Issues** 1. Experience of Caseworker / Health Care worker 2. System issues/conflict **Conflicts with policies** 1. Reunification 2. Consent 3. Information sharing 4. Feeling unsupported **Taking care of CSHCN is stressful** 1. Emotional impact of seeing the children deal with health issues **Lack of knowledge of the health condition/health status of the foster child** **Lack of Resources** **Conflicts with Biological Families**

Research Question 1: The Experience of Making the Transition

The actual research question for this section of the study was "What are the common experiences encountered by foster parents when caring for a child who is making the transition from the acute care setting to the foster home?" After several repeated analyses and reorganizations of the transcripts, four themes emerged from the interviews of the 18 participants that "fit" into the general answer to this question: a)

What is the motivation to do this type of work/caring; b) There is a need to be an advocate for the foster child I/we care for; c) Having previous experience is often helpful and d) There are many "lessons" that need to be shared.

Theme 1: The Motivation to do this type of caring. Although the participants were not directly asked the specific reason that they cared for foster children, nearly every participant described what motivated them or what underlying reason they had to get involved with foster children and especially why they continued to do it. What seemed especially significant was that many of these statements would come immediately after a description of some negative or challenging aspect of their experience. It became apparent early in the data collection process that many of these foster parents seemed to feel a need to express how important this work was to them despite how challenging it was in their eyes, often as if they did not want the study to be so overly negative as to potentially deter potential future foster parents from being involved. The participants understood how important they were and that if there continued to be a shortage, it would ultimately be the foster children who suffered. This theme of being there for the children was expressed by statements such as: "I love taking care of these kids. They need someone to love them and help them through this, and if they don't have us foster parents, then who will?" (Michelle, lines 102-104). There were also many participants who had much to say about the challenges they faced, yet they still found value and planned on continuing, as evidenced by this comment: "Maybe it's like giving birth and you say, I'll never do that again! And you do it again and you love it and you're glad you did." (Vanessa, lines 315-316).

Subtheme 1: The influence of Spirituality/God's will. For many of the participants, their faith in God or a strong faith driven reason to care for these children was the primary motivator for their involvement in this experience. Having a spiritual reason for working with foster children or stating that there was some sort of higher power involved in the purpose of their work was a significant subtheme for many participants. When a foster parents says "Okay, this is what we wanted to do. We thought about it. We prayed about it. God's giving us what we want." (Michelle, lines 113-114). Or they make a statement such as "The way that we were brought up in our faith is that you help other people, and whether it's a child or adult, everybody helps each other." (Jessica, lines 46-48). These participants are indicating that their role as a foster parent has been significantly influenced by a belief in a higher power. Another participant made it clear that she felt that God expected her to do the work that she was doing when she expressed the following statement:

> I feel like it gives me a feeling of if God were here, He would be caring for these kinds of children. He would be helping them, so if He would be here doing that, isn't that what I would want to do too? And that helps me carry through the times when I'm like, "I can't do this" ya know? I know it's what He would want me to do, to be that kind of person to care for the most vulnerable population that we have. (Sheila, lines 119-122).

Subtheme 2: The importance of making a difference for the child. Another strong subtheme that came through in the data analysis was the feeling by many foster parents that making the child's life better or making a significant impact (or difference) on the child's life or care was a major motivator to continue to do the work of fostering.

This was expressed with statements such as: "We want to make a difference in these kids' lives. That is our ultimate goal. Anytime we take a new child into our home, it's what can we do for them because they've already had a lot of trauma in their life." (Jean, lines 257-259).

Foster parents also felt that even though they understood the challenges they might face, they felt they could provide an alternative to what the foster child might be faced with:

"We were a last resort so kids didn't have to get split up from their siblings. And, you've already lost your parents, you didn't need to lose them too. And we really felt-we feel-that it's not the kids' fault and they need somewhere to go, and it's better to be in my crowded house than to be sitting at the police department or the Health and Welfare building." (Becky, lines 573-578).

Or with stories about how a decision to foster came about:

"So we went and met her and that PCS provider, I don't remember her name-but she gave our number to the social worker up at the PICU there and we just made contact and she invited me and my husband up to meet Stephanie and then we met her and stared to come home and discuss what that would mean for us, what would that mean for our family to bring her home, and just really fell in love with her and thought "hey, this is something we could do. We could provide her with a better home, instead of her living in the hospital." (Courtney, lines 5-13).

Having a significant impact that might last long after the fostering experience was also described by this participant:

"I didn't know what I could be put through until I did it. It's not fun most of the time, but I see great rewards. I mean, at some level, mentally, physically, and emotionally, you have that hope that it will stay with them for a lifetime. Maybe it will change their course. You hope for every kid that comes into your home that something you've done will change their course at some point." (Jane, line 813-818).

Subtheme 3: The impact of the experience on the foster parent or the foster family. Several participants in the study described aspects of the experience in terms of how it impacted themselves and/or their family. These types of experiences were categorized within the theme of *motivating factors* because the descriptions consistently impacted the participants' desire or willingness to continue to foster children with SHCNs. A statement such as: "I didn't know what I could be put through until I did it. It's not fun most of the time, but I see great rewards." (Jane, lines 813-814) gave a general sense of appreciation of the work. There were also expressions of specific rewards the foster parent sought when agreeing to care the children such as when this participant stated:

"I have to admit that my motivation was to get a little prize out of it, to take something home with me at the end of it. That bites you in the bottom. That makes it so much harder, because you realize you're committed to this little soul, yet they're going to leave you." (Vanessa, lines 231-236).

Or when this foster parent tearfully expressed her feelings about why she continues to care for foster children:

> "You just never…you love your kids so much, you just don't think there's enough love, I guess. And that you bring this child into your home and you see all their hurt. You heart melts and you just want to love them. They need your love and they need you." (Michelle, lines 276-279).

Although many of the participants in the study made it very clear that they had significant frustrations and ill feelings regarding their interactions with the various systems they dealt with (as described later in this chapter), there were several who felt the need to clarify how impactful the experience of fostering these children had been to them:

> The good in being able to care for kids outweighs the hard. It is an adjustment as a family to take in more kids, especially if you have other kids. And if there is a medical need, that's another adjustment. But if you have a heart to help kids in a hard spot, then the joy you get from being able to do that outweighs the bad; outweighs the adjustments you have to make." (Carla, lines 452-457).

> I can say that despite all the challenges, despite the agency involvement, the red tape, the hurdles, the low expectations of the state-all that aside-having her has been a complete joy. A complete and total joy. She is the light of our life. Anybody who she comes I contact with will be blessed in knowing her. I couldn't be more thankful to have her in my life. I would do it again, with all the challenges, to have that special child in my life." (Jessica, lines 435-444).

Important Observation/Outlier: It seems important to discuss the issue of money as a motivating factor for foster parents. As discussed in chapter 2, the foster parents who participated in this study were paid the same basic rate per month to care for the recently hospitalized children in their home as any other foster child, a rate that is solely determined by the age of the child. Prior to the data collection phase of this study, the primary researcher had a strong feeling that money would be discussed frequently by participants and would be listed as a common factor in either becoming a foster parent and/or deciding to continue to be a licensed foster parent who would be available to caseworkers when a child was in the hospital. However, while many participants were quite candid about the lack of available resources available to them as well as how much money they had to come up with from their personal funds, only one participant discussed money as a significant motivator in their decision to care for hospitalized children.

> "In the beginning he didn't have that much SSI. He was only getting $30
>
> a month because he was in the hospital. When it really started kicking in,
>
> it was probably November 2010. Then he was getting $650 a month.
>
> **MV**: But it didn't go to you?
>
> No, it went to the state. The state put it in an account. I think that's
>
> where they got the voucher money from after he had been there.
>
> **MV**: Did that change your motivation-as far as there being additional
>
> funding for you to be a foster parent, for medical versus non-medical?
>
> Yes, I think what you get paid a month is more. It was helpful that we got
>
> paid more, but it wasn't a deciding factor in the sense that we wouldn't do

foster care if we weren't get paid a stipend to take care of them. We did it

because that's what we wanted to do. But obviously, it's helpful because

taking on two additional children on my income was pretty…it could have

been taxing. (Ann, lines 208-227)

Theme 2: The Need to be an Advocate. The need to be a constant and

consistent advocate for the children in their care was a common theme expressed by the

participants in the study. Discussions about the need for advocacy seemed universal in

that nearly every participant would express how important they felt it was. Although not

every participant used the term "advocacy" in describing what they felt was an important

part of their work with the children, each transcript revealed some type of specific story

or case where the participant was challenged to meet what they felt was an important

need for the child in their care. And for most, these needs were often not easy to fulfill

for various reasons. Yet many of these participants felt the need to "work around" the

system if needed, usually because they had some strong feeling or unique insight that

drove their persistent advocacy. This led to the eventual structure of having comments

that fell into the theme of Advocacy fall into one of two subthemes.

Subtheme 1: You have to fight for the kids/have to "work around" the system.

Many participants in the study described their need to consistently advocate for the

children in their care. However, there were many descriptions of how the only way to get

what they felt were important needs met was to fight or go against the wishes of their

caseworker or be more assertive or aggressive than they felt a non-foster parent might

have to be given a similar situation. An example of this was this interview exchange:

It took us 2 months to get him on the right medication he needed for his

reflux. The doctors—I don't know what the deal was, but we had to call

and call constantly to get him on the medication. We had to call to get him

to get the G tube done. We had to fight for that. They were just going to

leave the NG tube in. He couldn't have that at 6 months old. Now that he's

had the G tube in, he's gaining weight, thriving, doing so much better. The

doctors can't even believe it's the same kid.

MV: Do you think that he would not have done as well if you hadn't

stepped up to be his advocate?

No. Honestly, no. I don't think so. If we would have stepped down and

been like, "Well, this is what the doctor said," I doubt it. I think he'd still

be that tiny, fragile—ya know? (Michelle, lines 140-150)

When asked about why they felt being an advocate was so important to them, this was a

good example of how several of the participants felt:

"I think you just do it [advocate] because you want what's best for the

child. You're their voice and you're the one that has them in your home

and you have to be able to speak up for them to make sure their needs are

met. Sometimes it's a battle. You know that the child needs more, but

you can't give it to them. It's a fine line between not pissing off Health

and Welfare, not pissing off the hospitals [laughs], but sometimes you

have to be assertive and say "no, this child needs help and I expect you to

do it." It's kind of crazy sometimes and puts the foster parent in a really

bad situation. I can see if you were a brand new foster parent and how

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scary that would be, having to fight those battles to try to get the help they

need. We've done it so long now, that it's second-nature." (Jean, lines

318-339).

Another foster parent described how her experience had pushed her desire to prioritize

the children's needs to a much higher level, even if it became contentious:

> I really want to advocate as much as possible and get as many resources
>
> involved as early as possible, because the early intervention is necessary.
>
> But they don't tell you all this stuff. And I don't know if every caseworker
>
> is like that. Um, we're on our third caseworker, and she actually seems
>
> pretty open. It might be because I'm a real pain in the ass, honestly. After
>
> two kids I'm like, "You know what, you just need to be straight up honest
>
> with me because I'm not going to continue doing foster care if you don't."
>
> (Jane, lines 658-669).

When asked to describe what she felt was a vital component of her care of foster

children, this participant was very clear about how aggressive she felt she feels she needs

to be:

> Sometimes with certain kids, you have to push. You have to push to get
>
> what the kid needs. They don't know and they're very busy. They have
>
> a million caseloads now, so you have to speak up for your child
>
> sometimes more than if it was your own child. (Becky, lines 319-325).

Later in the interview, she also returned to the theme of advocacy and had this to say:

> You think counseling just happens, but it doesn't. So it really was—you
>
> fought a lot for medical stuff that should have just been standard. And a

lot of the foster parents—not that they do it for the money, because it's

not some rich, fabulous thing—but on a daily basis it can wear you out,

so fighting for more than just "please eat your cereal" can be

overwhelming, so to have to fight for the medical stuff too, I think a lot

of times it just doesn't get done. (Becky, line 646-652).

Finally, although this comment was not about the foster child making the

transition from hospital to foster home rather it was given as an example of a previous

fostering experience, it exemplifies many participants' encounters with medical providers

where they felt the need to go above and beyond what they were initially told:

The doctors said it was eczema. We were like, "This is not eczema. I've

seen eczema before." He said, "Well, put this on her and she'll be fine."

Are you kidding me? So I had to fight for her to go to someone that

would help her and give her the right stuff. (Michelle, lines 158-192).

Subtheme 2: I know what is best. Several participants described how they often

had more knowledge or insight into the specific needs of their foster children. There

were often lengthy and detailed stories about how the foster parent had a perception of

special insight into the foster child's condition or health care need that would conflict

with what was occurring within the "regular" system that was available to them.

Whether this was true or not, this became an important subtheme in how the foster

parents perceived an important part of their role in the care of the child. This participant

felt that some sort of maternal instinct played a role in her motivation to advocate for her

foster child:

"We had to try and figure out who he needed to see and what was wrong. It was stressful. We'd take him to the pediatrician and it was like she wasn't listening. But then it's like, "She's the doctor, so—but I'm the mom." I knew something was wrong, but she wasn't listening. That was very frustrating and hard. It seemed like no one was listening."

MV: "Where do you think that comes from, that feeling when—you're telling me that you know him and they don't…?"

"I think it's a God-given gift that you know as a mother, even though he's not mine. I think that I've five of my own children. You just know when something's off. Biology has nothing to do with knowing something's wrong. I think if you raise a child you're with them all the time and you can read them. You know them. It's hard to explain, but you know when something's not right." (Michelle, lines 281-292).

This participant was very adamant that her time with the foster child, as well as her previous experience gave her an insight about the child that required her to step up and fight for the foster child despite having licensed professionals disagree with her:

At this point, we had already had him over a month. I said, "He doesn't social play. He doesn't side-by-side play. He doesn't really fight over things either. He just walks away if you take it from him. And then you could see him escalate and he would self-harm." And nobody would listen. I said, "I've seen this. He is—if it's noisy in the house and he doesn't know what do with himself because he doesn't know how to

interact with people, then he gets more and more of this nervous energy

and he throws himself off chairs. He bites himself. He threw himself into

window sills. We had stairs—we had to put baby gates over everything

because he tried to throw himself down stairs." And they said, "Well,

this is more of a psychological issue, where he may have been abused

and when the noise got really high and he was about to get smacked, this

is how he de-escalates himself." And I said, "It's not healthy to de-

escalate this way." And we ended up having pica issues and he would

put things in his mouth that he's not supposed to. And dad says, "Well,

I've never seen that." It turns out that dad was never really around, and

the caseworker didn't know what pica was and didn't think it was a big

deal, kids put things in their mouths. I said, "Well, he eats them. He eats

the toys. He chews them. He swallows them. It's a big deal. Because

when he's nervous he eats things he shouldn't eat. He's eating dirt when

there's food. I mean, we don't have locks on our cabinets. When they

want to eat, they can eat. When they say they're hungry, I hand them

something because that's what we were told to do, as long as it's not

ridiculous, you know." And so it took a very long time for them to do

another eval and that other eval said, "This child is significantly

delayed." And so he had some speech therapy after that. (Becky, line

212-251).

Finally, this experienced foster parent seemed to sum up how important it was to continue to advocate for the child while obtaining critical information in nearly every encounter with the health care system they had:

> "He ended up in the NICU for eight days and the PICU for two days. Um, that's when we found out his lungs were under-developed and he had a lung infection. Through that we also found that he had a hole in his heart and two other issues with his heart. So all of a sudden not only did we have a pediatrician, we had a cardiologist, and a pulmonologist, and a respiratory therapist. And we got him out of the hospital just in time to get a diagnosis of cancer that we fought for—not that we wanted that, just wanted to know what was going on—so now we had an oncologist, an ocular oncologist, we had home health, we had a physical therapist, an occupational therapist through home health, we had a speech therapist through Elks [Elks is a rehabilitation hospital loosely affiliated with a local children's hospital]. And I think that's all we had at that moment. So we have worked with a number of doctors for him and we have learned through the social workers in the hospitals where we've been at to ask every single question we could possibly think of, write down any questions before we get there, and be prepared to be pro-active and fight for anything that we feel is what we need to know." (Sheila, lines 248-263).

Theme 3: Having previous experience as a foster parent can be helpful. There was a fairly evenly distributed mix of experienced and new

foster parents that participated in the study. Of those that had worked in the

system with other children and/or had taken children from the hospital into the

home, a theme that centered on how helpful it can be to utilize "learned

lessons" or previous negative experience to improve their care of the foster

child. For some parents, this was important because they felt that they had not

gotten the training they felt they needed.

> We had some experience through another friend of ours that had a child
>
> with more significant drug issues going on. So we knew what we were
>
> getting into, which is why they called us. If we wouldn't have had that
>
> experience, we wouldn't have a clue. Because the state itself did nothing
>
> to prepare us to take a drug baby from the hospital. (Steve, lines 5-8).

This participant was able to remain calm and have seemingly more confidence

than most when she described her first few hours with a new foster baby:

> All we knew was the drugs. All the other things we found out as we had
>
> him, later on. But, just the drugs—I was a little scared. I had my two
>
> other boys with me that came to me at one and two, born addicted to
>
> meth. I was nervous because it was a baby. How was I going to deal with
>
> his withdrawals? But I knew I could cope with it because I helped these
>
> two other little guys, you know? (Michelle, lines 93-98).

Subtheme 1: "I'm glad I was a nurse." One important and anticipated sub-

theme that emerged from some participants was how they felt their educational

preparation as a nurse or health-care worker impacted their ability to care for a child

coming out of the hospital or how much it increased the quality of the care they were able

to provide.   When asked directly about that, this foster parent had this to say:

> **MV**: How do you think that would have impacted a non-nurse foster
>
> parent, especially someone who hadn't been with him all summer?
>
> I think it would have been pretty scary. He definitely needed a lot of
>
> attention and somebody who knew what to look for, so I feel like if he
>
> wasn't in medical foster care it wouldn't have gone as good. I took a
>
> couple weeks off work and got him established with his doctor and home
>
> care and physical therapy. I taught my husband a lot because he was a
>
> stay-at-home dad at the time. (Ann, lines 97-106).

Although there were only some rare mentions of any criteria involving the selection

criteria of foster parent recruitment, a few participants mentioned their feeling that their

medical background or training may have influenced the caseworkers' decision to recruit

them. This comment was one example:

> So we picked him up on Saturday just from being on the after-hours call
>
> list. They weren't looking for someone with a specific skill-set, although
>
> they did know that I was a midwife and had, in the past, worked for a
>
> pediatrician's office for some years. They knew I had some medical
>
> background if he needed some attention on that or that I'd at least be alert
>
> to his breathing and those sorts of things. (Jane, lines 7-18).

There were also several participants who mentioned how their previous experience or

training helped them when the children needed urgent care. This participant has this to

say about a specific incident that she dealt with:

Once I saw that his behavior was changing—and I was measuring his head

as well and saw that it had gone up, and with the behavior changes, then I

started calling him and we were communicating on the phone to see at

what point we were going to take him to the ER. Had I not been a nurse

already, I think I would have not gotten him to the ER as fast as I did. I

think they rely on the home health visits a little too much. (Carla, lines

275-280).

Subtheme 2: I'm glad I had some previous experiences with health issues.
Another distinct subtheme that emerged regarding previous experience working with

CSHCNs was when participants mentioned the fact that when their own family members

or when the foster parent themselves had some sort of chronic health issue, it helped in

their ability to care for the foster child. This participant gave a nice example of this

phenomenon:

On day 9, we got to take Adam home. He wasn't in for withdrawals, he

had failure to thrive, so he would not gain weight. He was born at 5

pounds but dropped down to 4. When we took him home, he was at a 4.8.

We finally got to take him home and the health problems started right

away. My youngest daughter was born prematurely at 29 weeks. She was

in the hospital a long time. She has cerebral palsy and a bunch of different

health problems, so I kind of knew what to look for. (Michelle, line 45-

59).

Although it was only mentioned one time by one participant, this statement from this

foster parent seemed to be very impactful on how her experience living with a chronic

condition influenced her mindset regarding the care of foster children with health issues:

> Generally, people are very intimidated when they hear that there's a child
>
> in need that has a lot of special needs. But in our case, we had previous
>
> experience from some friends of ours that had taken in foster kids with
>
> drug addictions and other similar situations. We already had a lot of
>
> exposure to children like Casey and so were pretty acclimated to what her
>
> situation was going to be like, what she was going to need, what we were
>
> getting ourselves into. It didn't faze us from that perspective. Also, I was
>
> born with a chronic health condition, so I've been exposed to disability my
>
> entire life so I'm not intimidated by it. I believe everyone deserves a
>
> chance. We were the people that were called upon and we were going to
>
> handle the task at hand and bring Casey home. (Jessica, lines 26-37).

Theme 4: Lessons Learned. This category is titled "Lessons Learned" mainly

because participants often would articulate things that clearly were important to them and

they felt needed to be shared. These items most often would come when they were asked

the question "What else would you like to share about the experience of caring for a

hospitalized foster child?" This category seemed essential to include in the study and

while not everyone might agree if these points are actual "lessons", the tone and emotion

of how each "lesson" was described made the primary researcher feel that they earned

their own distinct category or theme.

Subtheme 1: Communication is critical. Perhaps no other issue seemed to be more unifying amongst the participants as to the importance of having clear communication within each of the persons and systems with which these foster parents engaged. The majority of participants had at least one example of how some sort of communication issue significantly impacted their care of the foster child and their desire to continue to participate in the foster system. Many participants in this study expressed their desire to know as much information about the child in their care as possible. But several participants noted how much they appreciated health care workers or caseworkers addressing this need with informative and useful information, as example shows:

> The ophthalmologist, he would spend quite a bit of time explaining where
>
> the retinas had torn, what the risks are, how it's healing, what it's looking
>
> like, and why the retinal hemorrhaging that was happening was the best
>
> indicator of shaken baby, opposed to the brain bleed. And there was one
>
> other doctor. I don't remember his name because I only saw him once. He
>
> actually showed me the MRI picture of where John was bleeding and how,
>
> if it's healed properly, it absorbs, He was pretty informative. He was the
>
> one telling me how much force you have to use to cause this kind of
>
> hemorrhage and, um, and those were some things. He gave me a lot of
>
> useful information. (Jane, lines 285-306).

Another foster parent wanted to describe what she has learned after many years of taking care of foster children with SHCNs in terms of how she shared information with others. And in the end, she points out how important that was as she has realized how things often do not go according to what she has been told:

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Um, we enjoy working with the state [laughs]. There's a lot of people that are afraid of the social workers and view them as the enemy, especially home schooling families. We look at them as an ally, as a team member, and so we provide them information. That's why we send them our Thursday updates. Every case manager, every case, every child. So we keep in direct contact with them, and I don't necessarily expect an answer back. So I send them an email update on Thursday. I don't expect that they are going to respond unless there is a reason that they need to, and then I usually highlight it and put it in red, something to draw their attention to. And those first 30 days, especially straight out of the hospital when the emergency room or the NICU has been involved, everybody wants to know what's going on. Everybody wants to know what is the best option for this child. And so talking with everybody—whether it's email, phone call, texting, whatever their means is—but keeping everybody on the same pages is integral. The goal is that when the child is reunified that that is a happy placement and a safe placement, and the child goes home and the parents are able to care for the child adequately and the child does not come back into care. So, for us in Tim's case, we were prepared to send him home with all the documentation—I have a list, I actually have a book for him of every medical note from every appointment, anticipating that if he moved home, it would help the other providers if everything was laid out. The flip-side to that was, everything was laid out if we were keeping

him as well—which we weren't anticipating doing until we learned in

August that it was going to termination. (Sheila, lines 442-458).

There were several examples of foster parents having what seemed like conflicts

with the caseworkers with whom they worked. Yet during the interviews, some

participants seemed to think that the issue was not a conflict between foster parent and

caseworker, but instead the caseworker being unable to articulate information or even

opinion(s) because of policy or duty. This quote was one example of this:

I think open, honest communication as opposed to pat answers of "We

have to do reunification." If they could say, "Here's the goal. Here's the

difficulties we see with reunification." They can't say that. I mean, who

am I going to tell? I mean, who cares? I know people that if I told them—

not that I would—but "His birth mom's on meth". Nobody cares about

that. We're talking about taking care of the child and not gossiping about

the parents. (Jane, lines 692-701).

Subtheme 2: Information is Critical. When pressed about some of the important

things that the participants had learned about caring for children who had been

hospitalized, having as much information as possible about the child was stated by nearly

every foster parent who participated in the study. Participants often described their

frustrations with how little they knew about the foster child's health issues, issues with

biological parents, or the status of the legal case. Nearly every participant made it clear

to the primary researcher that having up-to-date, relevant information about the child in

their care was essential in their ability to care for the child. This concept is described in

more detail later in this chapter in other themes, however some foster parents chose to

share how the "lesson" they learned about the need for information shaped how they cared for the child being discussed or future experiences with foster children.

This participant's description of how things unfolded when she was able to obtain some of the foster child's hospital records seems to best sum up what many participants touched on when describing their experiences with information sharing:

And even though they [the records] weren't very detailed, they were informative. They described the baby's stay in the hospital. That was a huge factor in why they decided to place the baby in care. It was because—what it said in the paperwork was that the mom refused to hold the baby at the hospital. Even though the nurses would come in and mom would hold the bottle for the baby laying in the bed, but wouldn't touch the baby. The nurses would come in and pick the baby up and hand it to her and say, "You need to hold the baby when you're feeding her." The second they would leave, she would put the baby down. Or when she— when they told her to pick the baby up—and this is when a caseworker was there, and the investigator, and the nurse—they asked, "Okay, can you pick up the baby please?" And she grabbed her by the hand and lifted her up out of bed. And they were like, "Awww! Put the baby back down and we'll teach you how to pick her up." So understanding maybe what may have gotten the baby to the point of failure to thrive was really helpful because understanding failure to thrive is hard to wrap your head around until you see it, or until the environment that the baby was in is described to you. So, having some sort of understanding of why this child

acts the way he acts was nice. But you don't get much information, so I

think with time and experience—which you don't have a lot… -sometimes

you get experienced foster parents that say, "This is not what I want to be

doing. This is too hard. I feel too helpless and there's not enough support.

I can't do every time." Even though you don't encounter it every time, it is

a possibility as a foster parent. You say, "These kids need to be moved. I

can't handle it. I'm about to lose my mind. Rather than give me

information, I'm going to have you move these kids." They don't

necessarily know it's because they're not getting information—sometimes

it isn't—but sometimes, if there was more information and support, kids

could stay and [foster] parents wouldn't lose their minds. (Betsy, lines

638-674).

While this participant described how challenging it can be to deal with the issue of lack

of information, she also goes on to clarify what many other participants in the study

described - a conflict with policy(s) that puts caseworkers in a difficult situation:

I did talk to the caseworker about that and explained to her what a

difference that made for me. And they said, "Here's the thing, it's a

double-edged sword." They explained that it's difficult to give more

information and to find a happy-medium, because the problem is that

knowing more details about what the parents have done to the children has

the opposite effect rather than being a good thing. In the past, it has been a

bad thing. The foster parents no longer want to deal with the birth parents.

They resist reunification, which is the whole goal of foster care, and it

kind of backfires in a way. The more information people are given, the

more they don't want to do the work, and the more they don't want to help

the process. So they run into that problem, and I kind of understand it, but

it's difficult to come from a position that doesn't use—that I don't use the

information in that way. It's difficult to not be allowed that information,

but yeah, more information is really important. (Betsy, 706-725).

Another experienced foster parent was also able to articulate a potential

communication barrier that she has dealt with, but offers up a potential solution that she

thought of, based on her knowledge and experience:

Often times the case manager doesn't even see the child until a while later.

And I think that it's very good for that case manager to see the child when

they are first coming into foster care. And if the case manager is gone,

have someone else from the department stand in, and give a face—because

the hospital can tell things to the case manager that they can't tell us. And

if the case manager is there, we can get that knowledge. (Sheila, lines 962-

981).

Summary. These themes clarify and differentiate the principal experiences of

these participants in a meaningful way. As stated previously, each individual in the study

offered their unique perspective on fostering children coming out of the hospital, as well

as foster care in general. And while most participants were clear about what they think

could be improved within the system or system(s) that they dealt with, the organization of

this section served to demonstrate how meaningful these experiences were to each

participant.

Research Question 2: The Positive Aspects of the Experience

The second research question for this study focused on the positive aspects of the experience of taking the children home from the hospital. Participants were asked directly to describe what they considered positive aspects and from these answers, three themes emerged: a) caseworkers and health care workers meeting the needs of the foster parents; b) health care workers being supportive; and c) the effects of the experience on both the foster and the biological family.

Theme 1: Caseworkers and/or Health Care Providers meeting the needs of the foster parents. Many participants described situations or experiences where their assigned caseworker made a significant positive impact on their experience in the form of support, usually through high-quality communication skills or experience. One participant described it this way:

> Um, I—my caseworker, the safety assessor who was just for the first 30
>
> days, um, she's really good at giving me more information. This specific
>
> worker—I've worked with her on more than one occasion and she is one
>
> of the better—I was fortunate—she gives the most information of any of
>
> the workers that I have ever worked with. To me, it was all really valuable
>
> and helpful and really supportive. (Betsy, lines 547-575).

Another participant suggested that her caseworker made her feel supported not just with excellent communication and information sharing, but also with an anticipation of what the foster parents' needs might be:

> I never met her before, but we [foster parent and caseworker] clicked. I
>
> don't know if it's just because we were able to pull it off and bring them

both home fast. My husband and I are pretty easy-going and go with the

flow and we just work from there. I have heard that too—that people have

a hard time getting things. I never felt like—I felt like any time I called for

a voucher—and they would even call us. (Ann, lines 187-190).

Another example of this theme came in the way that the caseworker was able to

negotiate the tightrope of assisting the biological parents while supporting the foster

parents:

She [the caseworker] was a great communicator. It wasn't just her ability

to give information, but her ability to return phone calls [laughs]. It was

great! And she was just very supportive, um, in small things. For example,

we put all of our kids, when they were that young, to bed at seven-thirty

and Sara's mom insisted that she goes to bed at nine-- and the caseworker

facilitated a great conversation about children's development and how

much sleep they need, and supporting us while we had Sara but also

reassuring her mom that when she got her back she could go back to her

old schedule. She was very good about that. (Alicia, lines 251-277).

Theme 2: Healthcare workers being supportive. Many participants were eager

to discuss their interactions with healthcare workers when asked about the positive

aspects of foster hospitalized children. The vast majority of discussion(s) about

interactions with physicians and nurses were positive and resonated with descriptions of

participants feeling as if physicians and especially nurses would put in extra efforts,

clarify important information or sometimes show favoritism to the participants if they

knew that they were foster parents. An example was in this statement:

The nurses and the physicians in the NICU were congratulatory of us.

They treated us like we were first-time parents. They treated us like we

were bringing home our baby. It was a very unique experience, and we

were new—we hadn't taken a baby home before, so we had nothing to

base our experience on. We had no prior history. But it was actually quite

amazing and joyous. The staff understood what our role was. They

provided whatever support they could. They provided education, as much

time as we needed with them. It was great. (Jessica, lines 56-66).

There were also comments about nurses implying that they (the nurses) had

experience with discharging infants into foster care and therefore would put in some extra

effort or energy to help the foster parent or protect the foster child. The following

comment is an example of this:

They were very informative and very helpful. She even ran off other

things on methamphetamine addiction and oxycodone addiction, because

she said that "We don't know if he is, but these are the signs to watch for."

She also said, "Be careful popping his back, because if he is addicted, it

could go back in his system for 30 more days." So we were really careful.

She showed us how to pick him up, so we wouldn't pop his spine. They

were just very helpful, very informative. They knew he was going into

foster care, so it helped out. (Michelle, lines 425-430).

Or this comment inferring that the foster parent might need extra supplies based on the

nurses' insight: "One of the nurses was a foster parent and she knew the lacking's of the

system [laughs]. And so she was able to get extra diapers and things she knew we probably wouldn't get." (Carla, lines 249-263).

Many foster parents described feelings of not only being supported, but actually being favored by the nursing staff during visitation or discharge teaching. While often subtle, this comment described a very direct opinion from the nursing staff: "They [the nurses] did make a few comments about shaken baby and how this mom shouldn't get him back. Those kinds of people have their opinion, like, "This is really bad. I hope he stays with you." (Becky, lines 246-262). Or this comment about how the child in care may have gotten some type of preferential treatment due to his foster status:

> They were very willing to give support while he was in the hospital and if
> we had questions or any concerns at all, home health took over and was
> quick to respond. If there were issues the nurse would help me and make
> sure I was talking to the right person, which expedited the process of
> getting help for him. That if it was just a patient calling in, I don't know
> that I would have gotten as quick response. (Carla, lines 382-390).

During the discussions of follow-up care for the foster children in care, some participants painted their encounters with the system in a positive light, such as with this description:

> So even though we have our own private insurance, everything is through
> Medicaid for them. So long as you go to a provider that takes that. We
> haven't had any issues. Every health care provider we've had contact with,
> I've never had any issues with. Their availability has been excellent.
> Yeah, health care has been great! (Jessica, lines 347-358).

Subtheme 1: Being provided with important information with clear communication. A subtheme that seemed to emerge within the context of foster parents feeling supported by health care workers was one of clear communication of necessary information to the foster parent by the health care worker. Participants would express a feeling of being valued for their work when they felt that the nurse or physician took extra time or made some type of extra effort to clearly communicate some important detail about a task or an appointment related to the foster child. This participant described how consistent efforts to provide information added to her experience of fostering: "Um, the nurses shared a lot. And that was really helpful. They confided a lot of information to us. I don't know if they were supposed to do that or not, but they were so wonderful." (Vanessa, lines 83-90). Another participant clarified how his feelings of being supported when the nurses gave him insight into why things were being done in the care of his hospitalized foster child:

> And the nurses—they were really amazing. They also spent a lot of time helping us understand the monitors. I think after the first few days we had a really good understanding about what he was going through and also the process of how they were trying to make it better and how we were participating in that process as well. (Mike, lines 92-99).

Nurses were described in very positive terms by the vast majority of participants in this study. Some participants went into detail about why they looked on the nurses they worked with in a positive light regarding their communication and information sharing abilities:

The nurses were the ones that were there for us, the ones that knew him,

the ones that would ask to be on his shift or that would move our rooms so

that we could be with them. You get to know the nurses really well when

you're in chemo treatments or clinics. They know the rigmarole of chemo

and toxic drugs. I would call the nursing staff before the oncologist.

Because they were the ones that were there for the child. They were the

ones that knew how he reacted to his chemo treatments. (Sheila, lines

310-319).

There were also many descriptions of positive encounters with physicians and how the

communication skills of the physician made the experience much more positive for the

foster parent. This quote was an excellent example:

The physicians—there were actually two physicians caring for her during

the two days that she was there when we knew her, and I spoke with both

of them at length—one on the phone quite a bit. He would give me

updates every time he rounded. He was very thorough, very patient, and

willing to answer any questions. There were times when I actually called

him throughout the rest of the day with questions. He was always very

willing and really patient, was not hesitant or made me feel rushed or

hurried—nothing like that. He was just very willing to be a support to us

at this time. It was a great experience. I have nothing but great things to

say about that staff. (Jessica, lines 91-101).

Theme 3: How the Experience Effects the Foster and Biological Family. A

significant theme that emerged from the interviews with foster parents was the effect of

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the experience on the foster family. While this effect was sometimes expressed as a challenging or negative memory (which will be discussed later in this chapter), many participants described the effect of having a foster child coming home from the hospital in a positive light. Out of these varied descriptions, three subthemes emerged.

Subtheme 1: Helping the biological parents be better caregivers. Several foster parents made it a point to describe to the primary researcher how impactful it was to be able to help biological parents become better caregivers. This was often described in a positive way, even if it meant that the foster parent would have to give up caring for the foster child herself, as seen by this example:

In the beginning, I was told that unless she did a 180, she would not get her [the foster child] back. Um, and she did. She worked. Uh, I'm so proud of her! [laughs] She put in a ton of work and did what she needed to do, and it was a great process to watch her get her back. (Alicia, lines 331-364).

Other participants described how they would go over and above expectations to help the biological parent, usually because they knew it would most likely ultimately benefit the foster child. The following is an excellent example of this notion:

They were doing all the visits at the office supervised. And he [the biological father] hated the office. He told me, "I hate this office so much." And it's true. It's not inviting, it's not friendly, and they have a building where you can take a social worker there. You can make lunch, there's a living room, ya know. And I said, "Well, let me talk to your caseworker and see if you can get moved over there." By that point, within

about a month and a half, he really had mellowed out and appeared more

normal, and when he started visiting there he was a totally different

person. And then we said, "Okay, he can pick up at our house, because

picking up and dropping off in a parking lot with the kids crying, no. Let's

not do that. You can pick them up at our house and you'll have your

person with you to monitor them, and we'll put them in the car here and

you can drop them off here." And that transition went better, and the kids

didn't cry anymore when he was coming. And he would ask questions

like, "What are his favorite foods? And why does he cry every time I give

him a bath?" Then it was more—they were more wanting to know about

their kids and doing better. (Becky, lines 352-386)

Subtheme 2: The influence of the child on the foster family. Many participants

expressed how positive an experience it was to have the foster child come into the home

and influence other individuals in the foster home. Most of these stories involved how

the biological children of the foster parent were affected by the foster child. This

participant felt that the presence of the foster child gave her own children much better

insight into how to treat other people with medical conditions or disabilities:

The thing that I see residually now is the care my children give to others

that are different. Um, they are compassionate. They love, and I think they

see them as a, um, as people, not just as machines and equipment and

"weird." Like I think they see other children with disabilities as real

people because they were able to experience that and see Stephanie as a

real human that had the ability to communicate, even if it was different. So

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I see that in them now by the way that they treat others. It's been

awesome. (Courtney, lines 196-209).

This participant had a similar experience with her family:

I think that it's helping our family grow closer. It's helping us learn how

to take care—we've never done a G tube. We've done an NG tube because

of Meagan [biological child]. So it is helping us take care of a medically

fragile baby. In that sense, in case it ever occurs in the future for any other

foster children we may have. I like the fact that it's helping my kids see a

different side. (Michelle, lines 255-274).

Or this comment about how being able to help care for a younger baby was beneficial to

the participants' son:

Any child we are fostering adds a lot to the home and my son loves having

foster siblings. That was the only real baby we've had in the home, and he

loved having a baby around and helping take care of a baby, or learning

how to be with a baby. It was really beneficial and made him feel like a

big brother, and it gave him a lot of…added a lot of quality to his life.

(Betsy, lines 354-359).

This foster parent made it clear that the impact of having foster children in the home not

only changed the living status of her daughters, but also influenced their career decisions:

I would say that the biggest positive is that my girls who are now in

college have all opted to stay home, to live at home or stay locally because

they want to see these children grow up. Another positive is that both our

older daughters have decided to go into social work. (Sheila, lines 531-538).

There were also some general comments about how the foster family had made some type of change in their routines, even after the foster child was not present in the home anymore. This comment was a good example:

The family taught us recipes because they were Native American and Hispanic. They gave us recipes that we could work for the children that they were familiar with. They taught us songs that we could sing them to go to bed with because that is what they had done in their home. So we took on those traditions. I have to say two years later, we still cook those recipes. It's become a part of our family and our culture. And sometimes we laugh at the fact that, "Hey we had this recipe from that child." But that's part of how the foster children impact us as a family. (Sheila, lines 478-500).

Lastly, there were often comments or descriptions of experiences from foster parents about how hard or challenging the care of the foster children was or discussions about frustrations with many of the systems they had to deal with. Yet many participants, when asked directly, would seem to feel the need to express some sort of positive aspect of the experience, despite their frustrations. This comment was an example:

So someone asked me last week, "Do you recommend that we do foster care?" It was weird, the honest answer was "It's so overwhelming!" But the reality is, it is so wonderful to have him and to have him bless our other children, to have that interaction, and to watch him grow up, and to

know that he's in a better place. Everything about him is positive.

(Vanessa, lines 219-229).

Subtheme 3: Watching the foster child grow and develop. This subtheme was a strong presence in many of the interviews for this study. Many participants expressed a sense of joy or some sort of feeling of accomplishment when discussing why they continued to foster or especially when pressed to describe positive aspects of working with hospitalized foster children. Many participants teared up and/or became emotional as they reflected on some of the milestones they witnessed in the lives of the foster children or how meaningful many of the events were to them as they occurred. This statement was typical of many comments:

> We watched this girl go from not passing 6th grade twice to graduating from high school and she started college last week. That has been huge for us. And watching Allan go from this micro preemie to starting kindergarten last week. That has been our reward, seeing these two do so well. (Ann, lines 308-319).

Or this comment about how, despite overwhelming issues, the foster parent found some reward in how she felt she impacted the child's condition:

> Within three months, he talked, he fed himself. We never could potty train him [laughs]. That was about—we were not—that was one battle we did not take on hardcore. I let dad deal with that when he got them back. Um, the self-harm was drastically reduced. Pica was drastically reduced. He was in preschool—and I'd like to think that, because he was so little, it made a difference that there was normalcy and positive affection. There

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was normal consequence to things, instead of such a drastic—you know,

you did a little thing and get into huge trouble. (Becky, lines 461-475).

This comment seemed to sum up several of the participants' feelings about how their

work and care of the child made a difference for the foster child and made the experience

of caring for the child a positive one:

Little accomplishments that she had been able to do that she probably

would not have been able to do had she remained in the hospital setting,

and the growth that she did. Like, she eventually was able to sit up on her

own. These developmental landmarks were super important to me—so

sitting up on her own, then learning to crawl, then learning to stand. I

think those kinds of these really were like, "Wow, she's really thriving not

just surviving." She was not just living on a ventilator, she was thriving.

(Courtney, lines 180-195).

Summary. The comments about the positive aspects of caring for hospitalized

foster children were numerous and varied with these participants. It is important to

mention that many of these participants became emotional during the interview when

discussing things about the foster experience that they considered positive. It was quite

clear to the primary investigator that nearly every participant had deep feelings and

attachments to the children they cared for, and many of the participants stated this openly.

Research Question 3: The Challenging Aspects of the Experience

The third research question for this study was an attempt to allow participant to

voice what they considered challenging or negative aspects or elements of caring for

foster children making the transition from the hospital to their home. As with the

previous section, participants were asked directly to describe what they considered

challenging or negative. There were also many statements and discussions that occurred

in response to other questions that the primary researcher gleaned from the data and

categorized into this section. After a thorough analysis, six themes emerged: a)

communication issues; b) conflicts with policies; c) taking care of children with special

health care needs is stressful; d) lack of knowledge of the health condition/health status of

the foster child; e) lack of resources; and f) conflicts with biological families. There are

also various sub-themes contained within the themes which will be presented here.

Theme 1: Issues with Communication. Of all of the issues that participants in

the study labeled as a having a negative effect on their ability to care for foster children

transitioning into their home, breakdowns in communication or lapses in communication

related to the foster child was a near universal theme. Nearly all eighteen participants

had a story to tell about how they had to overcome some sort of important issue that

required their effort due to some sort of communication issue. This comment was one of

many examples offered:

> I didn't hear from anybody for two weeks. Then a month later I got a call
>
> after-hours saying, "The police want to make sure you have this child,
>
> because someone says they have the child." I mean it was a mess. (Betsy,
>
> lines 651-658).

As the data analysis took shape, two subthemes within the context of

communication problems were identified.

Subtheme 1: Working with an inexperienced caseworker/inexperienced health

care provider. Participants in this study related many stories about how much they relied

on their assigned caseworker to adequately care for the foster child. And so it was not surprising when several of them expressed frustrations about how a relatively new or inexperienced caseworker would create a significant challenge for the foster parent. Many participants expressed a perception that it was the new caseworkers' inability to communicate or anticipate what the foster parent might need to know as the driver of the foster parents' frustration. This comment by Jessica was an example:

> I think primarily our issue was new case workers coming on. We didn't have one specific case worker from beginning to end. They did hand it over to a new gal that didn't have experience in that job. We were her guinea pigs and she was our guinea pig. It created a lot of challenges and stress because she didn't know the process, the system. She was learning as she went along. (Jessica, lines 145-174).

This foster parent described a situation where she had a conflict with a new caseworker who was not aware of important policies that the foster parent had already been dealing with for some time:

> The new case worker kept arguing with us and telling us that we were jeopardizing Casey's safety by not providing a car seat. She made us feel like we didn't care about Casey. I had to go to a manager and found out that they should have been providing the car seat from the beginning. (Jessica, lines 240-262).

This participant describes his frustration with the lack of communication going on, and also goes on how frustrated he became when he tried to address the problem directly:

I don't know how long she's been at it, but her communication skills the

first 3 months were horrendous. It was more frustrating than not from our

perspective. She was like, "Yeah, I'm bad at communicating." And we

were like "You're the only one that can fix that. You have to fix your bad

communication. We don't know your job so we shouldn't be following

through with stuff that we should be talking to us on. We had this big

meeting and I mentioned that and got jumped on by the Health and

Welfare people. Ya know, I was thinking, "I don't need this." I didn't

need to come to this meeting with the supervisor of Health and Welfare to

be attacked because you misinterpreted what I said. I have a couple rough

edges from the system, as you can tell [laughs]. (Steve, lines 320-336).

This story sums up both the foster parents' frustration with the inability to give

consent and having an inexperienced caseworker leads to the "perfect storm" of

significant frustration when the caseworker fails to communicate their status:

If they [caseworker] don't show up and don't their job, it makes it

impossible to do yours. When they don't show up for a doctor's visit, or—

we had a scheduled, um, surgery for one of our foster children where the

case worker did not show up and they were going to cancel her surgery.

We couldn't get her on the phone, she didn't show up, um—she finally did

call. My husband did wait 45 minutes after the scheduled time for her to

call and say, "Oh, I'm so sorry. I overslept and didn't hear my phone."

And stuff like that happens, but for us it was really irritating. (Becky, lines

541-553)

This participant described a situation where the inexperience of the health care provider seemed to erode her confidence in his abilities as a physician:

I think that he was in and out of the room seven times the time that we were in here. He finally came in and sat down and kind of gave a sigh of exasperation and said, "That child has retinal blastoma. Do you know what that means?" And I quickly put two-and-two together and said yes. He says, "Okay, I'm going to give you some time to think about it." And he walked out of the room. And I never saw him after that. It was another physician that came in and I think he was having a really hard time struggling with the fact that here's a 13-week-old that has eye cancer and their office had never diagnosed anyone with eye cancer. I don't think he really knew what to do with a foster child because I think he expected me to respond differently than a birth parent would. But he's only ever worked with birth parents so he didn't know what I would do. I think he was in a very uncomfortable position. (Sheila, lines 347-379).

This comment was an even more succinct example of lack of confidence in the health care provider as their ability to communicate important information became clearer to the foster parent:

I would ask him [physician] a question and he wouldn't know the answer. He would literally—I wish I could remember some of the questions I had for him. Um, just like, "I don't know, I'll have to find that out." And I didn't understand why he didn't know. Why don't you know this? Um, so I don't know. He just didn't seem up to par. Because I took John out there

prior to taking him to the hospital because he was sick. I was asking him

about these things, and he was like, "I don't know, just give him this

nebulizer and do these things. And I was like, "Well, why do you want me

to do this if you don't know what's wrong with him. Like, I don't want to

be treating him for something we don't know what's going on." And he

was like, "well, I think this is the best thing to do." I don't know. He

couldn't answer my questions about vaccinations and why he was getting

a rotavirus one when he wasn't in daycare, and you shouldn't be giving

that if you don't go to daycare and aren't around a bunch of kids. He just

didn't have a lot of great information, in my opinion. (Jane, lines 344-

364).

Subtheme 2: Conflict with Systems. Communication breakdown within or

especially between the various systems that participants navigated was described by

many foster parents. As these caregivers relied on child welfare systems and health care

systems to assist them in meeting the needs of the children in their care, they also often

had to deal with the legal system as well. This led to many stories and descriptions of

negative events that affected the foster parents' ability to adequately care for the child.

This story was a great example of how challenging it was for the foster parent to

just come and visit their assigned foster child prior to being discharged from the hospital.

It involves all three of the systems the participant was dealing with creating roadblocks

for her ability to care for the child:

It was kind of complicated because some of the nurses didn't know that

we were allowed to be there even though we had the documentation from

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Health and Welfare that we were taking her home. They didn't always

want to be forthright with me with information because they questioned or

not whether we were the people that were supposed to get that

information. So we had a heck of a time with hospitals for a long time, and

then I finally got frustrated and called Health and Welfare. We met with

the administrator of the hospital and we didn't have any more problems

after that—but the first week was difficult. And another part of it was the

court orders from Bonner County were not necessarily in jurisdiction for

Kootenai County, and that was a mess even though it was a judge here that

signed that the child was to be placed immediately into foster care upon

leaving the hospital. It wasn't a Kootenai order, it was a Bonner County

order—so that just—when you have to cross those county lines, it gets

really difficult. (Jean, lines 31-43).

This participant describes a major breakdown in communication between the legal

system and the child welfare system:

We had an attorney help us become her legal guardian and just—I can't

even wrap my brain around everything that went wrong. Basically, they

never took all the steps that were necessary to fully complete that,

although we received documentation that it was completed. A week or two

after Stephanie passed away, her guardian ad litem called me and said,

"Hey we'd like to set up an appointment and come and meet Stephanie,

and, ya know, get this information to the judge." So that continued on for

months after Stephanie had already passed away. (Courtney, lines 263-

274).

This story from Michelle describes how the health care financing system (Medicaid) was

not in sync with her perception of the foster child's needs. She also eludes to a stigma of

"foster child" versus biological child:

I called them and said, "I have a little foster girl and she was referred here

for a rash and she needs to be ASAP." They asked for her insurance. I said

it was Medicaid and they were like, "Oh, well the first Medicaid

appointment we have is 3 months out."

MV: They actually used that phrase?

Yes. They said "Medicaid appointment." I was like, "She's two-years-old

and she's itching like crazy. Are you kidding me? You can't get her in

sooner?" And I said the doctors' name. "He really wants her to seen."

Then they were like, "Oh, if it's doctor so-and-so, we can get you in next

week." I was like, "Oh really?! Now that I used a doctor's name, then

you're willing to work with me." Maybe if I hadn't said she was a foster

kid, I don't know. (Michelle, lines 457-487).

This participant describes an essential underlying conflict between the need for

some type of efficiency in a system and the needs of an individual child with significant

health issues:

I think the issue is that the department is a bureaucracy. It has its strengths.

It takes this massive issue of taking children that are being neglected and

has built a good system to protect the children, um, physically. But then

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you come down to the emotional, bonding side a child needs, and they

need to be loved. They need to form those bonds. What happens is the

department wants to process these children. We've heard from case

workers, "I've got 30 kids. I've got 40 kids. Different cases I'm trying to

balance." And like any situation, we all have our own jobs, when you get

overwhelmed you go into production mode, and you can't do that with

children. Each child is a person that needs to be loved. (Mike, lines 295-

312).

Theme 2: Conflicts with Policy. Of all of the themes that participants in the

study discussed, being frustrated and/or confused about many of the policies that guided

the rules of foster parenting generated the most lengthy and passionate responses. Many

foster parents took the time to carefully explain to the primary researcher exactly how the

policy worked or was intended to work. The careful and detailed explanations often

seemed to be presented in an effort to convince the researcher (or anyone that might read

the final study) about how much they wanted the policy to be changed. Although this

will be discussed in more detail in chapter 5, it should be mentioned that many

participants discussed with the primary researcher their desire to participate in the study

with making a change in the current system as a major motivator, not just the $25 gift

card. And so when the topic of challenging issues came up during the interview,

frustrations with various policies garnered much of the time of each interview and

generated lots of emotion as the participants told their stories. In an effort to properly

contextualize these responses, four subthemes were created that best organized where

participants felt that policies created challenges to their ability to care for the children and became a negative aspect of their experience.

Subtheme 1: Reunification. Many participants in the study described in very strong terms how much of a negative impact the policy of making the reunification of foster children with their biological parents a priority over other options was. These feelings seemed to revolve around the timelines of the reunification process as well as the amount of resources provided to the biological parents during this time. An example of foster parent frustration was illustrated by this comment:

> Where I have concerns with the system is that I sometimes feel that when
> it gets close to those deadlines, I think that their standards are very low.
> One example is if a birth parent wants their child back, they only have to
> prove sobriety for a few months. And we all know that addictions are very
> difficult to beat. You might be able to quit for a couple months, but that's
> a short amount of time that might not stick. I think the state is too quick to
> return kids to parents after such a short amount of sobriety. I think, too,
> that basically their main criteria is the child has to be safe. Their life can't
> be in jeopardy, but peripheral circumstances don't matter as much. So it
> doesn't matter that they're living on food stamps. It doesn't matter that
> they could barely pay their rent. It doesn't matter that maggots are in the
> laundry room. It doesn't matter that they don't have a vehicle and they
> have to transport their kids on the back of a bike when it's 15 degrees
> outside. It doesn't matter as long as they're clean and showing some signs

of stability. I struggle with the fact that they return kids to the birth parents

before they are truly stable. (Jessica, lines 321-344).

The foster parent participants were not shy about offering their insights into how this issue of "prematurely" returning the children to the biological home may affect the children. The following comment was a good example of this issue:

The whole system isn't designed for success, in my opinion. They want to

push the kids back to the parents as fast as they can whether the parents

are ready or not. The parents go through these hard times, then the state

sets these minimum goals and they get the kids back. Okay, that's all nice

and good, but the reality is if it's only been 3 months, they haven't learned

anything. If you have a whole lifetime of doing certain things and acting a

certain way, you're not going to change in 3, 4, 5 months. You need more

education, more time, more ways to deal with stress, things like that. Kids

are stressful and what I've observed is the system wants to throw kids

back with their parents in a lot of cases when the parents aren't ready. And

what happens is the kids go back into foster care down the road. All that

does is ruin the kids. (Steve, lines 228-269).

Another comment that seemed to exemplify several participants' frustration with the reunification policies effect on the children in care was this one:

We've been told by the department that our emotions don't weigh into

this, that our bond with Cody doesn't play into their decision about where

he should be placed. My question still comes down to what they said

originally, which was "We don't want a child to be in foster care for more

than 15 months, because taking them away from that is too emotionally damaging to the child." So the department realizes there's an emotional attachment that happens, and yet when we express "We've come to love this little boy and feel like we would like to be considered as a potential to adopt him." And they say "Absolutely not, because that's not how we do it." Um, you just feel like the bureaucracy is so entrenched in its process that they've forgotten that it's about the child. He's the victim, and his best interest should be served above all others. Now who decides that is the key. Right now it's the department of Health and Welfare and they're a system. There's no place for hearing what the child would say, if he could speak. (Mike, lines 326-354).

It also became clear that several participants had developed a perception that the caseworkers that they were working with did not agree with the policies that they were tasked with enforcing. Participants would relay tales of how caseworkers might "let their guard down" or even trust the foster parent enough to be "honest" with the participant were not uncommon. An example of this is seen in this comment:

Depending on what Health and Welfare caseworker you get—I'm pretty straight forward, and I'll tell a case worker that I think reunification is a bad idea. And they can't say, "I agree with you." [laughs] They have to say, "Well, we need to work their plan" or—what I really feel like is they can never be honest which has to be horrible. (Jane, lines 591-600).

Jane also went on to illustrate her feelings with a specific example:

It was the mom's decision to terminate parental rights because she thought

John was best with us. Despite Health and Welfare telling her she has to

finish and reunify. So I think the most positive part was her recognizing

that John was growing and being healthy and she wasn't able to provide

what he needed at that time. And so that was positive. The negative side

was that Health and Welfare disagreed with her and she had to go

terminate her rights by herself with her lawyer. (Jane, lines 553-559).

A major element of this subtheme about the policy of reunification was the

difficulty foster parents had in emotionally attaching (or not) to the children in their care

because of how the reunification policy added a much higher "temporary-ness" to the

placement. Many participants made it clear that not knowing if or when their foster child

might suddenly leave their care might have been the most negative aspect of this

experience. Two of the best examples of this concept are offered:

I think that's one of the most frustrating parts about being a foster parent.

It wasn't just a month she was in our home, she was there about a year and

a half at that point and we developed such a relationship with both of

them. They were like our kids and knowing what kind of situation they

were going back into, it was disheartening and scary. I know the social

worker and the state's attorney were on our side, but their hands were tied.

We see and know what's going on. I just feel like they always want to put

the kid back with the parent, even though it's not appropriate. Even after

giving parents chance after chance to pull their crap together and they

don't, and they prove time and again that they're not going to, but "Oh

let's give them 60 more days to figure this out!" It's so frustrating when

you know nothing's going to change. Quit giving these parents that fail

time and time again so many chances. How many chances do we have to

give them before enough is enough? It just seemed like it was endless.

And you're doing nothing but costing the court and social workers time

and money. It's just frustrating. A year and a half of the unknown. In all

of that time, it's not like you're going to bond with the children. They do

tell you the whole time that the goal is to be reunified with the parents.

And you step back and go "Why?" (Ann, lines 440-498).

And while this issue was described by many participants in a negative sense, this

participant was able to describe how challenging it was for him and his family and yet

still find hope rather than be discouraged by it:

We feel like we're his parents, we're his family. And yet we are constantly

reminded by Health and Welfare that we're not, and so the emotional part

of this is that you form the attachment to him. We're the ones that are up

with him at night, or change a diaper, or feed him, or play with him. You

form this bond, and yet there is the constant threat that he'll be taken and

put somewhere else. So that is the most difficult part of this process, is

dealing with the emotion of knowing that he is, in essence, terminally ill.

At some point, he will be taken from your family unit after you have

bonded and loved him, and brought him all the way in. And the reality is,

it feels like every month he could be dead, like he's terminally ill. So you

go through this grieving process knowing he's going to be taken. Then

you go to court and find out that he's not, so you have him for another

month. It's again—another six weeks from now, there's going to be

another hearing, so it's a really tough emotional burden but it's worth it. I

wouldn't go back and say, "Never mind, we don't want him." (Mike, lines

231-261)

Subtheme 2: Consent. Another policy that some participants choose to paint in a

negative light as it pertained to the experience of caring for the children was the fact that

because of the legal status of the foster child, they rarely had the ability to make actual

decisions about the medical care of the child or sign a consent form for any treatment to

be done, even in an emergency. This seemed best exemplified by this comment:

There's been times I've had to take a child in the middle of the night to the

ER and it's really difficult for the ER doctor and nursing staff because

they're making phone calls in the middle of the night to get Health and

Welfare to do whatever it is that needs to be done. As a foster parent you

can take him to the doctor, but if it's the ER, you're fighting tooth and nail

with the hospital to get that done. I had a child not long ago that was

taken to the ER. Her appendix ruptured and they were like, "We need to

do surgery on her, but we can't because there's no consent from Health

and Welfare." It's like, what do you want me to do? Let the child die, or

do the surgery? Ya know, its things like that. You take the responsibility

and you pray and hope that you made the right decision, you fought with

the hospital, you got what you needed, then Health and Welfare calls and

says, "Sorry." And you have to fight with the hospital too because you're not the legal guardian. (Jean, lines 285-317).

As mentioned previously, foster parents in this study described conflicts with biological parents, however this conflict was magnified when the foster parent felt like the child welfare policy supported the biological parent over the foster parent in times of disagreement as evidenced by this comment:

I find it interesting that Health and Welfare took away the rights of the mother, but she has medical rights for him. That's not to me, smart. There would be a lot of times when he would get a fever and mom was just adamant—no it was a cough—she'd be "You go take him in!" for every single cough. Well, we have three other kids and when they get coughs we treat it with what we got at home. They're usually over their coughs in two weeks, but it takes some time, but it's not a big deal. They just get over it, but she always wanted him—and I didn't have any rights with that, so I had to allow her to have that power. I think that was the hardest part—in fact the doctor caught onto this quickly—that mom was very adamant that he be taken in for the smallest things, and the doctor would just say, "He's fine." I think it's because her propensity is that if you're uncomfortable, and if you're not well, you must take a medication to heal. I think that's how she's always been raised, so she always wanted that for him. (Mike, lines 172-183).

Subtheme 3: Sharing of Information. Lacking information was a noted frustration with many participants. This became a subtheme within frustration with

policy when comments or descriptions of events revolved around the actual policy the participant was working under being the source of the foster parent not having the information they felt they needed to be successful. A good example of this was stated with the following comment:

> I know that there is a lot of information that is not being given. The
> confidentiality law is that we are only provided as much information that
> is necessary. So if it doesn't seem necessary for the safety of the child, it is
> not something you are allowed to say. So as a case worker, you have to
> decide, or talk to a supervisor to decide what is considered necessary
> minimal amount of information. So you have to look at stuff and say,
> "What's necessary for this person to know for the basic care and needs if
> this child." And so it's difficult sometimes knowing that there is more
> information out there, and someone is deciding what you need to know.
> Depending upon how much personal knowledge you have of something,
> or some condition, or the foster care system, or the medical system, or any
> other system that we're working with—sometimes you need that extra
> information for it to click in your brain. (Betsy, lines 547-575).

This participant seemed feel like she wasn't being included in important communication due to the policy of the agency:

> I understand that the case worker doesn't have answers. I do know they
> are doing plan A, plan B, planning for the girls' future. Plan A is
> reunification. Plan B is plan B. I don't even know what plan B is. I talked
> to the case worker last week and I said, "Hey we have court coming up in

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the middle of August and it's a permanence hearing. I would like for all of

us to sit down and talk about what that's going to be like, as a family, so

the girls go into court and have a better idea." Like what is the outcome

going to be? I understand Health and Welfare doesn't have all the

answers, but a little bit more communication would be helpful. (Roxanne,

lines 417-455).

This comment was an example of what many participants expressed about how policies

about sharing of information became a detriment to their ability to care for the foster

child:

When a child's coming from a hospital you have generally blood work

that is coming with it, you have all the doctor's notes—they're coming

with it. And a lot of times, the caseworker has to contact the doctor and

say, "Okay, tell me about this," and get more information. And so it can

slow down that process because the caseworker has to get all of that

information together before they're going to contact us—afterwards, the

second time, after the child is already in our home. So it's just more

paperwork for the case manager. It's more information that they have to

sift through. The plus side of that though is that they have more

information that they can then share with us. So they're able to tell us,

"Positive for these drugs, or has this health history." So we're going to get

it, but it's going to be delayed. (Sheila, lines 710-728).

Subtheme 4: Feeling unsupported because of specific policies. This subtheme

emerged from participant's expressions of how they felt that the system (how policies

formed the process) created an unsupportive atmosphere for the foster parent. An example of how this parent felt about her encounter with the legal system:

I think the court system was the hardest. I had a good relationship with Health and Welfare. They did as good a job as they could. I feel like the court system really is what got us. Her attorney was not recommending her going back to Arkansas. I mean, we had all these people on our side, but the judge could do whatever they want. (Ann, lines 460-474).

This participant describes another example of how the legal system's policies, as well as feeling unsupported by her caseworker, created a negative experience as she felt she knew more about the child's needs than others:

I don't think he would have got the care. Dad was very adamant initially that there was nothing wrong with his son and he refused things. And in order to get a judge to go above dad, he [the physician] needed proof. And the case worker was just worried about other things and dealing with other things. And this other lady said, "Well, I have 15 years' experience." And I said, "You can't learn a kid in 20 minutes. He's not even going to open up and talk if he's nervous. How do you even know if he talks or not?" (Becky, lines 254-272).

This participant seemed to summarize what many participants expressed about their desire for the child welfare to change many of its policies, in this case the amount of time and required communication a caseworker is required to do:

What I've realized is that it's like the military. They say "We want you. We support you," until you leave then they don't care. The system is very

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similar to that. They promise you all this stuff and go to Pride classes.

They say "We'll give you support for this" but they don't—the follow-up

is not there. I would think that would be one of the biggest things—instead

of allowing the foster parents to come to them with issues that they should

be doing more check-ins with the foster parents. It should be, "What can

we do to help out?" (Steve, lines 338-352).

Theme 3: Working with Children with SHCNs can be stressful. Another

theme that was consistently expressed by participants revolved around descriptions of

how challenging the daily tasks and work of caring for their foster children felt to them.

Descriptions of being deprived of sleep were common, as in this comment:

I learned in a big way that 3 hours a sleep a night is not enough to

function. I can do 4 and be okay, but 3 hours a night is not a good thing.

Drug babies need to be held all the time for comfort. She would lay down

briefly, but then she needed to be held. House chores slack and things just

happen. That's just life, there's no choice. The baby comes first because

she's just a baby and helpless. (Steve, lines 171-179).

Or this comment:

One of the big things with Casey is that she had tremors. She had to be

swaddled constantly and held constantly. Ya know, around-the-clock, 24

hours a day, seven days a week for months. Actually we didn't sleep. One

of us was always awake with her. The only time that she slept was if we

were holding her and rocking her. It was challenging for us. We lost our

privacy. We lost our sleep. We lost basically any time together that we

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used to have because everything revolved around Casey, which I wouldn't have it any other way. It was challenging because we were both working full-time. So it made life very interesting just trying to get through those first couple of months. All you could do was hold this child and love on her and let time go by. That's all you could really do until the withdrawals symptoms went away. Once they did, we could get her on a more regular sleep schedule, but the first 3 months were pretty consistently lack of sleep and just swaddling a very irritable baby. (Jessica, lines 119-137).

There were also descriptions of how lack of sleep affected other members of the family, such as this comment:

Of course difficulty came when Stephanie was ill and I'd be up an insane amount of times, like 32 times a night sometimes, suctioning her, and getting back up, and setting an alarm, and suctioning her again. There was no sleep and the next day you still had family to take care of. (Courtney, lines 215-223).

Or this comment:

I was a single mom and foster parent, and I hadn't fostered a baby before. This baby, who not only looked like a newborn, acted like a newborn and did not sleep through the night. She was difficult to soothe at times. It was difficult at night especially, as it is for most parents. There were night time feedings and I did want to take advantage of those night hours as far as her health and growth. I saw it as a lot of opportunity to feed her because she didn't eat much at a time, so there were a lot of feedings, just a little bit at

a time. So that was difficult because I was working and taking classes,

but—so not having much sleep while working and fostering and taking

care of the three kids at my house had its challenges. (Betsy, lines 365-

374).

The presence of additional people or disruptions to the family routine due to the

health issue(s) of the foster parent often added stress to the participants' experienced, as

evidenced by statements like this:

Like I was saying before, just the intrusiveness of always having someone

in our home. That was really hard. Every week, there were a couple people

in our home, whether it was social work, home health, the physical

therapist—it was disruptive. How could it not be? (Ann, lines 322-333).

Or this:

The home health care visits, I wasn't quite prepared for that and the extent

of the visits we were going to have with him had he not gone back to the

hospital were—it was a lot. So I hadn't been prepared for that. I think he

had like six over the next two weeks but then he went into the hospital, so

he didn't go to those. (Carla, lines 285-292).

This comment summed up how the entire family might be affected by the foster child's

health condition:

For this particular child he was around-the-clock. He could not sleep, he

ate very little, and so somebody was always up with him 24/7. So we took

turns. I would walk the floor with him—and bear in mind we had four

other little ones in the home as well—but, I would walk the floor with him

and feed him and change him, and when I couldn't do it anymore, I would

pass him off to somebody else. And our five teens and my husband, all of

us, were 24/7 on top of everything. Rest when you can, take care of the

other children when you can, and work with this child to detox him. So we

have kind of learned as a family what children going through a detox will

need. (Sheila, lines 154-176).

This comment was an insightful description of how the foster child's recent history had

significantly impacted the child's behavior and therefore made taking care of her even

more challenging:

Well, she wasn't like a normal newborn because of the meth in her

system. She cried a lot more than most babies and she was much more

colicky. I felt like she had much more of an attachment disorder than

maybe some of the other children have had. I wondered if it was because

the first few days of being born, she didn't have that person there. She

didn't have that attachment to her mom or father. All she had were the

nurses. I don't think she got that initial attachment and that made it more

difficult. She was much more needy as far as needing someone to be right

with her all the time. It was really hard to get her to sleep in her bassinet or

crib because she needed someone with her all the time. That was more of

an adjustment. (Jean, lines 157-177).

There were also stories about how the serious nature of the foster child's health issues

could suddenly create a serious, stressful event that required immediate attention, such as

this story:

He pulled his tube out and we could put it back in, but without an x-ray

machine we wouldn't know if it went in the right place. So every time we

yanked it out, we'd have to bring him in to put it back in. No matter what,

they wouldn't know how to put it back in. They knew how to put it back

in, but it's a baby, so they'd be like, "Well…?" It was such a nightmare.

They'd have to get a special nurse and she'd be like, "I think this is the

right way." We survived, it was just kind of a trying time. (Michelle, lines

367-376).

Or this one:

I was dropping my kids off at school and I looked back in the car seat and

John was gray, he had stopped breathing. So I started stimulating him, I

started rubbing him. He started breathing again and I knew I would be

faster to drive him than to call EMS. So I put him in my lap, put on my

hazards, and drove to the ER. They immediately got him in and a couple

of times he just flat-lined, just stopped breathing. I'm bawling because I

have never seen a kid almost die on me. That was horrific. (Jane, lines

118-131).

This was another story that pointed out that even experienced foster parents can't

be prepared for everything:

With Tim, we were told he was taking longer to detox and we need to

keep definite eyes on him because there was just something else there that

nobody could really put their finger on what it was, but he being

monitored by the doctor about weekly until I ran him to the emergency

room at 5 weeks because he had stopped breathing. And there's a lot I'm willing to take, but when they're not breathing they are out of my element. So then he stopped breathing, we got him breathing again, and when it happened 20 minutes later, that's it. We just ran to the hospital. And he was taken straight by ambulance to the NICU downtown. (Sheila, lines 787-817).

Subtheme 1: The emotional impact of seeing the child. While nearly every participant in the study shared experiences or stories about the stress nature of caring for children with SHCNs, a sub-theme that emerged within this framework was how impactful the visualization, especially the initial visualization, of the foster child was to the foster parent. This participant described her fear about hurting the foster child following meeting her for the first time:

She was so small. She was 8 weeks early and was just under four pounds and had lost a bit of weight. It was almost scary to touch her. I had never seen a baby so small. It was—she was about the size of my hand, slightly bigger. It was just so small. When I first changed her diaper I was frightened that I was going to squeeze her too hard or something. The nurse had to show me how to put it on correctly. (Irene, lines 27-36).

Another participant had a similar story to tell:

I was very surprised when I saw Ally because I was expecting—they said about 5-months-old and Ally was 4-months-old, and she was one pound over her original birth weight. Which apparently she had gained while she was in the hospital. So she was at about 8 ½ pounds and she was 9 ½

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pounds when she came to me and she was probably not much longer than

when she was born. She looked like a newborn baby. So that was very

new for me to see a 4-month old baby that looked like a newborn. It was

just like, "Wow, I have a newborn baby here that's teeny tiny." It was just

very new and troubling. You expect to see this healthy-looking child, and

to be looking at this 5-month-old baby who is active and alert a little bit

larger, holding them and such—to see in the car seat this tiny little thing

that all of a sudden you have a newborn looking baby, a newborn acting

baby. It was just very delicate and fragile-seeming, and sad, and

emotionally wrenching. (Betsy, lines 72-103).

This participant was able to describe how witnessing the foster infant's systems following

drug exposure had an effect:

It was a little disconcerting when we first walked into the room. I walked

in and this man holding him—he was kind of holding him out—and he

was trembling, shaking. I said, "What's wrong?" I got really teary and I

knew he was addicted to drugs, but I wanted to understand what he was

going through. They said, "These little seizures, little convulsions. He's

just got so much in his system." It was really hard to see a little newborn

trembling like that and so discontent. (Vanessa, lines 45-52).

Although this participant was able to confront the challenge of seeing a child who

seemed to be suffering, that wasn't true for the entire family:

He didn't want you to touch him, but he didn't want you to leave. And so

as long as you sat there, he would stop, and that was probably five days of

that. But they warned us at one of the classes we took that there could

be—a lot of the kids had night terrors under five because you wake up in a

new place and it just scares you initially. And so that wasn't so bad, but

Thomas was a big, big two-year-old and he thrashed around. It wasn't a

seizure because he was coherent. He could talk with you, but his little

body was shaking. There was no fever, um, so it was sad to watch, I guess,

but I'm not very emotional so it was okay. But my husband couldn't be in

the room because it makes him cry. (Becky, lines 159-168).

Theme 4: Lack of Knowledge of the child's health condition/health status.

This was another theme that nearly all participants had feelings about. The desire to

obtain as much information about the foster children was described in the first section of

the analysis, however many participants in the study expressed a great frustration with

not having information that they felt was critical in their being able to adequately care for

the foster child. A good example of the overall feelings of many participants was

summed up with this comment:

I would think they [the State] need to get information for foster parents,

especially when it's concerning the health of the foster child. That's very

important. I just needed to know what the situation was, how intensive the

care would be that's required, since I have my own kids. I can't give 24-

hour care to one kid. They didn't know anything. I knew that he had been

in the ICU for a while. Um, but they couldn't tell me what his injuries

were or how severe they were or what level of care he'd require. If

they're asking a family to take a child into their home, they need to be able

to tell that family what it is they're bringing on. If a child has any kind of care that is going to require an alteration in the way a family lives their life—because of appointments or physical care that they need, any emotional or mental problems that will be an issue for the rest of the family—the caseworkers needs to make that known to the family ahead of time. Especially in this case. I understand that sometimes it's in the middle of the night, they're taking them straight into custody—but at this point, he had been in the hospital for almost two weeks and they should have been able to get that information ahead of time before calling us. (Carla, lines 416-438).

This comment was not a criticism of any aspect of the system as much as an example of the challenge of working with infants in the child welfare system:

The negative aspects are walking out of the hospital with a child that you have no idea what their medical history is. You have no idea if mom had allergies to anything that the child may have. They can't give you that information, just the caseworker. And if mom doesn't disclose it, the caseworker doesn't know. And so there's generally a week's gap in time before we find out any of that information. Especially with newborns. With older children, it's a little bit different. But with newborns, we have no idea what mom might have been reacting to, we have no idea if there's a history of milk allergy in the home and the child needs to be on a special formula as a precaution. (Sheila, lines 632-649).

This was another comment with a similar theme:

I've accepted the fact that you get the minimal amount of information and

just trust the worker that if it's something you need to know in advance,

that you will. [laughs] Which isn't always the case, because really it's just

general age and gender, and sometimes a name, and that's about it. So

added information like, "it's in the hospital" is useful and more

information than you sometimes get, but it's still when you hear "baby in

the hospital is the reason for foster care," and so you don't know how

much care the baby is going to need, especially when it's a baby. Injuries

can be a lot more debilitating or require that much more attention and

time. (Betsy, lines 49-65).

This was a good example of some important information not being given to the

foster parent: "With this particular child, we did not realize until later that he was blind

and that would have been helpful to know." (Sheila, lines 212-222). And then there was

this example of not having what most would consider essential information:

We actually had the wrong name for Thomas. His name was Timothy

Thomas and they had just given us Thomas, and that was his middle name.

So he just looked at us like we were crazy all the time. For three days we

called him the wrong name. (Becky, lines 64-68).

Later in the interview, Becky went on to describe additional information she wished she

had been given:

I think there are times when you're dealing a child that is raging and you

don't know why, it would be nice to have a little bit of a clue as to, you

know, "We suspect there might be this kind of abuse that had gone on, so

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watch out." But I would have really liked to have known if there was a

possibility of drugs in their system. That would have been something. I

would have had people there to help me with my children had I known we

would be looking at narcotics in their systems [laughs]. (Becky, lines 556-

580).

And this comment stated the issue in more direct way: "They [the state] tell you nothing.

You go into it blind. They don't tell you a thing." (Deena, lines 388-397).

And while there was a lot of frustration being communicated during the

interviews about this issue, there was only a little speculation about why it continued to

be a problem for foster parents. This comment gave some insight into what the

perception by some participants may be:

What they [the state] feel is vital for what a foster parent needs to know

has changed drastically since I started. When I first started foster care,

they told me everything. I knew what the psych eval was of the mom. I

knew if they had a criminal history record, I knew that. They shared all the

information pertaining to the child with you. And I knew the case plan. So

I knew if they were going to their drug courts. I knew if they were making

progress. They do not share any of that information any longer. Um, and

the reasoning is they have to protect the rights of the parent, which I think

is a bunch of crap, personally. (Jane, lines 630-649).

Theme 5: Lack of Available Resources. Most of the participants in the study

related a sense of duty or responsibility to care for the foster children transitioning from

the hospital, however many of them expressed feelings of not having or having access to

the resources they felt that they needed to adequately care for the children. Some participants went so far as to declare that this issue was a major factor in their decision about accepting another assignment or continuing as a foster parent.

This comment by Roxanne, seemed to clarify what many foster parents felt they needed to do when their advocacy for the children in their care yielded no results:

I think "Okay, it's just the three of us. We're going to have to make this thing work." We're not getting the support I would like from Health and Welfare, so I do the best I can with what I have. So show Lisa how to do a resume, show Lisa how to cook, show Mirea [foster child's sibling] how to cook, teach them how to clean. It just falls on me. (Roxanne, lines 394-403).

Although most foster parents did not describe significant problems with access to medical care, this participant described a situation where Medicaid did not seem to be meeting the child's needs:

Trying to get the medication she needed was another nightmare because Medicaid didn't want to pay for it because it wasn't an approved formula medication. But the pediatricians were saying, "No, she has to have this medication." Then it came down to who would pay. So Sam and I would pay for the meds because Medicaid wouldn't and then it was, "Who's going to reimburse me for the cost of these medication?" (Jean, lines 202-215).

This comment seemed to sum up the frustration that was expressed by several of the participants about the way caseworkers handle situations when they are taxed with increased workloads:

> Just sometimes I feel like—it probably all boils down to finances—but I feel like social workers have a lot on their plate and are maybe even over-loaded. It just seemed that way with every case I've had, even though they seem to care and have concern when I talk with them—I feel a little bit like "Okay, here's the situation. Here's the children. I got other issues I gotta deal with. If there's any huge burning fires, call me!" (Courtney, lines 367-389).

The following three comments illustrate what seemed like a sense of duty to care for the children despite not having adequate resources provided to them. This participant described how her immediate needs were not addressed by the state:

> We had a hard time getting what we needed from the state, [laughs] which is pretty common. We needed diapers and formula, and where the state used to help you get that in a reasonable amount of time, now they say they want the parents to get it--and clothes. They came with no clothes, no diapers, none of that. They want the parents to get it, but the parents don't get it, so the state just doesn't give it to you, was pretty much what our experience was. (Carla, lines 343-356).

Deena expressed what many participants seemed to be saying about how they felt that the foster children were not getting their needs met when foster parents lacked adequate resources:

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I saw quite the disparity between what the state demands and what people

can actually do. There's a wide gap there. The state will say "we want you

to do more with less" and that's kind of their whole theme and they don't

take into account that the kids are the ones paying for it. (Deena, lines

780-798).

Janet was a longtime foster parent who offered her perspective on this issue:

Because my food bill for the month is well over what I get for these kids.

I came in '08 when everything went down the tubes and there's a lot

people—there's a lot that comes out of your pocket, which is fine. You're

going into foster care, you know that. (Janet, lines 290-299).

Theme 6: Conflicts with the Biological Family. Although many participants

who had described their encounters or relationships with biological parents as positive,

there were many foster parents who were very clear in describing the negative aspects of

their relationship(s) with both biological parents as well as other members of the

biological family of the foster child in their care. These aspects ranged from having

conflicts with the parenting styles or values of the biological parents as well as being

angry about choices the biological parents would make during the time they were

supposedly working towards obtaining custody of their own children. A good example of

a conflict in parenting styles came from this comment:

These parents in particular were very—they liked to be in control and they

had ideas and things about the way things should be done. I had to weigh

that, weigh those things. So if I did things—like maybe I would forget to

send wipes—because things are different from placement to placement,

sometimes the parents are expected to bring those things—so they were at

daycare, the daycare doesn't have you provide wipes. So I'd send maybe a

bag of stuff without wipes not knowing that was the day the parents were

going to have a visit. The visits were very irregular to begin with, or they

happen as they happen. So maybe I didn't send wipes, and so they were

like, "They want to know why you didn't send wipes. Why wouldn't you

send wipes?" It's like all heck because I didn't send wipes to the daycare.

"Well can you make sure to do that from now on?" "I'll try to remember

that once a week, although I don't know when, I'll throw some wipes in.

(Betsy, lines 385-422).

This foster parent initially had described a positive relationship with the father of

the infant in her care, but that relationship soured when a conflict with how financial

resources were being allocated:

The family became upset when they found out Stephanie's social

security/disability check was coming here. He came to our door and said

he wished that I would give him some of that money because he thought I

was being dishonest taking that. I explained that Stephanie had a lot of

cares and a lot of expense, and that that was for Stephanie. So there were a

few times when—well never tenuous in the moment, never any yelling—

but always a feeling of "we better protect ourselves from this feeling and

situation." (Courtney lines 660 - 667).

There were also several descriptions of how participants became uncomfortable

about encountering biological family members in the hospital. And while there were a

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few positive descriptions about how the nursing staff handled these situations, there were also descriptions of how the biological family's presence at the hospital became a negative issue. This was a good example of this issue:

> The mom, while she's cordial to me, it's very awkward to be around her, so I just requested through social services that we can have some type of visitation schedule so that we weren't running into each other. Also, she brought people with her and there's only two people allowed at the same time at the bedside in the NICU, so I just said, "Can we do some type of visitation schedule that would work out for her too?" because they were allowing her to go to the hospital anytime she wanted. I ran into her one time and it was just weird, ya know. She wanted to take the baby home. She wanted it to be her baby. She was using meth so it didn't work out so well. (Irene, lines 114-121).

Although not common, one foster parent participant mentioned a situation where she was actually fearful of the biological parent and had a concern about safety: "I had a very angry parent that was Googling me and asking me where I lived and saying things like "You're not old enough to know what you're talking about." (Becky, lines 344-350).

Summary. Participants in the study had a lot to say about what they perceived as a negative experience or a challenge to their ability to care for the foster child. They identified many key themes or issues that previous research has identified as well as some that have not received attention before. Similar to describing the positive aspects of their experience, participants often became emotional when describing the negative aspects of the experience. None of the participants became tearful or upset, rather there often was a

sense of exasperation or frustration with hands clenched tight in a fist or the occasional dramatic waiving of arms as the story unfolded. This section of the analysis ended up having the largest number of themes and contains the largest number of significant quotes. This comes as no surprise as discussions about the challenging aspects of the experience seemed to take up the majority of the interview time. Finally, it seems important to mention that these foster parent participants seemed to have a near unanimous agreement that the challenges that they faced while caring for children transitioning out of the hospital are significant and require changes to the system. But as also stated previously, most of these participants expressed to the primary researcher that a major motivator in participating in the study was that they wanted an opportunity to voice their stories and their experiences to anybody who would listen as an attempt to improve the system. As seen in the above examples, many participants have strong negative opinions about their experience(s), however many of these same participants were emphatic about how much they cared about the children in their care as well as future foster children.

Overall Summary

The thematic summary presented earlier (figure 1) represents the primary researchers ordered representation of the initial groupings of the themes and sub-themes that arose from multiple readings and reviews of the individual participants' transcripts as well as reviews of field notes taken during each interview. Consistent with interpretive description methods, inductive analysis was used to link as many latent patterns that could be discovered within the participants own words (Thorne, 2008). Beginning with the first interview and continuing throughout the data collection phase of the study, the

primary researcher identified important notable elements after an initial reading of the transcript. This usually occurred with 1 to 2 weeks following each interview and usually (but not always) prior to the next interview with another participant being scheduled. An attempt to discriminate meaning from the perspective of the participant was the goal of the second and sometimes third re-reading of the transcript. The primary researcher would frequently check in with Dr. Lobo, a knowledgeable and experienced researcher, who would offer insight and advice as to what type of meanings may be coming from initial interviews and assisting the primary researcher in refining his own interpretation(s) being made based on his years of experience working with foster parents. This eventually led to small changes in the way that certain questions were presented to subsequent participants as well as additional probes when certain themes or concepts presented during an interview. Even though this phase of the analysis of data began to occur early in the data collection phase, it can still be labeled as the initial data analysis, similar to Morse's (1994) 1st phase of the Cognitive Process of Data Analysis. This was especially true as the primary researcher strived to explore and learn everything he could about the experience of caring for the foster child making the transition out of the hospital from the perspective of each participant in the study.

Following the completion of all interviews, each transcript was re-read in great detail by the primary researcher, often in random order, to identify any new elements or patterns that the foster parent participants may have been communicating during the interview. After many seemingly important sections of each written transcript were identified according to the rough, initial coding structure. Each section was then literally cut and pasted (actually stick pinned) to the wall of the primary researcher's office in one

of the initial sections labeled with one of the early themes. This sifting of patterns

emanating from the verbage of each transcript, as well as the frequent check of field

notes, was an attempt to follow Morse's 2nd phase of data analysis known as synthesizing.

Each individual quote from a participant was deconstructed, reviewed, and re-reviewed

for iteratively based placement into the proper theme and/or subtheme. This phase

resulted in the creation of additional themes and subthemes as well as the elimination of

some of the initial themes and subthemes.

Each individual section of participant narrative was then copied and pasted back

into several new documents, organized, at the time, by the structure of which section it

ended up residing on the primary researcher's office wall. It was during this lengthy

process where titles of themes and subthemes were refined as they were organized back

into documents on the computer screen. New explanations and meanings began to

emerge from the patterns that had been identified and, at times, required reorganizations

of bits of data or sometimes eliminating what had been originally thought of as

meaningful but then not actually "earning" a place in the final structure.

The final overall thematic structure was then described, at length, in the narrative

section with exemplars offered in an attempt to demonstrate the significance of each

theme or subtheme from the perspective of the participant. This process is similar to

Morse's 4th phase of Cognitive Process of Data Analysis, recontextualizing.

Chapter Summary

This chapter has presented an overview of the basic demographics, and the

analysis of the interpretive themes and subthemes. The messages being articulated by

these foster parents was sifted into multiple categories, all generated by the three original

research questions, and then processed and re-processed through the critical lens of the primary researcher. Aided by two experts with extensive experience in foster care, this data has been structured into an understandable and meaningful format that offers an overview of the experience of fostering hospitalized children from their perspective. The themes that emerged from this analysis give new light on how foster parents perceived and contextualize these varied experiences, in both positive and challenging definitions.

Chapter 5

DISCUSSION AND CONCLUSION

This chapter a) briefly describes the interpretations of the study; b) compares the findings of this study to the relevant literature; c) discusses the relevancy of the theoretical framework of Transition theory to the study; d) describes the strengths, limitations, and significance of the study; and e) concludes with a description of the implications of the study on the immediate needs of foster parents as well as future research.

Comparison of Interpretations to Relevant Literature

The insights and perspectives shared by the participants in this study build on previous knowledge that has been noted in other groups of foster parents who work with children with SHCNs as well as give additional insight not seen in previous research. The themes of needing to advocate for the foster child's needs, having adequate resources and a good relationship with assigned caseworkers, and suffering individual and family stress over the course of caring for the child have been noted in previous research with foster parents. The descriptions by these participants of how having previous experience as a foster parent is also a theme that has been noted in other studies with this population. The findings of this study do, however, give us some new and previously unrevealed insight into the motivations of these foster parents as well as how significant the specific policies and climate of the local child welfare agency impact the experience of working with a child with a health condition. The most significant new finding from this study is the importance of how critical the communication skills and the amount of support the health care team, especially nursing, is on the experience of the foster parent who cares

for the foster child making the transition from hospital to foster home. When foster parents feel supported by nursing staff and child welfare caseworkers in their role as caregivers of the foster child, foster parents relate these experiences as positive and potential motivators to continue in their role as foster parents. When foster parents have a perception of poor communication with their caseworker, especially about the policies that both the foster parent and caseworker are working under, the foster parent often labels that type of experience as negative a challenge for them in their desire to continue to be a foster parent for children in the hospital.

Specific Findings from Previous Research

As noted in Chapter 2, there has been a scant amount of research devoted to the experience(s) of foster parents caring for hospitalized children. This makes it difficult to directly compare what is previously known about the experience of caring for a foster child who is making the transition and how this research adds to that knowledge. This dearth of research also illuminates the obvious fact that much more research needs to be devoted to this unique aspect of the experience of being a foster parent who works with children with SHCNs. However, if one looks at some of the more general studies involving foster parents who care for children with SHCNs, some important and notable comparisons can be made.

Role and Characteristics of the Foster Parent

Many studies of foster parents have demonstrated that, although foster parents often describe financial strains and poor levels of reimbursement as a negative factor, most studies also reveal that the vast majority of foster parents who continue to serve as foster parents have varied non-financial motivators to continue to foster children

(Isomaki, 2002; Lipscombe & Moyers, 2005; MacGregor, Rodger, Cummings, & Leschied, 2006). There has been other research identifying inadequate financial reimbursement as a major contributing factor in the attrition of qualified foster parents (Avery, 1999; Brown & Rodger, 2009). Most of the participants in this study discussed what motivated their continued work with foster children with SHCNs, with a strong sense of spirituality, making a significant difference and the positive impact of the foster children on the foster family being the primary subthemes. These participants, as a group, did not differ from what previous research has shown. And while financial reimbursement has been demonstrated to be a significant factor in previous studies, the money issues that the participants in this study described as negative or challenging revolved around reimbursement for expenses and often a general description of how significant the financial obligations of caring for a foster child coming out of the hospital could be.

Although not asked directly, most participants in this study agreed that the actual monthly payments they received from the state for their service as foster parents did not fully cover their actual expenses. But many participants also alluded to the fact that they did not pursue the work of foster parenting as a source of income with two participants stating quite clearly that they felt that foster parents, as a group, know that the monthly payment is not going to be a lucrative source of income.

Relationships with Caseworkers

The findings of this study add to that premise of how significant this relationship impacts the experience of working with foster parents. During discussions of the negative or challenging aspects of the experience, almost every one of the eighteen

participants in this study expressed some type of negative aspect of their experience that ultimately was related to their perception of their assigned caseworker. These negative experiences ranged from dealing with inexperienced caseworkers, which often led to having a lack of confidence in the ability of the caseworker to meet their needs or a sense of frustration with a particular issue that was most likely based on some type of miscommunication between the caseworker and the foster parent. These frustrations from the participants in this study do not differ from what other research has demonstrated as the importance of the relationship with one's caseworker has been clearly documented in previous research with foster parents (Broady, et al., 2010; Brown & Rodger, 2009; Hudson & Lavasseur, 2002). This study also found that being frustrated with specific policies of the child welfare system is a major negative factor in the experience of caring for the foster child making the transition from the hospital to the foster home.

Although it was rarely directly expressed by participants, the inability to communicate the reasons for some of the policies by the caseworker or the lack of an ability to clearly express what the basis was for the existence of a policy could be inferred from many of the stories expressed in this study. As with all exchanges of information, it is always important to remember that there are individual perspectives on any situation and experience. The high number of relatively new caseworkers who, more than likely, have not had the opportunity to learn many of the important skills of communicating with foster parents and more than likely contributed to the number of and strength of many of the foster parent participants' frustrations and arguments against the policies they felt so strongly about.

Access to care

Foster parents expressing the inability to obtain needed health care for the foster child in their care has been noted in previous research (Avery, 1999; Lauver, 2008; Pasztor, Hollinger, Inkelas, & Halfon, 2006). Caring for a foster child that is financially covered by Medicaid has also been listed as negative factor in obtaining appointments (Schneiderman, Smith & Palinkas, 2012). In this study, only one participant described a concern about access that she felt was directly attributable to her foster child having Medicaid as their insurance carrier. None of the other participants in this study stated situations where they could not timely access the health care that they perceived the foster child needed. Most likely this is due to the fact that the majority of participants in the study resided in southwestern Idaho and although Idaho is a very rural state, the majority of the population of the state resides in this area and there is a children's hospital in Boise, with a concentration of most of the state's pediatric subspecialists within driving distance of the participants' residence. Living in a rural area with a low density of pediatric health care providers was noted as a likely contributing factor to this lack of access (Lauver, 2008).

Several of the participants described situations where they needed to make an urgent trip to a local emergency room with their foster child, but because access to needed health care for the foster child was not mentioned as a significant issue, it came as no surprise that utilizing the emergency room as a strategy to "bypass" barriers to pediatric health care was not discussed by any of the participants in the study. This is contrary to what has been seen in other studies with this population (Lauver, 2008; Pasztor et al., 2006, Schneiderman, McDaniel, Xie, & Clark, 2010).

Training

When discussing the emergency care of a foster child or a concern about their health, many participants in this study would also discuss the training that they had received prior to becoming a foster parent. Training and preparation for foster parenting has been noted as an important influence of the quality of the foster parenting experience (Pasztor, Hollinger, Inkelas, & Halfon, 2006; Risley-Curtis & Kronenfeld, 2001) and maybe even the most significant factor (Fees et al., 1998). Several of the participants in this study had strong criticisms of what they perceived as poor quality or even an absence of adequate preparation for the experience of working with foster children with special health care needs. Idaho, like many other states, has a specific requirement of pre-service training prior to becoming a licensed foster parent. This 27-hour curriculum covers 5 important aspects of foster parenting: a) Protection of children, b) Meeting children's developmental needs, c) Supporting relationships between foster children and their biological families, 3) Nurturing safe, long lasting relationships, and e) Working as a member of a team. There is no specific content of health issues or health care of children (Idaho Standards for Recruitment and Licensing, 2013). This policy does not differ significantly from training requirements of the majority of other states (Child Welfare Information Gateway, 2014). While several parents discussed this low quality or "lack of" training issue, many more discussed the importance of experience and improving confidence in their care that came from the day-to-day experience of caring for the foster child. This phenomenon is not new and has been described in previous studies (Lauver, 2008; Schneiderman, Smith, & Palinkas, 2012).

Feeling Supported

Having a sense of support from the child welfare agency has also been noted as a significant factor in the satisfaction and potential attrition of foster parents (Brown & Rodger, 2009; Hudson & Lavasseur, 2002; Lauver, 2008). This study demonstrated a similar theme in that many participants expressed a sense of feeling unsupported by many of the systems they dealt with. In this study, the sub-theme of "feeling unsupported" was placed in the general theme of "conflict with policy" primarily because most of the experiences these participants expressed as unsupportive were based on decisions made by caseworkers, supervisors and especially members of the legal system. More than likely these workers were following the policy that they were working under. As mentioned previously, policy conflict was a major source of frustration for this group. Many participants also mentioned having the support of other families and other foster parents that they networked with was a significant factor in feeling supported.

One study of foster parents working with children with SHCNs found that spousal support was a significant source of support, but all the members of that study were married and had partners at home at the time of the experience. Four of the eighteen participants in this study were single foster parents at the time of the experience, two of whom were caring for other foster children at the time. None of these four expressed feelings of not being supported during their individual experience fostering.

Importance of Health Care Providers and Nurses

An important theme that participants in this study discussed was the impact and importance of health care workers, specifically nurses, having on making their experience of transitioning from the hospital a positive one. Many of the participants in this study

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specifically mentioned the feelings they experienced when nurses in the hospital were encouraging and supportive of the foster parents having custody of the foster children patients. Although not unanimous, the majority of the participants in this study categorized their encounters with nursing staff while visiting the hospital as very positive. Participants also noted that when they perceived that the nurses that they worked with understood the unique needs of foster parents, it added a positive element to their experience. During the interviews, some participants expressed how much they appreciated the clear communication, extra effort to obtain needed supplies, and general appreciation for the presence of the foster parent. Although there have been no published studies on how nurses perceive foster parents or what types of teaching content nurses should specifically address with foster parents, some participants implied that there was an extra effort in making sure that the foster parent had a clear understanding about the child's medical condition and home-care needs, perhaps more than a non-foster (biological) parent. This seems important because not only has a lack of understanding of the foster child's medical condition when first coming into the foster home been identified as being a negative issue for foster parents of children with SHCNs (Lauver, 2008; Pasztor et al., 2006), it is a significant issue for non-foster families as well (Baker, 1991; Bent, Keeling, & Routson, 1996; Smith & Daugherty, 2000).

This appreciation and clear communication was not limited to nurses. Several stories were described of how supportive physicians, both primary care and sub specialists, were when dealing with the foster parent participant. Many participants in this study described how much they appreciated a skilled, experienced physician who took, what they perceived, extra time or effort to listen to them (the foster parent) and

acknowledge the foster parent's perspective and insight when making decisions about the foster child. Previous research has shown that foster parents may have difficulty working with physicians because foster children often have complex issues (on top of their medical issues) that may give providers a disincentive to see the foster child or provide care for them (Pasztor, Hollinger, Inkelas, & Halfon, 2006). Participants in this study did not describe this phenomenon in any overt manner. The primary negative experiences with physicians described in this study emanated from physicians being inexperienced or having poor communication skills that were not just limited to foster parents.

Relevancy of Theoretical Frameworks

The theoretical framework that this study was based on was Meleis' Middle Range Theory of Transitions (2007). Although originally developed for use in nursing research with different populations, mostly patients who were dealing with a significant personal health issue, it has subsequently become the basis for understanding the relationships of many significant issues faced by caregivers, including parents of children with significant health issues during episodes of hospital to home care or other levels of care (Chick & Meleis, 1986; Meleis, Sawyer, Im, Messias, & Schumacher, 2000). Although Transition Theory is a natural template for understanding how foster children adapt to making the transition from the hospital to the foster home, this study investigated the experience of the foster parents who were involved in caring for those children making this transition. In order to make sense of this transition, it was important to identify the components, or rather the patterns of the transition as seen in the perspectives of the foster parent participants.

Patterns of Transitions. Patterns of transition, as identified by Meleis (2007) can be multiple or single, sequential or simultaneous. As the analysis of the data in this study unfolded, it became clear how complex the transition(s) being experienced by the foster families were. And although each family in the study was very unique, patterns that were identified involving the recruitment, the initial meeting of the foster child (always in the hospital), and the many varied tasks following discharge into the foster home often had similar elements. These elements have begun the process of forming what is hoped to be a greater set of concepts that will allow nurses to improve their care of hospitalized foster children and their work with foster parents.

Properties of Transitions. Being aware, being engaged, understanding the changes that will occur during a transition, including the time span, the critical points of the transition, and the differences in each experience have all been identified as being significant in any meaningful transition (Meleis & Trangenstein, 1994). This study has placed the spotlight and how critical for all those who work with foster parents of hospitalized children to understand the elements of what the foster parents are dealing with as the child transitions from hospital to home as well as the transition that the foster family often experiences. When foster parent participants in this study engaged in this experience, the majority reported a sense of duty and a motivation to care for the child that was based on some sense of duty, either to their spiritual guide and/or to the foster child in need of care. These participants also almost universally agreed how important it was for them to have as much information about the child as possible and how important it was to feel supported by professionals that they worked with, including and especially the nurses in the hospital. A critical element of the successful transition from hospital to

home is how the nurse or nursing staff is perceived by the foster parent and how much the foster parent feels that the health care team values the foster parent.

Another critical point in the transition, as seen is this study, is the immediate time period following the foster child's discharge into the foster home. The need for accurate record keeping, clear communication about the follow-up care and potential emergency care of the child are critical for the foster parent. And a clear set of guidelines regarding the visitation and influence of biological parents during the fostering period are extremely important to the foster parent. And while specific timelines are nearly impossible to predict in both the discharge of the child from the hospital as well as the potential reunification with biological family, foster parents clearly crave any information about how these factors will play out in any way. Caseworkers can greatly increase the confidence and satisfaction of the foster parents they work with if they understand this need and utilize every resource they have available to them to maximize their communication to the foster parent in regards to these elements.

Strengths and Limitations

Strengths

Number of qualified participants. The actual number of foster parents who ended up participating in the study is a strength of the study. The experience of working with hospitalized children is a relatively new and fairly unique experience for most foster parents and there was some uncertainty about the researcher's ability to be able to identify a significant number of foster parents who met the criteria of this study to be able to participate and have the desire to participate. Foster parents are also usually very busy and often have limited free time. Having a final number of 18 participants who not only

met the criteria for the study but were also able to participate in the study gives this research a meaningful insight into the experiences of this group.

Desire of Participants to tell their story. Once a qualified foster parent was able to make time and sit with the interviewer, nearly every participant made it abundantly clear that discussing their experience and expressing their views was very important to them. The passion and emotion that emanated from many of the participants was very obvious and interviews often went longer than expected as participants continued to reveal meaningful experiences and opinions to the interviewer.

Use of Clinical Experts. Having the expertise and guidance of clinical experts added to the strength of this study. Having Dr. Lobo assist the primary researcher in almost every facet of the study greatly adds to the quality and integrity of the results of this research. And the changes made to the ordered presentation of the data following the evaluation of the data analysis by Dr. Godard also enhances the quality of this research project.

Limitations

Limited geographic range of setting. With the exception of one participant, the only social service agency that each participant had worked with was limited to two of the seven regions of the Idaho Department of Health and Welfare. The one exception was a foster parent who lived in a different part of the state and participated in the interview by phone.

Homogeneity of Sample. Another limitation to the study was the homogeneity of the sample of participants. All 18 of the participants in the study were white with no minority group represented. While this factor was not a surprise, given the demographics

of the recruitment area (90% white), it does limit the ability of the conclusions of this study being applied to other ethnic groups.

Single Interview. Each participant in the study was interviewed one time, either in the office of the primary researcher or in the participant's home. Before the participant was interviewed, they had a general idea of the topic, but did not know in advance of the specific details of the questions. Each participant would then offer up their best interpretation of what it was that they wanted to convey about their experience of caring for the foster child in their care at the time the experience occurred. For many participants, this meant that they had to reflect on an event (or events) that had occurred up to three years prior to the interview. This could lead to some vagueness or some missing details that could be important to the study. In an effort to help with potential effect, some participants were asked to look over the written transcripts of their interviews several weeks after the interview occurred, but only 2 participants were able to make the time to verify the content of their interview. Both of these participants made no changes to the transcribed data.

Novice Researcher. Although the primary researcher has extensive experience working with both biological and foster parents, the entirety of this experience has been as a clinician with a focus on health outcomes and improving parenting skills. According to Thorne (2008), a clinician who is attempting to become an effective researcher can often run into difficulty "undoing" the communication techniques that have served them in their previous role. This proved to be very true towards the beginning of interviews in this study as the researcher often found himself obtaining specific answers to questions rather than allowing participants to accurately reflect on their experience(s). Fortunately,

the researcher was able to consult extensively with the chair of his committee, Dr. Lobo, about this. Additionally, as each interview took place and the transcripts of each interview were analyzed, the interviewer was able to gain confidence and insight into the process. Increased use of silence and a better grasp of important points that might need clarification helped to improve the process and increase the quality of each interview as the process continued. Ultimately the researcher was able to shift the focus of the interviews from that of one with a clinical tone into much more of a research tone.

Significance of the Study

This study is significant primarily because it is one of the first formal inquiries into understanding the experience of foster parents who care for recently hospitalized children. The number of children coming into foster care has stabilized, yet the number of children surviving acute and chronic health issues continues to increase (Perrin, Bloom, & Gortmaker, 2007). A strong argument can be made that this increase in children with significant health issues is resulting in an increase in the need for qualified foster parents who can adequately care for them. But despite this need, there continues to be a loss of qualified caregivers who are willing to provide care for children with SHCNs (Dutton, 2016; O'Sullivan, 2015). Previous research involving foster parents who work with children with SHCNs has identified many factors that influence the foster parent's decision to continue fostering, however very few of those studies focused on recently hospitalized children. This study attempts of broaden the scope of the ages and diagnoses (and therefore the potential health issues) that foster parents might be forced to deal with.

Implications

     Implications for Nursing. As the number of hospitalized children being discharged into foster care grows, it is imperative that nurses who are working with these foster families understand the unique needs of the foster parent. This study points out how significant the foster parent's interactions with the nurses in the hospital can be. The nurse who is supportive, welcoming to the foster parent, and able to provide quality education about the foster child's health issues and care needs adds greatly to the satisfaction of the foster parent. A nurse who is knowledgeable about the likely lack of knowledge that a newly recruited foster parent may have about the child in their care, as well as the likely breakdown(s) in communication that may occur during the transition from hospital to home can be much more effective in ensuring that the needs of the foster child are met and the anxiety and frustration of the foster parent is reduced.

     Implications for Caseworkers. This study enlightens the fact that foster parents rely heavily on their assigned caseworker for crucial items in the care of the foster child making the transition from hospital to home. Of all of these items, clear, up-to-date and concise information about the child's health condition has been a consistent and vital theme expressed by the participants in this study. Inexperienced caseworkers, caseworkers with higher than expected caseloads, and policies that are perceived as ineffective and/or unnecessary by foster parents are factors that could be addressed and possibly modified by local child welfare agencies. At a recent panel discussion at a local university campus, the director of the Idaho Department of Health and Welfare identified the "unacceptable amount of turnover of Child Welfare caseworkers" as being the second most pressing concern to his administration in the near future (Boise State University

College of Health Sciences, 2015). The number one concern was the lack of accessible mental health services.

Implications for Research. This study is an initial attempt to begin to understand the experience of foster parents working with hospitalized children. It is important to continue to expand on this knowledge through additional research involving foster parents who live in other states and who work with different systems and work under different policies. While it isn't expected that there would be significant differences, the homogeneity and relatively small sample (compared to the number of foster parents nationwide) limit the transferability of the themes of this study to more urban and ethnically diverse populations. It also is important to start to address the issue of the training and preparation of foster parents who might work with children recently discharged from the hospital to their care. Idaho has specific guidelines regarding what is known as Treatment Foster Care, but these guidelines focus solely on foster children who have significant mental health issues not physical health issues (Idaho Department of Health & Welfare, 2013). None of the participants in this study had any specialized training they were required to complete related to specific health care issues, however 3 of the foster parents involved in the study were Registered Nurses and 1 participant was a licensed lay mid-wife. Although this study addressed the knowledge and potential anxiety of foster parents, much more needs to be learned about what formal training, if any, might significantly influence a more positive experience for foster parents who work with children with SHCNs, especially those that are hospitalized.

Additional research involving nurses, caseworkers, and even foster children would also add to an understanding of how to improve the experience of foster parents.

Nurses who work with foster children and who are involved in the inpatient education and subsequent discharge of the children into foster care are likely to be able to add to the understanding of the themes that this study has described as well as add new knowledge of the transition experience. The same can be said of caseworkers and the foster children themselves.

Chapter Summary

This chapter described the a) summary of interpretive findings; b) comparison of findings to relevant literature; c) strengths and limitations of the study; and d) significance of the study and implications for future research. This chapter concludes with some suggestions for areas of future research. While this is a small study exploring a relatively new phenomenon in nursing care, it seems important to point out that in these days of increasing attrition rates of qualified, experienced foster parents, there still exists a small group of dedicated, hardworking and caring individuals who continue to toil away in what many might consider a thankless task. These foster parents continue to make themselves available to care for what is arguably society's most vulnerable population: foster children who have significant acute and/or chronic health issues and are at the mercy of a complex and often underfunded group of systems that can challenge almost anyone. It is imperative that we continue to explore what these caregivers need and how we can empower them to continue to fill a vital and valuable role in caring for this vulnerable group of children.

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APPENDICES

Appendix A

Diagram boxes containing:

Nature of Transitions

Types
- Developmental
- Situational
- Health/Illness
- Organizational

Patterns
- Single
- Multiple
- Sequential
- Simultaneous
- Related
- Unrelated

Properties
- Awareness
- Engagement
- Change and Difference
- Transition Time Span
- Critical Points and Events

Transition Conditions: Facilitators & Inhibitors

Personal
- *Meanings*
- *Cultural beliefs & attitudes*
- *Socioeconomic status*
- *Preparation & knowledge*

Community

Society

Patterns of Response

Process Indicators
- Feeling Connected
- Interacting
- Location and Being Situated
- Developing Confidence and Coping

Outcome Indicators
- Mastery
- Fluid Integrative Identities

Nursing Therapeutics

The Mid-Range Transition Theory. (From Meleis, A.I., Sawyer, L.M., Im, E.O., Messias, D. K. H., & Schumacher, K. (2000). Experiencing transitions: An emerging middle range theory, Advances in Nursing Science, 23(1), 12-28.)

Appendix B

The University of New Mexico
Consent to Participate in Research

Exploring the Experience of Foster Parents as They Care for Children Who are Making the Transition from the Hospital into the Foster Home
Version: January 15, 2015

Introduction

You are being asked to participate in a study being done by Max Veltman, RN, MSN, CPNP. This study is part of his doctoral dissertation. The Principal Investigator for this study is Dr. Marie Lobo, PhD, RN, FAAN. Dr. Lobo is a professor at the University of New Mexico College of Nursing. This research is about the experience of foster parents who bring a foster child directly from the hospital into their home.

The experience of foster parents who care for a foster child during discharge from the hospital into the foster home is poorly understood.   There has been very little research on the experience of foster parents who care for children with health issues. Even less is known about the process of foster children being discharged from the hospital.

You are being asked to help in this study because you have been a foster parent who took a foster child into your home directly from the hospital. Approximately 20 – 30 people will take part in this study. Most participants will reside in Idaho. There may be some participants who reside in other parts of the country.

This form explains the study and any risks or benefits to you. If you have any questions, please ask one of the study investigators.

What will happen if I decide to participate?

If you agree to participate, the following things will happen:

Max Veltman will contact you and set up a time and location for an interview.   The interview may last up to 60-90 minutes. After the consent form is signed, we will want to get some information about you (age, gender, etc...). This will help us better understand the information you and others give us. Then a confidential interview will take place. You will be asked questions about the experience of working with a foster child. This child will be the foster child who came into your home directly from the hospital.   These questions will cover topics about your communications with caseworkers and health-care workers. There may be questions about how you worked with doctors or nurses. The questions will cover the time period while the child was hospitalized and after the child came to live in your home.   Your answers will help us understand your experience of taking in a foster child upon release from the hospital. To participate in this study you must agree to be audio recorded. The entire interview will be recorded for transcription into a printed document.   Your identity will only be known to the interviewer and Dr. Lobo.   All of the transcribed data collected during the interview will remain secured. Only the researcher and his committee will have access to it.

How long will I be in this study?

Participation in this study will take a total of approximately 60-90 minutes. You may be asked meet with the researcher again at a later date to review the content of your interview. This helps us ensure the accuracy of the data. This will be done at your convenience.

What are the risks or side effects of being in this study?

This study will have very minimal risks to you. The primary risk may be stress or emotional distress. Stress may occur when describing the experience(s) that occurred when working with the foster child. Previous research has shown that foster parents often have a deep emotional attachment to the children for whom they care for. Another risk that could occur is the potential loss of privacy or confidentiality. While every effort will be made to protect the information that you give the researcher, there is always some risk of a breakdown in the security of the information.

For more information about risks and side effects, ask the investigator.

What are the benefits to being in this study?

There may not be a direct benefit to you from being in the study. Your involvement may help foster parents who work with children that have health issues. It is hoped that more research may improve services for these foster parents. Identifying problems experienced by foster parents can help guide any needed improvements in the system.

What other choices do I have if I do not want to be in this study?

Your participation in this study is voluntary and confidential.

How will my information be kept confidential?

We will take measures to protect the security of your personal data. We cannot guarantee security of all study data.

Information contained in your study records will be used by the study staff. The University of New Mexico Institutional Review Board (IRB) may be permitted to access your records. There may be times when we are required by law to share your information.

Your name and other information will be stored in locked files and password-protected data storage devices. This data will be available only to authorized members of the research team for the duration of the study. Any data that are entered into a computer will have a unique study identification (ID) number, not a name or address. Any personal information and any record linking that information to study ID numbers will be destroyed when the study is completed. Information resulting from this study will be used for research purposes. This research may be published but you will not be identified by name in any publications. Information from your involvement in this study may be reviewed by federal and state regulatory agencies. It may also be reviewed by the University of New Mexico (UNM) Human Research Review Committee (HRRC). The UNM HRRC provides oversight of human research. There may be times when we are required by law to share your information.

What are the costs of taking part in this study?

There are not expected to be any costs to any participant in this study except for your time.

Will I be paid for taking part in this study?

Following the completion of the interview, each participant will receive a $25 gift card at that time. This gift card will be in the form of a pre-paid Visa card that can be used at any retailer who accepts credit cards.

How will I know if you learn something new that may change my mind about participating?

You will be informed of any significant new findings that become available during the course of the study. This may include changes in the risks or benefits resulting from participating in the research. It may also include new alternatives to participation that might change your mind about participating.

Can I stop being in the study once I begin?

Your participation in this study is completely voluntary. You have the right to choose not to participate. You may withdraw your participation at any point in this study. If you begin the study and then choose to stop you will still be given the gift card.

Whom can I call with questions or complaints about this study?

If you have any questions, concerns or complaints at any time about the research study, Max Veltman or one of his associates will be glad to answer them at 208-426-3707.

If you need to contact someone after business hours or on weekends, please call 208-949-5898 and ask for Max Veltman. If you wish to speak to someone other than Max Veltman, you may contact the Primary Investigator for this project, Dr. Marie Lobo, at 505-272-2637.

If you would like to speak with someone other than a member of the research team, you may call the UNMHSC HRPO at (505) 272-1129.

Whom can I call with questions about my rights as a research participant?

If you have questions regarding your rights as a research participant, you may call the UNMHSC HRPO at (505) 272-1129. The HRPO is a group of people from UNM and the community who provide independent oversight of safety and ethical issues related to research involving human participants. For more information, you may also access the IRB website at http://hsc.unm.edu/som/research/hrrc/irbhome.shtml.

CONSENT

You are making a choice about whether to participate in this study. Your signature below means that you have read the information in this form (or the information was read to you). By signing this consent form, you are not waiving any of your legal rights as a research participant.

I have had an opportunity to ask questions and all questions have been answered to my satisfaction. By signing this consent form, I agree to participate in this study. (A copy of this consent form will be provided to you).

_____ *(signature of participant)*

_____ *(date)*

INVESTIGATOR SIGNATURE

I have explained the research to the participant and answered all of his/her questions. I believe that he/she understands the information described in this consent form and freely consents to participate.

_____ _____
Signature of Investigator/ Research Team Member   Date

Appendix C

Interview Script

Each session will start with introductions, than a statement from the researcher:

<u>Introduction statement:</u>
I am interested in what nurses and other health care workers can do to improve the process of foster parents taking a foster child directly from the hospital into their home. After you fill out this questionnaire, I will ask you several questions related to your experiences when you worked with foster children who made the transition from the hospital into your home. If you are feeling uncomfortable or do not wish to continue the interview, please let me know immediately and we will stop the interview.

The researcher will then go over the consent form and explain it prior to obtaining the participants signature. The participant will also fill out the demographic questionnaire (see Appendix C)

The interview will then begin

Questions for the study:

1. How were you originally recruited by the social worker to care for ____NAME___ (the foster child who came into your care)?

2. Tell me about what you understood about ___NAME's___ health issues at that time?

3. What can you tell me about your interactions/communications with the nurses in the hospital during your time caring for ____NAME____?

4. How would you describe your interactions/communications with the physicians of the child during your time caring for ____NAME____?

5. When you came home with ___NAME___, how much of his/her care was as you expected?

6. What were some of the positive aspects for you while working with ___NAME___ during his/her transition from the hospital to your home?

7. What were some aspects of the experience of working with ___NAME___ that were challenging or stressful?

8. What were some issues that you had to deal with related to the various official agencies or systems that ____NAME___ was involved with? (see potential probes below)

   a. Medical system
   b. Legal system
   c. Child welfare system
   d. Schools
   e. Other
      i. (Specific agency)

9. How did they affect you?

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10. How did these experiences influence your decision to continue (or not continue) to be a foster parent?

11. Can you tell me if there is anything that you might do differently if you were to care for another foster child who was hospitalized and needed a foster home upon discharge?

12. Based on your experience, what can you share with me that you believe could be changed within the various systems to improve the process of foster parents caring for children leaving the hospital?

13. What should I have asked about your experience that I did not? A question that I have not asked that you feel should be asked about your experience?

14. What else would you like to share with me?

Variables to be gathered at the time of the participant interview

(This information will be obtained from a written questionnaire that the participant will fill out prior to the interview starting)

1. Current age (Date of last birthday: _____) "What was your age at your last birthday?"
2. Age (during the time of caring for the foster child)
3. How long ago was the experience of caring for the foster child making the transition (years/months)
4. Are you of Hispanic, Latino, or Spanish origin?
   a. No
   b. Yes: Mexican, Mexican A., Chicano
   c. Yes: Puerto Rican
   d. Yes: Cuban
   e. Yes: another Hispanic, Latino, or Spanish origin (ex. Argentinean, Columbian)
5. Race (what they consider themselves. They may pick more than one category)
   a. White
   b. Black or African American
   c. American Indian or Alaska Native
   d. Asian Indian
   e. Chinese
   f. Filipino
   g. Japanese
   h. Korean
   i. Vietnamese
   j. Some other race
6. Approximate household income level at the time of working with the foster child (this will be the income **WITHOUT** the additional monetary compensation received for services as a foster parent)
   a. <15,000 per year
   b. 15,001 to 25,000 per year
   c. 25,001 to 50,000 per year
   d. 50,001 to 75,000 per year
   e. 75,001 to 100,000 per year
   f. > 100,000 per year
7. Last year of school attended (Educational level)
   a. Did not graduate high school
   b. High school diploma or equivalency
   c. Some college with no degree
   d. Associates degree
   e. Bachelors degree
   f. Masters degree
   g. Professional or Doctoral degree
8. Total number of years of formal education. "How many years have you/did you attend school?"
9. Any other persons in the home during the time caring for the child making the transition from the hospital (Yes or No) (If yes, a chart describing each member of the household will be completed – see table below).
10. What were the ages of these other residents in the home? (see table below)
11. Of the children living in the home, were these children their own biological children or foster children?
12. Did any of these children have significant health issues?
13. Was this the first time the participant served as a foster parent? (Yes or No)

14. If a foster parent participant indicates that they had served as a foster parent prior to caring for a foster child leaving the hospital the number of previous foster children that the participant worked with and the types of health issues those foster children had will be documented.
15. Have they worked with children (foster or non-foster) who were hospitalized prior to this experience?

Copy of the chart each participant will be asked to fill out if they have additional persons living at home (an example of a household with 3 additional residents is given)

Other persons living in the home	Age of person (years)	Gender	Education (last grade completed)	If child: biological or foster? (B,F, N/A)	Health Status: Excellent Good Fair Poor (E,G,F,P)	Any significant health Issues of this resident (Y/N)	Any significant support offered to foster parent by this person? (Y/N)
Resident #1	30	Male	12	n/a	G	N	Y
Child #1	12	Male	5	B	E	N	N
Child #2	10	female	4	B	E	N	N

Variables pertaining to the specific foster child (or children) that the participant worked with. (if the participant worked with more than one foster child who made the transition from hospital to foster home, then an additional questionnaire will be supplied to the participant).

1. Age of the child while in the care of the participant (Months and years)
2. Reason for hospitalization
   a. Congenital health issue from birth
       i. If yes…specific diagnosis
   b. Prematurity
   c. Parents unable/unwilling to care for child
   d. Physical abuse of child (by anyone)
   e. Other
3. Total number of days the child spent in the hospital prior to discharge (if known)
4. Number of days between when the participant (foster parent) was recruited to care for the child and when the child was discharged from the hospital
5. Any home services provided to the foster parents related to the care of the child (example: home health nursing or respiratory care) Yes/No?
6. If so, what were they?
   a. Home Nursing Care?
   b. Respiratory Care?
   c. Skilled Therapy (services from any state agencies)?
   d. Other
       i. What specific type
7. Number of times (approximately) that the foster child needed to be transported to health or medical appointments while in foster care if known?
   a. 2x per week or more?
   b. 1-2x/week?
   c. 1x/week?
   d. less than 1x/week?
8. Any rehospitalizations, significant medical/surgical procedures or significant travel for medical procedures that the foster parent experienced while caring for the foster child
9. Was there any involvement of the biological parents during the time of caring for foster child such as supervised/unsupervised visits, presence at medical appointments, or legal

consent issues affecting care (this will probably come up during the interview if it exists, however it needs to be documented)

10. Do you wish to receive a copy of the abstract of this study after it is completed? ___ Yes ___ No

Appendix E

Recruitment Letter

Dear Foster Parent,

I am writing to tell you about a study being conducted by the University of New Mexico involving foster parents. This study will be looking at the issues faced by foster parents who have taken foster children into their home directly from the hospital. I received your name from the Idaho Department of Welfare's Family and Community Services division because you are (or were) a licensed foster parent. Additionally you may have worked with a foster child who had been in the hospital at the time they came into your care.

The purpose of this study is to identify common issues that foster parents have when they care for children going from a hospital into a foster home. There is little research on the foster parent's experience of caring for children who have been hospitalized. We know there is an increase in the number of foster children needing qualified foster parents to care for them upon discharge from the hospital. It is important to better understand the foster parent's perspective on this experience. A better understanding will allow health care providers to be able to improve the experience for foster parents.

People who agree to participate in this study will contact Max Veltman at 208-426-3707 or maveltman@salud.unm.edu . This will allow for a date and a time to meet for an interview to be scheduled. Interviews will occur at a place of your choosing where privacy, confidentiality and safety can be assured. Even though this study is sponsored by the University of New Mexico, all interviews are expected to take place in Idaho. People who complete the 45 to 60 minute interview will receive a $25.00 pre-paid credit/gift card. Just a small gift as appreciation for your time.

You may be eligible for participation in this study if you:

1. Are a current or former licensed foster parent in your state of residence. Most participants in this study are expected to be residents of Idaho, but there may be some participants who are or have been licensed in another state. You do not have to be currently licensed at the time of the interview. You will have had to have been licensed as a foster parent during the period when you cared for a foster child who was discharged from the hospital directly to your home.
2. Have cared for at least one (or more) children where the initial placement of the child into foster care began when the child was a patient in the hospital. This also could include an infant born in the hospital with a significant health issue.
3. Have been recruited by a child welfare caseworker to care for a child while the child was in the hospital, then provided foster to that child as they left the hospital and came to your home.

<u>IF YOU WISH TO PARTICIPATE:</u>
If you are interested in learning more about this study and/or participating, please complete the enclosed form. Then mail it back to me in the pre-paid envelope. You are also welcome to call me at 208-426-3707. You may also email me at: maveltman@salud.unm.edu . If desired, you may also contact Dr Marie Lobo, the Primary Researcher for this study, at 505-272-2637.

Participation in this study is completely voluntary. The identity of all participants in this study will remain confidential and will in no way affect your relationship with any caseworker or local or state child welfare agency.

You do not have to respond if you are not interested in this study. If you do not respond, no one will contact you. You may receive another letter in the mail which you can simply disregard.

Thank you for your time and consideration.   I look forward to hearing from you.

Sincerely,

Max Veltman, RN, PhD(c), CPNP-PC
PhD Student
The University of New Mexico
College of Nursing

Exploring the Experience of Foster Parents who care for children transitioning from the Hospital to the Foster Home

Please complete this card and return in the pre-paid envelope provided

I am interested in learning more about this study. Please contact me using the following information:

Name: _____

Address: _____

Telephone(s): _____

Best time and day to call: _____
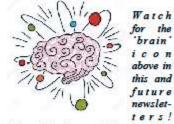
Email: _____@_____

Preferred form of contact:
__ Phone
__Email

Resource Family Newsletter

Health and Welfare West Hub

June–July 2015

Trauma Informed Parenting (TIP)

Watch for the 'brain' icon above in this and future newsletters!

This will indicate a TIP tip to help your family!

Trauma Informed Parenting-Tips:

Create a sensory box or basket! This box, full of items to help get the energy out, can be in your car for rides before/ after a visit. It can be placed near their 'space' or 'around' during those moments when you recognize their triggers (maybe coming home from school or going to bed, or dinner time).

Here's what can be inside:

*Weighted blankie to lay on top them or around their shoulders

*A squishy ball (offer variety of feels)

*Rubix cube

*I-Spy pillow

*Bean bag

*A warm up rice bag- place on their chest to help ground them

*Stretchy hug blanket (especially for those who lack touch)

*Salty or sour foods

*...anything else that is safe and uses as many senses at once.

See page 4 for an upcoming event where you can talk with other parents about sensory items and see some of these ideas first hand!!

RESEARCH STUDY—foster parents needed!!

Have you ever taken a foster child directly from the hospital into your home?

Would you like the opportunity to help improve the way foster children are discharged from the hospital?

If you are a licensed foster parent and cared for a foster child who came to your home directly from a hospital when they came into foster care, you may be eligible to participate in a research study exploring this experience through the eyes of the foster parent.

Eligible participants will be asked to sit down for a 45 -60 minute interview discussing the experience of working with a foster child coming into the home directly from the hospital.

Following the completion of the interview, each participant will receive a gift card valued at $25 in exchange for their participation.

If interested in participating, please contact Max Veltman at maveltman@salud.unm.edu or call at 208-426-3707

Appendix H

Question #1	Question #2	Question #3
	The Positive Aspects of the Experience	The Challenging Aspects of the Experience
Themes and Subthemes	**Themes and Subthemes**	**Themes and Subthemes**
Motivation to Foster God / Spirituality. Making a difference for the children. What the experience gives to the foster parent. **Advocacy** Have to fight / work around the system. I know best. **Previous experience as a foster parent is helpful** I'm glad I was a nurse/had experience working with CSHCN. **Lessons Learned** Communication is critical. Information is critical.	**Caseworker is Meeting the needs of the Foster Parent** **Health Care Workers are being supportive** Providing clear communication/needed information. **The Effects on the Family (both Foster Family and Biological Family)** Helping biological parents become better parents / assisting them with getting their children back. The influence of the child on the foster family. Watching the foster children growing and developing.	**Communication Issues** Experience of Caseworker / Health Care worker. System issues/conflict. **Conflicts with policies** Reunification. Consent. Information sharing. Feeling unsupported. **Taking care of CSHCN is stressful** Emotional impact of seeing the kids deal with health issues. **Lack of knowledge of the health condition/health status of the foster child** **Lack of Resources** **Conflicts with biological families**

1) Protocol Title (Version # and/or Version Date)

Exploring the Experience of Foster Parents as They Care for Children Who are Making the Transition from the Hospital into the Foster Home – 01.05.15

2) IRB Review History

N/A

3) Objectives

The purpose of this study is to identify and explore the common issues that foster parents encounter as they care for children making the transition from the acute care setting to the foster home. The specific aims are:

4. To describe the experiences that foster parents encounter, such as communication with health care workers and/or caseworkers; navigating child welfare and health care systems and accessing support services or obtain needed referrals for health care.
5. To describe any changes within their own biological family as they care for the foster child making the transition from being a patient in a hospital to being a child living in the foster home.
6. To describe experiences that the foster parent considers having a positive effect on their ability to care for the child during this transition.
7. To describe experiences that the foster parent considers having a negative effect on their ability to care for the child during this transition.

The specific research questions for this study will be:

1. What are the common experiences encountered by foster parents when caring for a child who is making the transition from the acute care setting to the foster home?
2. What experiences do foster parents consider having a positive effect on their ability to meet the care needs of the child and why?
3. What experiences do foster parents consider having a negative effect on their ability to meet the care needs of the child and why?

4) Background

Over the last 2 decades, there has been an increase in the number of children with significant health issues and complex care needs who are placed in foster care (Chernoff, Combs-Orme, Risley-Curtiss, & Heisler, 1994; Wang, Edelstein, Waldinger, Lee & Bath, 2011). Many of these children become the responsibility of local and/or state child welfare systems while they are admitted as inpatients in a hospital. This often requires the child welfare caseworker(s) to recruit a qualified foster parent who cares for the child when they are discharged from the hospital into the foster parent's home (Pecora, Whittaker, Maluccio, Barth & DePanfilis, 2009; Vig, Chinitz & Shulman, 2005). Yet while the incidence of this phenomenon seems to be increasing, there is a scant amount of published research devoted to the specifics of what this experience is like for the foster parents who provide the necessary care for these children.

Children in foster care have always had higher rates of significant health issues than non-foster children (Halfan, Mendonca, & Berkowitz, 1995; Steele & Buchi, 2008). Children who are the victims of abuse and neglect often end up being

admitted to hospitals with significant health problems and often these children must be placed in foster care due to the fact that the biological parent does not have the ability to take care of the child or is the perpetrator of the abuse. In the past, these children might not have survived, however advances in medical technology and care are allowing more and more of these children to survive and leave the hospital (Johnson & Kastner, 2005; Wang & Barnard, 2004). Caseworkers often find it challenging to recruit qualified foster parents to take on the duties of caring for these children as they often have demands that require significant amounts of time, energy and resources (Simms, Dubowitz & Szilagyi, 2000; Vig, Chinitz, & Shulman, 2005).

There is a growing amount of research devoted to the needs of children and families being discharged from the hospital (Snowden & Kane, 1995; Weiss, Johnson, Malin, Jerofke, Lang & Sherburne, 2008). Yet there is extremely limited research devoted to the needs of foster parents going through a similar experience. The only published research identified has dealt with foster parents caring for neonates exposed to Prenatal Substances and strategies to best prepare for these types of foster babies (Marcellus 2008, 2010). Literature involving foster parents who work with children with Special Health Care Needs (SHCN) has described many challenges faced by foster parents including communication breakdown(s) with caseworkers and/or health care providers, significant transportation demands for foster parents living in rural areas, and problems dealing with the various health care, legal and child welfare systems (Brown & Rodger, 2009; Lauver, 2008; Lerret, 2009; McCarthy, 2002; Pasztor, Hollinger, Inkelas & Halfon, 2006; Vig, Chinitz, & Shulman, 2005). This is believed to be a significant factor in the growing attrition rate of qualified foster parents and the difficulty recruiting new foster parents (Pecora, Whittaker, Maluccio, Barth & DePanfilis, 2009).

This study will add to the limited amount of knowledge of the experience of caring for foster children who are being discharged (making the transition) from the hospital to the foster home. Research that increases understanding of this phenomenon will aid in the ability of health care providers, especially nurses, to work with foster parents and ensure that the needs of these children are met during this critical phase of the child's care.

Chernoff, R., Combs-Orme, T., Risley-Curtiss, C., Heisler, A. (1994). Assessing the health status of children entering foster care. *Pediatrics, 93(4),* 594-600.

Risley-Curtiss, C. & Kronenfeld, J.J. (2001). Health care policies for children in out-of-home care. *Child Welfare, 80,* 325-350.

Wang, C., Edelstein, S.B., Waldinger, L., Lee, C.M., & Bath, E. (2011). Care of the foster child: A primer for the pediatrician. *Advances in Pediatrics, 58*, 87-111.

Pecora, P.J., Whittaker, J.K., Maluccio, A.N., Barth, R.P., & DePanfilis, D. (2009). *The Child Welfare Challenge: Policy, Practice, and Research, 3rd Ed.* New Brunswick, NJ: Aldine Transaction.

Vig, S., Chinitz, S. & Shulman, L. (2005). Young children in foster care: Multiple vulnerabilities and complex service needs. *Infants & Young Children, 18(2).* 147-160.

Halfon, N., Mendonca, A., & Berkowitz, G. (1995). Health status of children in foster care: The experience of the center for the vulnerable child. *Archives of Pediatric and Adolescent Medicine, 149*, 386-392.

Steele, J.S., & Buchi, K.F. (2008). Medical and mental health of children entering the Utah foster care system. *Pediatrics, 122*, e703-e709.

Johnson, C., & Kastner, T.A. (2005). Helping families raise children with special health care needs at home. *Pediatrics, 115(2),* 507-511.

Wang, K.W. & Barnard, A. (2004) Technology-dependent children and their families: a review. *Journal of Advanced Nursing, 45(1)*, 36-46.

Simms, M.D., Dubowitz, H. and Szilagyi, M.A. (2000). Health care needs of children in the foster care system. *Pediatrics, 106 (4),* 909- 918.

Snowdon, W.W., & Kane, D.J. (1995). Parental needs following the discharge of a hospitalized child. *Pediatric Nursing, 21(5),* 425-428.

Weiss, M., Johnson, N.L., Malin, S., Jerofke, T., Lang, C., and Sherburne, E. (2008). Readiness for discharge in parents of hospitalized children. *Journal of Pediatric Nursing*, 23 (4), 282- 295.

Marcellus, L. (2008). Administering love: providing family foster care to infants with prenatal substance exposure. *Qualitative Health Research, 18 (9),* 1220 – 1230.

Marcellus, L. (2010). Supporting resilience in foster families: A model for program design that supports recruitment, retention, and satisfaction of foster families who care for infants with prenatal substance exposure. *Child Welfare, 89(1)*, 7-29.

Brown, J. & Rodger, S. (2009). Children with disabilities: Problems faced by foster parents. *Children and Youth Services Review, 31,* 40-46.

Lauver, L. (2008). Parenting foster children with chronic illness and complex medical needs. *Journal of Family Nursing, 14(1*), 74-96.

Lerret, S.M. (2009). Discharge readiness: An integrative review focusing on discharge following pediatric hospitalization. *Journal of the Society of Pediatric Nursing, 14(4),* 245-255.

McCarthy, J.M. (2002). *Meeting the Health Care Needs of Children in the Foster Care System: Summary of State and Community Efforts*. Washington D.C.: Georgetown University Child Development Center. Retrieved July 18, 2013 from: gucdc.georgetown.edu/foster.html

Pasztor, E.M., Hollinger, D.S., Inkelas, M. & Halfon, N. (2006). Health and mental health services for children in foster care: The central role of foster parents. *Child Welfare, 85(1),* 33-57.

5) Inclusion and Exclusion Criteria

The informants who participate in the study will be foster parents who have cared for a child that was hospitalized when they initiated their care of that child and brought the child from the acute care setting (hospital) into their home. Individuals will be eligible to participate if they:

1. Are a current or former foster parent who has been licensed by their state of residence to be a foster parent. A participant does not have to be currently licensed at the time of the interview; however, s/he will have had to have been licensed as a foster parent during the period where they engaged in bringing the foster child home from the hospital if they are no longer a licensed foster parent at the time of the study.

2. Have cared for at least one (or more) children where the initial placement of the child into foster care started when the foster child was a patient in the hospital. The child would have been admitted to the hospital prior to entering foster care. This could also include an infant born in the hospital with a significant health issue.

3. Have been recruited by a child welfare caseworker to care for this child while the child was admitted to the hospital and continued to provide foster care as the child left the hospital and transitioned to the foster home.

4. Speak and read English.

5. Provided written consent to participate in the study.

Exclusion criteria include:

1. Adults unable to speak & read English

6) Number of Subjects (Recruitment Target)

The maximum number of participants for this study is expected to be 30-40. It is believed that as many as 200 potential participants will need to be contacted in order to arrive at a number of 30 eligible participants.

7) Recruitment Methods

Participants will be recruited primarily through recruitment letters sent via US mail. Key caseworkers from the Family and Community Services division of the Idaho Health and Welfare department will identify potential foster parents who meet eligibility criteria. The primary investigator will provide these caseworkers with stamped envelopes that contain information about the study as well as specific directions on how to address each envelope (see Appendix E). These caseworkers will address the envelopes and mail them to the potential participants. The information contained in the envelopes will explain the study and will ask the potential participant to contact the primary researcher if they desire to participate in the study. A copy of this letter is contained in Appendix A of this document.

Additionally, a notice/advertisement describing the study will also be posted in the monthly newsletter that is distributed to all licensed foster parents in the state of Idaho. This advertisement will briefly describe the study and how to contact the investigator for potential participation in the study. A copy of this advertisement is contained in Appendix B of this document.

Additionally, participants will be recruited through "word of mouth" or snowballing technique through various support groups that the primary researcher has access to. See Appendix B for the language of this contact.

8) Study Timelines

Following initial contact by the potential participant with the investigator, via email or telephone, participants will be invited to participate in a semi-structured interview at a time convenient for them. These interviews will occur at one of three places. The most likely location will be a city building in Nampa, Idaho that serves (among other things) children involved in the Idaho Health & Welfare system. This building is familiar to most foster parents in the area and has several rooms with comfortable chairs and tables that would be ideal for interviews. The participants can enter and leave the building without the knowledge of any employees of the Idaho Health & Welfare system. This building is a large facility with multiple, secure entrances. All employees of the Idaho Health & Welfare system use on entrance that allows them direct access to the parking lot where their vehicles (both personal and state) are located. Participants in the study would park in a separate location on the opposite side of the building and enter through the front (main) entrance. Due to the location of the interview room(s), there would not be any occasion where a Health & Welfare caseworker would be present in that area of the building. The building also has onsite counseling services that these participants can access should the need arise. Another option for the location of the interview setting is for the interview to take place at Boise State University in one of several secure meeting rooms located at the School of Nursing. This is a public building located in an academic setting. There are many secure, well-lit parking areas and 24-hour security for any after-hours interviews. Although not anticipated, participants would also have the option of engaging in the interview at their home. The primary researcher would travel to their home and that is where the interview would occur if the participant wishes this or feels it is more convenient.

Each interview is expected to take 60 – 90 minutes to complete. Following the completion of the interview, participants will be contacted again after the interview has been transcribed. Each participant will have the opportunity to meet with the primary researcher to go over the transcribed interview data and confirm its authenticity and also be given an opportunity to clarify, edit, or redact any of the interview data. This process is estimated to take approximately 60 to 90 minutes.

The estimated timeline for recruitment and completion of the interviews is 12 months. It is anticipated that the completion of the study and primary data analysis will be the spring of 2016.

9) Study Endpoints

N/A

10) Research Setting

The locations for the interviews to be done will be in a site selected by the participant. The potential locations will be one of the following:

1. A public building in Nampa, Idaho that, among other operations, provides services to foster parents in the area.
2. The participants' home.
3. A private meeting room at the School of Nursing at Boise State University (where the researcher is employed as an instructor).
4. Although not anticipated, a phone interview may be conducted.

The location for data analysis will be the office of the researcher, Max Veltman, which is located on the campus of Boise State University in Boise, Idaho.

11) Study Methods

Following approval by the University of New Mexico's Human Research Protections Office, participant recruitment will begin. This process will include:

1. A list of potential participants will be generated by key caseworkers in the Family and Community Services division of the Idaho Department of Health and Welfare. These caseworkers have access to the contact information of licensed foster parents in a 10 county area of Southwestern Idaho. These caseworkers (with approval from their supervisors) have agreed to allow their support staff to address envelopes that are pre-stamped and contain the recruitment letter, (see Appendix A), a response form (see Appendix B), and another smaller pre-addressed, pre-stamped envelope inside should the potential participant desire to participate in the study. A copy of the specific directions for caseworkers and support staff is contained in Appendix G of this document.
2. An advertisement (see Appendix C) for recruiting participants for the study will be placed in the monthly newsletter that the Idaho Department of Health & Welfare distributes to all licensed foster parents. This advertisement will appear in both the hardcopy newsletter as well as the emailed version of the newsletter. Permission for this advertisement has already been obtained from the Health & Welfare department.

Following recruitment to participate in the study, participants will be contacted and interviewed at the site selected by the subject (see section #10 for potential locations). This is where the data will be collected.

Following the completion of each interview, each participant will be given a $25 gift card that can be used as a cash voucher (credit card–like card) to be used at any retailer that accepts credit cards. Based on previous research with parents and families, this amount has been appropriate in offering some type of benefit for participation without providing an extreme incentive to coerce participation from unwilling persons. Participants will be allowed to keep the gift card even if they decide to withdraw from the study at any point following the completion of the initial interview.

It is estimated that recruiting participants and interviewing the participants will take 6 to 9 months. It is hoped that all data will be collected by November of 2015.

Each interview will be transcribed by the researcher. Individual participants will be contacted following transcription and given an opportunity to read over the transcribed data and offer clarification or deletion of any of the data. This

meeting will occur at one of the same locations described in section #10 of this document. It is hoped that this process will also be completed by November of 2015.

For this project, all quantitative data will be analyzed using SPSS software. The qualitative data coming from this project will be uploaded, managed and analyzed using CDC EZ-Text. CDC EZ-Text is a program that multiple members of a project can use while maintaining the security of the data. One of the members of the dissertation committee has experience using this software and has recommended it for use in this project. It has also been used in previous qualitative research (Koffman, Granade, Anwori, 2008).

The data will be analyzed by the researcher (Max Veltman) with input from the chair of his committee (Dr Marie Lobo) and assistance from the other members of his committee (Dr Averill, Dr Tinkle and Dr Gallegos). It is hoped that this process will be completed by February of 2016 and that the researcher (Max Veltman) is able to present and defend the final study by April of 2016.

Koffman, D.M., Granade, S.A., and Anwori, V.V. (2008). Strategies for Establishing Policy, Environmental, and Systems-Level Interventions for Managing High Blood Pressure and High Cholesterol in Health Care Settings: A Qualitative Case Study. *Preventing Chronic Disease: Public Health Research, Practice, and Policy, 5(3).* Pp. 1-16.

12) List of Appendices

1. Recruitment Letter (Appendix A)
2. Response Form (Appendix B)
3. Advertisement that will be placed in the Foster Parent newsletter (Appendix C)
4. Consent Form (Appendix D)
5. Demographics Worksheet (Appendix E)
6. Interview Script (Appendix F)

13) Data and Specimen Banking

Two codebooks will be created to serve as a link between identifiable data and the coded study data. One codebook (Codebook #1) will list the participant's name, contact information, and one additional identifier designating them as a "Participant __". A second codebook (Codebook #2) will only have data showing "participants" and their links with "Case Reports". Each data file containing all of the demographic data collected (see Appendix E of this document) as well as the transcribed interview data will be stored as a "Case Report ___". All participant identifiers will be removed during the transcription process and the transcribed interview will be uploaded and stored as a "Case Report".

Example: Participant Jane Doe will be identified as "Participant #6" in code book #1. In a separate code book (Codebook #2) stored in a different password protected cloud storage area, "Participant #6" will be linked with "Case Report K". Case reports will serve as the data to be used in the data analysis work with the primary researcher and his committee. Only the primary researcher and his

committee will have access to both of the codebooks. Each codebook will remain in a separate, password protected storage database with a different password access code. The codebooks will be kept for the duration of the study and publication and at the conclusion of the project, all data and written notes with identifiable information will be destroyed or deleted as appropriate.

14) Data Management

Two codebooks will be created to serve as a link between identifiable data and the coded study data. One codebook (Codebook #1) will list the participant's name, contact information, and one additional identifier designating them as a "Participant __". A second codebook (Codebook #2) will only have data showing "participants" and their links with "Case Reports". Each data file containing all of the demographic data collected (see Appendix E of this document) as well as the transcribed interview data will be stored as a "Case Report ___". All participant identifiers will be removed during the transcription process and the transcribed interview will be uploaded and stored as a "Case Report".

Example: Participant Jane Doe will be identified as "Participant #6" in code book #1. In a separate code book (Codebook #2) stored in a different password protected cloud storage area, "Participant #6" will be linked with "Case Report K". Case reports will serve as the data to be used in the data analysis work with the primary researcher and his committee. Only the primary researcher and his committee will have access to both of the codebooks. Each codebook will remain in a separate, password protected storage database with a different password access code. The codebooks will be kept for the duration of the study and publication and at the conclusion of the project, all data and written notes with identifiable information will be destroyed or deleted as appropriate.

All recordings will be transcribed by either the primary researcher or a paid transcriptionist. The audiofile recordings will be downloaded and stored in a secure database as mentioned previously. All transcribed documents will be downloaded and stored as Word documents in the same secure manner. If, during the clarification process where the participant meets with the researcher later, the participant changes or deletes sections of his/her transcribed data, that changed or deleted data will be changed or deleted in all of the databases and only data that the participant has reviewed (if they choose to) will be stored and analyzed.

15) Provisions to Monitor the Data to Ensure the Safety of Subjects

Provisions to Protect the Privacy of Subjects will include:

1. The researcher will not have access to the database from which potential participants are being recruited. He will not know any information about any participant unless/until they contact him after the potential participant inquires about participating in the study.

2. Each participant will decide where they wish the interview to take place. Each of the potential interview sites (see section #10) will be private (with the

possible exception of the participant's own home) and free of any "eavesdropping" issues.

3. All consent and data forms will remain with the researcher in a secured office following completion by the participant. All written and computerized data (including audio files) will be downloaded into a secure database following collection (see #13 & 14). All paperwork and forms will remain in a locked drawer in the locked office of Mr. Veltman at the Boise State campus.

4. If needed, the chair and members of the researcher's dissertation committee can access the data as part of the dissertation process. These 4 persons would be the only other people besides the researcher who would have this ability/opportunity.

5. No PHI will be collected from the participants in this study.

6. All recordings will be transcribed by either the primary researcher or a paid transcriptionist. The audio file recordings will be downloaded and stored in a secure database as mentioned previously (see section 11 – CDC EZ text). All transcribed documents will be downloaded and stored as Word documents in the same secure manner. Only the primary researcher will have access to these password protected storage drives.

To minimize the risk of the interview not being confidential, data collected from each participant will be identified and coded to protect the individual's confidentiality (see section 13).

To minimize the risk of having to deal with significant emotional feelings brought on by discussions of previous work with foster children, each participant will be reminded of this potential effect immediately prior to the interview taking place and the participant will be reminded that the interview is strictly voluntary. One of the sites available for interviews, the public building in Nampa, Idaho, is a clinic setting with in-house counselors that are available either immediately or within 72 hours for any follow-up care that the participant may desire or feel a need to access. If needed, an appointment for evaluation could be made at this facility for any participants in this study who might feel the need for such a service. Licensed foster parents are eligible for this service if needed.

This study is considered a minimal risk study and therefore no formal DSMP plan has been created

16) Withdrawal of Subjects

Participants will have the opportunity to withdraw from the study at anytime. As mentioned previously, participants will have the option to delete any or all sections or areas of content that is transcribed form their interview.

The primary researcher will remove participants at his discretion if and when situations of extreme emotional stress present during an interview. While not expected, discussions of working with foster children could potentially bring up memories that could elicit emotional distress in participants. The primary researcher who will be conducting all of the interviews is a nurse practitioner with extensive experience working with victims of trauma. This expertise will allow the researcher to identify participants who are experiencing significant stress and allow him to assess the need to end the interview and/or provide available onsite

mental health services to the participant if needed. These participants are also eligible for a referral to an Idaho Health and Welfare department caseworker should they feel the need to work with them.

17)   Risks to Subjects

This study will have no greater than minimal risk to the participants.   The primary risk will be some type of stress or emotional distress that may occur when describing the experience(s) that occurred when working with foster children.   Previous research has shown that foster parents often have a deep emotional attachment to the children they work with and there have been cases of foster parents experiencing grief, anger or other forms of emotional distress when discussing their work as foster parents in the past. The primary researcher has access to counseling services that each participant will be eligible for given their status as a licensed foster parent (see section #15). The vast majority of the interviews will take place at a site that has counseling available if needed.

 Another risk that could occur is the potential loss of privacy or confidentiality. As described in other sections of this document, every effort will be made to ensure that all identifiers associated with the data collected for this project will remain secure and confidential.

18)   Potential Benefits to Subjects

There will be no direct benefit to the participant. The Consent form describes the potential benefits to foster parents in general and how additional research could help design better systems and policies for future foster parents.

19)   Vulnerable Populations

The participants in this study are not considered a vulnerable population.

20)   Multi-Site Research

Following HRPO approval from the University of New Mexico, each site where interviews will take place will be provided with a copy of the study protocol and a copy of the consent form(s). In the event of any modifications to the study, all persons involved in the study will be notified by the researcher, Max Veltman. This would include the key caseworkers mentioned earlier (section #11) and their immediate supervisors, the director of the Nampa Family Justice Center, and the members of Mr Veltman's committee.

All necessary approvals for this study have been obtained and have been filed with the University of New Mexico's HRPO.

21)   Community-Based Participatory Research/Field Research

This study does not involve any CBPR research

22)   Sharing of Results with Subjects/Incidental Findings

As mentioned previously, each participant will have an opportunity to review his/her transcribed data from their interview.

Each participant in the study will have the opportunity to have the abstract of the final dissertation mailed to them if they desire. This will be indicated by the

participant during the interview and documented on the demographic data form (see Appendix E). Following the completion of the study, the researcher will mail a copy of the abstract of the final dissertation to the participant's home address if the participant indicated that s/he wished to receive a copy.

23) Resources Available

The Primary Investigator, Marie Lobo, who is overseeing the study, has had over 30 years of experience with research with children and their families in various settings including the hospital. The PI is the dissertation chair for the study coordinator and sole data collector, Max Veltman, the doctoral nursing student. The study coordinator and the sole data collector, Max Veltman, is a registered nurse, certified Pediatric Nurse Practitioner, and Masters prepared, PhD candidate in nursing and has 18 years of experience in pediatric health care. Max Veltman is a PNP in a Foster Child Clinic sponsored by the Idaho Health & Welfare Department, so has an established relationship with the Idaho Health and Welfare Department. The PI will be in weekly communications with Mr. Veltman as a resource for data collection, problem solving, and so forth. The study is supported through the process of data collection, analysis and dissemination by the dissertation committee consisting of Dr. Marie Lobo, Dr. Mindy Tinkle, Dr. Jennifer Averill and Dr. Cara Gallegos.

Financial resources for this project are currently limited to the researcher's professional development funds through his employer. The researcher currently has $2000 set aside for the expenses of this project, including transportation costs, participant incentives and postage.

Other resources available for this project include the researcher's access to a public facility with private meeting rooms for interviews as well as counseling services. Located in Nampa, Idaho, this facility is open on weekdays and is staffed with mental health providers who are available to assist adult victims of domestic abuse as well as pediatric victims of physical and/or sexual abuse. Interviews with participants will take place in this location where privacy is insured and mental health services, if needed, are available. The researcher also has access to this location on weekends and after hours for interviews that need to take place after normal working hours or weekends.

24) Prior Approvals/Attachments Requiring Signatures

See attached letters from the Idaho Department of Health & Welfare and the Nampa Family Justice Center

25) Confidentiality

All data collected for this study, including audiofiles of participant interviews, transcripts of these interviews, and all demographic data sheets will be kept in a secure, password protected database for the duration of the study and will be destroyed upon completion of the dissertation defense. Mr. Veltman has access to a password protected, secure server through his employment at Boise State University. This server is provided to him as a faculty member and it is specifically designed and intended for the storage of confidential information such as research data and student data.

The participant's identity in this study will only be known to the primary researcher.   See section 14 for details on how confidentiality of participants will be protected. Only the researcher and members of the researcher's committee (if needed) will have access to these data.

26) Provisions to Protect the Privacy of Subjects

Provisions to Protect the Privacy of Subjects will include:

1. The researcher will not have access to the database from which potential participants are being recruited. He will not know any information about any participant unless/until they contact him after the potential participant inquires about participating in the study.

2. Each participant will decide where they wish the interview to take place. Each of the potential interview sites (see #10) will be private (with the possible exception of the participant's own home) and free of any "eavesdropping" issues.

3. All consent and data forms will remain with the researcher in a secured office following completion by the participant.   All written and computerized data (including audiofiles) will be downloaded into a secure database following collection (see #25). All paperwork and forms will remain in a locked cabinet in the locked office of Mr. Veltman.

4. If needed, the chair and members of the researcher's dissertation committee can access the data as part of the dissertation process. These 4 persons would be the only other people besides the researcher who would have this ability/opportunity.

5. No PHI will be collected from the participants in this study.

27) Compensation for Research-Related Injury

N/A

28) Economic Burden to Subjects

N/A

29) Consent Process (including waiver request for HIPAA, waiver of HIPAA for recruitment only, Waiver of Informed Consent, and Alteration of Informed Consent)

Consent

Following recruitment and initial contact by the researcher, the participant will meet with the researcher at one of the locations designated for interviews to take place (see section #10). After a brief explanation of the study, the researcher will go over the 4 page consent form (see Appendix D) item-by-item with the participant. The participant will be asked by the researcher if s/he has any questions about the study or about how to contact the researcher (Max Veltman) or the chair of his committee (Dr Lobo) during their participation in the study. After answering all of the questions of the participant, the

researcher will ask the participant to sign the consent form. A staff member (if the interview is being held at the Nampa Family Justice Center) will sign the document as a witness. This staff member will not be an employee of the Idaho Department of Health & Welfare. If the interview is taking place at the participants' home, another family member will be asked to sign the consent form as a witness. After the consent is signed and witnessed, the researcher will sign and date the form and file it with all other consent forms in a secure location as mentioned in section #15.

Waiver or Alteration of Informed Consent: *Review the "CHECKLIST: Waiver or Alteration of Consent Process (HRP-410)"in the Click IRB Library to ensure you have provided sufficient information for the HRRC to make these determinations.*

N/A

Waiver of Written Documentation of Consent: *Review the "CHECKLIST: Waiver of Written Documentation of Consent (HRP-411)" in the Click IRB library to ensure you have provided sufficient information for the IRB to make these determinations.*

N/A

HIPAA Authorization

N/A

Waiver of HIPAA authorization: *Review the "CHECKLIST: HIPAA Waiver of Authorization (HRP-441)" in the Click IRB library to ensure you have provided sufficient information for the IRB to make these determinations.*

N/A

Non-English Speaking Subjects

N/A

Planned Emergency Research Consents

N/A

Cognitively Impaired Adults/ Adults Unable to Consent/ Use of a Legally Authorized Representative (LAR)

N/A

30) **Drugs or Devices**

N/A

UNM HEALTH SCIENCES CENTER

Human Research Review Committee
Human Research Protections Office

January 28, 2015

Marie Lobo, PhD, RN, FAAN
mlobo@salud.unm.edu

Dear Dr. Lobo:

On 1/27/2015, the HRRC reviewed the following submission:

Type of Review:	Initial Study
Title of Study:	Exploring the Experience of Foster Parents as They Care for Children Who are Making the Transition from the Hospital into the Foster Home
Investigator:	Marie Lobo, PhD, RN, FAAN
Study ID:	14-329
Submission ID:	14-329
Funding:	None
Grant ID:	None
IND, IDE, or HDE:	None
Submission Summary:	Initial Study
Documents Approved:	Protocol v2 01/09/2015
	Consent v01/15/2015
	Recruitment Ad submitted 01/09/2015
	Recruitment Letter submitted 01/09/2015
	Recruitment Response Form submitted 01/09/2015
	Directions for Caseworker Identifying Potential Participants submitted 01/09/2015
	Demographic Questions submitted 01/09/2015
	Interview Questions submitted 01/09/2015
Documents Acknowledged:	Signed Departmental Review Form dated 11/06/2015
	Letter of Support from Nampa Family Justice Center v10/10/2014
	Letter of Support from Idaho Department of Health & Welfare v09/05/2014
	Conflict of Interest documents, Human Subject Protection training and CV for PI.

The University of New Mexico • MSC08 4560 • 1 University of New Mexico • Albuquerque, NM 87131-0001 • Phone 505.272.1129 • Fax 505.272.0803 • hsc.unm.edu/som/research/hrrc •

BMSB B71

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Appendix K

Notification of Approval

To: Marie Lobo

Link: MOD00003879

P.I.:   Marie Lobo

Title: Foster Parents and Medically ill children

          This submission has been approved. You can access the
          correspondence letter using the following link:

Description: 14-329 Lobo (Godard) Mod#2 Approval Letter.pdf(0.01)

          To review additional details, click the link above to access the
          project workspace.

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Fax505.272.0803 • **hsc.unm.edu/som/research/hrrc** • BMSB B71