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The lived experience of being a mother of a child with severe cerebral palsy

Linda A. Moore
Medical College of Ohio

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FINAL APPROVAL OF THESIS
Master of Science in Nursing

The Lived Experience of Being a Mother of a Child with Severe Cerebral Palsy

Submitted by
Linda A. Moore

In partial fulfillment of the requirements for the degree of
Master of Science in Nursing

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Medical College of Ohio

2005
DEDICATION

This thesis is dedicated with admiration to the mothers who participated in this study and to all mothers who care for a child with cerebral palsy. You are a source of inspiration for me each day of my professional practice. You have shown me by your example what true love and commitment are. Thank you for making this project possible, it would have been impossible without you and your precious child.

I also would like to dedicate this thesis with love and appreciation to my husband Steve, and our children Julie and Steven. Your love and support throughout this study meant more to me than you will ever know. I love you all and thank you so much for helping me achieve my educational goal.

To my own mother, Betty Lou Dickey, RN; you taught me by your own wonderful example how to be a mother, and you were my first role model and teacher in the nursing profession. I dedicate this thesis with love to you as well for all that you have done to help me to become the person I am today.
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CHAPTER 1

Introduction

Each year approximately 10,000 babies born in the United States develop cerebral palsy (Waitzman & Romano, 1995). The initial presentation in children with cerebral palsy is a failure to meet early developmental milestones (Swaiman & Ashwal, 1999). The diagnosis of cerebral palsy not only includes the presence of a delay of developmental milestones; it also includes the persistence of primitive reflexes, the presence of pathologic reflexes, and the failure to develop protective reflexes (Swaiman & Ashwal). Parenting, and specifically being the mother of a child with severe cerebral palsy, is a unique experience that brings with it sorrows, joys, challenges and significant life changes.

This chapter introduces the subject of this research, which is the lived experience of being the biological mother of a child with severe cerebral palsy. It explores what is known and what gaps in the knowledge exist related to the experiences of parents caring for their child with severe cerebral palsy. This chapter will discuss the research problem, the purpose of the study, as well as a brief overview of the theoretical framework, and the relevant conceptual and operational definitions specific to the study. The significance of the study to nursing and healthcare will be addressed as well as the assumptions and limitations of the study. Chapter one will conclude with a summary of the contents of the chapter.

Statement of the Problem

Cerebral palsy is a condition caused by an abnormality in the brain causing difficulties in movement and coordination, with an onset in the developmental period of childhood. Studies have shown that the causes of cerebral palsy can include: cerebral malformation arising in the
gestational period, a destructive process in the antenatal, perinatal or early postnatal periods, or by various processes acting together (Menkes & Sarnat, 2000). The clinical picture of this disorder occurs along a spectrum from mild impairment, characterized by mild weakness of an extremity, to severe impairment, which is characterized by spastic paralysis of all four extremities, and any clinical presentation between these two extremes (Swaiman & Ashwal, 1999). Other disabilities are often present in conjunction with cerebral palsy. They include: mental retardation, seizure disorder, strabismus, and esotropia (Swaiman & Ashwal). Mild mental retardation has been reported in 26% of the cases of cerebral palsy, and severe mental retardation has been reported in up to 27% of cases (Hay, Hayward, Levin, & Sondheimer, 2003). Seizures have been reported in up to 50% of the cases of cerebral palsy (Hay et al.). Disorders of language, speech, vision, hearing, and sensory difficulties have been found in lesser degrees in the total cerebral palsy population (Hay, et al). Over 80% of all people with cerebral palsy developed the condition either before birth or within the first month of life (Waitzman & Romano, 1995). In most cases the cause of cerebral palsy is unknown. The life expectancy for a child with cerebral palsy is dependent upon the type and severity, the level of intelligence; children with profound mental retardation and severe quadriplegia have the shortest life expectancy (Swaiman & Ashwal). The median survival time for a child with severe cerebral palsy who is quadriplegic, unable to use their hands and mentally retarded is 11.8 years (Strauss, Shavelle, & Anderson, 1998). There is no cure for cerebral palsy; treatment is aimed at ameliorating symptoms and encouraging development (Larson, 1998).
Advances in medical technology and improved survival rates for premature infants have increased the incidence of this disorder. The incidence of cerebral palsy in the United States increased from 1.7 to 2.0 per 1000 births from 1975-1991 (Winter, Autry, Boyle, & Yeargin-Alsopp, 2002). The incidence of cerebral palsy is equal for males and females; however premature infants are at greater risk for cerebral palsy related to low birth weight and the insult of prematurity (National United Cerebral Palsy Association [UCPA], 2003). Most of these children live at home and the burden of care for them is placed on the parents (Gibson 1995). Most often the majority of this care falls upon the mothers (Gibson).

There is an enormous life change in the role of parenting when a child is diagnosed with a chronic neurological condition such as mental retardation or developmentally disability (Seideman & Kleine, 1995). There are multiple demands placed on the parent who cares for and rears a child with a chronic illness. Often, there are changes in lifestyle, family environment and relationships among family members. These changes require parents to adapt (Hentinen, & Kyngas, 1998; Gibson, 1995). Larson (1998) identified that mothers simultaneously embraced their child’s disability and rejected the limitation of the disability, aspiring for a more typical mothering experience. The adaptation or ineffective adaptation to the altered mothering role creates the lived experience.

Nelson (2002) identified a four-step process in mothering other than normal children. These steps include: the timing and emotions of becoming a mother of a disabled child, negotiating a new kind of mothering, dealing with life that will never be the same, and the process of acceptance versus denial (Nelson). Mothers are faced with the need to deal with a number of
challenges and stressors in their care-giving role that increases the risk of exhaustion and burnout. This is more often observed in mothers who have assumed this care out of necessity, not choice (Gravelle, 1997). One of the required major life changes is the surrendering of professional roles or careers in the workplace in order to achieve the increased parenting demands (Gravelle). This lifestyle change not only has an effect on the mother emotionally, it also affects the family financially and the community through the loss of a productive member of the workforce.

Recurrent chronic sorrow in parents of a child with a disability has been identified in several studies (Seidmen & Kleine, 1995; Kearney & Griffin, 2001; Gravelle, 1997; Mallow & Bechtel, 1999). Studies also have documented the positive aspects of parenting a child with cerebral palsy or mental retardation and developmental disability. These include: added emotional closeness among family members, enjoying typical family activities, positive relationships with healthcare providers, and mother’s relationship with the disabled child (Nelson, 2002; Seideman & Kleine; Knafl, Breitmayer, Gallow, & Zoeller, 1996). Kearney & Griffin (2001) identified themes of hope and joy in the context of sorrow in the care of a child with developmental disability.

Mothers who care for their child with cerebral palsy who reported high levels of stress and depression also reported low levels of social support, decreased size of the parent’s network of support, and ineffective parenting efficacy (Wanamaker & Glenwick, 1998). It is concluded that mothers who reported high levels of parenting stress reported fewer self-efficacy and social support resources than those mothers reporting less parental stress (Wannamaker & Glenwick). Similarly Failla and Corson-Jones (1991) reported that a positive score on the family hardiness
index has been correlated with an increase in family coherence, functional support and satisfaction with family functioning. Family hardiness is comprised of challenge, commitment, confidence and control, hardiness is known to positively influence health outcomes in stressful life situations (Failla & Corson-Jones, 1991).

There is a plethora of studies in the nursing literature related to parenting and caring for a child who is considered other than normal, and/or parenting a child with a chronic condition. The term “other than normal” includes children with mental or physical challenges (Nelson, 2002). There also have been several studies pertaining to mothering children with chronic illness and/or those with chronic medical conditions. However, there has been only one study identified related to the experiences of being a mother of a child with cerebral palsy, specifically spastic cerebral palsy (Glasscock, 1997). Spastic cerebral palsy according to Glasscock describes children who have developmental delays, involving upper and lower extremities and need help with activities of daily living (e.g., walking feeding, dressing). There are no studies describing the lived experience of mothers caring for their child with severe cerebral palsy, who is non-ambulatory and exhibits significant developmental delays. In the Glasscock study the use of the term spastic cerebral palsy could mean either moderately severe, or severe cerebral palsy according to the Swaiman and Ashwal (1999) criteria.

This study will document the lived experience of mothers of a child with severe cerebral palsy, which could also fit the criteria for spastic cerebral palsy. However, not all children with spastic cerebral palsy are considered to have severe cerebral palsy. Therefore, there is a gap in phenomenological knowledge of the lived experience of mothers caring for their child with
severe cerebral palsy. This study will help increase what is known about parenting a child with a
disability or chronic illness and will seek to build new knowledge related to the experience of
mothering a child with severe cerebral palsy.

Statement of Purpose

The purpose of this study is to explore the lived experience of being a mother of a child with
severe cerebral palsy. By understanding the lived experience for parents, practitioners are better
able to provide support, education and interventions aimed at enhancing the adaptation of
mothers who care for their child with cerebral palsy, which may in turn have a positive impact on
the adaptation and care of the child with cerebral palsy.

Theoretical Framework

The Roy Adaptation Model was utilized to develop the framework for this study of the lived
experience of mothers caring for their child with severe cerebral palsy. This theory is based on
the systems theory. Roy’s Adaptation Model (Roy & Andrews, 1999) has four essential
elements: the person who is the recipient of nursing care, environment, health and nursing. Roy
describes the recipient of nursing care as an adaptive system with coping processes; this adaptive
system can be an individual, family, groups, or even society. As a system, the recipients of care
are described as a set of parts, connected to function as a whole because of the interdependence
of the parts (Roy & Andrews). The Roy Adaptation Model describes regulator and cognator
subsystems that act together maintain adaptation in the four adaptive modes termed, physiologic-
physical, self-concept-group identity, role function and interdependence (Roy & Andrews).
The needs identified in the physiologic mode include: oxygenation, nutrition, elimination, activity and rest, protection, fluid and electrolyte balance, neurologic function, and endocrine function (Roy & Andrews, 1999). The self-concept mode need is described as psychic and spiritual integrity. Role function mode needs are identified as social integrity, the need to know who you are in relation to others so that you can act, and finally the interdependence need is identified as achieving relational integrity.

Roy and Andrews (1999) describe the environment as all conditions and circumstances influencing and affecting development and behavior. The three types of stimuli confronting a person in the Roy model are: focal, contextual, and residual stimuli. Roy asserts that health is considered a state and process of becoming integrated and whole. Adaptive responses in the model are described as those responses that promote integrity. Ineffective responses are those that do not contribute to integrity. The goal of nursing according to the Roy model is to promote adaptation for individuals and groups in each of the four identified adaptive modes (Roy & Andrews).

In this study the lived experience of mothers caring for their child with severe cerebral palsy is conceptualized using the Roy Adaptation Model (Roy & Andrews, 1999). The focal stimulus is seen as the chronic life long high disability status in the child with severe cerebral palsy. This necessitates a higher level of life change and adaptation for the mother than the adaptation and life change required for the mother of a child with a mild form of the disease, or the mother of a child with no identified health problem. This adaptation is reflected in the altered mothering role which results from the disability status of the child. The cognator and regulator subsystems work
together to form the mothers’ perception of the needs of this altered role. The mothers’ perception then is channeled toward meeting the needs perceived by her in each of the four adaptive modes. These responses are categorized as either adaptive or ineffective, which then are then fed back into the system at the level of the focal stimulus. The contextual stimuli in this study are all other environmental factors that contribute to the focal stimulus of the chronic and severe disability status in the child, which are identified by the study participants. The residual stimuli are all other stimuli that contribute to the focal stimulus but the effects of these stimuli are unclear in the mother’s adaptation and life change in the mothering role.

Phenomenology was used to explore the lived experience of mothers caring for their child with severe cerebral palsy. The purpose of the science of phenomenology is to describe the lived experience as a phenomenon of the appearance of things (Speziale, & Carpenter, 2003). “The purpose of phenomenological inquiry is to explicate the structure or essence of the lived experience of a phenomenon in the search for the unity of meaning which is the identification of the essence of a phenomenon, and its accurate description the everyday live experience” (Rose, Beeby, & Parker, 1995, p. 1124).

Research Question

What is the lived experience of being a mother of a child with severe cerebral palsy?
Definition of Terms

Lived experience

*Conceptual definition.* The perception of the adaptive system related to their integrated, compensatory and compromised responses in the adaptive modes to the identified focal contextual and residual stimuli.

*Operational definition.* The verbal perception of the life change and adaptation required as the mother of a child with severe cerebral palsy.

Mothers

*Conceptual definition.* An adult female human adaptive system, and the regulator and cognator subsystems that form the perceptions of altered parental role.

*Operational definition.* A female biological parent who is the primary caregiver for their child with severe cerebral palsy.

Child

*Conceptual definition.* A human adaptive system in the role of offspring with profound deficits in the physiologic mode as a result of severe cerebral palsy.

*Operational definition.* A male or female offspring between the ages of 4 and 11 years, who has a diagnosis of severe cerebral palsy.
Severe cerebral palsy

*Conceptual definition.* A profound alteration in the control of movement and posture in the physiological mode, which necessitates adaptation in the four adaptive modes (physiological, self-concept, role function, and interdependence).

*Operational definition.* A group of disorders characterized by marked abnormal control of movement or posture, in the absence of underlying progressive disease, with moderate to great limitations in everyday activities (Swaiman & Ashwal, 1999).

**Significance**

Cerebral palsy is the most expensive of all birth defects in terms of direct medical costs, developmental and special education services, and the indirect costs of lost work, and household productivity that is attributable to premature morbidity and mortality of persons born in the United States in 1988 (Waitzman & Romano, 1995). The estimated cost per case per year of patients with cerebral palsy was $503,000 in 1992; the lifetime expected costs exceed $2.4 billion dollars per case (Waitzman, & Romano, 1995).

This study will help to identify what the life experiences are for mothers who care for their child with severe cerebral palsy. The personal life of the mother and the family life can be profoundly affected by the diagnosis of chronic illness in a young child. In a study by Krulik et al, (1999) mothers of young children with a chronic illness across four different cultures were found to experience more stress than those of healthy children. In addition, the patterns of stress observed varied by culture, although the experience of stress was found to be consistent across all cultures. Experiencing multiple stressors over a long period of time can lead to a great deal of
stress and strain, which can leave the family at risk for ineffective adaptation (Failla & Corson-Jones, 1991; Huang, 1996). Some of the stress and strain identified is life changing in terms of the physical and emotional stressors for the primary caregiver (Gibson, 1995; Glasscock, 1997). The stressors associated with raising a child with a physical disability can have a profound effect on the adaptation and functioning of the family (Wanamaker & Glenwick, 1998).

A typical healthcare team for children with cerebral palsy includes: nurses, physicians, therapists, educators, social workers, and other professionals who assist the child in achieving maximum growth and development potentials (National UPC, 2003). Children with cerebral palsy often require long-term services from physical therapy, occupational therapy, and speech therapy. Mothers of children with severe cerebral palsy also spend countless hours in the offices of specialists such as neurologists, physiatrists, orthopedists, gastroenterologists, pulmonologists, and cardiologists for routine appointments as well as appointments for interval issues. The time spent with appointments alone is a significant life change for mothers related to time demands, and does not even address the time spent in the physical aspects of caring for such a child, or when the child becomes acutely ill and may need hospitalization.

The importance of a strong network of social support has been reported as a key factor in caring for a child with a chronic condition including: family support, having a faith in God, seeking assistance from community agencies and seeking support from nurses and healthcare professionals (Youngblut, Brennan, & Swegert, 1994). Social support also includes respite services, which allows the parent time to rebalance their life while healthcare providers care for their child (Gibson, 1995).
Regardless of the practice setting this study has relevance for all nurses, primarily through increasing the body of knowledge related to the care of families and children in which there is a child with severe cerebral palsy, and incorporating this knowledge into nursing practice. Adult family and pediatric practitioners have a role to fulfill related to assessment and interventions aimed at enhancing the parental adaptation of caring for a child with cerebral palsy. Pediatric practitioners could enhance the care of the child through a thorough understanding of the unique aspects of parenting, specifically a mother’s experience of caring for her child with cerebral palsy. Adult practitioners need to consider the aspects of parenting such a child when assessing the health and adaptation of a parent with severe cerebral palsy. Practitioners should understand that the experiences of raising a child with a disability is one that is highly individual, that in this experience there is pain and sorrow as well as joy, hope and optimism (Kearney & Griffin, 2001).

The co-investigator goes into this study with over 23 years as a registered nurse, with a variety of clinical experience related to the care of pediatric and adult clients. In my clinical experience, I have observed the mothers of profoundly handicapped children as they take on an altered mothering role to meet the complicated needs of these children. I have been awed by their unending hope and optimism in the face of some very grim circumstances. The love that they pour on these handicapped children, and the ways in which they sacrifice their own needs and desires for the welfare of their child is an inspiration to me. I believe that they have a very rich and beautiful love story to tell, and that that their story should be recorded so that others can understand and appreciate the experience of mothering a child with severe cerebral palsy. The
final research product will be shared with educational community of MCO, and professional peers of the co-investigator.

Assumptions

The major assumption of this research is that the experience of caring for a child with severe cerebral palsy will affect many aspects of the primary caregiver’s life. It is also assumed that when the primary residence of the child with severe cerebral palsy is with the biological mother at home, the mother assumes the role of primary caregiver for the child. It is further assumed that mothers are willing to openly and honestly discuss the experience of being the mother of a child with severe cerebral palsy, and that these experiences are life changing and unique. It is assumed that the phenomenological method will be an appropriate method to complete this research. It is further assumed that mothers as adaptive systems will use acquired and innate coping mechanisms in response to identified stressors, in an effort to adapt appropriately (Roy & Andrews 1999). It is further assumed that these responses will be in each of the four identified adaptive modes of the Roy adaptation model.

Limitations

The primary limitation in this research is the inexperience of the researcher in the technique of in-depth interviewing and in the analysis of the data. Another identified limitation of the study is the researcher’s professional experiences with the subjects of research in a private neurology practice. The researcher had to bracket existing knowledge and perceived understanding of the experiences of parents caring for a child with severe cerebral palsy. The small size and the use of a convenience sample is another identified limitation of the study.
Summary

This chapter introduced the research topic of the experiences of mothers caring for a child with severe cerebral palsy. It explored the previous research and identified the gaps in the research related to adaptation and coping in the mothers of these children. The purpose of the research, which is to explore the lived experience of being a mother of a child with severe cerebral palsy, was identified; in addition, the research question specific to this study was identified. A brief overview of the Roy adaptation model was discussed. Conceptual and theoretical definitions were reviewed as well as the assumptions and limitations of the study.
CHAPTER II

Literature

This chapter discusses the theoretical framework used in this study. Relevant research will be reviewed within the framework of the Roy adaptation model. A comprehensive review of the existing research utilizing the Roy adaptation model and pertinent to the study will be discussed. This review will include the identification of the adequacy and gaps in the current knowledge related to this particular study. The chapter will conclude with a summary of the literature review related to the lived experience of being a mother of a child with severe cerebral palsy.

Nursing Theoretical Framework

The Roy adaptation model (Roy & Andrews, 1999) guided the development of the theoretical framework upon which this study is based. The Roy adaptation model has been found useful in many clinical situations (Hanna & Roy, 2001). It has been frequently used in the care of newborn children and their families, and it has been useful in neuroscience nursing (Hanna & Roy). This model is an appropriate model in which to study the mothers of children with severe cerebral palsy, as this is a study of severe neurological deficit in a child and the response of mothers to that experience. The concepts of this model will be defined and the conceptualization of the study will be identified through the application of the Roy adaptation model. A schematic illustration of the concepts and variables of this study are included (Figure 1). Previous relevant studies using this model as a nursing theoretical framework will be discussed in relation to the present study.
To understand the core concepts of the Roy adaptation model, it is important to recognize the scientific and philosophic assumptions on which it is based. The scientific assumptions are based on systems theory and adaptation-level theories. The philosophic assumptions are based on the concepts of humanism and veritivity. The term veritivity is a term that was introduced by Roy and Andrews (1999) who assert that veritivity “pertains to the principle of human nature that affirms a common purposefulness of human existence” (p. 32). The scientific assumptions underlying the Roy adaptation model that have evolved from the systems theory include: holism, interdependence, control processes, information feedback, and complexity of living systems (Roy & Andrews; Hanna & Roy, 2001). The adaptation-level theory contributes the following principles to the scientific assumptions of the Roy model: behavior as adaptive, adaptation as a function of stimuli and adaptation level, individual or dynamic adaptation levels, and positive and active processes of responding.
The philosophic assumptions of the Roy adaptation model (Roy & Andrews, 1999) that originate from humanism are: creativity, purposefulness, holism and interpersonal process (Hanna & Roy, 2001). Veritivity as a philosophic assumption of the Roy adaptation model includes: purposefulness of human existence, unity of purpose, activity, creativity, and value or meaning in life (Hanna & Roy). These assumptions form the basis of the major concepts of Roy’s model, which are identified as: the person, the environment, health, and nursing.

The Roy (Roy & Andrews, 1999) model postulates that the recipient of nursing care can be an individual, a family, group, community or even society. The family structure, function and task are an environmental stimulus having an effect on the adaptation level of the individual and the family (Roy & Andrews). For example single parent families, families with a handicapped child, and two parent families, each has their own unique and interrelated function and tasks. For the purpose of this study, a family includes a mother and her child with severe cerebral palsy, and may include other children, a spouse, extended family members and any other type of family structure. However, the only required elements are the mother and her child with severe cerebral palsy, since it is the experiences of the mother in relationship to the child that is the focus of this study.

Roy also describes a person as an adaptive system; adaptive according to Roy is a human system that has the capacity to adjust to changes in the environment, and therefore affect the environment. Systems according to Roy are parts that are connected and function together as a whole because of the interdependence of the parts. Systems have inputs, outputs, controls, and feedback processes. Stimuli pool to make up a specific input, which is the adaptation level; a
person’s response is the output and is a function of a person’s adaptation level (Roy & Andrews, 1999). A person bases their response on their current level of adaptation and the environment forces. Adaptation level encompasses three levels of life processes, these levels have been identified as integrated, compensatory and compromised (Roy & Andrews).

The two major mechanisms identified for coping in this model are termed the regulator and cognator (Roy & Andrews, 1999). Coping processes have been identified as the key to understanding people and groups of people, termed relational people, the adaptation of these people and the role of the nurse in promoting adaptation for these persons and relational persons (Hanna & Roy, 2001). The regulator mechanism is viewed as responding automatically through neural, chemical and endocrine systems. In contrast the cognator is the response that elicited through cognitive–emotive channels and includes: perceptual-information processing, learning, judgment and emotion (Roy & Andrews).

The person as an adaptive system is affected by the world around and within them; this world according to Roy is called the environment (Roy & Andrews, 1999). The Roy adaptation model proposes that the environment is more specifically referred to as stimuli. There are three classes of stimuli that form a person’s environment; these classes are: focal, contextual, and residual stimuli (Roy & Andrews). It is the pooling of these stimuli that makes up a person’s adaptation level (Roy & Andrews).

The focal stimulus is the stimulus that is the most immediately confronting a person; this stimulus can originate from within the person or from external sources (Roy & Andrews, 1999). The focal stimulus in this study is identified as the severe and chronic high level of disability in
the child that is a result of severe cerebral palsy that in turn has a profound effect on the adaptation and behavior of the mother as an adaptive system.

Contextual stimuli are all other stimuli that are present that have some type of effect on the focal stimulus, but are not the center of a person’s attention (Roy & Andrew, 1999). These stimuli also originate from within or outside the person. Contextual stimuli influence how a person can deal with or adapt to a focal stimulus (Roy & Andrews). In this study mothers will identify the contextual stimuli in the mothering experience of caring for a child with severe cerebral palsy.

Residual stimuli are those stimuli with unknown effects on the present situation; these stimuli also originate from within a person or from the external environment (Roy & Andrews, 1999). The residual stimuli in this study have not as of yet been identified and are unknown. The adaptation level consists of the merging of the focal contextual and residual stimuli, and describes a person’s ability to respond to a given situation (Roy & Andrews). This study will seek to describe the adaptation level and coping processes of mothers as they care for their child with severe cerebral palsy.

Stimuli and adaptation level are considered input into the adaptive system, processing of the input by control mechanisms occurs and finally a person responds through behavior (Roy & Andrews, 1999; Fitzpatrick & Wahl, 1996). Behavior according to Roy and Andrews includes internal and external actions and responses. For the purposes of this study, the mothers’ perception and behaviors will be observed through the use of in-depth interviews that seek to capture the lived experience.
The role of the nurse is to promote adaptation through assessment of current responses and determines if they are effective for the patient (Roy & Andrews, 1999). The nursing process includes assessments by the nurse to identify, implement and respond to human coping process, the nurse response is to provide support and influence adaptation, using methods such as teaching (Hanna & Roy, 2001). This study will help contribute to the body of knowledge related to the care of children with cerebral palsy and their families.

Roy and Andrews (1999) have identified the coping mechanisms as the complex internal controls within persons that are either innate or acquired and contribute to person’s adaptation. Innate coping mechanisms are automatic or common to all in the species, in contrast acquired coping mechanisms are those mechanism that are learned (Roy & Andrews). The coping mechanisms can be further grouped into the regulator and cognator subsystems. These subsystems also contribute to a person’s adaptation (Roy & Andrews). The regulator is an automatic response that originates from neural, chemical and endocrine coping mechanisms, the cognator on the other hand is a learned response that responds through cognitive emotive channels (Roy & Andrews; Fitzpatrick & Wahl, 1996). The cognitive emotive channels are identified by Roy as: perceptual/information processing, learning judgment, and emotion. The coping mechanisms of the study mothers are critical concepts for this study, as these responses will be observed through the data collection process.

There are four modes of behavior that are the outcome of the regulator and cognator mechanisms, and are identified as the: physiological mode, self-concept mode, role function mode and interdependence mode (Roy & Andrews, 1999). Adaptive functioning of families with
children with developmental disabilities requires special efforts to adapt to the focal, contextual and residual stimuli through the four adaptive modes (Huang, 1996). For the purposes of this study each of the study participants adaptation level will be analyzed in the four adaptive modes (Figure 1).

The physiological mode is the human response to environmental stimuli that is manifested as the activities of cells, tissues, organs and systems in the body of a person (Roy & Andrews, 1999). The five identified needs within the physiological mode are oxygenation, nutrition, elimination, activity, and rest, and protection (Roy & Andrews). Children with severe cerebral palsy have alterations in the physiological mode such as alterations in muscle tone preventing ambulation and purposeful movement. The alterations in the physiological mode in the child with severe cerebral palsy impose alterations in the physiological mode for the mother who is the caregiver for the child. These alterations are in the form of physical caregiving demands that child requires.

The self-concept mode focuses on the psychological and spiritual aspects of a person’s life (Roy & Andrews, 1999). The basic need in this mode is to understand what one’s purpose is, related to who one is (Roy & Andrews). The self-concept mode can be further divided into the physical and personal self. Many researchers describe adapting to the diagnosis of a child with a chronic neurological condition as a process of enhanced self-development due to the multiple stressors that require the mother’s energy and attention (Gibson, 1995; Glasscock, 2000; Helitzer, Cunningham-Sabo, VanLeit & Crowe, 2002; Wannamker & Glenwick, 1998; Kearney & Griffin, 2001; Knafl, Breitmayer, Gallo, & Zoeller, 1996). For the purpose of this study, the
mothers’ psychological and spiritual characteristics, and life purpose as perceived by the participant will be addressed as aspects of the self-concept mode, by means of the interview process and data analysis.

Role function mode centers on the roles persons occupy in the community (Roy & Andrews, 1999). The basic need for this mode is social integrity (Roy & Andrews). A role is understood to represent a collection of expectations concerning how one person behaves to another person when each person occupies a different position (Roy & Andrews). Roy and Andrews define role transition as a continuous process that occurs during role change of “growth in a new role with increasing effectiveness of role behaviors” (Roy & Andrews, p. 452). Many studies have identified a new parenting role that emerged when a child has been diagnosed with a chronic condition, developmental disabilities or cerebral palsy (Failla & Corson-Jones, 1991; Gibson, 1995; Glasscock, 2000; Wannamaker & Glenwick, 1998; Seidemen & Kleine, 1995; Kearney & Griffen, 2001; Heitzler et al., 2002). For the purpose of this study the role transition begins at the time the child is diagnosed with severe cerebral palsy, and continues for an indefinite period, as the mother assumes the caregiving and altered mothering role that the child’s diagnosis and treatment require. This altered role function is a critical concept to this study.

According to Roy and Andrews (1999), the interdependence mode focuses on interactions of persons that concern itself with giving and receiving of love, respect and value, the basic need in this mode is affectional adequacy. There are two relationships identified as the primary focus of this mode; they are: relationships with significant others, and support systems (Roy & Andrews). Numerous studies have identified the importance of support systems in the adaptation
of parents caring for a child with a chronic condition and/or a neurological condition such as cerebral palsy (Case-Sasser, 1995; Failla & Corson-Jones, 1991; Freedman, Boyer, & Casobianco, 2000; Glasscock, 2000; Hentinen & Kyngas, 1998; Hirose & Ueda, 1990, Huang, 1996). For the purpose of this study the significant relationships and support systems for the mothers are identified by the study participants in the interview process. The Roy model has been utilized in over 163 studies; 69 of those studies were related to families, and of those studies, 29 were related to parent child nursing (Boston-Based Adaptation Research Nurse Society [BBARN], 1999). Subsequent to the BBARN study an additional 38 family-based studies using the Roy adaptation model have been identified (Hanna & Roy, 2001). There has been only one study that utilized the Roy adaptation model as a theoretical framework that is relevant for the present study. Huang’s (1996) doctoral dissertation tested the structural model of family hardiness, social support, stress, coping, and family functioning of families of children with developmental disabilities, which included children with cerebral palsy.

There are four essential elements of the Roy (Roy & Andrews, 1999) model: the person who is the recipient of nursing care, environment, health, and nursing. Roy has identified three types of stimuli confronting persons; these include focal, contextual and residual stimuli. The focal stimulus for the purpose of this study is the high level of disability in the child and chronic nature of the condition of severe cerebral palsy that requires a higher level of life change and adaptation for the mother who cares for this child. The Roy model demonstrates that the regulator and cognator coping processes work together to maintain adaptation in four modes. These modes are identified as the physiological, self-concept, role function, and interdependence modes. For the
purpose of this study the regulator and cognator coping processes will be observed through data collection of the study participants. These coping processes are interactive and the area of perception is where these processes overlap (Roy & Andrews 1999). Behavior and adaptation in the adaptive modes will be observed and discussed, and then analyzed in each of the four adaptive modes. The goal of nursing according to the Roy adaptation model is to promote adaptation and promote health. This theoretical model will provide a relevant and comprehensive framework for the purpose of seeking to understand the lived experience of being the mother and caregiver of a child with severe cerebral palsy.

Review of Research

There have been a plethora of studies related to childhood illness in the review of relevant research. However, many of these studies were conducted over 10 years ago, and the findings have a limited relevance for this study. There is only one study identified that documented the lived experience of being the mother of a child with cerebral palsy (Glasscock, 2000). There are no identified studies of being the mother of a child with severe cerebral palsy. This review of research includes studies of children with chronic disease states, developmental disabilities, medically fragile children, and studies specific to the diagnosis of cerebral palsy. This review will be organized according to common themes of the experience of parenting a child with a chronic condition or a neurological condition that were identified in the review of relevant research. These identified themes are: mother’s roles, family’s response, and family and social support.
Transformed Mothering Role

Caregiver

Several research studies have identified that the primary responsibility as caregiver of a child with a chronic condition or neurological diagnosis falls most often to the mother (Glasscock, 2000; Hirose & Ueda, 1990; Gibson, 1995; Seideman & Kleine, 1995; Gravelle, 1997; Hentinen & Kyngas, 1998). Glasscock identified that mothers caring for their child with cerebral palsy have multiple roles affected, experience different stressors, and use different coping methods. These mothers identified that they developed strategies that worked best for their family (Glasscock).

Mothers of children with disabilities spend more time engaged in the physical aspects of childcare. In addition, they are often expected to take on the roles of teacher, therapist and nurse (Helitzer, Cunningham-Sabo, VanLeit, Crowe, 2002). Mothers face many challenges in the caregiving role that greatly increased their risk of exhaustion and burnout, especially in the care of their child with a progressive illness (Gravelle, 1997).

Loss of Identity

Loss of identity and perceived lost goals and expectations for the future were identified themes by mothers of children with disabilities (Helitzer, Cunningham-Sabo, VanLeit, & Crowe, 2002). Many of the mothers described themselves as independent and pursuing dreams before their children were born, and that their identity was lost after the birth of their disabled child (Helitzer, et al., 2002).
Maternal Child Relationship

There is little data in the research that discusses the maternal child relationship when the child has a chronic condition or a neurological problem. Few studies even mention this significant relationship. Through caring for their child, mothers of children with chronic disease identified that they knew their child better than anyone else; this knowledge of the child was both intuitive and empirical (Gibson, 1995). Gibson identified that the mothers’ deep love and commitment to the child, and deep sense of responsibility that the child receive the best care possible, motivated and sustained the empowerment process that was identified as a positive coping skill.

The review of research identified that the role of the mother caring for a child with a chronic condition, developmental disability, or neurological disorder such as cerebral palsy, is complex. There have been several themes identified related to the parenting and mothering experience. They include family and social support, mother’s and family’s response, and a transformed mothering role. The theme of family and social support includes family relationships, family support, family hardiness, and support networks outside the family.

The mother’s and family’s responses include coping, which encompasses the sub themes of caregiver burden, empowerment, transformed parenting, facing adversity, living worried, and management. Emotional responses identified include: joy and sorrow, chronic sorrow, and frustration.

Only one study of a mother’s lived experience of caring for their child with cerebral palsy has been reported in the literature (Glasscock, 2000). However, there are no studies of the
experience of being a mother of a child with severe cerebral palsy, which is hypothesized to be a more difficult experience than caring for a child with mild or moderate cerebral palsy. This study will increase the knowledge related to the care of children with cerebral palsy and their families.

There has been little documentation in the current research of the maternal child relationship, and the implications of this relationship on the relationship with spouse and other family members, including other children in the family. There is little documentation of the experience of an acute illness that requires hospitalization for children with cerebral palsy, and the implications for the mothers who must give up the primary caregiver role while the child is hospitalized. There is little research documenting the impact of other conditions that are often seen in conjunction with cerebral palsy and the implications of these disorders on the child and the implications on the caregiving role for the mother.

Mother’s and Family’s Responses Coping

Caregiver burden.

Burden is defined as “appraised distress in response to caregiver experiences” (Vitaliano, Russo, Young, Teri& Maiuro, 1991, p. 393). Caregiver burden has been identified as a means of coping with the care of a child with a chronic condition or a neurological condition (Glasscock, 2000; Case-Sasser, 1995). In a metasynthesis of mothering other than normal children, Nelson (2002) found that all studies that sampled mothers’ caregiving outside the hospital identified caregiver burden as a theme, and identified that mothers lives were affected quite dramatically in the mothering of other than normal children. The mothers were most often the primary caregiver for the child, and reported receiving little help or support. Brust, Leonard and Sieloff (1992)
surveyed 133 mothers of disabled children and found that these mothers, on the average, utilized over 12 hours per day in the care of their disabled child. Glasscock (2000) identified caregiver burden as a theme in her qualitative research of mothers of children with spastic cerebral palsy. Caregiver burden encompassed the day-to-day caregiving, and included mothers’ time and energy and the emotional and physical care of the child (Glasscock, 2000).

Case-Sasser (1995) similarly described caregiving burden in terms of the positive and negative reactions that occur in caring for a child with a chronic illness or developmental disabilities. The positive reaction to caregiving was a learning experience, a challenging experience, contributing to interpersonal satisfaction and to a strong religious faith with facilitated adaptation (Case-Sasser). The negative reactions identified by the parents caring for a child with a chronic condition or a developmental delay included meeting the physical health needs of the child, which was increasingly more difficult and stressful both physically and mentally for the caregiver as the child got older (Case-Sasser, 1995).

Empowerment.

Gibson (1995) conducted a fieldwork study of mothers of chronically ill children to describe how the process of empowerment as a means of coping is observed in this population. Empowerment was conceptualized as a social process of recognizing, promoting, and enhancing the abilities of persons to meet their own needs, solve own problems and mobilize necessary resources to gain a sense of control in their life (Gibson). Mothers identified that empowerment was a transforming change in themselves and reported that they were empowered when they were full participants in their child’s care, and were heard by healthcare professionals (Gibson).
Transformed parenting.

Similar to the process of empowerment (Gibson, 1995) is the theory of transformed parenting that emerged from a grounded theory study of the parenting experience of a child with developmental delay or mental retardation by Seideman and Kleine (1995). Transformed parenting was identified as a means by which parents cope with the experience of parenting a child with developmental delay or mental retardation. Transformed was referred to as changes in the basic condition, nature or character of parenting role (Seideman & Kleine). This change in the parenting role went beyond the anticipated and expected role expectations to a new form of parenting (Seideman & Kleine). Transformed parenting includes an entrance process at the time of diagnosis, and a performance process that began with a response by the parents to the diagnosis (Seideman & Kleine). Parents responded to stress and environmental support, which were identified as parallel processes and demonstrated a transformed parenting role through seeking and mobilizing resources for their child (Seideman & Kleine).

Facing adversity.

Facing adversity is a conceptualization of parents’ experiences in caring for their child with a progressive condition in the complex chronic phase, as identified in a phenomenological study by Gravelle (1997). Facing adversity was viewed as a means of coping or adapting to their child’s condition. Defining adversity and managing adversity are the two components of facing adversity (Gravelle, ). Defining adversity included the individual hardships identified by parents, and managing adversity included managing changes in the child’s condition and in the caregiving role related to the change in condition (Gravelle).
The concept of defining adversity was influenced by the child’s individual condition, the way the parents viewed the child’s condition, acceptance of the child’s condition, living with loss, and gaining strength (Gravelle, 1997). Managing adversity included strategies to manage changes. They included, planning/preparing, negotiating, and utilizing resources (Gravelle).

_Living worried._

Living worried has been identified as a description of the lived experience of parenting a child with spina bifida as a means of coping with a congenital physical disability (Monsen, 1999). Mothers’ struggles to maintain equitable treatment for their child with spina bifida in healthcare, educational and social systems provides an example of living worried, an emotion that began for mothers at the time of the birth of the child and never completely subsides (Monsen). Mothers of children with spina bifida have identified feelings of hope, defeat, and resignation amidst constant worry about staying in the struggle and not giving up (Monsen).

_Management._

Family management styles of school-aged children with a chronic condition have been identified as a means of family coping (Knafl, Breitmayer, Gallo, & Zoeller, 1996). These identified family management styles include: thriving, accommodating, enduring, struggling and floundering (Knafl et al.). Thriving families showed no negative consequences for the family or members of the family; accommodative family style reported few negative consequences for the family related to the child’s chronic condition; enduring family management was primarily concerned with the difficulties associated with the child’s chronic illness (Knafl et al., 1996). Struggling management style had an overriding theme of parental conflict concerning the best
management of the child’s chronic condition (Knafl, et al.) Floundering management style was characterized by negativity and confusion related to managing the child’s chronic condition (Knafl, et al.).

Similarly, in a secondary analysis of the data in the family response to childhood chronic illness descriptions of three management styles were identified with regard to illness management in children with chronic medical conditions: (1) strict adherence, (2) flexible adherence, and (3) selective adherence (Knafl, K., Breitmayer, B., Gallo, A., & Zoeller, L., 1996, Gallo & Knafl, 1998). Strict adherence was observed as target behaviors that were based in the prescribed treatment plan (Gallo & Knafl,). Flexible adherence was observed as target behaviors that modified the prescribed treatment plan to make life more livable. Selective adherence is observed as target behaviors that differed from what healthcare professionals had advised (Gallo & Knafl). These identified management styles were implemented by the parents’ in response to the child’s chronic illness and have been identified as factors in the coping process with flexible adherence experiencing less negative consequences.

*Emotional responses*

*Joy and sorrow.*

Hirose and Ueda (1990) identified that mothers of children with cerebral palsy were more emotional in their reactions to the child’s diagnosis than fathers, who were more objective and realistic. Several authors have identified the experience of coping with parenting a child with a chronic condition, developmental disability or neurological problem as an experience of sorrow and/or chronic sorrow (Kearney & Griffin, 2001; Mallow & Bechtel, 1999; Hentinen & Kyngas,
In contrast to the findings of sorrow was the joy that has been identified as an unanticipated consequence of the sorrow (Kearney & Griffen).

Kearney and Griffin (2001) conducted a phenomenological study of six parents caring for their child with developmental disability, and developed a model between joy and sorrow to describe the parenting experience. The model identified undercurrents of confusion, doubt, ambiguity, and dynamic interactions of joy and sorrow, hope and no hope, defiance and despair.

A number of parents identified that sorrow originated from their dealings with other people’s frequent messages of negativity and hopelessness (Kearney & Griffen, 2001). Other factors associated with sorrow included the anticipated possibility of the child dying, learning of the child’s changed potential, being treated by others as if there were a death in the family, being left on their own by health system and feeling powerless (Kearney & Griffen). Chronic sorrow was an emotional response identified by all parents of children with developmental disabilities and those with a chronic illness (Seideman and Kleine, 1995; Gravelle, 1997; Mallow & Bechtel, 1999). Similarly, mothers and fathers exhibited initial patterns of sadness and grief at the time of diagnosis of their child with developmental disability; mothers’ emotional response most often progressed to chronic sorrow, whereas the fathers’ emotional response most often progressed to resignation (Mallow & Bechtel).

In contrast to sorrow was the identification of joy and an identified positive parenting experience. Themes that contributed to joy included the child not dying, the little things the child could do, and becoming stronger in the face of adversity (Kearney & Griffen, 2001). Parents clearly identified the child as a source of joy; these parents tried to keep hope alive.
despite the child’s identified limitations (Kearney & Griffen). They also kept hope and optimism alive through defiance of the child’s prognoses (Kearney & Griffen). These findings are similar to the findings of Seideman & Kleine (1995), that guarding hope represented the attempt to be hopeful for the best outcome while remaining cautious in parenting a child with developmental delay or mental retardation.

Mallow and Bechtel, (1999) found that mothers and fathers who experienced recurring chronic sorrow related to the care of their medically fragile child identified different triggers for the recurrence of these feelings. Mothers identified healthcare crisis as a trigger as compared to fathers who identified the crisis of the comparison of social norms between the medically fragile child and a normal child as a trigger of chronic sorrow (Mallow & Bechtel). Sorrow and fear in the adaptation of parents of a child with a chronic condition was identified in families experiencing parental conflicts (Hentinen & Kyngas, 1998).

Similar to the experience of chronic sorrow is the experience of depression. Wanamaker and Glenwick (1998) studied stress, coping, and child behavior in parents of preschoolers with cerebral palsy. Maternal depression was found to correlate with increased parenting stress and negatively related to mothers’ satisfaction with the parental role (Wanamaker & Glenwick). As maternal stress increased mothers felt more overwhelmed with the mothering role, and depression increased (Wanamaker & Glenwick). No other research studies reviewed identified depression as significant finding in the parenting experience of children with chronic condition or other disability.
Frustration.

Gibson (1995) identified frustration as a major theme experienced by mothers of chronically ill children as it related to the process of empowerment. Frustrations were categorized as frustrations within the family, frustrations with the healthcare system, and frustrations with self (Gibson). These mounting frustrations were found to force the mother to examine their situation critically (Gibson). Frustration was clearly seen as a catalyst for growth and change in the mothers (Gibson). Some of the frustrations identified included that mothers carried the burden for the care of the child and family, which caused tension in the relationship of the mother and father (Gibson). Mothers identified frustration with healthcare providers when they did not listen to their concerns or when they had lengthy delays and waiting long periods for physicians and nurses to attend to the child (Gibson). In addition, mothers identified frustration with self when customary ways of coping no longer were effective (Gibson). The experience of frustration and the critical reflection process led to an ability to take charge of the situation, which was a positive step to empowerment (Gibson).

Family and Social Support

Family Relationships

Family relationships have been identified as an important factor in the adaptation of families of children with chronic disease or neurological disorders (Glasscock, 2000; Seideman & Kleine, 1995; Hentinen & Kingas, 1998; Knafl Breitmayer, Gallo, & Zoeller, 1996; Youngblut, Brennan & Swegert, 1994; Hirose & Ueda, 1990). Glasscock examined the lived experience of 15 mothers of a child with spastic cerebral palsy, which included moderate and severe forms of
the disorder. The participants were recruited from a high-risk clinic for children with chronic illness and a neurology clinic in the United States. All of the mothers identified that strong family relationships were an important factor in caring for their child with cerebral palsy.

Hirose and Ueda (1990) in qualitative study conducted in Japan found that the marital relationship was an important support for coping behavior in mothers of children with cerebral palsy. In a theory of transformed parenting that emerged from a grounded theory study of 29 mothers and 13 fathers of developmentally disabled children, limited time and energy due to the complex care demands was shown to increase marital stress and contributed to divorce in nine couples (Seideman & Kleine, 1995). In addition mothers expressed concern about making time for the other children in the family (Seideman & Kleine). Good family relationships have been found to be part of quality adaptation; freedom to express feelings in the family was also identified as a part of good adaptation (Hentinen & Kyngas, 1998). Poor adaptation was associated with increased family conflicts in families of children with chronic illness (Hentinen & Kyngas).

Knafl, Breitmayer, Gallo and Zoeller (1996) identified various family responses to chronic illness, and their findings suggest that parental conflict over how to mange the child’s condition, and differing expectations of one another contributed to a negative family response to chronic illness. Conversely, parents who were found to be positively adapting to the chronic illness expressed mutuality in their definition and management of the situation (Knafl et al., 1996). The parents who were coping positively with the child’s chronic illness identified the added emotional closeness among family members as a positive consequence to the child’s chronic
illness (Knafl et al.). Similarly, in an exploratory study of medically fragile children, family strengths were assessed using the family strengths scale; the findings indicated that these families identified a moderate amount of family strengths (Youngblut, Brennan, & Swegert, 1994). The strengths identified included trust in each other, shared values and beliefs, limited conflicts, ability to express themselves within the family, family pride, family loyalty and the belief that things will work out well (Youngblut, et al., 1994).

**Family Support**

Many of the current studies pertaining to parenting a child with a chronic condition or a neurological condition have identified that support of the mothers by other members of the family is an important part of the adaptation process (Glasscock, 1997; Case-Sasser, 1995; Youngblut et al., 1994). Glasscock’s findings identified family support as an important factor for all of the mothers in the care of their child with cerebral palsy. Many of these mothers identified that respite services provided by family members was also very beneficial (Glasscock).

Case-Sasser identified in a study of 125 family member caregivers of chronically ill/disabled children that 58% of all caregivers reported assistance in care of the child by other family members that included mothers, fathers, sisters, aunts, cousins or others children. Similarly, Hirose and Ueda (1990) identified that mothers and fathers of children in Japan with cerebral palsy indicated that spousal support was an important aspect of coping with the care of their child. Mothers identified other family members as an additional source of support and informal supports consisting of family members (Youngblut et al., 1994). Friends and neighbors were consulted by mothers of medically fragile children in the areas of common childcare.
problems; such as toileting, sleep and nutrition (Youngblut, et al.). Gravelle (1997) identified that utilizing resources available, including respite care and support systems as important factors in caring for a child with a progressive illness during the complex chronic phase.

*Family Hardiness*

Family hardiness is a term used to denote the family strengths and durability, which serve to diminish the demands placed on the family and its members in the care of a child with developmental disabilities, and has been identified to be beneficial in maintaining health (Failla & Corson-Jones, 1991; Huang, 1996). Hardiness is associated with control, commitment and challenge; individuals characterized as hardy maintain an attitude that they can influence life events, instead of being controlled by them (Failla & Corson-Jones).

Huang’s (1996) doctoral thesis work tested the structural model of family hardiness on a sample of 152 parents of children with developmental disabilities. The findings reported that family hardiness and social support correlated positively with coping and family functioning (Huang). Family hardiness in mothers and fathers was significantly correlated to family coping and family functioning (Huang). Social support correlated positively with coping and functioning in fathers but not mothers (Huang). A decreased level of stress was correlated with an increase in family hardiness and social support (Huang). Mothers in the Huang study were found to possess more family strengths and more positive family functioning than fathers. It is suggested that this may be due in part to the mother being the primary caregiver of the child, who may have gained more problem-solving ability in managing day to day care issues (Huang).
Failla and Corson-Jones’ (1991) findings were similar to Huang’s (1996) that individual hardiness acts as a resistance resource that decreases the effects of stress, increases the use of social support and promotes adaptation. In this study only mothers’ responses were documented. Higher levels of family hardiness were associated with the use of coping behaviors, which in turn strengthened family relationships (Failla & Corson-Jones, 1991). Family hardiness was also found to be associated with stressful life events being perceived as a challenge and not a burden (Failla & Corson-Jones).

Support Network Outside the Family

Several studies have identified the importance of a support network outside the family (Gibson, 1995; Hentinen & Kyngas, 1998; Wannamaker & Glenwick, 1998; Youngblut, et al. 1994; Heilitzer, Cunningham-Sabo, VanLeit, & Crowe, 2002). Some identified support systems include healthcare professionals, other mothers in a similar situation, support groups and social supports. In a study of stress, coping and perceptions of child behavior in children with cerebral palsy, mothers with reported high levels of parenting stress and depression were related to low levels of social support satisfaction, support network size, parenting satisfaction and parenting efficacy (Wanamaker & Glenwick, 1998). Many chronic illnesses in children are adequately unstable so that the mothers are faced with multiple stressors on a regular basis (Krulik et al., 1999). Gibson (1995) conducted a fieldwork study to describe the process of empowerment in mothers of chronically ill children. Four components in the process of empowerment were described, including: discovering reality, critical reflection, taking charge, and holding on (Gibson). All of the mothers in the Gibson study identified that they benefited from the support
they received, and that the support came from spouses, family friends, healthcare professional and other mothers in similar situations. These mothers identified a sense of being understood and sense of connection in their associations with other mothers, which in turn contributed to their sense of empowerment (Gibson).

Hentinen and Kyngas (1998) studied the factors associated with the adaptation of parents with a chronically ill child. These authors identified that in order to cope effectively with a child’s chronic condition, parents needed to establish support systems in their community that led to improved adaptation (Hentinen & Kyngas). Mothers who reported increased social support reported fewer conflicts in the family, less sorrow and fear, better acceptance of the situation, and increased social relationships (Hentinen & Kyngas). Parents who received poor support from healthcare workers were found more often to have conflicts in the family, and demonstrated poorer acceptance of the situation than parents who had received an increased support from healthcare professionals (Hentinen & Kyngas). Mothers of a child with disabilities identified a lack of supportive friendships and relationships and further identified that the people who would listen to them were not friends, but instead were healthcare workers (Helitzer, et al. 2002). These mothers related that participation in a focus group with other mothers in similar situations increased their feelings of self worth, love, and acceptance (Helitzer, et al. 2002).

Summary

This chapter discussed the Roy (Roy & Andrews, 1999) Adaptation Model as the theoretical framework of this study of the experiences of being the mother of a child with severe cerebral palsy. There are four essential elements of the Roy model they include: the person who is the
recipient of nursing care, environment, health and nursing (Roy & Andrews). Roy describes the recipient of nursing care as an adaptive system, which is made up of parts connected to function as a whole, due to the interdependence of the parts (Roy & Andrews).

There are three types of stimuli that are confronting the individual that are identified in this model; they are focal, contextual and residual stimuli (Roy & Andrews, 1999). In this study the focal stimulus was identified as the high disability in the child, which results in an altered mothering role for the mother who cares for this child. The contextual stimulus in this study is identified as family and social support. The residual stimuli in this study are unknown at this time. The regulator and cognator coping processes act together to maintain adaptation in the physiologic, self-concept, role function, and interdependence modes (Roy & Andrews). These responses are identified as integrated, compensatory, or compromised and are fed back through the system again until they become adaptive (Roy & Andrews). For the purposes of this study the mother’s adaptation level will be observed and the lived experience captured through the use of in-depth interviews. The interview process will identify the regulator and cognator coping processes that enable the mother to adapt in each of the four identified modes.

The review of relevant research identified multiple studies related to childhood illness. However, few studies have been conducted specific to the parenting experience of mothers of children with cerebral palsy. There is no identified study of being a mother of a child with severe cerebral palsy. The parenting roles identified in the research pertaining to the parenting experiences when the child displays cerebral palsy, developmental disability, chronic disease and medically fragile conditions were complex. The studies reviewed included studies of the
parenting experiences of children with chronic disease states, developmental disabilities, medically fragile children and one study specific to cerebral palsy. Several themes were identified to capture the parenting experience. Just as each family has its own unique characteristics, so was the response of each family to the changed parenting role that was a result of the illness and or disability in the child.
CHAPTER III

Method

This chapter discusses the methodology of the research. It includes a description of the research design, setting and sample characteristics. The materials used in the study as well as the data collection procedure will be addressed. The study design of phenomenology and Colaizzi’s (1978) methodological process of data analysis is discussed. The chapter will conclude with a summary of the chapter contents. As previously discussed, the purpose of this study is to explore the lived experience of being a mother of a child with severe cerebral palsy.

Design

Guiding this qualitative research study is phenomenology, which will assist in illuminating the essence of the lived experience of mothers caring for their child with severe cerebral palsy. Phenomenology is regarded as both a method and way of thinking and perceiving (Speziale, & Carpenter, 2003). The purpose of phenomenological inquiry is to give meaning to the lived experience of a phenomenon by identifying the essence of the phenomenon through the description of the everyday lived experience (Rose, Beeby, & Parker, 1995). Phenomenology and Colaizzi’s (1978) method of data analysis is well suited to explore the phenomenon of this study and to support the understanding of the essence of the lived experience. Colaizzi’s methodology (1978) will be addressed in the data analysis section of this chapter.

Participants

The study will be conducted in Toledo, Ohio, which is the fourth largest city in the state, and located in the northwest corner of Ohio. The target population will be mothers who care for a
child with severe cerebral palsy. Study participants were recruited from the private practice of five neurologists practicing in a multidisciplinary clinic setting. The co-investigator/interviewer is an employee of this clinic. The interviews were conducted in a private conference room in the clinic. There were 3-5 study participants, each of whom is the mother and caregiver of their child age 4-11 years with a diagnosis of severe cerebral palsy. The mothers who met the research criteria were sent a letter (Appendix A) in the mail by their child’s neurologist informing them of the research project and invited them to participate. The lived experience of mothers was sought in this study because mothers’ most often are the primary caregivers for healthy children, as well as for those with a chronic medical condition (Krulik, et al., 1999).

Material

The materials used in this study were a voice–sensitive cassette tape recorder and blank cassette tapes in sufficient quantity so that each interview was on a different tape. A notebook was used to record reflections and impressions of the co-investigator/interviewer after each interview. The co-investigator individually interviewed the participants. The interview began with an open-ended question by the researcher to begin the sharing of information between the researcher and the participant. The researcher as an instrument and part of the study is a characteristic of qualitative research (Speziale, & Carpenter, 2003). Locked cabinets in the office of the principal investigator and the co-investigator were utilized to ensure the safety and security of the data.

Validity in qualitative research is searching for truths and understanding life experiences (Glasscock, 2000). This study seeks to understand the life experiences of the study participants
as it relates to the care and mothering of a profoundly handicapped child and to facilitate the understanding of the phenomenon as explored by these mothers.

Data Collection

Sampling.

A convenience, purposive sample was utilized in this study. The treating neurologist and the co-investigator identified subjects who met the study criteria of being the mother and caretaker of a child with severe cerebral palsy, 4-11 years. All subjects were able to speak English and were able to read and write. Mothers were not excluded from the study because of race, religion, marital-status or employment. The mothers who met the study criteria were mailed a letter (Appendix A) describing the research study, including the name of the co-investigator who would collect the data, and asked to participate in the study. Subjects were instructed to return the enclosed post card (Appendix B) by mail if they wished to participate. The letter informed participants that they were under no obligation to participate in the study and that they may drop out of the study at any time throughout the study, or after the study is completed if they so desire. Participants also were informed that there would be no repercussions if they chose not to participate in the study. The co-investigator contacted by telephone the women who returned the post card and the interviews were scheduled at that time. Informed consent (Appendix C) in writing was obtained at the first interview. Participants were recruited until five participants were recruited. For the purposes of this study saturation of the data was not attained.
Protection of human rights.

The prospective participants were informed in writing and in person during the explanation and signing of the informed consent (Appendix C) that they may refuse to participate in and drop out of the study at any time before, during or after the study is completed. The subjects were assured that the care of their child would in no way be affected by their participation in or refusal to participate in the study. Subjects were further assured that their relationships with healthcare providers in the clinic would not be affected in any way by their refusal to participate in the study. Subjects were informed that approval by the clinic board of directors and Institutional Review Board (IRB) of Medical College of Ohio (MCO) (Appendix D) was obtained prior to the implementation of this study. Privacy and confidentiality was maintained for participants and for the data derived from the interviews. The interviews were conducted in a private conference room of the clinic where the neurologist office is located. The principal investigator, co-investigator and transcriptionist were the only ones who had access to the tapes of the interviews. All of these people have completed training in Health Information Portability Accountability Act (HIPPA) requirements and the protection of human research participants. All study materials will be kept locked in a fireproof cabinet. Research subjects were assigned an identification number and the participant’s name, and the names of the child were not included on any of the follow up writings. Written documents from the study will be kept for 6 years, and then they will be destroyed and all papers shredded. Informed consent to participate in the taped interviews, and to print findings from the interviews were obtained prior to the first interview (Appendix C).
Data Collection.

An assumption of this study is that the participants who enrolled in the study truthfully and openly shared their experiences as a mother caring for their child with ______. Data collection was initiated after IRB (Appendix D) and the clinic board approval was obtained. A meeting was held with two of the neurologists in the clinic practice whose practice includes pediatric patients. After discussion of the inclusion criteria, potential subjects were identified; letters were drafted (Appendix A) to these mothers to ask for their participation in the study. Those mothers who returned the post card (Appendix B) that was enclosed with the letter were contacted by telephone by the co-investigator. Questions were answered, verbal consent was obtained and a meeting date was set up for the first interview. The interviews were conducted in a conference room of the clinic, which is located in the same building that the child’s neurologist office is located in. Confidentiality safeguards were discussed, as well as the use of a tape recorder to obtain data. The goal of the study was discussed in detail with each participant and questions or concerns were addressed before informed consent (Appendix C) was obtained. The informed consent was obtained through the reading aloud of the document by the co-researcher to the participants, and then securing the participant’s signature on the document.

Each interview began with the open-ended question, “Tell me what your experiences have been caring for _____ (the name of the child with cerebral palsy)?” Examples of follow-up questions included “what has been your greatest joy in mothering this child?” and “what has been the most difficult thing about being the mother of a child with severe cerebral palsy?” The interview in phenomenological study encourages respondents to describe their experiences and
share their stories to uncover common meanings (Sorrell, & Redmond, 1995). The research subjects were permitted to discuss whatever aspect of the mothering experience that they wished to discuss, and these mothers were given, as much time as they felt they needed to discuss their experiences. All of the interviews were tape-recorded and the interviews lasted from 1-1½ hours. All of the mothers were given the opportunity to contact the co-investigator by telephone in the weeks following the interview if there was additional information that they wished to share. None of the mothers contacted the co-investigator to provide additional information. An administrative secretary from MCO transcribed each of the tapes into a verbatim of the interview.

The co-researcher who conducted all of the interviews is an employee of the neurology office and each of the participants have previously interacted with the co-researcher in the role of nurse; this was a study bias and a potential threat to the validity of the study. However, the previous interactions with the co-investigator seemed to facilitate in the sharing of information by the participants because of the pre-existing relationship and rapport with the co-investigator. The co-investigator employed bracketing in regard to previous knowledge and professional experiences in the areas of professional nursing practice and life experiences with parents and children, to minimize this bias and threat to the validity of the study. Bracketing is deliberately seeing the other side of an issue and purposely allowing the researchers thoughts to be confused and uncertain to free the researcher from bias (Rose, Beeby, & Parker, 1995).

A limitation of this study is the lack of experience and skill in qualitative research of the co-researcher and tool for the collection of the study data.
Data Analysis

Data was compiled from the interview tapes and the verbatim transcription of the interviews with the study participants. Journaling by the co-researcher was employed to explore beliefs and assumptions of the researcher and to facilitate in the reductive process. The reductive process involves separating one’s beliefs and assumptions from the raw data and should occur throughout the study (Speziale & Carpenter, 2003). For the purposes of this research study the research data did not reach saturation. The data from this study was analyzed using Colaizzi’s (1978) methodology for data analysis, which assisted the researcher in identifying the patterns and themes in the mothers lived experience of caring for their child with severe cerebral palsy. Colaizzi’s methodology includes the following procedural steps:

1. Read all of the participant’s descriptions (protocols), in order to acquire a feeling for them.
2. Return to each protocol and extract from them phrases or sentences that directly pertain to the investigated phenomenon.
3. Formulate the meanings of each significant statement through creative insight, leaping from what clients say to what they mean. These meanings arrived at should never sever all connection with the original protocols.
4. Organize the formulated meanings into clusters of themes.
5. Exhaustive description of the investigated topic is formulated, through the integration of everything so far.
6. Integrate themes into an exhaustive description of the phenomenon.
7. Returning to participants and validate the descriptions from the data, if any new relevant data that emerges, it will be included in the final research findings.

The co-investigator read and re-read the protocols in the verbatim transcription and compared them to the cassette recordings, to make sense of them and to ensure that the transcription was valid as described in step one.

In step two the co-investigator read and re-read the protocols to find the phrases and sentences that pertained directly to this study. These phrases and sentences were verified as congruent with the data by review with the principal investigator and thesis committee.

The meanings of the significant statements were formulated through further immersion in the study data, and again these meanings were reviewed with the principal investigator and the thesis committee as described in step three of the Colaizzi method.

In step four the meanings that were formulated in the mothers experiences were organized into clusters of themes. These identified themes were evaluated in the context of The Roy Adaptation Model (Roy, & Andrews, 1999) the theoretical framework on which this study is based. Mothering a child with severe cerebral palsy and the adaptation it requires becomes the lived experience, which is the focus of this study. The co-investigator endeavored to allow for the emergence of the themes common to each study participant. Special attention was given to bracketing in this step so that preconceived thoughts would not affect the themes identified.

The exhaustive description of the mother’s experiences caring for their child with severe cerebral palsy was identified through an exhaustive description of all of the data from steps one through step five.
The themes identified in this study were incorporated into an exhaustive description of the lived experiences of mothers caring for a child with severe cerebral palsy in step six. As in each of the steps listed, support and insight were obtained from the principal investigator, and thesis committee members.

Summary

This chapter discussed the methodology for this research, which is phenomenology. It included a description of the research design setting and sample characteristics. The materials used in the study as well as the data collection procedures were discussed. The Colaizzi’s (1978) method of data analysis was discussed in terms of the study design and sample. The purpose of this study was discussed, which is to explore the phenomenon of the lived experience of being the mother of a child with severe cerebral palsy.
CHAPTER IV
Results

This chapter identifies and describes the study sample. The results are a description of the lived experience of being the biological mother of a child with severe cerebral palsy. The experience is presented in commonly identified themes that were elicited from interviews with the participants. A table is included to enhance the clarity of the identified themes and sub-themes. This phenomenological study was guided by the Colaizzi’s method of data analysis and the common themes of the lived experience were identified using this approach. The chapter concludes with a summary of the chapter contents. The participants’ names have been changed to maintain anonymity and confidentiality for the participants and their families.

Participants

Five mothers participating in this study were all Caucasian. Mother’s ages ranged from 21-45 years. The ages of their children with severe cerebral palsy ranged from 4 years to 11 years. All of these children are severely affected with cerebral palsy and are wheelchair dependant. Three of the mothers are married to the biological father of their handicapped child, one mother lives with her current husband who is not the biological father of her children, and one mother has little contact with the biological father of the handicapped child due to his incarceration.

Each mother discussed the onset of their child’s disease, which presented with different initial clinical manifestations and at different ages in each child. However, all mothers related that the child presented some degree of difficulty within the neonatal period. The mothers identified the clinical manifestations of illness and disability in the child as the beginning of the
altered mothering role.

All five of the children also have a seizure disorder, which is a common problem with children with cerebral palsy. Two of the children in this sample have intrathecal baclofen pumps in place to manage spasticity, and three of the children have gastrostomy tubes in place. One of the children in this sample also has a tracheostomy tube in place and requires supplemental oxygen. These children are all cared for in the home by their biological mother. One child has 16 hours per day of in-home nursing care and registered nurses care for another child 40 hours per week in a special needs daycare setting.

Findings

**Nancy:** Nancy is the mother of Sarah who is 4 years old. Sarah has a severe form of cerebral palsy as a result of Rett Syndrome; she has a seizure disorder and has a gastrostomy tube for supplemental feedings. Sarah was a full term infant with a birth weight of 8 pounds 14 ounces. Nancy works 30 hours per week in a medical office; she graduated from high school and has never been married. She has another daughter who is two years older than Sarah; she is healthy with typical development for age. Nancy’s sister lives with her and helps with the care of the children.

**Lori:** Lori is the mother of Tommy who has a twin brother; both boys have chronic medical problems, however, Tommy is more severely affected. Tommy has severe cerebral palsy, a seizure disorder and recently had a gastrostomy tube placed for supplemental feedings. Tommy was born at 28 weeks gestation due to a maternal placenta infection. Lori works outside the home on an as needed basis in the special school that the boys attend. She graduated from high school.
school and received some vocational/technical education after high school. Lori is married and lives with her husband and sons in a rural region of northwest Ohio.

**Mary:** Mary is the mother of Lena who was born at 41 weeks gestation. Lena has severe cerebral palsy, seizure disorder and because of her medical condition, was not expected to survive the neonatal period. She is now 6 years old with a gastrostomy tube, tracheostomy tube, supplemental oxygen and requires urinary catheterization daily. She has 16 hours of nursing care per day. Mary has a master’s degree in education and teaches fourth grade fulltime in a rural town where they reside. Mary is divorced and recently remarried; she also has a daughter who is 6 years older than Lena and who has no chronic medical problems, and is of typical development. Lena lives with her mother, step-father and sister.

**Bonnie:** Bonnie is the mother of Joshua who has severe cerebral palsy and a seizure disorder. Joshua was born at 30 weeks gestation and suffered respiratory distress at birth; he weighed 3 pounds 14 ounces at birth. Joshua has an intrathecal baclofen pump implanted for the treatment of spasticity. Bonnie is the mother of an older daughter and son who are both without chronic medical problems and are normal in development. Joshua lives at home with his biological mother, father, siblings and maternal grandmother who helps in the day-to-day care of Joshua. Bonnie does not work outside the home. She graduated from high school.

**Roberta:** Roberta is the mother of Spencer who has severe cerebral palsy and a seizure disorder. He was born at 34 weeks gestation and was treated for aspiration pneumonia at birth. Spencer has significant hearing impairment and is very small for his age, not registering on the normal growth curve for height or weight. Roberta has a medical assistant certificate but no
longer works outside the home. She has one younger daughter who has some mild language
delays but no chronic medical problems. Spencer lives in a suburban area with his biological
mother, father and sister.

**Table 1 Summary of Themes and Sub-Themes**

<table>
<thead>
<tr>
<th>Themes</th>
<th>Sub-themes</th>
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<tbody>
<tr>
<td>1. Mothers create unique ways of bonding and connecting with their child</td>
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<tr>
<td>2. Mothers describe positive aspects of their parenting experience</td>
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</tbody>
</table>
| 3. The child’s diagnosis of cerebral palsy is a lifelong journey of recurrent adversity eliciting a series of individualized responses | A. Timing of diagnosis  
B. Initial reactions of anger, denial, guilt, blame and frustration  
C. Reality of diagnosis elicits pain, sorrow and loss of dreams  
D. Adaptation encompasses acceptance and empowerment  
E. Advocacy for child  
F. Personal growth |
| 4. The mothering experience necessitates dealing with many types of burden | A. Always something to hurdle  
B. Physical demanding routine  
C. Complex competencies  
D. Chronic worry  
E. Inadequate respite time  
F. Financial |
| 5. Support from others is appreciated but not always received           | A. Spouse and family members  
B. Healthcare workers  
C. Support groups and others |
| 6. Typical family life is disrupted, resulting in altered relationships among family members | A. Other children  
B. Husband  
C. Parents |
Themes

There were six themes and several sub-themes that were elicited through analysis of the study data using the procedural steps of Colaizzi’s methodology. These themes and sub-themes were identified by all 5 of the study participants as common experiences of being the mother and caregiver of a child with severe cerebral palsy. The themes are as follows: 1) mothers create unique ways of bonding, connecting, and communicating with their child 2) mothers describe their child’s personality as a positive aspect of the experience, 3) the child’s diagnosis of cerebral palsy is a lifelong journey of recurrent adversity eliciting a series of individualized responses 4) the mothering experience necessitates dealing with lifelong burden 5) support from others is appreciated but not always received, and 6) typical family life is disrupted, resulting in altered relationships among family members.

Themes

1. Mothers Create Unique Ways of Bonding, Connecting, and Communicating With Their Child.

“That’s what we usually do a lot of in the evening. I hold her and we sometimes read books…She loves to be read to cause she just gets real calm. And she loves to be sung to, so you know she’s listening in that sense cause she just gets really relaxed…She will smile when she’s getting pleasure…So she can communicate and we’ve luckily been able to be able to learn to respond to it, understand her or not. That part makes it worth her being here, you know.”
“Now she’s starting to hug…she’ll put her arms around your neck stretched out, that feels nice… Now she’s more like, come here get in my face talk to me, and love on me…She’s doing speech therapy to try to learn switches on a communication board… she does attempt to hit them…hopefully she will finally be able to tell me something…when I pick her up from school she always, it feels more like a hit but she’s always like grabbing at my face, just to say, hi…she does have her ways of communicating. It’s just not always easy to figure out what it is though.”

“(child with CP) best feature is his humor. And I mean he gets jokes that, you know adult jokes and, laughs, just the other day we were flying a kite and (twin brother) was flying his and (child with CP) was holding his, so he held onto it and he (child with CP) let it go on purpose just to see his Dad run across the yard, it was hysterical, and I would say if we could get more of that out of him, like we’re working on it. Like he has a communication board and we try and be, you know because he is like everybody says, he is trapped you know… at least I have (child with CP) his giggle and smile and his humor.”

“I love my son dearly… I mean if I look at the turn my life has taken, to where I got my kids. That’s my life… And it’s always, now maybe that’s his purpose, maybe that’s it. And if that’s it then that’s okay…You can be having one (hell) of a day and he’ll just grin at you and people feel better. That’s just the way he is, there’s no taking that away from him…”
“…basically by eye movements… if he wants something and he sees it on the table, he might reach out and try to grab it. He doesn’t talk… I just sort of know… or he makes some sort of a noise…”

2. **Mothers Describe Positive Aspects of their Parenting Experience**

“...and there’s these old people and the thing that sticks with me the most is, you see these old people that you know they haven’t smiled in a while cause they hurt, they’re tired, and he’ll grin at them, and they just light up. I’m lucky, he’s happy… His life’s (shit) and why is he always so happy… if he’s not happy something’s wrong.”

“At least I have his giggle and smile and his humor, you know… And what we take for granted… He is happy to have the wind in his face”

“She’ll smile at you and get pleasure… I wouldn’t want her not to be able to interact with us and get enjoyment it’s nice to see her smile.”

“Being a single mom and having two kids, I can’t give her as much as maybe she craves, but, for the most part she’s pretty happy… It’s always so fun… because when she (child with CP) starts getting really giggly and stuff, I forget whatever I was doing and whatever I was mad at and it’s just, it’s nice to hear that.”

“He loves school now and the typical kids.”
3. The Child’s Diagnosis of Cerebral Palsy is a Lifelong Journey of Recurrent Adversity

Eliciting a Series of Individualized Responses

Sub-theme 3A. Timing of diagnosis.

“He was born 4 weeks early by date, but 6 weeks, he was considered 6 weeks early by exam. He wasn’t breathing very well so they took him into ICU and they had him in there for 2 days. They thought he was septic so they were doing the septic workup on him and they had started him on antibiotics. That was sort of difficult there, you know, knowing your child was in ICU…I went back to work, started him in a day care at like 7 weeks. Three weeks later they called work and they said, well we tried to wake him up and he’s lifeless, we’re calling the rescue squad…”

“We were like okay, you know, it’s twins, that’s why you’re elevated (alpha fetal protein) and, so, then, we were shocked. You know, happy but shocked…I had them right going into my seventh month… I had an infection in my placenta which made my water break. It was horrible because the doctor…was not positive, he was just shaking his head like this isn’t a good thing…We really started noticing (child with CP) his fourth month. With (twin brother) who is wanting to sit up, you know, and (child with CP) just laid, like he didn’t even really want to.”

“I was expecting everything to be pretty much normal, I had no complications or anything like that, and, so when she was born, she was having seizures, which we didn’t understand…she wouldn’t suck and swallow on her own and some other things.”
“She was full term, she was 8-14 so she was good size and the cord was around her neck and she broke her collarbone. She was throwing up all the time, she had acid reflux right away… and then she just liked to sit to the side, she couldn’t hold her head up yet but then you know she should have been holding her head up and she wouldn’t even hold it straight up. So they said she had torticollis… she wasn’t developing like she should.”

“Typical pregnancy born 10 weeks premature. He started out at 3 pounds 14 ounces…He cried once and then they put him on a vent for about 3 to 5 days…He was in the hospital for 6½ weeks…We got home and he just did the eat and breather thing but he did okay, he was delayed but nothing really shook me because he was born early.”

*Sub-theme 3B initial reactions of anger denial, guilt, blame and frustration.*

“I was angry in the beginning. I was very angry…it was just total anger at why. Why did this happen? And I went years blaming God…But it took me years to get my faith back. Because it was just like, why, why did you do this? How could you do this? What did he (child with CP) do? After when he was first born, then it was Oh God what did I do to make this happen?”

“It was just, it was weird. It was like I was in my own little world with her, not sure what was truly going on…I was oblivious to what was truly going on, but totally there and supportive of her (child with CP)...I would read things like; nobody’s really saying what’s wrong. But they don’t know. And I’d read like, well, if the baby can’t suck or swallow it could be severe, anywhere from mild to severe mental retardation.
I’m like, no, wait a minute. No, she’s, she doesn’t have that. Oh, yes she does. If she can’t do this, but no, she doesn’t, you kind of play that game cause nobody knows for sure… It was just real frustrating because I didn’t know what was wrong but yet when I’d go to the ER or our doctor visits or whatever, it was just confusing… “I didn’t blame anyone. I mean, there’s nothing, you know could have been controlled…At first everybody kept saying how frustrating it must be to me that I didn’t know what happened, why, what caused it. And I guess there were a few times I wanted to know, but then it was like it never became an obsession to me. Like some people want to know what caused it. And, I mean, I knew I had drank caffeine 3 times. I mean I was very cautious, you know, and I tried not to blame myself or anyone.”

“…his ear, nose and throat doctor said no, something is wrong, he really needs to see a neurologist. So then I was sort of like in denial at that time because he was premature and he was small…We kept thinking well, once he gets the PT and OT, maybe we would just do this for a couple years and then he would be fine.”

“It took me a while to do that, accept that, but okay, maybe I took too many hot baths. Like I didn’t know that until afterwards, you know, you’re not supposed to take a hot bath and it’s like, okay, did that cause the infection, you know, the whole battle of, what could I have done to not get an infection or maybe (Doctor) could have checked me more. You know, would you even see an infection in your placenta? I don’t know. But now I’m to the point where that’s irrelevant… It was hard though because I felt like I should have… I took my vitamins, but I felt like I should have done something…I had
that bitter feeling toward teenage pregnancies that smoke and drank and didn’t care and I did try to do what I was supposed to do …and they have perfectly healthy babies that they didn’t ever even want…in the beginning I would be like, that is just not right.

“(Getting the diagnosis) That definitely made me feel better because there’s no way in the world that anybody could cause Rett’s Syndrome. That does take that pressure off that, you’re not sitting there, well I did have a glass of wine or I did smoke a couple cigarettes or I didn’t take my prenatal vitamins at first because they gave me heartburn. You know, it is things like that I like what if, if I hadn’t had them cigarettes or I had taken them pills right from the beginning then she would have been fine. I was always thinking like that.”

Sub-theme 3C. Reality of diagnosis elicits pain and sorrow and loss of dreams.

“It’s traumatic to hear it and I’m sure to have to tell it… So when he (the neurologist) told us. (Husband) and I drove back home and we looked on the internet we didn’t even know much about cerebral palsy…I just remember sitting like it was yesterday, in the neurologist’s office…and then he was saying you know, mild, moderate, severe…I can’t speculate a whole lot but I do believe it’s more on the severe side… I just feel for every parent that has to go through that and hear that first word… I think from a mother’s point, I think, don’t get me wrong, I mean, I think it was harder, a little harder for him (husband)… because I think he had a vision of… brothers, playing, just shooting the basketball and being on the high school team and, you know, the milestones, I think that was his vision for a long time and I think with me… You know, I would say it just
takes a long time cause you know you grow, you grow up your whole life thinking, well I want my kid to play soccer, I want him to do what I did, or experience things, and when you have children that don’t, it just takes a long time to accept that they’re not going to it’s never going to happen with (child with CP).”

“He was about a year old when I just went over, went off the deep end. I mean I was ready for suicide I’d had enough. The only thing that stopped me was my three kids and I changed my attitude…I went through bouts of drinking…I fell into it for awhile but I don’t have time for that either. I can’t take care of (child with CP) if I’m intoxicated so now I am away from it.”

“… they told me over the phone that she was positive for Rett’s Syndrome and it hit me right away, cause I knew a lot about it and with Rett’s Syndrome they don’t get better…I figured she had it, but until you hear that for sure she does, there’s always that little hope that maybe it’s something else and it’ll just get better… It was very hard. It was quite a few days of crying and trying to figure out what to do but there’s nothing you can do and just have to live with it day by day. At first when she was diagnosed I was really sad… She could be crying and crying and crying and dad would walk in the door and she’d stop, but not for me… (After Dad left) then I’d be the one dealing with her when she was crying and I’d put her in her room and she’d be fine and then I’d feel real bad because she just didn’t want me. But in time I realized it was a lot for her body to handle. There are plenty of times that I get up and I just don’t want to do it today but I have to.”
“It was hard realizing and knowing that he was going to have a hearing loss for the rest of his life and wear hearing aids. That was rather difficult to accept at first… the hardest part was when he was probably about between a year and 2 years old, he wasn’t really progressing very well… I was praying a lot at that time and it just seemed like nothing would… You know, he wasn’t getting any better.”

“After about 2 or so weeks of having the trach, we had a talk with the doctor and he had talked with everybody (all the doctors) … they decided she has no quality of life, you need to let her off the vent and that was hard. You know a hard decision to make but we knew we needed to do that for her. You know, we couldn’t be selfish and let her keep living for, you know, us… I went through the grieving, the pouty time… I would say there were probably some times that I was sad, you know, especially when I was around certain people who had kids the same age as (child with CP) Then it was tough… When I was going through my divorce that was really hard. To have a child like (child with CP), because it was like, the neighborhood we were in, we just had nice families and you know I’d see them, all their kids, walking together and, you know, you just picture, I was like, that’s what I wanted. Now I have no husband and I have this child and I can’t even do anything with her…”

Sub-theme 3D. Adaptation encompasses acceptance and empowerment.

“...I think it started, for me, it just slowly became more of a way of life and then, you know, I understood he wasn’t going to get any better; it was going to be, he’s just going to progress really slowly and he’s going to have, you know, problems the rest of
his life. My husband took it much harder. He didn’t accept it for a long, long time…”

“I think I’m doing good, doing the best I can. I don’t know what else I could do.”

“What I felt back then and what I know now, it’s not as bad…But I’m ok now… And I think you think the worst, you know… You just have to keep an open mind and keep positive… I just know now that I’ve accepted it, that I feel that Matt and I were chosen. So that’s why I think it happened. God chose us to be their parents and care for them…I just don’t think that with mothers, it’s just like it’s a given and unconditional where (husband) I think, I do think he struggled a little more with acceptance…It is busy (life with child with CP) and it’s so rewarding, though…I do think that it will be a constant thing with (child with CP)…but when you know him, you know that it is well worth it… Like maybe when he (child with CP) was 3, I would get a lot more annoyed (waiting for extended periods in doctor office waiting rooms) but I think you see all the people that need help and you know that, sometimes I sit in the waiting room out in the lobby and I think they could be getting their first diagnosis. You know, so I’m not going to sit here and bellyache because, you know, because I just I feel for those people. Cause I don’t know what they’re going to get when they go in and it is hard.”

“Instead of giving up I took up a different perspective and that was okay. I’m doing what I have to do for my kids.”

“…gave us about 4 or 5 days to spend with her and she, we took her off the vent and she just kept going and you know, and lo and behold, she’s just, has always been a fighter. We don’t, I don’t know what possessed her to want to stay, but I’m glad she did,
for us… I’m very Blessed… I guess I’ve just looked at it; I had to look at it in the sense that God trusted us with her because I have these wonderful parents… And I think that’s the only way you can get through this situation is with it…We’ve just learned to adapt… This year was very hard when the school year started because (child with CP) was supposed to start kindergarten and I’ve been fine. I’ve been fine for several years. I had trouble looking at the kindergarten teacher. I had trouble, thank God!… it took me until the end of the year until I could finally look at them enjoy them (kindergartners) and smile at them. She (child with CP) should have been there. She should be standing in that line or she should be coming with that class or doing that with kindergarten”.

Sub-theme 3E. Advocacy for the child

“Would I give him up? No! Hell, no! I wouldn’t give him up even if it was worse. I mean, because he’s mine… No I’m not invincible, but I will do everything I can until I die to give him as much as he (child with CP) can have and if someone finally looks at me and says look there’s nothing more we can do, I will have to deal with that. But until that day it’s not going to happen… I refuse to give up my spot at therapy because once you’re out it takes years to get back in. I just don’t leave, they keep telling me, Mom you can take a break. I don’t want to I don’t have time to take a break now. I will take a break when he is older. Right now this is what we have to do.”

“… She’s getting her therapies and the best daycare she could get and she goes to all her doctors.”
“People just don’t understand, …with everything, it, you always have to like push for things and trying to get people to understand and know that everything is approved and legal and everything and you just have to fight for everything…the wheelchair that we picked out was okay for, okay, legal for transportation and stuff but it looked like it was a smaller type wheelchair, not the regular big type wheelchair. So then the bus driver kept saying, well, you know, this isn’t allowed on the bus. And I had to actually get the physical therapist to write a letter stating that this is a legal wheelchair and have proof. So that was difficult because he wasn’t able to ride the bus for like about 3 weeks and I had to transport him… We had to fight a lot for different things that we wanted to do with (child with CP) at school… a lot of things that we knew that he could do and they said, oh, no, he can’t do them or, you know, they just weren’t really, especially during kindergarten and first grade that they weren’t really willing to really try and work with him and we would fight with them about…”

Sub-theme 3F. Personal growth.

“...It was an experience, I mean, something I truly hope I never have to go through again. But I’ve learned a lot with her… I think I have, and I’ve learned to relax. I was just this young, new teacher, you know, trying to kill myself, coaching, and being the best I could be and never sitting down and, (child with CP) taught me to just chill out. That’s one thing I’ve learned from it… I look at what I accomplished and got through with her and I knew I could get through that time too (divorce)...In some sense it was like a relief that I had her and not a normal child because she was the way she was because she’d
ever suffer that pain of having to go through a divorce situation… It’s made me a better
person, a stronger person…I didn’t have a very good self-esteem and now I’d say it’s a
lot better. Because every time I’d ever have to do something to Lena I’d be like, no, no,
no, I can’t do that. That’s my initial thing to anything. I can’t do that or I don’t want to
do that. And then I sit and think for 2 or 3 minutes and I’m like, well you have to. And I
do it and I accomplish it.”

“I wouldn’t have traded the experience for anything…Not for me but for (child
with CP), I wish it could be more typical. But I wouldn’t trade the experience because
it’s, not that it’s fun, it’s life changing and I think it changes you for the better. So I
wouldn’t change it.”

“Life’s not fair, you know, that’s the whole. That’s the bottom line. But, I mean,
you just gotta take with what you get and learn and grow from it and better yourself…
I’m content with what I have … And we get more compliments on, you know, I can’t
believe you do it…sometimes that does get on my nerves cause it’s like, who
wouldn’t…I shouldn’t really let it get, on my nerves, but sometimes it does cause it’s
like, they want to give you a pity party but really we are blessed. They’re here and you
know they made it and you know that’s our family. That’s all we know.”

“I think I probably became more patient.”

“I went from being very submissive, not really caring, to being one that at least
when it comes to my kids, not myself, I never have regained it for myself. But when it
comes to my kids, don’t get in the way. If it’s got to be done, it’s going to be done right. And if I don’t like the answers I get I’ll go somewhere else…”

4. The Mothering Experience Necessitates Dealing with Many Types of Burden

Sub-theme 4A. Always something to hurdle.

“And you know, I think if you go into it and decide like Matt (husband) and I … think if we just open our mind and know that there’ll just always be something to hurdle. That we put the pump in to do the hip surgery but in the meantime we need to do the feeding tube so it’s like, you just know that something’s going to come your way. And then I don’t think you’re blown out of the water, as bad.

“Then at 8 months he seized…and we have been fighting ever since… I’m at the point where I need the answers for me and if there’s no answer to be found at least I know… I don’ expect any answers but it would be nice.”

“We were home maybe 8 weeks and one Sunday she just started turning blue, it looked like, and now I know she was having a seizure. We rushed her over to (local hospital) and then they brought her up here, directly up here, so and then we were here 2 months… we had gone back and checked to see if she still needed the trach, probably 3 years ago and yeah, her airway is just so collapsed they said that there is no way that she’ll be able to get it out. But that was okay too in one sense because we knew when she got sick we had access to get it out, you know, try to get it out so yeah it was kind of sad at one point cause, you know, she wouldn’t be as mobile.”
“When he started school when he was 3 in preschool, and then that was a little
difficult at the time knowing that, well, in order for him to ride a bus, he’d have to have a
wheelchair… I’ve been fighting a lot with school is, trying to get him more mainstreamed
with the typical peers, rather than just going out on the playground or being in class…
during the reading time and one of the kids will read to (child with CP) during that time.”

“We switched therapists because her first therapist didn’t, as she was regressing
she said we will just check her once a month… at first I’m like well yeah I guess there
isn’t nothing you can do, but then seeing other kids like you know, is she could be doing
more so we switched therapists… the new therapist is just great with her.”

Sub-theme 4B. Physical demands.

“It’s continuous it starts in the morning. I get my coffee which is my only quiet
time and from there it’s, you go from feeding you get him dressed, you get him his pills,
sometimes you feed him, sometimes you don’t, depends on what it is. Then you go and
you try to get some laundry in or something and then between, because then its
lunchtime, so it’s continuous… there’s no time for life, I mean, that is your life. Good,
bad or otherwise.”

“When Dr. P. said he might need a feeding tube, a jolt just went through me like,
cause I’m the one that feeds him. And it’s like I felt bad and I’m like is he skinny
because of me or maybe I don’t feed him enough… With (child with CP) everything is
just blown up 100% as far as time consuming. Like just bathing him or dressing him or
feeding him, what a normal drill would be, you know, okay, you know, 20 minutes
feeding and, you know, but with (child with CP) it’s like everything is just slowed down. Which is okay, I’m more used to it now but it’s like it does blow your day as far as you know you just got to allow for it, you know, I need to you know, I need to allow 45 minutes to an hour to feed him. I can’t just, as far as like running to McDonald’s and whipping it back to your kid, that doesn’t happen…I haven’t found a bath seat that I like yet and so we still get in together and that’s, we have a garden tub it’s getting harder for me to get in with him and get out because he’s longer…I have to go over the side with him and step down in it and … so I think bathing is hard for us. And it’s just the whole battle of you want to bathe your child every day. But can you physically, mentally do it every day?”

“I’ve got to wake (older sibling) up so that so she can keep (child with CP) occupied so I can get in the shower in the morning and then I have to make sure I have enough time to give her medicines which takes quite a few minutes and it’s just a whole, it’s a whole different lifestyle. Most people in the morning, if they don’t have kids, can just get up and get dressed and go. That is so not my life…Just going places is so different. I don’t know what I’m going to do to go to the grocery store. She can still fit in a cart now but when she gets older I can’t push a cart and a wheelchair…I’m loading and unloading a 70 pound wheelchair and with a 30 pound kid in it and so, and it’s hard… Even just taking her to daycare is different; because you can’t just open the door and say okay see you later. You have to say her pump was turned off at such and such a time, she hasn’t had breakfast, she hasn’t had her morning meds or you have to bring in
food because all of the kids eat differently and her food is typically pureed… And then once I get off work at 4, after working 6 hours, I get off at 4 and usually get home about 5:30 once I pick everybody up and then, make dinner… (child with CP) can’t do anything for herself and brushing her teeth is always fun because she grinds her teeth all the time and likes to grind her teeth when you stick the toothbrush in her mouth and doesn’t want to let go of the toothbrush so that’s always fun. So we do that at night in the bathtub where she is in the bath chair, and she can’t move around or fall over, she’s strapped in her chair and can’t go nowhere so I can brush her teeth and clean her G-tube.”

“IT’s getting to be harder on us physically lifting her.”

“You know it has always been hard we have always had to take extra equipment with us, whether it was like a feeding seat or now we’re just using his wheelchair because he’s bigger now… I can’t take him to the grocery store at all cause it’s just, he can’t sit in the cart and I can’t push a wheelchair and a cart at the same time… But he started dropping off his, his curve a little bit… but we would still keep feeding him and everything and he was still gaining weight and stuff, so that was hard to try to actually get, get him, actually making sure he’s getting enough food and stuff in him.”

Sub-theme 4C. Complex competencies.

“I’ve learned more with him than I think nurses know because so many things are thrown at you that, you don’t have training. You don’t have education. But all of a sudden you’re learning to do shots, you’re doing therapy, you’re doing CPR, you’re doing everything that you don’t expect to do.”
“We brought him home and everything went good. I mean it was chaos but it was good. You know, they (twins) came home on oxygen and we had our tanks and, you know, in the beginning you have a lot of appointments so you’re taking these tanks all over creation. And we had to check their eyes for a long time because of I think the oxygen, isn’t it? So, that was traumatic.”

“We went home and I worked with her some more... I had to learn to tube feed her, put the tube down her throat, which was incredible… I worked and worked and worked with her to get her to try to swallow and realistically she was drinking but she wasn’t swallowing it. I mean it was going in her mouth but it was coming right back out. And she wasn’t breathing properly. She had a floppy larynx… put her trach in, a feeding tube…because they tried to wean her off the ventilator and she just couldn’t, her carbon dioxide levels would stay so high. And she did pretty well with that and then eventually they noticed she wasn’t urinating on her own so we to, I had to learn to cath her and I was like, no, because I would watch two nurses try to do it and I’m like, you want me to do this?”

Sub-theme 4D. Chronic worry.

“I don’t relax (when child with CP is with her Grandma) because I have been like, I’m always listening for her… if I hear anything that might sound like a beep I’m like, oh, (child with CP) pump oh wait she’s not even home… and when she’s going to be gone this weekend I am, I’m already worried not that her, her grandma takes great care of her, but just that, it is hard to turn it off after… I’m going to be nervous that
something’s going to happen or you know, she’s, her G-tube’s going to come out and she’s not going to be able to get it back in, or something like that.”

“When we first start seeing neurologist, I was like, the first visit I was okay about and then after we started seeing him more often, I started getting panic attacks every time we would come over there to see him… But then, like about 2 or 3 years ago, it just seemed like, you know, everything then was like calmer and I stopped with those panic attacks…”

“When I got pregnant with her (other child), we were really nervous about everything. And then, I had complications with her. So then we were wondering well, are we going to have another child like (child with CP)? And I was supposed to have an amnio and I refused to have the amnio because I felt that whatever it showed, we’re not going to change anything… Another thing that’s really hard is when he gets sick. You just don’t know like what’s hurting him. Does he have a sore throat? Does he have an earache? That’s another really difficult thing, should we call the doctor, is it a virus? It’s always hard to know especially if he just starts crying, does his teeth hurt? Is he having growing pains? That’s really difficult, something we have trouble trying to figure out what is wrong. Because he doesn’t speak, he can’t tell us what’s wrong, what’s hurting him.”

“I know that my job is right here and I’m going to be doing this for the rest of my life. I mean, even if he’s (child with CP) in a home, I’m still going to have that worry and that responsibility to make certain that everything’s covered.”
“It took 20 years off of me in those years (when he was having seizures) because it’s just so, I don’t know, every time he’s had one I thought, this time he is going to stop breathing…he hasn’t had one (seizure) for a year and half and I don’t, you know, whether, you know, prayer, or Keppra, or whatever it is... I’ll take it because that was a huge thing in our family because it was a lot and they weren’t stopping and we were going to the emergency room a lot so that was traumatic, but now, and that’s why I think it’s a lot easier now, because I’m not on edge.”

Sub-theme 4E. Inadequate respite time.

“I can’t just leave (child with CP) with a babysitter because there’s not many people that know about a G-tube and how to take care of it and what happens if this or that… You don’t get a break very often. Actually I went to the grocery store by myself last week. That’s the first time in very, very long time, I think like ever…(child with CP) Dad’s mom takes (child with CP) and (other child) usually every other Saturday night and keeps them overnight until Sunday morning. So it’s not a huge break but it’s, it’s nice. It’s nice to go out and have a good time and get up in the morning and get the kids and start it all over again…Sometimes I just want to get out, sometimes you just want to pretend that it’s not your life. You just want to go out and do what everybody is doing but you can’t.”

“We don’t really go out much, but when we do (child with CP) always comes along with us and so does his sister, we hardly ever get a babysitter.”
Sub-theme 4F. Financial.

“With the Bush cuts; it’s possible I may lose my BCMH (insurance benefit). Then I don’t know what I’m gonna do… Lets see what ball you can throw in my court this time, cause they’ve already cut our Healthy Start .”

“I would say, in dealing with a handicapped child I would say financially it’s a huge, it’s not a burden, but I say that’s, that’s, there is a big chunk of responsibility on parents and, you know, we want to do the best thing for (child with CP) and we want to get the best services for him and if you can’t get them, that is a lot on (Dad’s) point and, part of life with (child with CP) financially, you know…The only thing that upsets me is the BCMH thing… as far as having a child with as many needs as (child with CP) has and as many devices that we need, just chairs, wheelchairs, just sitting arrangements or anything, neck braces, I just feel like it’s kind of not fair to penalize the parent that does go out and works their butt off and have a good job and so, yeah, we have it, our primary insurance and they do a lot, they pay a lot and it’s just not fair I think to my (husband) to penalize for him for working and stepping up to the plate so they say… I’m just saying its not fair how, how it’s put together…We have a good insurance, it pays 80%…I just went to Rite Aid and got our itemized receipts for prescriptions… it was $4,500. I don’t care what kind of job (my husband) has, that is a lot of money just for medicine…(child with CP) is expensive… I do think okay; maybe I should get a job but like (husband ) said, what employment? As many times as you run to the doctor and (child
with CP) has the farthest to school and lately it’s been a struggle for him as far as pain, literally it would be a nightmare.”

“You’re not worried about oh, what new movie’s out, I want to go see that new movie. No, it’s not, you know, yeah, that new movie’s out but that money to go get that is, you know is a prescription or, I mean most of hers are paid for but you know, diapers, wipes, and things like that a typical four year old doesn’t need any more, but some of that stuff’s paid for but there’s always, always plenty of things that need to be paid for.”

“But now we have another problem on our hands too. We lost our BCMH, our secondary insurance, so now we’re going to have a financial problem on our hands… So we have had to do some adjustments, that way.”

5. Support From Others is Appreciated but not Always Received

Sub-theme 5A. Spouse and family members.

“My sister lives with me and she helps out a lot. She’s more like; they say she’s the man of the house…because if something’s broken, she fixes it. She takes out the garbage, and she helps with dinner and laundry and she watches the kids if I just need to run somewhere or she goes with me to help…It’s hard when, a lot of people have their parents and, yeah, my parents are there, but a lot of people can have their parents baby-sit or, and that’s something I can’t do…My sister and (child with CP) Grandma are the only ones that will watch her…Because well nobody else in my family is interested in taking care of the G-tube…especially my mom not wanting anything to do with it. That is hard because that’s my mom and I talk to her about everything and she listens but then when I
tell her what happened at her house when the G-tube came out she didn’t want anything to do with it she said that is disgusting, don’t talk about it…”

“And luckily my saving grace were my parents, how supportive they were… my dad helped me get through dealing with just how bold some of them (the doctors) were. We have that family support. And that was huge, because I couldn’t have done it all by myself…” “My husband now is the same (as maternal grandmother in terms of help).” “From day one watched me, learned to do everything to (child with CP) and learned how to catheterize and take care of her and he just loves her to pieces.” “He is a rare form…” “He just loves her so much…” “But you have to have the support and I did. I can’t imagine people who go through it and don’t have their parents there or a support system because it has to be so difficult and I, like I said, I’ve just been so lucky to have that and I know that’s what’s kept me sane and able to take good care of her… God trusted us with her because I have these wonderful parents, and so does (ex-husband) he has good parents too.”

“I’d say (husband) and then my mom help me the most…She (maternal grandmother) lives like an hour and 20 minutes away. She comes like every other weekend. You know, she’s just like me; she’s the second mom. I don’t want to be selfish but it’s scary for me cause I think… Their grandma is like that for them… she’s helped me through like going out in public and just taking it in stride with it, so she’s done a lot. I’m just nervous cause she’s getting older, you know.”
“My husband’s there but he don’t help, he never has… He’s got the denial. And maybe I would have had it had there been more support. But without that support, you can’t both deny it. Or nothing happens to him. He (child with CP) doesn’t get the help he needs, and that’s my job… Between my mom and I we keep it together, I don’t know, I mean I know I’d probably do it but I’d be a wreck.”

“And my husband didn’t, doesn’t really help, I mean he helps out but he doesn’t like help out at getting dressed, help getting him dressed and feeding.”

*Sub-theme 5B. Healthcare workers*

“A lot of it has to do too with me being more at peace and being able to accept it easier is because I worked in a doctor’s office and I worked with his pediatrician and I was able to talk to the doctors about everything and even like, when we would see a specialist, I would go back to my doctors and say, this is what the specialist said and they helped me through all of that.”

“I didn’t realize how much you thrived on those people (nurses in the ICU) being with you and needing their support and their knowledge… the nurses are there to really help talk you through it… When we left there (the Pediatric ICU) I was so grateful because the nurses did say if you get nursing hours you take every hour that they will give you, they were very adamant that I get everything I could and I’m so grateful to this day because I would be insane by now without them (nursing hours)…(homecare nurses) have been with her this whole time and I totally credit (child with CP) still being here
because of them and that they take such good care of her. We do too, but I mean
(homecare nurse) is just a saving grace to us.”

“(Nurse) in Neonatal intensive care unit that basically helped us through and she
was wonderful.”

Sub-theme 5C. Organizations, support groups and others.

“The Rett.net helps so much because there’s like 600 families registered… it
gives you lot of hope. That helped me a lot to not be as sad because I’m not the only one
out there…If it wasn’t for having a handicapped child I would have never known any of
these people. It’s a whole new group of friends; group of people you talk to and it
changes your whole outlook on life.”

“I have a lot of friends that feel comfortable, they have been with Tommy since
the get-go, so, I have two girlfriends that I went to school with, when we were, like, 2
years old, our moms were best friends, and we’re so, you know, I trust them completely
so, I do get breaks and stuff so I feel fortunate there.”

“God sent you (supervisor at work) to us, He knew I needed you because I’ve
had some up and down moments and she was always the one to count on to talk me
through them besides my father and mom…I wouldn’t have met this person or that
person and you know different parents of children with handicapped children, so it has
been a unique experience… I always tell my friends there are four of us (friends from
high school) one teaches mentally handicapped, another teaches handicapped preschool
children and the third works in a group home setting with handicapped people. God just said give (Mother of child with CP) a connection.”

6. Typical Family Life is Disrupted, Resulting in Altered Relationships Among Family Members

Sub-theme 6A. Siblings of child with cerebral palsy.

“He (Brother) is terrified of him, not terrified of him, he’s terrified that he’s (child with CP) gonna die…he’s almost 17 and still it terrifies him… My daughter on the other hand, she treats him (child with CP) like he’s normal, for the most part…but she does feel that (child with CP) is more important than her. And it’s like, no honey, he’s not more important. He’s more time consuming. But he’s not more important… we’ve had several times that she’ll (sister) try to talk with him through a seizure. Just trying to talk to him where he (brother) just sits there and watches he is just terrified. He is terrified, and I just think that he’s afraid he’s going to die.”

“I think there was a lot of jealous issues, which is I think, I think that’s typical of twins regardless. He (child with CP) does take a lot of me and then in the beginning I felt guilty because I did tend to (child with CP) but it’s like in the beginning it’s like (child with CP) was the one that was screaming, you know, so you gotta go where you’re most needed. So, but I did have a lot of guilt with (twin) because I felt like I really didn’t sit down and play with him on the floor and developmental wise it was because I really couldn’t. I was just so tired. (Child with CP) was just unhappy. So now twin and (child with CP) have a better relationship I think. Twin gets it now. He understands that (child with CP) has his deal and that’s why he needs me a little bit more and I do take time out
of my week and just take twin somewhere. If just to the grocery or whatever, he knows it’s just him and I … He’s grown up a lot, maturity wise, like if I need a diaper or his pills or anything, he’s willing to do it and he knows his hips are painful and if (child with CP) cries sometimes he just needs re rooted and (twin) will say I’ll re-root him… I think it will make him a better person. I think he will understand you know kids like (child with CP)”

“Now she’s almost to the age where, you know, she enjoys being with (child with CP) but doesn’t, like it’s hard to interact with someone that doesn’t respond to you quickly. I think for kids anyway. They don’t get, you know, you can’t just carry on a conversation with (child with CP), you have to be patient and wait for her response and so it’s hard for (sister) in that sense. Every once in a while, she’ll do something sweet. You know she loves her, so.”

“That time was a little hard too because (sister) needed all the attention because she was a baby, but then (child with CP) needed attention too. And then (child with CP) at that time became really jealous of (sister) and he stopped eating. So it was hard then, you know, taking extra amount of time to even try to feed him that’s when he started losing, you know, like not gaining any weight, and losing just a couple ounces here and there. He was fine at school but then at home, it took him probably about maybe a year or so to get used to (sister) and start eating again. And then (sister) just loves (child with CP), she helps out with brother… she wants to help; I don’t really force the issue. She
just offers to help and everything, it is so cute. They get along great now. He’ll reach out and he’ll touch her.”

“People don’t realize what, how hard it is and how hard it can be and they say, well, let’s just go here or let’s just go there. It’s not that simple…It’s definitely a huge lifestyle change, because you can’t do a lot of the things that you would do with a typical child… Just trying to go to the park is very difficult. You have to have her (child with CP’s) pump bag, is it hot? And her stroller, and then (other daughter) needs to be pushed on the swing and she wants help down the slide and so everything’s just changed cause it’s a lot harder to do a lot of things… her sister is fantastic with her (child with CP) and I think having a handicapped child has made her a better kid and I think will make her a better person.”

Sub-theme 6B. Husbands.

“I mean, that’s something that I know that inflicts on my marriage where he is having the seizures that he has now. For the last 2 years he is better off in bed with us with us because I’m afraid to put him by himself (in bed). But I mean I’ve got a 10 year old child in between my husband and I, and I know that don’t help but at least I feel better knowing…”

“On the marriage side of it, (Husband) sleeps with (child with CP) because I could not sleep with, you know, and even in the beginning I checked around for monitors and there’s nothing out there… I couldn’t sleep if I…cause that’s when (child with CP) had his seizure when he was asleep, in other words, early morning and…so it’s like, and
we thought well maybe put a bed in the bedroom and then, but there is still, (Husband) needs to be right next to him, yeah, and even though it has been a year and a half since he has had one I’m still used to (Husband) being with him, so, that’s kind of hard in some ways, but in other ways it’s not because we’ve both have peace of mind.

“I never would have thought, wondered who in the world would want to be with me you know. Here I am with (child with CP), he (new husband) doesn’t mind taking her places and different things like that.

“Our relationship (husband and wife) has been strained form day one then when he was born it became even more so.”

“You know it changes you, it changes who you are, changed everybody in this family.”

Sub-theme 6C. Grandparents of child with cerebral palsy.

“Family life changed, like my mom has a real hard time with (child with CP). She will take (sister) in a heartbeat. But (child with CP) is a whole another story.”

“ We had mayhem go down about the same time he was born and she (maternal grandma) moved in with us and she’s been there ever since.”

“And my Mom to this day she probably comes over to watch (child with CP) four or five times a week…”

“Mom is my rock, and I can’t imagine them (the boys) losing her.”

Mothers caring for a child with severe cerebral palsy create unique ways of bonding and connecting with their child and describe positive aspects of their parenting experience. The
child’s diagnosis of cerebral palsy is a lifelong journey of recurrent adversity eliciting a series of individualized responses. These responses include the timing of the diagnosis, the initial reactions of anger, denial, guilt, blame and frustration. The reality of the diagnosis elicits pain, sorrow and loss of dreams. Adaptation encompasses acceptance and empowerment. Mothers display a spirit of advocacy for their child and demonstrate personal growth through the experience. The mothering experience necessitates dealing with many types of burden including: always something to hurdle, physically demanding routine, complex competencies, chronic worry, inadequate respite time and financial issues. Support from others is appreciated but it is not always received. Support comes from spouse and family members, healthcare workers, support groups and others. Typical family life is disrupted resulting in altered relationships among family members including other children, husband and parents.

Summary

This chapter identified and described the study sample. The phenomenon of the lived experience of being the biological mother and caregiver of a child with severe cerebral palsy was described through common identified themes. The themes and sub-themes were extracted from the data obtained in the interviews with the mothers. Actual quotes by the mothers were used to elaborate on each of the identified themes. The Colaizzi method of data analysis was used to guide this phenomenological study.
CHAPTER V

Discussion

This chapter discusses the findings of this study of the lived experience of being the biological mother of a child with severe cerebral palsy. The study findings are discussed in comparison to those findings contained in the review of current research. The findings are also discussed in terms of the theoretical framework of the Roy Adaptation Model. Conclusions, implications for nursing practice, implications for nursing theory, and, implications for nursing education are also discussed, as well as recommendations for further research. The chapter concludes with a summary of the chapter contents.

Findings

All of the children in the study have a severe form of cerebral palsy. However, cerebral palsy is a disorder that encompasses many other medical diagnoses and a continuum of clinical findings even within the sub-classification of the severe form of the disorder. Each of the children in this study was unique in their developmental abilities and their coexisting conditions, this made each mother’s experience somewhat unique. This factor made it more difficult than anticipated to find common themes in the mother’s experiences. The themes outlined in chapter four will be discussed here followed by a discussion of how these themes correspond to the theoretical framework of the study.

The Roy Adaptation Model was used as the theoretical framework for this study. A person according to Roy and Andrews (1999) is an adaptive system that has the capacity to adjust to changes in the environment and therefore affect the environment. Stimuli pool to make
up a specific input, which is the adaptation level (Roy & Andrews). The Roy adaptation model proposes that the environment is more specifically referred to as stimuli and that, these stimuli form a person’s environment. There are three classes of stimuli that form a person’s environment they are focal, contextual, and residual stimuli. It is the pooling of these stimuli that make up a person’s adaptation level. The focal stimulus is identified as the stimulus most immediately confronting a person; it can originate from within the person or from external sources (Roy & Andrews). In this study the focal stimulus was the severe and chronic high level of disability in the child, which has a profound effect on the adaptation, and behavior of the mother as an adaptive system. This began for all of the mothers in the study with the child having problems early in the neonatal period.

The contextual stimuli are all other stimuli that are present that have some type of effect on the focal stimulus but are not the center of the person’s attention (Roy & Andrews, 1999). The following stimuli that have been identified by the mothers in this study are considered contextual stimuli. The child’s personality, support and/or the lack of support, altered relationships among family members, many types of burden that confront the mother, and recurrent adversity that elicits individualized responses from the mother all have some effect on the focal stimulus of the severe and chronic disability in the child as a result of the severe cerebral palsy.

The residual stimuli are factors with unknown effects on the present situation and can originate from within a person or from the external environment (Roy & Andrews, 1999). The residual stimuli by definition are unknown and are not identified in this study.
The Roy model has identified that coping mechanisms are the complex internal controls with persons that are either innate or acquired and contribute to a person’s adaptation. For the purposes of this study there will be no discussion of the innate or automatic coping mechanisms, which are common to all species. The acquired coping mechanisms, which are learned, are in the cognator subsystem (Roy & Andrews, 1999). The coping mechanisms of the mothers in this study were observed through the interview process.

The four modes of behavior that are the outcome of the regulator and cognator mechanisms are the physiological mode, the self-concept mode, the role function mode, and the interdependence mode (Roy & Andrews, 1999). The themes and sub themes of this study will be discussed in terms of these four adaptive modes.

The physiological mode according to the Roy model is the human response to environmental stimuli that are manifested as the activities of cells, tissues, organs, and systems in the body of a person. The five identified needs of this mode are oxygenation, nutrition, elimination, activity and rest, and protection (Roy & Andrews, 1999). The mothers in this study reported inadequate activity and rest behaviors in their lives related to the cared demands of their child.

The self-concept mode focuses on the psychological and spiritual aspects of a person’s life, the basic need in this mode is the need to understand what one’s purpose is related to who one is (Roy & Andrews, 1999). All of the mothers in the study talked about their purpose in raising their children. They also talked about feelings of improved competence related to caregiving activities.
The role function mode centers on the roles person occupy in the community, and the basic need for his mode is social integrity (Roy & Andrews, 1999). A role is understood to represent a collection of expectations concerning how one person behaves to another person when each person occupies a different position (Roy & Andrews). The mothers in the study discussed the complexity and burden of their altered mothering role.

The interdependence mode focuses on interactions of persons that are concerned with the giving and receiving love, respect and value (Roy & Andrews, 1999). The mothers in the study discussed their role as primary caregiver of child with severe cerebral palsy, which altered the relationships with spouse, other children, parents, others, and support systems. The basic need in this mode is affectional adequacy, and the two relationships that are identified as the primary focus of this mode are relationships with significant others and relationships with support systems (Roy & Andrews). The behaviors from each of the adaptive modes can be further subdivided into integrated compensatory and compromised responses (Roy & Andrews). These behaviors are then fed back into the system as part of adaptation level (Roy & Andrews).

The following is a discussion of each of the themes identified and a discussion of these themes in terms of the theoretical framework. The themes will also be discussed in terms of the review of literature.

*Theme 1. Mothers Create Unique Ways of Bonding, Connecting, and Communicating with their Child*

All of the mothers created ways to communicate with their child with severe cerebral palsy. Each of them discussed strategies for communication and understanding their child’s needs
depending upon their child’s unique abilities. This adaptive behavior is part of the interdependence mode of the Roy (Roy & Andrews, 1999) adaptation model. It is through this bonding connecting and communicating in unique ways with their child that these mothers were adapting to the focal stimulus. This is similar to the findings of Gibson (1995) that mothers caring for children with chronic disease know their child better than anyone else and that this knowledge is both intuitive and empirical. All of the mothers felt a deep sense of love and commitment for their child with cerebral palsy. This is similar to the findings of Gibson who identified that the mothers’ deep love and commitment to the child, and deep sense of responsibility that the child receive the best care possible sustained and motivated the empowerment process and is identified as a positive coping mechanism.

Theme 2. Mothers Describe Positive Aspect of Their Parenting Experience

Mothers describe their children with cerebral palsy as happy and that this aspect of their personality brings joy to not only the mother, but in some cases to the whole family and to others outside the family. All of the mothers’ expressions became very joyful even laughing and smiling when discussing this aspect of their child with cerebral palsy. This finding would also be a coping behavior of the interdependence mode of the Roy (Roy & Andrews, 1999) adaptation model. Finding joy in their child with severe cerebral palsy assists the mother in adapting to the focal stimulus. This is consistent with the findings of Kearney and Griffen (2001) that clearly identified those parents caring for a child with developmental disability or chronic illness experienced positive parenting experiences in the form of joy and identified that the child was a source of that joy.
Theme 3. The Child’s Diagnosis of Cerebral Palsy is a Lifelong Journey of Recurrent Adversity Eliciting a Series of Individualized Responses

3A. Timing of Diagnosis

Mothers described in detail the events surrounding their child’s diagnosis, even though several years had passed since that time, they were able to recall the details with amazing clarity including the sequence of events leading up to the diagnosis as well as the actual day the diagnosis was delivered. Mothers described a unique timing and clinical presentation of illness and disability around the time of diagnosis. This adaptive behavior would be in the self-concept mode of the Roy (Roy & Andrews, 1999) adaptation model. The individual timing of the diagnosis for each child marks the transition for each mother of the need to make adjustments in her own self-concept mode and begin to question what the purpose of this new altered mothering role will be. According to the research, the entrance process for the transformed parenting role begins during this time period (Seideman & Kleine, 1995). There were no studies that discussed the timing of the child’s diagnosis and the mothers’ description of this period of time in the child with cerebral palsy’s life.

3B. Initial Reactions of Anger Denial, Guilt, Blame and Frustration

Mothers displayed a spectrum of negative emotions at the time of the child’s diagnosis with cerebral palsy. Some of these emotions lasted for a long period of time and others for shorter periods of time. The emotions did not seem to be in any type of a pattern or in identifiable stages. All of the mothers did not go through each of the emotions of denial, guilt, blame and frustration. All of the mothers did, however, experience at least one of these
emotions. Roy and Andrews (1999) places these initial coping reactions in the self-concept mode. As the reality of the diagnosis began to become very apparent the mothers in the study began to experience a variety of initial coping reactions. The research reveals that the performance process of the transformed parenting role begins through a response by the parents to the child’s diagnosis of developmental delay/mental retardation (Seideman & Kleine, 1995). Gibson (1995) found in her research of mothers of children with chronic illness that frustration was a major theme experience of mothers related to the process of empowerment. Frustration was clearly seen as a catalyst for growth and change (Gibson). No other research documenting the initial reactions of anger, denial, guilt or blame could be found. These findings in this study may be related to the existing relationship the researcher had with the mothers in this study. All of the mothers knew the researcher well through her work as a registered nurse in their child’s neurologist office. These participants may have felt more comfortable sharing these emotional responses with someone they knew and trusted.

3C. Reality of Diagnosis Elicits Pain, Sorrow and Loss of Dreams

The reality of the child’s diagnosis and the consequences of that diagnosis in terms of developmental and health related issues was very painful for the mothers. Again each mother had a unique experience as far as timing and which presenting problem in the child initiated an evaluation from healthcare providers that culminated in a painful diagnosis. One mother said, “It’s traumatic to hear it and I’m sure to have to tell it… I just feel for every parent that has to go through that and hear that first word…” All of the mothers described the pain and sorrow of the loss of dreams for their child in things such as the everyday milestones that the child would never do like play on a school sports team, or that the child would have to get a wheelchair to go
to school. This pain and sorrow is recurring for some mothers and continues throughout the parenting experience. Adaptive behavior is in the role function mode (Roy & Andrews, 1999). The mothers in this study expressed sorrow and loss of dreams over the realization that their child would never fulfill many of the usual customary societal roles and stages that children progress through. The loss of identity and perceived loss of goals and expectations for the future were identified themes by mothers of children with disabilities (Helitzer, Cunningham-Sabo, VanLeit, & Crowe, 2002). Several studies have identified that coping with the experience of parenting a child with a chronic condition/developmental disability or neurological problem is and experience of sorrow and/or chronic sorrow (Kearney & Griffin, 2001; Mallow & Bechtel, 1999; Hentinen & Kyngas, 1998; Gravelle, 1997; Seideman & Kleine, 1995). Mothers elicited sadness and grief at the time of diagnosis of their child with developmental disability; mothers’ emotional response most often progressed to chronic sorrow (Mallow & Bechtel).

3D. Adaptation Encompasses Acceptance and Empowerment

Each of the mothers discussed an individualized process leading up to acceptance and empowerment. One mother said, “it just slowly became a way of life and you know, I understood that he wasn’t going to get any better…he’s just going to progress really slowly.” According to the Roy (Roy & Andrews, 1999) adaptation model acceptance and empowerment are part of the role function adaptive behaviors. In the literature empowerment was conceptualized as a social process of recognizing, promoting and enhancing abilities of persons to meet their own needs, solve their own problems and mobilize necessary resources to gain a sense of control in their life (Gibson, 1995). Mothers identified that empowerment was transforming change in themselves
and were empowered when they were full participants in their child’s care and were heard by healthcare professionals (Gibson). Gibson found four components in the process of empowerment in the care of a child with a chronic condition. These four components are discovering reality, critical reflection, taking charge and holding on.

One mother stated, “I look at what I accomplished and got through with her and I knew I could get through that time too (divorce)…In some sense it was like a relief that I had her and not a normal child because she was the way she was because she’d never ever suffer that pain of having to go through a divorce situation… It’s made me a better person, a stronger person…I didn’t have a very good self-esteem and now I’d say it’s a lot better. Because every time I’d ever have to do something to Lena I’d be like, no, no, no, I can’t do that. That’s my initial thing to anything. I can’t do that or I don’t want to do that. And then I sit and think for 2 or 3 minutes and I’m like, well you have to. And I do it and I accomplish it.”

3E. Advocacy for the Child

Three of the five mothers verbalized a need to advocate for their child with severe cerebral palsy. One mother said, “…I’m not invincible, but I will do everything I can until I die to give him as much as he (child with CP) can have and if someone finally looks at me and says look there’s nothing more we can do, I will have to deal with that. But until that day it’s not going to happen.” The behavior for this sub theme is in Roy and Andrew’s (1999) role function mode. In this adaptive mode mothers fiercely took on the role of social and community advocate for their child making sure that they received all the benefits and services that the mother felt they deserved. There was only one study in the review of literature that identified advocacy for the
child as a finding in parents of children with chronic disease and or developmental disability. Gibson (1995) identified that a mother’s deep love and commitment to the child and deep sense of responsibility that the child receive the best care possible motivated and sustained the empowerment process that was identified as a positive coping skill.

3F. Personal Growth

All of the mothers were able to identify ways in which they had experienced personal growth through the experience of caring for a child with severe cerebral palsy. Although each of them agreed that is was not an experience that would have wished for but one that they are glad now that they experienced. One mother said. “I wouldn’t have traded the experience for anything.” Another mother said, “Life’s not fair, you know that’s the whole bottom line but you just gotta take with what you get and learn and grow from it and better yourself.” Roy’s (Roy & Andrews, 1999) adaptive self-concept mode is the identified adaptive behavior of this sub theme. As the mothers in this study adapted to caring for their child with severe cerebral palsy, they were able to identify positive aspects of the aspect in terms of their own personal growth. This is supported in the research by Case-Sasser (1995) who identified positive care giving reactions of a positive learning experience, a challenging experience, contributing to interpersonal satisfaction, and contributing to a strong religious faith, which facilitates adaptation. Many researchers have described adapting to the diagnosis of a child with a chronic neurological condition as a process of enhanced self-development due to the multiple stressors that require the mother’s energy and attention (Gibson, 1995; Glasscock, 2000; Helitzer, Cunningham-Sabo, Van-Leit, & Crowe, 2002; Wannamaker & Glenwick, 1998; Kearney& Griffin, 2001; Knaf,

Theme 4. The Mothering Experience Necessitates Dealing with Many Types of Burden

4A. Always Something to Hurdle

All of the children in the study were at least 4 years of age at the time of the interview and each of the mothers identified that they realize that they are always going to be obstacles to hurdle in the care of their child. Each mother identified different aspects of their child’s care as obstacles at this time. One mother said, “I think if we just open our mind and know that there’ll just always be something to hurdle.” This is exemplified in Roy’s role function mode. This positive attitude came after years of caring for the child and adapting to the altered mothering role in the role functions mode. This finding is similar to the findings in the literature that reveal defining adversity includes the individual hardships identified by parents in caring for a child with developmental disabilities, and managing adversity includes managing changes in the child’s condition and in the care-giving role related to the change in condition (Gravelle, 1997).

4B. Physical Demands

All of the mothers verbalized that there were multiple physical demands placed on them as primary caregiver for their child with severe cerebral palsy. Activities of daily living such as ambulating, bathing, dressing, eating and drinking were all impaired to a significant degree for each of the children in the study. Every mother had a unique approach to the physical aspects of the child’s care. Some of the differences in care were likely due to the differences in development that each child displayed. The ages of the children 4-11 years also varied the burden of physical demands placed on the mothers, with the older children being heavier and
more difficult to care for physically. According to Roy and Andrews (1999) the physiological mode is the adaptive behavior in this sub theme. It is the alterations in the physiological mode of the child that creates significant chronic disability in the child and creates a physical burden for the mother in terms of the daily physical care that child requires. This physical burden requires adaptive behavior on the part of the mother in the physiological mode. Similarly, the review of research found that the negative reactions of caring for a child with a chronic condition or a developmental delay include; meeting the physical health needs, caring for the child as they get older, physical and mental energy required, and the endurance and responsibility required (Case-Sasser, 1995). Caregiver burden has been identified as the means of coping with the care of the child with a chronic condition or neurological condition (Glasscock, 2000; Case-Sasser, 1995). Meeting the physical needs is difficult, demanding, and stressful and caring for the child is more difficult as the child gets older (Case-Sasser). The caregiver requires a great deal of time and energy, both physically and mentally, and requires strong endurance and encompasses an enormous amount of responsibility (Case-Sasser).

4C. Complex Competencies

Three of the mothers discussed the complex competencies required in the care of their child with severe cerebral palsy. In the clinical practice of the co-researcher it has been observed that all five of these mothers engage in complex competencies. These competencies were individualized to each child and changed over time according to changes in the child’s condition. As one mother said, “I’ve learned more with him than I think nurses know because so many things are thrown at you that, you don’t have training. You don’t have education. But all of a
sudden you’re learning to do shots, you’re doing therapy, you’re doing CPR, you’re doing everything that you don’t expect to do.” This behavior is in the self-concept mode of adaptive behavior of the Roy (Roy & Andrews, 1999) adaptation model. Each of these mothers expressed the difficulty in accepting the complex competencies required at first, only with encouragement and time were they able to feel successful at these competencies. Acquiring on these new competencies required adaptation in the self-concept mode. This finding is similar to the findings in the research that mothers of children with disabilities spend more time engaged in the physical aspects of childcare; in addition, they are often expected to take on the roles of teacher, therapist and nurse (Helitzer, Cunningham-Sabo, Van-Leit, Crowe, 2002).

4D. Chronic Worry

Four of the five mothers identified chronic worry as a sub theme in the care of their child. This worry is directly related to the level of care and commitment that these mothers exhibit in the care of their child. Each mother identified individualized worries related to their child’s primary health problems in conjunction with severe cerebral palsy. One mother said, “I don’t relax (when child with CP is with Grandma) because I have been I’m always listening for her… and when she is going to be gone this weekend I am, I’m already worried not that her, her grandma takes great care of her, but just that it is hard to turn it off after… I’m going to be nervous that something going to happen you know.” This behavior is part of the self-concept mode of adaptive behaviors (Roy & Andrews, 1999). Chronic worry as expressed by the mothers is part of the self-concept mode and occurred after the mothers became fully immersed in their altered mothering role. Similarly in the research living worried has been identified as a
description of the lived experience of parenting a child with a congenital physical disability (Monsen, 1999). Mothers identified feelings of hope defeat and resignation amidst constant worry about staying in the struggle and not giving up (Monsen, 1999).

4E. Inadequate Respite Time

Four of the five mothers in the study are the primary caregivers for their child with cerebral palsy; one mother does have 16 hours of nursing care per day and one mother takes her child to a special needs daycare 40 hours per week. This is consistent with the findings of several studies that have identified that the primary responsibility as caregiver of a child with a chronic condition or neurological disorder most often falls to the mother (Glasscock, 2000; Hirose & Ueda, 1990; Gibson, 1995; Seideman & Kleine, 1995; Gravelle, 1997; Hentinen & Kyngas, 1998). This behavior is encompassed in the interdependence mode for those mothers who receive respite support (Roy & Andrews, 1999).

4F. Financial

Four of the five mothers identified financial burden as a source of difficulty in caring for a child with severe cerebral palsy. The only mother who did not mention financial difficulty was the mother who has 16 hours of respite nursing care per day that is covered by insurance. This mother is employed outside the home full-time. The other four mothers related that they had great difficulty trying to work outside the home because of the care giving responsibilities of their child with severe cerebral palsy. Each of these four mothers also discussed the financial hardship that the governmental cuts to the BCMH fund made that cut some of their insurance benefit. There were no data in the research to support the finding that caring for a child with
severe cerebral palsy creates financial burden. This finding intertwines within the role function mode, because this mode centers on the role a person fulfills in society (Roy & Andrews, 1999). The mothers who discussed financial hardship were experiencing alterations in the role function mode as a result of the care and responsibilities of caring for a child with severe cerebral palsy. This could negatively affect the mother’s adaptation efforts.

Support from Others is Appreciated but not Always Received

5A. Spouse and Family Members

All five of the mothers identified support from others as an important aspect of the mothering experience, although not all of the mothers were able to identify spouse or family members who were supportive. One mother said, “my sister lives with me and she helps out a lot...because if something is broken she fixes it. She takes out the garbage and helps with dinner, the laundry and she watches the kids or she goes with me to help...” Another mother said, “my husband’s there but he don’t help, he never has... between my Mom and me we keep it together.” According to the Roy (Roy & Andrews, 1999) adaptation model this adaptive behavior is centered in the interdependence mode which focused on interactions of persons that are concerned with giving and receiving love, respect, and value. This support in the interdependence role could be positive when it is present, and possibly a negative force when it is absent. A plethora of studies have identified the importance of support systems in the adaptation of parents caring for a child with a chronic condition and/or a neurological condition such as cerebral palsy (Case-Sasser, 19995; Failla & Corson-Jones, 1991; Freedman, Boyer, & Casobianco, 2000; Glasscock, 1997; Hentinen & Kyngas, 1998; Hirose & Ueda, 1990; Huang,
1996). Case-Sasser found that 58% of all family member caregivers of chronically ill/disabled children report assistance in care or the child by other family members that includes; mothers, fathers, sister’s aunts, cousins or other children. Those mothers who reported feeling empowered to care for their chronically ill child identified that they benefited from the support they received from family, friends healthcare professionals and other mothers in similar situations (Gibson, 1995).

5B. Healthcare Workers

Three of the five mothers identified support from healthcare workers as beneficial. These mothers identified healthcare workers in the early phase of the child’s diagnosis as supportive. One mother said, “I didn’t realize how much you thrived on those people (nurses in the pediatric ICU) being with you and needing their support and their knowledge…the nurses are really there to help talk you through it…” Roy and Andrews (1999) identifies this adaptive behavior in the interdependence mode. Once again, mothers who received support viewed the support as positive and appeared to adapt to stressors with more ease than those who did not receive support. They seemed to experience more stress in the day-to-day management of their child. Similarly in the research, several studies have documented the importance of a support network outside the family. Some of the identified support systems include healthcare professionals, other mothers in similar situations, support groups and social supports (Gibson, 1995; Hentinen & Kyngas, 1998; Wannamaker & Glenwick, 1998; Youngblut, et al. 1994; Heilitzer, Cunningham-Sabo, VanLeit, & Crowe, 2002).
5C. Support Groups and Others

Three of the five mothers identified either an organization an individual or a support group that was beneficial to them in the care of their child with severe cerebral palsy. One mother said, “If it wasn’t for having a handicapped child I would have never known any of these people. It’s a whole new group of friends; group of people you talk to and it changes your whole outlook on life.” Another mother said, “God sent you (supervisor at work) to us, He knew I needed you because I’ve had some up and down moments and she was always the one to count on to talk me through them, besides my Mom and Dad….” This sub-theme is also part of the interdependence mode of the Roy (Roy & Andrews, 1999) adaptation model. Findings in the research included that parents responded to environmental support and demonstrated a transformed parenting role through seeking and mobilizing resources for their child; stress and support were identified as parallel processes (Seideman, & Kleine, 1995). Increased social support correlated positively to decreased stress and increased family hardiness (Huang, 1996).

Theme 6 Typical Family Life is Disrupted, Resulting in Altered Relationships Among Family Members

6A. Other Children

Each of the five mothers identified that caring for a child with severe cerebral palsy affected the relationships of the siblings to the child with cerebral palsy. The siblings displayed a continuum of emotions from jealousy to concern that the child with cerebral palsy may die. Mothers identified that the child with cerebral palsy takes more of their time leaving less time for the other children, which also affects the relationships. One mother said, “He’s (brother of child
with CP) terrified that (child with CP) going to die…. he’s (brother of child with CP) is almost 17 and it still terrifies him. My daughter on the other hand, she treats him (child with CP) like he is normal for the most part.” Another mother said, “ That time was a little hard too because (sister) needed all the attention because she was a baby, but then (child with CP) needed attention too. And then (child with CP) at that time became really jealous of (sister) and he stopped eating.” The Roy (Roy & Andrews, 1999) interdependence mode is the adaptive behavior in which this sub theme demonstrates. All of the mothers identified the alteration in relationships that took place by having a child with severe cerebral palsy. All of the mothers expressed desire to make time for their other children in spite of the difficulty in doing that sometimes. In the research it was shown that poor adaptation was associated with increased family conflicts in families of children with chronic illness (Hentinen & Kyngas, 1998). The parents who were coping positively with their child’s chronic illness identified the added emotional closeness among family members as a positive consequence to the child’s condition (Knafl et al, 1996). Good family relationships were part of quality adaptation (Henitnen & Kyngas).

6B. Husbands

Four of the five mothers discussed aspects of the relationship with their spouse that was changed as a result of having a child with severe cerebral palsy. One of the mothers has little contact with the biological father of her child with severe cerebral palsy due to his current incarceration. One mother is divorced from the biological father of her handicapped child. Two of the mothers discussed the impact on their marriage of having the child sleep with them, due to
excessive concern over possible exacerbation of seizure activity. One mother said, “I mean that’s something that I know that inflicts on my marriage where he is having the seizures that he has now. For the last 2 years he is better off in with us because I’m afraid to put him by himself (in bed). But, I mean, I’ve got a 10 year old child in between my husband and I, and I know that don’t help but at least I feel better knowing…” This sub-theme also would be considered as part of Roy’s (Roy & Andrews, 1999) interdependence mode. The relationship of husband and wife is probably the most profoundly affected relationship when a child with severe cerebral palsy enters the family. Stress in the marital relationship was verbalized by several of the mothers and the focal stimulus of the child’s illness and disability seemed to be at the root of the stress. The review of research reveals that thriving families showed no negative consequences for the members of the family. Enduring family management was primarily concerned with the difficulties associated with the child’s chronic illness, floundering family management was characterized by negativity and confusion related to managing the child’s chronic conditions (Knafl, Breitmayer, Gallo & Zoeller, 1996). Tension was created between the mother and father because of the child’s health problems (Gibson, 1995). The marital relationship is an important support for coping behaviors for mothers of children with cerebral palsy in Japan (Hirose, & Ueda, 1990). Complex care demands were shown to increase marital stress and contributed to divorce due to limited time and energy because of complex care demands (Seideman & Kleine, 1990).
6C. Parents

Two of the mothers identified an altered relationship with their parents since the birth of the child with cerebral palsy. One mother identified that her own mother will care for her typical child but has difficulty with the child with cerebral palsy and rarely will care for her. Roy’s (Roy & Andrews, 1999) interdependence mode is the appropriate mode for this sub-theme. There was no data in the research that identified altered relationships among parents of mothers of children with severe cerebral palsy.

Conclusions

The experience of being the mother of a child with severe cerebral palsy is a difficult journey that begins at the time of the child’s diagnosis and continues throughout the lifetime of the child. The individual timing of diagnosis varied, however, each mother experienced initial reaction of anger, guilt, denial, blame, or frustration. The high level disability of the child is both severe and chronic in nature and pervades all aspects of the life of the mother. The mother’s life is altered to the greatest degree, as she is most often the primary caregiver for the child. The entire family is changed by the experience altering relationships between family members. The husband and wife relationship is altered to the greatest degree; this is likely due to the extreme stress that the child places on each individual and on the marriage relationship. Mothers sacrifice a great deal of themselves to care for a child with severe cerebral palsy and demonstrate a high level of love and commitment to their child. Mothers appreciate support when they receive it and identify supportive relationships as important aspects of the mothering experience.
Limitations

The study design included a review of literature and choosing a theoretical framework for the study prior to data collection is considered a limitation in qualitative research. Bracketing was used in terms of prior knowledge and experiences gained through the co-researcher’s professional nursing practice with parents and children with cerebral palsy, including previous experiences with the mothers in the study sample. A journal was kept to facilitate bracketing, however, some of the knowledge was difficult to bracket and may have impacted the interview process.

Another limitation of this study included the co-researcher’s lack of skill and experience in the qualitative research process in terms of the interview process. The interview process may have been leading and questions were asked of the mothers in an attempt to obtain answers to specific types of questions.

Another limitation would be the sampling procedure; all of the mothers were Caucasian, live in the same geographical area and bring their child to the same neurology group for care. Obtaining a more diverse sample would have given results more reflective of the population. Based on the co-researchers clinical experience it has been observed that the experience of caring for a child with severe cerebral palsy can be a very positive one for the mother and child and that the mothers display a deep love and commitment for their child. It was surprising to the researcher that this finding, although not contradicted, was not strongly elicited from the interview data. It is postulated that these mothers have so many emotions pertaining to this experience and that they have no outlet to express the negative emotions. When the opportunity
to discuss whatever aspect they wished to discuss became available, the mothers used the outlet of a safe and trusting atmosphere to unload some of those painful and difficult emotions that they experience on a day-to-day basis. This researcher has observed these mothers many times expressing extreme joy and unconditional love in their relationship with their child with severe cerebral palsy.

Implications

Using the Roy adaptation model as the theoretical framework for this study, the lived experience of mothers of children with severe cerebral palsy was investigated. The Roy adaptation model (Roy & Andrews, 1999) as a framework was a valuable part of the study and enhanced the understanding of the interview data obtained and the identified themes that were elicited from the data, giving a useful framework of adaptation with which to apply the findings. This model could be used in future qualitative studies of diverse topics as all lived experience is related to adaptation and the responses to identified stimuli illustrating that this theoretical framework is an excellent framework to use in both individual adult and pediatric populations as well as group and community populations.

The role of the nurse is to promote adaptation through assessment of current responses and determine if they are effective for the patient (Roy & Andrew, 1999). The nursing process includes assessment by the nurse to identify, implement and respond to human coping processes (Hanna & Roy, 2001). The nurse response is to provide support and influence adaptation (Hanna & Roy).
There are several implications for nursing practice that have been identified from this study. Mothers caring for a child with severe cerebral palsy at home are often very isolated and identified receiving varying levels of family support. Only one mother identified having in-home nursing support in the care of her child and one mother took her child to a special needs day care center where there are nurses to care for the children. Four of the mothers identified that the support of nurses at the time of the child’s diagnosis was beneficial. Mothers did not identify that same support when the child was hospitalized at a later time in life. Nurses who care for families and children need to strive to provide increased levels of support to the child and members of the family throughout the lifespan of the child. It is imperative that nurses realize that when a child is hospitalized that mothers who have been performing many of the same complex competencies at home now have to relinquish all control of their child and their care to a nurse in a hospital. Nurses should strive to work more collaboratively with these mothers and allow mothers to participate in care even allowing the mother to perform some of the complex competencies if they wish to, or provide the mother with much needed respite time.

In terms of healthcare provider education there is a gap in the knowledge that may have created some difficulties for the mothers in this study. Mothers identified negative interactions with professionals who didn’t understand their child and their child’s needs which created difficulties and stress for the study mothers. One mother stated, “That’s one thing I’ve never batted an eye at. If I don’t like somebody that’s working with him then we are gone. I’ve left three doctors and three therapists, maybe four therapists…Every time he worked with her, he cried… he just didn’t respond to her.” Nursing education should be implemented at the
undergraduate and graduate level to increase understanding and awareness of this particular population of children. Nurses practicing in all fields should be educated regarding this population of children. It is relevant for nurses in the acute care areas of labor, delivery, postpartum, nursery, intensive care nursery, pediatrics, pediatric intensive care, emergency, medical/surgical, and surgery. It is also relevant for nurses practicing in ambulatory healthcare offices of adults, pediatrics, home healthcare, public health settings, school nursing, insurance case management and others. It is important that nurses who care for other members of the family understand that having a child with severe cerebral palsy impacts the health of everyone in the entire family.

There are several types of programs that could be implemented to assist the mothers of children with severe cerebral palsy. These programs could provide advanced practice nurses with specialization in family and/or neurological care to make home visits to families and provide much needed support for parents and families and in home assessment and treatment for the child. All of the mothers discussed the physical hardships associated with caring for a child with severe cerebral palsy. An in home visit would alleviate some of that physical hardship of having to take the child to a clinic for a visit. Several mothers in the study identified the desire to have a cerebral palsy support group in which they could participate. An online support group led by nurses should be implemented so that parents, siblings and families could find support and connect families to others facing similar challenges. Telephone triage systems, or on-line communication systems should be set up in the medical office of the child’s neurologist so that the parent of a child with severe cerebral palsy could call in and speak with a nurse specially
trained in the care of special needs children to discuss day-to-day changes in their child’s condition. Nurses should advocate for healthcare policy reform related to funding cuts in BCMH and other similar programs lobbying at the State and Federal levels.

Recommendations for Further Research

The recommendations for further research in this population are numerous. Additional qualitative studies should be completed using larger sample size and mothers of children in other geographical areas and of varied ethnic and socioeconomic status. Interviews should be conducted until saturation is reached. Studies should also be completed with mothers caring for children with moderate and mild degrees of cerebral palsy and compared to the findings of mothers of severe cerebral palsy. This qualitative study should be replicated with mothers of children older than 11 years and the findings compared to the findings of this research. A longitudinal study beginning in the neonatal period and continuing throughout the lifetime of the child would likely yield additional relevant data in terms of the mothers lived experience. There are any number of quantitative studies that could be implemented to yield additional relevant data in this population. Quantitative studies that determine emotional responses and stress levels through the use of standardized scoring tools could assist in identifying the mothers’ emotional response to the experience. All of these studies both quantitative and qualitative could be replicated using a sample of fathers of children with severe cerebral palsy as well.

Summary

This chapter discussed the findings of this study of the lived experience of being the biological mother and caregiver of a child with severe cerebral palsy ages 4-11 years. The study
findings were discussed in comparison to those findings contained in the review of current research. The findings were also discussed in terms of the theoretical framework of the study, the Roy Adaptation Model. Conclusions, implications for nursing practice, implications for nursing theory, and, implications for nursing education were also discussed, as well as recommendations for further research.
REFERENCES


December 1, 2003

Dear Mother of (child’s name),

Linda Moore, BSN, RN is the nurse that works with me in the neurological care of your child. She is currently working on a masters degree in nursing at the Medical College of Ohio. As part of the requirements for that degree, she is conducting a study of the experience of being a mother and caring for a child with severe cerebral palsy. I support this study and feel that the information gained will be useful for nurses, physicians and other healthcare workers who care for children with severe cerebral palsy and their families. This study is being conducted by the Medical College of Ohio. The Toledo Clinic is only involved as the place where the study will be carried out. It is important that you understand that the Medical College of Ohio, Toledo Clinic Inc. Board of Directors, and the physicians of the Department of Neurology of Toledo Clinic Inc have approved this study.

You have been chosen as a possible participant in this study. Your participation in the study would include an audiotaped interview with Linda where you could share your story and experiences in caring for (child’s name). This private interview would take place in the conference room of the Toledo Clinic Inc. A follow up phone call with Linda would also be a part of this study. The purpose of the phone call would be to give you the opportunity to share any additional information you may wish to share.

If you choose to participate, please return the enclosed card in the envelope provided. You will then be contacted by phone to set up a convenient time for the initial interview. If you have questions about the study, and would like additional information you may contact Linda Moore, BSN, RN at 419-479-5560 during regular business hours. You may refuse to participate in the study or drop out of the study at anytime throughout the study. It is important for you to understand that your participation is voluntary and that your child’s care will not be affected in any way by your participation or refusal to be part of the study. We cannot offer any type of compensation for your participation in this study. I know however that Linda will be very grateful if you choose to be part of this study.

Sincerely,

(Treating neurologists signature)

APPROVED BY MCO IRB
I would like to take part in the study of the lived experience of being the mother of a child with severe cerebral palsy. Please contact me at _______________ (phone number) to set up a date and time for the interview.

APPROVED BY MCO IRB

__________________________  __________________________
Signature                      Date
RESEARCH CONSENT FORM FOR ADULT SUBJECT INFORMED CONSENT

Research Project Title: THE LIVED EXPERIENCE OF BEING THE MOTHER OF A CHILD WITH SEVERE CEREBRAL PALSY

Principal Investigator Janet Robinson, PhD, RN        Phone number 419-383-5892
Other Staff: Linda Moore, BSN, RN        Phone number 419-479-5560

What you should know about this research study:
• We give you this consent form so that you may read about the purpose, risks, and benefits of this research study. All information in this form will be communicated to you verbally by the research staff as well.

• Routine clinical care is based upon the best-known treatment and is provided with the main goal of helping the individual patient. The main goal of research studies is to gain knowledge that may help future patients.

• We cannot promise that this research will benefit you. Just like routine care, this research can have side effects that can be serious or minor.

• You have the right to refuse to take part in this research, or agree to take part now and change your mind later.

• If you decide to take part in this research or not, or if you decide to take part now but change your mind later, your decision will not affect your routine care.

• Please review this form carefully. Ask any questions before you make a decision about whether or not you want to take part in this research. If you decide to take part in this research, you may ask any additional questions that you may have at any time.

• Your participation in this research is voluntary.

PURPOSE
You are being asked to take part in a research study of the lived experience of being a mother of a child with severe cerebral palsy. The purpose of the study is to learn about the experiences and feelings that mothers go through when they care for their child with severe cerebral palsy. You were selected as someone who may want to take part in this study because you care for your child who has severe cerebral palsy. Two to four other mothers who also bring their child to the same neurology office at Toledo Clinic Inc. will be invited to join in the study.

PROCEDURES AND DURATION
If you decide to take part in this study, you will be asked to fill out a survey regarding age, marital status, race, education, and employment status. You will also be asked to take part in a 60-90 minute audiotaped interview. You will be asked to tell what it has been like to mother a child with severe cerebral palsy. The
interview will audiotaped so that your descriptions can be accurately obtained. A secretary, who will not have your name, will transcribe this tape into a written text. This written text will not include your name or any information that could identify you as part of the study. You will also be asked to take part in a short (15 minutes) follow up phone call two weeks after the interview, to clarify any issues and give you the opportunity to share additional information.

RISKS AND DISCOMFORTS
The risk of significant sadness or discomfort caused by this interview is low; however describing your feelings may cause some sadness and discomfort. If this occurs you may want to see your primary care provider for an evaluation and possible treatment. If you do not have a physician, you will be assisted in finding support services. There is a risk of the unintentional loss of your confidentiality during this study. Every effort is being made to keep private your part in this study.

BENEFITS AND/OR COMPENSATION
The researchers believe that the results of this study will provide information that will be of value for nurses who care for children and families where there is a child with severe cerebral palsy in the family unit. It may be beneficial for you to share your experiences, although we do not, and cannot guarantee or promise that you will receive any benefits from the study. We regret that there will be no compensation for you to participate in this study.

ALTERNATIVE PROCEDURES OR TREATMENTS
The alternative to taking part in the research is to choose not to take part in the research.

CONFIDENTIALITY
By agreeing to take part in this research study, you give to the Medical College of Ohio, the Principal Investigator and all personnel associated with this research study your permission to use or disclose health information that can be identified with you that we obtain in connection with this study. We will use this information for the purpose of conducting the research study as described in the research consent form.

The information that we will use or disclose includes the findings from the entire group. Individual findings will not be released. We may use this information to share findings from the whole group in nursing literature, so that this information is available to nurses who care for children with severe cerebral palsy and their families. We may use this information ourselves, or we may disclose or provide access to the information to Toledo Clinic Inc. as part of the research study. Under some circumstances, the Institutional Review Board and Research and Grants Administration of the Medical College of Ohio may review your information for compliance audits.

The Medical College of Ohio is required by law to protect the privacy of your health information, and to use or disclose the information we obtain about you in connection with this research study only as authorized by you in this form. There is a possibility that the information we disclose may be re-disclosed by the persons we give it to, and no longer protected. However, we will encourage any person who receives your information from us to continue to protect and not re-disclose the information.

Your permission for us to use or disclose your personal health information as described in this section is voluntary. However, you will not be allowed to participate in the research study unless you give us your permission to use or disclose your personal health information by signing this document.

You have the right to revoke (cancel) the permission you have given to us to use or disclose your personal health information at any time by giving written notice to Janet Robinson, PhD, RN School of Nursing, Medical College of Ohio, Collar Building, 3015 Arlington Avenue, Toledo, Ohio 43614, and phone number

Consent Form Version Date: 11/11/03
Page 2 of 4
APPROVED BY: MCO IRB
FROM [Redacted] TO [Redacted]
419-383-5892. However, a cancellation will not apply if we have acted with your permission, for example, information that already has been used or disclosed prior to the cancellation. Also, a cancellation will not prevent us from continuing to use and disclose information that was obtained prior to the cancellation as necessary to maintain the integrity of the research study.

Except as noted in the above paragraph, your permission for us to use and disclose personal health information will stop at the end of the research study.

A more complete statement of Medical College of Ohio’s Privacy Practices are set forth in its Joint Notice of Privacy Practice. If you have not already received this Notice, a member of the research team will provide this to you. If you have any further questions concerning privacy, you may contact the person identified in the Notice.

COST TO YOU FOR TAKING PART IN THIS STUDY
There will be no costs to you to take part in this study.

IN THE EVENT OF A RESEARCH-RELATED INJURY
In the unlikely event of injury resulting from your taking part in this study, treatment can be obtained at Medical College Hospital. You should understand that the costs of such treatment would be your responsibility. Financial compensation is not available through Medical College Hospital or Toledo Clinic. If you feel taking part in this study has injured you, please contact Linda Moore, BSN, RN at 419-479-5560. By signing this form you are not giving up any of your legal rights as a research subject.

VOLUNTARY PARTICIPATION
Taking part in this study is voluntary. If you decide not to take part in this study, your decision will not affect your future relations with the Medical College of Ohio, its personnel, and associated hospitals or the Toledo Clinic Inc., and any of its associated physicians. If you do decide to take part in this research, you are free to withdraw your consent and to discontinue your participation at any time without a penalty.

CONTINUED NEXT PAGE
OFFER TO ANSWER QUESTIONS
Before you sign this form, please ask any questions on any aspect of this study that is unclear to you. You may take as much time as necessary to think it over.

AUTHORIZATION
YOU ARE MAKING A DECISION WHETHER OR NOT TO PARTICIPATE IN THIS RESEARCH STUDY. YOUR SIGNATURE INDICATES THAT YOU HAVE READ AND UNDERSTOOD THE INFORMATION PROVIDED ABOVE, HAVE HAD ALL YOUR QUESTIONS ANSWERED, AND HAVE DECIDED TO PARTICIPATE.

BY SIGNING THIS DOCUMENT YOU AUTHORIZE US TO USE OR DISCLOSE YOUR PERSONAL HEALTH INFORMATION AS DESCRIBED IN THIS FORM.

The date you sign this document to enroll in this study, that is, today's date, MUST fall between the dates indicated on the approval stamp affixed to the bottom of each page. These dates indicate that this form is valid when you enroll in the study but do not reflect how long you may participate in the study. Each page of this Informed Consent Form is stamped to indicate the form's validity as approved by the MCO Institutional Review Board (IRB).

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<th>Name of Subject (please print)</th>
<th>Signature of Subject or Legally Authorized Representative</th>
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<td>Signature of Witness to Consent Process (when required by ICH guidelines)</td>
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YOU WILL BE GIVEN A SIGNED COPY OF THIS FORM TO KEEP.
If you have any questions concerning this study or consent form beyond those answered by the investigator, including questions about the research, your rights as a research subject or research-related injuries, please feel free to contact R. Douglas Wilkerson, Ph.D.; Associate Vice President for Research; Medical College of Ohio at (419) 383-4251.
Medical College of Ohio
INSTITUTIONAL REVIEW BOARD

MEMORANDUM

TO: Janet Robinson, Ph.D., R.N.
Department of School of Nursing
MCO

FROM: Daniel Cipriani, Ph.D., P.T.
Vice-Chair, Institutional Review Board
Research and Grants Administration

DATE: December 18, 2004

SUBJECT: IRB #104571 - The Lived Experience of Being a Mother of a Child with Severe Cerebral Palsy

The above project was reviewed and approved by the Vice-Chair of the Institutional Review Board as an expedited review (categories #6 & #7). This includes review and approval of the Consent/Authorization for Use and Disclosure of Protected Health Information Form (version date 11/10/2003). The full board will review it at its meeting on 02/19/2004.

APPROVAL DATE: 12/18/2003
EXPIRATION DATE: 12/17/2004

NOTE: THE ATTACHED CONSENT FORM WITH REQUIRED AUTHORIZATION FOR USE AND DISCLOSURE OF PROTECTED HEALTH INFORMATION LANGUAGE INCLUDED (VERSION DATE 11/10/2003) WITH THE IRB APPROVAL STAMP IS THE ONLY VALID VERSION. IT MUST BE COPIED AND USED FOR INFORMED CONSENT FOR ALL STUDY PARTICIPANTS. THIS FORM MUST BE SIGNED AND DATED BY ALL STUDY PARTICIPANTS ENROLLING IN THIS RESEARCH. STUDY PARTICIPANTS MUST BE GIVEN A FULLY SIGNED AND DATED COPY OF THIS FORM IF THEY CHOOSE TO PARTICIPATE IN THIS RESEARCH. THE FIRST PAGE OF THE FORM MUST DISPLAY APPROPRIATE MEDICAL COLLEGE OF OHIO LETTERHEAD, ORIGINAL OR COPIED.

It is the Principal Investigator's (P.I.'s) responsibility to:

1. Abide by all federal, state, and local laws and regulations; the MCO's federal assurance and institutional policies for human subject research and protection of individually identifiable health information and be sure that all members of your research team have completed the required education in these areas.

2. Ensure that all subjects, or their legally authorized representatives, date the Consent/Authorization for Use and Disclosure of Protected Health Information Form at the time they sign this form to give consent to participate in the study and authorize use and disclosure of their protected health information. Each participant must be given a signed copy of this document. For study subjects that are registered at the Medical College of Ohio (MCO) a copy of the signed and dated Consent/Authorization for Use and Disclosure of Protected Health Information Form must be placed in each individual's MCO medical record as well. If consent or authorization is revoked by a subject, it is the responsibility of the P.I. to obtain the required signed documents and submit these to MCO's Health Information Management Department as required by institutional policy in compliance with the Health Insurance Portability and Accountability Act of 1996 (HIPAA) Privacy Rule Privacy Rule (45 CFR 164).

3. Comply with the HIPAA Privacy Rule and institutional policy regarding the accounting and tracking of uses and disclosures of protected health information.

4. Promptly notify the IRB at (419) 383-4251 of any untoward incidents or unanticipated adverse reactions that develop in the course of your research on human subjects. Please complete and submit RGA Form 317 for ALL SUCH REPORTS for this protocol. The Principal Investigator is also responsible for submitting to the MCO IRB reports of adverse events that occur at other sites conducting this study and for maintaining an up-to-date cumulative table of adverse events (RGA Form 316) and submitting it to the IRB for each research project. The Principal Investigator is responsible for reporting adverse events to the appropriate federal agencies and the sponsor (when one exists).

5. Report promptly to the MCO IRB any deviations, violations or participant non-compliance from the IRB approved protocol in accordance with the procedures outlined in RGA Form 309. In your report include the protocol number and title, the subject's initials and study I.D. number, date of the event, a brief description of the occurrence and a
description of any corrective actions taken. The Principal Investigator is responsible for reporting deviations, violations and participant non-compliance to the appropriate federal agencies and the sponsor (when one exists) in accordance with federal regulations, institutional policy and any other legal agreements with these organizations.

6. Obtain prior IRB review and approval for changes in procedures, inclusion/exclusion criteria, study personnel, source of participants, new or additional advertising materials, modifications to subject payments, and for any and all changes to the informed consent/assent/authorization for use and disclosure of protected health information documents.

7. Report promptly new information affecting the risk/benefit ratio and obtain prior IRB approval for any changes in the informed consent/assent documents that may be required by the new information.

8. Obtain prior IRB review and approval for all modified and/or added incentives going to the P.I., study coordinator, other study personnel, and/or the institution. These incentives may be in the form of money or other items of value, including, but not limited to, equipment, such as computers, and intangibles, such as frequent flyer miles.

9. Approval by the MCO Institutional Review Board does not take the place of any other approval required by the Medical College of Ohio, non-MCO performance sites, the government and/or the study sponsor.

To request review and approval for changes to IRB approved research, please complete and submit RGA Form 314 (http://www.mco.edu/research/rga_forms/rga314.doc) with a copy of all materials relevant to the requested change (including consent/assent/authorization for use and disclosure of protected health information forms if applicable) with the changes underlined. If you are requesting review and approval of consent/assent/authorization for use and disclosure of protected health information forms, please attach a clean copy of the revised forms for the IRB to stamp. Please remember that all changes submitted to the IRB (regardless if they are generated by a sponsor, the P.I. or requested by the IRB) must be signed and dated by the Principal Investigator.

IRB protocols must be reviewed and reapproved not less than once per year. Research and Grants Administration will try to remind you when reapproval is due. However, it is the responsibility of the Principal Investigator to have his/her own reminder system in place to initiate the re-approval process at least a month prior to the expiration date shown above. Please note that Federal Regulations prohibit the extension of this expiration date.

When you decide to stop this research, you must complete and submit a final report (RGA Form 320) to the IRB for review.

Enclosures: Stamped Consent/Authorization for Use and Disclosure of Protected Health Information document

EAS/m

DIRS MPA # M-1358
The Lived Experience of Being the Mother of a Child with Severe Cerebral Palsy

Open ended questions to be used in the study

1. Tell me what it has been like for you being the mother of a child with severe cerebral palsy?
2. Tell me what it was like for you when (Child’s name) was a baby?
3. How has this experience of caring for a child with severe cerebral palsy affected your role as a mother?
4. In what ways has your life been changed as a result of caring for (child’s name)?
5. Who or what would you describe as support systems for you in caring for this child?
6. Can you describe for me how you felt when you were first told of your child’s diagnosis with cerebral palsy?
7. If you were talking with a mother with a newly diagnosed child with cerebral palsy, what would you share with her about your experiences?
8. Is there anything else about this experience that you would like to share with me?
ABSTRACT

This qualitative study describes the lived experience of five mothers who care for their child with severe cerebral palsy. The phenomenon was elicited utilizing Roy (Roy & Andrews, 1999) adaptation model of nursing as the theoretical framework and phenomenology implementing Colaizzi’s (1978) method of data analysis. The themes identified capture the collective experiences of these women.

The study examines an altered mothering role that begins with the diagnosis of the child with severe cerebral palsy and the adaptation necessary to care for the child. It describes how the mothers bonded and communicated with their child. Mothers also described how they dealt with multiple burdens, adapted with and without support and the altered family relationships that resulted. There is a description of the intense emotional responses of these mothers to the experience, and the positive aspects of this parenting experience.