THE CATHOLIC UNIVERSITY OF AMERICA

The Lived Experience of Mothers Caring for an
Adolescent or Young Adult with Severe Cerebral Palsy

A DISSERTATION

Submitted to the Faculty of the

School of Nursing

Of The Catholic University of America

In Partial fulfillment of the Requirements

For the Degree

Doctor of Philosophy

©

Copyright

All Rights Reserved

By

Agnes M. Burkhard

Washington, D.C.

2011

The Lived Experience of Mothers Caring for an
Adolescent or Young Adult with Severe Cerebral Palsy

Agnes M. Burkhard, PhD

Director: Janice Agazio, PhD, RN, CRNP

Cerebral palsy is one of the most common causes of childhood disability, and a major

cause of severe disability in children. Mothers of adolescents and young adults with

severe CP often assume a role exceeding the usual normative activities of parenting in

relation to the intensity, complexity, and temporal nature of the family caregiving

experience. The aim of this phenomenologic inquiry was to explore the lived experience

of maternal caregiving as experienced by mothers caring for adolescents and young

adults with severe CP. Furthermore, the study sought to examine the essential aspects of

this human experience using the phenomenological contextual processing and analysis

method proposed by van Manen (1990).

Eleven mothers were interviewed using a semi-structured interview format. One

overarching theme, *A Different Life*, and four inter-related essential themes emerged from

the narratives. The overarching theme, *A Different Life*, was revealed in the mothers'

stories of their unexpected roles as the parent of a child with severe disabilities. The first

essential theme, *Managing an Unexpected Life*, was uncovered in the experiential

descriptions of a maternal caregiver role that included elements that differed from

mothers of typically developing children. The second essential theme, *Finding My Own

Way*, was associated with mothers seeking and finding their own approaches to balancing

the demands of caregiving and family life. The third essential theme, *Serving as My

Child's Voice*, was revealed in the advocacy activities on behalf of their child and other

community members with disabilities; and the fourth essential theme, *Facing an

Uncertain Future*, was uncovered in experiential data suggesting uncertainty associated

with their child's age-triggered transitions in the health care and educational settings, and

with the prospect of maternal caregiving in the future.

Future research is needed to gain a better understanding of the support needs of mothers

caring for adolescents and young adults with severe physical disabilities. This study

suggests the need for improvements in the delivery of family-centered health care

services for adolescents and young adults with severe CP and their families, and the

development of interventions to support and sustain family caregivers over the prolonged

course of maternal caregiving.

This dissertation by Agnes M. Burkhard fulfills the dissertation requirement for the doctoral degree in Nursing approved by Janice Agazio, PhD, RN, CRNP, as Director, and by Barbara Moran, PhD, CNM, FACCE, and Michaela L. Farber, PhD, BCD, LCSW-C as Readers.

_____

Janice Agazio, PhD, RN, CRNP, Director

_____

Barbara Moran, PhD, CNM, FACCE, Reader

_____

Michaela L. Farber, PhD, BCD, LCSW-C, Reader

Dedication

This dissertation is dedicated to all mothers caring for children with disabilities. My heartfelt gratitude and sincere thanks go to the mothers who generously shared their family caregiving stories. They are women of incredible strength and resilience who epitomize the essence of motherhood. My most sincere hope is that their voices are adequately reflected in this work.

This dissertation is also dedicated to my family. I thank my husband, Dave, for his love, support, and encouragement. I also thank my children, David, Catherine, and Laura, for bringing joy to my life on a daily basis. Lastly, I dedicate this work to my parents John and Agnes McCaffrey, who have always believed in me and encouraged me to pursue my dreams.

Table of Contents

List of Tables

Acknowledgements

I wish to acknowledge my dissertation committee for their guidance in assisting me to give voice to the experiences of the maternal caregivers. I am indebted to my former major advisors Sister Mary Jean Flaherty PhD, RN, FAAN, for offering great insight and wisdom as I worked toward selecting a topic and planning my research, and Sister Mary Elizabeth O'Brien PhD, RN, FAAN, for her methods expertise and guidance in developing my proposal.

I am especially thankful for the efforts of my major advisor, Janice Agazio, PhD, RN, CRNP for her steadfast support, encouragement, expertise, and enthusiasm. I am also appreciative of my committee members Michaela L. Farber, PhD, BCD, LCSW-C and Barbara Moran, PhD, CNM, FACCE for their valuable insights, feedback, and support.

I offer sincere thanks to Sister Rosemary Donley PhD, ANP-BC, FAAN, for encouraging me to pursue doctoral studies, and for being a wonderful mentor and role model.

I also would like to thank my siblings, Aileen, Kathleen, Susan, and John, and my friends, CUA classmates, and Marymount University colleagues for their friendship and support during my doctoral program.

Lastly, I would like to acknowledge the support of The Arc of Northern Virginia and Sigma Theta Tau International, Kappa Chapter.

Chapter I

The Problem

It has long been acknowledged that children with disabilities benefit from a nurturing family home environment. According to the American Academy of Pediatrics (1995), a nurturing home environment maximizes the capabilities of a child with a disability, minimizes the effect of impairment, and reduces or prevents hospitalizations. Parents caring for children with disabilities, including adolescents or young adults with physical disabilities, are often challenged in creating a nurturing home while balancing the demands of parenthood and family life. These parents must often assume a family caregiver role that far exceeds the usual normative activities of parenting in relation to the intensity, complexity, and temporal nature of the family caregiving experience.

Families caring for adolescents and young adults with the significant functional, and often cognitive, limitations related to severe cerebral palsy are a case in point. It is mothers, most often, who assume the role of primary caregiver in managing the care of their medically fragile adolescent or young adult with long term complex care needs associated with cerebral palsy and related co-morbidities.

Background of the Problem

Cerebral palsy (CP) is the most common childhood physical disability, and a major cause of severe disability in children. CP is non-progressive, and includes any one of a number of neurological disorders that appear in infancy or early childhood and permanently affect motor function (Murphy & Such-Neibar, 2003). CP, except for mild forms, can usually be detected in the first 12 – 18 months of life, when "children fail to

meet their major developmental milestones and show qualitative differences in gross motor function or unusual stiffness or floppiness" (Rosenbaum, 2003, p. 970).

The estimated prevalence of CP is 3.9 children per 1,000 children, or 1 in 303 children (Centers for Disease Control and Prevention, 2010). Each year, approximately 8,000 infants, plus 1,200-1,500 pre-school aged children are diagnosed with CP, and there are an estimated 764,000 children and adults in the United States with this diagnosis (United Cerebral Palsy, 2001).

Over the last four decades, despite advances in medical science, the prevalence of CP has remained unchanged (Clark & Hankins, 2003). Offsetting improved medical care are several key contributing factors including increased use of reproductive technologies (Hvidtjorn et al., 2006), and a rise in multiple births (Hirtz, et al., 2007), that contribute toward the prevalence of premature and low birth weight infants at risk for CP. Additionally, improvements in neonatal care have increased the survival rates of premature and low birth weight infants who are at risk for CP due to a special vulnerability of the white matter of the brain (Volpe, 2003).

It is important to note that CP does not only affect premature or low birth weight infants. While term infants are at a relatively low absolute risk, they constitute approximately half of all births of children with CP with underlying causes including perinatal stroke, intrauterine exposure to infection, multiple births, genetic abnormalities, and birth asphyxia (Nelson, 2003). Interestingly, recent evidence that compared health outcomes for infants delivered at 37 or 38 weeks, or at 42 weeks or later, to those

delivered at 40 weeks, found an association between gestational age and an increase risk of CP (Moster, Wilcox, Vollset, Markestad, & Lie, 2010).

The hallmark of CP is motor dysfunction. Cerebral palsy is often classified according to the type of motor dysfunction, and further categorized according to the distribution of the impaired limbs. Pelligrino (2007) has suggested that while there are clinical advantages in classifying CP on the basis of neuromotor characteristics, there is great variability within the subtypes and recent efforts to classify according to functional distinctions are often helpful in predicting long-term functional outcomes.

The Gross Motor Function Classification System – Expanded and Revised (GMFCS – E&R) (2007) was developed to provide a standardized classification of motor disability in infants under age 2 years to children aged eighteen years (Palisano, Rosenbaum, Bartlett, & Livingston, 2007). The focal point is the child's self-initiated movements. The GMFCS- E&R is based on a five level ordinal grading scale. The levels are differentiated by functional limitations and the need for assistive technology. The lower levels include Level I criteria that includes walking without restrictions, Level II walking with limitations, and Level III walking using a hand held mobility device. The higher levels, which describe more significant functional impact, are Levels IV and V. The criteria for Level IV include use of wheeled mobility in most setting and the requirement for 1 to 2 persons to assist with transfers, and Level V includes severe limitations in head and trunk control and the requirement for extensive technology and physical assistance (Palisano, et al. (2007).

In addition to impaired motor function, individuals impacted by CP may have other impairments that interfere with their ability to function in daily life and may create even greater activity limitations. Additional impairments, most often occurring in individuals with significant motor dysfunction (GMFCS- E&R Levels IV and V), may include spasticity (Pelligrino, 2007); seizure disorders; communication, hearing and visual problems; cognitive and attention deficits; and emotional and behavioral issues (Paneth, et al., 2005). Intellectual disability (ID) has been found to be one of the most limiting co-morbidities (Jones, Morgan, Shelton, & Thorogood, 2007). Interestingly, children with CP born prior to 36 weeks gestation are often less cognitively impacted than those born after 36 weeks. Liptak et al. (2001) has suggested that the periventricular leukomalacia that affects motor abilities in pre-term infants has less effect on cognition than the insults that affect term infants.

Children with the more severe forms of cerebral palsy are at greatest risk for significant intellectual disability (Pellegrino, 2007) and multiple co-morbidities. The Surveillance of Cerebral Palsy in Europe (SCPE) (2002) secondary data analysis of 6000 children with CP suggested that 20.2% of the children had both a severe intellectual disability and an inability to walk. While CP is considered non-progressive, the functional consequences of the disorder can progress. Children with the more severe forms of the disorder are prone to develop orthopedic complications that may reduce their functional abilities over time (Liptak & Accardo, 2004).

CP is a costly disorder. In 2003, it was estimated that the average lifetime cost of direct care for an individual with cerebral palsy was $921,000 and that estimated lifetime

costs of all individuals with CP born in 2000 will total $11.5 billion (CDC, 2004).

Families often incur direct financial burdens related to medical expenses not covered by

health insurance, and when a family caregiver, usually a mother, elects to withdraw from

the workforce to care for her disabled child (Wilson, et al., 2005). Maternal departure

from the workforce is found to occur more often in families caring for children with

serious health needs requiring the provision of extensive medical and therapeutic

caregiving (Leiter, Krauss, Anderson, & Well, 2004). In a secondary data analyses of the

National Survey of Children with Special Health Care Needs (2005-2006), Okumura,

Van Cleave, Gnanasekaran, and Houtrow (2009) found that more substantial functional

limitations and health condition instability were associated with increased odds of

parental work loss.

Influence of Society and Policy

Before the mid 20th century, few children with severe forms of CP survived to

adolescence or adulthood. Young children with significant physical or intellectual

disabilities were often placed in residential state institutions. This trend began to change

in the 1960's, when political, social, and economic changes led to the depopulation of

state residential institutions, with the movement of disabled individuals into the

community (Anderson, Lakin, Mangan, & Prouty, 1998). The passage of the

Rehabilitation Act of 1973 (PL 93-112) and the 1975 federally mandated special

education services and related disabilities legislation (PL 94-142), along with support

from families and disability advocacy groups, subsequently resulted in the vast majority

of children with severe disabilities remaining in the community and living in their family

home. As the result of these societal and policy changes, family members began to assume a myriad of parental and caregiver responsibilities to manage the long term care of their child with a functional disability.

Adolescence and early adulthood are recognized as life transition periods for all individuals, including both typically developing children and children with disabilities. They are complex periods of biological, social, and emotional change. The transitions usually involve preparing to move from school to work, home to community, and pediatric to adult-oriented health care (Dosa, White, & Schuyler, 2007). While children with disabilities, including CP, are eligible for special education and therapeutic health care services in the school setting - many of these services will not be accessible to individuals as young adults once they reach the age-triggered milestone of "aging out" (Kastner, Walsh, Savage, & Christeson, 2007). This trigger point most often occurs between the ages of 18 - 22 years, as the complex social structures that have included educational, health, and rehabilitative services and supports in the pediatric health care and school settings are terminated. Subsequently, young adults with significant disabilities like CP, will most likely require, but will have difficulty accessing similar services and supports in the community setting.

Clinical experts and professional organizations, including the American Academy of Family Physicians and the American Academy of Pediatrics, have recognized the need to develop and implement transition-planning supports as individuals and families prepare for adulthood (Betz & Telefair, 2007). Evidence suggests that families have concerns about this transitional period during adolescence and early adulthood (Geenen,

Powers, & Sells, 2003), service provision becomes fragmented after adolescence (Stevenson, Pharoah, & Stevenson, 1997) and individuals with serious physical impairments and multiple health conditions, face more complex transitions (Kelly, Kratz, Bielski, & Rinehart, 2002).

Parental Caregiving and Childhood Disability

It has been suggested that in caring for a child with a chronic condition, including disabilities, parents assume four major caregiving responsibilities: (a) managing the illness; (b) identifying, accessing, and coordinating resources; (c) maintaining the family unit; and (d) maintaining self (Sullivan-Bolyai, Sadler, Knafl, Gilliss, & Ahmann, 2003). Family caregivers are faced with balancing the demands of daily disability management, along with the usual demands of parenting and family life.

There is a large body of nursing and social science literature that has focused on the demands and stressors for parents caring for children with chronic health conditions and disabilities. Within this literature, there has been a focus on family management of chronic childhood illness (Judson, 2004; Knafl & Deatrick, 2003; Ray, 2002), family management of a specific disabilities (Van Riper, 2007; Appelbaum, 2007; Moore, 2005; Glassock, 2000), family decision making (Gallo, Angst, Knafl, Hadley, & Smith, 2005), specific points in the family illness trajectory (Gravelle, 1997), and the stress and well-being of parental caregivers (Dellve, Samuelsson, Tallborn, Fasth, & Hallberg, 2006; Han, 2003; Newman, 2005;).

The literature specifically focused on families caring for children with cerebral palsy reflects a predominant focus on family stress (Button, Pianta, & Marvin, 2001;

Glenn, Cunningham, Poole, Reeves, & Weindling, 2008; Manuel, Naughton, Balkrishnan, Smith & Koman, 2003), adaptation (Florian & Findler, 2001; Lin, 2000; Magill-Evans, Darrah, Pain, Adkins, & Kratochvil, 2001; Rentinck, Ketelaar, Jongmans, & Gorter, 2006), and parental well-being (Barlow, Cullen-Powell, & Cheshire, 2006). A targeted review of the literature focused on the "lived experience" of caring for a child with CP revealed a small number of published and unpublished studies. Glassock (2000) examined the lived experience of being the mother of a young child age 1 – 5 years with spastic CP. In a master's thesis, Moore (2005) examined the experiences of five mothers caring for young children, aged four to eleven, with severe CP and intellectual disabilities. Lastly, in a doctoral dissertation Appelbaum (2007) presented the findings of phenomenological inquiry focused on the lived experience of fathering a child, aged 5 to 27 years, with CP.

In spite of the large body of literature focused on families in the context of childhood disabilities, several gaps were noted in the literature particularly in families caring for a child with severe cerebral palsy. These gaps included the limited research focused on the totality of the maternal caregiving experience, and the limited research focused on the transitioning adolescent and young adult family.

It is well documented in the literature that mothers are the family members that usually assume the major responsibilities for family caregiving (Hoffman & Mitchell, 1998; McKeever & Miller, 2004; Ray, 2002;). Denham (2003) has suggested that in families mothers play a key role in family health management, health concern decision-making, health activities coordination, and provide most family caregiving tasks. Yet, in

the context of childhood physical and intellectual disabilities, this aspect of maternal life and the meanings attached to the caregiving experience are not well understood as limited studies have focused on the day to day caregiving experience of mothers.

The transition from adolescence into early young adulthood is a recognized transitional period in the development of family life. While there is an existing body of literature focused on the caregiving experiences of women caring for young children with disabilities including CP, research on the adolescent and young adult period is scarce. Consequently, little is known about the phenomenon of maternal caregiving and the lifeworld of mothers caring for adolescents and transitioning young adults with severe physical disabilities related to cerebral palsy during this critical period of family life.

In summary, over the last several decades, despite advances in medicine, the prevalence of CP has remained unchanged. Social, political, and economic changes have resulted in more parents, predominantly mothers, assuming the role of primary caregiver for their medically fragile adolescent with severe CP. Yet, much remains unknown about the family caregiving experiences of these mothers, particularly during the transitional period of adolescence into young adulthood.

Purpose of the Study

The purpose of this study was to explore the essential elements of caregiving as experienced by mothers caring for an adolescent or young adult with severe physical disabilities related to cerebral palsy.

The research aimed to answer the following core questions:

1. What is the essence of the phenomena of caregiving as experienced by mothers caring for adolescents and young adults with severe physical disabilities related to cerebral palsy?

2. What meanings do such mothers ascribe to their experiences?

Philosophic Orientation

Munhall (2001) has suggested, "In many human experiences, the cry for human understanding cannot and should not be ignored." (p.151). In order to focus on the human experiences of everyday caring as a maternal caregiver for an adolescent or young adult with severe CP, a phenomenological perspective was adopted for this study. The purpose of phenomenological research is to "borrow" other people's experiences and their reflections to try to gain a better understanding of the experience and its meaning in the context of the human experience (van Manen, 1990).

Phenomenology is both a philosophy and research perspective. The focus of phenomenological inquiry in nursing is to seek the understanding of human experience, so that nurses can better understand the meaning of being human.   The goal of phenomenological inquiry is to know the world as it is lived by revealing the hidden and unexamined meanings that dwell in our everyday world of experience (Welch, 1999). Van Manen (1990) proposed the purpose of such inquiry is to explicate the meaning of human phenomena and understand the lived structures of the meanings. He described the product of such an inquiry as bringing us in more direct contact with the world.

For this study, the phenomenological inquiry approach proposed by van Manen (1990) was used for data collection and analysis. This method allowed for the systematic

study of the mother's lifeworld as experienced, and sought to uncover the nature or

meaning of everyday maternal caregiving experiences in the adolescent and young adult

family. Van Manen (1990), whose approach was influenced by European and North

American phenomenological perspectives, has suggested that hermeneutic

phenomenology is a "human science which studies persons" (p. 6). The hermeneutic

approach tries to be attentive to both the descriptive and interpretive aspects of the

lifeworld experience. Benner (1985) proposed that there are three essential tenets of

hermeneutic phenomenology: (1) "human beings are self-interpreting. Their

interpretations are not just possessions of self; they are constitutive of self"; (2) "to be a

human being means that the kind of being is an issue, that is, the person takes a stand on

the kind of being he or she is"; and (3) "the self is not a radically free arbiter of meaning.

Though meanings can undergo transformations, they are limited by a particular language,

culture, and history." (p. 5).

Conceptual Orientation

In qualitative research, a conceptual or theoretical lens can be used to guide a

study for the purpose of identification of issues and questions that are important to

examine (Creswell, 2003). This study was guided by two complementary conceptual

orientations. Specifically, the Family Health Model (Denham, 2003) and Life Course

Theory (Elder, Johnson, & Crosnoe, 2004). These orientations were used to guide the

formulation of research questions and interview guide.

The Family Health Model (Denham, 2003) is an ecological conceptualization of

the interactive relational systems relevant to families and their health. Family health is

assumed to be a collective experience that is affected by individual and family factors and

member processes that are supported and challenged by the values, goals, and resources

of the larger embedded society. Mothers play a key role in family health, including the

functional process of family caregiving. Denham (2003) proposed the term "caretender"

to describe a maternal role in which the greatest responsibilities for the core processes of

family health, including caregiving, are assumed in order to meet the daily and incidental

individual and family needs related to health, illness, and disability management. In this

model, family members are viewed as care providers across the life course, and family

caregiving is proposed to be an active accommodation that family members use to assist

one another with changing needs over the life course.

A central premise of Life Course Theory is that no period of life can be

understood in isolation from people's prior experiences, as well as their aspirations for

the future. Life course refers to "the age-graded, socially-embedded sequence of roles

that connect the phases of life" (Mortimer & Shanahan, 2004, p. xi). The life course

orientation is grounded in the contextualist perspective and emphasizes the concepts of

trajectories, transitions, turning points, and social pathways. Trajectories are a sequence

of roles and experiences made up of transitions. Transitions often involve "changes in

status or identity, both socially and personally, that open up opportunities for behavioral

change" (Elder, et al., 2004,p. 8). The concept of turning point refers to significant

changes in the direction of one's life, and social pathways are viewed as the trajectories

of family life, education, work, and residence that are followed by individuals and groups

in society. These concepts emphasize the temporal nature of lives, "with age and its

varied connections to time becoming a primary vehicle for understanding the changing

contexts of lives (Elder, et al., 2004, p. 8).

In the life course orientation, the transition from adolescence to adulthood is one

of the most pivotal turning points in the life course (Uhlenberg & Mueller, 2004). Hogan

and Ashtone (1986) described this transition as involving multiple transitions in areas

such as education, employment, and family, with the outcome of each having important

consequences for future options. Uhlenberg and Mueller (2004) suggested that although

this transition is a unique individual developmental and social process, numerous

indicators including education completion, obtaining suitable work, enjoying satisfying

relationships, and good health are the usual desired outcomes.

Elder, et al. (2004) described the life course orientation as being based on five

general principles: (a) human development and aging are lifelong processes; (b)

individuals construct their own lives through choices and actions taken within the

opportunities and constraints of history and social circumstance; (c) the life course of

individuals is embedded and shaped by the historical times and places they experience

over their lifetime; (d) the developmental antecedents and consequences of life

transitions, events, and behavioral patterns vary according to their timing in a person's

life; and (e) lives are linked interdependently and socio-historical influences are

expressed through this network of shared relationships. In the life course orientation,

family caregiving can be viewed as a life contingency that illustrates the interdependent

links among family members. Moen, Robison, and Fields (1994) suggested that family

caregiving serves to highlight life course trajectories and transitions in terms of its

prevalence, timing, duration, and context, as women become caregivers in response to situational imperatives that render a family member unable to manage the tasks of independent living.

Definition of Terms

For the purpose of this study, the following theoretical and operational definitions of terms were formulated:

Adolescent

For the purposes of this study, an adolescent is theoretically defined as "the period between puberty and adulthood" (National Institutes of Health, n.d.). The adolescent in this study is operationally defined as an individual child aged 14-18 years

Young Adult

For the purposes of this study, a young adult is theoretically defined by being in the substage period between adolescence and adulthood (Erickson, 1997).

Such a young adult is operationally defined as an individual aged 19-22 years.

Maternal Caregiving

For the purposes of this study, maternal caregiving is theoretically defined as maternal actions that are taken with "concern for other family members generated from close intimate relationships and member affections, resulting in watchful attention, thoughtfulness, and actions linked to members' development, health and illness needs." (Denham, 2003, p. 126).

Maternal caregiving is operationally defined as the self-identified female that assumed the greatest responsibility for the processes of direct physical and emotional

care directed toward the adolescent or young adult family member with cerebral palsy living in the family home.

Cerebral Palsy

For the purpose of this study, cerebral palsy is theoretically defined as "a group of disorders of the development of movement and posture, causing activity limitation, that are attributed to non-progressive disturbances that occurred in the developing fetal or infant brain" (Rosenbaum et al., 2005, p. 572).

Cerebral palsy is operationally defined for this study by a parent's report of her child receiving the diagnosis of CP, and the child's meeting the functional criteria of motor dysfunction on the GMFCS – E&R (Palisano, et al., 2007).

Severe Cerebral Palsy

For the purpose of this study, a severe level of cerebral palsy is theoretically defined by the child's level of CP meeting the criteria of Level V on the GMFCS – E&R (2007). Specifically, the Level V criteria include full-time wheelchair use, limited ability to maintain anti-gravity head and trunk postures and control of arm and leg movements, and assistance from 1 or 2 persons for transfers (Palisano, et al., 2007). For the purpose of this study, severe cerebral palsy is operationally defined as meeting the GMFCS E&R Level V and being a full-time wheelchair user due to motor function limitations associated with CP.

Assumptions

The following assumptions are foundational to this investigation:

1. The investigative interviews, conducted at one point in time, are reflective of the mothers' lived experience acquired during the process of maternal caregiving.

2. The caregiving experiences shared by the mothers reflect the essential elements of their caregiving phenomenon.

3. The mothers that participated in the study are able to accurately describe their experiences.

Significance

Nurses and Health Care Providers.

It is essential for nurses, other healthcare providers, and the community support workforce to gain a better understanding of the experiences of mothers caring for adolescents and young adults with functional limitations, and often multiple co-morbidities, related to severe CP. Because phenomenologic inquiry is the study of the lifeworld, it offers the possibility of plausible insights that bring us more in contact with the world of human experience (van Manen, 1990), specifically the experience of maternal caregiving in the context of childhood disabilities. The knowledge gained from this research offers the potential of increasing this understanding of maternal caregiving, and the identification of strategies that sustain, support, and enhance family caregiving with the goal of improving health and lifelong functional outcomes for both the care recipient and the caregiver.

Nurses are in a unique position to be advocates, and information gleaned from this study will be useful in the support of health policy and program initiatives to promote

family caregiving activities and family-centered care for adolescents and young adults with complex health needs. Knowledge gained from this study is also useful in the arena of health care education as educators aim to enhance students' knowledge and competence in caring for individuals and families with disabilities. Lastly, this study provides direction for future nursing, healthcare, and social science research focused on family caregiving in the context of childhood disability, specifically maternal caregiving during the transitional period of adolescence into young adulthood.

Caregiving Families

For adolescents and young adults with severe CP and complex medical needs the caregiving experiences of their mothers represent an important factor for consideration when making decisions about their ability to live in their home or independently in the community. For the participating maternal caregivers, their involvement in the study offers an opportunity to give a voice to their experiences and thus potentially facilitate an insight into the challenges and rewards of parenting a medically fragile adolescent or young adult with physical disabilities, and related co-morbidities.

<div align="center">

Summary

</div>

In this chapter, background information on the prevalence of CP and health concerns related to the severe forms of the disorder is presented. Perspectives of maternal caregiving in the context of childhood disabilities and the status of related research were addressed. The research problem, purpose of the study, research question, philosophical orientation, conceptual orientation, and assumptions of the study were

described. The significance to nursing, healthcare, and caregiving families, along with the originality of the research, was discussed.

Chapter II

Review of the Literature

The purpose of this investigation was to explore the essential elements of caregiving as experienced by mothers caring for adolescents and young adults with severe cerebral palsy. A review of the literature was conducted to examine issues, conceptualizations, and investigations associated with family caregiving, with an emphasis on maternal caregiving in the context of childhood disability. It includes literature and studies from the disciplines of nursing, medicine, psychology, sociology, and associated health sciences.

The chapter is organized into six sections and explores selected literature related to: (a) cerebral palsy; (b) conceptualizations of disability; (c) conceptualizations of family caregiving; (d) family caregiving in families with childhood chronic conditions and disability; (e) family caregiving in families with a child with cerebral palsy; and (f) disability in the context of the adolescent/young adult family.

Overview of Cerebral Palsy

Historical Perspective

Cerebral Palsy (CP) was first described by Dr. William Little in 1862 and was initially called "Little's Disease". Little described the disorder as appearing to strike a child in the first year of life, to adversely impact motor development, and not to improve over time (Jones et al., 2007). He noted that the majority of affected children were born prematurely or had traumatic births, and suggested the disorder was connected to a lack of oxygen at birth (Aker & Anderson, 2007). Sigmund Freud disagreed and suggested

that both antepartum and postpartum factors might causally be related to CP (Murphy & Such-Neibar, 2003). However, it was Little's assertion that the disorder was related to asphyxia that remained the prevailing theory for the next 100 years. It was not until the 1980's that biomedical advances revealed that 70% of the cases occurred as the result of unknown causes (Krigger, 2006). While it is known that premature and low birth weight infants are at increased risk for CP due a vulnerability for white matter injury resulting in periventricular leukomalacia and intraventricular hemorrhage, the causes in term infants are less clear and may be related to congenital brain malformations, coagulation abnormalities, and viral agents (Pellegrino, 2007).

Definition of Cerebral Palsy

In 2005, the United Cerebral Palsy (UCP) Executive Committee for the Definition of CP proposed an updated definition of CP in light of emerging understanding of developmental neurobiology, and changing conceptualizations about impairments, functional status, and communication. The updated definition of the disorder, which is well accepted and frequently cited in the literature, defines CP as:

> A group of disorders of the development of movement and posture, causing activity limitations, that are attributed to non-progressive disturbances that occurred in the developing fetal or infant brain. The motor disorders of cerebral palsy are often accompanied by disturbances of sensation, cognition, communication, perception and/or behavior, and/or by a seizure disorder. (Rosenbaum, et al., 2005, p. 572).

Cerebral Palsy Classification Systems

It is important to note that CP is not an etiologic diagnosis, but a descriptive term. It refers to a wide range of static cerebral disorders that are associated with motor impairment (Bax, Goldstein, Rosenbaum, Leviton, & Paneth, 2005). The functional limitations and degrees of disability associated with CP can vary widely. There are several classification systems for the disorder. The major components of CP evaluation and classification include: motor abilities, associated impairments, anatomic and radiological findings, and causation and timing of the brain injury (Paneth, et al., 2005).

The Gross Motor Function Classification System (GMFCS) was developed in 1997 to provide a standardized classification of motor disability in children with cerebral palsy aged six to twelve years. An expanded version, the Gross Motor Function Classification System – Expanded and Revised (GMFCS – E&R) was published in 2007 to include criteria for individuals aged twelve to eighteen years. The focal point is the child's self-initiated movements. To date, there is no GMFCS designed specifically individuals over the age of 18, however, the GMFCS level around age 12 has been found to be highly predictive of adult motor function (McCormick, et al., 2007).

The GMFCS and GMFCS – E&R are based on a five level ordinal grading scale. The levels are differentiated by functional limitations and the need for assistive technology (Beckung, et al., 2007). The levels progress from Level I criteria which include "walking without restrictions; limitations in more advanced motor skills" to Level V which is described as "limited control of movement and posture; all areas of motor function are limited; no independent mobility" (Palisano, et al., 1997, p. 214). The

GMFCS has been deemed a valid and reliable tool for use in clinical work and research

involving the functional levels of children and adolescents with CP (Beckung, Carlsson,

Carlsdotter, & Ubebrant, 2007). While the classification system was originally intended

for professional use, evidence also suggests the reliability of families classifying their

child's movements using the GMFCS (Morris, Kurinczuk, Fitzpatrick, & Rosenbaum,

2006).

The GMFCS and GMFCS – E&R classification systems have also been used as a

functional scale for adults, with evidence suggesting that the aging process in

adolescence and adulthood negatively impacts functional levels in individuals with CP.

In a retrospective study, 46% of adults with CP were one or more levels higher on the

GMFCS in adulthood as compared to childhood or adolescence, reflecting diminished

functional status in adulthood (Reiner & Bjarnason, 1999). It has been suggested that

this may be due to both aging-related muscular skeletal impairments and secondary

factors exacerbated by limited access to medical and therapy services after transitioning

out of school systems (Livingston, Rosenbaum, Russell, & Palisano, 2007).

CP is often also classified by the part of the body affected and the predominant

motor disorder. These classifications include hemiplegia (unilateral impairment),

diplegia (motor impairment of the legs with limited involvement of the arms), triplegia

(three limb involvement), and quadriplegia (four limb involvement) (Rosenbaum, 2003).

The most common impairment is spasticity, with dyskinetic and ataxic movements

occurring less often (Pellegrino, 2007). While impairment-focused classifications are

helpful, it has been suggested that an evidence-based functional classifications, like the

GMFCS scales, are more stable over time and predictive of adult motor function

(McCormick, et al., 2007) and long term functional outcomes (Rosenbaum, et al., 2002).

As stated by Shapiro (2004), CP is "a useful, albeit imperfect construct" (p. S6).

He suggested that the current definitions and classifications of the diagnosis CP do not

encompass the full spectrum of motor disorders, and do not address the broader issues of

neurodevelopmental dysfunction including the interaction of cognitive, communication,

executive, behavioral and motor dimensions, and associated disorders.

Co-morbidities

In addition to impaired motor function, an individual with CP may have other

associated disorders and impairments that interfere with their ability to function in daily

life and may create even greater activity limitations. Additional impairments may

include seizure disorders; communication; hearing and visual problems; cognitive and

attention deficits; and emotional and behavioral issues (Paneth, et al., 2005). Common

health concerns include nutrition issues, gastrointestinal problems, impaired sensation to

touch and pain, decreased bone density, impaired oral motor functions, contractures, and

urinary incontinence (Krigger, 2006; Jones, Morgan, & Shelton, 2007).

In a Swedish population-based study of 411 children with CP born between 1991

and 1998, the incidence of co-morbid impairments increased significantly with GMFCS

levels (Himmelmann, Beckung, Hagberg, and Uvebrant, 2006). For children meeting the

criteria for GMFCS Level I, 79% had no co-morbid impairments. This starkly contrasted

with children meeting GMFCS Level V, in which 89% had two or more accompanying

impairments.

One of the most limiting co-morbidities associated with CP is mental retardation or intellectual disability (ID) (Jones, et al., 2007; Liptak, et al., 2001). The presence of ID creates additional challenges in promoting function, increasing developmental capabilities, and preventing secondary impairments in children with CP. Himmelmann, et al. (2006) found that among children with CP, 40% had an intellectual disability. While ID is most commonly seen in individuals with spastic quadriplegia and is significantly related to GMFCS levels IV and V (Kennes, et al., 2002; Liptak, et al., 2001), it can occur in any type of CP. Of note, children with CP and a seizure disorder have been found to have a higher prevalence of intellectual disability (Venkateswaran & Shevell, 2008).

In a study of the health status of 408 school-aged, pre-adolescent children with CP, GMFCS level was found to have a modest statistical significance in association with their functional sensory, intellectual, and emotional health status (Kennes, et al., 2002). In this investigation of parental assessments of cognitive impairment for children meeting the criteria for Levels IV and V, more children were judged to have severe cognition limitations. In another study of children (n=235) with moderate to severe CP, the most severely impacted children, those who met the criteria for GMFCS level V and had feeding tubes, were found to have lower mental age, more missed days of usual activities, increased use of medical resources, lower quality of life, and worse global and mental health (Liptak, et al., 2001). These children required the extensive assistance of parental caregivers due to complex limitations in self-care functions such as feeding, dressing, bathing, and mobility.

Life Expectancy

Today, because of improvements in medical care, rehabilitation, and assistive technology, an estimated 65-90% of individuals with CP live into their adult years (National Institutes for Neurological Disorders and Stroke, 2007). However, life expectancy is related to severity of disability. Strauss and Shavelle (2001) suggested that while a child with mild hemiplegia will probably have a typical lifespan, a child with spastic quadriplegia might not live beyond age 40. Key associated co-morbidities have been found to potentially curtail the lifespan of individuals with severe CP.

Based on a comprehensive systematic review of the literature, Katz (2003) concluded that the presence of an intellectual disability, tube feedings, urinary incontinence, and the presence and severity of seizures were associated with a diminished lifespan. Yet, improved life expectancy gains for individuals with severe CP have been recently noted. In one of the few large-scale cohort studies, a secondary data analyses of 47,259 individuals receiving CP services from the State of California between 1983 and 2002, by Strauss, Shavelle, Reynolds, Rosenbloom, and Day (2007) found an appreciable improvement in life expectancy for individuals with severe CP. For children, identified as "severe" according functional criteria similar to the GMFCS, life expectancy improved 3.4%. While the analysis did not specifically explore the reasons, the authors suggest that early recognition and treatment for infections, utilization of ventilator support, and the use of gastrostomy tube feedings for nutritional support may have been the major factors in reducing the number of children that died, and thereby increasing life expectancy.

In summary, motor impairments are the hallmark of CP. The GMFCS and GMFCS – E&R are evidence-based tools that offer a predictor of functioning in the domains of mobility and self-care. CP is often accompanied by co-morbidities, which are more often found in individuals meeting the criteria for Levels IV and V on the GMFCS scales. Several co-morbidities, specifically intellectual disability and seizure disorder, are associated with diminished self-care abilities; complex care needs and a diminished life expectancy. However, gains have been noted in the life expectancy of children with severe CP. While advances in medical science and technology have contributed to these gains, for a child or young adult with long-term functional limitations associated with severe CP, the provision of high quality care by a family caregiver has the potential to impact health, well-being, quality of life, and life expectancy.

Conceptualizations of Disability

While individuals with disabilities have always been a part of human society, conceptualizations and definitions of "disability" and "childhood disability" have evolved over the last centuries. Notably, the language of disability has changed dramatically in the last decade with disability no longer being considered an individual attribute, but rather an interaction between an individual and the environment (Boyle, Bailey, & Mossey, 2008; Institutes of Medicine, 2007). Iczzoni and Freedman (2008) suggest that societal definitions of disability are important because they "implicitly connote goals, which in turn suggest potential solutions and targets for action" (pg. 332). Baxter (2007) shared a similar view in suggesting that definitions of disability influence societal attitudes and government policies.

In the landmark text, *The Future of Disability in America*, the Institute of Medicine (2007) suggested that the absence of universally accepted definitions and conceptualizations to describe and discuss disability has been a major barrier in consolidating scientific knowledge related to the conditions contributing to disabilities and the design of interventions to prevent, mitigate, or reverse them. Simeonsson, et al. (2002) expressed a similar concern in reporting the challenges in the development of broad definitions and measures of disability to address the unique developmental and functional characteristics of childhood disability.

The World Health Organization's International Classification of Functioning, Disability, and Health framework (ICF), proposed in 1980 and revised in 2001. This model offered an approach to conceptualizing disability, quite different from the earlier medical and social welfare models. Simeonsson and colleagues (2002) described the first edition as having the following defining features of: (a) it conceptualized disability as a consequence of an underlying health condition attributable to disease or injury; (b) it differentiated the consequences on the levels of the human experience in body, person, and society; (c) it emphasized that disability was not uni-dimensional, but manifested itself at different levels of human functioning, performance limitations, and the experience of disadvantage; and (d) it provided a taxonomy of numeric codes. Most importantly, it was an attempt to provide a common language and a universal standard for classifying disabilities.

The second ICF edition, published in 2001, further describes human functioning and disability as the product of a dynamic interaction between various health conditions

and environmental and personal factors. Human functioning and disability are viewed at the level of the body, the human as a whole, and the whole interacting with the environment. These levels involve human functioning in terms of body functions and structures, activities, and participation in community life. Of note, "the term *disability* serves as an umbrella term for impairments, activity limitations, and participation restrictions" (Institute of Medicine, 2007, p. 38). The ICF model has been described as having the potential to serve not only as a classification tool, but also as a framework for social policy, research, education, and clinical practice (Rosenbaum & Stewart, 2004).

The CanChild Centre for Childhood Disabilities Research has offered a broad definition of childhood disability with a focus on impact, function, and development. This definition was aimed at offering a unifying definition and description of childhood disability that captures the notion that conditions that cause childhood disability impact the development and function of children. This view is clearly reflected in the Centre's the definition as proposed by Rosenbaum, et al. (2007, p. 3):

Childhood disabilities refer to differences in children's development or current functioning (in any or all of the spheres of physical, cognitive, affective, social, communicative, or sensory function) resulting from interactions of conditions that are intrinsic to the child, and environmental factors which may present barriers to full development and function. Such conditions (intrinsic) and the interactions of these within environmental settings, including societal attitudes and values (extrinsic), present special challenges for the child and their family, as well as for institutional systems, communities, and future employers.

By definition, childhood disability may present a constantly changing picture, with new outcomes emerging from old. Throughout their growing years children are by nature in a state of change and development; hence disorders of development may have diverse and cumulative impacts on many aspects of a child's development and function as the child grows. Similarly, children's and families' needs change constantly throughout childhood and adolescence. Supports and services, as well as research, must be designed and constructed in a manner that is sensitive to and addresses these issues so that full inclusion and participation of children with disabilities is possible.

In summary, conceptualizations of disability, including childhood disability, have the potential to impact societal attitudes and values, clinical practice, research, and policy. Over the last several decades, conceptualizations have evolved from a medical model with an emphasis on the management of a physiological problem into a broader bio-psychosocial conceptualization which views the interactive relationship between health conditions, body structure and function, activity, and community participation factors. Conceptualizations, such as the one put forth by the CanChild organization, offers a broad view that recognizes the developmental implications for both child and family. Conceptualizations of disability and childhood disability are important to consider when examining the maternal caregiving experience as this phenomenon occurs within historical, social and political contexts. In phenomenological research, as we explore human experiences and the possible meaning structures of our lived experience, we take "into account the socio-cultural and historical traditions that have given meaning

to our ways of being in the world (van Manen, 1990, p. 12).

Conceptualizations of Family Caregiving

Over the last several decades, family caregiver research has flourished with a primary focus on the aging family, and more recently on more diverse families including families caring for children with chronic conditions and disabilities. The evolution of this research offers insight into the depth of the complex caregiving experience, as over time investigators began to look at conceptualizations of caregiving more broadly in terms of experience, relationships, societal expectations, and social and economic consequences. This section will briefly explore the evolution of adult family caregiver studies, including some seminal studies that set the stage for later family caregiver investigations focused on younger families.

Trends in Caregiver Research

Family caregiving has existed throughout history and takes place in the context of relationships. It has been described as the product of social policy influenced by clinical, fiscal, legal, and humanistic factors (Lefley, 1997). The family caregiving literature has grown rapidly since the mid 1970's, with much of the work done by the disciplines of gerontology, nursing, psychology, sociology, and social work. Based on a review of the early literature, Perrin (1992) observed that this area of interest grew in response to an aging population and suggested that the focus of early investigations was on both the situations of caregiving and the consequences for caregivers. She also described much of this early family caregiving research in the 1970's as lacking a theoretical base due to a collective sense of urgency to explore this phenomenon.

In one of the first seminal family caregiver studies, Golodetz, Evans, Heinritz, and Gibson (1969) examined the role of the family caregiver in households (n=59) caring for a chronically ill family member. They proposed the neologism "responsor" as a name for the family caregivers, to reflect the dual duties of the caregiver, namely response and responsibility (p. 386). Caregivers were described as generally wives and daughters who lived alone with the ill family member, who were forced to assume complex responsibilities of care, with very complex patterns of interaction. The investigators suggested eight roles as key to the responsor role: (1) health communicator; (2) medication administrator; (3) diet manager; (4) supervisor of physical activities; (5) user of special equipment; (6) provider of special equipment; (7) special care provider; and (8) full time supervisor. Based on their findings, the authors proposed a framework to describe the complex interactions between health professionals, family members, and patients with an emphasis on care provision by family members and the supervision of family member care by health care providers.

Poirier and Ayres (2002) suggested that early research, such as Golodetz, et al. (1969) had a profound effect on the caregiving research that followed. They stated, "this portrait of the family caregiver as under qualified, trapped, alone, and female strongly influenced subsequent research that focused almost exclusively on women and usual sought to quantify the burdens of care, including social isolation, financial strain, and physical and psychological disability" (p. 83).

Gordon, Benner, and Noddings (1996) later proposed a much more complex portrayal of the family caregiver in their exploration of the practical and theoretical

thinking on caregiving practice. In their presentation of essays related to caregiving, they offer a more contemporary lens on today's reality of family caregiving. They suggested that although caregiving has been women's traditional work, the capacity to care resides in all human beings. This capacity is "determined not by gender, but by experience and relationships, social expectations, and social and economic arrangements" (Gordon, et al., p. xii). The authors conceptualized caregiving as demanding an intricate combination of abstract learning, reasoning, relational intelligence, social learning, and skill knowledge. As part of the relational intelligence, they stated "caring demands that one dwell – as Martin Heidegger would have described it – with another" (p. xiii). They also proposed that the quality of the caregiver relationship was dependent not only on the skills and receptivity of the caregiver, but also on the responsivity and response of the care receiver. They suggested that the "timing, context, and the ability to perceive a range of human possibilities is central to both caregiving and receiving" (Gordon, et al., p. xiii).

In analysis of the concept of family caregiving, Swanson, et al. (1997) suggested that the literature (n=63) of empirically based and other related articles on family caregiving in the nursing and health-related literature published between 1985-1997 categorized caregiving with task, transition, role, or process orientations. In the reviewed literature that emphasized task, caregiving was defined in terms of the provision, time, and effort related to the care for individuals with a focus on the personal care, health-related, and household tasks. Caregiving, viewed from the transition orientation, extended the perspective to include both performance of task and the more complex aspects of care management. Caregiving, as a role, put forth the concept as an extension

of the roles customarily enacted by family members and/or others. Lastly, in caregiving viewed as process orientation, the process subsumed the tasks and roles into categories that encompassed the multiple tasks and roles of caregiving.

Examples of these approaches in the conceptualization of the caregiver role are abundant. This is particularly striking in the early literature focused on caring for an aging family member, and the nursing literature offers examples of these approaches. A well-recognized example of both the role and transition approach to define family caregiving in the early nursing literature was the career perspective on family caregiving proposed by Lindgren (1993). In a qualitative study (n=10) of the spousal caregivers of individuals with Alzheimer's disease and/or dementia, Lindgren examined major categories of the caregiver experience namely care recipient's behaviors; decision-making and management strategies; feelings, beliefs, and values; supports from family and health care providers; and caregivers self-care and personal history. Based on this data, three stages of the caregiving career emerged. These stages included the: encounter, enduring, and exit stages. The encounter stage includes the receipt of the diagnosis, adjusting to the impact of the diagnosis, and making life changes. In the enduring stage, the heavy workload stage, the caregiver adjusts to the role and establishes routines for handling the illness situation. It is during this stage that caregivers can become enmeshed in the caregiving role and experience stress related to feeling overwhelmed, isolated, and frustrated with a sense of loss. Lastly, the exit stage occurs when caregiving responsibilities become less intense due to the institutionalization or death of the care receiver.

Over the last two decades, nursing investigators have identified the limitations posed when negative caregiving conceptualizations such as burden, stress, and coping are used as the lens for caregiving research. Ayres (2000) suggested that this emphasis on the negative aspects might be "a consequence of the failure of early caregiving instrumentation to discriminate between the experience of caregiving and the caregivers' response to the disabling or fatal illness" (p. 424). In a triangulated study, she subsequently focused on caregiver's general process of making meaning, or "making sense", of caregiving situations. The purposive sample of caregivers (n=36), including men (n=11), were caring for family members aged 14-99 years of age with a variety of chronic illness and disability diagnoses. In a triangulated design using two qualitative strategies, namely thematic and across case analyses and narratives, the author integrated the findings using a hermeneutic spiral of interpretation technique. Caregivers were noted to use expectations, explanations, and strategies to integrate caregiving into the larger contexts of their lives. The expectations were found to have grown out of life experiences, and explanations were based on personal philosophies, moral principles, or strongly held beliefs about the world or themselves. The caregiver strategies appeared to reflect anticipated care needs, priorities, and organized daily activities.

In a more recent analysis of the concept of caregiving, Hunt (2003) suggested that use of multiple terms to describe the effect of caregiving has led to confusion in the synthesis of caregiving literature. In her analysis of theoretical, research, and review articles published between 1980 and 2002, positive, negative, and neutral conceptualizations were identified. Negative conceptualizations included caregiver

burden, caregiver strain, caregiver stress, and the hassles of caregiving. A common theme among these labels was that an imbalance existed between the physical and mental resources required to care for the recipient and those available in the family unit (Hoffman & Mitchell, 1998). Early descriptive caregiver studies were noted to focus on the negative psychological and physiological health effects associated with caregiver burden. Positives conceptualizations included caregiver esteem, caregiving satisfaction, finding meaning through caregiving, and caregiver gain. This conceptualization began to appear more often in the literature in the 1990's. Newer neutral conceptualizations, such as caregiver appraisal, followed in the later part of that decade that allowed caregivers to indicate positive, negative, or neutral feelings about a caregiving situation. Hunt concluded that early descriptive studies suggested the negative physical and psychological effects of caregiving, while more recent investigations have included a focus on positive aspects, however, more research is needed to better understand the multiple conceptualizations associated with family caregiving.

In summary, although family caregiving has existed throughout history, it has only gained the attention of health practitioners, scholars, and policy makers over the last five decades. From the initial studies in the 1960's until the 1980's, caregiving was viewed for the most part as dangerous, challenging, and burdensome (Poirier & Ayres, 2002). The negative impact of disability on the lives of families became the dominant view in the literature, and was the driving force behind the caregiving research agenda for decades (Kearney & Griffin, 2001). More recent conceptualizations, beginning for the

most part in the 1990's, have offered a broader perspective of caregiving as an embodied, relational, contextual, and complex human experience.

Family Caregiving in Families with Childhood Chronic Conditions and Disability

While much can be learned from the adult caregiver literature, families caring for children with chronic health conditions and disabilities face unique challenges and often more extensive and unusual needs. Research describing the family experience of raising a child with a chronic illness or disability began in the 1960's. Davis (1963) published one of the earliest studies that examined family caregiving in the context of childhood chronic illness and disability. In a qualitative study of families impacted by childhood polio, a major finding was miscommunication between the family and health care providers. Specifically, he found divergent perspectives held by parents and children, in contrast to the physicians and nurses. The parents and children "held very different definitions of the situation with regard to the child's condition and prognosis" (Davis, 1963, p. viii). This was found to occur most often when children experienced more significant functional limitations caused by the disease.

Much has been written since that time about caring for children with chronic conditions or disabilities; however, this body of literature remains less developed than that focused on the aging family, and there remains a heavy focus on the burdens of caring. Green (2007), a sociologist and parent of an adult child with disabilities, proposed that the while there has been a pronounced shift away from an exclusively negative focus in the elder care literature, the shift to include the positive attributes and benefits of caregiving has been slower in the literature on parenting a child with

disabilities. This observation supported an assertion by Kearney and Griffin (2001) that historically in the literature, including the nursing literature, the tragedy, burden, and pain of having a disabled child are implicit.

A review of the pediatric literature revealed two broad categories of scholarly work and research focused on the family caregiver experience. Most published studies and proposed conceptual models can be placed into the categories of caregiver adaptation to or family management of the chronic condition/disability. The caregiver adaptation literature focuses primarily on family stress, coping, wellbeing, resilience, subjective and objective burden, and mental health. In contrast, the family management literature focuses on family roles, tasks, and the managerial aspects of family response to chronic health or disability concerns.

Caregiver Adaptation

Childhood caregiver research focused on family adaptation is found in the nursing, medical, sociology and psychology literature, with a limited number of studies focused on families with a child with cerebral palsy. The following selected studies are representative of the larger body of literature focused on caregiver adaptation.

Maternal adaptation to mothering an "other than normal child" was the focus of a metasynthesis by Nelson (2002). This analysis and synthesis included the examination of 12 qualitative studies published between 1991 and 1999. While there was heterogeneity in the mothers sampled and the children's disabilities, the common process oriented themes included: (a) becoming the mother to a disabled child; (b) negotiating a new kind of mothering; (c) dealing with a changed life; and (d) the process of acceptance/denial.

While not all disabilities were evident at the time of the child's birth, shared emotional themes during the initial phase included fear, despair, anxiety, grief, and disappointment, which progressed to the next phases of negotiating a new kind of mothering and life changes. The author suggested that although the term "caregiver burden" was not overtly articulated in each study, mother's lives were dramatically altered because they were overwhelmingly the primary caregiver of their children and perceived little assistance or relief.

The concept of "normalcy" appears often in the caregiver adaptation research. Thorne, Radford, and Armstrong (1997) examined caregiver's (n=46) perspective on caring for a severely disabled child with a long-term gastrostomy tube. The interpretive descriptive study was conducted as part of a larger, longitudinal study on nutrition factors, complication rates, and caregiver satisfaction with gastrostomy services. The children were aged 21 months to 19 years, with a mean age of 9 years. The majority of the children were disabled from birth and wheelchair dependent. Nine categories of coping were identified, falling under the 3 major categories of "managing the gastrostomy", "dealing with people", and "maintaining normalcy". Adaptability, problem solving, and "knowing the child" were found to be essential qualities for successful coping with gastrostomy management. Notably, the caregivers in this study worked to foster their child's capacity for normal social interactions with others outside the family and to maintain family functioning and their own personal respite time.

Similarly, in a grounded theory investigation, Judson (2004) examined the process of mothering a child dependent on parenteral nutrition. Nineteen mothers of children

aged 2 months to 16.5 years were interviewed. Of these children, 26% had been on parenteral nutrition for their entire lives. Judson identified three adaptive phases that she called "gaining control", "taking control", and "maintaining control" resulting in a grounded theory of protective care. The antecedents, strategies, and consequences of protective care included committing to care, watching over, challenging the system, promoting normalcy, putting life into perspective, and celebrating the positive.

Both the Thorne, et al. (1997) and Judson (2004) studies support the conceptualization of family normalization as proposed by Deatrick, Knafl, and Murphy-Moore (1999). These authors conducted an analysis of the concept of "normalization" in families caring for children with chronic conditions in an effort to refine the concept and explore the related social, cultural, ideological, and moral issues. Based on a review of 33 theory and research articles representing 14 studies, the attributes for normalization were inductively derived. The five attributes included acknowledgement of the condition and its potential threat to lifestyle; the adoption of a "normalcy lens" for defining child and family; engagement of parental behaviors and family routines consistent with the normalcy lens; development of treatments consistent with the normalcy lens; and interaction with others based on view of child and family as normal. The concept "normalcy lens" was described as use of the interpretive lens to support the story of "family life as normal".

In examining family stress and adaptation, Van Riper (2007) added to the large body of literature focused on families with children with Down syndrome. In a descriptive, correlational investigation, she examined the maternal perception (n=76) of

family adaptation. The average age of the child was 7.5 years, with 85% of the sample being younger than 14 years. Using the Resiliency Model of Family Stress and Coping, she examined family adaptation and the linkages between family demands, family resources, family problem solving and coping, and adaptation. Findings supported the growing body of literature that suggest that many families with a child with Down syndrome respond with resilience and adaptive functioning. Three family variables, namely family demands, family resources, and family problem-solving communication, were associated with family adaptation, while family demands had a negative association with this variable. While seventy percent of the mothers rated their family's overall functioning as a 4 or 5 on a 5 point (5 = excellent) scale, many families had high levels of demands with mothers commenting on the need for family members to constantly juggle demands.

Delve, et al. (2006) also examined the stress in their investigation of the well-being, stress, and support resources of families (n=138) caring for children with disabilities related to rare disorders. The majority of the children, 88%, were less than 12 years of age. The parental participants included mothers (n=136) and fathers (n=108). The Swedish prospective study measured parental stress and perceived strain using the Parenting Stress Index, and overall well-being and support resources using the Ladder of Life and Interview Schedule of Social Interaction instruments. Measures were obtained at baseline, 6 months, and 12 months after a family support intervention program. Parents were found to have high levels of stress, particularly mothers of children with behavior-related and physical disabilities. In families with childhood physical disability,

most mothers (86%) and half of the fathers (52%) perceived a strained physical workload that was higher than in families with no physical disabilities.

Focusing on coping in another group of families with childhood disabilities, Hilbert, Walker, and Rinehart (2000) examined functioning of family caregivers (n=125 primary caregivers; n=89 secondary caregivers) caring for children with Sturge-Weber Syndrome (SWS). Mothers comprised 96% of the primary caregiver category. Using mixed methods, the investigators sought to examine family functioning and caregiver reaction to caring for a child with the rare, progressive, congenital disease. The typical child was between 6 and 15 years of age. The hallmark of SWS is a port wine stain that may cover up to 80% of the body, and the disease has an unpredictable course leading to developmental delays, seizures, emotional disorders, cerebral hemorrhage, and death. Findings included negative responses to caregiving by both primary (mothers) and secondary caregivers (fathers) with significant impacts on family schedule, health and finances, and esteem from caregiving. Family schedules were most impacted with less independent children. While esteem in the caregiver role was correlated with more years in caregiving, the negative aspects of caregiving were not significantly correlated with the number of years in the caregiver role. In response to open-ended questions, many parents expressed bewilderment, pain, denial, and anger at "not having the perfect child", in contrast to others that described their children as "treasures" for whom they had the privilege of caring.

Gravelle (1997) looked at the day-to-day experiences of parents caring for a child with a progressive disability and life limiting illness. Using Giorgi's phenomenologic

approach, she explored the experiences of parents caring for a child with muscular

dystrophy. Five mothers and three couples were interviewed. The central emerging

theme was "facing adversity" with two distinct but closely connected sub components of

"defining adversity" and "managing adversity". Parent's adversity related to the

progressive nature of the child's illness. The findings suggested that due to the

progressive nature of the disorder, parents experienced a myriad of changes that affected

all levels of their family. With each change, parents redefined adversity and developed

new strategies to manage it. Mothers, as the primary caregivers, described the amount

and significance of change to be greater than that reported by fathers. Caregiver fatigue

was noted to have a significant impact on the mothers' lives.

In a frequently cited investigation, Larson (1998) examined the lives, daily

occupations, and well-being of low income Mexican-American mothers parenting a child

aged 5-11 years with "high burden" disabilities. High burden was defined as children

having a combination of characteristics that limited self-care skills, severe cognition

issues, physical impairments, or severe behavioral problems. During in-depth interviews

with mothers (n=6), lasting a minimum of 22 hours, Larson found that mothers linked

their own subjective well-being with feelings of success in mothering and their child's

progress. She concluded that these mothers were "embracers of the paradox" – the

tension between their child's current circumstances and their hopes and desires for the

future. The mothers all wished for a miraculous cure for their child, yet at the same time

expressed a deep love and affection for the children in their current state. She described

this tension as:

> The driving force which energized the mothers to seek solutions, daily orchestrate routines, find programs, and search for answers for their child's sake. The energy behind their maternal work was this paradox, understanding the impaired condition of their child and yet fully embracing a more hopeful future as well as guarding against a painful one. (p. 871).

The mothers were described as appearing to gradually revise and reconstruct the meaning of events through a powerful rationale process that counteracted negative emotion and decreased the diminishment of subjective well-being.

A qualitative study by Kearney and Griffin (2001) suggested similar findings. In a phenomenological inquiry into the parental caregiving experiences of parents (n=6) caring for young children, aged 3-6 years, with significant intellectual disabilities, the paradoxical themes of joy and sorrow in caregiving were identified. The parents, two couples and two single mothers, voiced the experience of having a "curious combination" of joy and sorrow, confronting sorrow, and personal growth in their suffering. Confusion, doubt, and ambiguities were also intrinsic to the parent's experience; yet, joy was also identified as a central theme to the parents' reality. The investigators suggested that the further exploration of the experience of joy, and studies focused on the parents of older children, are important areas for future research.

To tackle the cultural emphasis on the negative aspects of caregiver burden, Green (2007) sought to further examine the experiences of 81 mothers caring for preschool to high school aged children with disabilities. This sample, with a child mean age of 5 years, included 31% mothers caring for a child with cerebral palsy. This study used a combination of quantitative and qualitative methods to examine how perceptions of stigma, objective burdens, and subjective burdens affected the perceived benefits of

caring for their children. While the study had some distinct methodological limitations including use of an instrument, a measure of perceived benefits, without a record of reliability, the results of this study suggest that the experience of parenting a child with disabilities is quite complex. Mothers were more likely to report being affected by the constraints of objective burden (i.e. financial stressors, time constraints) rather than the emotional distress of subjective burden. The qualitative findings, supported by the quantitative piece, revealed that meeting the personal, medical, educational, and social needs of a child with a disability, in the context of negative public attitudes and poorly coordinated service systems, can be physically exhausting and financially draining for mothers.

Chronic Condition or Disability Management

The body of literature focused on chronic condition or disability management tends to place an emphasis on social positioning, roles, tasks, routines, and practices. In a secondary data analysis of three previous mixed methods studies, McKeever and Miller (2004), sought to gain understanding of the maternal practices of mothers (n=66) caring for children requiring technological support or with physical disabilities. The children were aged 6 months to 14 years of age. Using Bourdieu's theorization of social life, the investigators examined the means used by mothers to improve their personal or their disabled child's social positioning. While the data suggested that the majority of the women experienced psychological and somatic distress, physical exhaustion, social suffering, and economic disadvantage as a consequence of parenting a child with disabilities, the vast majority described their experience as richly rewarding. Mothers

reported intense feelings of love, pride, and respect for their children, and worked to uphold their child's personhood and value.

In looking at maternal routines and occupations, Cronin (2004) qualitatively examined how a child's "hidden" disability influences these aspects of maternal life. Interviews were conducted with the mothers (n=22) of children with cystic fibrosis and attention deficit hyperactivity disorder to contrast mother's activities and routines. While the daily routines suggested that the time spent in child-related activities was similar in both groups, the mothers of children with cystic fibrosis were satisfied yet more willing to subjugate their interests to be the idealized "super mom". Both groups of mothers were noted to under-represent the burden and special care needs of their child.

In a grounded theory investigation by Kirk, Glendinning, and Callery (2005) of families caring for technology dependent children, the concept of roles associated with family caregiving emerged. The family participants included mothers (n=23) and fathers (n=10) of 24 children. The researchers identified several themes related to the role-related nature of caregiving in the context of parenting a child with special health care needs. Parents reported perceiving their roles as multifaceted having both parenting and nursing dimensions, and reported performing clinical procedures on their own children as the most distressing part of their parenting. Importantly, parents identified concerns related to "being an agent of pain rather than providers of comfort and protection as distressing" (p. 460).

Leiter, Krauss, Anderson, & Wells (2004) examined role collaboration played among mothers (n=31) and early intervention specialists (n=19) in negotiating the

provision of care for young children with disabilities. In this qualitative study, she also explored the health care work performed by mothers. She concluded that the early intervention program created a "micropolitical situation" by attempting to create and enforce social roles for mothers, urging them to comply with therapeutic imperatives. While this work can be viewed as an extension of mothers' typical care, at times it was an exception as the scope of care work increased to where mothers learned specialized therapeutic and medical knowledge and skills usually associated with professional care.

Models of Chronic Condition or Disability Management

Based on descriptive research and literature reviews, several models of chronic childhood condition/disability management have been published. In the early 1990's, Knafl and Deatrick (1990) published an initial conceptualization of the family management style framework (FMSF). Based on a review of the literature, the authors identified patterns of family response to managing chronic conditions as a typology. The initial framework included the components of situation definition, management behaviors, and sociocultural contexts, and focused on the interplay of family member definitions and childhood illness management behaviors. This model was subsequently refined based on later qualitative research. The newer typology included five management styles including: thriving, accommodating, enduring, struggling, and floundering (Knafl, Breitmayer, Gallo, & Zoeller, 1996).

Later work by Knafl and Deatrick (2003) led to further revision of the FMSF and those changes included the dimension of perceived consequences, with recognition that perceived outcomes can shape management behaviors and affect subsequent definitions

of the situation. The dimension of sociocultural context was also expanded to include

family perceptions of factors that influence family definition and management of

childhood chronic conditions.

More recently, Grey, Knafl, and McCorkle (2006) have begun to build upon the

FMSF framework to develop a framework focused on self and family management of

chronic conditions. The "Self and Family Management Behaviors" framework is focused

on risk and protective factors that influence individual's and family's ability to manage

chronic illness and disability. The model focuses on identification of target interventions

and outcomes, rather than typology. This model appears suited for both adults and

children, and individuals and families managing chronic health conditions

Another model, which focuses on both adaptation and management was

developed by Ray (2002). The "Parenting and Childhood Chronicity Model" is focused

on "special needs parenting" and a description of the work required to raise a child with a

chronic health condition. This model was the result of qualitative data collected through

3 iterative cycles of interpretation with different parent samples. The version was initially

developed as part of a study on stress and coping, and was subsequently validated by

families (n=30). The parent participants included mothers (n=30) and fathers (n=13).

The non-categorical sample included the families of children, aged 15 months to 16

years, with multi-system health conditions and disabilities. Children with developmental

disabilities or behavioral issues alone were excluded. The key components of the model

include "doing the medical care", "parenting plus", "working the system", "minimizing

the consequences for family", and "keeping yourself going". The author reported

findings of parental resentment for the time, effort, and emotional energy needed in the administration, coordination, and advocacy roles that are part of special needs parenting, and that the more expertise gained in providing for these aspects of the caregiving process, the more invisible and taken for granted the efforts become. She suggested that this phenomenon placed parents at risk for acquiring increasing caregiver responsibilities, until they faltered in their ability to keep up with the workload.

In a later secondary analysis of data, Ray (2003) used Gidden's structuration theory to examine the social and institutional conditions that shape special-needs parenting. These conditions were those present in the health, education, and social service systems. Ray found developmental patterns among the families, including parents being forced to acknowledge negative societal attitudes toward disability as a pervasive societal issue. This occurred most often as children aged and the gap between the child's abilities and their peers grew more visible. Acceptance issues were an underlying ideological issue in the data, and much parenting effort was aimed at helping the child find a place in community.

In summary, since the 1960's, researchers have explored the experience of family caregiving in the context of childhood chronic illness or disability. However, this body of literature remains less developed than the related literature focused the aging family. There has also been a slower shift in the pediatric literature from a focus on the negative aspects of family caregiving to a more neutral approach. While a limited number of investigations and several models of family caregiving have been put forth, more work is

needed to better understand family caregiving in the context of childhood disability and to move forward with the development and testing of theoretical models.

Family Caregiving in Families with a Child with Cerebral Palsy

The research focused on the families of children with cerebral palsy is consistent with the greater body of childhood disability literature in its focus on parent adaptation. Most studies have looked at discreet concepts related to family functioning such as caregiver adaptation, quality of life, stress, and needs; few offer a broad perspective on the family caregiving experience. More recently, in a limited number of studies, investigators have begun to explore the not only the psychological dimensions, but also the physical dimensions of caregiver health.

Caregiver Adaptation

Lin (2000) explored the relationship between family coping and family adaptation in families with a child with cerebral palsy. Guided by the Resilience Model of Family Stress, Adjustment and Adaptation (McCubbin & McCubbin, 1996) and family life cycle theory, this is one of the few studies based on an explicit theoretical framework. The sample of 274 primary caregivers was 89.4% female, with a mean age of 39.9 years. The children were aged 1.3-21.9 years, with a mean age of 11.3 years. Families with adolescents (age 13-16) comprised 21% of the participants. The variables of interest in this descriptive study were family coping with CP, family adaptation, and family life cycle stages. Five factors of coping behaviors were found to underlie family coping behaviors, namely, positive family appraisal, support from concerned others, spiritual support, personal growth, and advocacy. Interestingly, a family coping with CP was

found to be dissimilar at different points in family life cycle stages. Families with school-aged children were found to have better adaptation than families with adolescents and families with young adults. The investigator suggested that although this might be explained by the perception of most parents that children are more challenging during the adolescent or young adulthood years, or the limitations of service systems, the evidence suggests that positive family appraisal was found to account for the largest portion of variance in family adaptation. She recommends continued family research focused on family adaptation at different stages of the family life cycle. An additional recommendation for future research was to examine differences in groups based on the severity of the disorder.

Florian and Findler (2001) examined the risk-resistance factors for maternal adaptation among mothers of children with CP in Israel. The quantitative study compared 80 mothers of children with CP, aged 3-7 years, with a control group of 80 mothers of non-disabled children. The majority (72.5%) of the children with CP had moderate to severe impairments. The variables of stressful life events, maternal self-esteem, self-mastery, social support, mental health, and marital adaptation were examined. Moderate, yet significant, differences were found between the two groups for the number of stressful life events reported and the adaptation indicators of mental health and marital satisfaction. No differences were found in levels of self-esteem; however, lower levels of self-mastery were noted. The authors suggest that self-esteem is developed and shaped during early life while mastery refers to one's ability to control the forces impacting one's life. Feelings of mastery may also be more vulnerable in families

caring for a child with disabilities since the future for families may be less clear and less predictable.

In a later literature review to examine the process of adaptation in parents of children with cerebral palsy, Rentinck, et al. (2006) evaluated 20 cross-sectional studies. The authors concluded that among these studies there was a lack of consensus about terminology for the important conceptual terms and only scarce information about the adaptation processes that parents might go through following the diagnosis of cerebral palsy. Blurred concepts included family functioning, well-being, and social support. The authors suggested that to gain a deeper insight into the adaptation process, it is essential to recognize that adaptation is a multifactor process determined over time, and recognition needs to be given to the different developmental stages of family life.

A more recent qualitative inquiry by Pelchat, Levert, and Bourgeois-Guerin (2009) investigated the similarities and differences in the adaptation/transformation process in mothers (n=13) and fathers (n=13) living with a child with CP on the individual, parental, marital and extra-familial levels. Parents were found to have to undergo a key adaptive task, namely assuming their normalcy. Parents reported feeling stigmatized by society, and needed to undergo a normalization process to position their parenthood within a normative space at the individual, parental, and marital levels. Fathers were found to have more difficulty bonding with their child, using escapist behaviors, while mothers devoted their energies caring for their child. While parents shared a common objective, namely the child's autonomy, there marked differences in the way they pursued this goal. Mothers' associated autonomy with relational and

communicational aspects of relationships, namely with other people's acceptance of the child. Meanwhile, for fathers, autonomy was connected with the child's developmental progress. While these viewpoints were divergent, they were found to be complimentary for family adaptation.

Barlow, et al. (2006) examined maternal psychological well-being and self-efficacy in relation to maternal perceptions of children's eating, sleeping, and mobility. The sample included mothers (n=78) residing in the United Kingdom caring for children aged 1-15 years with CP. The mean child age was 6 years old. Half of the children had significant co-morbidities related to cerebral palsy. The findings suggested that mothers of children with CP experienced higher levels of anxiety compared to population reference norms, and child sleep problems were associated with maternal anxiety levels.

Manuel, et al. (2003) assessed the role of child disability severity and functional status as predictors of maternal depressive symptoms. The participants were 444 mothers of children aged 1.1 to 17.8 years of age. The Functional Independence Measure for Children, the Global Rating Scale, the Impact on the Family Scale, and the Center for Epidemiologic Studies – Depression Scales, and the Maternal Social Support Scale were used. The results suggested that almost a third of the mothers' scores detected depressive symptoms. Interestingly, the child's disability severity and functional status did not consistently predict mother's depression. The mothers of high functioning children experienced more distress and they perceived lower levels of social support than mothers with lower functioning children.

In another international study, conducted in the Netherlands, Schuengel et al. (2009) examined parents' reactions to receiving the diagnosis of childhood CP and resolution of the initial reaction. In this qualitative study, the authors examined differences among parents in relation to the age of the child, and the child's motor ability based the GMFCS. Data was collected in semi-structured 10 – 20 minute interviews. Resolution was identified when parents "appeared to have been able to move past the crisis of diagnosis, were oriented to the present reality, and were able to flexibly integrate anything they learned along the way about the CP of their child in their view of their relationship with their child" (p. 674). The children were classified as toddlers (n=51), school-aged (n=107), or teenage (n=97). In the total sample (n=255), 81.6% of parents demonstrated resolved reactions regarding their initial reactions to their child's CP diagnosis. The percentage was noted to be lowest in the toddler group (78.5%) and in 68.9% parents of children meeting the criteria for Levels IV and V on the GMFCS (n=63). Findings suggested that resolution in the parents of toddlers is mainly demonstrated by their focus on their thoughts and expectations surrounding the diagnosis, while resolution in the parents of teenagers mainly entails focusing on concrete actions and measures to support their child.

Caregiver Quality of Life

A limited number of studies have focused on the QOL of parents caring for children with CP. In a small scale study in Turkey, Eker and Tuzun (2004) examined the quality of life and consequent burden of mothers of young children with cerebral palsy, as compared to mothers with minor health problems, in Turkey. Forty mothers of

children aged birth to 12 year, with cerebral palsy, and 44 mothers of similarly aged children with minor health issues, participated in the pilot comparison study. Findings of this small-scale study suggested that the quality of life of mothers of children with CP was rated as lower than the other mothers, and that the severity of the child's motor disability, based on the GMFCS scale, significantly lowered mothers' scores versus those in the comparison group.

In another quality of life study in Australia, Davis, et al. (2009a) conducted a grounded theory study exploring the impact of caring for a child aged 3-18 years with CP on mothers (n=24) and fathers (n=13). In semi-structured interviews, parents identified how they rated their QOL, issues that impact their QOL, and what they needed to improve their QOL. Caring for a child CP was found to affect parent's physical well-being, social well-being, freedom and independence, family well-being, and financial stability. Parents reported needing support for making their child's home environment more accessible. Although a previous investigation suggested that the severity of physical disability impacts family functioning including stress (Eker & Tuzun, 2004), this small scale investigation found no apparent differences in the issues families face or parental QOL in relation to different levels of physical impairment. The inconsistent findings between these two investigations must be considered in light of sample sizes and potential differences in cultural and societal conceptualizations of disability in the Australia and Turkey.

Caregiver Stress

In another recent investigation, Glenn, et al. (2008) examined factors predicting parenting stress in mothers (n=80) of very young children with cerebral palsy. Children had a mean age of 19.6 months. They identified relatively limited research focused on families with cerebral palsy, and that most past studies reported overall higher than average parenting stress levels. Using the Parenting Stress Index and Scales for measuring family needs, supports, adaptability, and coping, the majority of the mothers were stressed but below the usual threshold for therapeutic intervention. Overall, mothers reported caring for their children as rewarding and had good emotional attachments to them. The participants with children who were rated as more demanding and less adaptable were found to have higher stress levels. Additional high stress factors for the mother included feelings of isolation and poor spousal support.

Parkes, McCullough, Madden, and McCahey (2009) confirmed the role of challenging child behaviors as a contributor to parental stress. In a cross-sectional survey of 102 parents in Ireland, they sought to describe the health of children with CP and predict parental stressors. Based on the Child Health Questionnaire, children with CP were found to have overall poorer physical health compared to those without CP. For parents, stress as measured by the Parenting Stress Index Short Form was higher than the normative population. While several variables, namely intellectual disability, child general health, GMFCS level, seizures, and feeding were associated with parenting stress, only child behavioral problems remained statistically significant accounting for 28% of the variance observed in parenting stress.

Caregiver and Family Needs

Two recent studies have explored the family needs of the parents of children and adolescents with CP. The purpose of these inquiries were to gain an understanding of the needs of families caring for children and adolescents with CP. Palisano et al. (2010) surveyed 501 parents (77.6% mothers) to identify the differences in the numbers and types of family needs expressed based on the age and gross motor function level of their child using a modified version of the Family Needs Survey (FNS). The effect of GMFCS level was found to be significant with the parents of children meeting criteria for Levels IV and V reporting greater needs for information, support, community services, finances, and explaining to others family function. An unexpected finding was that the age of the child was not found significantly impact identified family needs. In their discussion of finding, the investigators suggested that the tool, the FNS, had been developed for families with younger children and their attempt to adapt the tool may not have been successful.

In another needs survey, Buran, Sawin, Grayson, & Criss (2009) piloted the Family Needs Assessment Tool (FNAT) to determine the needs of parents with CP and to verify the internal reliability of the tool for measuring the needs of these families. Surveys were sent to 823 families, with a response rate of 57% (n=466). Mothers completed almost 75% of the surveys, with 40% of the children identified as wheelchair users. In this investigation, the FNAT was deemed to be a reliable instrument based on the three subscales designed to measure critical dimensions of need: service (.83), information (.95) and obstacles to treatment (.82). The average stability over two weeks

was r=.77. The greatest needs information related to plans for the child's future and

available services. The greatest service needs related to recreational, special therapies,

babysitting, and respite care. While a smaller portion of the sample identified obstacles

to treatment, transportation and health care costs were identified as the greatest issues.

Most of the narrative responses provided by participants focused on obstacles of

communication with health care providers and the unique experiences they had learning

to navigate the healthcare system.

Caregiver Physical and Psychological Health

Lastly, there have been few large-scale studies focused on both physical and

psychological health of caregivers. Brehaut et al. (2004) conducted a population-based

study of family caregivers (n=468) of children with cerebral palsy in Canada. This

investigation sought to address two noted major weaknesses in previous studies, namely a

focus on only psychological health of caregivers and potential biases related to the

recruitment of families from small specialized clinics which were likely to limit the

sample to children with more severe disabilities. This study sought to compare the

overall health of caregivers of children with CP with that of a population-based

representative sample of parents in Canada. The caregiver samples of both the caregiver

and population samples were 94.4% and 93% female respectively.   The findings

suggested that compared to the general population of family caregivers, the caregivers of

children with CP were likely to report poorer psychological health and cognitive issues,

and far more physical health problems. These chronic health issues included back pain,

hypertension, stomach ulcers, and vision problems. Participants also reported lower incomes, despite no educational level differences.

In a secondary study using the same participants, Parminder et al. (2005) sought to develop a multi-dimensional model of the determinants of psychological and physical health of adult family caregivers of children with CP. The investigators identified that the most important predictors of caregivers' wellbeing were child behavior, caregiving demands, and family function. In this sample, a high level of child behavioral problems were associated with lower levels of both psychological and physical health, while fewer child behavioral problems were associated with a higher self-perception and a greater ability to manage stress. Fewer caregiving demands and higher levels of family functioning were also associated with better psychological and physical well-being. The influence of social support provided by extended family, friends, and neighbors on health outcomes was found to be secondary to the influence of the immediate family working closely together in caregiving responsibilities.

In a smaller, but more recent investigation in Ireland, Byrne, Hurley, Daly, and Cunningham (2010) reported on a survey of the health of 161 family caregivers of children with CP. The aim of the study was to assess the health of family caregivers and identify vulnerable populations. The survey respondents included 100 women and 61 men; only 8 of these participants were not the parent. Female caregivers were found to spend significantly longer hours caring for the children. They also were found to have statistically significant lower scores on all eight domains of the SF-36 Health Survey, a norm-based generic measure of overall health functional status and health related quality

of life. These domains included physical functioning, physical role, bodily pain, general health, vitality, social functioning, emotional role, and mental health. Female caregivers also scored lower than their counterparts in the general population on all eight domains, and male caregivers scored lower in six domains than their counterparts. Of note, female caregivers caring for a child with more functional limitations scored lower in every domain except general health. Finally, caregivers who spent longer hours caring, of whom the greater proportion was female, were found to have poorer mental health than those spending fewer hours in caregiving activities.

Phenomenologic Inquiries

As this literature review suggests, most investigations have focused on the examination of discrete concepts related to the family caregiving experience in the context of caring for a child with CP. While these investigations have advanced our understanding of the phenomena, they have not necessarily enlarged our broader understanding of the day-to-day lifeworld experiences of mothers caring for adolescents and young adults with CP. To date, a small number of investigators have used a phenomenologic approach to explore the broader family caregiving experience in families with children with CP. Most of these studies are unpublished, and have focused on families with younger children.

Glassock (2000) examined the experience of mothering a young child with spastic cerebral palsy. Fifteen mothers of children aged 1 to 5 years, being treated at high risk and neurology clinics, participated in this investigation. Using the Colaizzi phenomenologic analysis method, four clustered themes emerged. The themes were

caregiver burden, family/social support, women's/mother's roles, and socioeconomics. Each of the interviewed mothers reported caregiving burdens, with caregiving being described as time consuming and difficult. Yet, all of the mothers indicated a positive perception of their caregiver role. Strong family relationships were present for the participants, although they did experience impacts on their school, employment and financial status.

In a master's thesis, Moore (2005) reported on a phenomenologic inquiry into the maternal caregiving experiences of mothers caring for young children (aged 4-11 years) with severe cerebral palsy. Using Roy's Adaptation Model as a conceptual orientation and Colaizzi's descriptive method, she found that caregiving experiences pervaded all areas of the mothers' lives. The maternal caregiving experience was described as being anticipated as a lifelong journey, with the complex themes of sorrow, chronic worry, adaptation, advocacy, and personal growth. Unlike the participants in Glassock's study, this sample of mothers reported issues related to lack of support from family and community. Nevertheless, the overriding experience of these mothers was found to be positive, with a deep sense of love for and commitment to their child.

In a more recent inquiry, Huang, Kellett, and St. John (2010) described the lived experience of Taiwanese mothers after learning that their child had cerebral palsy. This phenomenological inquiry, conducted in 2005-2006, interviewed 15 mothers of children aged 8 months to 14 years to learn more about the Asian maternal experience in the context of childhood disability. While the investigation was conducted in Taiwan, it specifically sought to address the need for more studies to address the unique influences

of culture in the growing multi-cultural global population, and to add to the limited body of knowledge of the experiences of parents living in non-Western countries. Using an interpretive approach, four themes emerged. These themes included: feeling out of control and powerless; mistrusting healthcare professionals; release and confirmation; and feeling blamed for not following traditional cultural practices. All mothers in this study voiced the experience of deep despair upon learning of their child's diagnosis. Mothers also experienced grief, anger, and frustration when health care professionals failed to be empathetic, offer hope, and be supportive of parents. A unique finding of this study was that family members often blamed the mother for the child's disability. The investigators attributed this finding to the Chinese cultural belief, still held by many, that a parent, family member, or ancestor may have done a "misdeed" that has caused the child's disability.

In one of the few qualitative caregiving studies focused on the fathers of children with severe cerebral palsy, Appelbaum (2007) examined the experience of being a father to a child with severe cerebral palsy using a phenomenological approach. For this unpublished doctoral dissertation research, the investigator interviewed the fathers (n=6) of children aged 5-27 years. Two of the children resided at home, and four lived in a residential school setting. Eight themes focusing on raising a child with a severe physical disability emerged from this study. The themes included: lost at birth; my beautiful and unique child; illness as a way of life; partner loyalty and commitment; how the world received my child; health care providers - I'm here; torn- when you child can't live at home; and faith. Among the interesting findings from this qualitative inquiry was the

role of grandparents in facilitating the residential school setting placement and the fathers' sense of protectiveness for both their child and spouse. The fathers, with a child living out of the family home, described ambivalent feelings of guilt and relief related to their caregiving experience. All of the fathers shared the perception of being excluded by health professionals in health care decision-making for their child, with the usual focus of professionals being on the child's mother.

In summary, research focused on the families of children with cerebral palsy is consistent with the greater body of childhood disability literature in its focus on parent adaptation, and in its more limited focus on parent physical and mental health. Most studies have looked at discreet concepts related to family functioning and few offer a broad perspective on the family caregiving experience. Several phenomenological studies have sought to explore, describe and, interpret the maternal and paternal caregiving experiences in the context of childhood CP. These investigations have focused primarily on mothers with children under the age of 14 years, or in one case on a small sample of fathers of children with a very wide age range. To date, no published phenomenological investigation has examined the maternal caregiving experience during the important transitional periods of adolescence and young adulthood.

Disability in the Transitioning Adolescent/Young Adult Family

Developmental Issues

Adolescence and the transition to young adulthood are recognized as a critical developmental phases for both the individual and the family. Piaget (1971) and Erikson (1963) are among the theorists who have offered perspectives on the stages of cognitive

and behavioral development. A contemporary, Havighurst (1971) suggested that the tasks of adolescent development included coping with physical changes, developing and refining interpersonal skills, acquiring education and training for adult roles, resolving identity issues, acquiring new values, and becoming behaviorally and emotionally autonomous. Families caring for adolescents with disabilities face unique challenges in managing the transition to between two life stages. While there are no standard trajectories for the transition from childhood to adulthood (Uhlenberg & Mueller, 2004), social norms suggest movement toward autonomy. For adolescents and young adults with disabilities, such as those with severe cerebral palsy, this transition often will not conform to the expected life course trajectory. Consequently, the maternal and family caregiving experience will also differ from the social norm. The contemporary body of literature, focused on families of adolescents with disabilities, predominantly focuses on family adaptation and management during this transitional period.

Caregiver Adaptation

While most of the literature has focused on families with young children, or heterogeneous age-related samples, a few studies were located that focused solely on the families of adolescents with disabilities. Schneider, Wedgewood, Llewellyn & McConnell, (2006) examined the challenges faced by families (n=20) caring for adolescents with severe intellectual disabilities. In these families, the mother most commonly was self-identified as the primary parent-caregiver (n=17). Using an *ecocultural* interview methodology, the investigators sought to identify the challenges and accommodation strategies used by the families to sustain a meaningful family

routine. The in-depth interviews revealed both internal and external family challenges. Internal challenges included changing family roles and relationships, particularly as older siblings left home and younger siblings became either embarrassed or more protective toward the disabled sibling. Interdependent relationships were formed between parents and siblings as they became capable of assuming some aspects of the family workload. Parents also reported difficulties as their disabled child grew in size and strength during puberty, and some identified the realization of the "foreverness of care". Lastly, they faced the internal challenge of the loss of the support of grandparents, typically grandmothers, due to declining health or death. The investigators suggested that some families accommodated to these internal challenges by one parent assuming the primary caregiver role for managing disability related activities, while other couples shared the responsibilities. Parents also were noted to protect siblings' level of involvement in assuming responsibility for the adolescent with the disability, and planned family activities that would facilitate family time spent together. The primary external family challenge related to service discontinuity particularly as the transition to adolescence marked the beginning of an overall decrease in services. Families were found to use three strategies to manage these challenges, namely: advocacy, taking on the role of a care coordinator, and thus forfeiting their time, money, and employment.

In another qualitative study, Todd and Jones (2005) examined the experience of mothers (n=30) caring for adolescents with intellectual disabilities during midlife, or middle age, suggesting that during in this period of the lifecourse, mothers may face the dual management of their child's and their own lifecourse management. Based on in-

depth interviews, the investigators concluded that a highly prominent feature of many mothers' accounts was the importance they attached to living an ordinary as possible family life. A number of events were identified as impacting the mother's lives during this period including the departure of other children from the home, personal health challenges, and changes in the level of the adolescents service provision. Many mothers, facing a period when they would be spending more time with their child as the child transitioned out of school services, suggested the reduction in services occurred at a time of increased support needs. Maternal concerns included the awareness that there would be limited socialization opportunities for their child, and that the mother would become the child's major social companion. The experiences of these mothers suggested some confusion and isolation as they reorganized their lives and transitioned into midlife.

MacDonald and Callery (2007) identified the paucity of literature on the impact of caring for a child with a disability over time. Based on qualitative interviews with mothers (n=19) and fathers (n=7) caring for children and young adults with complex health care needs and intellectual disabilities, the authors designed a developmental map to describe the trajectory of caregiving. The authors sought to identify and illustrate how developmental changes in children are intricately related and cumulative in terms of parental needs, services, and policies. Their four-stage map included the developmental periods of infancy, beginning school, school-aged, and high school through young adulthood. The parent's experiences were noted to have changed over time with the high school through young adulthood stage being discernable by the increased intensity of the caregiving needs and parental concerns for the future for their child. This data supported

Schneider et al. (2006) findings that suggested that the physical demands of caring for an adult-sized child, and the loss of support from aging grandparents, created the need for more care support at a pivotal time when parents anticipated the loss of school-based services.

In one of the few studies focused specifically on families with adolescents and young adults with cerebral palsy, Magill-Evans, et al. (2001) examined the "long-standing belief" that families of children with a disability have less positive family relationships than families of children without disability. Using Bronfenbrenner's ecological framework, the researchers sought to compare family functioning, life satisfaction, perceived levels of social support, and future expectations between two groups. A sample of 90 families with a family member with CP, and 75 families without a member with CP, completed the Family Assessment Device, the Life Situation Survey, the Multidimensional Scale of Perceived Social Support, and the Futures Questionnaire. Participant families that included mothers, fathers, and siblings were divided into subgroups based on child age (adolescent or young adult) and child cognitive status. While families of adolescents and adults with CP anticipated less success in their child's future relations, post-secondary education, employment, and independent living, on many of the measures there were not significantly different from the families of typically developing adolescents and young adults. Within each group, variability was found with some families experiencing different levels of disruption in family functioning, while other families managed very well during this transitional phase of adolescence. Of note, the severity of involvement of the adolescent or young adult's cerebral palsy did not seem

to influence mother's satisfaction with their life situation, social support, or perception of family functioning. The authors did note that selection bias must be considered as a possible explanation for this finding, with overburdened mothers opting not to participate in this study.

A more recent investigation by Davis, et al. (2009b) aimed to identify the domains of quality of life for Australian adolescents with CP, seeking the perspectives of both adolescents (n=17) and primary caregiving parents (n=23). While this grounded theory investigation focused on domain identification, interesting information about the adolescent transitioning family emerged. The semi-structured interviews with the teens and parents revealed many QOL issues beyond functioning; these included physical health, functioning, pain, social well-being, acceptance, participation, independence, and supportive physical environment. Interestingly, only parents referred to communication, relationships, access to services, parent health, and having adequate financial resources as QOL issues. While there was no variation in themes accorded to GMFCS level, it must be noted that inclusion of adolescents was dependent on their ability to communicate. This limitation accounted for the larger number of parent participants.

Summary

In summary, the family caregiving literature in the context of childhood disability has primarily focused on family adaptation and chronic condition/disability management. While this literature has enhanced our understanding of the caregiving phenomenon, conflicting findings, the intense focus on adaptation and management, and the heavy focus on young children, leaves room for further research. Much of the research on

families of children with disabilities assumes a "state of stasis" across the lifecourse

(Grant, Nolan, & Keady, 2003, p. 342), often ignoring normative events and milestones

that shape family caregiving (Schneider, et al., 2006). Although more researchers have

begun to embrace a broader life course perspective, most family caregiver research

focuses on either families caring for the very young or the very old (Blacher, 2001).

Adolescence and young adulthood are recognized as unique transitional periods

between childhood and adulthood with significant physical, emotional and social change.

It poses the prospect of changing family life and caregiver experiences. This review of

the literature suggests the need to further explore the phenomenon of family caregiving in

the context of cerebral palsy, particularly during these transitional years. The knowledge

gained in this study offers the potential to assist in promoting an enriched and fuller

understanding of a not-well- understood phenomenon, namely, the day-to-day

experiences of mothers caring for adolescents and young adults severely impacted by

cerebral palsy and the meanings ascribed to these experiences.

<center>**Chapter III**</center>

<center>**Methodology**</center>

Little is known about the family caregiving experiences of mothers caring for adolescents and young adults with severe cerebral palsy, and many questions remain unanswered about the meanings they ascribe to caring for their disabled child. As human meaning underpins human action, and thus to better understand these mothers' caregiving experiences, a hermeneutic phenomenological inquiry method was selected for the current investigation. The approach developed by Max van Manen was selected to explore the mothers' perceptions of their lifeworlds as experienced in caregiving. This chapter focuses on the methodology, and aims to describe the philosophical orientation, design, setting, participants, human subjects considerations, instrumentation, and general steps for data collection and analysis employed in this study.

<center>**Phenomenology**</center>

Philosophical Orientation

Hermeneutic phenomenology is both a philosophy and method of inquiry. It has its origins in philosophy in Germany before World War I, and has since maintained a position in modern philosophy. Phenomenology grew out of "a critique of positivism, as inappropriately applied to human concerns" (Cohen, 1987, p. 31). The word "phenomenon" comes from the Greek word, *phaenesthai*, which means "to show itself" (Heidegger, 1962, p. 29). The motto of phenomenology: *Zu den Sachen* means "let's get down to what matters" (van Manen, 1990, p. 184) reflects its emphasis on the experiential aspects of the human "lifeworld". The term "phenomenology" was first

<center>69</center>

noted in the 18th century text of Immanuel Kant, who used the term in the scientific context (Cohen, 1987). Since that time, the phenomenological tradition has made strong contributions to the discipline of philosophy, and has inspired researchers to study the *Lebenswelt*, the world of everyday lived experience of humans in their natural setting (Cohen, 1987).

To prepare for this investigation, it was essential for the investigator to gain an understanding of the history and conceptual underpinnings of the philosophy of phenomenology. Van Manen (1990) has been strongly influenced by the German, French, and Dutch phenomenology traditions, and early phenomenological philosophers such as Edmund Husserl, Martin Heidegger, and Maurice Merleau-Ponty. All three philosophers sought to study "experience to know the world as it is lived by revealing the hidden, unexamined meanings that dwell in our everyday world of experience and practice" (Welch, 1999, p. 238).

Edmund Husserl, a preeminent philosopher, suggested that the "lifeworld" is understood as what individuals experience pre-reflectively, without resorting to interpretation (Dowling, 2007). He proposed that phenomenology proceeds by "seeing, clarifying, and determining meaning, and by distinguishing meaning" (Husserl, 1964, p. 58). His student, Heidegger, later advocated for ontological inquiry with a more interpretive, or hermeneutic, approach to the exploration of lived experience. Heidegger argued that the primary phenomenon of interest to philosophy was the "meaning of being" which is the nature or meaning of the phenomenon (Heidegger, 1962).

In contrast to Husserl and Heidegger, who were focused on the abstract nature of being, Merleau-Ponty built upon their writings with a concern for the science of human beings. In his text, *Phenomenology of Perception*, he suggested the need for a philosophy that would be a rigorous science, but it also offered an account of the worlds of space and time (Merleau-Ponty, 1962). His philosophy was one of perception, intentionality, and embodiment (Thomas, 2005). Merleau-Ponty (1962, p. xi) also suggested that truth does not dwell in the "interior" of man, "man is before himself in the world and it is in the world that he knows himself". He proposed four existentials as belonging to the fundamental structure of the lifeworld: lived space (spatiality), lived body (corporeality), lived time (temporality), and lived human relation (relationality) (van Manen, 1990).

Van Manen, a Canadian phenomenology scholar, has been recognized as offering a contemporary approach to phenomenology with strong philosophic roots built upon the works of the classic German, French, and Dutch phenomenologists. His approach also offers some solutions to nurses facing the challenges of phenomenological reduction and reflects the continuing evolution of phenomenology as a methodological approach (Munhall, 2007; Dowling, 2007).

Van Manen (1990) has suggested a human science approach to phenomenology. He defined human science as "the study of 'persons' or beings that have 'consciousness' and that 'act purposefully' in and on the world by creating objects of 'meaning' that are 'expressions' of how human beings exist in the world" (p. 3). His approach is both descriptive and interpretive. He has suggested that in phenomenological study it is not

enough to simply recall experiences, but the experience must be recalled so that the essential aspects of this experience are brought back in such a way that "recognize this description as a possible experience, which means as a possible interpretation of that experience" (van Manen, 1990, p. 41).

Study Design

In hermeneutic phenomenological research science, the emphasis is always on the lived experience. The purpose of phenomenological research is to *examine* other people's experiences and their reflections to try to gain a better understanding of the experience and its meaning in the context of the human experience (van Manen, 1990). While it can be said that phenomenology has no single established method, van Manen (1990) proposed that the philosophic tradition, body of knowledge, and insights offer a methodological ground for human science research. He described hermeneutic phenomenological research as the dynamic interplay among six research activities. According to van Manen (1990), these activities include:

(a) turning to a phenomenon which seriously interests us and commits us to the world; (b) investigating experience as they are lived rather than conceptualized it; (c) reflecting on the essential themes which characterize the phenomenon; (d) describing the phenomenon through the art of writing and rewriting; (e) maintaining a strong and oriented pedagogical relation to the phenomenon; and (f) balancing the research context by considering parts and wholes (pp. 30-31).

In the actual research process, an investigator may work on these activities intermittently or simultaneously.

The first activity, turning to a phenomenon, focuses on the nature of the lived experience. According to van Manen (1990), lived experience is both "the starting point and end point" for phenomenologic inquiry and the aim of inquiry is "to transform this experience into a textual expression of its essence" (p. 36). He further suggested that lived experiences "gather hermeneutic significance as we reflectively gather them by giving memory to them" (p. 37). It is through meditations, conversations, daydreams, inspirations, and other interpretive acts that we give meaning to them.

In preparation for the current study, it was essential for the investigator to consider and identify personal attitudes, beliefs, biases, motives, and intuitions related to the phenomenon of family caregiving in the context of childhood disability. While van Manen does not embrace Husserl's view of bracketing one's beliefs, he suggests that an investigator must "come to terms with his/her (sic) assumptions, not in order to forget them again, but rather to hold them at bay…" (p. 47). Munhall (2007) suggested the term "decentering" to describe the vital process of clearing one's vision and thinking of assumptions, and the term "unknowing" to free oneself from possible of prejudice or bias. To facilitate these process activities and to promote introspection of this investigator in the current study, a personal journal was used to record this investigator's thoughts related to the phenomenon and inquiry throughout the study. A journaling session was conducted prior to and at the completion of each interview. Observations, interview details, and ongoing reflections were noted in the journal entries.

The second activity, investigating the experience as it is lived and experienced, involves "search(ing) everywhere in the lifeworld for lived experience material that, upon

reflective examination, might yield something of its fundamental nature" (van Manen, 1990, p. 53). The hermeneutic interview, close observations, experiential descriptions in the literature and arts served as methods of gathering experiential data. For the current study, the primary form of data collection was the use of the hermeneutic interview in which the researcher served as both participant and instrument. In phenomenology, the purpose of the interview is to serve as a means for exploring and gathering experiential narrative that can serve as a source of understanding a phenomenon, and it can be used as a process to develop a conversational relation with the participant about the meaning of the experience (van Manen, 1990). The semi-structured lifeworld interview attempts to understand the themes of every day lived experiences from the participants' own perspective. Kvale and Brinkmann (2009) proposed that the aim of the interview is to seek a description of the lived experience, including specific situations and events, with the interviewer exhibiting openness to new and unexpected phenomena.

For the current study, a hermeneutic semi-structured interview guide (Appendix A) was developed by the investigator and provided the open-ended questions that facilitated the interview process. To assure the interview questions relevance and face validity, the interview guide was reviewed by four subject matter experts. The experts included two health care clinicians, a disability advocate, and the parent of an adolescent with severe CP. All of the professionals had extensive experience in the field of childhood disabilities, and the parent met the study inclusion criteria. Prior to commencement of the study, the experts were asked to review the semi-structured interview guide to ensure that the questions and probes were simple and brief, directed

toward the phenomenon of interest, and contained vocabulary appropriate to the educational level of participants. All of experts reported that that the guide's questions were appropriate with regard to its focus on the phenomenon of maternal caregiving, wording, and vocabulary.

The subsequent activities outlined by van Manen (1990) are briefly described in this section, while the actions specific to the current investigation are described in the data analysis section of this paper. Thus, the third activity outlined by van Manen (1990) involves phenomenological reflection on the data. The transcribed experiential narratives, observation notes, literature, and artifacts are examined by the investigator for themes that are understood to be the structures of the experience. Van Manen (1990) described themes as "the experience of focus, of meaning, of point … they describe an aspect of the structure of the lived experience" (p. 87). Themes are uncovered from the hermeneutic interview by isolation of thematic statements and the composition of linguistic transformations.

The fourth activity, related to phenomenological writing, actually involves a set of activities that "fix(es) thoughts on paper" (van Manen, 1990. p. 125). Van Manen suggests that the textual approach should be decided in terms of the phenomenon under study. Therefore, emerging themes were used as a generative guide for writing. Both themes and sub-themes were analyzed and interpreted during the writing process, and the data were interpreted in relation to the four existential lifeworlds, namely: *spatiality* (lived space); *corporeality* (lived body); *temporality* (lived time); and *relationality* (lived human relations).

Lastly, van Manen (1990) has described phenomenology as a philosophy of action (p. 154). In the fifth and sixth activities of his method, he proposes the need to maintain a strong and oriented relation to the phenomenon, and to balance the research whole and parts. Texts need to be oriented, deep, and rich. Rich descriptions explore the meaning structures beyond what is immediately experienced. While phenomenology does not assume a specific social or political agenda, the investigator is called to take a practical action approach. Essential activities include using findings to discover new sources for informing research activities and practice-oriented competence.

Setting and Participants

Setting

The current study was conducted in the community natural setting. The setting of the family home or other natural setting offered the potential to provide a comfortable atmosphere for the parent-participant and was conducive for carrying out the 60-90 minute interview. For the current study, nine interviews were conducted in the family home, one was conducted at a coffee shop, and one was conducted in a private office space.

Participants and Sample Formation

Following Institutional Review Board (IRB) approvals at The Catholic University of America (CUA), a purposive sample of 11 mothers who were the primary family caregivers of adolescents/young adults with severe cerebral palsy (GMFCS E&R Level V) were recruited to participate in this study. A purposive sample is most commonly used in phenomenological inquiry. This method of sampling selects individuals for study

participation based on their experiential knowledge of a phenomenon for the purposes of sharing their knowledge (Speziale & Carpenter, 2007). In qualitative studies, the focus is on the quality of information obtained from participants, and quality data are best obtained from articulate, well-informed, and information-rich participants.   The power of purposeful sampling lies in this selection of information rich cases for an in-depth study of the phenomenon (Higginbottom, 2004).

Maternal participants were recruited from the membership of a chapter of a non-profit community-based national advocacy organization of and for people with intellectual and developmental disabilities. Participants were also recruited using network sampling. Network sampling is recognized as a valuable strategy in qualitative research for identifying participants who know other potential participants who can provide insight and essential information about the experience that is being studied (Patton, 2002).

Participants were required to meet the following inclusion criteria: (a) self-identify as the maternal caregiver of an adolescent or young adult with cerebral palsy; (b) a willingness to participate in an interview in the home or other mutually agreed upon setting, and follow-up phone calls as part of the data collection process; and (c) able to read and speak English. The participants' adolescent/young adult care receiver was required to meet the following criteria: (a) age of 14 -22 years; and (b) meet the criteria of Level V on the GMFCS–E&R.

An invitation (Appendix D) to participate in the study was disseminated in four editions of the electronic newsletter of the community advocacy organization (Appendix

E). The invitation included information about the study's purpose, inclusion criteria, time commitment, and contact information for the investigator. Potential participants were asked to respond to the investigator directly. Two participants were recruited by way of the electronic newsletter.

Network sampling was accomplished by using personal contacts and invitational flyers (Appendix D). The investigator sought to expand the number of participants by asking participant mothers and professional contacts if they knew of mothers potentially interested in the study. If they did, the investigator requested the individual share the investigator's contact information and a paper and/or electronic version of an informational flyer with the network contact. Nine participants were referred to the investigator by way of network recruitment.

Once a prospective participant contacted the investigator, the investigator again explained study's purpose, inclusion requirements, time involved, and anticipated duration. This information was provided by phone or email. An interview appointment was scheduled via phone or email once the participant verified meeting the inclusion criteria, and expressed interest in participating in the investigation. The child's GMFCS level was confirmed by verification that the child was a full-time wheelchair user.

Protection of Human Subjects

In the process of the protection of human subjects, it is essential to maintain an awareness of the well-established ethical principles of autonomy, beneficence, and justice (Orb, Eisenhauer, & Wynaden, 2001). Prior to the commencement of this investigation,

approval was obtained from the Committee for the Protection of Human Subjects at The Catholic University of America.

In consideration of protection of human subjects, the following concerns were addressed in this investigation: informed consent; benefits and risks; and confidentiality. Obtaining written informed consent is essential for the conduct of ethical research (United States Department of Health and Human Services (USDHHS), 2001). This investigation's consent form (Appendix B) included the essential elements of informed consent in research as outlined by the Code of Federal Regulations 45, Section 46.116 (USDHHS, 2001). These elements include: an explanation of the purpose of the research activity; a description of procedures; a description of the foreseeable risks or discomforts; a description of benefits; a disclosure of alternatives; an assurance of anonymity and confidentiality; an offer to answer any questions; a non-coercive disclaimer; and the option of withdrawal from the study at any time. Additionally, participants were informed of the use of audio-tape recording of their interviews, and their right to terminate the interview or request that the audio-tape recorder be turned off at any time. Participants were also advised that if any evidence of child abuse or neglect was uncovered during the home visit or interview, as a legally mandated reporter, the investigator would be required to submit a report to the local child protection authority.

There were no immediate risks anticipated for participation in this study. However, if a participant exhibited signs suggesting emotional distress during the interview, the investigator was prepared to provide emotional support and to refer the individual to an appropriate referral source. Potential benefits of participation in this

investigation included offering the participants an opportunity to talk about their experiences and concerns in a safe environment, and thus potentially gain personal insights into their lived caregiving experiences.

In gathering informational data, confidentiality was maintained by assigning each participant a code number as a substitute for their name. The master list of these codes was maintained by the investigator and stored in a locked location separate from the micro-cassette audiotapes, with restricted access only to the investigator. The assigned code numbers were the only identifying information recorded on tapes and transcripts. Participant names were not identified on the tapes, and participants were informed in advance of the use of a professional transcriptionist. Digital versions of the audiotapes, that contained no identifying information, were sent electronically to the out-of-state transcriptionist. The transcriptionist was informed of the confidential nature of the data as part of the contractual agreement. This organization was well-versed in the maintenance of confidential data.

Instrumentation

In phenomenologic research, the investigator serves as the primary instrument in carrying out the inquiry for studying the "lived experience" phenomena. For the purpose of the current study, however, two additional written instruments were used. The first instrument, the *Maternal Caregiver Focused Interview Guide*, developed by the investigator, was used during the interview process (Appendix A). This interview guide included open-ended and clarifying questions to facilitate the expression of the participants' lived experiences. For the proposed study, the guide was reviewed by a

content expert, as described in an earlier section, to ensure the face and content validity of the instrument prior to the initiation of the study.

The second instrument, the *Demographic Questionnaire* (Appendix C), was developed by the investigator to collect demographic data about the study participants. This information included maternal age, child age, race, employment status, marital status, education level, number of children, number of hours the child participates in out-of-home activities each week (school, therapeutic day program), number of hours of professional caregiver service each week, and a description of the child's level of disability and related health concerns.

Data Collection Procedure

The procedures for data collection used throughout this study is described below.

1. At the time of initial contact between the investigator and the prospective mother - participant, the information about the study was provided, and the prospective participant was asked to confirm the eligibility criteria.

2. If the mother met the criteria and agreed to participate, an interview was scheduled for the family home or in a mutually agreed upon location.

3. In preparing and prior to each interview, the investigator reflected on personal beliefs, preconceptions, intuitions, motive, and biases as to "decenter" and to achieve a state of "openness". These thoughts were recorded in a personal journal.

4. At the beginning of the interview, *informed consent* was obtained, and the mother was asked to complete the Demographic Questionnaire.

5. When the Demographic Questionnaire was completed, a code number was placed on the form by the investigator, and was be placed in a sealed envelope. The questionnaires were stored by the investigator in a locked place separate from the interview tapes and transcripts.

6. Two audiotape recorders, a digital recorder and a micro-cassette recorder, were placed on a convenient surface so that the investigator could control the device at all times. Two recorders were used to ensure recording in the event of mechanical failure of one of the recorders. Participants were reminded that at any time during the interview they could request that the recording devices be turned off for any reason.

7. Consent for audio-taping was verbally acknowledged at the beginning of the taped recorded interview. The lead question was presented, and the probes were interjected during the interview. Each interview lasted as anticipated for 60-90 minutes. When the interview was complete, or upon the request of the participant, the tape recorder was turned off. The code number was noted at the beginning and end of each taped interview.

8. The investigator requested permission from all of the participants to contact them by phone if the need for clarification of the narrative material arose.

9. The micro-cassette audio tapes, consents, and demographic questionnaires were secured in separate locked drawers. The micro-cassette audio tapes are destroyed after the completion of the dissertation defense. The tapes are

erased and manually removed from the casing and destroyed in compliance
with IRB rules.

10. A professional transcriptionist service transcribed the interview tapes. Upon
receiving the transcribed records, the investigator listened to each audiotape to
detect and correct transcription errors.

11. Written transcripts, consents, flyers, and other materials will be preserved for
five years upon completion of data analyses and then destroyed in compliance
with IRB rules.

Data Analysis Procedures

The data derived from the Demographic Questionnaire were analyzed to obtain
descriptive information about the participants. *HyperResearc*h, a qualitative software
program, was used to organize the narrative transcript data and to record thematic
associated notes. Van Manen (1990) described the meanings or essence of phenomenon
as never being simple or uni-dimensional. The investigator began the analytic process by
reflecting on lived experience, and moved into a reflective analysis of the structural or
thematic aspects of the recorded experience. Van Manen (1990) describes thematic
analysis as the process of "insightful invention, discovery, and disclosure" (p. 88), and a
"process of recovering the theme or themes that are embodied or dramatized in the
evolving meanings and imagery of the work" (p. 78).

For the current investigation, van Manen's (1990) approach to isolating thematic
statements was utilized. First, a holistic reading was carried out for each narrative,
followed by several selective readings of highlighted areas, and lastly a detailed reading

approach that considered each sentence and sentence cluster. The aim of this analysis was to determine incidental and essential themes. Once themes were identified, they became objects of reflection and considered in light of the four lifeworld existentials – lived space, lived body, lived time, and lived human relation. These existentials were used as a guide to interpret the phenomenological descriptions. This multi-step process was also used to create the phenomenological text. Van Manen (1990) described this process as a linguistic project to make "some aspect of our lived world, of our lived experience, reflectively understood and intelligible" (pp. 125-126). A central concern to phenomenological analysis is responsive-reflective writing.

Trustworthiness

The rigor of interpretive phenomenological inquiry has direct implications for the legitimacy of the findings. Lincoln and Guba (1985) summarized this concern with the basic question: "How can an inquirer persuade his or her audience (including self) that the findings of an inquiry are worth paying attention to, worth taking account of?" (p. 290). Unlike the positivist quantitative paradigm that relies on objectivity, reliability, and validity, an alternate paradigm is required for qualitative inquiries. Lincoln and Guba (1985) proposed an alternate paradigm to include criteria for determining the trustworthiness of qualitative inquiry, namely: credibility; transferability; dependability; and confirmability.

To address trustworthiness, several activities were incorporated in the current study. These activities addressed referential adequacy and member checking. The interviews were audiotaped allowing for examination and comparison at a later date with

descriptions and interpretations. An experienced qualitative researcher reviewed the first

two transcripts and participated in a debriefing exercise. Once initial data analysis was

complete, a summary of the analytic themes, interpretations, and conclusions were shared

with two participants to establish accuracy of the findings. These participants were

selected based on their willingness and availability to participate in a follow-up phone

meeting after the investigation. During these participant consultations, the investigator

sought verification of the summary as a reflection of an adequate representation of their

actual experience.   An audit trail was also established. This trail included raw data in the

form of audiotapes, the demographic instrument data, written field notes, interview

transcripts, and methodological notes.

Limitations

Ramos (1989) suggested three types of problems that may weaken qualitative

studies: the design, the researcher's interpretation of the subjective data, and the

researcher/participant relationship. These are all possible concerns; therefore, strategies

to address trustworthiness and ethical considerations were incorporated into the design of

the study and analysis of the data.

There are, however, several methodological limitations in the study that need to

be considered. First, as in all qualitative inquiries, the findings from this small purposive

sample cannot be generalized to all mothers caring for adolescents or young adults with

severe CP. Secondly, the recruitment of participants from the membership of an

advocacy organization and use of network sampling strategies potentially contributed to a

biased sample. Individuals recruited through network sample are not independent of one

another (Burns & Grove, 2005), and may possess characteristics that are potentially different from mothers who do not participate in such organizational networks. Further, the mothers unable or unwilling to participate in this type of study were not heard, and their experiences may also differ from those who became participants for this study. Third, recruitment efforts were focused on one geographical area using network sampling, and the use of this sampling approach contributed to a demographically homogenous sample, whose experiences may not be representative of caregivers in other settings. Lastly, only one interview was conducted with each participant. While the participants appeared comfortable sharing their stories during the initial interview, such a novelty interview may bring about information that may not necessarily be representative of on-going or typical lived in experiences of these caregivers; hence, a second interview might have yielded additional experiential data once a relationship had been established with the participant.

Summary

This chapter has provided a description of the philosophical orientation, design, setting, sampling, human subjects considerations, instrumentation, and general steps for data collection and analysis for the current study. The phenomenological approach suggested by van Manen (1990) was used for the study design and data analysis. The study aimed to unveil the complex, dynamic experience of family caregiving as experienced by mothers caring for adolescents and young adults with severe functional disabilities associated with CP. A total of 11 mothers caring for an adolescent or young adult were interviewed for this human science inquiry.

Chapter IV

Presentation of Findings

The purpose of this study was to explore the essential elements of caregiving as experienced by mothers caring for an adolescent or young adult with severe physical disabilities related to cerebral palsy. The research questions that provided the initial focus of this study were: (a) What is the essence of the phenomena of caregiving as experienced by mothers caring for adolescents and young adults with severe physical disabilities related to cerebral palsy; and (b) What meanings do such mothers ascribe to their experiences?

The study employed the hermeneutic phenomenological inquiry approach put forth by Max van Manen to explore the mothers' lifeworld as experienced. Van Manen (1990) suggested that all phenomenological human science research efforts "are really explorations into the structure of the human lifeworld - the lived world as experienced in everyday situations and relations" (p. 101). Van Manen (1990) also suggested that in human science, the interview serves a two-fold purpose: first, the interview serves as "a means for exploring and gathering experiential narrative material that may serve as resource for developing a richer and deeper understanding of a human phenomenon"; and second, as "a vehicle to develop a conversational relation with a partner (interviewee) about the meaning of the experience" (p. 66).

For the current study, experiential data was gathered from 11 mothers. Each mother participated in an interview lasting 60 – 90 minutes. The interviews were conducted in the family homes of nine participants, and at alternate locations selected by

two participants. During the interviews, the investigator had the opportunity to meet eight of the participants' adolescent/young adult children. While meeting the participants' children was not a requirement for participation in the study, most of the participants requested that the interview be scheduled for a time that would allow the investigator to briefly meet their child. These meetings offered the opportunity for the participants to introduce their child, while the investigator was provided with the opportunity to observe the interactions between parent and their child. Only two children, who required close parental monitoring due to health concerns, remained present during the actual interviews.

In this investigation, the interviews served as a means for identifying the essential themes or "structures of the experience" (van Manen, 1990, p. 79). Van Manen (1990) proposed that in "determining the universal or essential quality of a theme, our concern is to discover aspects or qualities that make a phenomenon what it is and without which the phenomenon could not be what it is" (p. 107). The transcribed experiential narratives and observation notes were examined for common themes, which are understood to be the structures of the experience. First, multiple holistic readings were conducted of each narrative, followed by several selective readings of highlighted areas, and lastly, a detailed reading approach that considered each sentence and sentence cluster was implemented. The aim of this analysis was to determine both the essential and incidental themes. In discerning the essential or universal themes from incidental ones, an investigator must seek to determine if the phenomenon is still the same when themes are

changed or deleted, or when and how the phenomenon loses its fundamental meaning when changes occur (van Manen, 1990).

For the current study, thematic analyses aimed to discern themes that recurred as commonalities among the participants. The approach selected for this writing was two-fold: first, the author identified emerging essential themes as a generative guide for writing, and second, the author examined the phenomenological description against the existentials of relationality (lived human relations), corporeality (lived body), temporality (lived time), and spatiality (lived space). According to van Manen (1990), these existentials or conceptual themes are four fundamental themes that "pervade the lifeworlds of all human experience, regardless of their historical, cultural, or social situatedness" (p. 101). These existentials will be used as an interpretive guide for a discussion of the themes in Chapter V.

To present the findings of this investigation, the chapter is organized as follows: (a) a description of the participants; (b) a description of their children; (c) an overview of the essential themes; and (d) a description of the participants' experiential lifeworld as experienced in everyday situations and relations.

Description of the Participants

The sample consisted of 11 Caucasian mothers who self-identified themselves as being the primary maternal caregiver for an adolescent or young adult with severe CP. Nine of the mothers were the biological mothers of their children, and two mothers had adopted their children in international adoptions. The mothers ranged in age from 42 to 62 years, with a mean age of 52.6 years. All of the mothers had attended college, with ten

having completed undergraduate college degrees and six having also completed post-graduate work or been awarded a Master's degree. The mothers were all married to the father of their child with CP. One participant had recently reunited with her spouse after a prolonged separation. Ten mothers had one or two other children besides the targeted child with CP. One mother had no other children, and was a parent only to the child with CP. Siblings ranged in age from 16 - 26 years, with a mean age of 22.7 years. Five siblings resided full-time in the family home, five were attending college and resided part-time in the family home, and three resided in their own residence.

Five mothers were employed full-time, four were employed part-time, and two were not employed outside of the family home. Of the employed mothers, three were employed as special education professionals and one was the director of a program for young adults with developmental disabilities. Several participants were actively involved in community advocacy activities at the local and state level, serving on advisory boards on behalf of individuals with disabilities.

All of the participants were the self-described primary family caregiver for their child. However, most of the participants placed a special emphasis on sharing the importance of the "team approach" to caregiving that highlighted the high level of involvement of their spouse in providing direct care for their child. In one family, a sibling was actively involved in providing respite care but this involvement was an exception. For the majority of the families, siblings were part of the family recreational time and occasionally provided assistance with tasks such as meeting the child's school

bus or spending time with the child while their parent ran a brief errand, but they typically were not routinely involved in a caregiver or respite role.

For seven families, the team caregiving approach included some form of assistance from professional or compensated caregivers such as personal care attendants and companions. The number of hours varied among families, and ranged from one to eight hours each day, with an average of four hours each day. Mothers that were employed full-time were most likely to utilize compensated caregiver services, most often for weekday coverage when their child arrived home from school. Three families used weekend services. Four families opted not to seek assistance from compensated caregivers for reasons including cost and the desire to maintain family privacy. Several families hired college students to serve as a companion for their child for an average of 2 hours each week. Mothers arranged this type of service to facilitate recreational activities for their child with a similarly aged companion, and to allow for family respite time.

In summary, the participating mothers were middle-aged, married, college-educated, and Caucasian. Most were employed full-time or part-time outside of the family home. Their spouses were reported to be very involved in caregiving activities. Ten of the participants had other children. While several families utilized some type of out-of-family assistance with physical care and respite, all mothers maintained a primary caregiving role.

Description of the Children

The participants' children with CP included four females and seven males, and ranged in age from 15 – 22 years, with a mean age of 18.6 years. All met the criteria of

Level V on the GMFCS – E&R based on parent description, and were full-time

wheelchair users. The nine children under the age of 22 years spent on average 6.5 hours

at public school each day. All nine children were receiving special education services.

Eight children were enrolled in specialized academic programs for individuals with

developmental/intellectual disabilities, and one was enrolled in a traditional high school

program that included advanced high school academic coursework. Two participants had

children that were 22 years of age. These two children had transitioned out of public

school services. One child, with an intellectual disability, attended a 7-hour community-

based adult day program for adults with developmental disabilities 3 days/week. The

other child, without an intellectual disability, was enrolled in community college courses.

This coursework was primarily completed on-line in the family home, with an additional

2.5 hours spent twice each week on the community college campus accompanied by her

father.

All of the children (n=11) experienced multiple co-morbidities commonly

associated with severe CP. These co-morbidities, as reported by the participants,

included: intellectual disability (n=9); visual impairment (n=7); communication

impairment (n=7); feeding impairment (n=7); urinary/bowel incontinence (n=7); and

seizure disorder (n=7). There was one child without any of the above noted co-

morbidities/impairments.

All of the adolescents and young adults were reported to have experienced

multiple hospitalizations for surgeries focused on managing spasticity and dystonia, and

musculoskeletal complications associated with CP. Of note, virtually all parents reported

their child experiencing one or more complicated hospitalizations with adverse events such as wound infections, pneumonia, medication errors, uncontrolled pain, and skin breakdown, which they reported as having a significant impact on their child's recovery and their own maternal caregiving experience during hospitalization and subsequent home recovery. Among this group of children, the co-morbidities that appeared to have the greatest impact on overall health were the presence of a seizure disorder and a significant intellectual disability. Most participants described their children as particularly vulnerable to respiratory infections and seizure disorder issues that require close parental monitoring, medical evaluation, and frequent hospitalizations.

In summary, the adolescent and young adult children, aged 15 – 22 years, were all full-time wheelchair users, and most experienced multiple-co-morbidities associated with severe CP. The majority of children were under the age of 22 years, attending public school, and receiving special education services. Two children, aged 22 years, had "aged" out of public school services and were attending other programs.

Overview of Essential Themes

Within the interviews, the maternal caregiving experience was significant in terms of the deep impact it had on the mothers' lives. Beginning with their child's birth or adoption, subsequent diagnoses of cerebral palsy in early childhood, and transition into adolescence and young adulthood, the mothers' stories revealed the joys, sorrows, and challenges associated with the experience of caring for a child with severe CP. While these maternal caregiving stories included some elements that might be experienced by the mothers of typically developing adolescents and young adults, many elements

reflected a maternal caregiving experience that was quite different from the usual normative activities of parenting in relation to the intensity, complexity, and temporal nature of the family caregiving experience.

The analyses of interview text revealed one overarching theme and four essential themes that emerged as representations of the lived meaning of maternal caregiving for the participants. The overarching theme that emerged from the mothers' stories of caring for an adolescent or young adult with severe CP was the theme of A Different Life. Directly related to this overarching theme were four themes that offered a fuller description of the essential elements of A Different Life. The essential themes were:

- Managing an Unexpected Life

- Finding my Own Way

- Serving as my Child's Voice

- Facing an Uncertain Future

These four themes, shown in Table 1, co-exist and are inter-related offered a new perspective on the experience of maternal caregiving in the context of rearing an adolescent/young adult with CP. Within each essential theme, there were several sub-themes that further expressed the thematic elements of each theme and offered the opportunity to examine this phenomenon in a new light.

A Different Life

The overarching theme, A Different Life, was revealed in the participants' stories of caring for a child with severe functional disabilities that required a high level of maternal caregiving. Participants described lives that were different in terms of their

expected life as a mother and family caregiver. Most suggested that this was not a life that they would have planned or chosen for themselves or their family members, and that accepting aspects of this type of life as a maternal caregiver had been difficult. Nevertheless, within the interview text mothers' experiential caregiving stories reflected a deep love and commitment to their child as these women embraced their maternal caregiving role and managed a complicated life, committed to caregiving, aimed to normalize and optimize family life, and advocated for their child.

Table 1
Essential Themes and Thematic Elements

Essential Themes	Thematic Elements
Managing an unexpected life	Unexpected role Call to action Unchanging role Managing complicated health concerns Maintaining strength Dealing with a team
Finding my own way	Balancing family demands Surrounding myself with supportive people Managing my emotions Living with my decisions Finding meaning in my and my child's life
Serving as my child's voice	Helping others understand my child Advocating for my child Advocating for other children and families
Facing an uncertain future	Seeing my child in a new light Preparing for difficult transitions Aging together Uncertainty lies ahead

For the participants, many aspects of caregiving in their child's adolescence or young adulthood years had changed little since their child's early years. For all of the participants, this maternal caregiving experience was vastly different from the parenting and family life course they had anticipated prior to their child's birth or adoption. Participants described their child's early years as very challenging as they sought and received their child's diagnosis of CP, struggled to come to terms with the diagnosis, learned to care for a child with multiple health concerns, and focused on mobilizing healthcare, therapeutic, and educational resources. Yet, the adolescent and young adult years remained just as challenging as the families faced new milestones and transitions.

Milestones and transitions were important elements of the caregiving stories as mothers provided a temporal context to the experience of a life that differed from their expected life. For many mothers, the often repeating experience of witnessing their children miss many of the significant developmental milestones of childhood, and later, adolescence, had been a continuing reminder of how different their lives were from the mothers of typically developing adolescents and young adults. For example, Nancy (all names have been changed to protect confidentiality), the mother of a teenager with severe CP and an intellectual disability, described her recurring experience of recognizing her life as "different" with use of the metaphor of "mile markers":

> You go along for years, and you just kind of do what you're doing day to day and it's all fine and then you hit some kind of a mile marker that causes that same transition, if you will, that you go through when you first find out that you have a child with a disability. And you go through all of that questioning and you hit that again and again and again. We tend to like to think that it's a process you go through, the stages. You've heard the stages of grief. You go through those. And then we tend to think it's just over. And really unlike dealing with the death of

somebody, and I have not really experienced the death of someone close to me so I may be very wrong about this, but you think that you kind of deal with it and eventually you've dealt with it and it's done. But when you live with a child with a disability they never go away and so that process continues over and over and over again and you come to acceptance and that's good for a couple of years and then something happens. They move to high school. This year my daughter should have been off in college. This is the beginning of a new stage in our life. And so, again, you kind of go through all that transition and the same stages again. So in the sense of something memorable I would say a repeating, this is a repeating process and those kind of sad or bad memorable things are those moments when you realize you've missed a milestone and you are confronted with the extent of how different your life is and also how disabled your child is.

Much the same, Eileen, the mother of a medically fragile adolescent daughter with CP and multiple co-morbidities summed up her and her spouse's outlook on this experience as, "It's a different life, it's a different life than we would have chosen, but we would not change it". She further elaborated on how her view and expectations of life have evolved since the birth of her daughter::

We look at our daughter and we still, we still have a picture of what she would be doing now if she didn't have the disabilities. So I look back on things, and I remember those feelings. I remember feeling lost. I remember feeling the injustice of it. Why did this happen to my child? Why is this my life? I remember fighting it. I don't want this life. This is not what I signed up for. I'm in love, I'm married, I want to have a family, and this isn't it. All of that, that was long ago. Now I realize that when, I don't even know when it happened, but acceptance sort of crept in, and this kid who we just love with all of our hearts just kind of took over.

Terry shared a similar view when she reflected on her life in the context of her son's disability, "There are days when I go 'what would our life be like if…?', but then again I tell myself, 'I wouldn't change it'.".

Within the interviews, all mothers shared stories of personal growth, strong relationships with their spouses and children, personal struggles, family caregiver challenges, and the forging of important personal and professional relationships that they

attributed to living a different life than they expected. When describing the essence of

her maternal caregiving experience, Kate stated, "It [maternal caregiving] will become a

part of your life, whether you want it to or not, so you might as well take it and go run

with it." Meg stated, "I think it [my life] could have been a lot different, [however] the

caregiving and parenting challenges don't look as daunting anymore. It's just something

that we have to do." Echoing the sentiments of several participants, Diane reported, "It's

just the way life is. We just have to deal with the life we have. They say life is what

happens when you are making plans."

Managing an Unexpected Life

For the participants, the experience of managing a different life began in the

context of their child's premature birth, neonatal health crisis, or in the cases of adoptive

parents, the first meeting with their child. For all of the participants, the prospect of

having a child with severe CP was an unexpected life event. The biological mothers

anticipated the birth of a healthy child. The adoptive mothers, while aware that their

prospective adoptive child might have some health issues, did not anticipate the potential

magnitude of a significant childhood disability. Although the first days of parenting

differed for each participant, all described this time as being a very emotional and

stressful period for themselves and their spouses. Early events associated with their

child's neonatal hospitalization or adoption, and subsequent diagnosis with CP appeared

to greatly influence mothers' expectations of themselves as they assumed a maternal

caregiving role. During the interviews, in addition to sharing the day-to-day experiences

of caring for an adolescent or young adult child, mothers revisited their child's birth

story, early caregiving experiences, and the circumstances associated with receiving the news of their child's diagnosis. These early experiences appeared to have had a profound and continuing effect on the mothers' sense of efficacy as a maternal caregiver.

An unexpected role. A recurring theme in the caregiving narratives was the mothers' need to assume new roles that they had not anticipated or previously associated with motherhood. For example, when reflecting upon her experiences as a new mother in her daughter's early months and years of life, Eileen recalled the emotions and self-expectations related to giving birth to a very premature infant who was subsequently diagnosed with cerebral palsy and multiple co-morbid conditions in the first year of life:

> I mean, she came home on you know on apnea and bradycardia monitors, and I started off my motherhood with this kid that came out of an NICU after three months. I thought I was an honorary R.N. by the time I brought my child home. But I think that's what happens that we are just so immersed as mothers and fathers in this medical world with our children that these become the priorities, and we have to be on all the time, and I put my expectations really at a 150%. I was the one who was supposed to be everything. I was supposed to be the physical therapist, the special education teacher, the occupational therapist, the developmental pediatrician, and vision teacher. I was supposed to be the wheelchair man. From birth to age 3, I don't think I slept more than 4 hours…I was doing the work of 7 people.

Similarly, Nicole described herself as "my daughter's personal care nurse", and Kate shared her experience of taking on new roles as a first time mother caring for her son at home after a life-threatening, unanticipated neonatal health crisis that resulted in multiple health issues. She recounted,

> The one thing I never wanted to be in my whole life was a nurse, and I just was like – I remember my sister saying she wanted to be a nurse when we were growing up, and I was like, "Oh my God that sounds like the worst job"... and so I was, you know, turning into a nurse.

Diane described her frustration with expectations that she assume roles for which she did not feel qualified. She stated, "I spent, I don't even, I can't even count how many hours I've spent doing exercises with my son, but I'm not a PT. I'm not a speech therapist. I will freely admit that and I'm not a teacher". Many mothers reported that these types of experiences continued throughout their child's childhood and into adolescence and young adulthood, as the mothers were expected to assume the unexpected roles of coordinator of care, therapist, nurse, and teacher. While the mothers of typically developing children might assume similar roles, the temporal nature and intensity of these roles were different for these participants.

Call to action. Another important thematic element was mothers' sense of being "called to action" in their early days of motherhood. All of the participants recognized that they were caring for a medically fragile infant or an infant at risk for potential health issues. However, only a few mothers received the official diagnosis of CP in the early months. Most of mothers were informed of the risk of CP, and health providers assumed a "watch and wait" stance. Participant narratives of the "watching and waiting" period, their child's subsequent diagnosis, and the ensuing emotional response were another integral part of their recognition that life was not going to be as expected. For example, Helen reported 'I think the big "things are going to be different in our life' awakening was when he was officially diagnosed".

Interestingly, all of the mothers, aware of the risk of CP, sensed that something was not right with their child and many assumed a pro-active stance in seeking an official diagnosis. For all mothers, having an official name or diagnosis for their child's health

issues was both devastating and empowering. The diagnosis was described as painful and frightening, and yet it allowed them to give a name to their child's health issues and to begin to seek support. Nancy described the experience of seeking and receiving the diagnosis as offering her and her spouse "something to stand on":

> She [daughter] was about a year old but it [cerebral palsy diagnosis] was not a surprise. It was kind of like "all right, let's stop dancing around this. Let's call a horse a horse". She was a preemie so she had a very rough beginning and for only a couple of months thought maybe we'd escaped with a miracle child. And that very quickly, she's a year old and not rolling over. Something's not right. We knew it. The pediatricians at the time didn't want to say it. We were living overseas and we were dealing with military doctors who were not used to dealing with a lot of kids with disabilities. And they didn't want to say CP. We pressed and said, "Come on and give us something to stand on here. What are we dealing with?" It's easier to name it than to just go, you know what, she's a year old and she can't roll over. This is not typical. So she was about a year old when we found out her diagnosis.

Helen also reported an early recognition that her son was not meeting developmental milestones in a manner similar to older siblings. While she was determined to obtain a diagnosis, her spouse desired to maintain the "wait and see approach". After researching potential diagnoses in her old college textbooks, she insisted on a referral to a pediatric neurologist. She recounted the experience of having diagnosis of CP confirmed, "I would talk to my husband and say, "Something's wrong with this child," he [spouse] would go, "No no, he'll catch up." The ride home from the appointment the day of the diagnosis was the longest, coldest ride ever because it finally hit my husband."

For Carol, receiving the official diagnosis was painful experience, but it also provided her the opportunity to dialogue with her spouse and to jointly devise a plan to

care for their son. She offered a description of the day of her son's diagnosis, and her

family's resulting actions:

> We went to and had a full evaluation done, and it was one of the saddest days of
> my life because the institute's people pretty much laid out what they anticipated
> would be my son's future for us. They didn't candy coat it, and they were very
> frank with us, and I think at the time my husband and I probably weren't quite
> used to that kind of frankness coming from doctors because everyone else was
> saying, well, they really didn't know…I suppose after a period of mourning my
> husband and I just kicked into gear and decided that we were in our plan which
> was always our plan. This was to do the most for our children and our child as we
> could. So we just resorted to that plan, and got over our disappointment, and
> grieving, and whatever, and uh started raising our child as best we could.

Because the mothers' children were identified as being "at risk" for CP, the

experience of receiving an official diagnosis of cerebral palsy for their child was

devastating, but not unexpected. Many mothers, however, suggested that the manner in

which the news was delivered had a profound impact on their family. While some

reported receiving this news from health care professionals in a caring and sensitive

manner, several mothers reported challenging circumstances. Vera's experience of

receiving the official diagnosis left her and her spouse at a loss for where to begin the

process of caring for a child with a significant disability. She recounted the story of

receiving the diagnosis at a pediatric hospital:

> So we got the CAT scan, and the radiologist slapped up these two X-rays, and
> "Here's the normal brain, and here's Jane's brain." You know... and it was like,
> like, "Whoa! Shock!". And so, we thought, "we'll just go see the pediatrician [at
> the pediatric hospital] and see what, you know, what he has to say". So, we went
> to his office, hoping that he would be there and could speak to us. The nurse said,
> "Well, he doesn't work here any more. He went back to California." And like...
> "Well, what do I do?" And she[(nurse] said, "Well, you don't need to come back
> here any more. You have your diagnosis." And I'm like, "Well, what do I do? I
> have this child with cerebral palsy. What do I do?" And she said, "Well, call
> your local [community-based] pediatrician."

Like Vera, most of the participants, shared the experience of leaving the health care provider office or facility with the new diagnosis, little information, and having received little or no direction for locating community resources for services and support. It must be noted that at the time that these mothers received the diagnosis, few had access to electronic resources (such as those obtainable through internet). Sandy voiced her experience of receiving little information and needing to independently seek out written resources:

> You would think they would give out more information than they did. When they said "he may have cerebral palsy", I went out and bought books, you know, on the diagnosis and tried to read all I could read because I didn't know what to expect.

Many mothers also shared the experience of feeling alone and unsupported in the early days of parenting and caregiving, and initially struggled with trying to locate resources after receiving little guidance from their child's health care providers. For example, Helen described the experience of receiving her son's diagnosis as "It was life changing or an eye opener that day he was definitely diagnosed. It was, to me, very cold and cruel because we weren't given any guidance".

These early experiences can best be described as the impetus for a "call to action" for the mothers to assume new roles as they learned to care for their child, locate and navigate community services and supports, and balance the delicate demands of family life.

Unchanging role. For the mothers of typically developing children, adolescents and young adults, the maternal roles changes as children grow, develop, and seek independence and autonomy. For the participants, the magnitude of maternal role

change appeared to vary in relationship to the developmental level of their child.

Namely, parent-child relations appeared to be impacted by the absence or presence of an

intellectual disability.

For the two mothers of children without an intellectual disability, while the

physical care requirements of their children have changed little, the parent-child

relational aspects have changed significantly as their children have aged into adolescence

and young adulthood. For example, Vera described her daughter as "as a bright girl, but

having a body that does not work". While she described her daughter's physical care

needs as increasing and functional abilities decreasing as the result of surgeries since she

entered adolescence, she shared the satisfaction experienced as her relationship has

changed with her daughter maturing into young adulthood:

> Seeing my daughter mature and seeing her developing into a caring person, a
> person who wants to contribute, a person who longs to be part of mainstream
> society and stuff, is rewarding, because, you know, I feel like... well, you know,
> she's growing up! So, watching her growing up, and being like the other two
> girls [siblings] in that way, has been rewarding.

For the mothers of children with an intellectual disability, however, the parent–

child relationships were described as having far fewer changes from earlier years. For

example, Nancy described her maternal role as "a role that never changes". Most

children were described as being fully dependent on their parents due to functional and

cognitive limitations. For example, in discussing her relationship with her son with an

intellectual disability, Meg reported, "You know, we are his parents and he's very, very,

very close to us because he didn't have to go through a normal development and really

separate from us as much as probably a normal kid would do"

When reflecting upon her overall parenting experiences over the last 19 years as the parent of two children, one of a child with severe CP and an intellectual disability and one of a typically developing child, Nancy offered a description of the contrasts between raising a child with and without a disability in terms of the parental role:

> I think that like raising any child you have your moments of pure joy and you have your moments of pure terror. There are good things. There are bad things. There are good days. There are bad days. I think that the unique experience of raising a child with a disability, especially a severe disability, is that the balance of that that you have with a very small child, a two year old or three year old, you have those wonderful blissful moments followed immediately on the heels by a massive all out tantrum. You have those incredibly sleepless nights when they're up all night. You have those moments when they're sick and you're on call 100 percent. And then you have those wonderful moments where you're playing and there's just joy because of their willingness to engage with you. When you have typically developing children they start to push away and by the time they hit teenage years you have wonderful moments with them but you don't have all—I mean some people do have lots of tantrums. I have friends who have teenagers who have tantrums. But as they get older they go away to college. You have less of those moments and more of just the easier moments. You're no longer in charge of them. They're in charge of themselves. And your role changes. It doesn't change when you're dealing with a child with severe disabilities. That role never changes. You're still in that same role you started off in. And two things with that – it gets old and it gets tiring. The longer it goes on, the harder and the more wearing it becomes. And I think that's the unique experience. A lot of it's the same as dealing with a typically developing child. It just doesn't change very much. You stay in that mode of small childcare. You're still doing all of the physical things that you did for small children and you're still dealing with the good and the bad in all. And it's still all you. Even a teenager who's having a tantrum is more likely to go upstairs and slam their door and deal with it themselves. Call a friend. Text them. Something. A two year old is not going to do that. It's all directed at you, whether it's the love or whether it's the anger. It's all directed at you. And that's true with children with severe disabilities. I think that's unique. And over the long haul it can be wearing.

For the mothers in this study, particularly the mothers of children with an intellectual disability, the overall physical care requirements of their children have changed little since early childhood. Meanings were captured as several mothers used

terms such as "infant" or "small child" to describe the type care required by their child, and placed their description of their child's needs within the context of developmental levels and milestones. For these mothers, children have remained completely dependent for all aspects of care. In describing her medically fragile adolescent daughter, Nicole reported, "My child depends on us for everything. She's not able to care for herself in any way, shape or form. At the age of seventeen, developmentally she hangs out about between seven and twelve months in development. So you're talking about a seventeen year old, five foot six baby".

Similarly, Eileen detailed the daily care required by her daughter who has visual and cognitive disabilities in addition to CP:

> [My daughter] has never grown [developed] beyond about a six-month old, which means she can hold her head up, and she can roll over on one side, but she's still diapered, she still needs full support for sitting just like she did when she was a tiny baby. We put our babies in bouncy chairs and all that. She still needs repositioning in bed. She needs total support for showering. She is not a toileting child or adult. She never made that milestone, so she's completely diapered, and her nutrition, her medication, and her hydration need to be completely supervised, or I have to give her everything, so she's not able to eat anything on her own, or even say when she needs something. So it really is pretty much like having a baby for many, many years.

Nancy described her thoughts on this aspect of caregiving using the analogy of a young child crawling away from their parents seeking independence and autonomy:

> In general it's an extension of the care giving that you would do for a young child. It just doesn't end. So in some ways it doesn't feel a whole lot different than just caring for a very young child because you start off with them when they're very young and they just don't push away that typically developing children do. Typically developing children start pushing away from you the minute they crawl out of the room for the first time and you realize they have their own agenda. Uhm, kids with disabilities don't do that. They don't ever push away and it's not maternally, it's not your instinct to push your own child away. So we stay on that track of just continuing to care for them as though they were very young children.

So in some ways it's a continuation of that. Obviously there are moments when you go "this kid is 19 and I'm still performing the same kinds of things that we would do with a very young child".

Most mothers reported that the physical care requirements of their child had become the "norm" and consequently they tried to spend time considering the continuing nature of physical caregiving. Nonetheless, every so often they would consider the unchanging nature of their work and its impact on their lives. Terry described how she occasionally reflects on the unchanging aspects of caregiving and its tiring effects:

Because I've been dealing with it so long, I think on the one hand it's just become the norm to have to deal with this, but then when I stop, and think about it, and think, you know, it's basically like having an infant because you do have to transfer him to potty in the toilet, and you have to brush his teeth and, you know, make sure he's washed up, and we give him a shower, and all those things. Uhm, if he wakes up during the night and doesn't have his blanket you have to get up, and come down and, you know, cover him up again if he's twisted in the sheets or whatever, uhm that type of thing gets old.

Similarly, Eileen reported having "normalized" her caregiving experience, and it is often only when she seeks the assistance of others that the magnitude of the experience becomes evident:

I don't think that I stop and think about how fatiguing my day is. This is my normal life. This is what I do. This is how my child needs to be taken care of. When I notice how huge it is, is when I have to ask somebody else to do something for me. If I'm going to go away or I just need to get to an appointment or do something for a couple of hours, then I realize the training that needs to happen just to walk out for a few hours.

For these mothers, while the physical demands of providing an intense level of care has been challenging, perhaps the greatest challenges are the continuing and constant nature of care, and the recognition that their child's needs have not and will not change. In describing the overall experience of caring for her son, Carol summarized the biggest

challenge to be, "Just the constancy of the care in the sense that I don't mind doing the medications or wiping his mouth or anything…I just couldn't go run an errand if I wanted because Tom is here. So for me, the biggest challenge I guess is the constancy of care".

Managing complicated health concerns. Within the interviews, another common thematic element was the mothers' experience of learning to expect the unexpected from their child. This experience appeared to be closely tied to their child's health. All of the participants' children had experienced multiple surgeries to address spasticity and musculoskeletal complications associated with severe CP. While a few mothers described their children as being in overall good health, several of the children had periodic hospitalizations related to acute health events such as pneumonia or uncontrolled seizures. A few of the children were described as particularly vulnerable to life threatening illnesses and experiencing frequent hospitalizations. For example, Nicole described her daughter's vulnerability to infection in terms of, "One really bad cold that could end up as pneumonia and she could end up in the hospital on a ventilator at like the snap of a finger because there's nothing. She has no shield." Similarly, Kate, reported her son had experienced frequent hospitalizations associated with pneumonia, "Everything affects him now so he gets sicker a lot more now than he used to as far as those kind of sicknesses, and we usually plan on being in the hospital once every six months for some reason".

When discussing the experience of caring for their child during and after a hospitalization, most mothers noted that their child's surgical or illness recovery often

followed an unexpected course requiring an extended hospitalization and rehabilitative

period. For example, Carol, whose son had recently experienced a prolonged

hospitalization and recovery due to surgical complications, suggested the complexity of

her son's health status when she stated, "He is a complicated ecosystem and that you

can't touch just one part and it doesn't affect the other." She further suggested that the

complexity of the health care delivery, namely her son's numerous specialized health

care providers, contributed her son's risk of unanticipated health complications. She

stated, "At times he's been hospitalized, you know, the big problem is that people [health

care specialists] come in who see one piece of him. And it's not unusual for Tom … I

think it [son's health status] is more complicated".

Meg shared the story of her son's recent hospitalization for spinal surgery that

unexpectedly resulted in a wound infection requiring an additional 10 days in the

hospital, home IV antibiotic therapy, and major drug withdrawal symptoms once he was

home. She reported that while health care professionals and family focused on managing

her son's pain, they were unaware of his growing physical dependence on the narcotics:

> I worried because he went through the horror of this [extended hospitalization]
> with all these operations and then …they had to keep him on it [narcotic pain
> medication] for a much longer period of time. Well, he got addicted to it, and
> when we started withdrawing him from it, he became really dependent and scared,
> and he was like a different person. I mean, I didn't really recognize him. He
> wanted to go back into the hospital. I was like, oh, my gosh! This isn't even my
> boy anymore.

Having witnessed many prolonged hospitalizations associated with health

complications, Nancy described the pro-active stance she has assumed in alerting health

care providers to her daughter's history of complicated hospitalizations and adverse

reactions to medications:

> If she has a surgery and I mean we've just learned at this point, she's had so many surgeries that we've learned at this point to just say right up front, "Look, you need to understand that she's not going to follow whatever course it is that you think she's going to follow. We're going to be here longer than you anticipated and we're going to have some kind of complication. I can't tell you what it's going to be but there will be something." She'll throw a bowel blockage. She'll go into "seizureville" and have a lot of seizures. Whatever it is, she's not going to react the typical way. And with medications why would she react typically?

One experience common to all of the mothers was the challenge associated with

caring for their child at home after the hospitalization. Many mothers described these

experiences as the most challenging aspects of caregiving. Mothers reported that while

their spouses were supportive, it was up to them to assume the primary responsibility

during their child's recovery period. It was also during these periods that many

adaptations had to be made in the family caregiving routine. Mothers reported needing,

to and being expected to, spend more time in providing direct care, assuming

responsibility for skilled nursing procedures, and thus becoming very limited in the

amount of time that they were able to spend outside of the family home. In describing

her son's recent hospitalization, Meg explained the trepidation she experienced when she

assumed responsibility for her son's intravenous [IV] antibiotic therapy:

> If I had any questions about it … I wasn't shy about calling. You have to be aggressive. You don't just sit around and wait for it to fall apart. We had one nurse that did the wound care, and we had the IV nurse, and they would come on different dates. The IV nurse would come once a week and clean everything, and check the pic line, but I did all the I.V.s myself.

It was during these periods that mothers reported to most often experience

emotional distress and coping concerns. Vera shared a story to reflect her emotional state

during one of her daughter's hospitalizations for a major surgical procedure. She

reported that as her daughter's hospital discharge date approached, she began to feel

increasingly anxious about resuming full responsibility for her daughter's care:

> They [hospital staff] knew that I was going home, and I'd have to take care of her, so they trained me. … they only told us [participant and spouse] [to be] very careful... very specifically, you know, what to do. And, in fact, they spoiled me, because, there were a couple times, to be honest, I had these little, little, meltdowns, right before we went home, because I realized, "they've been doing everything, and now I have to do everything!" you know? But once we got home, you know, it was okay. It was just, uh, I had been spoiled.

Helen reported feeling overwhelmed by post-operative caregiving responsibilities

after her son's recent spinal surgery. For Helen, this emotional response was

compounded by her son's preference for her to be his sole caregiver. She described her

decision to go along with her son's desire, and her emotional outlet for coping with the

demands of solo caregiving:

> We've had him in casts from here to here or thigh to ankle with a bar in between … and I'm the one home with him 24/7 taking care of him and he does not want his father taking care of him so it's kind of difficult for me when my husband comes home from work to go, "I need to get out of the house." If Charles got upset and started crying, I'd say, "Fine, fine, I'll stay" because I didn't want this child who's – well, when he had his back surgery, 63 staples in his back, screaming and hollering … it's challenging and there are days when I could do what I – do what I call purge/cry in the shower."

When she discussed her daughter's multiple surgeries, Eileen described the

recovery period as "just killing my spirit" and "taking the winds out of my sails". She

reported past struggles with watching her daughter, who does not understand the surgical

procedure due to an intellectual disability, suffer with excruciating post-operative pain.

Eileen went on to talk about the difficulties of caring for an adolescent in a half body cast

that "makes her [daughter] three times heavier because she's as stiff as a board, and

heavy". She asserted her belief that health care providers do not have an inkling of what it is like for families caring for their child at home, particularly during post-surgical rehabilitation periods. She suggested that health care providers have preconceived notions associated with families caring for a child with a physical disability. The first notion being families are self-sufficient when it comes to managing their child's care. She stated, "We just get sent home because we're self sufficient, we go away, deal with it, "come back for your follow up [appointment]". Eileen offered a second notion related to health care providers' belief in "safety nets", which she suggested actually do not exist, to support families who do require assistance. Eileen went on to contrast her usual maternal caregiving experience, with one that occurs during the prolonged rehabilitation and recovery period:

> It's stepped up because we have surgery, and recovery from surgery, and it's more intense. Okay, it's the emotional part. That's why I go to counseling when she has to go into surgery because she is so miserable. She is so sad. It is living with crying for hours, hours in the day. Four hours of crying in a jag, and it really is hard, and to think I have to voluntarily do this. I have to work myself up to it, so when I say five months, it sincerely is that for a surgery that will be out of the hospital in three to five days, and she'll be recovering for ten weeks, and it takes me five to six months to get through it. It's that big.

Maintaining physical strength. In the interviews, all of the participants remarked upon their need to maintain physical strength in order to be able to continue caring for their child. The ability to lift their child was revealed as an essential aspect of the caregiving experience. While acknowledging that their children have grown to the size of small adults, mothers reported that the gradual change in their child's size and weight have allowed them to adapt over time. Helen reported, "I've lifted him everyday of his life since he was four pounds. I've grown and developed as he has". Vera shared a

similar view, "By God's grace, I'm you know, a pretty strong person, and you know, Jane only gains weight one pound at a time! So, my back has strengthened along with her".

Nevertheless, as their children have moved into adolescence and young adulthood, physiological changes in both the mothers and their children have created additional challenges. For some mothers, the aging process, other health concerns, prolonged heavy lifting of their child, and managing heavy wheelchairs have resulted in back injuries. In describing the influence of her aging body on the physical aspects of caregiving, Nicole suggested that her caregiving activities have evolved to be less spontaneous and more planned:

> I am now forty-two. I had her [gave birth] when I was twenty-five. My body is different. What I can do is different compared to what I could do when she was younger and smaller. So yeah it has definitely changed. It's become much more you have to think about things now. Things have to be planned … spur of the moment doesn't work.

For the children, mothers reported the presence of contractures, increased spasticity, and poor muscle tone as contributing to making transfers and positioning increasingly difficult. Several participants mentioned that mechanical lifts are available to assist with transfers. Some mothers already have installed a lift in their home while others identified the probable need to obtain one in the future. Mothers who had a mechanical lift in their home, often reported to not use them due to the additional time required to use the equipment. Several families had adapted their homes to include an elevator or first floor bedroom, because they were no longer able to carry their child to the second floor of their home.

The ability to lift their child for the purpose of transfers and positioning was often cited as being an all-important aspect of caregiving, often related to both parental convenience and concerns that a mechanical lift or lifting assistance may not always be available. For example, Nancy shared the story of having recently taken her daughter for an x-ray. She reported that if she had not been able to independently lift her daughter on to the x-ray table, she would have had to travel a longer distance at an inconvenient time to a radiology facility equipped with more personnel to assist with lifting. Nancy also shared her frustration regarding her daughter's physical therapist and teachers ongoing insistence that her daughter be taught to bear weight for transfers, and her reasons and decision to disregard this. For example,

> I'm going to pick her up out of the wheelchair and put her on the toilet, put her in bed, whatever. I'm going to continue to do that because I need to do that because as soon as I stop doing that I'm not going to be able to do it. And the reality of life is there are 100 situations a week in which I have to be able to lift her. And if I lose that I'm not going to be able to take care of her… I'm working on my own skill and that is I need to maintain my own strength and my ability to pick her up. She's 110 pounds. She's a big kid. I need to be able to lift her up.

However, the interviews also revealed that the ability to lift their child was closely tied to mothers' self-expectations of being a successful caregiver and able to independently care for their child. For Eileen, the loss of her ability to lift her daughter contributed to her feeling inadequate as a caregiver and mother:

> I'll tell you there's a moment in time that I remember very clearly feeling inept, feeling like not a good mother when I realized that I truly, physically could not lift my daughter off the floor by myself anymore. And we did a lot of floor work. We did a lot of PT, and that was something that I did every single day, and we played, and played, and played, and she had a lot of gross motor play with me. And there came a time, and it has been in the last five years, where I realized, "man, I just can't get off the floor with you [daughter]. I can't pick you up, and then get to my knees, and squat, and lift you up. With my body mechanics, I

can't lift anymore. I can't just do it anymore. You're too long. You're too stiff because over time you have changed". She's very, very, very, very rigid now, and she's a big floppy baby. So I really used to be able to just kind of ball her up, and lift her up, and go. But those are times I just I get depressed. I think, "man, I'm not as good a mom as I used to be".

Like many of the mothers, Kate reported relying both on physical exercise to strengthen her back, and her spouse to share the lifting responsibilities. She stated, "It is a concern for the future because both of us even have had back problems so we just try and stay, in the best shape we could or else if I'm having a problem my husband does it and visa versa, so we work together on that." Similarly, Terry, who reported a recent episode of a potentially life limiting disease, reported relying heavily on her spouse to lift and transfer her son. She described a recent observation made by her son's teacher in relation to her limited caregiving support system. She recounted that the educator observed, "You're a disaster waiting to happen". Meaning that, you know, if Ed [spouse] died tomorrow, what would I do? How would I lift Tom?".

Dealing with a team. Caring for a child with CP and multiple co-morbidities requires the involvement and support of multiple professional health related disciplines. Within the interviews, all of the participants reported collaborating with numerous health and educational professionals, beginning in their child's infant or toddler years and continuing into adolescence and young adulthood. The health care professionals included pediatricians, specialty physicians, nurses, physical therapists, occupational therapists, speech therapists, and nutritionists. The educational professionals included early childhood developmental specialists, psychologists, teachers, social workers, and case managers. These teams are significantly larger and more specialized than health care and

educational teams with whom the parents of a typically developing child would interact and collaborate.

While many mothers struggled in their child's early childhood with locating and navigating available resources and supports, presently, all mothers reported valuing the medical, therapeutic and educational services that their children have received. In describing the community of professionals in her son's life, she stated, "We [participant and spouse] always say that 'we have this great village to help us'". Meg reported much the same as she described the experience of seeking services for her son. She stated, "We always managed to run into the right person at the right time".

For the participants, the recognition that a team approach was required to care for their child was at times challenging. Dealing with the large number of professionals involved in their child's care, mothers reported receiving conflicting instructions and advice. For example Carol reported "Each [health care team member]…recommends, one contradicts what others have said… and they act as if it's the only thing that we deal with". Vera described the importance of the relationships that she established with her daughter's physical, occupational, and speech therapists at a local pediatric center, and described it as a "very positive place". Conversely, Sandy shared the experience of having difficulty over several years locating a therapist that both she and her son liked. She stated, "There's only one pediatric therapist in town and we just really didn't care for her … if he doesn't care for a therapist, he's not going to do the work".

Yet another important aspect of this thematic area relates to opening the family home to compensated or professional caregivers. For some participants, particularly

mothers that returned to full-time employment during their child's infancy or early

childhood, this experience began with babysitters and eventually moved into the hiring of

personal care attendants to assist with the physical care requirements of their children.

For many mothers, this process has not been without challenge. Terry reported to have

had compensated caregivers coming to her home for several hours each week for several

years. Her experience included personal care attendants and college-aged companions

for her son. She voiced the experience of loss of privacy and the challenge of

maintaining personal interaction boundaries with long term professional caregivers. She

initially described her husband as being the only one "bothered" by the loss of family

privacy, but upon further consideration, she was also often uncomfortable with having

caregivers in her home:

> I have a friend who pays for respite care providers for extra time but sends them home because when she comes home, she says if "I want to run around in my pajamas, I can". I'm kind of that way too, although there are times when I'll just go and put my pajamas on anyway. I don't care. I think, yes, there are times and especially with this one older woman [personal attendant] because she's always telling me that the trials and tribulations of her family and because she's worked with us for so long, she is kind of like family but it's awkward. You know, because there are times when I'm just like, I don't really care. I'm tired. I just want to go upstairs for five minutes.

In a similar drift, Eileen indicated family privacy concerns as her rationale for not

utilizing professional caregiver services. However, she acknowledged that this decision

would need to be revisited in the future, as she and husband are less able to provide the

high level of care required by her daughter:

> You lose your privacy, and that's a big deal to us [participant and spouse]. We really like being quiet on the weekends, and we're not really sure what that's going to be like to have somebody come in to help us with [our daughter]. But we know

we have to get her used to it and we have to get used to it, and I'm not sure we're ready for it yet.

While opening their home to a stranger is uncomfortable for some mothers due to loss of privacy, for others the expense of bringing someone into their home is equally daunting. While some children who are enrolled in the state birth injury fund program or the state Medicaid community based waiver program are eligible for a designated amount of home care or respite, finding qualified professional caregivers can prove challenging. Maternal concerns centered upon about locating quality, trustworthy workers. Helen commented on her additional difficulties in locating qualified, personal care attendants in her county due to state guidelines that offer caregivers a higher rate of compensation in the neighboring jurisdictions:

> If we can't find an attendant, for lack of better words, the good ones are 10 miles down the road, the next county. Finding an attendant at $8.42 an hour that I would trust with my son um, on a full-time basis, it's going to be almost impossible to find.

Another concern, raised by all mothers, was locating professional caregivers that provided quality care. While some mothers had established long-standing relationships with caregivers who in some cases began as their child's babysitter, others did not begin to use personal care attendant or respite services until their child entered adolescence. Nicole, who had only recently started using professional caregivers, suggested that in her experience, while some caregivers provide for the physical aspects of care, the less tangible interpersonal aspects of giving care were lacking:

> They [compensated personal care attendant] have a different idea of what care is. They would come into our home and turn on the "Oprah Show" and sit on the sofa and my daughter would be in her wheelchair and that's how it would be for four and a half hours and then they would feed her, clean up her face, change her

diaper and go home. There was no interaction with my child. There's no touching my child, talking to my child and that wasn't acceptable.

Nicole resolved this issue by seeking an agency that allowed her to become the "boss" in recruiting her own caregivers, which she has done through personal contacts at her church.

The hospital setting offered another venue for the mothers' interaction with yet another care provider team. For the mothers, the establishment of a trusting relationship with the professional nursing staff was a key element to their child's hospitalization. Several mothers shared their experiences of caring for their child during a hospitalization and their interactions with hospital nurses. These experiences appeared quite varied, with several mothers reporting their best experiences having occurred at the same specialty hospital nearly 1000 miles from their homes, where they had traveled for their child's surgery. Nancy described this facility's staff as having garnered her trust, "All they [hospital nurses] deal with are kids who walk through the door with a disability. So they were truly, truly prepared … to take care of her if we had walked out of the door". She contrasted this experience with one at a local hospital when her daughter went into a coma after the placement of a Baclofen pump. She stated, "They're [hospital nurses] not used to dealing with kids who come in with a disability and then become sick. That was beyond really their ability and the procedure and everything that went with it was also beyond their scope".

All of the mothers shared their reluctance to leave their child, and virtually all reported that either they or their spouse remained at their child's hospital bedside at all times. Terry reported of her son's surgeries, "I've stayed in the hospital because I didn't

know what would happen if I didn't stay in the hospital. I wasn't completely trusting of

the nursing staff". In describing her experiences during her son's hospitalizations, Helen

suggested the nurses' reliance on her to direct her son's care. She stated, "The nurses

depend on me 100% … maybe because I do take the lead, especially – well, the last

couple surgeries, they've been extended stays, five, seven days in the hospital and I stay

with him".

Most mothers reported not minding remaining at their child's bedside and

providing for the majority of their child's physical care in the hospital setting, such as

turning, repositioning, and changing linens. Their narratives suggested that they viewed

these actions as an essential part of their role as a parent and family caregiver. However,

Nicole described a recent experience in which "a gift" was offered by the nursing staff

that led to the establishment of trust.

> One of the best gifts when we had in [a recent] hospitalization was [when] the
> nurses came in to change her [daughter's] bedding. They wouldn't let me change
> her bedding. They were very kind about it and said, "You know what, you're
> going to sit there and we're going to do this. They wouldn't let me [change the
> bedding]. There are many, many nurses that in the past would have said "Oh
> you're going to do it, sure no problem, I'm going to take care of my other
> patients". These two particular didn't. It was a gift to me because I naturally will
> say "Oh I can do that. That's not a problem" … But they did their job and that
> was awesome because at that point I knew I had a team I could trust. If they said
> go get a cup of coffee, I knew I could leave and there would be a nurse there and
> they wouldn't leave.

Finding My Own Way

For all of the participants, the experience of caring for an adolescent or young

adult with severe CP has presented great challenges, yet, the mothers also identified

plentiful opportunities for personal growth. While some mothers reported their child's

adolescent or young adulthood years as being less challenging than the early childhood years, other mothers suggested that caregiving has not become any easier, it just became different. Common to all mothers was the experience of continuing to struggle with the delicate balance of the heavy demands of caring for their child with disabilities and other aspects of their busy lives as they have entered into their middle age years.

During the interviews, participants gave voice to their efforts to cope and manage the demands of caring for a child with severe disabilities by surrounding themselves with supportive people, managing their emotional response, accepting difficult decisions that have been made concerning their child and family, and seeking meaning and purpose in their and their child's lives.

Balancing family demands. Within the interviews, mothers' descriptions of actions aimed at balancing the demands of family life were an important thematic element. All mothers shared the challenges of caring for a child that required frequent medical appointments, hospitalizations, surgeries, therapy sessions, and an intensive home exercise regime with the demands of caring for their other children. Most participants emphasized their efforts to try to normalize their family life for their child with CP and other children. Meg stated that if she were to offer advice to new parents about parenting a child with CP, it would be the following: "Be a mom first; treat your child as normally as possible. You know, like she was just a normal person".

Mothers also stressed their efforts to ensure that they did not overburden their other children. For example, Carol when describing the close relationship between with her son with CP and her typically developing teenage daughter firmly stated, "It's never

her job to take care of Tom. You know. Never. We rarely use her as our back up because,

you know, she needs her own life. We don't want her life defined by Tom [her brother]".

Mothers reported that balancing the needs of all of their children was particularly

challenging when their children with CP were younger, and many voiced a sense of guilt

over not meeting the needs of all of their children. For example, Sandy shared what was

described as a frequently occurring experience associated with her two typically

developing sons:

> I went to bed feeling guilty because my other two children were able bodied and could take care of themselves. They would ask me to do something or another with them or for them, maybe play a game and it would usually involve a time when I was busy taking care of Charles, maybe feeding him, dressing him, or whatever and I'll say, "As soon as I'm done here." Well, that "as soon as I'm done here" never came and I'd forget, they'd stop asking me. I'd go to bed and remember I never did play that game with Jonathan so I dealt with a lot of guilt raising my kids.

Many mothers described special efforts that they took to ensure that their other

children were in involved in community and recreational activities. Kate found this to be

especially difficult when her son with CP had multiple, frequent, prolonged

hospitalizations. She described these times as especially challenging as she aimed to

balance family demands, normalize family life, and be available for both of her sons:

> Nick [younger sibling] was home and he was going through his regular stuff whenever Sean was in the hospital it was a real hardship because I didn't want to deprive Nick of having a regular life of being in the Boy Scouts, or the Cub Scouts, or playing on a team or whatever he wanted to do, uhm, go to a friend's house, or sleep over, or whatever. I wanted him to feel like he had a somewhat of a, you know if you say normal life, and so when Sean was in the hospital and usually when Sean's in the hospital it's not for just a day or two it's for weeks. That was tough when Nick was little, and especially when Nick wanted me to be home every day after school and help him or play with him, or whatever, when he was in those younger elementary school grades.

Similarly, Vera shared her experience of trying to balance the needs of her

daughter with CP with the needs of her two other daughters during their adolescent years:

> I know I did spend an awful lot of time with Jane, when the three of them were growing up. And you know, when the two older were teenagers, they said things, that, you know, they expressed the fact that I was spending so much time with Jane, and they felt she [Jane] was the favorite and all that. Then I always felt bad, so, I would try to at least spend time with the two older [girls] if nothing else, you know, talking with them for a half an hour late at night.

Within the interviews, mothers alluded to their long-standing marriages as a

source of pride, and stressed that a team approach to caregiving was an essential part of

their marital relationship. Several mothers expressed relief that they and their spouse had

defied the trend of high divorce rates among the parents of children with disabilities.

Several cited statistics associated with divorce and talked about their relief at avoiding

being part of this trend. Eileen stated, "It's an 81% divorce rate for people, couples with

kids with disabilities and I know I'm very, very, very lucky". Nicole reported being

encouraged to seek early marriage counseling by a social worker present at the time of

her daughter's diagnosis. She reported, "the social worker told us eighty percent, that's

what it [divorce rate] was because it was sixteen years ago. I remember it like it was

yesterday, that eighty percent of all marriages where there is a child with a disability end

in divorce".

Similarly, Nancy discussed her experience of marriage in the context of childhood

disability, and the offered "teamwork" as an explanation for the long-term success of her

marriage:

> There are such horrible statistics about having a child with a disability. The statistics I think are in the 90's for divorce rate. It's really very high. And I can't say it's all been sunshine and roses. There were some really hard times and some

really difficult times especially when she was young and we had these literal days of screaming. She never slept. She cried all the time. And I don't mean a nice little soft weepy cry. It was a screaming at the top of your lungs cry. And that's hard. That's hard on a marriage. But if you hang in there long enough and you stay on the same team, I think in some ways it actually brings you closer because it does require teamwork. You have to be in the same boat. And I really think if you can hang in there long enough to stay with it that it actually starts to bring you closer together.

All of the mothers shared the desire to spend more time alone with their spouse, both at home and in recreational pursuits outside of the family home. Caregiving demands, busy work schedules, and difficulty locating reliable respite services were described as contributing to few opportunities to spend alone time with their spouse. Terry described her family's daily routine which included a high level of caregiving by her spouse. She described her son as being very attached and dependent upon her spouse. She stated, "He's [son] very attached to his dad. And so, he, when Dad comes home, it's like he gloms on to Dad and wants everything done for him by Dad".

She continued to describe her experience in terms parental exhaustion and the impact on communication within her marriage:

> My husband's tired. You know, we hardly ever, during the week, we don't really talk to each other, other than in passing… I don't see my husband again until he climbs into bed like 10:30 at night with me because he usually falls asleep with Karl.

In reflecting upon some of the limitations imposed by long-term caregiving, several participants mentioned the challenges of not being able to vacation or travel with their spouse. Eileen described her family's decision not to vacation outside of the family home due to the challenges of locating an environment that would be conducive to caring for her daughter:

My husband and I really, we don't vacation. We've set the house up so that we can be as relaxed, and comfortable as we can in our home, but it is hard to take [Lisa] out of this environment. She needs to get out of her chair every two hours and you can't stretch a 5'2" grownup, adult woman in a lot of places except her bedroom … But like taking her someplace, going to my mom's house or to my brothers' and sisters' homes, it's a big deal. We have to pack up a lot. We have to take a lot with us, and it's just not easy, so at our age, we just go "we'd rather stay home.

Terry described having made a similar decision to "stay put', rather than trying to make arrangements for respite care for her son. She further suggested that this decision has led to a sense of "isolation", particularly as she looks to her friends whose children are of similar ages:

Terry: I think the best example is our friends who are now entering a phase in their life where they have so much more freedom. And we don't. You know, we can't go away for—or at least we haven't figured out how to go away for three days by ourselves … it's isolating having a kid like Tom in some ways isolating. Not 100 percent, but, it is. You know. It is. It's just easier sometimes to stay put and not go out or not make the necessary arrangements.

Like Terry, Diane framed her situation in terms of being at a point in family life that she expected to have the freedom to travel with her spouse. She lamented the fact that she does not expect to have an "empty nest":

How are we going to have an empty nest some day so my husband and I could actually travel together, you know, even between then and now because, you know, that's frustrating. That's one of the biggest frustrations is my husband and I can't leave the country together.

On a similar note, Sandy shared her frustration locating respite care which would allow her and spouse the opportunity to head out for an occasional dinner or movie without her son. While a local community organization offers respite service, her son required some special assistance that was beyond the type of assistance provided by the organization.

> If you're not needing somebody full-time but to get somebody in here that's trained enough that can, you know, lift him and put him in the bed and get him out of bed, it's really hard to find people, good people. … You'd have to go through the whole list [community organization] calling everybody [volunteers] okay "Can you lift a hundred and sixty pounds? Are you willing to take him to the bathroom?" And so you have to just kind of explain that babysitting is a whole lot different than having an actual caregiver come in.

Like many of the parents, Eileen described her daughter as being quite portable for traveling when she was younger, she stated, "I really used to be able to just kind of ball her up, and lift her up, and go." However, as her daughter has aged, family travel has become increasingly difficult. As participants' children have grown into adolescence and young adulthood, the transport of heavy wheelchairs and requirement for specially adapted vehicles has made travel and accessibility more complicated. Many mothers reported that visiting the homes of extended family and friends was very challenging and often quite difficult if not impossible due to the logistical challenges. Often, the visit was made impossible because of the lack of safe access or the inability to use a wheelchair in these homes.

Sandy shared her frustrations in trying to identify potential family vacation opportunities:

> To go to the beach, you can't, I can't get him in the water. Um, to go to a pool, I can't take him swimming unless there's a lift. … You think to an amusement park, any amusement park unless he can transfer he can't ride. You know? Where do you go? Where do you go?

On the same note, Terry shared the story of a recent summer vacation to beach. Her family opted to take the vacation while her son attended camp. She described the vacation as "freeing" in that it allowed her family to spend time at a favorite location that is not conducive for her son due to his health concerns:

It was so amazing to have ten days without him, and when we were at the beach, because you can't go to the beach with Tom. It just doesn't work for him, you know. It's hot and sunny and he can't get in the water. So we had given up the beach over these years … And it was kind of, "my god, this is how life is for other people". You know, we could go for a walk together. We missed him every day. I don't mean like we resented when he came home. But there was something very freeing about not having him for a few days and it was a little hard almost when he came back and now I couldn't go do that errand.

Surrounding myself with supportive people. For all of the participants, finding sources of personal support and surrounding themselves with supportive network of people was an important part of their caregiving story.

Most of the participants identified their spouse as their main source of support, with the others identifying extended family members or friends. Within the interviews, all mothers expressed a strong need for spousal support, and many described it as the key element for their successful parenting and family caregiving.

When asked about her main source of support, Nancy stated, "My husband absolutely. Absolutely number one". Eileen shared her experience of spousal support in terms of having a partner in caregiving that has contributed to her parental and caregiving efficacy. She stated,

I have to tell you with a resounding positive, positive the best person in my life is my husband and he really keeps this house grounded, and he keeps me grounded. And all the guilt that I just told you that I feel, he takes that burden. He lessens that. He makes me feel that I'm a very good mother and he is truly a partner. So he is just as much a caregiver for our daughter… But I could not, [Lisa] would not be where she is if it wasn't for her dad.

All of mothers described their spouses as active parents, and for many their spouses assumed responsibility for providing a sizable portion of their child's physical care. For example, Terry reported, "I have a husband who's terrific. He gets up with

Karl now at 5:00 in the morning during the school year because the bus comes at 6:00

am." Many mothers reported that their spouses bathed, fed, dressed, or toileted their

child, often adjusting employment schedules to be available for medical appointments

and child care coverage in the event their child was unable to attend school. In detailing

her family's post-dinner nightly routine, Nicole described how her spouse spends time

each evening with her daughter offering her a chance for respite:

> He'll [spouse] read her a story. She [daughter] loves to snuggle. She's a big
> snuggler so she'll curl her whole body into the side of you and just have the
> biggest grin on her face as you're reading or we'll watch a movie. My husband
> will just have her with him … It's usually one of the boys [spouse or son] to give
> me a moment to just go read or I'll meet someone, a friend for coffee. That's
> usually my time to not be her mom.

Several mothers also identified their other children to be an important source of

emotional support. The participants whose other children had transitioned into young

adulthood most often noted this. Helen described her two older boys as among her

greatest sources of support, stating, "Now that my two older boys are young adults

themselves, and they were four and two when Charles [child with CP] was born because

they grew up and they've been around, they're very supportive now". Similarly, Kate

proudly shared a story in which her older daughters surprised her by arranging a get-away

weekend for her and her spouse and provided respite care.

Another source of support was extended family members. Most often mentioned

were the participants' parents and spouses' parents. A few mothers reported to have

parents or in-laws living in the vicinity, however, most grandparents lived at a distance

and provided occasional respite and ongoing emotional support. Mothers reported having

needed much emotional support during the early years of parenting and caregiving. In

acknowledging the support that she received from her mother, Nicole described her mom

as "a tremendous gift to us [the family]". However, many participants reported to have

lost parents to death or have aging parents that are no longer able to contribute the same

level of support that was available in earlier years.

In describing the support provided by her mother, Eileen described the changing

nature of this support as her mother has aged:

> My mother is too old. There is no way she can lift [Lisa] or do any of the
> personal care that [Lisa] needs, but she's wonderful to augment. So if Grandma is
> here, I can be cooking dinner, or entertaining, or doing anything. Grandma is
> reading books. Grandma can help [Lisa] eat. Grandma can do that kind of stuff,
> but I had to get her dressed, and put in the chair, and move her out here in the
> kitchen, and that kind of stuff.

Similarly, Kate described the changing nature of extended family support and her

support needs over time:

> [In earlier years] everybody else was younger and the nieces and nephews were
> around to help babysit and my husband's parents were around, and my parents
> were still young, so everybody was there to babysit. Now, you know, his parents
> have passed away and his nieces and nephews are married and have their own
> kids and their own families, and they've moved away. And it's a little different
> now but it's okay because, uh, it's not the same as it was when we needed them.

Conversely, several mothers shared situations in which extended family,

particularly grandparents, have not been supportive. These situations were cited as

sources of sadness and frustration for the participants and their spouses. For example,

Diane described a situation within her extended family:

> My husband's parents have a hard time. They are older and are the generation
> where if Marie was their child, she would have been in an institution, but they
> don't get it. They don't understand. We've had a lot of struggles with his side of
> the family.

Vera also shared a similar story of her daughter not being accepted by her paternal grandfather, and what she considered to be at the root of this situation:

> My parents were always, have always, been supportive even though they're in another state, so we don't see them very often. But, they were always very accepting of Jane. I can't say that, so much of my of my husband's parents, especially his dad… he doesn't know what to do with Jane. [I think] it's coming out of fear, disappointment, I don't know, maybe just ignorance.

All of the mothers identified friends as another great source of support. Interestingly, most often described were friends who were also the parent of child with disabilities. Vera shared that her friendships were formed as the result of her daughter being accepted by other parents. She stated, "I've had to watch Jane go through life being rejected, and you know, ignored. That's kind of from the quote/unquote 'normal world' ... but in the process, we've [family] made some wonderful friends, who also have children with disabilities".

Diane shared her experience of seeking support from other mothers who have a child with disability. She also described the experience of a long-term friendship with a group of these mothers:

> I talked to quite a few moms, and just compared notes, and kind of be your shoulder. I have three other mothers, we get together not on a regular basis but every once in a while one of us will email each other and say "can we do a night in the next couple of weeks?"... And so we get together every couple of months. More often you get together with a small group of people that you connect with and even though there's email I think the personal thing, the personal … like you can just go and give someone a big hug if they need it that type of support. I also have found it extremely helpful to know a parent with a child with a very similar level of disabilities who is just a few years older. One of the things I really struggled with early on was okay how do I find the resources, what kind of wheelchairs, what are the thing that I need to be doing for Edward. I needed someone whose kid was just 3-4 years older.

A few mothers identified a spiritual source as their main source of support. For example, Vera stated, "I think the biggest thing that helps me get through the day is my faith in God". Similarly, Diane responded with humor stating, "After chocolate, coffee and maybe a new pair of shoes, [chuckle], my husband, my faith; I probably should have said God first." Both participants also cited members of their church community as being very supportive of their family. Within the interviews other mothers did not mention any spiritual or religious sources of support.

Mothers described varying levels of support by health care professionals. Within the interviews, many mothers did not identify health professionals when they were asked to identify their key supporters. Several did mention the value they placed on the supportive nature of their relationships with their child's physicians. This supportive relationship seemed to occur most often when associated with a long-standing relationship. Kate reported to have experienced a large amount of support from this type of relationship. She stated, "Sean's doctor is amazing. He's even given me his number and his email and … [Physician said] "call my nurse and tell her you've sent me an email and we'll deal with it" … Just knowing that he's behind me there with any question. It is just great". Nicole lamented the loss of time spent with her daughter's neurologist due to changes in the health care delivery system. She reported that when her daughter was younger, she'd have the opportunity to spend nearly an hour with the physician to get her questions answered. She contrasted this with her more recent experiences and stated, "Now I'm lucky if I get fifteen minutes and I'm talking to a nurse or a nurse practitioner which is great if they know their stuff, but I'm not talking to the neurologist anymore".

The mothers' relationships, in general, with health professionals appeared complicated. While mothers placed high value on these relationships and expressed appreciation for the efforts of health professionals on behalf of their child, they also described interactions that led to the emotional response of guilt. This emotional response is described in detailed in the following section.

Managing my emotions. Within the interviews, the mothers described many emotional responses in the context of parenting and caregiving that are similar to those experienced by mothers of typically developing children. However, their descriptions included unique elements in relation to the nature, frequency, intensity, and precipitating factors associated with their emotional responses. For example, while the emotions of joy and happiness in the context of caregiving were acknowledged and celebrated, mothers also acknowledged experiencing significant guilt and frustration in the context of caregiving.

Within the interviews the experience of finding joy and happiness in caregiving was an emotional response shared by several participants. For example, when outlining the daily care that she provided for her daughter, Eileen described herself as having found a "balance of joy and the job of caregiving". Vera shared the happiness that she often experiences on a daily basis when caring for her daughter, reporting, "Sometimes we [participant and daughter] have great fun. She's [daughter] got a good sense of humor, so when I'm helping her, we're laughing".

Similarly, Nancy described her daughter she has a wonderful sense of humor. She state, "She's very funny. She has kind of a dry sense of humor. And there are times when

she will just say something that just makes me laugh. And those are wonderful moments

when we can just really share her sense of humor and her take on the world". She went

on to describe the best part of her day as "Those little quiet moments when my daughter

is happy and we're able to connect with her in a way that is just in some ways very

typical. And those are those moments where you really just go 'this is all good'".

Several mothers shared anecdotes of memorable experiences in which they

experienced profound joy as their child communicated with them in a meaningful and

reciprocal manner:

> I definitely will cry at this story. He was—this was when he was very small and
> he was in a special education sort of preschool then, right? And they were the first
> ones to get him some kind of communication device. And they just had a simple
> recorder that he would hit a button and they had programmed it to say, "I love you
> momma". And I came to pick him up one night and he pushed that button over
> and over and over. He did not—his gaze did not leave mine as if he'd been
> waiting to say that for four years. Wow. How do you beat that? You know? A
> little drool, a little dirty—how do you beat that, you know?

After discussing some of the difficulties she has faced in caring for her son, Kate

shared a similar experience in relation to her son's first smile when he was several years

of age:

> But of the happier times, one of the biggest days was – and he must have been, I
> don't know a couple years old, when he smiled. The first time he smiled. Oh, my
> husband and I were just like, "Oh, my God, is it an accident, did he just [smile?],
> and so that was just so memorable an, then after that we could get him to laugh by
> saying silly things and singing silly songs. And so we knew it wasn't just an
> accident that it was meaningful and he was smiling because he was happy, and
> that was just so exciting. I just remember it like it was yesterday, and so that's
> been neat.

Another dominant emotion that emerged in the interviews as common to all of

women in this study was guilt. Interestingly, none of the mothers suggested guilt

associated with the potential causes of their child's disability. Instead, many of the

mothers struggled with self-recrimination associated with the sense of not having done all

that could have been done to maximize their child's functional abilities. Their

descriptions of this emotional response was one that vacillated between expressions of

profound guilt and the recognition that they had done all that they could with their

personal resources, namely time and energy to promote their child's abilities. The

mothers attributed their emotional response to two sources. First, these mothers

attributed their sense of guilt to not fully living up to their responsibilities as a parent and

family caregiver. Second, they experienced a sense of guilt as a reaction to admonitions

from professional caregivers, namely therapists and physicians, who were described as

being focused on what the mothers needed to be doing at home for improving their

child's functional abilities.

For example, Eileen discussed her experience of guilt in relation to her own self-

expectations as a maternal caregiver, and her concerns about her ability to maintain her

caregiving role in the future:

> I think I'm not as good as I could be. I feel a lot of times I feel failure. A lot of
> times I feel if I put more time into this, would [Lisa] be better at that? If I could
> do this, would she be better at that? So I think that I've kind of guilted myself
> over the years and felt that how am I going to do this as I get older?

Carol reported a similar experience, and further described her attempts to

realistically define personal priorities and seek self-forgiveness:

> I constantly feel like I'm letting him down. I look at his wrists and it's we should
> be getting a better brace for him or, you know, there's just so many things. As I
> was saying before, on the one hand you have to be forgiving. There are so many
> things you can't do it all at one time. But also I feel guilty that we haven't been
> able to do X, Y, Z. I know that he should be in the stander more. I know he should

be using his electric wheelchair more but it's easier to push him in his push chair, you know that kind of stuff.

Nicole framed her experience in the context of her religious beliefs, and self-recognition of being "very human and flawed". She offered an example of an internal dialogue that she has experienced when she is exhausted and weary in her role caregiver role:

> It is really hard when you're begging God to make it all better because the next thing out of your mouth is because "I just can't do this anymore". What mother says that? So then you carry the guilt of being tired [voice breaking up- [teary]] and having difficulty carrying the burden but at the same time, you flip that coin and how can you not want to carry the burden because she's beautiful and she's innocent and she never asked for any of this. So how can you not want to fight for that?

Many mothers suggested that their personal guilt was compounded by their perceptions of physician and therapist criticism of their actions. Helen shared the details of an experience while attending a therapy appointment during her son's early years. On this particular day she reported that she was teary, and felt overwhelmed with feelings of inadequacy as his maternal caregiver. She reported that she was taken aside by an early intervention program counselor, who shared invaluable advice:

> She [counselor] says, "What's going on?" I explained the guilt I was feeling. She said, "Oh, for crying out loud." She said, "You are his mother. Be his mother. Let the physical therapist do the physical therapy. Let the speech therapist do the speech therapy. Let the teachers do the teaching. You be his mother, take care of him and don't worry about the rest". That was like God knew I needed to hear that. That made all of the world of a difference – all the difference in the world. I started being – I started being less critical of myself -- that yeah, I'm his mom. You're the physical therapist; you do all that stuff because first of all, he doesn't want me doing it, and I can't do it all.

In describing her experience of guilt over her son not meeting the functional expectations of his therapist, Kate reported that she would change therapists to avoid feeling that both she and her son were not meeting therapists' expectations:

> People [therapists] don't do it so much now but when he was younger people did "let's do this, let's try this, and let's try that". [They were] always trying to kind of fix him. And, you know, I'm sure sometimes it does work and some kids learn to use their legs and walk and all, but for Sean it just didn't happen. So I...we just have to say "okay let go of that and move on". And, in the past sometimes when he was younger I would even find another therapist or whatever that didn't make me feel guilty.

When asked what advice she would share with other parents who were caring for a child with disabilities, Vera acknowledged her belief that feelings of guilt and inadequacy are an expected part of the caregiving experience. She stated, "You know the feelings of inadequacy, the feelings of "why me, or, [why] him?" Those are all normal. So don't feel guilty about them because everybody goes through them." However, she followed this advice with a description of her efforts to manage her sense of guilt which was primarily associated with a sense of not meeting physician and therapists expectations:

> I just had to kind of buck up, when you know, the doctors or the therapists or whatever, would, you know, give me these dirty looks, like, you know, "You're not doing your job!" And, I just acted like "well, you know... some things are more important, you know". I say, "If I had done everything that all the doctors and all the therapists asked me to do, we would not get past breakfast, and then it'd be time to go to bed!" So, I had to pick and choose what I was going to do, but then, you know, I always felt inadequate, because I'd go back to the therapist, and [they'd say] "Well, why haven't you done the exercises?"

Another emotional response that was common among the participants was frustration. The participants identified several key areas as sources of frustration. These sources included their own desire to have a life with more freedom, their child's

challenging behaviors, friends and extended family members not understanding the caregiving experience, and health care professionals' having unreasonable expectations.

Vera described her struggle to balance caregiving responsibilities with other desired aspects of her life. For this mother it included the desire for employment outside of her home and the freedom to socialize with friends and travel without having to make substantial respite care arrangements for her daughter:

> There is always the balance of being home with my daughter, and then "quote, unquote - wanting a life". And I do have, you know... I do have to resist the temptation to compare myself with everybody else, 'cause that's not the situation I'm in. But, yeah, just the [lack of] freedoms, are frustrating.

On a similar note, Helen shared her recollection of a recent conversation with her spouse on the topic of "empty nest syndrome". She reported that the missed milestone of sending her son off to college, brought to both her and her spouse's attention the freedoms that their peers with typically developing children are experiencing at the same point in their lives:

> My husband often talks about that [caring for an adolescent with disabilities]. He said, "Can you imagine what we'd be doing if we didn't have Charles now or if Charles were normal?" He'd be off to college now. We'd have that empty nest syndrome. Um, jealousy, envy. We often look at our – our peers whose children are off in college pursuing whatever they want, finishing up in high school and the parents are coming and going freely, traveling, doing whatever they want. We lost that freedom and it hurts sometimes.

Within the interviews, several of the mothers of children with a moderate intellectual disability identified challenging child behaviors as a source of frustration and emotional discomfort. Most mothers reported that although excessive crying behaviors occur less frequently in adolescence than in early childhood, as the children have aged, different behavioral challenges have arisen. The behaviors in adolescence and young

adulthood included anger directed at the mother and spouse, and behaviors associated

with anxiety disorders. When describing the behaviors, without being prompted by the

interviewer, most mothers included an explanation of the source of their child's behavior.

For example, Nancy described an incident that occurred the evening before the interview

for the current study including her belief that her daughter's reaction to her disability was

a contributing factor:

> Last night we had a good three hours of screaming. So we still have that but it's
> not quite as much. So in that respect it's different. She also now has gained some
> literacy skills like I said earlier so that's improved her quality of life, our quality
> of life because it has given her some things she can do independently. She's also
> over the years gained an awareness of her limitations, which she does not see her
> cognitive limitations but she does see her physical limitations and so we do spend
> a lot of time at this point dealing with that and if you throw the anxiety disorder
> on top of that and we spend a lot of time dealing with her reaction to her
> disability.

On a similar note, Terry described her son's behavior as a coping mechanism for

his frustration of not having his needs met:

> If he's in a good mood, It's all is just smooth and flowing, but if he's in a snit or
> something, then we have to deal with [challenging behaviors]. You know, he
> might yell at me, or call me "idiot mom", or do something like that, just to get his
> tension out if I'm not doing what he wants me to do.

In another example, Helen described her son's behavior as being associated with

his frustration over his physical limitations and inability to leave the home on his own.

She described her son as strongly desiring independence, and shared that "he pitched a

fit" on a recent weekend wanting to go out in the evening to socialize. She stated, "He

doesn't want to sit home on the weekend with mom and dad but what other choices do

we have? So that's challenging – and yeah, I don't see that addressed in any of the books

(on disabilities) that I've got". She further described her method for coping with her

son's challenging behavior:

> I do what I call purge/cry in the shower because this parent who also told me about the local early intervention program when Charles was born. Her one word of advice to me was, and I believe her, "Don't ever let your son see you cry about him." And when those moments hit me and he gets me real upset – sometimes Charles can be very cruel with his words and I know where it's coming from but day after day, it builds up and I can't take it anymore, that's when I go into – I'll say, "Mommy needs to take a shower" and he's fine and I go take a shower and in the shower, I do my purge crying and then come out feeling much better.

Living with my decisions. All of the participants' stories included narratives of

difficult decisions that they made in relation to their child's medical treatment, surgeries,

therapies, and family life. While some of the stories presented unique situations, other

contained elements that were common to the experience of all mothers. Whether the

situations were unique situations or commonalities, the descriptions of the circumstances

suggested a high level of significance in terms of the maternal caregiving experience.

Mothers revealed decisions that were clear cut, and others that created incredible stress

for themselves and their families. For many mothers, these decision stories that were

shared continue to have long term ramifications as their children have aged.

For example, Nicole shared the powerful story of how a treatment decision that

she and her spouse consented to resulted in her daughter's blindness. According to

Nicole, during her daughter's infancy, a physician suggested a medication to control

seizure-like activity. Her daughter developed toxic levels of the drug that required a

critical care hospitalization and resulted in her daughter's cortical blindness. She offered

her perspective on how she would handle this type of situation if it were to arise again,

and how she has coped with her decision:

If I were that parent today knowing what I know, I would have stopped. I would have investigated. I would have "Googled". We didn't have Google. You know? I mean I would have talked to four or five parents. I would have followed that path all the way down until I couldn't follow it anymore before I would ever agree to yes let's go ahead and do that [administer medication] … We've got to live with that choice. I mean I don't wallow in that choice because we made the best one at the time but it does teach you.

A more common experience related to difficult decisions that the mothers made regarding therapies and in particular, physical and occupational therapies. All of the children received intense physical and occupational therapy during their early childhood with the goal of maximizing functional abilities. Mothers reported that during the therapy sessions, they were advised on follow-up exercises and activities to be performed at home. Vera described her frustration with what she viewed as unreasonable expectations and her resultant decision. She described her personal decision as one that placed a heavy emphasis on the development of her daughter's intellect, rather than placing a primary emphasis on her functional development:

I mean, they [physicians and therapists] all had their list of things that they wanted Jane to do at home. And, for... you know, I tried to do everything, but it just... you know, with two other children, I mean... it was impossible! And I always felt, you know, if only these people knew what they're asking! You know, I joke with people, and I say, "If I had done everything that all the doctors and all the therapists asked me to do, we would not get past breakfast, and then it'd be time to go to bed!" So, I had to pick and choose what I was going to do.

She went on to describe her efforts to reconcile her decisions and suggested that her daughter's hands were reminder of her choices:

Now, whether that was a right choice, or not, I don't know. But to me that was, it's just our... kind of our natural family orientation anyway. I felt like, "Well, this is what I'm going to emphasize here." So, I did. And yeah, I have regrets. Sometimes I think, "Well, maybe Jane's hands would be better, if I had spent more time, you know, stretching, and stuff like that." But, there's only so many hours in the day and so I made... I made that choice.

Kate shared a similar sentiment when she reflected on making therapy and health-related treatment decisions for her son. She placed her decisions in the context of accepting her son's disabilities:

> And there was all kind of like different people [health care professionals] saying different things about try this, do this and at some point in time I just had to say for me, personally, I just had to say no, you know what, I'm going to accept him like he is and we're just going to go about it our own way. And we're not going to make our lives trying to do something like this where I really don't see it working. So sometimes we just took that attitude like let's do what's best for us as our little family. It might not be what other people do but we're going to choose what fits in with us, so.

Similarly, Sandy shared a story that was based on an incident that occurred on the day of her interview. She had just returned from a physical therapy session with her son who was recovering from recent orthopedic surgery. At this session, she reported to have met with the therapist to discuss her son's therapy goals. Sandy voiced frustration over her need to repeatedly negotiate therapy goals for her son in light of his age and level of disability:

> They [therapists] put too much expectation on him walking and not that I wanted to be doubtful or be negative, but the doctor said, "He's never going to walk. He may be able to stand up and help transfer". But even now the therapist said something today about him walking. I'm like "that's not the objective right now". The objective is just to get him standing … they had and have too many unrealistic expectations …but there comes a point when you've got to realize, okay, he's fifteen. He can't hold a pencil. He's not ever going to hold a pencil.

Finding meaning in my and my child's life. Another important thematic element that was revealed during the interviews was the mothers' attempts to find meaning in their own and their child's lives. Several mothers suggested that their decisions to seek a career in the disability community were the direct result of having a child with a disability. Others suggested their child's purpose as to having had a positive

impact on family relationships with their children being described with terms such as "gifts" and "glue". For example, Eileen described her son as, "He's really kind of like the glue that's kept our family going and together."

In reflecting upon her career as an educator, Terry suggested that parenting her son has given her a special sensitivity that allows her to be more supportive of other parents with special needs children:

> I think that's one thing having Karl, and living this life I've been able to see as a teacher, and talk to parents, and say look, you know, if your child can do one [math] problem, that's all I want … I come at it from a different viewpoint…I guess I like to just be the shoulder.

Similarly, Nancy described her effort as an "educator of special educators" to share the special insights that she has gained as the parent of a child with disabilities with other educators:

> Give the parents credit for what they know. And I give the same advice to teachers as well when I am teaching other teachers of students with disabilities. Give the parents credit for what they know. Yeah. No, they're not teachers or healthcare people. But they live with this child every day. They're on the front lines. They know the nuances of what's happening and you've got to take that into consideration and work with them. Try to meet them where they are.

In reflecting upon the overall impact that her daughter has had on her and her spouse's life course, Eileen suggested that her daughter has positively impacted not only her career, but also her marriage, and expression of humanity:

> I would not be doing what I'm doing right now if I hadn't had [Lisa], so she has shaped and formed a lot. She has also made me very aware of just how lucky I am. I think she's made our marriage stronger where other marriages have faltered and failed. I think she makes us realize that we're a team and we're all we've got [chuckle]. We've got to keep going. And I think she makes me love people more. I think she gives me an enormous capacity for empathy, and compassion.

As Eileen continued her reflective thought, she began to speak of her conceptions of her daughter's purpose. She stated, "There is a purpose to everybody's life and what my daughter is going to do is to be happy, have a satisfying day, be able to contribute to her community, be able to have friendships, all to the extent that she can". Several other mothers described their thoughts in a spiritual context. For example Carol referred to her son as a "gift" as she described the impact he has had on her family. She suggested that he "brings out the best in people", and that he has facilitated the open expression of love within her family:

> We call him our Buddha. We really think that - don't mean to be sappy or whatever, but I never wanted a kid like Tom and I never, I never wanted a special needs kid. And I don't know that I'm particularly good at it. But here he is and he is just this gift that we've been given. He's just like this Buddha in our lives that teaches us things we didn't want to know.

Nicole also sought to explain her thoughts on her daughter's life purpose framed within the lens of her religious beliefs. She described her internal conflict as she has sought to reconcile her beliefs with her emotional pain, when she sees her daughter suffering:

> The hard part is watching her suffer. Now I look at her suffering through the eyes of faith so therefore I understand. I believe that she suffers for a cause higher than herself and that she knows through our experiences at Lourdes, through our experiences that we've had with this child, she knows this is her job and she asks us to accept that and to walk with her. That's what we know and that's the gift that faith has brought us but it makes it no easier for me to look at her in the middle of a seizure knowing who what soul is this saving? Is it saving my soul? Isn't it supposed to be the other way around? Aren't I the one that's supposed to suffer for my child? So it's quite a journey. It is not an easy simple thing. Life never is.

Serving as my child's voice.

Within the interviews, all of the participants had assumed varying roles as a disability advocate. For all of the participants, the role of parent advocate was deemed to be essential in the educational and health care settings. Mothers' experiential descriptions of advocacy as part of the caregiver role focused both on day-to-day situations and on special circumstances in which they served as their child's voice. This description was particularly evident in the stories shared by mothers of children with an intellectual disability or communication disorder. For example, Nicole, the mother of an adolescent daughter with an intellectual disability and multiple, complex health issues summed up her role and responsibility as the primary advocate for her daughter:

> I learned that she has one advocate, well she has three [participant, father, and sibling] but there is one [person] that is with her all the time and that is me. She has no one's voice but mine and if I don't get loud and I don't act boldly on her behalf, no one will.

For most of the participants, another important part of the advocate role occurred in the context of supporting other parents of children with disabilities. For a few participants, parental advocacy entailed becoming a community advocate in the context of becoming involved with policy-making and advocacy organizations at the local and state levels.

Helping others understand my child. For the participants, an essential aspect of serving as an advocate related to helping others understand their child. When asked to describe their child, all of the participants provided a description that highlighted their child's strengths and abilities. For example, Carol stated, "So Tom is 21 … He is a great

kid. That's the headline. The disability is not the headline". Similarly, Diane described

her son as "He is a charming, happy, interesting person, minimally verbal, can answer

"yes" to my questions, smiles a lot, and is very interested in music". Meg also described

her child as in terms of his social strengths:

> He's just got a wonderful personality. He's very motivated, very social, very loving, very kind, and just has a wonderful personality. He rarely gets angry about stuff, although he does. He has gone through bouts of depression now and then but, basically, he's got a very wonderful, charming personality.

> Eileen explained the challenges she has faced in trying to get other people,

specifically health care providers and educators, to better understand her daughter's

communication that consisted of prolonged bouts of crying:

> People are missing her cues, and so she still kind of communicates like a baby. "You've ignored me and I'm going to cry until you come to me". " I don't want to do this". "I have to stop doing this". So it was communication. It's just that it didn't fall into what they were familiar with, that she really was communicating … it was very basic, but it was her communicating.

> For some mothers, efforts extended into healthcare situations. For example, when

recounting a recent hospital stay for her daughter, Nancy recalled how she and her spouse

requested her daughter be admitted to the pediatric unit, rather than an adult unit. This

request was based on her knowledge of her daughter's special needs and past interactions

with health care providers:

> We very specifically asked her neurosurgeon to put us on the pediatric floor even though she's 19 because she just needs nurses who are going to treat her like she's 5 because really cognitively that's where she is… Don't treat her like she's 19. I know she looks like she's 19. She's not. You need to treat her like you're going to treat the five year old across the hall. And if you can talk to her like that and if you can deal with her, think of her as five, she's going to do better. And they were willing to do that. They were willing to defer to me on certain things in terms of how to approach her and that was very helpful I thought especially in this last hospitalization.

The educational setting was the location in which Diane had experienced considerable frustration in helping the school staff to better understand her son. She described this situation as being a very stressful experience for her and her spouse that repeated itself with each new academic year. To introduce her son to the teaching staff, she resorted to videotaping her son at home to convince the school staff of his abilities:

> We've had a lot of challenges with school, because some of the times his teachers and the staff in the schools don't always or have not always taken the time to understand how to best reach him because of his communication challenges and vision issues. He has cortical vision impairment. He interacts and learns differently from any child that most of them have seen before and, you know …when we go from one year to the next, he would have new teachers and they would sort of start over again as if he were a kindergartener. They expect him to prove to them that he knew everything that he had learned from kindergarten on forward before they would start with that year's subject, and you know to, he would be completely bored, and shut down by the third week of school, and at that point they would say well, obviously, he can't do anything.

Advocating for my child. Beyond helping others to understand their children, mothers reported assuming a continuous role as advocate. Nicole described the need to "trust your gut as a caregiver, as a mom". She also suggested that when she needs to advocate on her daughter's behalf she believes in the presence of an "internal little voice that God has graced us all with and when you ignore that voice is when you get yourself in trouble, and you get your kid in trouble".

Carol suggested the advocacy role as part of her description of the responsibilities of parents of a child with disabilities. She suggested, "You have to be your kid's advocate and champion". Similarly, when discussing her role as a parent advocate, Eileen suggested that she has needed a firm understanding of the roles of healthcare providers and that her motivations were based on her desire to ensure that her daughter

was receiving quality services. She stated, "You have to advocate, and you have to know that people are doing their job well, or that they are a good professional or not a good professional".

Diane described her role in terms of being both a protector and vigilant parent advocate during her son's recent hospitalization. She stated, "I took on the role of making sure that the hospital people were doing the right things like giving him the medication that he was supposed to be having and not giving him the medication that he wasn't supposed to be having. You know, not making all those medical errors".

Carol described hospital staff as desiring her presence during her son's hospitalizations due to his verbal communication limitations. She described herself as an important "linchpin" in advocating for her son. She also recalled a situation that occurred in the previous year, when her son was hospitalized due to pneumonia. She described herself as having to assume a "mother bear" protective role when a physician appeared to not respect the dignity of her son's life:

> So the pulmonologist comes in the room, looks at Tom's chart, looks at Tom, sum total of three minutes, maybe. And we knew that there was some possibility he'd have to go in the ICU because, you know, his oxygen levels were really low. So the guy [pulmonologist] says to us, Tom's in the room, the guy says to us, "If we put him in the ICU do you want us to do everything we can?" Okay. You know. So it takes your breath away, I said this kid is not dying. He's got pneumonia but—this guy had made an assessment about him in three minutes, about the quality and the value of his life.

Kate suggested that as her son has aged into young adulthood, she has felt more empowered as an advocate and better prepared to make health decisions on his behalf as compared to during his early childhood years:

Kate: You just learn and you get experiences and we stand up for our rights much more now for what we think is good for Sean and not necessarily good for what the doctor thinks it is. We don't always agree and we stand up for it and we get second opinions and we try and figure things out. When we were younger and when Sean was younger we did not do that, we just went with what the doctor said and it always wasn't right.

Advocating for other children and families. The advocacy experiences of the participants often extended beyond efforts to ensure quality care and outcomes for their own children. Several participants described their involvement in informal endeavors to support other parents with children with disabilities. Sandy reported on her recent efforts to assist a friend who recently had given birth to a child with disabilities. She reported providing information on early intervention programs, therapists, and insurance reimbursement, with her motivation being rooted in not receiving support when her son was born. She stated, "I'm just trying to help her get some aid because nobody helped us when my son was little … I had no clue about services". Similarly, Helen described her efforts to become involved in supporting other parents as having its basis in her experience of feeling unsupported in her son's early years:

I became very active in a parents' support group because there was no one there for me when my son was born and diagnosed and I don't want that to happen again. I care. I carry a calling card around with me, a business card with my name and email on it and I hand it out to people at Costco because we'll get to talking … I see the child in the wheelchair and I'll say, "Are you new to the area?" And they're like, "Yeah, but we don't know where to go for services … I give support that way.

Nicole also described efforts to support a friend who recently gave birth to a medically fragile infant with disabilities. During the interview, she outlined the advice that she had offered her friend. She reported this to include seeking out a supportive

developmental pediatrician, accepting respite care, and to establish a good relationship with her insurance company, specialty physicians, and specialty nurse practitioners.

Within the interviews, many mothers also reported being involved in community advocacy activities. The mothers' advocacy activities included involvement with policy-making and advocacy organizations at the local and state levels. Several mothers, that were professional special educators, reported being involved with advocacy activities within their school districts. Others were involved with advocacy activities at state and county government. Helen described her involvement on a policy-making governmental board that establishes policy for organizations providing services for individuals with disabilities. Similarly, Eileen reported on her activities with a government council that has been tasked with identifying gaps and finding solutions for services for individuals with disabilities.

Several mothers also reported having been involved in prior research studies focused on families of children with disabilities. Vera reported that her motivation for study participation was to assist professionals in gaining a better understanding of disabilities. Similarly, Helen and Kate reported that they participated in university-based academic learning activities for health care students with the aim of promoting the provision of better health care for individuals with disabilities. For example, Helen and her son have participated in "grand rounds" for physical therapy students.

Facing an Uncertain Future

Within the interviews, the mothers revealed feelings of uncertainty when they considered life in the future for themselves and their children. The mothers' narratives

suggested that they had begun to see their children in a new light, as the children have undergone puberty and face age-triggered transitions into adult health care and social support systems. The interviews suggested reluctance, on the part of most mothers, to look too far ahead into the future. Central to these accounts were the mothers' descriptions of feeling unsettled as they and their family faced these new transitions in the family life course. Additionally, the mothers' narratives suggested sense of uncertainty when considering their roles as future caregivers and as they and their children age together.

Seeing my child in a new light. For all of the mothers, different aspects of their child's transition into adolescence and young adulthood have been challenging. Several mothers shared stories associated with the behavioral and functional changes that they have noted in their child since entering puberty. Vera reported that she had expected emotional and behavioral changes, but was surprised by accompanying physical changes. She stated, "Once those hormones kicked in, Jane... I can't quite explain it, but it was like my daughter had a different body, all of a sudden or not all of a sudden. And she actually lost some of her [functional] abilities."

A few mothers with sons suggested their unexpected sense discomfort in providing for the physical aspects of caregiving as theirs sons' entered puberty. Terry state, "I think now that he's turning 17, hormonal issues are kicking in, so it's hard for me. It's uncomfortable for me as a woman." Similarly, Sandy shared her amazement that her son, who does not have an intellectual disability, has not yet expressed emotional discomfort as she has had to continue to provide for his full physical care:

I thought by now surely he would be like "I don't want my mom bathing me and taking care of me". You know, that's what I worried about a lot too as he was getting older. (I was) thinking "what are we going to do when he gets to the point where he doesn't want me to help with, you know, toileting and cleaning [bathing]?".

Still, another important aspect of these stories was the mothers' perception of others looking at their child in a new light, and their fears for a potential lack of acceptance by others. Carol shared a story of an event that occurred the day before her interview. She reported having traveled to an urban center with her son for a lunch outing. As they proceeded down the street, they were approached by a stranger who pointed to her son in his wheelchair and asked, "What's wrong with him?". Carol reported that despite experiencing emotional distress, she simply responded, "Nothing, what's wrong with you?"

Helen recounted her experience of others' changing reactions to her son since he entered puberty, and shared the story of an interaction with a young man with CP who offered her advice on this topic:

All his life my son has been the cute, sweet, young boy with the smile. Everybody flocked to him. The [young man with CP] said, and that's the way it was for him and then all of a sudden, he wasn't that little boy anymore. He was a young man with facial hair and all the hugs and all the attention he was getting stopped and he said that was the hardest thing for him to understand and to accept. He told me that about 10 years ago and now I'm starting to see it. My son is 18 and I can see he's maturing. You know, I have to shave him every other day. I never thought I'd have to shave my son.

Another mother, Nicole, contrasted her perceptions of others' reactions to her daughter as an adolescent as compared to the early childhood. She suggested that this was a societal issue that had great emotional impact when she was out with her daughter in community:

[In early childhood], she was sort of in a stroller and not in a wheelchair so you didn't have the impact right away of people understanding that you are with someone who was handicapped and that changes a lot especially when they hit puberty and people's perception when you're walking in. When she was little, you'd walk down in the mall and people would stop and they would coo even until she was six or seven because she just looked younger and she wasn't in a really big wheelchair and it would be "Oh, she's so sweet. She looks like a four years old. Oh she's sleeping." … To look at her, you wouldn't know something was wrong. She just looked sleepy and then you have that transfer of time into puberty and then people move out of your way. They don't stop. They look at her and then they look away, so it all changes. So the emotional impact I think is much greater.

Preparing for difficult transitions. When reflecting upon their child's move into adolescence and young adulthood, many mothers identified two age-triggered transitions as having or, potentially having, a great impact on their maternal caregiving experience. First, the transition out of the public school educational setting, and secondly, the transition from pediatric to adult healthcare services. While most of the participants' children had not yet reached these milestones, within the interviews it was evident that mothers were already considering how these transitions would impact their child and family.

All of the mothers suggested that transitions in the past had been difficult for their child, and that many past transitions had impacted the entire family unit. For example, Terry anticipated the difficulties her son will face as he moves from the educational to the work setting. She stated,

I (have) fear as we move into this (Tom's prospective) work environment. Tom doesn't adapt to change really well. I mean he is a creature of habit and it's difficult for him to make changes. He tends to find somebody he trusts and sort of glom on to them and that's us [family] … I don't envy him going into a new place that he doesn't know.

Many participants shared stories of difficulties that occurred with past transitions, particularly in the educational settings such as a move from the elementary school to middle school setting, or the move from one classroom to another. These transitions were described as hard for the child, mother, and family, and often involved the loss of trusted relationships and the building of new relationships with professionals responsible for providing care.

As Carol shared the story of a difficult transition between schools for her son, she began to reflect upon her role as his advocate and her fears for the future when she is no longer able to advocate on his behalf:

> Each and every time my son changed schools was difficult. And with the best intentions and the best planning it's difficult to put him in a new situation because he's such a complicated kid. They need to build a whole world around him at a school. And it's, it's, there's a lot of bumps in getting it right. I remember the worst was he was in elementary school here, had a wonderful support system. They worked for a solid year to make sure the middle school could take him and he knew everything. Well, it just so happened that we moved into this house days before he went to middle school. And we didn't have a phone. I mean we didn't have a phone yet that was working. So they were trying to call us his first day of middle school and they couldn't reach us. Long story short they didn't have an aide for him. They didn't have anybody that could feed him, toilet him, or talk to him in any way. So he sat there first day, new school, big kids around, you know, wet as he could be. Nobody fed him. And it just those kinds of things, I mean, it's an example of the difficulty of these transitions. But it was also the kind of thing that sets me back. I mean what if we hadn't been around? What if we were gone now and that happened? Who was going to look after him? Who's going to go raise hell the next day? You know. So I would say those sort of major markers are very difficult times because it's just not as simple as, you know, throwing him in the car and taking him to a new school.

Eileen used the term "daunting" to describe her thoughts on her daughter's upcoming transition out of the educational setting. She shared her concern, that when her daughter leaves the educational setting, she will lose the support of a large inter-

disciplinary team. Eileen stated, "I could sit in educational meetings, we could discuss, and collaborate, and look at what was going to make my daughter more successful, and what we were going to do, and I felt like I had some backup". On a related note, she feared that the loss of the educational team would mean that no one outside of her family would "know" her daughter:

> It's very scary because then it's really "just going to be my family". It's just going to be my daughter's family that's going to know her. There's not going to be anybody else out of this house that's going to know what she likes or doesn't like. And that's a funny feeling. It's a funny feeling.

For the two mothers of children with severe CP but without an intellectual disability, concerns focused on finding college programs that would offer the types of support services that their child would need to live outside of the family home. They identified that their children would still need full assistance with activities of daily living including bathing, toileting, dressing, transfers, transport, and meals, and reported being unsure if there was college environment that could support independent living for their child.

For the mothers of children with severe CP, and a co-morbid intellectual disability, concerns focused on locating post-secondary school programs that would offer services to meet their child's vocational or supported employment, rehabilitative, and social needs. When asked about maternal caregiving in the future, Nancy discussed her daughter's transition out the educational system, and her uncertainty regarding her daughter's options for employment and community engagement:

> Over the short course I don't see a lot of changes [in caregiving]. I think she'll continue to stay here and we'll continue to be her primary care givers. How long will that last? I don't know. What is she going to be able to do once she ages out

of the school system? I don't know. I think a lot of that depends on funding. Right now we're not in a very good budget place. Funding is looking bad. So what will be available for her? I really don't know. She has some skills, mostly computer related skills, which if we can find some kind of a place where she could use those skills that would be fabulous. But the reality is this is still a child who cannot get her lunch out of her backpack. She can't put her coat on. She can't take herself to the restroom. So she's going to always need to have supported employment. She's not going to be independently employed.

Similarly, Eileen shared her experience of readjusting her vision of her daughter's post secondary school life:

It's a lot of work, and it took a lot of adjusting in our thinking. Our approach has changed in the last seven years or so when we really realized that her communication was not coming along. So as her communication wasn't developing, we started to realize that opportunities for her were shrinking because, even though I'm not a fan of supported employment, with the opportunities for supported employment, really become less, and less, and less, and less if the adult can't communicate in any real purposeful way.

Kate shared the positive story of her 22 year old son's recent transition out of public school special education services to a day center. She reported that she had spent months making multiple visits to different programs to try to identify the best program for her son. She described herself as a worrier when it came to selecting programming options for her son, but was relieved and satisfied by the services offered at his new program. In particular, the nurses gained her praise for offering reassurance and support, and for providing services beyond that offered by the school health staff at her son's secondary special education program:

The nurses at the new day program are allowed to do so much more than the county school nurses that it's almost like "wow". The county school nurse was only supposed to do this and she couldn't do that. They would get real nervous they couldn't use a pulse ox [oximeter] and so they were calling 911 a lot. But at the day program they're just so on top of things and the nurses have had so much more experience with many varied disabilities. And so that just kind of made it a

lot better for me because I'm kind of a worry wart … they've reassured me, they're just great, and I'm sure that soon they'll be like a second family, too.

Within the interviews, several mothers shared the challenges that they have faced in locating specialty physicians as their child transitioned to adolescence. For example, at the time of the interviews, Carol was looking for a new orthopedist, Nancy for a psychiatrist, Eileen for a neurologist. The mothers reported that over the course of managing their child's health care, they were sometimes faced with trying to locate and establish relationships with new pediatric providers who could better managing their child's emerging health issues. Now their chief concerns were focused on their child's upcoming health care transition to adult health care. Namely, the anticipated difficulties in locating adult primary care and specialty physicians that were equipped to deal with a young adult with severe CP and multiple co-morbidities.

Many mothers reported to have established long term professional relationships with pediatric health care providers that they trusted, that they felt truly understand their child's needs. Mothers verbalized anxiety over the future loss of these relationships. For example, Carol stated,

> For most of Tom's life he got a lot of his care through [an academic medical center] - neurology, orthopedic, and, movement disorder. He's aging out of that system. The neurologist …he's a wonderful man. I keep saying, "You're going to break up with us pretty soon, aren't you?" And he says, "Aw, no!" But he means yes. We have to find other care.

Kate was grateful that her son's pediatric CP specialist, with whom her family has had a 22 year professional relationship, had agreed to see her son beyond his 22nd birthday. She described this physician as "an amazing source of support", and reported that the physician had provided the family with his personal phone number in the event

they needed to reach him to discuss their son's emergent health concerns. One of her greatest transition-associated fears was related to this physician approaching retirement age:

> He's [physician] actually getting to the age where he might retire and it's getting kind of sad to me … he usually only does see adolescents, but he told me that he would see Sean as long as I wanted him too, for as long as we need him to.

Aging together. When asked about their vision of their family in the future, several of the participants voiced their plan to "age in place", in the family home providing care for their child as long as physically possible. In discussing her future plans as a family caregiver, Kate stated, "Well my husband and I always talk and we say that as long as we are able, even if we're 100 years [old] and we can still take care of our son, he will be here at home with us". Another mother of a medically fragile child, Nicole, shared her thoughts in the context of a dialogue that she recently had with her young adult son about his responsibility to care for his sister in the event of her and her spouse's deaths, "We do not want her in a home, in a facility. We don't want her in a nursing home. We have not seen good results from that. She will die quickly".

On a similar note, Eileen stated, "She [daughter] is always forever my child 7 days a week, 24 hours each day... we will always have this adult child with disabilities home with mom and dad, and we're all aging in place". She went on to consider her concerns regarding the impact her aging body will have on her ability to provide quality care for her daughter. Eileen stated, "The responsibility is what kind of scares me a little bit as her mom. Am I going to be able to give her the best? Am I going to be able to do

the best?" Similarly, Nancy shared her and her spouse's decision to care for their

daughter at home as long as they are able:

> So I think that at some point down the road, maybe ten years, as we are hitting our
> 60's and our 70's we're going to have to start thinking about, okay, where is she
> going to go from here? When we start getting to the point where we can't
> physically manage her, then we have to start thinking about it. So we'll get there.
> We don't spend a lot of time worrying about that at this point.

Conversely, several other mothers shared their intention to eventually seek an

alternate living situation for their child. For example, Terry reported that she anticipated

that her son would be living with her for the foreseeable future. She and her spouse plan

to seek a retirement community that would have health care services and activities that

would interest her son, but she envisioned him eventually needing to move to a group

home. Helen described her vision for her son's living arrangement, as "ideally, this

would be a small group living situation with other young adults with similar disabilities

in the community-setting". Meg also shared her plan to seek a group home for her son

out of concern for both her age, and the desire to assist her son with this transition.

Uncertainty lies ahead. When asked about their vision of caregiving in the

future, most mothers framed their responses within two distinct concerns. These

concerns were, first, financial planning for future care, and secondly, concerns related to

direct caregiving in the future. The financial planning concern appeared to be a tangible

and easy to talk about aspect of future care planning. All of the participants reported to

have taken actions, or to be planning actions, related to financial planning to ensure that

funds would be available to pay for professional care expenses for their child. For

example, when asked about caregiving in the future, Nicole responded, "So I don't think

about the future because it overwhelms me. We have [however] taken steps financially".

Similarly, Eileen reported, "We have taken steps to try to prepare financially for her so

that whatever comes down the road, there will be that piece in place. That's the one thing

we do try to look at long term."

Many mothers used terms such as "scary" and "overwhelming" when describing

the experience of considering life in the future for themselves, family, and child. For

example, Vera stated, "I have just kind of learned…well, made myself live day by

day…rather than trying to think too much about the future. Because it is scary!". Diane

echoed this sentiment, stating "it's very scary because…I'm almost 59 years old, oh my

God, my son is going on 16. I really don't, at this moment have a clue as to what

happens next for him and me". Nicole further elaborated on her description of the future

as overwhelming when she described her daughter, who has experienced several recent

episodes of critical illness. She stated, "I don't know if she is going to take that [next]

breathe, so I don't worry about the future because I don't know what we have so I leave it

alone."

Most participants voiced a reluctance to look too far into the future with some

offering a timeframe of how far into the future they are willing to consider. For example,

Nancy offered her personal timeframe for future considerations. She stated, "We don't

spend a lot of time worrying about that [the future] at this point. We try to look five

years, maybe even six, seven, eight years down the road". Conversely, most parents

suggested that their focus is on facing day-to-day concerns, rather than spending too

much time being focused on the future. Diane rationalized her outlook as an attempt to

deal with the most pressing issues and to avoid feeling overwhelmed with the myriad of

issues of concern for her son:

> One of my philosophies has always been deal the most important issue that's facing me now rather than trying to deal with every issue that is because if I try to deal with every issue there is, I won't be able to do any of them.

Meg shared similar thoughts and identified her reluctance to look too far into the

future for her family as a coping mechanism for dealing with the anxiety associated with

incertitude:

> I'm of the mind, if we can make it work today we're in good shape. No. That's not completely true but it's hard to think too far ahead with Tom [son]. I mean you know you need to and we've done financial planning…but my darkest days come when I think about when I'm not here who's going to take care of Tom, what if my daughter is not there, and how...vulnerable he is. And so there's a coping mechanism of not projecting too far ahead.

Terry voiced a recurring thought that occurs when she is assisting her son with his

daily care. This anecdote was reflective of an often unspoken, but often alluded to,

concern and unanswered question that was central to the accounts of all of the mothers

caring for their adolescent or young adult child with severe CP:

> As I get him dressed or do anything…even putting on his socks… I'm thinking, "You've got to help me a bit …you've got to learn how to do this". Well he physically can't get down to put on his socks…I sit there and in the back of my mind [think] who's going to do this for him, you know, if something happens to me?

Summary

This chapter offered a detailed description and analysis of the mothers'

experiences caring for an adolescent or young adult with severe CP. One overarching

theme and four essential themes were uncovered during the analysis of experiential

narratives. The overarching theme of "Living a Different Life" was central to the

accounts of the mothers as they shared that their lives were not ones that they could have planned for or that they would have chosen, but they were deeply committed to their children and their role as a maternal family caregiver. The four themes that exemplified the essential elements of the experiential narratives were: (a) Managing a Different Life; (b) Finding My Own Way; (c) Serving as My Child's Voice; and (d) Facing an Uncertain Future. The final chapter includes an analysis and discussion of the themes in light of the four existentials of lived body, lived relationships, lived space, and lived time. It also includes a discussion of the findings as related to existing research, and offers recommendations related to nursing research, education, and practice.

Chapter V

Summary of Findings

The purpose of this study was to explore the essential elements of caregiving as experienced by mothers caring for an adolescent or young adult with severe physical disabilities related to cerebral palsy. The research questions that provided the initial focus of this study were: (a) What is the essence of the phenomena of caregiving as experienced by mothers caring for adolescents and young adults with severe physical disabilities related to cerebral palsy; and (b) What meanings do such mothers ascribe to their experiences?

This chapter will discuss the major findings in this study. Study results are considered in light of existing theoretical literature and research. The first section of this chapter addresses the methodology and key findings. The second section offers a discussion of the major thematic elements in relation to the existential lifeworlds of lived space, lived body, lived time, and lived relation. The third section consists of a discussion of findings in relation to selected ethic of care theories. The fourth section reviews existing phenomenologic family caregiving research focused on cerebral palsy, and discusses thematic elements in relation to family caregiving research focused on CP and other childhood disabilities. The final section will include a discussion of study limitations, and recommendations for nursing practice, education, research, and policy.

Methodology and Key Findings

Methodology

The study employed the hermeneutic phenomenological inquiry approach put forth by Max van Manen (1990) to explore the mothers' world of lived experience. In hermeneutic phenomenological research science, the emphasis is always on lived experience. The purpose of phenomenological research is to borrow other people's experiences and reflections to try to gain a better understanding of the phenomena and its meaning in the context of the human experience (van Manen, 1990). This approach, which is both descriptive and interpretive, was appropriate for the exploration of the phenomena of maternal caregiving among mothers caring for an adolescent or young adult with severe CP, as this has been a phenomenon about which little was known.

The participants (n=11) were recruited from the membership of an advocacy organization of and for individuals with developmental disabilities, and by way of network sampling. Experiential narrative data were collected in interviews conducted in the family home or at alternate location designated by the participant using a semi-structured interview guide and a demographic questionnaire designed by the investigator. Data were analyzed using the phenomenological contextual processing and analysis approach proposed by van Manen (1990). Several activities were incorporated into the study design to ensure methodological rigor. These included verbatim transcription of interview audiotapes, transcription verification, methods expert review of initial transcripts, member checking of analytic theme descriptions and interpretations, and maintenance of an audit trail.

Key Findings

Within the interviews, the experience of maternal caregiving in the context of caring for an adolescent or young adult with severe CP was found to be a complex life experience that had a profound impact on the mothers' lives. Beginning with their child's birth or adoption, subsequent diagnosis of cerebral palsy in early childhood, and transition into adolescence and young adulthood, the mothers' stories revealed the joys, sorrows, and challenges associated with the experience of caring for a child with severe CP. While these maternal caregiving stories included some elements that might be experienced by the mothers of typically developing adolescents and young adults, many elements reflected a maternal caregiving experience that was quite different from the usual normative activities of parenting in relation to the intensity, complexity, and temporal nature of the family caregiving experience.

The analyses of interview text revealed one overarching theme and four essential themes that emerged as representations of the lived meaning of maternal caregiving for the participants. Within the mothers' stories of caring for an adolescent or young adult with severe CP was the overarching theme of *A Different Life*. Directly related to this overarching theme were four themes that offered a fuller description of the essential elements of *A Different Life*. The essential themes were:

- Managing an Unexpected Life

- Finding my Own Way

- Serving as my Child's Voice

- Facing an Uncertain Future

These four themes, which are inter-related and co-exist, offered a new perspective on the experience of maternal caregiving in the context of adolescent/young adult disability, specifically severe CP. Within each essential theme were several sub-themes that further expressed the common thematic elements and offered the opportunity to look at this phenomenon in a new light.

Lifeworld Existentials

The four lifeworld existentials, namely, lived space (spatiality), lived body (corporeality), lived time (temporality), and lived relation (relationality) provide a lens to facilitate interpretation and discussion of the lived experience of maternal caregiving. Van Manen (1990) suggested these four fundamental structures are helpful guides for reflection, as these elements form the intricate unity of the lifeworld. Munhall (2007) supported this assertion, suggesting analysis of phenomenological data in relation to the four lifeworlds offers the potential to further "our understanding of the person in the world" (p. 194). Therefore, these lifeworld existentials were selected as a guide to discuss the thematic elements uncovered in the current study.

Lived Space

The existential, lived space, has been defined as "felt space" (van Manen, 1990, p. 102). Lived space is recognized as largely pre-verbal and something most individuals do not reflect upon. Van Manen (1990) proposed that in general, "we become the space we are in", and that "lived space is the existential theme that refers us to the world and landscape in which human beings move" (p. 102). Therefore, an examination of lived space offers the potential to uncover more fundamental meanings of the lived experience.

In the study, the families' home was central to the mothers' accounts of the caregiving experience. The mothers' narratives suggested their homes were the epicenter of caregiving and were largely considered to be a haven for themselves and their family members. Alternatively, for several mothers, the home was a space that was reluctantly shared with other caregivers, e.g., compensated caregivers, and on occasion, a space that represented a loss of personal freedom. As the epicenter of caregiving activities, the family homes symbolized a safe, comfortable, and mostly accessible space for the mothers to provide care for their children. Home was the place where most family caregiving activities occurred. During the interviews, mothers pointed out architectural and design adjustments that had been made to their homes with the goal of making the environment more conducive to care. Mothers sought to make their caregiving spaces accessible for wheelchairs, standers, mechanical lifts, and in some cases hospital beds, all the while decorating these spaces to look like a home and not a health care space.

While the mothers' homes were the location of the most intense physical caregiving activities, several mothers described attempts to make their home a comfortable refuge for themselves, their child, and their other family members. Homes represented a sanctuary, a place family members could "be themselves" and "be a normal family". Their home provided a space that was devoid of curious stares, of people asking "what's wrong with him/her?" It appeared to also provide a space where mothers were able to protect and shelter their child from a world that is not always accepting of individuals with disabilities.

While home most often appeared to be viewed as a haven, for several mothers it occasionally became a place from which to escape. Particularly, during periods of acute child illness, recovery, and rehabilitation from surgery, or behavioral challenges, home appeared to represent a disquieted place. It was most often during post-hospitalization that home became less of a haven and more of a challenging space as mothers' freedom became restricted due to the increased needs of caregiving for their child, changes in routines, and their child being unable to resume school and recreational activities outside of the home. However, most mothers appeared to have accepted this situation in their caregiving as a part of their "normal" life and as a temporary situation, and made special efforts to plan activities outside of the family home which offered a break from their caregiving routines and responsibilities.

For some mothers, home also represented a personal space that was reluctantly shared with compensated caregivers such personal care assistants and respite workers. While the mothers who employed personal care staff to assist with caregiving shared their appreciation of the assistance they received from these individuals, they also suggested a loss of family privacy and concern for the impact this had on their spouse and other children. Other mothers had opted not to utilize personal care staff because they valued family privacy in their home and were not yet ready to share their home with strangers.

The existential of lived space was also revealed in the physical proximity the mothers maintained with their child. Many mothers, particularly those whose child was medically fragile, reported the need to remain physically close to their child in order to

monitor their child's health needs. This situation most often happened when children had uncontrolled seizures or required suctioning. This type of physical proximity was also associated with maternal acute attentiveness and vigilance. Several mothers slept in a space adjoining their child's bedroom, to be alert to their child's calls for assistance and to be available for their child's toileting, turning, and repositioning during the night. In this context, these mothers' lifeworld was guided primarily by the demands of their child's needs. In several cases, the mothers reported their child desired someone to remain physically close to them or "within shouting distance" throughout the day. This child's desire was related and perceived through both their child's need for real or true assistance with virtually all activities on account of functional limitations, and the child's emotional need for reassurance due to their high level of functional dependence on others. Therefore, the mothers' references of not expecting to experience an "empty nest" can be interpreted as having both spatial and temporal elements. Several mothers voiced the recognition, and the associated disappointment at the prospect, of never having a home that would be empty of children.

Within the interviews, several mothers identified the loss of favorite spaces, outside of the family home, imposed by their child's limitations in accessing others' homes and public spaces. For example, several mentioned favorite vacation spots, such as the beach or a cabin in the woods that were no longer a possibility for family outings due to their child's intolerance to heat and wheelchair accessibility issues. Losses associated with issues of accessibility appeared to be an issue that was not often present in early childhood, but one that developed over time as the child grew larger and

wheelchairs became a necessity. In their child's younger years, mothers reported their children being more portable and could be picked up and carried to any location. This loss of favorite space appeared to be particularly meaningful for the mothers, as it represented the loss of a place their family could spend time alone and create special family memories – away from the usual place of maternal caregiving.

In the mothers' narratives, stories associated with the hospital setting offered further insight into another spatial element of the mothers' lifeworld. Hospitals appeared to represent a physical space that required the mothers to assume a protective and vigilant stance, and adjust family routines to remain at their child's bedside. The hospital bedside was a space mothers dreaded, knowing their child was at risk of an adverse event. This knowledge was based on past experience with issues arising due to medical co-morbidities or provider error. The hospital setting was also a space in which the child was "not known" by their care providers, and mothers needed to introduce their child's needs and desires to the providers. At the same time, they needed to interpret the environment for the child who may not have understood the reason for the hospitalization. In this type of "unfamiliar" space, mothers needed to assume the role of expert caregiver as they supervised, directed, and often assumed responsibility for the physical aspects of their child's care.

Lived Body

The existential of *lived body* refers to "the fact that we are always phenomenologically in the world" (van Manen, 1990, p. 103). Van Manen proposed that when we meet another person in his or her environment or world, we meet the person

through his or her body. Munhall (2007) suggested the mind is embodied and therefore offers a wonderful access to lived experience as we all "negotiate experience through the unity of mind and body" (p. 195). The analyses of the narrative data, in light of the existential of lived body, offered insight into several aspects of the maternal caregiving experience. First, the mothers live in a world with societal expectations of women as mothers and family caregivers. All of the mothers' stories suggested an embodied commitment to mothering and caregiving based on maternal love, empathy, and compassion. The mothers met the world each day with an attitude of physical and emotional strength. The analyses illustrated that the mothers' sense of physical strength was closely tied to their efficacy as a caregiver. Mothers talked about their physical strength most often in terms of strategies to retain the abilities to lift and transfer their child as the child grew older and larger. Several mothers disregarded professional health care provider advice to use mechanical lifts because of their desire to "continue lifting" as their continued expression and commitment to mothering. These actions appeared to be associated not only with the pragmatics of day-to-day caregiving concerns, but also to an attitude of "as long as I can lift this child, I can care for this child".

Another interesting element of lived body was the mothers' experience of embodiment of emotions. While the mothers articulated the emotions most often associated with caring for their child, including joy, happiness, guilt, and frustration, several stressed the importance of avoiding the showing of "negative" emotions in the presence of their child with CP. Mothers sought to be emotionally strong for their

children and families, sought out other releases for the "negative" emotions, and aimed to

present a positive demeanor in their child's and family's presence.

The analyses also suggested the mothers' experiences of physical closeness to

their child allowed them to be attuned to their child's health concerns. Their child's

health often required vigilant observation for subtle emotional, physical, and behavioral

cues of developing health concerns. This type of vigilance supported the assertion by

McKeever & Miller (2004) that the mothers of children with disabilities "know" their

child in a way few others do and are uniquely attuned toward them.

Lastly, mothers also appeared to be attuned to their own aging bodies, with some

identifying how aging has impacted their caregiving abilities, namely their energy levels

and ability to lift and transfer their child. Several mothers mentioned their ages during

the interviews, and suggested they were having difficulty carrying out the same activities

as they did during their child's earlier years due to their aging bodies and own health

concerns.

Lived Time

The existential of *lived time* is "subjective time as opposed to clock time or

objective time" and is "our temporal way of being in the world" (van Manen, 1990, p.

104). Van Manen further suggested whatever has happened in the past "now sticks to me

as memories or as (near) forgotten experiences that somehow leave their traces on my

being – the way I carry myself, the gestures I have adopted, the words I speak and the

language that ties me to my past" (p. 104). The mothers in the current study showed

considerable evidence of the influence of subjective time on the caregiving experience.

The interview narratives suggest experiences in their early days of parenting, and even prior to the birth of their child, had a profound impact on their current maternal care practices. One mother recounted her experience in early childhood and adolescence of being fearful of a neighbor child with developmental disabilities. Early events and experiences associated with the process of receiving the news of their child's diagnosis and early interactions with health care professionals were also significant. Mothers used language such as "it seems like we just received the diagnosis yesterday" and were able to provide detailed accountings of the experience.

The interview texts also revealed the presence of scheduled daily routines associated with caregiving. These scheduled routines were highly structured, and each participant offered an hour-by-hour description of their child's scheduling and care needs. Several mothers suggested that their child did not respond well to transitions or change, therefore they viewed the unvarying schedules as promoting harmony in the family home and lifeworld. While the mothers placed a high value on the benefits gained from the structured daily routine, the narrative analysis also suggested that many mothers desired to have more flexibility and spontaneity in their daily lives.

Van Manen (1990) suggested it is "through hopes and expectations (that) we have a perspective on life to come" (p. 104). Within the experiential narratives, mothers revealed a heightened awareness of the future that appeared to be associated with uncertainty. When asked about their vision of maternal caregiving in the future, most mothers appeared to take a moment to reflect on the question and then articulated a general sense of being unable to fully visualize what this experience would be like. As

mentioned in the description of the essential theme, *Facing an Uncertain Future*, mothers used words such as "scary" and "overwhelming" to describe their experience of contemplating the future. All of the mothers voiced uncertainty in terms of the types of services and funding that will be available to support their child and family caregiving efforts in the future. Several suggested uncertainty in relation to their ability to sustain their current level of caregiving activities as they age. Lastly, a few suggested uncertainty in regard to the life expectancy of their medically fragile child. Commonalities among all the mothers included their recognition they were avoiding thinking about the future, their preference being to focus on present day concerns. Yet, at the same time, the mothers suggested their awareness that age-triggered transitions in the educational and health care systems associated with adolescence and young adulthood would eventually require them to reconsider future life for themselves and their child.

Lived Relation

The existential, *lived relation*, is comprised of the relations "that we maintain with others in the interpersonal space that we share with them" (van Manen, 1990, p. 104). Van Manen proposed, "As we meet the other we are able to develop a conversational relation that transcends the self" (p. 105). He further suggested that in a "larger existential sense human beings have searched in this experience of other, the communal, the social for the sense of purpose in life, meaningfulness, and grounds for living" (p. 105). Munhall (2007) further elaborated on this idea and suggested "individuals provide meaning in their experiences through the expressions of their thoughts, feelings, motives, desires, and emotions" (p. 196).

Within the interviews, mothers explicitly and implicitly suggested the close nature of their relationship with their child. The mothers' focused on the child's strengths and the positive impact their child has had on their lives and the lives of others. However, the child was also described by their mother as being very dependent on them due to functional, and in some cases, also intellectual limitations. This level of dependence appeared to be most often associated with the developmental level of the child. Kittay (1999), a philosopher and the mother of a daughter with an intellectual disability, suggested "independence, acceptance, and normalcy are generally the goals of parents of disabled children – not very different from the goals of most parents raising typically developing children" (p. 23). Yet in the situation of parenting a child with a severe or profound intellectual disability, she acknowledged that a lifelong dependency may be inevitable, and particularly in cases when non-parental caregiving options do not exist or are not preferred. Kittay proposed, "while dependency is often socially constructed – *all* dependence is not" (p. 17). In the current study, while mothers' early efforts focused on maximizing their child's abilities to be independent, as their children entered adolescence and young adulthood, the mothers appear to have accepted their child's limitations and have begun to come to terms with the dependent nature of their parent-child relationship.

Many mothers also suggested that as the main caregiver, they were the recipients of the unconditional love of their child. The notion of unconditional love, being loved without regard for behaviors or actions, is most often discussed in terms of a parent's unconditional love for their child. Most typically developing adolescents and young adults experience periods of dissatisfaction in parent-child relationships. In the current

study, most mothers reported that beginning in their child's early years they have sensed, and, at times, became surprised by their child's unconditional regard and love.

Communication between mother and child was another important element of lived relation. While the type of communication between mother and child varied with each pairing due to most of the children having a significant communication disorder, the mothers valued this relational interaction whether it was through speech, use of an augmentative communication device, or non-verbal communication such as a smile.

Within the interviews, the mothers also suggested their maternal caregiving experience had resulted in strong spousal and sibling relationships in the family. For most of the women in this study, spousal relationships were described in terms of support, loyalty, and commitments. Yet, mothers shared the common challenge of finding time to be alone with their spouse, and having the opportunity to engage in social engagements and recreational activities with their spouse outside of the family home. When their other children were young, mothers feared that the time and energies placed in their relationships with their child with a disability would have a negative impact on their relationships with their other children. Over time, they have realized this relationship had actually a different effect, namely, it enhanced the relationships between themselves and their other children. Another area of enriched relationships for the mothers were their relationships with the parents of other children with disabilities and most extended family members.

Discussion

The current study suggested the experience of caring for an adolescent or young adult with severe CP is a complex experience that has a profound impact on many aspects of the mothers' life. Many of the essential thematic elements uncovered in this phenomenologic inquiry reinforce previous theoretical and research literature. Other thematic elements offer an opportunity to view this experience of maternal caregiving in a new light. This section will discuss the thematic elements in relation to feminist ethics of care theory, previous phenomenologic inquiries focused on the experience of caring for a child with CP, and previous family caregiving research focused on cerebral palsy and childhood disability.

Ethics of Care Theory

This study connected with the theoretical work of several feminist thinkers who have offered explanations for why women assume primary responsibility for care in many societies. Care focused feminists have developed ethics of care to explain the moral language of care. Tong (2009) proposed these theorists focus on the nature and the practice of care and "regard women's capacity to care as a human strength, not a weakness" (p. 163).

Gilligan (1982), author of the seminal text *A Different Voice*, suggested women have three levels of moral reasoning. In the first level, an individual's moral agent overemphasizes her own interests; in the second level, the moral agent overemphasizes others' interests; and in the third level, an individual strikes a balance between her own interests and the interests of others.

In the current study, mothers appeared to recognize and to be actively working toward striking a balance between the needs of their child and their own needs. While the mothers were highly focused on their child's needs and willing to subjugate personal desires, they demonstrated remarkable self-awareness of their own interests and needs. The narratives provided examples of the multiple strategies mothers used as they sought to balance the demands of caregiving with their own desires. These included actions such as surrounding themselves with supportive people, arranging for time away from caregiving responsibilities, and in some cases working outside of the family home. The third level of moral reasoning was also evidenced by the generally held attitude of acceptance that can best be summarized as, "this is just the way that life is – it is, what it is".

The study findings also connected with the work of Noddings (1996). In proposing a feminist ethic of care over an ethic of justice, Noddings put forth a relational ethic of care based on the universality of a caring attitude. She proposed that we act from a natural caring that impels us to help others. She suggested a caring individual, referred to as the "one-caring", comes across to the "cared-for" in an attitude of reciprocity. In the context of the maternal-child relationship, she suggested it is "in this engrossment (of mother and child) that the one-caring assumes her full individuality in relatedness" (p. 22). She further suggested that, while what goes on in caring is rational and carefully thought out, the basic relationship is not, and neither is the required awareness of relatedness.

In the current study, the maternal-child relationship reflected elements of the Noddings' ethic of care. In their roles as caregivers, mothers demonstrated the attitudes of warmth and trust necessary for caring relationships. Noddings' assertion that the one-caring views the child's world through both sets of eyes was particularly descriptive of the mothers' experience in the current study. Due to their child's disabilities and co-morbid conditions, mothers in the current study must often assume the dual perspective seeing the world through their child's eyes.

Lastly, the findings also resonated with the feminist ethic of care as put forth by Ruddick (1995). Ruddick's theory of maternal practice puts forth that "to be a 'mother' is to take upon oneself the responsibility of child care, making its work a regular and substantial part of one's working life" (p. 17). Ruddick proposed that mothers are committed to meeting the demands that define maternal work, namely, demands for preservation, growth, and social acceptability. These three demands are constitutive of maternal practice. Preservation, or preservative love, involves actions of protective care, concerns associated with child safety and well-being. The second demand, to foster growth, is associated with nurturing a child's emotional and intellectual growth. The third demand is not based on children's needs, but on social group criteria of acceptability. The criteria of acceptability "consist of the group values that a mother has internalized as well as the values of group members whom she feels she must please" (p. 21).

In the current study, mothers demonstrated a high level of activity that can best be described as work, to protect and care for their vulnerable child. In keeping with

Ruddick's suggestion that "as a species, all children share prolonged physical fragility and therefore prolonged dependence on adults for their safety and well-being" (p. 18), the mothers put tremendous efforts into promoting and ensuring the health, safety, and well-being of their child. Mothers also placed great emphasis on nurturing not only their child's emotional and intellectual growth, but also to maximize their physical functioning. Ruddick proposed that children "grow 'naturally', if provided favorable conditions for growing" (p. 19). In the current study, mothers demonstrated intense and sustained efforts to provide the favorable conditions for their child's growth and development. Mothers also described efforts to socialize their child for acceptance in a world that is not always welcoming of individuals who are different. Examples included involving their child in extended family activities, seeking opportunities for child and community engagement, respectfully answering questions about their child, and responding to the stares of others with a polite smile. The experiential narratives suggested maternal challenges associated with rejection, stigma, and a sense that their child has not always been "accepted by the normal world".

In a critique of Ruddick's work, Kittay (1999) suggested the maternal practice experience is altered among mothers caring for dependent persons with disabilities. She stated "when the commitment to the child (with disabilities) has been made, preservative love comes to occupy an overridingly central place in one's maternal practice" (p. 16). Specifically, she suggested a child's fragility elevates this aspect of maternal practice. Findings in the current study support this notion as mothers were noted to be highly engaged in the preservative love activities associated with health, safety, and well-being,

but were also engaged in nurturing their child's growth and facilitating social

acceptability. It was noted, however, that the experiential narratives focused on a child's

acute illness, surgery, hospitalization, or rehabilitation did include a heavier emphasis on

the maternal practices associated with preservative love.

Lived Experience of Caregiving in the Context of CP

Three previous studies have addressed the lived experience of caring for a child

with CP. While these studies focused on the experiences of mothers with young children

(Glassock, 2000 & Moore, 2005) or fathers (Appelbaum, 2007), it is important to

consider the findings in light of the current investigation as some study themes parallel

those uncovered in the current study and some differ.

Glassock (2000) examined the experience of mothering a young child with spastic

CP. Using a phenomenological approach, she found the clustered themes of *caregiver*

burden, *family/social support*, *women's/mother's roles*, and *socio-economics*. Glassock's

description of caregiver burden included the day-to-day caregiving responsibilities that

impacted the mothers' time and energies, and possessed some similarities with the

experiential qualities of the current study's theme of *Managing an Unexpected Life*.

However, in the current study, these experiential data were not interpreted thematically in

terms of "caregiver burden". Of note, Glassock's essential theme of *family/social*

support and women's/mother's roles included narratives that did not differ greatly from

the experiences shared by the mothers of the adolescents and young adults in the current

study. For example, in both studies, mothers reported seeking out supportive

relationships and described in detail the impact of caregiving on activities of daily living

and family relationships. A fourth theme identified by Glassock, namely *socio-economic concerns* associated with employment and financial status, was not a dominant theme in the current study's narratives. Perhaps the mothers of the older children had already sorted out employment decisions by the time their child reached adolescence and young adulthood, and their families had benefited from the financial security often associated with more time in the workforce.

Moore's (2005) master's thesis research, involving the lived experience of five mothers of young children, aged 4 – 11 years, with severe CP, found complex themes associated with sorrow, chronic worry, adaptation, advocacy, and personal growth. Moore reported the themes of: (a) mothers creating unique ways to interact with their child; (b) mothers describing positive aspects of parenting; (c) child's diagnosis is a lifelong journey of recurrent adversity; (d) mothers' experiences necessitate dealing with many types of burden; (e) support from others is appreciated but not always received; and (f) typical family life is disrupted resulting in altered relationships among family members.

The current study lends support to several of Moore's findings. For example, Moore's thematic element of "many types of burdens" included sub-themes associated with the physical demands of maternal caregiving, the acquisition of complex caregiving competencies, and inadequate family respite. Additionally, Moore identified the CP diagnosis narrative as being very meaningful for mothers. In this study, mothers offered an accounting of the CP diagnosis experience in exquisite detail although these experiences had occurred several years earlier. Moore also reported participants as

having the perception of a lack of support from community and some family members, and the mothers' conscious decision to seek out and surround themselves with supportive extended family members, most often grandparents, and friends. Interestingly, in her study of mothers with young children, Moore suggested the presence of maternal concern for disrupted sibling relationships, namely sibling fear, jealousy, and needs for attention. In the current study, mothers reported having these concerns when their children where young, but reported enhanced sibling relationships as their children have moved into adolescence and young adulthood.

In a third phenomenologic inquiry focused on family caregiving in the context of CP, Appelbaum (2007) examined the experience of being the father of a child with severe CP. Interestingly, several themes in the current study of the maternal experience align with the paternal study findings. For example, Appelbaum reported the paternal experience to include efforts to recognize and focus on child strengths, manage the stress associated with child illness and hospitalizations, facilitate spousal partner loyalty and commitment, and concern for the way the child is received in the world. These efforts were similar to those found among the mothers in the current study. A key difference between the two studies relates to findings associated with the parental role of health care advocate. Appelbaum reported fathers' experiences of being marginalized by health professionals in the health care decision-making process, as their spouses were recognized as the key health care decision maker. Conversely, in the current study, while mothers reported being a key player in health care decisions made for their child, and

their interview narratives suggested their perceptions of their spouses as having a very active role in health care advocacy on behalf of their child.

Discussion of Previous Studies in Relation to Essential Themes

The overarching theme, *A Different Life*, was uncovered in participants' stories of living a life that was different than expected. None of the mothers had anticipated being the parent and maternal caregiver for a child with severe physical disabilities. Consequently, their lives were different, and often more challenging, than the lives that they had expected in terms of the temporal and relational aspects of family caregiving. Yet, in spite of the differences and demands, mothers described lives that were deeply enriched by their maternal caregiving experience and the satisfaction gained in embracing their role, managing their complicated life, committing to caring, normalizing and optimizing family life, and advocating for their child.

Managing an Unexpected Life

The first essential theme, *Managing an Unexpected Life*, was revealed in the mothers' experiential stories focused on the unexpected nature of their lives. From the time of their child's diagnosis, mothers felt obliged to assume a parenting role that required many different competencies other than those required of parents of typically developing children. One of the unique competencies was the ability to swiftly take action in locating, accessing, and navigating a complex array of health care services for their young child. Often this began at a time when mothers were struggling to deal with their child's diagnosis, and they perceived little support and initial direction from health care providers. Mothers were then quickly thrust into the position of dealing with teams

of medical and educational specialists, whose primary aims were to maximize their child's functional abilities and health.

While the mothers highly valued the services of the professionals, they often perceived unrealistic expectations on the part of professionals in terms of the mothers' responsibility for follow-through on rehabilitative activities at home. Mothers became the "linchpin" on the team, with a dual role as their child's parent and the expert manager of health and caregiving concerns. As their child matured, mothers often made decisions associated with rehabilitative and medical treatment goals. These decisions, which did not always align with professional recommendations, were made with the goal of maximizing what the mothers' perceived as their child's strengths, the recognition that their child could not always be "fixed", and an acceptance of their child's limitations.

Beginning in their child's early years, and continuing into adolescence and young adulthood, mothers in the current study reported often experiencing exhaustion associated with the physical demands of caregiving and recognized the unchanging nature of the care that they provided over time. Yet, despite the exhaustion, the mothers strongly desired to continue to be the primary "carers", as they viewed this as an essential part of their role as a mother.

The thematic elements uncovered in the current study lend support to several studies focused on family caregiving in the context of CP. For example, the current study's experiential narratives suggested positive and negative impacts associated with caregiving that mirror those found in a grounded theory investigation of the quality of life (QOL) of 37 Australian parents caring for children aged 3 – 18 years with CP (Davis et

al., 2009a). The purpose of this investigation was to explore the impact of caregiving on parental QOL and to examine whether the impact changes from early childhood to adolescence. Davis et al. reported this study was, to their knowledge, the first qualitative study of the QOL of parents of children with CP. Their sample of 24 mothers and 13 fathers, included 12 parents caring for a child that met the criteria for GMFCS Level V. Findings suggested that family caregiving can negatively and positively parental QOL. Negative impacts included demands on physical health, disrupted sleep, difficulty maintaining social relationships, pressure on marital relationships, difficulty taking family vacations, limited freedom, limited time, a child's long-term dependence, difficulty maintaining maternal employment, financial burden, difficulty accessing and funding services, and insufficient support from services. Positive impacts included, the parents' ability to build new support networks and parents' ability to draw inspiration from their children. Interestingly, for this sample, no differences in quality of life were found among participants based on their child age or severity of disability.

The thematic elements in the current study offered support for impacts of several QOL issues such as those related to a child's long term dependence, maintaining physical health, call to action, and dealing with a team. Several QOL issues were also supported by the thematic elements associated with the essential theme *Finding My Own Way* such as maintaining social and familial relationships, and limited freedom.

Similarly, Green (2007) investigated caregiver burden and benefit in a mixed methods study of 81 parents of children with disabilities, including the mothers of children with CP. This study was an examination of the daily hassles, emotional distress,

and benefits experienced by mothers of children with disabilities. Using a mixed method survey, findings suggested caring for a child with disabilities required: intensive and time consuming contact with the medical delivery system; placed considerable demands on mothers' time; was physically exhausting; and impacted the maternal ability to meet employment expectations. Supportively, the current study showed mothers' experiences in managing complex health concerns and physically demanding caregiving.

In the current study the diagnosis disclosure story was an important element in the mothers' caregiving stories as they assumed their unexpected role. These findings lend support to those in an earlier study related to the diagnostic disclosure of disabling conditions (Davies, Davis & Sibert, 2003). While these investigators focused on the parents of children with severe cerebral palsy or a lethal genetic disorder, findings suggested that the parental experience was significantly impacted by the parents' perception of practitioner sensitivity. Sensitive practitioners were characterized as having the attributes of technical expertise, good communication, interpersonal and time management skills, as well as human sympathy and understanding. In contrast, insensitive practitioners were characterized as not having these essential attributes, and as demonstrating an "unwilling(ness) to enter the lifeworld of parents and understand it (diagnosis) from their perspective" (p. 81). In the current study, mothers placed high value on effective, sensitive, and empathic health care provider communication.

The current study's thematic element of *Dealing with a Team* supported recent research by Wiart, Ray, Darrah, and Magill-Evans. (2010) that examined mothers' experience of collaborating with therapists to jointly develop child rehabilitative therapy

goals. In this qualitative investigation of 39 parents of children aged 2-17 with CP, parents identified the challenges associated with collaborative goal setting with therapists, with predominant parental goals being associated with their child's happiness and acceptance by others, and parental recognition of "we can't do it all". In this investigation, mothers reported struggling with balancing therapy demands with the demands of everyday life. Similar to the current study findings, mothers placed high value on a balanced family life and reported making the decision at times to forego therapists' recommendations to promote a balanced family life. The findings associated with mothers' decision making also relate to the essential theme of *Finding My Own Way*.

The current study's essential theme of *Managing an Unexpected Life* also supports findings in several earlier studies that focused on the management of childhood chronic illness and disability**.** For example, Sullivan-Bolyai, et al. (2003) proposed four major caregiving responsibilities and actions based on a synthesis of the parental family caregiving literature. These responsibilities were identified as: (a) managing the illness; (b) identifying and accessing community resources; (c) maintaining the family unit; and (d) maintaining self. While the authors aimed to identify the major caregiving responsibilities performed by mothers and fathers caring for a child with a chronic condition, this included both children with chronic illnesses and disabilities. The management categories identified by the authors closely align with several essential themes identified in the current study. For example, the responsibilities associated with managing the child's illness or disability related to several of the sub-themes within the

essential theme of *Managing a Different Life*. The responsibility of identifying and accessing community resources related to the current study's thematic elements of managing complicated health concerns and call to action. Lastly, the responsibilities of maintaining the family unit and maintaining self closely align to the current study's essential theme *Finding My Own Way*.

Likewise, the current study's findings lend support for Ray's (2002) model of special needs parenting, Parenting and Childhood Chronicity (PACC). This model was based on the findings of an interpretive qualitative study of mothers caring for a child with special health care needs. It focused on the work of special needs parenting and how parents work to minimize consequences to the family. The model proposed that special needs parenting responsibilities included managing the medical care, advocacy efforts, and working the health, educational, and social service systems. The construct of minimizing consequences included actions to optimize parent physical and emotional health, maintain personal relationships, and provide parental attention to siblings.

Many of the elements in the comprehensive PACC model are reflective of the findings in the current study. While this model focused solely on responsibilities and actions, many of these elements are closely aligned with the maternal caregiving activities uncovered in the current study. For example, the model's sections focused on managing medical care and working with the health, educational, and social service systems reflect the thematic elements of managing complicated health concerns and building a team in the current study. In addition, the constructs of minimizing

consequences to the family and advocacy efforts correlate nicely to themes in *Finding My Own Way* and *Serving as My Child's Voice*, respectively.

In a metasynthesis of 12 qualitative maternal caregiving studies, Nelson (2002) proposed 4 steps associated with mothering a child with a mental or physical disability. These steps, based on a secondary analysis of study findings and categorized themes, include: (a) becoming the mother of a disabled child; (b) negotiating a new kind of mothering; (c) dealing with life: it will never be the same; (d) and the process of acceptance or denial. While a major limitation in this metasynthesis was associated with the heterogeneity of the groups of mothers, the findings in the current study offer support for several, if not all, of the steps. Both studies' findings suggest the experiences of trying to manage the emotions associated with the diagnosis, the steep learning curve associated with caregiving in the early years, a perceived lack of support by the health care system, dealing with uncertainty, seeking a new normalcy, and the emotional pain associated with a perceived lack of support by extended family members.

Finding my Own Way

The second essential theme, *Finding My Own Way,* was revealed in narratives associated with mothers seeking and finding their own ways of successfully living their different life. This caregiving experience was found to require an ongoing effort to balance family demands, determine best options and decisions, and manage all of the emotions associated with family life and caregiving. Mothers identified caregiving as not being easier or harder in adolescence and young adulthood, but just different in this transitional period of family development. The narratives revealed the mothers'

experiences of joy, happiness, guilt, and frustration, and the challenges associated with managing difficult child behaviors. Mothers also voiced the conscious decision to surround themselves with supportive people. Most mothers did not have extended family residing their local area, but family members, especially grandparents, offered incredible support from near or far. However, over time, many grandparents were no longer able to maintain an active support role due to illness or death. A few mothers reported the decision to distance themselves from extended family members who appeared to reject their child. Spousal relationships were found to be especially important and involved a strong sense of teamwork and commitment. An important part of this essential theme was the mothers' experiences of gaining a sense of empowerment over time to make decisions that they thought were best for their child and family, and the recognition of needing to accept the outcomes and repercussions of these decisions. Lastly, the quest to find meaning in their own and child's life was revealed in narratives associated with the impact their child had on their own lives, and the lives of others, and the relationships and career decisions that have evolved from this caregiving experience.

As discussed in previous sections, balancing the demands of family and home life were an essential part of the maternal caregiving experience (Glassock, 2000; Moore, 2005; Ray, 2002). The thematic element of *Balancing Family Demands* in the current study supported findings in the earlier studies with regards to mothers' actions to maintain family relationships, care for siblings, maintain employment, and manage the family home.

Mothers also voiced the conscious decision to surround themselves with supportive people (Glassock, 2000; Moore, 2005). In the current study, most mothers did not have extended family residing their local area, but family members, especially grandparents, offered incredible support from near or far. However, over time, many grandparents were no longer able to maintain an active support role due to illness or death. Similar to the findings of Bourke-Taylor, Howie, & Law (2010), a few mothers reported the decision to distance themselves from extended family members who appeared to reject their child. In support of Appelbaum (2007), the current study found spousal relationships to be especially important as they involved a strong sense of teamwork and commitment.

The current study's narratives revealed the mothers' experiences of joy, happiness, guilt, and frustration, and the challenges associated with managing difficult child behaviors. These emotions mirror those reported in previous studies (Bourke-Taylor, Howie, & Law, 2010; Glassock, 2000; Moore, 2005) that found that the lives of mothers with disabilities may be much more emotionally complex than generally assumed (Green, 2007; Kearney & Griffin 2001). In a phenomenological inquiry of six parents of children with developmental disabilities, Kearney and Griffin found the themes of joy and sorrow, suggesting a dynamic interplay between these emotions. The authors described mothers as strengthened by the experience as they developed new perspectives on life as the result of their experiences and challenges.

The current study's participants' experience of feeling unsupported by health care professionals in the early days was a recurrent theme in several studies (Davies, et al.,

2003) and lends support to a recent study of Taiwanese mothers caring for children with CP. In a phenomenological investigation, Huang, et al. (2010) examined the experience of Taiwanese learning of their child's diagnosis of CP. While the findings of this study must be considered in light of the Taiwanese culture, a recurrent theme was the mothers' experiences of grief, anger, and frustration when health professionals failed to provide empathetic support. Empathetic support was also a need similarly identified by mothers in the current study, who expressed the desire for health care professionals to take note of the complex and competing demands in their lives.

Bourke-Taylor, et al. (2010) reported on a qualitative analysis of eight mothers of school-aged children with disabilities, which included several children with severe CP. The study found significant mental health issues including anxiety and clinical depression among mothers. The authors identified several key issues that challenged the mothers, namely, the need to be highly organized, the ability to accept missing out on opportunities in their own lives, and the ability to separate from their child. While the mothers in the current study did not report significant mental health issues, there were several other areas of similarities between the studies. The similar findings included mothers' anxiety and guilt about sibling care and coping skills, community access and physical accessibility issues, and concerns associated with the availability of support services. The current study also found that mothers design and implement highly organized routines to meet the daily demands of caregiving.

When considering the temporal nature of the family caregiver experience, Grant, et al. (2003) offered a theoretical model of mapping temporality in family caregiving

based on two processes, the transactional nature of caregiving and the development of caregivers' expertise over time. This model focused on the families of children with intellectual disabilities and was influenced by the lifecourse perspective. The authors proposed six stages of family caregiving: (a) Building upon the Past, prospective parents engage in anticipatory activities as they depict 'caring about' their prospective children and family; (b) Recognizing the Need, occurs when parents become aware that they are, or are about to become, the parent of a child with disabilities; (c) Taking it On, parents may begin to feel isolated, marginalized, and extended family and social relationships may become compromised as they struggle to seek a sense of normalcy; (d) Working it Through, includes a proactive stance by families in managing their affairs and acquiring expertise in everyday caregiving; (e) Reaching the End, the parents reach the "twilight of their commitment to caregiving", associated with a heightened sense of caregiving enrichment, less stress, and better ability to use the coping and caring skills acquired over time; and (f) A New Beginning, when family members move their child to residential placement and experience a sense of marginalization of the knowledge, insights, and expertise accumulated over their child's lifetime.

While this model focuses on families, not just mothers, the current study offered support for the stages of (b) Recognizing the Need, (c) Taking it On, and (d) Working it Through in the findings associated with balancing family demands and acquiring expertise to making health care decisions. The current study did not support (e) Reaching the End and (f) A New Beginning. While the mothers in the study, had not yet reached the "Twilight of their Commitment to Caring" they did voice concerns associated with

their child' continuing care needs and uncertainty for their and their child's future as they aged. A key difference between the current study's findings and model proposed by Grant, et al. relates to future uncertainty. These differences will be discussed in a later section on *Facing an Uncertain Future*.

Serving as my Child's Voice

The third essential theme, *Serving as My Child's Voice*, was in the experiential narratives associated with advocacy activities on behalf of their child, other children, and community members with disabilities. The mothers were proactive in assisting others, namely health care and educational professionals, to better understand their child. Often because of communication impairments, the mothers served as their child's voice in articulating their child's likes, dislikes, preferences, and desires. Mothers suggested this was an integral part of their role as parent and advocate. Of note, mothers' advocacy activities, on their own children's behalf occurred primarily in the health care and educational settings.

These findings confirmed research related to perceptions of delivery service among the families of adolescents and young adults with CP. In a qualitative investigation of 49 adolescents and 39 young adults and their families, Darrah, Magill-Evans, and Adkins (2002) reported family's accounts of constantly having to work the system to advocate for their child with CP. These study participants also suggested that many service providers did not understand the needs and abilities of their child. Ray (2002) used similar language in the Parenting and Childhood Chronicity model. One key section of the model, based on earlier qualitative work, is focused on parents' efforts

within health, social service, and educational systems that are often perceived as being unsupportive to families. Bourke-Taylor, et al. (2010) reported a similar finding that mothers constantly served as advocate and coordinator of care due to parental perceptions of children not being understood by others and their inability to advocate for themselves.

In the current study, the mothers' efforts extended beyond their own child. All were involved on an informal basis with supporting other families managing childhood disabilities, and many were involved in professional and volunteer advocacy efforts in the community on behalf of individuals with disabilities. Klein and McCabe (2007) reported on the experiences of 14 mothers of children with disabilities who were employed in the disability field. Like the mothers in the current study whose employment related to disability services, these mothers suggested that their caregiving experiences had impacted their credibility with other parents, career choices, personal and professional growth, and recognition of mothers' expertise.

The experience of personal growth, as the result of caring for a child with disabilities, was noted in several investigations. Davis, et al. (2009) reported that parents drew inspiration from their child, and often referred to the courage and resilience that their child possessed. Green (2007) reported that over time, "the advocacy skills and accompanying confidence that parents gain, can spill over into other areas of life and be a source of self esteem" (p. 158). Findings in the current study were consistent with these previous studies as mothers voiced a sense of pride and empowerment when sharing their caregiving stories.

Facing an Uncertain Future

The fourth essential theme, *Facing an Uncertain Future*, was uncovered in experiential data associated with narratives that included recollections of earlier difficult transitions, and concerns associated with difficult transitions that lie ahead as their children traverse the societal and policy boundaries between adolescence and adulthood. When mothers considered caregiving in the future, they used terms such as "scary" and "overwhelming". Mothers appeared comfortable talking about financial planning for the future, but more tentative when considering how they will manage their child's care requirements in the future, upcoming age-triggered transitions in health care and educational services, and their vision of future family life. All mothers suggested an initial plan to "age together" in the family home. They admitted that while the concern of caregiving in the future was often at the forefront of their mind, they avoided dwelling it.

A few mothers, whose children experienced fewer co-morbid health concerns, anticipated seeking a community group home placement for their child in the future. These mothers suggested they viewed this as viable alternative for their child to allow for the transfer of day-to-day caregiving responsibilities and to increase their child's community participation. For most mothers, particularly those whose children experienced multiple medical co-morbidities and can best be described as more vulnerable and medically fragile, there were no plans for the child to eventually move to an out-of-home placement. These mothers were adamant that they planned to provide care in the family home for as long as possible.

All mothers expressed concerns associated with the availability and quality of community programs, funding for services, and current public policies that they perceived as not supporting full inclusion or community participation for their child. Maternal uncertainty was also associated with future health care, educational, and vocational transitions. Mothers recalled past transitions that proved to be difficult for their child and family, and voiced uneasiness about the age-triggered challenges that lie ahead. These transitions included their child's transfer from pediatric to adult health care services, and movement out of the public school system to a day program, vocational program, or higher education venue. Most suggested these transitions were on their "radar" and were concerns they thought about often, but they would delay decision-making and action until a time when the concerns needed to be addressed.

While the first three essential elements, namely *Managing an Unexpected Life*, *Finding My Own Way*, and *Serving as My Child's Voice*, in the current study offer support for findings previous caregiving studies and theoretical literature, the essential theme of *Facing an Uncertain Future* was found to be different from earlier findings focused on uncertainty in the families of children with CP. Perhaps, these differences or omissions relate to the observation that most of the existing family caregiving literature, in the context of CP, tends to focus on younger families (Glassock, 2000; Moore, 2005), groups of families with children of varying ages (Appelbaum, 2007), or on discreet concepts such as stress (Button, et al., 2001; Glenn et al., 2008; Manuel, et al., 2003), adaptation (Florian & Findler, 2001; Lin, 2000; Magill-Evans, et al., 2001; Rentinck, et al., 2006), parental well-being (Barlow, et al., 2006), and more recently quality of life

(Lin, 2000; Davis et al., 2009a). These focus areas mirror the general childhood disability literature. As earlier referenced, Grant, Nolan, and Keady (2003) proposed the last two stages of family caregiving to be *Reaching the End* and *A New Beginning*. The current study failed to support those stages as most mothers indicated their plan to age together with their child in the family home. The mothers in the current study did not appear to the see the new beginning as suggested by Grant el al., but instead voiced unease associated with an uncertain future that would include several age-triggered transitions for their child.

Over the last two decades, nursing and social science researchers have examined the phenomenon of uncertainty in different samples of family caregivers, and have sought to advance the scientific understanding of the concept. Parental uncertainty, in the context of childhood illness and disability, has been examined in the parental caregivers of pre-adolescents with chronic conditions (Garwick, Patterson, Meschke, Bennett, & Blum, 2002), adolescents and young adults with mental illness (Jivanjee, Kruzich, & Gordon, 2009), children with cancer (Lin, Yeh, & Mishel, 2010), children with brain tumors (Hutchinson, Williard, Hardy, & Bonner, 2009), and grandparents with primary caregiving responsibilities for children with developmental delays and disabilities (Janicki, McCallion, Grant-Griffin, & Kolomer, 2000). These investigations have focused on uncertainty as it relates to the psychological impact of the illness experience. Similarly, in a synthesis of studies focused on uncertainty in childhood illness, Stewart and Mishel (2000) suggested that parental uncertainty occurs in relation to the diagnosis experience, illness trajectory, illness causation, and long-term survival.

In the current study, only a few mothers expressed uncertainty regarding the illness/disability trajectory for their child and long-term survival. Many of the children were viewed as being "relatively healthy" by their parents, and CP is not a progressive disease. While all of the children face future health concerns, and the potential for diminished functional abilities, the mothers of most of the children did not express uncertainty in relation to their child's illness/disability trajectory. This observation might be explained by the mothers having cared for their child with CP for 15-20 years, possession of a comprehensive understanding the disability trajectory, and having become expert caregivers. Instead, all mothers voiced uncertainty associated with their own personal limitations, community supports for their child, and the future transitions that lay ahead.

The concept of transition had garnered much attention in the health and social science disciplines over the last three decades, and has been used in diverse ways. Following a comprehensive review of the concept of transition in health literature, Kralik, Visentin, and Van Loon (2006) concluded that "transition is a way that people respond to change over time when they need to adapt to new situations or circumstances in order to incorporate the change event into their lives" (p. 322). Time is recognized as an important element in transition. This assertion lends support to the life course paradigm which subscribes that the life course is a series of interdependent age-graded trajectories, such as work and family, which are shaped by age, social structures, and biological change (Elder & Johnson, 2003). Transitions often involve "changes in status or identity,

both socially and personally, that open up opportunities for behavioral change" (Elder, et al., 2004, p. 8).

For mothers in the current study, the anticipation of their child's approaching age-triggered transitions in education and health care was a source of uncertainty and ambiguity. Turner (2000) suggested transitions have a liminal quality, namely, being an ambiguous period of being "betwixt and between" (p. 358). Turner likened this period to being in a wilderness, as individuals "pass through a cultural realm with few or none of the attributes of past or coming state" (p. 359). The mothers in the current study voiced experiences that were analogous of being in a liminal state. While mothers had past experiences with caregiving transitions, such assuming the role of caring for child with significant disabilities and managing their child's entry into educational and health care services, the mothers recognized their child's age-triggered transitions associated with adolescence and young adulthood as having liminal qualities, namely, a period of uncertainty.

The transition needs of adolescents and young adults with special health care needs, and their families, are topics that have gained increased attention over the last two decades. Children with special health care needs include "that are or who are at risk for chronic physical, developmental, behavioral, or emotional conditions and who also require health and related services of a type or amount beyond that required by children generally" (McPherson, et al., 1998). Betz and Nehring (2007) suggested that transitions for this population and their families are not well understood by professionals due to the limited amount of available evidence. Based on a review and analysis of 43 studies over

the last two decades, Betz (2004) concluded that current transitional research is in its early stages, and its research primary focus has been on the issues confronting the adolescent and young adult as they transition to adult health services such as transfer criteria and transition barriers. While most investigations have focused on the adolescent and young adult transition perspectives of self care in the context of a variety of chronic health concerns (Lawton, Rankin, Peel, & Douglas, 2009; Kirk, 2008; Miles, Edwards, & Clapson, 2004) and more recently models of family centered care (Duke & Scal, 2011), fewer studies have examined the parental perspective on health care transition. A review of the literature revealed very few studies focused on the transition experiences of parents caring for adolescents with both special health care needs and disabilities. In case studies of three parents caring for adolescents with neurodevelopmental disabilities, Hartman, DePoy, Francis, and Gilmer (2000) found that adolescents with both special health care needs and disabilities do not follow the typical developmental sequence of adolescents. They suggested the primacy of the diagnosis, the timing, and its nature in the lives of the youth and their families influenced the parental perception of their child's transition to adulthood. In this investigation, child age and maturation were found to have a moderating effect on the parents' sense of burden and view of independence as a goal for their child.

In another of the few investigations that included the parental perspective on the transition for young adults with chronic health concerns and disabilities, O'Connell, Bailey, and Pearce (2003) reported on the findings of focus groups conducted with Australian young adults, parents, and case managers. Family caregivers described a

health care system that relied heavily on families to shoulder the burden of care for the young adult with CP. Caregivers suggested issues with locating and accessing services, problems with dealing with new issues such as adolescent sexuality, and having to manage difficulty situations without support. The current study lends support to these findings, as mothers shared concerns associated with locating and accessing health care, and social and vocational services that are geared toward the young adult.

In a qualitative study of eight Australian mothers caring for an adolescent or young adult daughter with serious or profound neurodevelopmental disabilities, Murray (2007) found the educational transition period to be "no transition". While this study focused more on educational rather than health care transitions, Murray interestingly reported the notion of transition to have little meaning to these mothers as they reported the experience as being one of continuation, rather than transition, in the context of their role as a maternal caregiver. These findings both support and run counter to those in the current study. The experiential data in the current study suggested that the mothers viewed upcoming transitions as meaningful and as holding the potential to significantly impact their maternal caregiving experience. Paradoxically, the mothers voiced the notion of the unchanging nature of their caregiving experience and their plans to age-in-place with their children.

By way of examining the maternal caregiving experience among mothers caring for adolescents and young adulthoods with severe CP, the current study has brought to light a different experience and interpretation of maternal uncertainty. This experience centers on concerns associated with the mothers' ability to sustain their current level of

caregiving activities as they age, the availability of quality community supports and funding for their child's future care, and their child's upcoming transition to adult services.

Limitations

There were several limitations within the current study. First, the study findings and interpretation must be considered within the context of the research design and research methodology. As in most qualitative inquiries, the sample size was small. The findings of this study cannot be generalized, and only reflect the study participants' experiences. Secondly, the sample was homogeneous as most participants were recruited by way of network sampling. Few mothers responded to invitations to participate in the study that were placed in the electronic newsletter of an advocacy organization. This low response rate to the newsletter invitation might suggest that some mothers were too busy or overwhelmed to find time to participate, were reluctant to share their caregiving narrative, were suspicious of investigator's intentions, or did not have internet access to view the invitation. Consequently, the study findings are potentially biased as the sample might have only included mothers who perceived their lives were under control, had more positive beliefs about their life circumstances and maternal caregiving experience, or had a strong need to "present a positive front".

Recommendations

Munhall (2007) suggested that the significance of phenomenological research is best demonstrated by "stating the implications for change that emerge from the interpretations we glean from our participants on the meaning of various experiences"

(p.154). She further suggested that results from a phenomenological inquiry could be used to develop recommendations for changing practice and policy development, increasing our capacity for care and compassion, and for raising our consciousness as to what was not known or was erroneously known. On a similar note, Lauterbach (2007) suggested that, "as a human caring science and art, nursing's ultimate goal is to care for persons and human systems experiencing the unfolding life processes by using informed, timely, and appropriate care based on human caring and understanding." (p. 217).

The current study serves as a guide for future nursing practice, education, and policy to support the vital contributions of family caregivers in the context of childhood disability. The study also serves as a guide for future research studies as we seek to explore and better understand the phenomenon of family caregiving among families caring for adolescents and young adults with severe CP. This section will offer strategies for improving support for families caring for a child with disabilities by way of practice, education, research, and policy change recommendations.

Recommendations for Practice

The experiences of mothers caring for adolescents and young adults suggested a high level of involvement with members of the interdisciplinary health care team beginning at, or shortly after, their child's birth or adoption. The accountings of receiving their child's diagnosis of CP played an important part in the current study's narratives, and in previous studies. Health care providers must consider the significance of this news, and utilize communication techniques that assist families in coping with this information. Neonatal and pediatric nurses, along with other members of the

interdisciplinary team, have the opportunity to profoundly impact the early caregiving experiences of mothers. The mothers of children with severe CP have voiced the need for support and information during their child's infancy and early childhood, and again in adolescence as they began facilitate their child's transition to adult health and community services. Clinical staff at pediatric inpatient and outpatient settings, must be equipped with knowledge of community resources and supports available to families.

Importantly, a patient and family-centered care approach is essential, not only to promote and facilitate the best possible health and functional outcomes for the child, but also to support and enhance family caregiving. Professionals need to be supportive and empathetic in their approaches to families recognizing that a patient will determine the level of family involvement if he or she is developmentally mature and competent to do so (Institute for Patient - and Family - Centered Care, 2010). Health care professionals, should place priority on implementing the practices of patient and family-centered care that include the provisions of sharing information with families in ways that are useful and affirming, formal and informal support, collaborative relationships with families, and empowering each child and family to make decisions about health (Johnson & Eichner, 2003). It is also essential that the family-centered approach to care continue beyond the pediatric setting and into adult oriented health services and settings.

Health care transitions, specifically the movement from child-centered to adult-oriented health services is an area that has gained increased attention over the last decade, particularly for children with special health care needs. Betz and Telfair (2007) report the absence of a formalized service pathway to assist families with health care transitions.

These authors suggest that major reform would require a "massive retooling of service systems" and these reforms are unlikely (p. 5). Consequently, health care professionals must acquire the knowledge and skills to assist families in facilitating successful transitions. Working with families to develop a health care transition plan is an essential part of health care services. This must include activities focused on three key elements: (a) accessing adult primary and specialty care medical providers; (b) assisting families in maintaining or obtaining health insurance; and (c) assisting adolescents and young adults, or if necessary their parents, with assuming responsibility and managing their health to the best of their abilities (Betz & Telfair, 2007).

Within the interviews, the mothers offered advice that they would share with healthcare providers with the intention of increasing health care providers understanding of their needs as a family caregiver. This advice is summarized as follows:

- Greet parents and their child with a smile, and say "How can I help you?". Health care providers don't realize how important a smile and the offer of support is to parents. Consider that starting with the "positive" helps to deal with some of the "negative."

- Be supportive of parents and encourage parents … give an indication that you have some understanding of their situation. Ask them about their views and perceptions.

- Don't talk always just to me, you can acknowledge and talk directly to my child.

- Give parents credit for what they know. Ask parents, "What do you think is going on here? Or what would you find helpful here?"

- Be honest with your assessments, but recognize that parents might only be able to take in so much information at a time.

- Tell the truth, don't be evasive, and allow for time and follow up and to ask questions.

- Don't assume that I want to be the professional care provider around the clock, and offer to provide for the physical care needs of my child while hospitalized, it's nice to have a break from the daily routine of providing care.

- Be realistic with your goals of what you want me to do with my child. I am the mother, not a health care professional.

- Recognize that usually our plates are already full with family responsibilities. Take into consideration that we often have other children and we are trying to give them the best care we can.

- Recognize that caring for a child with disabilities impacts the whole family.

Education

The Institute of Medicine (IOM) has identified the core competencies needed for health care professional education programs. IOM's overarching vision is that "All health professionals should be educated to deliver patient-centered care as members of an interdisciplinary team, emphasizing evidence-based practice, quality improvement, approaches, and quality improvement" (IOM, 2003, p. 45). The provision of patient-centered care is one of the core competencies. Patient-centered, or family-centered, care includes the identification, respect, and care about patient's differences, values, preferences, and expressed needs. It is essential that disability content be included in

nursing and other health care disciplines pre-licensure and advanced education curriculum. Individuals with developmental disabilities are a growing population as more individuals with developmental disabilities are living longer lives. Curriculum content focused on care individuals with developmental disabilities and their families needs to be emphasized in the curriculum across the lifespan.

Educational efforts must extend beyond the university setting to the health care setting. Staff development efforts must focus on interdisciplinary approaches to care, application of research, and use of best practices in caring for individuals with developmental disabilities. Health care professionals must also educate themselves on strategies to provide optimal support for caregivers, based on best evidence, with the goals of promoting quality outcomes for both caregivers and care receivers.

Research

Caregiver research, focused on families in the context of childhood disability, must take into account the changing capabilities and needs as caregivers and care receivers age and move across the lifecourse. The findings in the current study suggest the need for additional research to be focused on maternal and paternal caregiving in the context of severe childhood disability.

While the existing caregiving literature includes a heavy emphasis on examining the families of young children, more research needs to be focused on adolescent, young adult, and adult families. Life expectancies for individuals with developmental disabilities have significantly increased over the last several decades; subsequently the trajectory of family caregiving has also increased. It is well recognized that overall good

health, both physical and emotional, is essential for optimal caregiving. The better the caregiver health, the more likely they are to continue in their roles (Talley & Crews, 2007). As mothers look to continue their caregiving activities in their middle years, it is essential to gain a better understanding of their health status and health promoting practices. Previous studies have placed an emphasis on examining the psychological health of mothers; few studies have explored their physical health or health promoting behaviors. Research is also needed to explore the lifeworlds of older mothers who continue to care for their adult with severe physical disabilities into their senior years, along with investigations focused on the caregiving roles of fathers and siblings.

Another area of needed exploration is the area of parental advocacy in the health care setting. Some parents will need to continue to advocate for and make key health care decisions for their child through adulthood. The basic social processes that parents use to advocate for their children, particularly adolescents and dependent young adults, are not well understood and warrant further study. Inquiries focused on the parent-provider relationship are also needed, to learn more about the development of trust, communication and collaboration in the health care setting.

In the current study, maternal caregivers perceived their children to be at increased risk for medical errors and quality of care issues while hospitalized. Additional study is needed to examine these perceptions, and to determine if individuals with developmental disabilities are at higher risk for adverse events and other quality concerns while hospitalized

Research on diverse populations of mothers caring for adolescents and young adults is also needed. In the current study, the participants were all white, college educated, married, financially stable, and middle-aged. Future research must include participants of varying race, ethnicity, education level, socio-economic status, marital status, and ages.

Lastly, but importantly, the phenomena of uncertainty and transition warrant further examination. The current study uncovered the essential theme of *Facing an Uncertain Future*. This theme, and its related sub themes call for further investigation to better understand the phenomenon of uncertainty among the mothers of adolescents and young adults with severe CP and other disabilities. Future research focused on the phenomenon of transition is also needed as a better understanding of the parental perspective of health care transitions for adolescents with special health care needs and disabilities will enhance professionals' abilities to better meet the needs of families during this important period of the lifecourse.

In summary, there are many areas that call for further exploration and explanation, as we seek better understand this experience, and ultimately design and implement evidence-based interventions to support and sustain family caregiving. Future research has the potential to provide the foundation to build supports and services to enhance the quality of the family caregiver experience, and promote the health and quality of life for both the caregiver and the care receiver.

Policy

The delivery of health care and community support services play an important part in sustaining and supporting family caregivers. Both organizational and public policy needs to place priority the provision of quality services to promote the health and wellbeing of caregivers and care receivers. Additionally, it is essential that policy support community access and engagement. Health care and community support organizations must uphold their ethical responsibility to protect and care for individuals with disabilities, by designing organizational policy that supports the provision of quality family-centered services. Organizations must facilitate service delivery that recognizes the inherent dignity and worth of all individuals that they serve. Within the study, mothers shared experiences of feeling unsupported, exhausted, and at times concerned for the quality care that their children received. Health organizations need to put in place policies that promote high quality health outcomes for all individuals, including those with disabilities. Mothers also voiced uncertainty as they looked to caregiving in the future and were unsure if quality supports would be available for their child.

Talley and Crews (2007) framed family caregiving as public health issue, suggesting that family caregivers are the foundation of an enormous system of care in our nation and that priority must be given to determining the services and interventions that are most useful to caregivers. This is especially timely, as we face budget shortfalls and diminished funding sources at the local, state, and federal levels of government.

Within the current study, participants were concerned about the limited funding available for the expansion of Medicaid waivers to allow for expanded home services for

individuals with developmental or intellectual disabilities. These waivers fund personal

care assistance, companion and respite services, along with supported employment and

residential support services. With these government-funded waivers families are able to

make service delivery decisions that best meet the individual needs of their child.

Several participants expressed concerns regarding a recent state government decision to

appropriate the limited state financial resources towards congregate housing. Specifically

this concern is focused on the funding allocated toward building a replacement facility

for a state residential institution that houses individuals with developmental disabilities.

Nurses and other health care professionals are in the position to become informed and to

advocate for quality services for individuals with disabilities.

Conclusion

This chapter presented a summary and discussion of findings of a qualitative

investigation focused on the lived experience of eleven mothers caring for adolescents

and young adults with severe CP. A phenomenologic approach, as put forth by van

Manen (1990), was used to explore the essences of the phenomenon of maternal

caregiving and to interpret the meanings ascribed to the experience. Caring for an

adolescent or young adult with severe CP was found to be a complex life experience that

had a profound effect on many aspects of the mothers' lives. The analyses of interview

narratives suggested one overarching and four inter-related and co-existing essential

themes. The overarching theme was *A Different Life*. The four essential themes were:

(a) *Managing an Unexpected Life*; (b) *Finding My Own Way*; (c) *Serving as My Child's

Voice*; and (d) *Facing an Uncertain Future*. These themes were discussed in light of

existing theoretical and research literature. Additionally, this chapter described the

limitations of this study, recommendations for future research, and implications for

nursing practice, policy, and education. This study has given voice to the experiences of

mothers caring for adolescents and young adults with severe functional disabilities. By

gaining a better understanding of this maternal caregiving experience and the meanings

ascribed to the experience, health care professionals have the potential to help support

and sustain mothers as they care for their child over the lifecourse into adolescence,

young adulthood, and beyond.

Appendix A: Maternal Caregiver Focused Interview Guide

Lead question
What is it like to care for *(child name)*?
(Insert name of adolescent/young adult with cerebral palsy).

Probes
- Describe a typical day in your life.
  - What helps you get through the day? What hinders you getting through the day?
- Tell me about a time when caring for *(child name)* was particularly memorable, meaningful, rewarding, or difficult for you.
- What types of supports do you have caring for your child?
- Has caring for your *(child name)* changed over time?
  - What was it like in early childhood?
  - What is it like in adolescence and/or young adulthood?
- What have been your expectations of yourself, as a mother and caregiver?
  - Have these expectations changed over time?
  - If so, how have you felt about these changes?
- Are there any individuals that have had a positive or negative influence on your caregiving experience over the years?
  - If so, who were they and in what ways were they influential?
- Has the experience of caring for *(child name)* impacted different aspects of your life? For example, your relationships with other people? Your health? Your employment status or work life?
- Are there any important life events, turning points, or transitions that come to mind when you consider your caregiving experience?
- What do you see in the future for yourself, child, and family?
- What do you think about when you consider caregiving in the future?
- If you were asked to give advice to someone just starting to care for a child with disabilities similar to those experienced by (*child name*), what would you share about caregiving in the adolescent and/or young adult years?

Is there anything we haven't discussed that you believe is important for nurses and other health care providers to know about your experience caring of for an adolescent/young adult with cerebral palsy?

Appendix B: Consent Form

CUA

THE CATHOLIC UNIVERSITY OF AMERICA

School of Nursing
Washington, D.C. 20064
202-319-5400
FAX 202-319-6485
Consent to Participate in Research Project

Investigator: Agnes Burkhard, MSN, RN, APHN-BC, Doctoral Candidate	**Phone**: (703) 477-4855
Supervisor: Janice Agazio, PhD, CRNP, RN	**Phone**: (202) 319-5719

Description: I understand I am being asked to participate in a research study about the experiences of caregiving among mothers caring for adolescents/young adults with cerebral palsy. I also understand that Agnes Burkhard is carrying out this research in fulfillment of the requirements of a doctoral dissertation.

Procedures: I understand that I am being asked to fill out a brief demographic form after which I will participate in an audio taped interview that will take approximately 60-90 minutes. The interview will be conducted at a time that is convenient for me, and in an appropriate setting of my choice. I may also be asked to participate in a follow-up phone interview for additional data or clarification of data obtained in the first interview.

Benefits: I understand that participation in this research will not benefit me personally in any way, but may provide information that is helpful to other parents, community professionals, or health care professionals such as nurses.

Risks/Inconveniences/Discomforts: I understand that I may experience mild emotional distress. If so, the interview will be stopped and appropriate support will be initiated. The researcher, Agnes Burkhard, is an experienced parent/child health and developmental disabilities nurse who can provide support and guidance and if necessary, refer me to appropriate counseling resources. I understand that another inconvenience will be the time needed to participate in the interview. I also understand that the researcher, Agnes Burkhard, is a registered nurse and is therefore required by law to report any suspected child abuse or neglect.

Right to Withdraw: I understand that my participation in this study is voluntary and that I may withdraw at any time without penalty. I also understand that I may request that the audiotape recorder be turned off at any time I do not want my comments recorded.

Confidentiality: I understand that no identifying information will be included on audio recordings or transcribed notes, and will destroyed thereafter. I am aware that the researcher may share the summarized results of this research, without identifying my responses, or me with other parents of children with disabilities or members of the professional community. I further understand that no identifying or individual results from this study will be shared with anyone in any form. Only the researcher's supervisor will have access to the coded transcripts.

```
APPROVED
CUA IRB 00000082

Expires: DEC 1 5 2010

Protocol  09-115
```
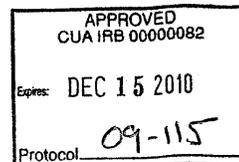
The skills to succeed and the values to guide
www.nursing.cua.edu

Agreement by the Participant:

I understand I am not obligated to participate in this study.

I understand that I may withdraw at any time without penalty or loss of benefits.

I understand that the researcher is required to report any suspected child abuse or neglect to the local child protective agency.

I understand that all information given during this interview will be kept confidential.

I understand that my research records, like hospital records, may be subpoenaed by court order or may be inspected by federal regulatory authorities.

I have had an opportunity to ask questions about the research and/or my participation in the research, and these questions have been answered to my satisfaction.

I volunteer to participate in this research study.

I have received a copy of this signed Consent Form.

_____   _____
Participant Signature   Investigator Signature


_____   _____
Date   Date

Any complaints or comments about your participation in this research project should be directed to the Secretary, Committee for the Protection of Human Subjects, Office of Sponsored Programs and Research, The Catholic University of America, Washington, DC 20064: Telephone 202-319-5218

216
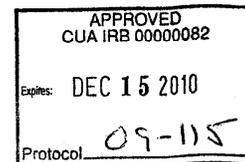
Participant ____

Participant Demographic Questionnaire

Please complete the following questionnaire:

Mother's age _____

Race (please circle your response)
African American   White   Latina   Asian   Other _____

Your employment status outside of the family home (please circle your response)
Full-time   Part-time   Not employed outside the family home

Marital status (please circle your response)
Single   Married   Divorced   Separated

Education level (please circle your highest education level)
Some High School   High School Graduate   Some College
College Graduate   Post-graduate Work

Number of children _____   **Ages of children** _____

Number of children residing in the family home _____

Current age of your adolescent/young adult with cerebral palsy   _____

Number of hours your adolescent/young adult attends school each day   _____

Number of hours of professional caregiver assistance (i.e. nurse, home health aid, personal care assistant) in your home each day/week   _____

Please circle any of the following health concerns that your child experiences:
Visual impairment
Hearing impairment
Communication impairment
Intellectual disability (mental retardation)
Feeding impairment
Feeding Tube
Urinary incontinence
Bowel incontinence
Seizure disorder

Appendix D: Invitation Informational Flyer

An Invitation

Mothers caring for an adolescent or young adult with cerebral palsy are invited to give voice to their experience by participating in a nursing research study. This study is being conducted by Agnes Burkhard RN, MSN, doctoral nursing candidate at The Catholic University of America.

The aim of this study is to learn more about the day-to-day family caregiving experiences of mothers during their child's transitional years of adolescence to young adulthood. The knowledge gained from this research will assist nurses, healthcare providers, and community support personnel in gaining a better understanding of the maternal caregiving experience, and in the identification of strategies that sustain, support, and enhance family caregiving.

Mothers are invited to participate if they are:

1. The mother of an adolescent or young adult with cerebral palsy
2. Their child is between the ages of 14-22 years
3. Their child uses a wheelchair full-time for mobility

Participation in this study will require one (1) 60-90 minute interview at the location of your choice, and possibly one (1) follow-up phone call.

To learn more about this study, please contact by email or phone:

<div align="center">

Agnes Burkhard RN, MSN, APHN-BC
PhD Candidate
Researcher
The Catholic University of America
School of Nursing
48burkhard@cardinalmail.cua.edu
(703) 477-4855

</div>

Appendix E: Letter of Support

The

Arc of Northern Virginia

Building Communities for Citizens with Disabilities
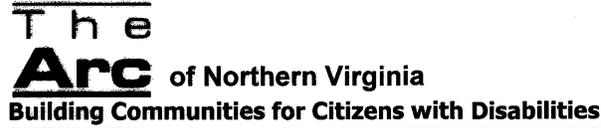
98 N. Washington St.
Falls Church, VA 22046
703-532-3214 - off
703-532-3398 - fax
Tx Id #54-0675506

Name of study: Finding Meaning in Maternal Caregiving: The Lived Experience of

Caring for an Adolescent or Young Adult with Cerebral Palsy

Researcher: Agnes Burkhard, RN, MSN, APHN-BC

Purpose and Description of the Study:

The purpose of the study is to explore the lived experience of maternal caregiving as experienced by mothers caring for adolescents and young adults with cerebral palsy. This study will be carried out as doctoral dissertation research. Mothers of adolescents and young adults who meet the following criteria, will be invited to have an interview with the investigator. The location of the interview will be determined by the participant, and the audio taped interview will last approximately 60-90 minutes.

Participant Criteria:
     1) Self-identification as the maternal caregiver of an adolescent or young adult with cerebral palsy, who meets the following criteria:
          a) Age 14-21 years
          b) Motor function that meets the criteria for Level V on the Gross Motor
     Function Scale for Classification of Cerebral Palsy (GMFSC)
     2) A willingness to participate in a 60-90 minute interview.

The Arc of Northern Virginia understands and supports the purpose and description of the study. The Arc of Northern Virginia will support this study by disseminating information about the research and the researchers contact information to our membership community.

_____   10/19/09

Nancy Mercer   Date
Co-Executive Director
The Arc of Northern Virginia

References

Aker, J. & Anderson, D. J. (2007). Perioperative care of patients with cerebral palsy. *AANA Journal, 75*(1), 65-73. Retrieved from http://www.aana.com/Resources.aspx?id=5324

American Academy of Pediatrics Committee on Children with Disabilities (1995). *Guidelines for home care of infants, children and adolescents with chronic disease. Pediatrics, 96*, 161-164. Retrieved from http://pediatrics.aappublications.org/

Anderson, L. L., Lakin, K., Mangan, T., & Prouty, R. (1998). State institutions: Thirty years of depopulation and closure. *Mental Retardation*, *36*(6), 431-443. doi:10.1352/0047-6765(1998)036<0431:SITYOD>2.0.CO;2

Appelbaum, M. (2007). *Appreciating life: Being the father of a child with severe cerebral palsy*. (Doctoral dissertation). Available from ProQuest Dissertations and Theses database. (UMI No. 3266519)

Ayres, L. (2000). Narratives of family caregiving: The process of making meaning. *Research in Nursing & Health, 23*, 424-434. doi:10.1002/1098-240X(200012)23:6<424::AID-NUR2>3.0.CO;2-W

Barlow, J. J., Cullen-Powell, L. A., & Cheshire, A. (2006). Psychological well-being among mothers of children with cerebral palsy. *Early Child Development and Care, 176*(3&4), 421-428. doi:10.1080/0300443042000313403

Bax, M., Goldstein, M., Rosenbaum, P., Leviton, A., & Paneth, N. (2005). Proposed

definition and classification of cerebral palsy: Introduction. *Developmental*

Medicine and Child Neurology, *47*, 571-572. doi:10.1017/S001216220500112X

Baxter, P. (2007). Disabled child or child with a disability. *Developmental Medicine &*

Child Neurology, 49, 803. doi:10.1111/j.1469-8749.2007.00803.x

Beckung, E., Carlsson, G., Carlsdotter, S., &Ubebrant, P. (2007). The natural history of

gross motor development in children with cerebral palsy aged 1 to 15 years.

Developmental Medicine & Child Neurology, 49, 751-756. doi:10.1111/j.1469-

8749.2007.00751.x

Benner, P. (1985). Quality of life: A Phenomenological perspective on explanation,

prediction, and understanding in nursing science. *Advances in Nursing Science*,

8(1), 1-14. Retrieved from:

http://journals.lww.com/advancesinnursingscience/pages/default.aspx

Betz, C. (2004). Transition of adolescents with special health care need: Review and

analysis of the literature. *Issues in Comprehensive Pediatric Nursing, 27*, 179-

241. doi:10.1080/01460860490497903

Betz, C. L., & Nehring, W. M. (2007). *Promoting health care transitions for adolescents*

with special health care needs and disabilities. Baltimore, MD: Brookes

Publishing.

Betz, C. L., & Telfair, J. (2007). Health care transitions: An introduction. In C. L. Betz &

W. M. Nehring (Eds.), *Promoting health care transitions for adolescents with*

special health care needs and disabilities. Baltimore, MD: Brookes Publishing.

221

Blacher, J. (2001). Transition to adulthood: Mental retardation, families, and culture.

    American Journal of Mental Retardation, 106, 173-188. Retrieved from:

    http://www.aaiddjournals.org/loi/ajmr.1

Bourke-Taylor, H., Howie, L., & Law, M. (2010). Impact of caring for a school-aged

    child with a disability: Understanding mothers' perspectives. *Australian*

    Occupational Therapy Journal, 57, 127-136. doi:10.1111/j.1440-

    1630.2009.00817x

Boyle, C. M., Bailey, P. H., & Mossey, S. (2008). Representations of disability in nursing

    and healthcare literature: An integrative review. *Journal of Advanced Nursing,*

    62(4), 428-437. doi: 10.1111/j.1365-2648.2008.04623.x

Brehaut, J. C., Kohen, D. E., Parminder, R., Walter, S. D., Russell, D. J., Swinton, M.,

    O'Donnell, M., & Rosenbaum, P. (2004). The health of primary caregivers of

    children with cerebral palsy: How does it compare with that of other Canadian

    caregivers? *Pediatrics, 114*(2), 182-191. doi:10.1542/peds.114.2.e182

Buran, C. F., Sawin, K., Grayson, P., & Criss, S. (2009). Family needs assessment in

    cerebral palsy clinic. *Journal for Specialists in Pediatric Nursing, 14*(2), 86-93.

    doi:10.111/j.1744-6155.2008.00176x

Burns, N., & Grove, S. K. (2005). *The practice of nursing research: Conduct, critique,*

    and utilization (5th ed.). St. Louis, MO: Elsevier Saunders.

Button, S., Pianta, R. C., & Marvin, R. S. (2001). Partner support and maternal stress in

    families raising young children with cerebral palsy. *Journal of Developmental*

    and Physical Disabilities, 13(1), 61-81. doi:10.1023/A:1026509400487

Byrne, M. B., Hurley, D. A., Daly, L., & Cunningham, C. G. (2010). Health status of

    caregivers of children with cerebral palsy. *Child: Care, Health and Development,*

    36(5), 696-702. doi:10.111/j.1365-2214.2009.0147.x

Clark, S. L., & Hankins, G. D. (2003). Temporal and demographic trends in cerebral

    palsy – fact and fiction. *American Journal of Obstetrics and Gynecology, 188*,

    628-633. doi:10.1067/mob.2003.204

Centers for Disease Control and Prevention. (2004). *Economic costs associated with*

    mental retardation, cerebral palsy, hearing loss, and vision impairment – United

    States, 2003. (MMWR Weekly Report, no. 53(03), pp. 57-59). Atlanta, GA:

    Author. Retrieved from:

    http://www.cdc.gov/mmwr/preview/mmwrhtml/mm5303a4.htm

Centers for Disease Control and Prevention (2010). Cerebral palsy. Retrieved from

    http://www.cdc.gov/Features/CerebralPalsy/

Cohen, M. Z. (1987). A historical overview of the phenomenologic movement. *Image:*

    Journal of Nursing Scholarship, 19(1), 31-34. doi:10.1111/j.1547-

    5069.1987.tb00584.x

Creswell, J. W. (2003). *Research design: Qualitative, quantitative, and mixed methods*

    approaches (2nd ed.). Thousand Oaks, CA: Sage Publications.

Cronin, A. F. (2004). Mothering a child with hidden impairments. *American Journal of*

    Occupational Therapy, 58(1), 83-92. doi: 10.5014/ajot.58.1.83

Darrah, J., Magill-Evans, J., & Adkins, R. (2002). How well are we doing? Families of adolescents or young adults with cerebral palsy share their perceptions of service delivery. *Disability and Rehabilitation, 24*(10), 542-549. Retrieved from: http://www.neuropsychologyarena.com/disability-and-rehabilitation-0963-8288

Davies, R., Davis, B., & Sibert, J. (2003). Parents' stories of sensitive and insensitive care by paediatricians in the time leading up to and including diagnostic disclosure of life-limiting condition in their child. *Child: Care, Health & Development, 29*(1), 77-82. doi:10.1046/j.1365-2214.2003.00316x

Davis, E., Shelly, A., Waters, E., Boyd, R., Cook, K., Casey, E., Davern, M., & Reddihough, D. (2009a). The impact of caring for a child with cerebral palsy: Quality of life for mothers and fathers. *Child: Care, Health, and Development, 36*(1), 63-73. doi:10.1111/j.1365-2214.2009.00989.x

Davis, E., Shelly, A., Waters, E., MacKinnon, A., Reddihough, D., Boyd, R., & Graham, H. K. (2009b). Quality of life of adolescents with Cerebral Palsy: Perspectives of adolescents and parents. *Developmental Medicine & Child Neurology, 51*, 193-199. doi:10.1111/j.1469-8749.2008.03194x

Davis, F. (1963). *Passage through crisis: Polio victims and their families*. .New Brunswick, NJ: Transaction Publishers.

Deatrick, J. A., Knafl, K., & Murphy-Moore, C. (1999). Clarifying the concept of normalization. *Image-Journal of Nursing Scholarship, 31*(3), 209-214. doi:10.1111/j.1547-5069.1999.tb00482.x

Dellve, L., Samuelsson, L., Tallborn, A., Fasth, A., & Hallberg, L. (2006). Stress and well-being among parents of children with rare diseases: a prospective intervention study. *Journal of Advanced Nursing*, *53*(4), 392-402. doi: 10.1111/j.1365-2648.2006.03736.x

Denham, S. (2003). *Family health: A framework for nursing practice*. Philadelphia: F. A. Davis. doi:10.1177/1074840703255447

Dosa, N. P., White, P., & Schuyler, V. (2007). Future expectations: Transition from adolescence to adulthood. In M. L. Batshaw, L. Pellegrino & N. J. Roizen (Eds.), *Children with disabilities* (6th ed.) (pp. 387-408). Baltimore: Paul H. Brookes Publishing.

Dowling, M. (2007). From Husserl to van Manen: A review of different phenomenological approaches. *International Journal of Nursing Studies*, 44, 131-142. doi:10.1016/j.ijnurstu.2005.11.026

Duke, N. N., & Scal, P. B. (2011). Adult care transitioning for adolescents with special health care needs: A pivotal role for family-centered care. *Maternal Child Health, 15,* 98-105. doi:10.1007s10995-009-0547-1

Eker, L., & Tuzun, E. (2004). An evaluation of quality of life of mothers of children with cerebral palsy. *Disability and Rehabilitation*, *26*(23), 1354-1359. doi:10.1080/09638280400000187

Elder, G. H., & Johnson, M. K. (2003). The lifecourse and aging: Challenges, lessons, and new directions. In R. A. Settsten & J. Hendricks (Eds.), *Invitation to the life course: Towards new understandings of later life* (pp. 49-81). Amityville, NY: Baywood.

Elder, G. H., Johnson, M. K., & Crosnoe, R. (2004). The emergence and development of life course theory. In J. T. Mortimer & M. J. Shanahan (Eds.), *Handbook of the Lifecourse* (pp. 3-19). New York: Springer.

Erikson, E. (1963). *Childhood and society*. New York: W. W. Norton.

Erikson, E. (1997). *The life cycle completed*. New York: W. W. Norton.

Florian, V., & Findler, L. (2001). Mental health and marital adaptation among mothers of children with cerebral palsy. *American Journal of Orthopsychiatry, 71*(3), 358-367. doi:10.1037//0002-9432.71.3.358

Gallo, A., Angst, D., Knafl, K., Hadley, E., & Smith, C. (2005). Parents sharing information with their children about genetic conditions. *Journal of Pediatric Health Care*, *19*(5), 267-275. doi:10.1016/j.pedhc.2005.05.008

Garwick, A. W., Patterson, J. M., Meschke, L. L., Bennett, F. C., & Blum, R. W. (2002). The uncertainty of preadolescents' chronic health conditions and family distress. *Journal of Family Nursing*, 8(1), 11-31. doi:10.1177/107484070200800102

Geenen, S. J., Powers, L. E., & Sells, W. (2003). Understanding the role of health care providers during the transition of adolescents with disabilities and special health care needs. Journal of Adolescent Health, 32(3), 225-233. doi:10.1016/S1054-139X(02)00396-8

Gilligan, C. (1982). *A different voice: psychological theory and women's development.* Cambridge, MA: Harvard University Press.

Glassock, R. (2000). A phenomenological study of the experience of being a mother of a child with cerebral palsy. *Pediatric Nursing*, *26*(4), 407-410. Retrieved from: http://www.pediatricnursing.net/

Glenn, S., Cunningham, C., Poole, H., Reeves, D., and Weindling, M. (2008). Maternal parenting stress and its correlates in families with young children with cerebral palsy. *Child: Care, Health and Development, 35*(1), 71-78. Retrieved from: http://www.wiley.com/bw/journal.asp?ref=0305-1862

Golodetz, A., Evans, R., Heinritz, G., & Gibson, C. D. (1969). The care of chronic illness: The "responsor" role. *Medical Care, 7*, 385-394. doi:10.1097/00005650-196909000-00006

Gordon, S., Benner, P., & Noddings, N. (Eds.) (1996). *Caregiving: Readings in knowledge, practice, ethics, and politics.* Philadelphia, PA: University of Pennsylvania Press.

Grant, G., Nolan, M., & Keady, J. (2003). Supporting families over the life course: Mapping temporality. *Journal of Intellectual Disability Research, 47*(4), 342-351. doi:10.1046/j.1365-2788.2003.00495.x

Gravelle, A. M. (1997). Caring for a child with a progressive illness during the complex chronic phase: Parents' experience of facing adversity. *Journal of Advanced Nursing*, *25*(4), 738-745. doi:10.1046/j.1365-2648.1997.1997025738.x

Green, S. E. (2007). "We're tired, not sad": Benefits and burdens of mothering a child
with a disability. *Social Science & Medicine, 64*, 150-163.
doi:10.1016/j.socscimed.2006.08.025

Grey, M., Knafl, K., & McCorkle, R. (2006). A framework for the study of self- and
family management of chronic conditions. *Nursing Outlook, 54*(5), 278-285.
doi:10.1016/j.outlook.2006.06.004

Han, H. (2003). Korean mothers' psychosocial adjustment to their children's cancer.
Journal of Advanced Nursing, *44*(5), 499-506. doi:10.1046/j.0309-
2402.2003.02833.x

Havighurst, R. J. (1971). Developmental tasks and education (3rd ed.). New York:
Longman.

Hartman, A., DePoy, E., Francis, C., & Gilmer, D. (2000). Adolescents with special
health care needs in transition: Three life stories. *Social Work in Health Care,
31*(4), 43-57. doi:10.1300/J010v31n04_03

Heidegger, M. (1962). Exposition of the question of the meaning of being. In E. C.
Polifroni & M. Welch (eds.), *Perspectives on philosophy of science in nursing:
An historical and contemporary anthology* (pp. 247-272). Philadelphia:
Lippincott.

Higginbottom, G. (2004). Sampling issues in qualitative research. *Nurse Researcher
12*(1), 7-19. Retrieved from: http://nurseresearcher.rcnpublishing.co.uk/

Hilbert, G. A., Walker, M. B., & Rinehart, J. (2000). "In for the long haul": Responses of parents caring for children with Sturge-Weber Syndrome. *Journal of Family Nursing, 6*(2), 157-179. doi:10.1177/107484070000600205

Himmelmann, K., Beckung, E., Hagberg, G., & Uvebrant, P. (2006). Gross and fine motor function and accompanying impairment in cerebral palsy. *Developmental Medicine and Child Neurology, 48,* 417-423. doi:10.1111/j.1469-8749.2006.tb01289.x

Hirtz, D., Thurman, D. J., Gwinn-Hardy, K., Mohamed, M., Chaudhuri, A. R., & Zalutsky, R. (2007). How common are the "common" neurologic disorders? *Neurology*, *68*, 326-337. doi:10.1212/01.wnl.0000252807.38124.a3

Hoffman, R. L., & Mitchell, A. (1998). Caregiver burden: Historical development. *Nursing Forum, 33*(4), 5-11. Retrieved from: http://www.wiley.com/bw/journal.asp?ref=0029-6473

Hogan, D. P., & Ashtone, N. M. (1986). The transition to adulthood. *Annual Review of Sociology, 12*, 109-130. doi:10.1146/annurev.soc.12.1.109

Huang, Y., Kellett, U. M., & St. John, W. (2010). Cerebral palsy: Experiences of mother after learning their child's diagnosis. *Journal of Advanced Nursing*, 66(6), 1213-1221. doi:101111/j.1365-2648.2010.05270x

Hunt, C. K. (2003). Concepts in caregiver research. *Journal of Nursing Scholarship, 35*(1), 27-32. doi:10.1111/j.1547-5069.2003.00027.x

Husserl, E. (1964). The train of thoughts in the lectures. In E. C. Polifroni & M. Welch (Eds.), *Perspectives on philosophy of science in nursing: An historical and contemporary anthology* (pp. 247-272). Philadelphia: Lippincott.

Hutchinson, K. C., Willard, V. W., Hardy, K. K., & Bonner, M. J. (2009). Adjustment of caregivers of pediatric patients with brain tumors: A cross-sectional analysis. *Psycho-Oncology, 18*, 515-523. doi:10.1002/pon.1421

Hvidtjorn, D., Grove, J., Schendel, D. E., Vaeth, M., Ernst, E., Nielsen, L. F., & Thorsen, P. (2006). Cerebral palsy among children born after in vitro fertilization: The role of preterm delivery. *Pediatrics, 118*(2), 475-482. doi:10.152/peds.2005-2585

Iczzoni, L. I., & Freedman, V. A. (2008). Turning the disability tide: The importance of definitions. *JAMA, 299*(3), 332-334. Retrieved from: http://jama.ama-assn.org/

Institute for Patient- and Family-Centered Care (2010). *Definition of patient- and family-centered health care.* Retrieved from http://www.ipfcc.org/faq.html

Institute of Medicine (2003). *Health professions education: A bridge to quality.* Washington, DC: National Academies Press.

Institute of Medicine (2007). *The future of disability in America.* Washington, DC: National Academies Press.

Janicki, M. P., McCallion, P., Grant-Griffin, L., & Kolomer, S. R. (2000). Grandparent caregivers I: Characteristics of the grandparents and the children with disabilities for whom they care. *Journal of Gerontological Social Work, 33*(3), 35-55. Retrieved from: http://www.tandf.co.uk/journals/WGER

230

Jivanjee, P., Kruzich, J. M., Gordon, L. (2009). The age of uncertainty: Parent

    perspectives on the transitions of young people with mental health difficulties to

    adulthood. *Journal of Child and Family Studies, 18*, 435-446.

    doi:10.1007/s10826-008-9247-5

Johnson, B. H., & Eichner, J. M. (2003). Family-centered care and the pediatrician's role.

    Pediatrics, 112(3), 691-696.

Jones, M. W., Morgan, E., Shelton, J. E., & Thorogood, C. (2007). Cerebral palsy:

    Introduction and diagnosis. *Journal of Pediatric Health Care, 21*(3), 146-152.

    doi:10.1016/j.pedhc.2006.07.003

Judson, L. H. (2004). Protective care: Mothering a child dependent on parental nutrition.

    Journal of Family Nursing, 10(1), 93-120. doi:10.1177/1074840703260907

Kastner, T. A., Walsh, K. K., Savage, T. A., & Christeson, E. B. (2007). Service, legal,

    and ethical issues pertaining to the continuum of needs of adolescents with special

    health care needs and disabilities. In C. L. Betz & W. M. Nehring (Eds.),

    Promoting health care transitions for adolescents with special health care needs

    and disabilities. Baltimore, MD: Brookes Publishing.

Katz, R. T., (2003). Life expectancy for children with cerebral palsy and mental

    retardation: Implications for life care planning. *NeuroRehabilitation, 18*, 261-270.

    doi: 10.1007/s10882-009-9145-9

Kelly, A. M., Kratz, B., Bielski, M., & Rinehart, P. M. (2002). Implementing transitions for youth with complex chronic conditions using the medical home model. *Pediatrics, 110*(6), 1322-1327. Retrieved from: http://pediatrics.aappublications.org/

Kennes, J., Rosenbaum, P., Hanna, S., Walter, S., Russell, D., Raina, P., Bartlett, D., & Galuppi, B. (2002). Health status of school-aged children with cerebral palsy: Information from a population-based sample. *Developmental Medicine & Child Neurology*, *44*, 240-247. doi:10.1111/j.1469-8749.2002.tb00799.x

Kearney, P. M., & Griffin, T. (2001). Between joy and sorrow: Being the parent of a child with developmental disabilities. *Journal of Advanced Nursing, 34*(5), 582-592. doi:10.1046/j.1365-2648.2001.01787.x

Kirk, S. (2008). Transitions in the lives of young people with complex healthcare needs. *Child: Care, Health and Development, 34*(5), 567-575. doi:10.1111/j.1365-2214.2008.00862.x

Kirk, S., Glendinning, C., & Callery, P. (2005). Parent or nurse? The experience of being the parent of a technology-dependent child. *Journal of Advanced Nursing, 51*(5), 456-464. doi:10.1111/j.1365-2648.2005.03522.x

Kittay, E. F. (1999). Not my way, Sesha, your way slowly. In J. E. Hanigsberg & S. Ruddick (Eds.), *Mother troubles* (pp. 3-27). Boston, MA: Beacon Press.

Klein, S. M., & McCabe, H. (2007). From mother to disability professional: Role change, resilience, and rewards. *Journal of Early Intervention, 29*(4), 306-319. doi:10.1177/105381510702900403

Knafl, K. A., & Deatrick, J. A. (1990). Family management style: Concept analysis and

    development. *Journal of Pediatric Nursing, 5*(1), 4-14. Retrieved from:

    http://www.pediatricnursing.org/

Knafl, K. A., & Deatrick, J. A., (2003). Further refinement of the Family Management

    Style Framework. *Journal of Family Nursing*, *9* (3), 232-256.

    doi:10.1177/1074840703255435

Knafl, K., Breitmayer, B., Gallo, A., & Zoeller, L. (1996). Family response to childhood

    chronic illness: Description of management styles. *Journal of Pediatric Nursing,*

    11(5), 315-326. Retrieved from: http://www.pediatricnursing.org/

Kralik, D., Visentin, K., & van Loon, A. (2006). Transition: A literature review. *Journal*

    of Advanced Nursing, 55(3), 320-329. doi:10.1111/j.1365-2648.2006.03899.x

Krigger, K. W. (2006). Cerebral palsy: An overview [Electronic version]. *American*

    Family Physician, *73*(1), 91-102. Retrieved from:

    http://www.aafp.org/online/en/home/publications/journals/afp.html

Kvale, S., & Brinkmann, S. (2009). *Interviews: Learning the craft of qualitative research*

    interviewing (2nd ed.). Thousand Oaks, CA: Sage Publications.

Larsen, E. (1998). Reframing the meaning of disabilities to families: The embrace of the

    paradox. *Social Science & Medicine, 47*(7), 865-875. doi:S0277953698001130

Lauterbach, S. S. (2007). Meanings in mothers' experience with infant death: Three

    phenomenological inquiries. In P. L. Munhall (Ed.), *Nursing research: A*

    qualitative perspective (4th ed.) (pp. 211-236). Sudbury, MA: Bartlett and Johns

    Publishers.

Lawton, J., Rankin, D., Peel, A., & Douglas, M. (2009). Patients' perceptions and

    experiences of transitions in diabetes care: A longitudinal qualitative study.

    Health Expectations, 12, 138-148. doi:10.1111/j.1369-7625.2009.00537x

Lefley, H. P. (1997). Synthesizing the family caregiving studies: Implications for service

    planning, social policy, and further research. *Family Relations, 46*(4), 443-450.

    doi:10.2307/585104

Leiter, V., Krauss, M. W., Anderson, B., & Wells, N. (2004). The consequences of

    caring: Effects of mothering a child with special needs. *Journal of Family Issues,*

    25(3), 379-403. doi:10.1177/0192513X03257415

Lin, L., Yeh, C., & Mishel, M. H. (2010). Evaluation of a conceptual model based on

    Mishel's theories of uncertainty in illness in a sample of Taiwanese parents of

    children with cancer: A cross-sectional questionnaire survey. *International*

    Journal of Nursing Studies, 47, 1510-1524. doi:10.1016/j.ijnurstu.2010.05.009

Lin, S. (2000). Coping and adaptation in families of children with cerebral palsy.

    Exceptional Children, 66(2), 201-218. Retrieved from:

    http://www.cec.sped.org/content/NavigationMenu/Publications2/exceptionalchild

    ren/

Lincoln, Y. S., & Guba, E. G. (1985). *Naturalistic inquiry*. Newbury Park, CA: Sage

    Publications. doi:10.1016/0147-1767(85)90062-8

Lindgren, C. L. (1993). The caregiver career. *Image: Journal of Nursing Scholarship,*

    25(3), 214-219. doi:10.1111/j.1547-5069.1993.tb00784.x

Liptak, G., O'Donnell, M., Conaway, M., Chumlea, W., Worley, G., Henderson, R.,

    Fung, E., Stallings, V., Samson-Fang, L., Calvert, R., Rosenbaum, P., &

    Stevenson, R. (2001). Health status of children with moderate to severe cerebral

    palsy. *Developmental Medicine & Child Neurology*, *43*, 364-370.

    doi:10.1111/j.1469-8749.2001.tb00223.x

Liptak, G., & Accardo, P. J. (2004). Health and social outcomes of children with cerebral

    palsy. Journal of Pediatrics, 145(2), s36-s41. doi:10.1016/j.peds.2004.05.021

Livingston, M. H., Rosenbaum, P. L., Russell, D., & Palisano, R. J. (2007). Quality of

    life among adolescents with cerebral palsy: what does the literature tell us?

    Developmental Medicine & Child Neurology, 49, 225-231. doi:10.1111/j.1469-

    8749.2007.00225.x

Magill-Evans, J., Darrah, J., Pain, K., Adkins, R., & Kratochvil, M. (2001). Are families

    with adolescents and young adults with cerebral palsy the same as other families?

    Developmental Medicine & Child Neurology, 43, 466-472. doi:10.1111/j.1469-

    8749.2001.tb00744.x

Manuel, J., Naughton, M. J., Balkrishnan, R., Smith, B. P., & Koman, L. A. (2003).

    Stress and adaptation in mothers of children with cerebral palsy. *Journal of*

    Pediatric Psychology, 28(3), 197-201. doi:10.1093/jpepsy/jsg007

Mac Donald, J., & Callery, P. (2007). Parenting children through complex care: A

    journey through time. *Child: care, health and development, 34*(2), 2-7-213.

    Retrieved from: http://www.wiley.com/bw/journal.asp?ref=0305-1862

McCormick, A., Brien, M., Plourde, J., Wood, E., Rosenbaum, P., & McLean, J. (2007). Stability of the Gross Motor Function Classification System in adults with cerebral palsy. *Developmental Medicine & Child Neurology, 49*, 265-269. doi:10.1111/j.1469-8749.2007.00265.x

McCubbin, M. A., & McCubbin, H. I. (1996). Resilience in families: A conceptual model of family adjustment and adaptation in response to stress and crisis. In H. I. McCubbin, A. I. Thompson & M. A. McCubbin (Eds.), *Family assessment: Resiliency, coping and adaptation: Inventories for research and practice* (pp. 1-64). Madison, WI: University of Wisconsin Publishers.

McKeever, P., & Miller, K. (2004). Mothering children who have disabilities: a Bourdieusian interpretation of maternal practices. *Social Science & Medicine, 59*(6), 1177-1191. doi:10.1016/j.socscimed.2003.12.023

McPherson, M., Arango, P., Fox, H., Lauver, C., McManus, M., Newacheck, P. W., Perrin, J. M., Shonkoff, J. P., & Strickland, B. (1998). A new definition of children with special health care needs. *Pediatrics, 102*, 137-140. doi:10.1542/peds.102.1.137

Merleau-Ponty, M. (1962). Phenomenology of perception. In E. C. Polifroni & M. Welch (Eds.), *Perspectives on philosophy of science in nursing: An historical and contemporary anthology* (pp. 328-338).

Miles, K., Edwards, S., & Clapson, M. (2004). Transition from paediatric to adult services: Experiences of HIV-positive adolescents. *AIDS Care, 16*(3), 305-314. doi:10.1080/09540120410001665312

Moen, P., Robison, J., & Fields, V. (1994). Women's work and caregiving roles: A life

    course approach. *Journal of Gerontology, 49*(4), S176-S186. Retrieved from:

    http://www.geron.org/Publications/The%20Journal%20of%20Gerontology:%20P

    sychological%20Sciences

Moore, L. (2005). *The lived experience of being a mother to a child with severe cerebral*

    palsy. (Master's thesis). Available from ProQuest Dissertations and Theses

    Database. (UMI No. 1426288)

Morris, C., Kurinczuk, J. J., Fitzpatrick, R., & Rosenbaum, P. L. (2006). Who best to

    make the assessment? Professionals' and families' classifications of gross motor

    function in cerebral palsy are highly consistent. *Archives of Diseases of*

    Childhood, 91, 675-679. doi:10.1136/adc.2005.090597

Mortimer, J., & Shanahan, M. J. (Eds.). (2004). *Handbook of the Lifecourse*.

Moster, D., Wilcox, A. J., Vollset, S. E., Markestad, T., & Lie, R. T. (2010). Cerebral

    palsy among term and postterm births. *JAMA, 304*(9), 976-982.

    doi:10.1001/jama.2010.1271

Munhall, P. L. (2001). Phenomenology: A method. In P. L. Munhall (Ed.), *Nursing*

    research: A qualitative perspective (3rd ed.) (pp. 123-184). Sudbury, MA: Jones

    and Bartlett.

Munhall, P. L. (2007). A phenomenological method. In P. L. Munhall (Ed.) *Nursing*

    research: Qualitative perspective (4th ed.) (pp.145-159). Sudbury, MA: Jones and

    Bartlett.

Murray, S. (2007). Families' care work during the transition from school to post-school for children with severe disabilities. *Family Matters, 76*, 24-29. Retrieved from: http://www.aifs.gov.au/institute/pubs/fammats.html

Murphy, N., & Such-Neibar, T. (2003). Cerebral palsy diagnosis and management: The state of the art. *Current Problems in Pediatric and Adolescent Health Care*, *33*(5), 146-169. doi:10.1111/j.1365-2214.2006.00644.x

National Institutes for Neurological Disorders and Stroke. (n.d.). *Cerebral Palsy*. Retrieved from http://www.ninds.nih.gov

National Institutes of Health. (n.d.). Puberty and adolescence. Retrieved from http://www.nlm.nih.gov/medlineplus/ency/article/001950.htm

Nelson, A. M. (2002). A metasynthesis: Mothering other-than-normal children. *Qualitative Health Research, 12*(4), 515-530. doi:10.1177/10497320219120043

Nelson, K. B. (2003). Can we prevent cerebral palsy? *New England Journal of Medicine, 394*(18), 1765-1769. doi:10.1056/NEJMsb035364

Newman, D. M. (2005). Functional status, personal health, and self-esteem of caregivers of children in a body cast. *Orthopaedic Nursing*, *24*(6), 1-13. Retrieved from: http://journals.lww.com/orthopaedicnursing/pages/default.aspx

Noddings, N. (1996). The cared for. In Gordon, S., Benner, P., and Noddings, N. (Eds.), *Caregiving: Readings in knowledge, practice, ethics and politics* (21-39). Philadelphia, PA: University of Pennsylvania Press.

O'Connell, B., Bailey, S., & Pearce, J. (2003). Straddling the pathway from paediatrican to mainstream health care: Transition issues experienced in disability care. *Australian Journal of Rural Health, 11*, 57-63. doi:10.1046/j.1440-1584.2003.00465.x

Okumura, M. J., Van Cleave, J., Gnanasekaran, S., and Houtrow, A. (2009). Understanding factors associated with work loss for families caring for CSHCN. *Pediatrics Supplement, 124*, S392-S398. doi:10.1542/peds.2009-1255J

Orb, A., Eisenhauer, L, and Wynaden, D. (2001). Ethics in qualitative research. *Journal of Nursing Scholarship*, 33(1), 93-96. doi:10.1111/j.1547-5069.2001.00093.x

Palisano, R. J., Almarsi, N., Chiarello, L. A., Orin, M. N., Bagley, A., & Maggs, J. (2010). Family needs of parents of children and youth with cerebral palsy. *Child: Care, Health and Development, 36*(1), 85-92. doi:10.1111/j.1365-2214.2009.1030x

Palisano, R. J., Rosenbaum, P. L., Walter, S. D., Russell, D. J., Wood E. P., & Galuppi, B. E. (1997). Development and reliability of a system to classify gross motor function in children with cerebral palsy. *Developmental Medicine and Child Neurology, 39*, 214-223. doi:10.1111/j.1469-8749.1997.tb07414.x

Palisano, R., Rosenbaum, P., Bartlett, D., & Livingston, M. (2007). *Gross Motor Function Classification System: Expanded and revised (GMFCS)*. Retrieved from http://www.canchild.ca/en/measures/gmfcs.asp

Palisano, R. J., Copeland, W. P., & Galuppi, B. E. (2007). Performance of physical activities by adolescents with cerebral palsy. *Physical Therapy, 87*(1), 77-87.

Paneth, N., Damiano, D., Rosenbaum, P., Leviton, A., Goldstein, M., & Bax, M. (2005). The classification of cerebral palsy. *Developmental Medicine & Child Neurology*, *47*, 574-576.

Parkes, J., McCullough, N., Madden, A., & McCahey, E. (2009). The health of children with cerebral palsy and stress in their parents. *Journal of Advanced Nursing, 65*(11), 2311-2323. doi 10.1111/j.1365.2009.05089.x

Parminder, R., O'Donnell, M. O., Rosenbaum, P., Brehaut, J., Walter, S. D., Russell, D., Swinton, M., Zhu, B., & Wood, E. (2005). The health and well-being of caregivers of children with cerebral palsy. *Pediatrics, 115*(6), e626-e636. Retrieved from: http://pediatrics.aappublications.org/

Patton, M. Q. (2002). *Qualitative research and evaluation methods*. Thousand Oaks, CA: Sage.

Pelchat, D., Levert, J., & Bourgeois-Guerin, V. (2009). How do mothers and fathers who have a child with a disability describe their adaptation/transformation process? *Journal of Child Health Care, 13*, 239-259. doi:10.1177/1367493509336684

Pellegrino, L. (2007). Cerebral palsy. In M. L. Batshaw, L. Pellegrino & N. J. Roizen (Eds.), *Children with disabilities* (6th ed.) (pp. 387-408). Baltimore: Paul H. Brookes Publishing.

Perrin, J. I. (1992). Family caring and caring in nursing. *IMAGE: Journal of Nursing Scholarship, 24*(2), 127-131. doi:10.1111/j.1547-5069.1992.tb00237.x

Piaget, J. (1971). *Science of education and the psychology of the child*. New York: Viking Press.

Poirier, S., & Ayres, L. (2002). *Stories of family caregiving: Reconsiderations of theory, literature, and life.* Indianapolis, IN: Center Nursing Publishing.

Ramos, M. C. (1989). Some ethical implications of qualitative research. *Research in Nursing & Health. 12*, 57-63. doi:10.1002/nur.4770120109

Ray, L. D. (2002). Parenting and childhood chronicity: Making visible the invisible work. *Journal of Pediatric Nursing*, *17*(6), 424-438. doi:10.1053/jpdn.2002.127172

Ray, L. D. (2003). The social and political conditions that shape special needs parenting. *Journal of Family Nursing, 9*(3), 281-301. doi:10.1177/1074840703255436

Reiner, A. M., & Bjarnason, H. K. (1999). Growing up with CP: The effect of physical maturity on individuals with cerebral palsy. *Developmental Medicine and Child Neurology, 41*(80), 11. Retrieved from: http://journals.cambridge.org/action/displayJournal?jid=DMC

Rentinck, I. C. M., Ketelaar, M., Jongmans, M. J., & Gorter, J. W. (2006). Parents of children with cerebral palsy: A review of factors related to the process of adaptation. *Child: Care, Health and Development, 33*(2), 161-169. Retrieved from: http://www.wiley.com/bw/journal.asp?ref=0305-1862

Rosenbaum, P. (2003). Cerebral palsy: what parents and doctors want to know. *BMJ, 326*, 970-974. doi:10.1136/bmj.326.7396.970

Rosenbaum, P., Dan, B., Leviton, A., Paneth, N., Jacobsson, B., Goldstein, M., & Bax, M. (2005). Proposed definition and classification of cerebral palsy. *Developmental Medicine & Child Neurology*, *47,* 572-574. doi:10.1017/S001216220500112X

Rosenbaum, P., Law, M., Darrah, J., Gibson, C., King, G., Majnemer, A., Milner, M.,

    O'Donnell, M., Richards, C. L., & Wood, E. (2007). Setting research priorities

    for childhood disability: Report from CIHR Opportunities Project. Retrieved

    from: http://www.canchild.ca/en/ourresearch/priorities.asp

Rosenbaum, P., & Stewart, D. (2004). The World Health Organization International

    Classification of Functioning, Disability and Health: A model to guide clinical

    thinking, practice and research in the field of cerebral palsy. *Seminars in Pediatric*

    Neurology, 11(1), 5-10. doi: 10.1016j.spen.2004.01.002

Ruddick, S. (1995). *Maternal Thinking*. Boston, MA: Beacon Press.

Scal, P., & Ireland, M. (2005). Addressing transition to adult health care for adolescents

    with special health care needs. *Pediatrics, 115*(6), 1607- 1612.

    doi:10.1542/peds.2004-0458

Schneider, J., Wedgewood, N., Llewellyn, G., & McConnell, D. (2006). Families

    challenged by accommodating to the adolescent years. *Journal of Intellectual*

    Disabilities Research, 50(12), 926-936. doi:10.111/j.1365-2788.2006.00925.x

Schuengel, C., Rentinck, I. C. M., Stolk, J., Voorman, J. M., Loots, G. M. P., Ketelaar,

    M., Gorter, J. W., & Becher, J. G. (2009). Parents' reaction to the diagnosis of

    cerebral palsy: Associations between resolution, age and severity of disability.

    Child: Care, Health and Development, 35(5), 673-680. doi 10.111/j.1365-

    2214.2009.00951x

Simeonsson, R. J., Leonardi, M., Lollars, D., Bjorck-Akesson, E., Hollenweger, J., & Martinuzzi, A. (2002). Applying the International Classification of Functioning, Disability, and Health (ICF) to measure childhood disability. *Disability and Rehabilitation, 25*(11), 602-610. Retrieved from: http://www.ingentaconnect.com/content/apl/tids

Shapiro, B. K. (2004). Cerebral palsy: A reconceptualization of the spectrum. *Journal of Pediatrics*, Supplement, S3 - S7. Retrieved from: http://www.jpeds.com/

Speziale, H. S., and Carpenter, D. R. (2007). *Qualitative research in nursing: Advancing the humanistic imperative*. Philadelphia: Lippincott Williams & Wilkins.

Stevenson, C. J., Pharoah, P., & Stevenson, R. (1997). Cerebral palsy – The transition from youth to adulthood. *Developmental Medicine & Child Neurology, 39*(5), 336-342. doi:10.1111/j.1469-8749.1997.tb07441.x

Stewart, J. L., & Mishel, M. H. (2000). Uncertainty in childhood illness: A synthesis of the parent and child literature. *Scholarly Inquiry for Nursing Practice, 14*(4), 299-319. Retrieved from: http://nursing.researchtoday.net/

Strauss, D., & Shavelle, R. (2001). Life expectancy in cerebral palsy. *Archives of Disease in Childhood, 85*(5), 442. doi:10.1136/adc.85.5.442a

Strauss, D., Shavelle, R., Reynolds, R., Rosenbloom, L., & Day, S. (2007). Survival in cerebral palsy in the last 20 years: Signs of improvement? *Developmental Medicine and Child Neurology, 49*, 86-92. doi:10.1111/j.1469-8749.2007.00086.x

Sullivan-Bolyai, S., Sadler, L., Knafl, K. A., Gilliss, C. L., & Ahmann, E. (2003). Great

   expectations: A position description for parents as caregivers: Part 1. *Pediatric

   Nursing*, *29*(6), 457-461. Retrieved from: http://www.pediatricnursing.net/

Surveillance of cerebral palsy in Europe (SCPE) report (2002). *Developmental Medicine

   and Child Neurology, 44,*633-640. Retrieved from:

   http://www.wiley.com/bw/journal.asp?ref=0012-1622

Swanson, E. A., Jenson, D. P. Specht, J., Johnson, M. L., Maas, M. & Saylor, D. (1997).

   Caregiving: concept analysis and outcomes. *Scholarly Inquiry for Nursing

   Practice: An International Journal, 11*(1), 65-76. Retrieved from:

   http://journalseek.net/cgi-

   bin/journalseek/journalsearch.cgi?field=issn&query=0889-7182

Talley, R. C., & Crews, J. E. (2007). Framing the public health of caregiving. *American

   Journal of Public Health, 97*(21), 224-228. doi:10.2105/AJPH.2004.059337

Thomas, S. P. (2005). Through the lens of Merleau-Ponty: Advancing the

   phenomenological approach to nursing research. *Nursing Philosophy, 6,* 63-76.

   doi:10.1111/j.1466-769X.2004.00185.x

Thorne, S. E., Radford, M. J., & Armstrong, E. (1997). Long-term gastrostomy in

   children: Caregiver coping. *Gastroenterology Nursing, 20*(2), 46-53.

   doi:10.1097/00001610-199703000-00004

Todd, S., & Jones, S. (2005). Looking at the future and seeing the past: The challenge of the middle years of parenting a child with intellectual disabilities. *Journal of Intellectual Disability Research, 49*(6), 389-404. doi:10.1111/j.1365-2788.2005.00675.x

Tong, R. (2009). *Feminist thought.* Boulder, CO: Westview Press.

Turner, V. (2002). Liminality and communitas. In M. Lambek (Ed.), *A reader in the anthropology of religion* (pp. 358-374). Malden, MA: Blackwell Publishing.

Uhlenberg, P., & Mueller, M. (2004). Family context and individual well-being: Patterns and mechanisms in the life-course perspective. In J. T. Mortimer & M. J. Shanahan (Eds.), *Handbook of life course* (pp. 123-148). New York: Springer.

United Cerebral Palsy (2001). *Cerebral palsy*. Retrieved from http://www.ucp.org

`Venkateswaran, S., & Shevell, M. I. (2008). Comorbidities and clinical determinants of outcome in children with spastic quadriplegia cerebral palsy. *Developmental Medicine and Child Neurology, 50*, 216-222. doi:10.1111/j.1469-8749.2008.02033.x

Van Manen, M. (1990). *Researching the lived experience*. Albany, NY: SUNY Press.

Van Riper, M. (2007). Families of children with Down syndrome: Responding to a "Change in plans" with resilience. *Journal of Pediatric Nursing*, *22*(2), 116-128. doi:10.1016/j.pedn.2006.07.004

Volpe, J. J. (2003). Cerebral white matter injury of the premature infant – more common than you think. *Pediatrics, 112*, 176-180. Retrieved from: http://pediatrics.aappublications.org/

Welch, M. (1999). Phenomenology and hermeneutics. In E. C. Polifroni & M. Welch

    (Eds.), *Perspectives on philosophy of science in nursing: An historical and*

    contemporary anthology (pp. 235-246). Philadelphia: Lippincott.

Wiart, L., Ray, L., Darrah, J., & Magill-Evans, J. (2010). Parents' perspectives on

    occupational therapy and physical therapy goals for their children with cerebral

    palsy. *Disability and Rehabilitation, 32*(3), 248-258.

    doi:10.3109/0963820903095890

Wilson, L. S., Moskowitz, J. T., Acree, M., Heyman, M. B., Harmatz, P., Fernando, S. J.,

    & Folkman, S. (2005). The economic burden of home care for children with HIV

    and other chronic illnesses. *American Journal of Public Health, 95*(8), 1445-

    1452. doi:10.2105/AJPH.2004.044248