

ABSTRACT

Title of Document: THE EXPERIENCES AND NEEDS OF
PARENTS WHOSE CHILDREN DIED DUE TO
DEGENERATIVE DISABILITIES:
A QUALITATIVE ANALYSIS

Jennifer Smith Stepanek
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Directed By: Professor Paula Beckman
Department of Special Education

Remarkable advancements in life-saving technology have led to prolonged survival rates for premature infants and young children who have experienced trauma, illnesses, or medical disabilities. However, this progress has also led to a concurrent increase in long-term morbidity, including chronic and degenerative health conditions that result in early death. Early interventionists, special educators, and other multidisciplinary professionals are subsequently working with a growing number of families who are facing the potential deaths of their children due to life-threatening disabilities. To support parents facing such loss, an understanding of their life experiences and support needs is essential. However, most research related to supporting grieving parents is based on samples drawn from self-help bereavement support groups which typically consist of parents whose children died

as a result of catastrophic illnesses or trauma. Little is known about supporting parents whose children are diagnosed with life-threatening or degenerative disabilities. This qualitative inquiry explored the experiences and needs of 7 bereaved parents whose children died between the ages of 3 and 21 due to a degenerative neuromuscular disease. Four professionals also participated for triangulation in this national study. Narrative analysis was used to search for themes in the stories shared by participants. The themes that emerged for parent experiences include: abundant stress from dissonance, exhaustion, chronic changes, unanticipated shock, and profound grief; ongoing struggles for validation; and, the positive impact of formal and informal supports. The themes that emerged for parent needs include: hope, information, useful resources, helpful networks, healthy partnerships, choices, and validation. Finally, the themes that emerged for preferred supports during loss and bereavement include: professionals' awareness of and attention to parent experiences and needs throughout the child's lifespan; ongoing connections with providers and activities that were a part of the child's life; and, support options beyond traditional bereavement groups. The results are discussed with reference to previous and emerging theory and research in parental bereavement. Practical implications and future research are also discussed.

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By

Jennifer Smith Stepanek

Dissertation submitted to the Faculty of the Graduate School of the
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Advisory Committee:
Professor Paula Beckman, Chair
Associate Professor David Cooper
Associate Professor Brenda Jones Harden
Associate Faculty Researcher Diane Kelly
Professor Joan Lieber

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Dedication

This research endeavor is dedicated to the children whose journeys touched our lives yesterday, to the children whose journeys touch our lives today, and to the children whose journeys will continue to touch our lives in every tomorrow – simply because these children are a part of a journey, and therefore, they matter.

This includes the children discussed by the participants in this study.

And, it includes my own four children – Katie, Stevie, Jamie, and Mattie Stepanek.

Your lives had meaning, still have meaning, and will continue to have meaning.

Thank you for the many gifts of the journey.

Acknowledgments

This dissertation symbolizes the commencement of nearly a quarter century of growth, and of learning and understanding about “the things that really matter.” Although I consolidated information and insights that are now a part of this manuscript, there are many people who were a part of this effort who deserve acknowledgement. The parents and providers who shared so much of their time and energy and spirit as they shared personal experiences truly gave life to this research endeavor. Because of them, powerful realities and lessons now emerge from these pages. These realities and lessons will surely make a difference for many other parents and providers who love and care for children.

Without bias (of course), my dissertation committee is indeed the finest in the world. I would like to thank my advisor, Dr. Paula Beckman, for always believing in parents and families, and for validating and supporting so many of us in our journeys. I would also like to thank Dr. Joan Lieber and Dr. David Cooper for being such an important part of my academic pursuits at the University of Maryland, and for being such enthusiastic and helpful members of my committee. For years I considered “Paula, David, and Joan” the “Peter, Paul, and Mary” of early childhood special education. Truly, this trio knows how to both work and play well with others, and they are an invaluable source of knowledge and inspiration for many people who pursue high goals. Dr. Diane Kelly and Dr. Brenda Jones Harden were also members of this extraordinary team. I am not sure either of them knew what they were getting into when they accepted the invitation to serve on this committee, but I am grateful that they said yes. They have been most encouraging and contributed essential feedback that helped shape this “brief” qualitative manuscript.

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My son, Mattie J.T. Stepanek, grew up “earning a Ph.D. with mom.” He willingly and eagerly went to classes with me his entire life. He helpfully read to me and patiently discussed so many aspects of this doctoral program and dissertation with me. He encouragingly helped me study and prepare for exams and presentations. And he was so excitedly proud of me when ‘we’ passed comprehensive exams and moved to “all but dissertation” after so many years of life wedged into the ongoing aspects of earning a doctoral degree. There are no words that adequately express the appreciation and respect I have for my son, and his essential role in so many levels of this endeavor. Thank you. I love you. And know that your name and spirit are right here with mine.

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CHAPTER I

INTRODUCTION

When a child dies, it upsets the natural order of life cycles that we expect in modern society (Bowlby, 1980; Linzer, 1977; Rando, 1985). Children are not supposed to die, especially before their parents. And when they do, bereaved parents must seek new meaning in life and work hard to redefine their parenting roles and sense of self (Center for the Advancement of Health, 2004; Rando, 1983; Riley, LaMontagne, Hepworth, & Murphy, 2007). According to Jackson (1977), the physiological, psychological, and social relationships between parents and their children “may well be the most intense life can generate” (p. 187). Parental bereavement, therefore, is a very challenging and complicated life event.

Life-threatening Disabilities

Across the recent decades, remarkable advancements in life-saving technologies have led to increased survival rates for infants and children who would have died previously from various life-threatening conditions (National Center for Health Statistics [NCHS], 2007; Skolnick, 1991). Premature infants, survivors of traumatic events, and children with disabling conditions and life-threatening illnesses are increasingly benefiting from state-of-the-science medical care and are living longer and fuller lives (Cooper & Kennedy, 1989; Hughes, Johnson, Rosebaum, & Liu, 1989; Kleinberg, 1987). However, this progress has also led to a concurrent increase in long-term morbidity, including chronic and degenerative health conditions and early death (National Commission to Prevent Infant Mortality, 1988; Perrin, Bloom, & Gortmaker, 2007).

Depending on the definitions applied, 18 % or more of the children living in the United States have some type of disabling or chronic health condition that requires medical, emotional, physical, or educational support services beyond that required by children in general (Newacheck & Halfon, 1998; van der Lee, Mokkink, Grootenhuis, Heymans, & Offringa, 2007). These definitions include life-threatening disabilities such as neuromuscular disease, non-progressive disabilities such as cerebral palsy, and chronic health conditions such as asthma. Indeed, a growing number of children with chronic healthcare needs are requiring attention and support from professionals across a variety of disciplines (Perrin et al., 2007). The provision of a free, appropriate, and public education to all children, regardless of a child's physical, medical, or cognitive condition became a landmark federal decision with the passage of the 1975 Public Law 92-142. In 1986, Public Law 99-457 redefined the provisions of Part B of this law that serves children ages 3 through 21, and Part H was added to entitle eligible children ages birth to 3 for education services. Today, this law is known as the Individuals with Disabilities Education Act (IDEA, P.L. 108-446). Under Part C of IDEA (formerly Part H), the guaranteed provision of educational services includes infants and toddlers with disabling conditions, and mandates that education professionals recognize the integral role of parents and families in a young child's life. Today, more than 6 million children ages birth through 21 receive early intervention and special education services under the ongoing revisions of public laws that define IDEA.

There are no available statistics indicating the number of children who die due to chronic health conditions or life-threatening disabilities while enrolled or eligible for special education services under IDEA. Although not all chronic conditions are

considered life-threatening, professionals who provide early intervention and special education services are encountering a growing number of young children who are considered medically fragile and who have degenerative and progressive disabilities that do result in early death (McGonigel, Kaufman, & Johnson, 1991). In fact, most infants and young children who are diagnosed with degenerative health conditions become eligible for special education services under IDEA because of the physical and/or cognitive effects that such conditions have on their ability to achieve age-appropriate development and educational milestones (IDEA, P.L. 108-446).

Concurrent with advances in medical technology and changes in education laws, there has been a paradigm shift in special education that includes the delivery of family-centered services to young children with disabilities (Dunst, Trivette, & Cross, 1986; McGonigel et al., 1991; Shelton & Stepanek, 1994; Turnbull & Turnbull, 1986). The view that families are complex, mutually dependent social systems has prevailed for many years (Minuchin, 1974). In other words, families represent a complex unit with various patterns of interactions and relationships. When there is a change in one member's functioning, this typically results in changes in the functioning of other family members (Dunst, 2002).

In 1949, Hill conceptualized an early theory of family response to adversity, the *ABCX Model* of stress and adaptation. In this theory, adaptation to adversity grows from an interaction of family response to a particular crisis (X) with: the stressor event that impacts or changes the family unit (A); the resources that a family has to prevent and respond to a crisis (B); and, how the family defines the adverse event based on how it affects the family (C). In 1983, McCubbin and Patterson revised this theory and defined

the *Double ABCX Model* of family stress and adaptation to cumulative adversity. In this *aAbBcCX Model*, a *pile-up* of pre-crisis (a) and post-crisis (A) stressors interact with existing resources available to a family (b) and new resources that become available to respond to a crisis (B). In addition, a family's perception of pre-crisis stress (c) and the cumulative pre- and post-crisis stressors and resource availability (C) interact with a family's response to the actual crisis (X). This accumulation of interactive stressors and perceived sources of support are correlated with the ability to respond or adapt to adversity. According to McCubbin and Patterson, when families have the resources they need, they are better able to adapt to adversity by coping with *stress* (i.e., an imbalance of demands and the ability to respond to such demands) and minimizing *distress*. (i.e., a disorganized state in functioning due to an imbalance of demands and the ability to respond to such demands).

Researchers have concluded that parents whose children have any type of disability or illness report higher levels of both emotional and physical stress than parents whose children are healthy (Carnevale, Alexander, Davis, Rennick, & Troini, 2006; Dellve, Samuelsson, Tallborn, & Lillemor, 2006). Also, as the profound effect of a child with a disability on a family has been increasingly documented (Beckman, 2002; Trivette & Dunst, 2004), professionals began to recognize that their important roles in interacting with families beyond the provision of direct services (Bruder & Dunst, 2005; Seligman & Darling, 2007). For more than two decades, researchers have written about the importance of both formal and informal supports that are provided by health, education, and other disability service systems that meet the needs of children and families who are

coping with various types of disabilities (Beckman, 1996; Dunst, Trivette, Starnes, Hamby, & Gordon, 1993; Singer, Powers, & Olson, 1996).

According to Dunst et al. (1993), family support ideally benefits all members of a family, builds on existing social networks, enhances coping in response to adverse situations, and maximizes a family's control over services since the family should be considered the expert regarding their child. In addition, researchers have recently begun to address the issue of *family outcomes* with respect to benefits experienced when children receive specialized education or medical services. Bailey and Bruder (2005) reported that family outcomes involve more than the receipt of formal services and supports. Rather, this is a concept that includes incidental benefits that are available to a family simply because services or supports are provided by professionals. These authors cited an example of this type of support:

Providing parents with information about their child's condition is a service; if the parents understand that information and find it helpful in describing their child's condition to others, advocating for services, or responding effectively when their child becomes upset, a benefit has been experienced and a family outcome has been achieved (Bailey & Bruder, 2005, p. 2).

The importance of family-centered care, which emphasizes working with and supporting families rather than just the child, has thus become increasingly apparent to researchers and interventionists who work with infants and children. Under Part C of IDEA, children ages birth to 3 years who are eligible for early intervention have their services listed on an Individual Family Service Plan (IFSP), which includes statements from the family about the child's strengths and needs. Additionally, the IFSP includes

information from the parents about the family's concerns, priorities, and resources related to the child's development and education, including available sources of, or the need for, various types of family support. Children ages 3 through 21 who are eligible for special education and related services under Part B of IDEA receive an Individualized Education Plan, in which families collaborate as partners with the professionals who will be delivering services to their children (IDEA, P.L. 108-446).

With this pedagogical shift towards family-centered services and the emphasis on family input, supports, and partnerships (Beckman, 2002; Bruder & Dunst, 2005; Shelton & Stepanek, 1994), many competent professionals often develop close ties with their young clients and families. As early interventionists and other professionals in the special education system often work with the same children and families across several years, particularly close bonding can occur (Dunst, 2002; Small, 1991), and the very notion of the family-centered approach fosters this closeness and supportive relationship. Additionally, parents of children who have disabling conditions often define their lives in terms of meeting the unique and varied needs of their child and define their relationships to include the professionals who work with their children (Chomicki, Sobsey, Sauvageot, & Wolgosh, 1995).

According to Chomicki et al. (1995), when a child with a chronic or life-threatening disability dies, parents report that their own purpose in life becomes unclear, and that they feel a sense of disconnection from both peers and the various professionals who had been involved with the family during the child's life. They report that when a child with a disability dies, the reason for a family's relationship to a professional is gone. However:

the parent may not be willing or even able to relinquish these relationships, especially when the intensive needs of the child have brought them into a world in which these are all or almost all of the people they know. Health care and education professionals must take their cues from the parents, but they must be prepared to help them through a transitional period until they begin to establish a new life (Chomicki et al., 1995, p. 27).

Although it is undeniably difficult and challenging to comprehend, when working with children who have life-threatening conditions, teachers and education professionals must be prepared for the possibility of a child's early death (Stepanek & Newcomb, 2006). Adequate preparation, at both preservice and inservice levels, is necessary for professionals to meet the unique and varied needs of each child and family facing death and loss when a condition is considered life-threatening (Bruder & Dunst, 2005; Harper, 1993; Roberts, 1988; Stepanek, 1995; Seligman & Darling, 2007). Because professionals who work in the early interventionist and special education systems under IDEA are connected to the families they serve through partnerships and support, it is imperative that they understand issues related to parental grief and bereavement, especially related to the loss of a child with a disability.

Statement of the Problem

Given the importance of supporting families within the special education system, an examination of the research underlying parental loss, grief, and bereavement is both timely and important. However, most literature that exists specifically in this area is theoretical, conceptual, or descriptive in nature, and tends to focus on negative consequences of parental grief rather than coping resources and perceived sources of

support (Riley et al., 2007). To date, the relatively small database of empirical research on parental bereavement has primarily investigated:

- Perinatal grief and parental grief related to death during or shortly after birth, including prematurity, congenital conditions, and Sudden Infant Death Syndrome (Vance, Boyle, Najman, & Thearle, 2002; Woodward, Pope, Robson, & Hagan, 1985);
- Gender differences in coping with grief (Bohannon, 1991a; Devine, 1993);
- Differences in grief and coping based on the amount of time since a child died (Alexy, 1982; Wheeler, 1994);
- Differences in grief and bereavement between bereaved parents, spouses, and adult children (Leahy, 1993; Nelson & Frantz, 1996); and,
- Bereavement differences between parents whose children died by traumatic accidents, suicide, or murder (Drenovsky, 1994; Miles & Demi, 1992; Murphy, 2000).

Several studies exist that explore the grief of parents whose children died due to a catastrophic illness such as cancer (Clerici et al., 2006; DeCinque et al., 2006; Rando, 1983), but only a few studies explore parental grief after the loss of a child who was diagnosed with a life-long or a life-threatening disability (Aho, Tarkka, Astedt-Kurki, & Kaunonen, 2006; Chomicki et al., 1995; Milo, 1997; Wood & Milo, 2001).

Most researchers comparing parents with other bereaved individuals (e.g., spouse, sibling, and child of the deceased) report that parental grief is especially severe and prolonged in duration, and that there are unique psychological and sociological factors that make parental bereavement difficult to resolve (Klass & Goss, 2003; Leahy, 1993;

Rando, 1985; Shapiro, 1994). For example, many parents and families face an identity crises or a crisis of personal meaning after the loss of a child (Fletcher, 2002; Wheeler, 2001), and they report feelings of being disconnected from other family members and peers following the death of a child (Meert, Thurston, & Briller, 2005). Some researchers have compared the various sources and experiences and duration of grief across parents whose children have died suddenly versus following an anticipatory period. Based on the results of data gathered from participants of bereavement support groups, several of these investigators have reported that the suddenness and recency of a child's death correlates with more intense and prolonged grief responses in bereaved parents (Reif, Patton, & Gold, 1995). However, other researchers report that there are no such differences, and conclude that the death of a child leads to intense and prolonged grief responses no matter how or when a child dies (Arnold, Gemma, & Cushman, 2005).

In 1983, Rando evaluated the grief and bereavement experiences of 54 parents whose children died from cancer during the previous 2 months to 3 years. She found that anticipating a child's death did ameliorate the intensity and duration of parental grief if a child died within 18 months to 2 years from the time of diagnosis. However, she found that when parents had more than 18 months to 2 years from the time of diagnosis to anticipate their child's death, the intensity and duration of their grief and bereavement exceeded that of parents whose children died either suddenly or after a briefer time frame. In addition, Rando reported that parents who were highly involved in the care of their dying children showed prolonged rumination about the deceased child, and were often unable to emotionally or physically tend to other responsibilities and family members following the death of the child. She speculated that if parents have fewer than

18 months to prepare for the death of a child, they do not have adequate time to adjust to the terminal nature of the child's condition, whereas a longer period of anticipation and increased involvement in meeting the child's atypical care needs may actually encourage parents to deny the possibility of the child's death, especially when the child survives the disease and *beats the odds* for a prolonged period of time (Rando, 1983).

Rando (1983) also found that while there seemed to be a gradual decrease in the intensity of parental grief across the first 2 years following the death of a child, there was a subsequent increase in intensity during the third year of grieving. Parents who anticipated the deaths of their children scored higher on scales measuring social isolation, denial, guilt, and other indicators of intense grieving during the third year of bereavement, compared to parents whose children had died of cancer more recently. Because her study design was cross-sectional rather than longitudinal though, it is not clear whether the parents whose grief was higher at 3 years after death would have also scored higher on grief scales earlier during their bereavement.

Despite growing interest in this topic, a limited knowledge base is available to train qualified professionals and to guide special educational providers in best practice. Furthermore, the data that do exist about parental grief come primarily from questionnaires, self-report surveys, and other descriptive research gathered during studies utilizing member-led, self-help groups for families who have lost a child to death (Stepanek, 1998). Upon examination of the participant demographics, it can be concluded that most of the families represented in parental bereavement support groups lost a child either to a traumatic event (e.g., accident, injury, violence, suicide) or to a catastrophic illness (e.g., cancer, acute infection).

In 1995, Schwab confirmed that parents whose previously healthy children died from a sudden traumatic accident or illness make up the majority of participants in bereavement support groups, whereas parents who have lost a child to a long-term, progressive health condition or to a degenerative disability are statistically under-represented or absent in such groups. Schwab also found that many parents who chose to attend groups reported doing so because they sought to connect with other parents who lost a child, whereas parents who did not attend such groups reported a desire for a more personal or informal source of support, including contact with peers and professionals who had experienced a similar loss (i.e., death of a child with a disability).

Few researchers have attempted to seek evidence through controlled studies to measure the helpfulness of such groups, and those studies have had methodological flaws and yielded conflicting results (Rowa-Dewar, 2002). However, it is clear from the participant data in these and in other descriptive studies that some families utilize these groups for years and even decades after their children have died (Gottlieb, Lang, & Amsel, 1996; Leahy, 1993; Wheeler, 1994). This indicates that this type of support is helpful to some families whose children have died suddenly or after a catastrophic illness, as these families cope with intense and enduring aspects of parental bereavement.

Unfortunately, because families whose children die as a result of progressive, degenerative, or life-long disabilities are absent or under-represented in self-help bereavement groups, there is a paucity of empirical data exploring the specific experiences and needs of these parents. Although data exists regarding how to best support families whose children have non-progressive disabilities such as cerebral palsy (Skok, Harvey, & Reddihough, 2006), whose children have catastrophic or life-

threatening illness such as cancer (Boman, Lindahl, & Bjork, 2003), and whose children have died from traumatic events or illnesses (Gudmundsdottir & Chesla, 2006), there is very little information to guide training and support with respect to families whose children have life-long degenerative disabilities that result in early death. Regrettably, by the nature of their disease and its progression, these are children and families with whom early interventionists and special educators are very likely to work.

Examining the subjective experiences and perceived support needs of parents whose children have died or who might die is a very complicated and complex process. The sensitive nature of the issues being explored makes many researchers hesitant to request family participation in quantitative or qualitative research designs, especially during what may be an intensely painful period in their lives (Dyregrov, 2004). However, Dyregrov reported that most parents who participate in research about their grief and their deceased child report that they find the experience very helpful. Furthermore, exploring and understanding the experiences, needs, and grief of families whose children have been diagnosed with and died from a progressive life-threatening disability is an essential task to provide accurate information to professionals in the special education system who work with and support these families.

Purpose

According to Isaac and Michael (1997), grounded research is the only way to make rational choices in educational and medical programs and to “build a stable foundation of effective practices as a safeguard against faddish but inferior innovations” (p. iii). There is a growing interest in research related to parental grief and bereavement. Evidence of this can be measured by the increased number of theoretical and descriptive

articles, chapters, and books related to these topics, offered by both professionals and parents across the past two decades. However, the unique processes of grief and appropriate supports related to the loss of a child due to a degenerative disability is poorly understood because of a lack of research within this particular population. Most research on parental bereavement that is available is based on convenience samples of member-led self-help groups. Parents whose children die from life-long progressive diseases tend to be under-represented in these groups, and therefore, little can be said about their experiences, coping styles, or support needs and preferences.

Because teachers and other direct service providers offer some level of formal and informal supports to children and families, awareness and understanding of family experiences and needs should be grounded in theory and research. Due to a lack of information grounded in research with families who have experienced loss due to a degenerative condition, professionals who work with these families through early intervention, special education, and other disability-related programs lack adequate or accurate information to guide personnel preparation, or to guide an understanding of best practice or appropriate family supports and partnerships with them. The purpose of the current research study is to better understand and describe the experiences and needs of families whose children have died from degenerative disabilities.

According to Creswell (2003), a particular characteristic of good qualitative research focuses on a single phenomenon so that patterns of similarities and dissimilarities in narrative data can emerge. There are a number of chronic medical conditions and degenerative diseases associated with childhood mortality (Newacheck & Haflen, 1998; van der Lee et al., 2007). Therefore, the researcher of the proposed study

will concentrate on one particular type of degenerative condition--childhood neuromuscular disease.

More than 43 neuromuscular diseases have been the focus of research and support services provided by the Muscular Dystrophy Association (MDA), a non-government, voluntary health organization. These diseases, which affect more than 1 million people in the United States, are grouped into eight different categories: muscular dystrophies, motor neuron diseases; metabolic diseases of the muscle, diseases of the peripheral nerves, inflammatory myopathies, diseases of the neuromuscular junction, diseases due to endocrine abnormalities, and other myopathies (MDA, 2007). There are a variety of medical and symptomatic diagnostic criteria for each of the diseases, and the age of onset of symptoms for various forms of the diseases can range from before birth through adulthood. The severity of symptoms and progression of each disease also varies greatly, depending on which disease is diagnosed and the age of onset. Neuromuscular diseases can involve neurological, muscular, cardiac, respiratory, endocrine, digestive and other major body systems, and most of them involve some level of progressive muscle weakness or deterioration that results in limited or devastated voluntary movement. Advances have been made in decreasing the severity of symptoms and slowing the progression of a few of these diseases; however, there are no known cures for the neuromuscular diseases that are a focus of the MDA. Although a few of the 43 neuromuscular diseases have a projected slow progression, many of them have a notable or rapid progression, and a number of these diseases result in a shortened lifespan, including childhood mortality (MDA, 2007).

To date, very little empirical or descriptive information from research exists about the subjective experiences or perceived support needs of this population, which is typically served by the special education system. This study provides information for professionals involved with personnel preparation, for professionals involved in the delivery of services to children with degenerative disabilities, and for professionals who provide support to families whose children have these life-threatening conditions. Additionally, this information can be used by disability-specific and healthcare organizations that often provide support and advocacy services for these children and families within the education system.

Data for this study were gathered in narrative form by collecting personal stories shared by parents whose children: were diagnosed with a neuromuscular disease prior to age 8 years, lived with the condition for more than two years, received special education services under IDEA, and died before age 21. These criteria were established to ensure that findings would be relevant to early intervention and special education professionals who work with children and families under IDEA. Data were also gathered from providers who were recommended by parent participants. Based on the data obtained, the investigator searched the responses of participants in this study for patterns and themes that offered insights into the experiences and support needs of parents whose children died from degenerative disabilities. Insights related to parental bereavement and coping after the loss of these children were also explored. In addition, the researcher compared and contrasted the findings of this narrative analysis with the results of previous theory and research related to parental bereavement. As a result, this study is a groundbreaking interpretive endeavor generating knowledge and understanding of this under-represented

research population. This information can be added to the theoretical framework that guides training and practice in education, health, and disability-related service systems.

Definitions

This research provides an improved understanding of the experiences of parents whose children have died as a result of a degenerative disability—specifically neuromuscular disease. Creating a solid base of evidence for this scientific inquiry relies on a shared understanding of definitions and technical terms that will be used in the study. The terminology used throughout this manuscript will be based on the definitions listed in this section.

Bereavement, grief, and mourning. Distinctions among bereavement, grief, and mourning have been inconsistent in research. For this study, definitions for these terms are based on a research review offered by the Center for the Advancement of Health (2004). The term *bereavement* is used broadly and defined as the loss of a loved one due to death. The terms *grief* and *mourning* have often been used interchangeably in literature. For this study, the term *grief* is used and defined as the specific cognitive, emotional, and social experiences and reactions that occur as a result of bereavement. Sometimes grief is perceived and reported by an individual (e.g., feelings of sadness, distress, or anger), and sometimes grief is observable by others (e.g., crying, social withdrawal, or throwing things). With this explanation of terms, bereavement can be considered a universal experience, whereas the perceived or expressed responses, intensity, and duration of grief can be considered unique and variable.

Life-threatening condition. A life-threatening condition is a circumstance or state-of-being that necessitates some type of medical intervention or treatment (Pearsall, 2002).

For this study, a catastrophic life-threatening condition is defined as something that begins suddenly in an apparently healthy individual. This definition includes the diagnosis of a catastrophic illness or condition such as cancer or an acute infection, as well as sudden or traumatic injuries such as a motor vehicle accident or a near-drowning. With this explanation of terms, a life-threatening condition is something that might be treatable or curable with medical intervention, or it might result in death in spite of medical intervention.

Life-threatening disability. A disability is a condition that limits an individual's movements, senses, or typical activities in some way (Pearsall, 2002). When the disability endangers the medical stability of an individual to the point where death might occur in the absence of intervention, a disability is considered life-threatening. For example, a person with severe asthma or a cardiac impairment that severely limits the ability to participate in acts of daily living could be considered a life-threatening disability.

Degenerative disability. A degenerative disability is a disability that results in the gradual deterioration or progressive loss of one or more body systems or organs (Pearsall, 2002). Some degenerative disabilities result in a slow progression of impairment and do not impact the lifespan. Other degenerative disabilities are more rapid in progression and are associated with a shortened lifespan. An individual can be born with a degenerative disability, such as a genetic neuromuscular disease that progresses in severity across the lifespan. An individual can also be diagnosed with a disability sometime during the lifespan due to a genetic or environmental condition, or as a result of some catastrophic illness or traumatic event. For example, a person may be diagnosed with an incurable

cancer that progresses across months or years and results in early death despite medical intervention.

Neuromuscular disease. Neuromuscular disease is a degenerative disability that results in a progressive loss of neurological, muscular, cardiac, respiratory, endocrine, digestive, and/or other major body systems (MDA, 2007). Most neuromuscular diseases involve some level of progressive muscle weakness or deterioration resulting in limited or devastated voluntary movement. The appearance of symptoms and diagnosis of a neuromuscular disease can occur at any time during the lifespan, from infancy through adulthood. Some neuromuscular diseases are associated with rapid progression of symptoms and result in early death. This is true of several neuromuscular diseases that are typically diagnosed during infancy and early childhood.

Significance and Implications

After an international literature review, The Center for the Advancement of Health (2004) concluded that there is a need for professional training in grief and bereavement. This group also reported that most training efforts in this area have been focused on physicians, and that most other personnel in the helping professions receive no training at all regarding loss and bereavement, and are therefore unprepared personally and professionally to deal with grief associated with the death of a child. Although it is a normal response to loss, grieving can be intensely painful and a disorganizing experience that may seem abnormal. Grieving individuals are at risk for developing physical and psychiatric disorders (Romanoff, 1993). Because the death of a child can be challenging in so many ways, training professionals to be aware of issues related to loss and to be prepared for the potential of a child's death is essential (Taylor & Gortler, 1993). Clinical,

social, and emotional issues related to loss are highly relevant to family and professional decision-making, attitudes, and abilities (Jellinek, Catlin, Todres, & Cassem, 1992).

Furthermore, competent professional support can facilitate coping as families deal with the finality of loss (Harmon, Glicklen, & Siegel, 1984; Meert et al., 2005).

The findings of this study will expand the knowledge base about parental grief and bereavement that follows the loss of a child due to a life-threatening disability. This will be useful for personnel preparation programs, as educators and other professionals are trained to become highly-qualified to serve children and families according to the training regulations defined under Part D of IDEA. The results of this study may also help improve how professionals support young children who are served under Part C or Part B of IDEA in the context of a family-centered approach to care. Education specialists including early interventionists; teachers; physical, occupational, and speech therapists; counselors; and social workers, professionals, and paraprofessionals who provide support through parent information centers under IDEA will have access to more accurate information about the children and families with whom they are creating partnerships through the education system. This study may also be useful in program evaluation, for educational, medical, and disability-specific organizations that offer support to families and that offer support and advocacy services to families whose children receive special education services.

Methodology and Research Questions

There are many ways to explore the perceived experiences and needs of bereaved families. However, capturing and interpreting the narratives told by parents in a natural and richly-detailed manner would offer the most genuine source of information, and

would lead to accurate understandings of how professionals can best support these families. Therefore, a qualitative research design was used for this study.

Qualitative research involves an in-depth exploratory examination of how and why human feelings and behaviors unfold, rather than seeking a quantitative and conclusive explanation of what and where and when such feelings and behaviors might occur (Bogdan & Biklen, 1998; Eisner & Peshkin, 1990). According to Isaac and Michael (1997), qualitative research “reflects the role of subjective judgment in generating data” (p. 218) and strives to preserve “the real life context in which events occur . . . with a minimum of intrusion and an absence of any attempt to control or manipulate variables” (p. 219).

Mostly conducted in natural settings, this type of investigation relies heavily on participant perspective gathered from small, purposeful, and focused samples, and it yields a wealth of descriptive data supported with anecdotal quotations. The trademark of a qualitative research design is the grounded theory that emerges from the data collection, through an approach that preserves any prejudgments that might affect the outcome (Isaac & Michael, 1997). Thus, an inductive approach to data analysis is used to produce theories, rather than an attempt to prove or disprove any particular hypotheses (Bogdan & Biklen, 1998). Confidence in the results comes from careful attention to credible and believable findings; the transferability of the findings to other contextually similar situations; dependable conclusions that are consistent with other available studies; and the ability to confirm the process and product of data collection and analysis through outside auditing (Isaac & Michael, 1997).

The current study utilized a qualitative approach for gathering information and

formulating theories about parental experiences, bereavement, and support needs related to the loss of a child with a degenerative disability. Because this is a new body of research, a purposeful sample of families whose children died from a specific category of degenerative disability was sought for participation. To increase the knowledge base and understanding of parental bereavement following the death of a child diagnosed with a life-threatening, degenerative disability, the following three research questions guided this qualitative inquiry:

1. What are the subjective experiences of parents whose children have died due to a degenerative disability
 - a. Around the time their children are diagnosed with a degenerative, life-threatening disability?
 - b. During their children's lives?
 - c. Around the time of their children's deaths?
 - d. Since the time of their children's deaths?
2. What do parents of children who died from degenerative disabilities perceive as needs related to supporting their children and coping with loss?
3. When a child with a degenerative disability dies, what can professionals in education, health, and advocacy organizations say or do that might be most supportive?

CHAPTER II

LITERATURE REVIEW

Despite the progress that has been made in saving the lives of children, there has been an increase in long-term morbidity in infants and children. A growing number of children now live with chronic and degenerative health conditions that will still result in early death (National Commission to Prevent Infant Mortality, 1988; Perrin et al., 2007). As health care and medical technology advanced, there was a drop in mortality rates related to disabling conditions that previously resulted in immediate or early death. However, there has been a concurrent increase in the prevalence of infants, children, and adolescents living longer lives with these severe or degenerative conditions (Committee on Children with Disabilities, 1998). It is estimated that up to 1 million children living in the United States live with a serious, chronic medical condition (Levetown, 2000). Although statistics vary, roughly 40,000 to 55,000 children will die in the United States each year from these conditions (American Academy of Pediatrics, 2000; Guyer et al., 1999; Hoyert, Arias, Smith, Murphy, & Kochanek, 2001; MacDorman & Atkinson, 1999).

This revolution in modern day childhood mortality—in how and when children die—has resulted in a change in society views regarding the death of a child (DeJong-Berg & Kane; 2006; Gudmundsdottir & Chesla, 2006). Dorsel and Dorsel (1986) postulated that childhood death is no longer common. Consequently, the death of a child has become a profound, overwhelming, and shocking event for parents, even when anticipated due to a life-threatening condition (Christ, Bonanno, Malkinson, & Rubin, 2003; Dorsel & Dorsel, 1986; Rando, 1985; Rowa-Dewar, 2002; Stepanek & Newcomb,

2006; Stroebe & Schut, 2005). Indeed, there exists a general societal discomfort associated with childhood death. Moreover, there remains a residual reliance on historical views of mourning as being unresolved, and possibly pathological, *tasks* of grief. As a result, a frequent community response to grieving families whose children have died is a societal distancing due to feelings of discomfort and helplessness (Chomicki et al., 1995; DeJong-Berg & Kane, 2006; Oliver, Sturtevant, Scheetz, & Fallat, 2001; Rando, 1992; Shapiro, 1998).

Traditional studies in grief and bereavement have been multidisciplinary in nature, with the bulk of the research generated by researchers in the fields of psychology, medicine, and nursing (Hogan, Morse, & Tason, 1996; Neimeyer & Hogan, 2001; Parkes, 2001; Stroebe, 1992). However, the decreased mortality statistics across recent decades (NCHS, 2007) combined with the increased number of individuals who are living with chronic and disabling conditions and receiving community services and supports (Cooper & Kennedy, 1989) has resulted in a growing interest in the grief literature by researchers in other disciplines. In particular, professionals in social sciences, anthropology, and education are beginning to produce theoretical perspectives and practical findings related to bereavement and grief that may be associated with the life-threatening conditions of the children and adults they serve (Beckman, 2002, Bruder & Dunst, 2005; Center for the Advancement of Health, 2004).

This chapter synthesizes an exploration of bereavement and grief literature across disciplines that is relevant to the death of a child with a life-threatening condition or disability. The chapter begins with a general overview of the history and theoretical approaches to grief and continues with a discussion of the unique aspects of bereavement

and grief associated with the loss of a child. Following this historical synopsis, a review of empirical studies dealing specifically with parental bereavement will be offered. This empirical review will be presented in two parts. The first part will present a synthesis of the methods and results of the available literature. The second part will include an analysis of the methodology and limitations of these studies. The chapter will end with a discussion of the current review of the literature and directions for future research.

Historical Background of Research on Bereavement and Grief

For centuries, there have been literary narratives and published accounts of the grieving process and outcomes associated with losing a loved one (Parkes, 2002). The earliest known published research was offered in 1858 when a physician reported an increased mortality risk among widows and widowers (Marcey, 1995). A half-century later in 1917, Sigmund Freud offered the first theory on the psychology of grief following a significant loss, in a publication titled “Mourning and Melancholia” (Davies, 2004; Stroebe, 1992). He hypothesized that grieving is a task to be performed, and that this function allows the bereaved person to become cognitively detached from memories and connections to the deceased (Stroebe & Schut, 2005).

According to Freud, a person should be able to withdraw emotionally from the deceased individual after a period of grief and then live contentedly with reconstructed meanings for life, thus completing the work of grieving (Hogan et al., 1996; Rando, 1985, 1986). When his own daughter died however, Freud could not detach himself from the loss or from memories of his daughter or from his chronic mourning. He described this personal experience of ongoing grief nearly a decade later in a condolence letter he

sent to a friend whose son had recently died (Davies, 2004). Freud's theory did not match his experience, but his theoretical views inspired other professionals to explore the complex nature of coping and bereavement.

The first major research endeavor was in 1944, when Erich Lindemann published "Symptomatology and Management of Acute Grief," which has become a classic study in bereavement (Marcey, 1995). Lindemann, a psychoanalyst building on the theoretical work of Freud, identified five components in acute grief: somatic disturbance, preoccupation with the image of the bereaved, guilt, hostility, and disorganized behavior (Lindemann, 1944). He also defined characteristics of normal grief and abnormal grief, which he referred to as *morbid* or *unresolved grief* (Kubler-Ross, 1969). According to Davies (2004), these early approaches to scientifically explaining bereavement reflected the thinking of the times and were aimed at conscious expressions of feelings to detach oneself from the reality of loss and resolve feelings of grief. Although these early theories and conclusions have been questioned or criticized by subsequent researchers, they have had a lasting impact on the nature of what is believed today about bereaved individuals, and they have formed the basis of ongoing scientific investigation (Davies, 2004; Gudmundsdottir & Chesla, 2006; Kubler-Ross, 1969; Marcey, 1995; Rando, 1985; Stroebe, 1992).

By the late 1960s, Bowlby was combining the early psychoanalytical approaches to explaining grief with new cognitive and behavioral models being explored in psychology. Based on his work in the developmental concepts of bonding and attachment, Bowlby (1969) hypothesized that grief is an expression of separation anxiety and loss. He theorized that grief occurs in three stages: yearning and searching,

disorganization and despair, and reorganization and reintegration. He added an additional stage, numbness, several years later (Bowlby, 1973). Bowlby's grief theory was explained as an outcome of subconscious processes of childhood bonding experiences, and thus, death results in unwanted separation from an attachment figure (Hogan et al., 1996). Recovery from grief then, was much like recovery from a disease. Although there were remnants of the concept that grief is an achievable, goal-oriented task with the outcome of detaching oneself from the deceased, Bowlby's and other prevailing theories in the 1960s and 1970s combined a more biological understanding of bereavement with the earlier psychoanalytical approaches and psychological factors of grief (Stroebe, 1992).

In 1977, Gauthier and Marshall conceptualized grief as something that led to great psychological and physiological changes in a bereaved person, but explained that such changes were normal. In this behavioral theory, bereavement was a process influenced more by external environmental factors such as social support than by internal factors such as cognition. Littlefield and Rushton (1986) also offered a sociobiological approach to explaining grief, suggesting that the measurable impact of the death of a family member was directly related to the importance that person had for the genetic survival of the bereaved individual. This view has been rated by other theorists as a backwards trend in thinking and in nature (Hogan et al. 1996), because it incorporates the concept of kinship and gene survival into a person's grief response.

Cognitive models of stress and coping were becoming a part of theoretical and analytical approaches to understanding grief by the later 1970s and early 1980s. Such theories suggested that the stress that occurs when a loved one dies may stretch or exceed

the limits of the bereaved person's ability to cope (Horowitz, Wilner, Kaltreider, & Alvarez, 1980). The work of grief is therefore an evolving process that involves learning and adaptation to the changes that result from the death (Horowitz et al., 1980; Kubler-Ross, 1974; Rando, 1984).

In her classic book *On Death and Dying*, Elisabeth Kubler-Ross (1969) enumerated what are now universally referred to as the five stages of grief: denial of the tragic reality; anger at oneself, another person, or a higher power; bargaining for more time or a miracle of some sort; depression and extreme sadness or despair; and, acceptance or resolution of the catastrophic news or event in one's life. Originally, she offered these stages to explain how individuals face their own deaths after being diagnosed with a terminal condition (Kubler-Ross, 1969). Across the years though, her linear approach to facing grief has been widely recognized by healthcare providers, clergy, educators, and researchers across a variety of disciplines, and applied to many forms of catastrophic loss, ranging from the loss of income or personal rights to the loss of a loved one through divorce or death (Arnold et al., 2005; Gudmundsdottir & Chesla, 2006; Lazenby, 2006; Meert et al., 2005; Moses, 1992; Rando, 1992).

During the 1980s and early 1990s, Rando (1985, 1992) integrated behavioral models that incorporate the impact of external factors in the grief work with the emerging cognitive models that rely on the varying personal and unique internal aspects of how individuals grieve. She suggested that bereavement related to any type of loss can be accommodated for a healthy outcome by following a '6 R' process. The six aspects of Rando's proposed process are:

- Recognize, acknowledge, and understand the loss;
- React to the separation by experiencing the pain and expressing the psychological reactions to the loss and to associated secondary losses;
- Recollect the deceased and re-experience the relationship through memories and revived feelings;
- Relinquish old attachments to the deceased and to what was assumed about life while the deceased was alive;
- Readjust and reconstruct new relationships with the deceased and with the surrounding world to form a new identity and move forward, but without forgetting the deceased or old assumptions about life; and,
- Reinvest in one's self and one's life and one's world.

For more than a century, much has been discussed and written about the work of grief, and about the various stages individuals theoretically go through while mourning the death of a loved one. On the one hand, it is easy to understand grief as a universal concept, and to accept that for as long as humans have existed, there has been the reality of death and thus, grievous reactions to loss. However, across the past quarter century, the numbers of multidisciplinary researchers attempting to organize, understand, explain, and even ameliorate the effects of bereavement and grief have increased dramatically (Center for the Advancement of Health, 2001; NCHS, 2007). The result is a growing awareness that bereavement and grief are very personal matters that lead to a wide range of subjective reactions that are unique to each person and not necessarily linear in nature (Kubler-Ross, 1969, Rando, 1983; Stroebe 1992).

Contemporary researchers have now begun to question some of the long-standing beliefs related to bereavement, especially those that explain grief work as a way to resolve issues related to loss, and to detach from the emotional connections to the deceased (Field, Gal-Oz, & Bonanno, 2003; Gudmundsdottir, 2000; Klass, Silverman, & Nickman, 1996). More current studies have led multidisciplinary professionals to suggest that numerous factors may complicate reactions to grief. For example, grief responses to death following a lengthy illness may be different than grief responses to a sudden trauma (Drenovsky, 1994), and a relationship with the deceased person that was marked by dependency, particularly the loss of a child, may affect the intensity or duration of grief responses (Leahy, 1993; Rando, 1992). As current researchers seek to redefine grief processes, an understanding of such unique factors and how they may affect the personal experiences of bereaved individuals is necessary.

Unique Aspects of Parental Bereavement

Grief may indeed be a universal experience, but the ways in which individuals will perceive and respond to loss vary (Smart, 1993; Stroebe & Schut, 2005). There are many factors that may influence these responses, such as: the age and developmental stage of the deceased person; the nature and quality of the relationship with the deceased; and, whether loss was sudden, anticipated, or violent (Center for the Advancement of Health, 2004). Additionally, there is a growing trend in grief literature for researchers to attend to factors such as familial relationships (Nelson & Frantz, 1996), social supports (Schwab, 1995), spirituality (Brotherson & Sonderquist, 2002), and culture (Riches & Dawson, 2002) as factors that may impact the experience and expression of grief.

Historically, grief was seen as work to be done, with theoretical views focused on negative or pathological responses to death that are resolved through detachment (Davies, 2004; Hogan et al. 1996; Lindemann, 1944; Rowa-Dewar, 2002; Smart, 1993; Stroebe, 1992). Additionally, the historical approach to research in bereavement has been through studies with adults, and the focus has been on the deaths of spouses and other adults late in life (Bowlby, 1969; Horowitz et al., 1980; Lindemann, 1944). The death of a spouse or an aging parent, even when tragic and unexpected, is still considered a *normative event* by most people (Gudmundsdottir & Chesla, 2006; Kubler-Ross, 1969; Rando, 1985). Only in recent years has there been a shift in attention to the concept of ‘non-normative’ loss, and the specific factors that may affect the grief responses and bereavement of parents whose children have died (Braun & Berg, 1994; Chomicki et al., 1995; Davies, 2004; Rando, 1985; Skolnick, 1991; Wheeler, 2001).

Even though the literature did not focus on children until very recently, society has generally recognized the untimely deaths of children for centuries, at least in literary form (Anselment, 1993). Accounts of poetry and prose written about deceased children, as a part of commemoration or compassion or consolation, have been recorded since the 17th century (Dye & Smith, 1986; Stroebe, 1992). Pediatric death statistics prior to the 20th century are not available, but researchers estimate that at that time, at least 25 percent of all children would die before their tenth birthdays (Anselment, 1993). Until the early to middle 1900s, health care professionals had very little to offer children who had injuries, illnesses, or disabilities beyond an attempt to ease symptoms (Hockenberry, Wilson, Winkelstein, & Kline, 2003). As a result, it was not uncommon for children to die, and for them to die at home with their parents and other extended family members

providing their care (Field & Cassel, 1997). Not only are children now living longer lives in spite of disabilities and life-threatening conditions (NCHS, 2007; Perrin et al., 2007), but also the children who do die are most often in hospital settings under the care of professionals, with parents assisting in some level of care (Dorsel & Dorsel, 1986; Field & Behrman, 2003; MacDorman, & Atkinson, 1999). These changes have generally led to feelings of discomfort and shock when a child dies (DeJong-Berg & Kane, 2006; Oliver et al., 2001).

The death of any person significant to a survivor can be a traumatic event that leads to a crisis of meaning and life purpose as the bereaved responds to such loss (Parkes & Weiss, 1983; Rubin & Malkinson, 2001). Death is an irreversible loss, and thus, survivors must reinterpret and assimilate their lives and their environments as they grieve such a loss (Gudmundsdottir & Chesla, 2006). Yet the death of a child is a loss that violates the natural order of what we expect and assume, and is therefore a particularly devastating loss that can lead to complicated bereavement (Chomicki et al., 1995; Davies, 2004; Miles & Crandall, 1983; Parkes, 2001; Rando, 1985; Rowa-Dewar, 2002; Smart, 1993; Wheeler, 2001). Rando (1986) explained that children are an extension of their parents' hopes and dreams and needs for the present and for the future. When a child dies, the resulting non-normative and irretrievable loss is traumatic, and subsequent grief responses can be complicated as parents search for some type of continuing bonds and meaning (Braun & Berg, 1994; Davies, 2004; Miles & Crandall, 1983; Rando, 1985). Rando (1986) theorized that traditional linear approaches to understanding grief, in which individuals detach from a loved one, are not reasonable for bereaved parents. She said

that detachment from one's own child and from parental hopes and dreams for the future is unnatural, inappropriate, and too difficult to expect of a parent.

Researchers are beginning to find many distinguishing characteristics of parental grief. One of these characteristics is the extreme guilt many parents report feeling. Condon (1986) said that even when they know their perceptions are illogical, parents often feel they have failed as protectors of their children. Another issue that complicates parental grief is the nature of the child's death, or whether the death was anticipated or sudden) (Binger et al., 1969; Chomicki et al., 1995; Drenovsky, 1994; Kerner, Harvey, & Lewiston, 1979; Kirshenbaum & Zeanah, 1984; Miles & Demi, 1992; Rando, 1983; Seecharan, Andresen, Norris, & Toce, 2004).

Some researchers report on the devastating effects of the sudden, unanticipated loss of a child on parents (Drenovsky, 1994; Miles & Demi, 1992; Seecharan et al., 2004). Others offer details on the complicating factors and detrimental outcomes associated with the anticipated loss of a child who was diagnosed with a catastrophic illness or a severe disability (Binger et al., 1969; Chomicki et al., 1995; Kerner et al., 1979; Kirshenbaum & Zeanah, 1984; Rando, 1983). There are also researchers who conclude that even though parents bereaved by the sudden deaths of their children report higher levels of grief than parents whose children die after an illness and anticipatory period, both groups of bereaved parents express a strong desire and need to share stories about their deceased children, about their experience of loss, and about their grief (Brotherson, 1999; Klass & Goss, 2003).

In 1983, Rando wrote that the understanding of the impact of sudden versus anticipated child death is a very complex issue. She stated that parents whose children

were diagnosed with an illness or disabling condition at 6 to 18 months before death had an optimum opportunity to prepare for the death of their child. She speculated that this was because a sudden trauma or shorter illness does not allow adequate time for parental adjustment to a terminal condition, and that a longer lasting illness or disability may lead to parental denial of the possibility of early death since the child did survive so long with the condition or disease. Kirshenbaum and Zeanah (1984) also concluded that anticipatory grieving and parental involvement with a child's chronic illness or disability might be associated with better adjustment following the child's death. However, they said that long term or high levels of involvement were associated with prolonged rumination about the deceased child and with neglect of other responsibilities including appropriate attention to surviving siblings, to work duties, and to tasks of daily living.

Riches and Dawson (2000) also reported a wide range of social and cultural variables that may impact parental bereavement, including gender and parenting roles. They said that people within the same family who have experienced the loss of the same loved one are likely to grieve in very different ways. However, one of the most dramatic shifts in theoretical perspectives of parental bereavement is the growing understanding that grief takes place in a social world in which the child once lived, and in which bereaved parents must remain (Gudmundsdottir & Chesla, 2006; Klass et al., 1996). This has led to a focus on what researchers call *continuing bonds* (Klass & Goss, 2003; Robinson, Thiel, Backus, & Meyer, 2006). Indeed, for many bereaved parents, sharing memories and exploring the significance of their children's lives and deaths for years, even decades after their children have died, is a meaningful and desired part of

their grieving experience (Davies, 2004; deJong-Berg & Kane, 2006; Stepanek & Newcomb, 1996).

According to Klass (1996), grieving parents need to be consoled. Such solace and alleviation of sorrow and distress often is found through:

- Linking objects (e.g., the child's toys, poetry, artwork, clothing);
- Self-validating truths (e.g., something meaning that a parent shared with a child such as watching the sunset, collecting shells, or playing a certain game); and,
- Memories of the child (i.e., personal memories and also memories shared with or by others).

Linking objects and self-validating truths can connect a parent to the child's life somehow, which evokes a sense of presence. Memories, while painful reminders of loss at first, can become an essential part of a bereaved parent's everyday life as they bring a parent out of the present and to a time when the child was alive (Klass, 1996). Rather than letting go of connections to their deceased children, grieving parents adapt, grow, and change these connections as they move forward in bereavement.

Constructing a narrative and sharing stories of their child's life and death is also an important part of the parental bereavement process (Gudmundsdottir & Chesla, 2006). However, this process is dependent on having opportunities for appropriate, accepted, and ongoing conversational remembering (Riches & Dawson, 2000; Toller, 2005).

Across the past few decades, a number of self-help social networks and support groups have been established by and for families who have lost a child to death (Rando, 1985; Schwab, 1995). In spite of the existence of these groups, some bereaved parents cannot always find someone in their family or in these networks with whom they feel they can

share such stories (Riches & Dawson, 2000; Stepanek & Newcomb, 2006). This can be an added burden at a profoundly challenging time (Rowa-Dewar, 2002).

According to Stroebe and Schut (2005), the intensity and duration of grief are the two factors most reliably associated with complicated grieving and poor outcomes for bereaved parents. Although there is no quantified definition of what constitutes normal intensity or duration for grief, the experiences of bereaved parents are often severe and prolonged compared to the grief experiences of other bereaved populations (Nelson & Frantz, 1996). In 1983, Rando wrote that parents reported a lessening of the intensity of their grief 2 years after the death of their child. But in the third year, they reported a subsequent increase in the intensity of their grief. Other researchers, however, argue that the duration of grief after the death of one's child should not be considered pathological, because remaining connected through some bond with or to the deceased child is both common and helpful to adjustment (Dawson & Riches, 2000; Gudmundsdottir & Chesla, 2006; Klass et al., 1996; Rubin, 1993).

Based on this brief overview of the unique aspects of grief related to the loss of a child, it can be concluded that theoretical perspectives on parental grief have changed throughout the past century, and that they have received considerable attention in the past quarter century. It can also be concluded that parental bereavement is a particularly difficult process, one that may be more intense and longer lasting than the grief that results from other losses, and one that involves some level of sustained connection between parents and their deceased children (Christ et al., 2003; Klass et al., 1996; Rando, 1983; Riches & Dawson, 2000; Rubin & Malkinson, 2001). These are complex

issues that require a careful exploration of empirical data that support both theoretical views and practical implications.

Synthesis of Research Related to Parental Bereavement

In this section, empirical data related to understanding and supporting parents during bereavement and grief are synthesized. By providing an empirical context for parental bereavement, information is available about specific needs for continued research related to:

- The various factors that may impact parental grief responses;
- Parental grief related to children who die as a result of catastrophic life-threatening conditions and degenerative disabilities;
- How parents reconstruct meanings after a child's death and possible social support systems that may enhance positive outcomes; and,
- Appropriate training and support for teachers and other professionals who work with children who have disabilities and their families.

Selection of Studies for the Current Review

The term *child* has connotations of youthfulness. However, in the literature it is a label that has been applied to individuals ranging from newborn infants to adults in their geriatric years. Because the specific interest at hand is the integration and presentation of research findings that may be relevant to special education professionals who serve children and families under IDEA, the term *child* in this manuscript will apply to individuals from infancy to age 21 years. However, articles that deal solely with infant deaths as a result of perinatal or neonatal conditions will be excluded from this review, as this population is not likely to be served under IDEA. This includes: infants who do not

survive past birth; Sudden Infant Death Syndrome; and, the death of an infant before age 12 months due to complications of prematurity, congenital anomalies, or sudden illness. For the same reason, articles dealing solely with the deaths of adolescents or young adults due to violence—including suicide, homicide, drug-related or drunk-driving incidents, and military casualties—are also excluded from this review.

Studies included for review were selected from a computer search of ERIC, PsycLIT, PsycINFO, Social Sciences Citation Index, Medline, and the University of Maryland databases.

In addition, an ancestral search was conducted with two professional peer-reviewed journals that deal solely with issues related to grief and bereavement: *Omega: Journal of Death and Dying* and *Death Studies*. The database search was conducted using various combinations of the following keywords: *death, grief, bereavement, mourning, parent, child, family, coping, chronic, traumatic, disability, degenerative, anticipated, sudden, education, and teacher*. This search resulted in 917 possible references, but a review of abstracts revealed that most of these resources were either theoretical in nature, or were studies related to bereavement associated with perinatal or neonatal deaths; the deaths of adult children, spouses, or parents; and, the violent or sudden deaths of teenagers and young adults. A total of 44 articles from the databases were found to have empirical data related to parental bereavement as defined above, and were thus chosen for inclusion in this review. An additional 3 articles that did not overlap with the database search were found in the ancestral search of the two professional journals. No true controlled studies were found for inclusion in this review. Rather, the results of all of the articles in this review are based on qualitative, comparative, or descriptive methodology.

The final selection of 47 articles was sorted into eight categories based on theoretical factors generally found to influence parental grief and bereavement (Davies, 2004; De Vries, Dalla Lana, & Falck, 1994; Rando, 1984). The distribution includes the following categories and number of articles that will be reviewed in each category:

- Grief responses across bereaved individuals (e.g., parents, spouses, siblings, adult children) yielded six articles;
- Grief responses across type of death (e.g., sudden, anticipated) yielded six articles;
- Grief responses within type of death (e.g., cancer, congenital disease) yielded 13 articles;
- Grief responses across parents by gender yielded three articles;
- Grief responses related to the death of an only child yielded three articles;
- Meaning reconstruction during parental bereavement (e.g., connectedness, redefining parental roles) yielded nine articles;
- Social support from groups during parental bereavement yielded five articles; and,
- Informal support from professionals during parental bereavement yielded two articles.

The results of the review are summarized in Appendices A through H. Within the appendices, the following information is summarized when available for each study: basic participant information, number of participants, selection source, the relationship of the participants to the deceased child, the number of years the participants were bereaved prior to the study, the ages of the children at time of death, the causes of death, the assessment methods and tools used to gather information, basic concerns regarding the

methodology of the study, and general findings reported by the author(s). The first part of this review will be a synthesis of the descriptive data and findings according to the eight categories into which the articles have been sorted. An analysis of limitations based on methodology used in the studies will follow.

Grief Responses Across Bereaved Individuals

Six studies were found for this review that explored the nature and quality of relationships among adults or adolescents and their deceased family members. The researchers of these studies focused on the interaction of relationship roles with grief responses and coping strategies (See Appendix A). In four of these studies, the grief reactions of either related or unrelated bereaved spouses, bereaved adolescent or adult children, and bereaved parents were compared (Hogan et al., 1996; Leahy, 1993; Middleton, Raphael, Burnett, & Martinek, 1998; Reif et al., 1995). The researchers of two studies reported findings that compared the grief reactions of participants specifically within the same families. One of these two studies focused on parents and grandparents who were related to the same deceased child (Ponzetti, 1992). In the other study, the focus was on parents and adolescent siblings who were bereaved of the same child (Nelson & Frantz, 1996).

The participants in five of the studies comparing bereaved adults or adolescents were solicited through various support groups (Hogan et al., 1996; Leahy, 1993; Nelson & Frantz, 1996; Ponzetti, 1992; Reif et al., 1995), and in one study, referrals were made by hospital personnel based on death records (Middleton et al., 1998). Though such information was not always included, most of the participants were described as White, middle class income, Christian, and married. Information on the length of time the

participants had been bereaved prior to the study varied greatly. No information was available for this factor in two studies (Middleton et al., 1998; Ponzetti, 1992), and in one study, a mean length of 4 years of bereavement was listed (Nelson & Frantz, 1996). One study compared participants whose length of bereavement ranged from 1 month to 17 years (Reif et al., 1996), and one study compared participants whose length of bereavement ranged from 6 months to 37 years (Hogan et al., 1996). Only one study limited the criteria to participants who had been bereaved for a similar length of time, specified as 1 month to 2 years (Leahy, 1993).

The ages of the deceased person were not always included in the findings (Leahy, 1993; Nelson & Frantz, 1996). When they were included, the ages of the deceased varied greatly, ranging from 2 to 85 years (Hogan et al., 1996), from one month to 17 years (Reif et al., 1996), from 6 months to 70 years (Middleton et al., 1998), and from 1 month to 30 years (Ponzetti, 1992). The causes of deaths across all studies included both sudden and anticipatory losses resulting from illness, chronic disease, accident, trauma, violence, and/or suicide. The methods used to gather data included open-ended interview question either face-to-face or by telephone, and a variety of written-response questionnaires or checklists that record self-reported information about grief responses (e.g., Beck Depression Inventory).

Comparison of unrelated bereaved adults. Hogan et al. (1996) compared 34 unrelated bereaved adults who had lost a parent, a child, or a sibling, using qualitative methodology and open-ended questions in telephone interviews. The authors reported that bereavement follows traditional patterns and stages of grief regardless of how a person dies, and regardless of the relationship of the survivor to the deceased. Although

the questions asked are not listed and there is no information on which participants experienced the loss of a loved one suddenly versus following an anticipatory period, these researchers also concluded that the anticipation of a death due a diagnosed condition does not lead to ameliorated or foreshortened grief.

The researchers of the three other studies comparing unrelated bereaved adults reported very different results. Based on self-report questionnaires, two researchers reported that bereaved mothers (Leahy, 1993) and bereaved parents in general (Middleton et al., 1998) have significantly higher and more intense levels of grief than bereaved spouses or offspring. Leahy's study included 255 women, of which 58 were bereaved mothers, and who all completed a short form of the Beck Depression Inventory (BDI). The study by Middleton et al. included 120 participants, of which 36 were parents, and who completed a bereavement questionnaire created for the study. The intense grief responses reported in both of these studies included depression, guilt, social withdrawal, and hopelessness.

One researcher reported that the amount of time since death was the strongest indicator of severe distress (Reif et al., 1995). The 158 participants, of which 140 were parents, completed an *Impact of Event Scale* to measure stress responses after loss, as well as two measures assessing the availability and usefulness of social supports. Based on responses to these measures, Reif et al. reported that the perceived helpfulness of others was beneficial to bereaved individuals, and that when bereaved individuals perceived that they had available and compassionate help from others they reported better coping patterns than other bereaved individuals.

Comparison of related bereaved adults. Ponzetti (1992) compared 15 couples, 6 mothers, and 28 grandparents who were bereaved from the death of the same child using an unspecified questionnaire. They concluded that parents tended to report feelings of grief related to their deceased child, whereas grandparents reported more feelings of grief related to their adult children (i.e., the parents of their deceased grandchild). Parents in this study also reported treating their surviving children (i.e., siblings of the deceased child) differently since the death of one child. Grandparents reported feeling differently about other family members but not behaving any differently toward them since the death occurred (Ponzetti, 1992).

To study how different types of death and bereavement may affect family interactions, Nelson and Frantz (1996) compiled family cohesion and interaction data from a group of parents who had lost a child due to suicide, an accident, or an illness. They compared the findings with data obtained from a portion of these parents' surviving children who were classified as bereaved adolescent siblings. They used *Bloom's Family Scale* as the instrument intended to measure family closeness, but no data were reported on the reliable or valid use of this measure with bereaved individuals. Nelson and Frantz concluded that the cause of death made no significant difference in closeness ratings among any dyads examined—parents to surviving children, spouses to each other, and surviving siblings to their mothers or fathers. Additionally, family functioning and levels of cohesion were unaffected by the type of death. Although the nature of death was not correlated with levels of cohesion, these researchers reported that the more family conflict parents reported, the more distant they felt from their surviving children. Conversely, the more perceived cohesion the parents reported, the closer the bereaved

parents felt toward their surviving children. The adolescent siblings in this study generally reported higher levels of family conflict than their parents reported. Although many of them reported feeling closer to their mothers before the death of their siblings, most of the bereaved adolescents reported feeling closer to their fathers after the deaths, and more distant from their mothers especially if there were high levels of family disengagement and conflict reported (Nelson & Frantz, 1996).

Grief Responses Across Type of Death

Six studies were found for this review that explored the differences in grief responses of parents based on how their children died (See Appendix B). The participants in four of these studies were solicited through support groups for bereaved parents (Alexy, 1982; Drenovsky, 1994; Miles & Demi, 1992; Wheeler, 1994). The participants for one study were solicited from referrals made by hospital personnel based on death records (Seecharan et al., 2004). The participants of another study were solicited through mailings sent out to all alumni of a particular nursing school to recruit those who had lost a child anytime during the previous 75 years (Arnold et al., 2005).

Though such information was not always included, most of the participants were described as White, middle class, Christian, and married. Information on the length of time the participants had been bereaved prior to the study varied greatly. No information was available for this factor in one study (Drenovsky, 1994), and in two studies the range was from 1 to about 50 years (Arnold et al., 2005; Wheeler, 1994). In three studies, the length of time of bereavement varied less, with ranges of 1 to 9 years (Alexy, 1982), 2 months to 7 years (Miles & Demi, 1992), and 7 months to 3 years (Seecharan et al., 2004).

The ages of the deceased person were not always included in the findings (Drenovsky, 1994). When they were included, the ages of the deceased varied greatly, ranging from 1 to 18 years in one study (Miles & Demi, 1992) and from birth or infancy to adult or late adulthood in four of the studies (Alexy, 1982; Arnold et al., 2005; Seecharan et al., 2004; Wheeler, 1994). The causes of deaths across all studies included both sudden (i.e., no warning) and anticipatory losses (i.e., condition diagnosed at least 14 days prior to death) resulting from illness, chronic disease, accident, trauma, violence, and/or suicide. The methods used to gather data included open-ended interview questions either face-to-face or by telephone, and a variety of written-response questionnaires or checklists that record self-reported information about grief responses.

Comparison of grief responses across parents. Based on interviews and self-report questionnaires completed by 74 nursing alumni who had lost a child at any point during the previous 62 years, due to any illness or trauma anytime from infancy to adulthood, Arnold et al. (2005) concluded that parental grief is intense and lasting, no matter how or when a child dies. These results were based on responses to measures that were created by the authors for this study, but with no reports on reliability, validity, or how the measures were designed. The results of three other studies comparing parents whose children died from illness or trauma had different findings (Drenovsky, 1994; Miles & Demi, 1992; Seecharan et al., 2004, Wheeler, 1994).

Drenovsky (1994) studied the conditions under which a parent might be more likely to express anger at a deceased child for dying, and/or a desire to seek retribution for the death in some way. Most of the 39 couples in her study lost their children suddenly. Based on the written responses of these participants who completed a scale

intended to assess depressive symptoms in a general population, Drenovsky reported that the suddenness of a child's death is correlated with an increase in parental anger, compared to the grief of parents whose children die of illness. However, she also stated that neither anger nor a desire to seek retribution had a significant effect on parental levels of depression. Furthermore, when compared to parents who had anticipated their children's deaths, parents whose children died suddenly had significantly lower levels of depression according to this researcher. Whereas the parents who had anticipated their children's deaths scored higher on depression scales (with mothers scoring higher than fathers), the depression levels were still within the normative data range and not considered pathological.

Miles and Demi (1992) analyzed the written responses of 132 parents, who answered three open-ended questions related to perceived stress and feelings of guilt. Most of these parents lost their children to suicide or accidents. The researchers found that 92% of the 62 parents whose children had died by suicide expressed feelings of guilt associated with their children's deaths, compared to 78% and 71% of the parents whose children had died after an accident (n = 32) or chronic illness (n = 38), respectively. Overall, the parents of children who died by suicide rated feelings of guilt as their most pervasive and unsettling grief reaction compared to other parents in the study, who ranked feelings such as loneliness, loss of control, sadness, and despair as the most distressing aspects of their grief (Miles & Demi, 1992).

To describe the grief responses of bereaved parents who had experienced the death of a child in the previous 3 years, Seecharan et al. (2004) interviewed 79 parents

and guardians of 59 deceased children who died anytime from infancy to adulthood from any type of illness or trauma. The Texas Revised Inventory of Grief and a *satisfaction with care* survey were used as the measures. They concluded that although mother and fathers generally reported similar levels of overall grief, mothers whose children died suddenly reported slightly more intense grief reactions than mothers whose children had died as a result of a chronic condition (Seecharan et al., 2004).

Wheeler (1994) reported on her findings after analyzing surveys completed by 203 parents whose children died from various causes and across the previous 1 to 48 years. She used the *Grief Experience Inventory (GEI)* which has been found to have reliability on some subscales related to grieving. She also used the *Purpose in Life (PIL)* instrument that has been useful in occupational, religious, and prison settings. Wheeler concluded that whereas most bereaved parents report a crisis of meaning in life following the death of a child, a lower purpose in life was perceived and reported by parents whose children died by suicide, and also by parents whose children died recently and by parents who lost their only child (Wheeler, 1994).

Comparison of coping styles across parents. In 1982, Alexy interviewed and collected self-report questionnaire data from 25 mothers and 17 fathers whose children had died from either cancer or a sudden trauma. The measure was a questionnaire created by the researcher for the study, and the reliability results were based on inter-rater agreement obtained from graduate students in a university counseling department. He reported that bereaved parents, regardless of how their children died, preferred different types and sources of support during different phases of their grieving. During the early phases of grieving, parents reported that they had more ambiguous feelings, emotions,

and impulses rather than cognitive processing of their loss that might lead to some meaning reconstruction (Alexy, 1982). These parents reported needing counseling and a supportive listener during this phase, so they could freely express all their feelings. Alexy said that during later phases of yearning and loneliness, parents dealt more with their ideas and beliefs about the meanings of life and loss, with a focus on thoughts of their child and the events leading up to death.

According to Alexy (1982), during the *disorganization phase* of bereavement parents reported less of a focus on either action or cognition, and that they were more focused on the intensity and pain of their grieving. Finally, during the *reorganization phase*, “a time lasting indefinitely when bereaved parents are gradually able to reconstruct their lives” (Alexy, 1982, p. 506), parents reported more of a need for organizing their insights regarding the meaning of their child’s life and death, and their own purpose in life. Alexy surmised that at this point in the grieving process, parents were trying to integrate their grief into daily living. Although the findings reported by this researcher are rich in detail, the participants who participated in this study had a great degree of variation in length of time since their child died (1 to 9 years), in the ages and developmental stages of their deceased children (6 months to 28 years), and in the amount of support they had sought during their bereavement (one support group meeting to 36 different meetings across years).

Arnold et al. (2005) reported similar results about the grief responses of bereaved parents. They concluded that the coping styles and reported support needs of parents varied, regardless of how or when their children died. These results were based on measures created by the researchers for their study, but without any information on the

design, reliability, or validity of the measures. According to these researchers, at least 25% of the parents in this study reported that after the death of their child, they felt ignored by family, by friends, and by professionals who once supported or cared for their children in some way, perhaps due to discomfort with the issue of childhood loss (Arnold et al., 2005).

Grief Responses Within Type of Death

Thirteen studies were found for this review that explored the differences in grief responses of parents whose children died after a prolonged anticipatory phase, due to a catastrophic illness or a chronic disability (See Appendix C). The participants in four of these studies were solicited through a review of hospital records (Clerici et al., 2006; deCinque et al., 2006; Papadatou, Yfantopoulos, & Kosmidis, 1996) or hospice records (Corden, Sloper, & Sainsbury, 2002), and in five studies, participants were solicited through support groups for bereaved parents (Aho et al., 2006; Gillis, Moore, & Martinson, 1997; Milo, 1997; Rando, 1983; Wood & Milo, 2001). In one study (Lister, 2005) participants were solicited through support groups, mailings, newsletters, and personal invitation. In one study (Kreicbergs, Valdimarsdóttir, Onelöv, Henter, & Steineck, 2004), participants were invited to the study through nationwide mailings in Sweden. In two studies (Chomicki et al., 1995; Goodenough, Drew, Higgins, & Trethewie, 2004), the selection process is not detailed. Descriptive information about parent demographics was generally lacking across the studies.

Information on the length of time the participants had been bereaved prior to the study was missing in two studies (Chomicki et al., 1995; Wood & Milo, 2001). In three studies, parents had been bereaved for about 2 years (Clerici et al., 2006; Corden et al.,

2002; Gillis et al., 1997); in one study parents had been bereaved 2 months to 3 years (Rando, 1983); in two studies parents had been bereaved from about 1 to 7 years (Goodenough et al., 2004; Milo, 1997); in two studies parents had been bereaved for 4 to 9 years (deCinque et al., 2006; Kreicbergs et al., 2004); and in three studies parents had been bereaved for as little as 2 months and as long as 3 years (Aho et al., 2006; Papadatou et al., 1996) or as long as 18 years (Lister, 2005).

The ages of the deceased child were not always included in the findings (Clerici et al., 2006; deCinque et al., 2006; Kreicbergs et al., 2005). In three studies, the ages of the deceased ranged from preschool years to adolescence (Chomicki et al., 1995; Goodenough et al., 2004; Papadatou et al., 1996). In one study the ages of the deceased ranged from newborn to 2 years (Aho et al., 2006). In five studies the ages of the deceased ranged from 1 month to 18 years (Corden et al., 2002; Gillis et al., 1997; Lister, 2005; Rando, 1983; Wood & Milo, 2001). And in one study the ages of the deceased ranged from 10 months to 37 years (Milo, 1997).

The causes of death in five studies (Aho et al., 2006; Chomicki et al., 1995; Corden et al., 2002; Milo, 1997; Wood & Milo, 2001) were severe or life-long disabling conditions, and the cause of death in all other studies was cancer (Clerici et al., 2006; deCinque et al., 2006; Gillis et al., 1997; Goodenough et al., 2004; Kreicbergs et al., 2005; Lister, 2005; Papadatou et al., 1996; Rando, 1983). The methods used to gather data included case study, open-ended interview questions either face-to-face or by telephone, and a variety of written-response questionnaires or checklists that record self-reported information about grief responses.

Anticipating a child's death. In 1996, Papadatou et al. conducted a retrospective study exploring personal accounts of the perceived coping styles and support needs of 15 Greek mothers who had chosen to care for their children dying from cancer either at home or in the hospital as their children's condition became terminal. All of the children were ages 2 to 16 years at the time of death, and the mothers had been bereaved 6 months to 3 years prior to the interviews that were a part of the study. The measures used included a review of hospital records and participant self-report on both the *GEI* and various open-ended questions. The researchers reported that each mother's decision to care for a dying child at home versus in the hospital was based on a combination of child and parent preference, and that emotional and psychological factors were highly related with the decision to choose homecare (e.g. more familiar, normal, comfortable, no restrictions on time spent with child, more control). Also, those mothers who chose homecare cited a strong family network, which then played a significant role in the psychological support of the mother after her child died at home (Papadatou et al., 1996). On the other hand, medical factors (e.g., hope for better pain control) were reported by the mothers who chose the hospital as the place of death for their children as being highly related to their decision-making processes. However, these mothers also reported some psychological factors (e.g., the potential of more available support, the security of nearby professionals, the availability of professionals and other parents with whom they could discuss the situation and/or their feelings) as contributing to their decision-making process (Papadatou et al., 1996).

As a part of their study, Papadatou et al. (1996) also sought to identify some of the major needs identified by mothers surrounding the time of their child's death. Desired

facilitators of successful homecare as reported by the participating mothers included:

- The presence of a some type of a professional, even if he or she just provided emotional support, and not medical care;
- Regular communication with professionals for guidance and reassurance;
- An open exchange of information between professionals and parents so that the parents would not feel guilty or have any regrets related to any decisions being made with regard to their child;
- The availability of medications at home; and,
- Someone to help with household chores and tasks of daily living while the mother cared for the dying child.

Mothers whose children died at home rated the support of family members as high, whereas mothers whose children died in the hospital rated the support of other parents of children with illnesses as most helpful during the anticipatory period. Also, 60% of the mothers in this study reported that they had regrets about the way they handled their child's illness. Many of these mothers reported questioning why they had not stopped treatments sooner to prevent their children's ongoing pain, and others questioning why they had not sought second opinions, or whether they had done enough medically and emotionally for their child. These findings suggest that feelings of guilt are associated with parental perceptions of “doing too much” or “doing too little” and occur regardless of where a child dies (Papadatou et al., 1996).

In a different study of the effects of a prolonged anticipatory period before a child's death, Chomicki et al. (1995) conducted and reported on three in-depth case studies of two mothers and one father whose children with severe disabilities died

between 3 and 15 years of age. They found no support for the theoretical view that parents who have the opportunity to anticipate their children's deaths experience ameliorated or foreshortened grief and bereavement. Rather, they concluded that the intense emotions associated with grieving continue to emerge at peak times for an indefinite length of time during the life of the parent (Chomicki et al., 1995). The parents in this study reported that even though they knew for years, or even more than a decade that a child might die, they felt a lack of preparation for anticipating and coping with the deaths of their children. They cited years of living with hope for a good outcome, and large amounts of attention devoted to the daily routines focused on the various medical, educational, and emotional needs of their children as some of the reasons they not only felt unprepared, but also responded to the death with both shock and disbelief. One parent reported that the child's death "so disrupted the already disrupted normal routines" of daily life, that the result was a feeling of disorientation, confusion, and inconsolable grief in the months immediately after the death "but no one seemed to notice, and I guess that was just fine with me" (Chomicki et al., 1995, p. 23).

Recently, Aho et al. (2006) explored the experiences of fathers who anticipated the deaths of their children who had been diagnosed with a life-threatening disability. They asked 8 fathers to complete open-ended written questionnaires, and then to respond to interview questions by telephone or in-person interviews 6 months later. The interview questions were not specified. The researchers reported that the fathers' anticipatory feelings included fear, uncertainty, a lack of knowledge, and a feeling that they were powerless to do anything that might really help their child. According to these

researchers, the fathers' anticipatory feelings were highly correlated with their reported grief responses after their children died.

Grief after anticipated loss. The researchers of all 13 articles focusing specifically on parents whose children died after a lengthy illness or life-long disabilities report that anticipating the death of a child does not appear to decrease the perceived intensity or duration of parental grief and bereavement, including feelings of shock, denial, anger, guilt, anxiety, and sadness (Aho et al., 2006; Chomicki et al., 1995; Clerici et al., 2006; Corden et al., 2002; deCinque et al., 2006; Gillis et al., 1997; Goodenough et al., 2004; Kreicbergs et al., 2005; Lister, 2005; Milo, 1997; Papadatou et al., 1996; Rando, 1983; Wood & Milo, 2001). For example, Lister (2005) conducted a qualitative study exploring parental bereavement associated with a child's illness that lasted longer than 6 months. She reported that both grief responses and making meaning out of loss began with most of the 16 bereaved parents in her study when their children were first diagnosed, and that these processes continued through the years of their children's lives, and into the years beyond their children's deaths. Many of the researchers of these 13 studies also concluded that the grief of parents whose children die after a prolonged health condition is intense, although the impact of the loss is not always recognized or appreciated or validated as being so intense by others because of the child's disability (Aho et al., 2006; Chomicki et al., 1995; Lister, 2005; Milo, 1997; Wood & Milo, 2001).

Rando's earlier evaluation (1983) of the grief and bereavement experiences of 54 parents whose children died from cancer during the previous 2 months to 3 years resulted in somewhat similar findings. She concluded that anticipating a child's death did ameliorate the intensity and duration of parental grief if a child died within 18 months to

2 years from the time of diagnosis. However, she found that when parents had more than 18 months to 2 years from the time of diagnosis to anticipate their child's death, the intensity and duration of their grief and bereavement exceeded that of parents whose children died either suddenly or after a briefer time frame. She speculated that if parents have fewer than 18 months to prepare for the death of a child, they do not have adequate time to adjust to the terminal nature of the child's condition. She said that a longer period of anticipation and increased involvement in meeting the child's atypical care needs may actually encourage parents to deny the possibility of the child's death, especially when the child survives the disease and beats the odds for a prolonged period of time.

Rando (1983) also found that although there seemed to be a gradual decrease in the intensity of parental grief across the first 2 years following the death of a child, there was a subsequent increase in intensity during the third year of grieving. Parents who anticipated the deaths of their children scored higher on scales measuring social isolation, denial, guilt, and other indicators of intense grieving during the third year of bereavement, compared to parents whose children had died of cancer more recently. Additionally, she reported that high parental involvement with the complex care needs of their dying children was associated with prolonged rumination about the deceased child, and with an emotional or physical withdrawal from other responsibilities and family members following the death of the child. However, Rando's study design was cross-sectional rather than longitudinal, and thus, it is difficult to draw conclusions about rumination and to know whether the parents whose grief was higher at 3 years after death would have also scored higher on grief scales earlier during their bereavement.

Two studies were undertaken by researchers who conducted semi-structured

interviews with parents whose children died due to complications of a severe disability or a chronic health condition. Wood and Milo (2001) studied the experiences of 8 bereaved fathers whose children died between 7 months and 16 years of age, and Milo (1997) explored the experiences of 8 mothers whose children died between the ages of 10 months and 37 years of age. The fathers in Wood and Milo's study did not differ in grief responses from fathers in other studies of parental bereavement, but they did report feeling like the death of a child with a disability is a "double loss" (p. 643). These fathers said that the first loss is the loss of dreams for a typical or healthy child, and the second loss is the loss of the child after years of loving and caring for the child despite the daily challenges and crises (Wood & Milo, 2001). These fathers also reported choosing a stoic expression as they grieved, and relying on activities such as work and exercise to cope with their grief rather than social supports. The mothers in Milo's (1997) study reported similar feelings of a *dual loss*, and of not having their grief validated due to the fact that their child had a disability. These mothers reported relying on cognitive coping strategies to help them find meaning in the pain of having a child with a disability, and of losing that child to death.

After analyzing the responses of bereaved mothers from *GEI* scales and semi-structured interviews, Milo (1997) reported a number of findings related to maternal loss of a child with a life-threatening disability, including:

- They felt set apart because their love for the child and their loss were not validated by others, most likely due to the fact that the child had a severe and life-threatening disability;
- They had to work through two difficult transitions—disability and death;

- They generally felt that raising a child with a disability was not an experience they would have expected or welcomed but that it had been one of the defining experiences of their lives and had transformed them in many positive ways;
- The experience of raising a child with a severe disability profoundly shifted the mothers' sense of identity, world view, relationships, spirituality, and priorities—both during the life of the child and after death;
- They were usually able to restore a sense of well-being in the world, after birth, after the diagnosis of their child's disability, and once again after the death of their child;
- They used cognitive coping strategies of construing benefits or gains, finding meaning, reestablishing control, and using humor more than they used downward comparison (i.e., comparison with the worst-case scenario) to restore their assumptive world; and,
- The mothers who used cognitive coping strategies early and extensively were better able to cope than those who delayed using them or who did not use them extensively.

The 8 fathers in the study conducted by Aho et al. (2006) reported similar feelings. They said that they felt the long term stress of their children's disability inhibited their ability to express post death grief. The researchers did not specify the questions that the fathers responded to, but said that the fathers reported feeling like they had to grieve privately since others might not understand their children's worth due to the nature of the child's disability (Aho et al., 2006).

In addition to feelings of disorientation and inconsolable grief during the period just after a child with a chronic or life-long condition dies, some researchers report that parents also have recurring sorrow and grief for years, and that parents report feeling that life is changed completely and forever (Chomicki et al., 1995). Based on case studies of 3 bereaved parents, Chomicki et al. reported that parents who lose a child after an anticipatory period may express a desire or make a commitment to assist others, and to improve conditions for others who in some way are involved with children who have life-threatening conditions (i.e., parents, educators, nurses, other professionals) through education and advocacy work. The parents in this study reported that children with disabilities are powerful teachers who can “inspire us with their very existence. Their presence is often more eloquent than words and more powerful than actions” (Chomicki et al., 1995, p. 25).

Chomicki et al. (1995) concluded that like parents whose children die suddenly, parents who anticipate their children’s deaths report needing to find significance in the lives and in the deaths of their children. However, because of the various complications and issues associated with the child’s disability, the significance of the child’s life, and of the parents’ loss is not well-recognized by other families, even families who have lost a child suddenly and know intimately the pain of parental bereavement. These researchers reported that well-meaning friends and relatives attempt to console the bereaved parents of children with disabilities:

with expressions concerning the child’s limitations and the reduced quality that those limitations put on the child’s life. While the loss of a child with disabilities results in a cessation of duties often involving arduous and repetitive activities and

an end to the daily grind of feeding, toileting, dressing and lifting and exercising, such expressions are hardly consoling for individuals who love that child unconditionally. While the loss of a child with a disability is likely to result in an initial sense of relief and release from these tasks, the mourning process is likely to include much soul searching on the part of the parents as they sort out how this child has impacted upon their life (Chomicki et al., 1995, p. 23).

Gillis et al. (1997) explored the applicability of a commonly used grief symptom checklist to gain an increased understanding of the unique factors associated with the process of parental bereavement. They said they also wanted to better understand the potential use of this checklist for gaining insight into the issue of complicated or problematic grieving that may be associated with anticipatory loss. These researchers analyzed the responses of 97 bereaved parents who represented a subset of a larger study already in progress, and whose children had died due to cancer anytime from 1 month to 17 years of aged. They concluded that compared to general populations of bereaved parents, parents whose children die of cancer report more somatic symptoms of grief than behaviorial or affective symptoms of distress.

In Australia, Goodenough et al. (2004) analyzed responses to a different checklist and to questionnaires that were completed by 25 mother-father dyads whose children had died from cancer. The parents in the study had been bereaved sometime during the previous 5 years, and their children averaged 7 to 10 years of age at the time of death. They concluded that fathers whose children died in a hospital rather than at home reported higher levels of depression, anxiety, and stress both before and after the child's death. They also concluded that mothers in this study reported high levels of grief

responses both before and after the child's death regardless of where the death occurred. In their description of participants, Goodenough and colleagues reported that the children who died in hospitals lived an average of 218 or more miles from the hospital, whereas the children who died at home lived an average of 80 or fewer miles from the hospital. They did not offer any information about how the actual distance from the hospital setting and the resulting physical distance between various family members may have interacted with reported stress levels. Nor did they discuss the possibility of altered or disrupted caregiving roles due to the child's illness and the physical distance between family members..

Kreicbergs et al (2004) compared questionnaires results from 449 Swedish parents whose children had died from cancer in the previous 4 to 9 years with the results of 457 Swedish parents who had not experienced such loss or a catastrophic illness. The questionnaires were created by the researchers for the study, and validity for the measure was obtained through bereaved parents, although it is not clear if this group of parents overlapped with the bereaved parents who participated in the study. They concluded that when a child's death is caused by a malignancy, parents are commonly exposed not only to their own loss, but also to the protracted physical and emotional suffering experienced by the child. The researchers reported an increased risk of anxiety and depression for bereaved parents during the first 4 to 6 years after the death of a child. They also stated that bereaved mothers reported more psychological distress than non-bereaved mothers, and that bereaved fathers reported more distress than non-bereaved fathers if the deceased child was more than 9 years of age. No discussion was offered about the types of stressors the non-bereaved parents had experienced related to their children.

Other unique factors may be associated with the stress and grief experienced by parents whose children die after a prolonged illness or severe, life-long disability. Corden et al. (2002) used semi-structured interviews with 16 families whose children had died in the previous 2 years due to cancer, a metabolic disease, or a severe or progressive disease. They found that all parents in their study had a significant drop in family income after the death of their child, because of a loss of social security benefits for the child with a disability. At times, this was a decrease of up to 72% of a family's income. Furthermore, parents reported that even though they were logistically able to return to work after the death of a child, re-engagement with employment was often difficult due to a lack of training and experience during the years of caring for their ill or dying child, and due to their immense grief reactions related to the loss of their child (Corden et al., 2002). As a result, the negative financial impact found for families whose children died after a prolonged and severe disability can extend for years.

Professionals, support, and anticipated loss. Most parents whose children die from catastrophic illnesses or life-long disabilities have extensive interactions and collaborative relationships with the multidisciplinary professional who provide some type of service, support, or care for their children (Chomicki et al., 1995; Clerici et al., 2006; deCinque et al., 2006; Lister, 2005). Some parents whose children die after a prolonged illness report that friends and professionals who cared for their children provided more support after the deaths of their children with disabilities than their own family members provided (Lister, 2005).

In the study of 15 bereaved mothers whose children died at home or in the hospital in Greece, Papadatou et al. (1996) reported that mothers' satisfaction with the

care provided by health professionals was high when rating nurses and social workers. However, these mothers provided lower ratings when evaluating physicians and psychologists. Furthermore, the mothers in this study rated the love, support, and caring attitude their child had received from nurses, social workers, and other members of the healthcare team as the factor that satisfied them the most during the terminal phase of their child's illness, and that helped them cope with their loss. When asked to identify what was most dissatisfying during this period, the majority of these mothers referred to the behavior of some physicians who were described as abrupt, unavailable, or lacking sensitivity, and a perceived atmosphere of rejection, discrimination, and disrespect towards the needs of the dying child and the parents by many of the physicians (Papadatou et al., 1996).

In a qualitative study of 9 Australian parents whose children died of cancer, deCinque et al. (2006) stated that parents expressed a desire for more supportive contact from professionals involved with their child's care both before and after the death of the child. These parents said they would have liked more information before their children's death about what to expect, including typical expressions of parental bereavement after the prolonged illness of a child, so they might have been practically and emotionally more prepared for the loss of their child (deCinque et al., 2006). Parents whose children died after a prolonged period also expressed a desire to have the option of speaking with other parents who had experienced a similar loss of a child with a disability or chronic health condition (Chomicki et al., 1995; deCinque et al., 2006).

Clerici et al. (2006) interviewed 17 families whose children had died in the previous 1 to 2 years due to cancer. They found that more than 50% of the families

spontaneously sought some type of contact with the professionals who had been involved with the care or support of their children. The parents in this study said that having some type of contact, even minimal contact, with the professionals who cared for their children before death was seen as helpful support as they grieved the loss of their children, and craved a connection to them. Hearing the voices of the professionals that were associated for so long with their children's lives was viewed by the parents in this study as extremely helpful. None of the parents sought contact to complain about the care their children received; instead, they sought contact for connection and to express appreciation (Clerici et al., 2006).

Parents in several studies reported a desire to thank the professionals who cared for their children with words, a card, or a small symbolic gift, and to have some connection to the families of other children who were roommates or in educational, medical, or other organizational programs together due to the nature of their health condition or disability (Chomicki et al., 1995; Clerici et al., 2006). Some researchers have concluded that many parents whose children die after a prolonged anticipatory period also have a desire to return to the hospital or other locations in which their children spent considerable amounts of time, even when the time there was filled with challenges, and even when the initial visit is emotionally difficult for the bereaved parent (Clerici et al., 2006; deCinque et al., 2006).

Grief Responses Across Parents by Gender

Three studies were found for this review that explored the possible differences between the grief responses and coping styles of bereaved mothers and bereaved fathers (See Appendix D). In one study, participants were solicited through support groups for

bereaved parents (Devine, 1993); in one study participants were solicited from an another study already in progress based on a population derived from support groups (Bohannon, 1991a); and in one study participants were gathered through a combination of support group and mail solicitation based on obituaries and hospital records (Schwab, 1996). When included, demographic information described the majority of participants as White and middle class. Two of the three studies comparing bereaved mothers and bereaved fathers were conducted with married couples who lost the same child to death (Bohannon, 1991a; Schwab, 1996). The relationship among the participants in the final study was unclear (Devine, 1993).

Information on the length of time the participants had been bereaved prior to the study was missing in one study (Schwab, 1996). In one study, the length of time parents had been bereaved ranged from 2 months to 5 years (Bohannon 1991a), and in one study the length of time parents had been bereaved ranged widely from 3 months to 40 years (Devine, 1993). The ages of the deceased children ranged from prebirth to adulthood in all four studies. The causes of death were variable, and included both sudden and anticipated deaths due to accident, trauma, illness, and disability. The methods used to gather data included case study, semi-structured interviews and questionnaires and a variety of written-response questionnaires or checklists that record self-reported information about grief responses.

Schwab (1996) studied the response of 35 married couples whose newborn to 40-year-old children died from stillbirth, SIDS, cancer, illness, AIDS, accidents, suicide, and other trauma. Most of the participants solicited through support groups for this study had children who died suddenly or after a brief anticipatory period, whereas the participants

who were not in bereavement support groups and who were solicited by mail through hospital records or obituaries were parents whose children died after a prolonged illness or chronic condition. Based on her research, Schwab concluded that bereaved mothers tend to score higher than bereaved fathers on many grief responses, including despair, guilt, and somatic symptoms (Schwab, 1996). However, she reported that there were no significant differences between bereaved fathers and bereaved mothers on measures of denial, isolation, death anxiety, or loss of appetite (Schwab, 1996).

Two of the studies comparing the grief responses of bereaved mothers and bereaved fathers reported on the correlation of marital satisfaction and interactions before the death of a couple's child compared to marital satisfaction and grief responses after the death of the child (Bohannon, 1991a; Devine, 1993). Bohannon (1991a) collected self-report data on the *GEI* from 33 husbands and wives whose newborn to adult-aged children had died in the previous 2 months to 5 years. She collected the same type of data 3 times across 1 year, hypothesizing that data collection at a single point in time may not allow for a comparison of the amount of synchrony of grief responses within parents or between spouses over a period of time as parents move through various stages of grieving. In her results, she reported that early on in parental bereavement, higher levels of marital distress prior to a child's death are correlated with higher levels of grief responses at time of a child's death (Bohannon, 1991a). However, Bohannon also reported that this effect diminishes to a non-significant correlation for mothers after 1 year, and disappears altogether for fathers after 1 year.

Devine (1993) studied the marital relationships and gender-based grieving responses of 109 bereaved mothers and fathers (all but 12 were married) whose children

aged birth to 39 years died from a variety of anticipated or sudden causes. Her measures included: the *Spanier Dyadic Adjustment Scale*, which has normative data based on divorced couples; the *COPE Scale* and the *Perceived Social Support Scale (PSS)*, both of which have normative data based on undergraduate students. The couples were told not to include their spouses when answering questions on the *PSS* measure. Devine concluded that marital satisfaction before the death of a child is the greatest predictor of marital status and satisfaction after the death of a couple's child. The results of this study as well as the study conducted by Bohannon (1991a) were based primarily on responses from couples who were still married from 3 months to 40 years after the death of a child.

Grief Responses Related to the Death of an Only Child

Three articles were reviewed that studied the effects of losing an only child on parental bereavement. All three articles were authored by the same researcher (See Appendix E), and all three of these studies were small components of one larger study based on a single sample of 80 White, bereaved mothers. Each of the three articles includes a report on a different aspect of a single measure completed by the participants during an interview conducted by the researcher. All participating mothers had lost their only child. Solicitation for participation was done through a bereavement newsletter mailing list that was sent to individuals who had no surviving children. Most of the deceased children were teenagers or young adults at the time of death, and the length of time of parental bereavement prior to the study was 9 years. The cause of death for 73% of the deceased was an accident, and the cause of death for 27% of the deceased was an illness.

Based on responses to a revised *Life Attitude Profile*, 75% of the mothers in Talbot's (1996; 1997a; 1997b) studies were classified as *survivors*, whereas 25% were classified as *perpetually bereaved*. The perpetually bereaved mothers were defined as experiencing high levels of grief, although the mothers reported not often discussing their grief with others. In her 1996 study, Talbot reported that those mothers who were perpetually bereaved did not report being actively engaged in a grief support group or any volunteer or community activities, and that they perceived their family and/or friends as unhelpful to them. The 5 mothers who scored highest on being perpetually bereaved reported feeling like they would be denying their child's existence if they were to set new goals, live a new purposeful life, or move beyond their role as their child's mother. All 5 of these mothers reported being unable to reach out for help, and continued to experience recurrent grief, helplessness, mental instability, and physical ailments related to stress.

The mothers who were defined as survivors reported being able to discuss any remaining feelings of grief with others when necessary, and were more likely to have remained married to their children's father and have established significant relationships with other children since their child's death (Talbot, 1996). The survivor mothers were also more likely to be involved in some type of volunteer activity within their communities. The 5 mothers who scored highest on being survivors reported an ability to see their child as a separate and distinct personality, and reported making a conscious decision to survive and to reinvest in life. All of the survivor mothers reported seeking and accepting help from others, and learned to use a wide variety of coping skills to deal with their grief and take care of themselves. All of these mothers also reported “continuing to experience periodic shadow grief, and see bereavement as an evolving,

lifelong learning process with some positive benefits” (Talbot, 1996, p. 77).

In her 1997 articles, Talbot reported that mothers who were classified as survivors learned to keep their “motherhood” identity in new ways. This was in contrast to the mothers who were classified as perpetually bereaved, and who were reported to have ongoing ambivalence about living, have little or no hope for the future, and have difficulty integrating their role as a *mother* in any way other than being a *bereaved mother*. Whereas survivor mothers were able to consciously make a change in how they approached life so that they were able to integrate the loss, perpetually bereaved mothers focused primarily on feeling and defining their loss.

Meaning Reconstruction and Parental Bereavement

Nine studies were found for this review that explored how bereaved parents seek to find or reconstruct meaning in life after the death of a child (See Appendix F). The participants in five of these studies were solicited through support groups for bereaved parents (Bohannon, 1991b; Braun & Berg, 1994; Fletcher, 2002; Riley et al., 2007; Wheeler, 2001), the participants in two of the studies were solicited through a combination of support groups and personal invitation (Brotherson, 1999; Brotherson & Soderquist, 2002), and the participants in two of the studies were solicited through mailings based on hospital records (Meert et al., 2005; Robinson et al., 2006). When specified, the demographics of the majority of participants described them as White, well-educated, and Christian.

Information on the length of time the participants had been bereaved prior to the study was missing in one study (Braun & Berg, 1994). In two studies parents had been bereaved from about 7 to 18 months (Bohannon, 1991b; Fletcher, 2002); in one study

parents had been bereaved for about 2 years (Meert et al., 2005); in one study parents had been bereaved for 1 to 4 years (Robinson et al., 2006); in two studies parents had been bereaved for as little as 1 month and as long as 40 years (Wheeler, 2001) and 49 years (Brotherson, 1999); and in one study parents were described as having been bereaved for minimum of 2 years, but with no information about the actual length of time (Brotherson & Soderquist, 2002).

The ages of the deceased child were not always included in the findings (Braun & Berg, 1994). In seven of the studies, the ages of the deceased ranged from newborn or infancy up to adulthood (Bohannon, 1991b; Brotherson, 1999; Brotherson & Soderquist, 2002; Meert et al., 2005; Riley et al., 2007; Robinson et al., 2006; Wheeler, 2001), and in a case study of two families, one of the deceased child was 5 months of age at death, and the other was deceased at 17 years of age (Fletcher, 2002). The causes of death in all nine of the studies were due to various illnesses, accidents, and trauma. The methods used to gather data included case study, open-ended or semi-structured interview question, and a variety of written-response questionnaires or checklists that record self-reported information about grief responses.

Life crisis and meaning reconstruction. All of the articles reviewed for this section had findings that led the researchers to conclude that bereaved parents, regardless of how or when their children die, experience long lasting grief and a crisis of meaning in life that leads them to seek reconstructed meanings and some type of a new connection to their deceased children (Bohannon, 1991b; Braun & Berg, 1994; Brotherson, 1999; Brotherson & Soderquist, 2002; Fletcher, 2002; Meert et al., 2005; Riley et al., 2007; Robinson et al., 2006; Wheeler, 2001). To explore the ways that bereaved parents

develop an understanding of the life crisis that results from the death of a child and how they incorporate or accommodate such a loss into their new life reality, Braun and Berg (1994) interviewed 10 mothers whose children died suddenly from either an illness or a trauma. The methodology was a qualitative approach gathering narrative data, but no specified interview questions were included in the report. The nature of parents' meaning structures at the time of their children's death was found to be the variable that was most correlated with how parents found meaning in life after the deaths of their children. Prior meaning structure was conceptualized as how each parent described the collection of beliefs, assumptions, values, and norms about the reality of life prior to a child's death (Braun & Berg, 1994).

Braun and Berg (1994) wrote that parents who reported pre-existing reality and meaning structures that could account for a child's death while a child was alive (i.e., children do die) did not experience as much discontinuity in their meaning structure during bereavement. Furthermore, they claimed that if the explanation of a child's death did not fit satisfactorily into the meaning structure a parent had before death (i.e., children do not or should not die), then disorientation resulted during bereavement. They described disorientation as world-shattering experience during which existing beliefs, assumptions, values, and norms are dismantled in a chaotic manner. Finally, they reported that in the most extreme cases of disorientation, suicidal ideation may occur, and that reorientation must occur for bereaved parents to restore a sense of meaning and purpose in life (Braun & Berg, 1994).

Riley et al. (2007) analyzed the questionnaire responses of 35 mothers whose children died during their first 3 years of life due to accidents, illness, or chronic health

conditions. The questionnaires included the revised *Life Orientation Test*, the *COPE Scale*, the *Inventory of Social Support*, the *Hogan Grief Reaction Checklist*, the *Inventory of Complicated Grief*, and the *Posttraumatic Growth Inventory*. Although statistics were included regarding either the reliability or the validity of each scale, little or no information was offered about the intended use of the scales to measure parental bereavement and grief responses. The researchers stated that mothers who perceived themselves as optimistic reported less intense grief reactions and less distress than what is typically reported by bereaved mothers whose grief is considered complicated. Additionally, Riley and colleagues found that mothers who reported using active methods of coping and those who actively sought various forms of support were more likely to have lower levels of grief reactions (e.g., intrusive images, yearning and searching behaviors, disbelief, numbness) and responses usually associated with poor health outcomes. These mothers were also more likely to have higher levels of reported personal growth. The researchers concluded that although optimism is rarely described as an important dispositional factor in bereavement research, in this study the protective properties of optimism were supported by the strong relationship found between optimism and grief responses in bereaved mothers. In fact, out of the numerous measures and scales used in this study, optimism was the only variable that had a unique contribution in predicting grief responses (Riley et al., 2007).

Religiosity in parental bereavement. Meert et al. (2005) hypothesized that although a child's death can shatter parents' personal identities, disrupt their relationships, and challenge their worldviews, spirituality is a human characteristic that can help mediate such life crises and help bereaved parents reconstruct meaning in life

after their children's deaths. They wrote that spirituality can foster the ability to rise above a challenge or crisis in life, as well as the ability to seek meaning and purpose, and connection to others. This in turn can lead to the reconstruction of meaning in life after something so unnatural in order as the death of a child. To explore such issues, these researchers conducted semi-structured interviews using seven open-ended questions with 33 parents of 26 children who had died in a pediatric intensive care unit 2 years earlier due to an accident, trauma, or acute or chronic illness (Meert et al., 2005). The researchers reported that this sample of bereaved parents represented about half of the families who were invited to participate in the study. To draw conclusions from their data, Meert and colleagues analyzed the results of the qualitative methodology and resulting thematic codes using a quantitative statistics program. According to these researchers, the parents in this study reported intense spiritual needs, with the main spiritual need being to maintain some type of connection with their child. They also reported that professionals can help support parents' spiritual needs through words and actions that demonstrate a caring presence and that give truthful information to parents.

The researchers of three other articles in this section reported similar results from their studies (Bohannon, 1991b; Brotherson & Soderquist, 2002; Robinson et al., 2006). Robinson et al. (2006) analyzed the responses of 56 parents whose newborn to 18-year-old children died in a pediatric intensive care unit as a result of being withdrawn from life support due to a traumatic illness or injury. The five open-ended questions used in this study focused on the perceived availability of helpful supports around the time of a child's death in the hospital. The researchers reported that spiritual and religious themes were included in the responses of 73% of parents who were answering questions about

what had been most helpful to them around the time of their children's deaths, and about what advice they would offer to others who were facing end-of-life issues. The four themes that emerged in this area were: prayer, faith, access to and care from clergy, and belief in a spiritual or transcendent parent-child relationship that endures beyond death.

Brotherson and Soderquist (2002) focused on understanding the spiritual issues addressed in parental accounts of losing a child and how an understanding of this might be related to the therapeutic implications for professionals in multidisciplinary helping professions who work with families whose children die. Based on qualitative methodology and in-depth interviews with 19 parents whose children died at 18 months to 25 years of age as a result of an accident or cancer, these researchers concluded that spiritual elements play an important role in the coping process for many bereaved parents, but that this reality has not received significant attention in the scientific or therapeutic literature. They also reported that maintaining a connection to the deceased child through religion or spirituality was viewed as supportive by bereaved parents, as were the benefits of rituals and the support of clergy that are often a part of organized religions (Brotherson & Soderquist, 2002). Bohannon (1991b) studied the religiosity of 143 bereaved mothers and 129 bereaved fathers whose newborn to adult children died of various causes in the previous 8 to 18 months and found similar results. Her results were based on a statistical analysis of parent responses on the *GEI* combined with their responses to two questions regarding their religious denomination and their church attendance. Talbot concluded that bereaved mothers generally have higher scores on all grief measures than bereaved fathers, but she also reported that church attendance was correlated with lower levels of despair and loss of control for bereaved mothers, and that

church attendance was correlated with decreased levels of anger and guilt for all bereaved parents in the study.

Seeking new connections to deceased children. Several of the studies reviewed for this section included reports on specific ways bereaved parents reconstruct meaning in life and on how they create new connections with their deceased children (Brotherson, 1999; Fletcher, 2002; Meert et al., 2005; Riley et al., 2007; Robinson et al., 2006; Wheeler, 2001). Wheeler (2001) conducted a descriptive study to explore two aspects of the search for meaning in parental bereavement: the search for cognitive mastery and the search for renewed purpose. She interviewed families using open-ended questions that focused on their bereavement and grief experiences and their perceived meaning in life since the time of their children's deaths. Wheeler analyzed the responses of 176 parents in four different bereavement support groups whose children age birth to 48 years had died from any cause and at anytime in the previous 40 years. She reported that bereaved parents who were able to find meaning in the death cited connections with other people, the memory of the child, and positive personal growth resulting from exploration of life meanings after a child's death as the most supportive coping styles, and as most related to meaning reconstruction after loss. The majority of parents in this study reported believing that their lives did have meaning since the death of the child, and that this meaning came from connections with people who had experienced a similar loss, from participating in activities that the child once enjoyed or that reminded them of the deceased child, from personal beliefs and values, and from other various connections with the deceased child.

The desire to share the experience of loss with other people was a common theme across studies related to meaning reconstruction and parental bereavement (Brotherson,

1999; Riley et al., 2007; Wheeler, 2001). The researcher in the studies conducted by Brotherson (1999) and Riley et al. (2007) reported that the desire to share one's loss experience with other people was related to better bereavement outcomes for parents. They also reported that this process of sharing stories was correlated with less intense grief reactions for the parents in their studies. Furthermore, the perceived social support reported by parents in these studies was said to be characterized by empathy and warmth, which gave parents an appropriate outlet for their expressions of emotional distress so that they felt better able to normalize and accept the feelings of grief related to the loss of a child.

Fletcher's (2002) findings were based on case studies and interviews with only two parents—one who lost an infant to an illness and one who lost a teenager to an accident. However, this researcher reported that parents need communication outlets and connections to others who might best understand their experience of loss and their grief responses. The parents in other studies also reported maintaining a connection to their deceased children in a variety of ways, including: organ donation and charitable fundraising related to the cause of a child's death (Meert et al., 2005); intermittent or ongoing contact with professionals involved in the child's care (Meert et al., 2005; Robinson et al., 2006; Wheeler, 2001); memorials, symbolic mementos, and rituals related to religion or activities enjoyed by the child (Bohannon, 1991b; Brothers & Soderquist, 2002; Meert et al., 2005; Robinson et al., 2006); and, reaching out to other parents who have experienced a similar loss, through affiliation in or establishment of a bereavement support group (Brotherson, 1999; Fletcher, 2002; Wheeler, 2001).

Support from Groups During Parental Bereavement

Five studies were found for this review that explored the role of support groups for bereaved parents (See Appendix G). The participants in three of these studies were solicited through support groups for bereaved parents (Brabant, Forsyth, & McFarlain, 1995; Thuen, 1995; Toller, 2005), the participants in one of the studies were solicited through hospital records (deJong-Berg & Kane, 2006), and the participants in one of the studies were solicited through a combination of support groups and mailings based on hospital records and obituaries (Schwab, 1995). When specified, the demographics of the majority of participants were described as White, well-educated, and middle class.

In two of the studies parents had been bereaved from about 6 months to 29 years (Thuen, 1995; Toller, 2005); in one study parents had been bereaved for fewer than 3 years (deJong-Berg & Kane, 2006); in one study parents had been bereaved for 1 to 4 years (Schwab, 1995); and in one study parents had been bereaved for more than 12 months but no other specific range of time (Brabant et al., 1995). In one study, the ages of the deceased ranged from birth to 16 years (deJong-Berg & Kane, 2006); in three studies the ages of the deceased ranged from infancy to adulthood (Brabant et al., 1995; Schwab, 1995; Toller, 2005); and in one study the ages of the deceased range from newborn to geriatric years (Thuen, 1995). The causes of death in all five of the studies were due to various illnesses, accidents, and trauma. The methods used to gather data included telephone or face-to-face interviews, and a variety of open-ended or semi-structured interview questions and checklists that record grief responses.

Availability of social support. Several researchers looked at the availability and role of social supports for bereaved parents. Generally, parents in these studies reported

that it was not always easy to find someone with whom they could straightforwardly talk and share stories about their grief and about their deceased child, and as a result they turned to community support groups for bereaved parents (Brabant et al., 1995; deJong-Berg & Kane, 2006; Schwab 1995). Brabant et al. (1995) studied both the source and continuity of support received by bereaved parents within four different social contexts: family, friends, co-workers, and clergy. Their results were based on responses to three questions that compared the perceived expectations and availability of supports from family members and from coworkers, peers, clergy, and others. More than half of the 14 parents in this study reported a perceived lack of support from both family members and friends, as well as less support than expected from clergy. Even when the support was forthcoming, most participants reported that it was short-term, and that other family members told them that the loss was too devastating and so they were thus unable to provide emotional support to the grieving parents.

Some parents reported that after initially and briefly feeling quite supported, family members and friends suddenly expected them to move on in life and not bring up the subject of the deceased child anymore (Brabant et al., 1995). This resulted in reported feelings of hurt and anger on the part of the grieving parent. Many of the participants in this study reported that they felt most supported by their coworkers, who provided both emotional and practical support (e.g., completing on-the-job tasks, filling in for the bereaved parent at the office).

Helpfulness of support groups. As a part of an evaluation of bereavement care and support groups in Norway, Thuen (1995) analyzed the self-report questionnaire responses of 164 bereaved individuals who had lost a family member in the previous 24 years, and

at any point in life ranging from birth to geriatric years, and due to any type of illness or trauma. This researcher reported that bereaved parents and those who had lost a family member suddenly were more likely to attend support groups for the bereaved, and they were more likely to rate these support groups as helpful than individuals who were bereaved following an anticipatory period. However, these results were based only on the responses of those participating in Norwegian support groups for the bereaved, and these participants represented fewer than 50% of those invited to participate in this study. No information is available about those individuals who chose not to participate, including the nature of their deceased family members' deaths, whether or not they ever participated in a support group, and how they would have rated their perceptions of the helpfulness of support groups for the bereaved.

To evaluate the usefulness of support groups specifically created for bereaved parents, deJong-Berg and Kane (2006) conducted telephone interviews with 21 families whose children, aged birth to 16 years, died in a pediatric hospital in the previous 3 years due to a variety of illnesses, trauma, and congenital diseases. The survey measure used during the interviews was created by the researchers for their study. These researchers reported that the families who received information about parent bereavement support groups and then chose to participate in them rated them as helpful. However, like the parents in Thuen's (1995) study, these ratings of the helpfulness of bereavement support groups were based on the responses of participants who in fact, utilized these types of social supports. According to deJong-Berg and Kane, 75% of the families who were contacted declined to participate in this study. Nothing is known about this group of families who chose not to participate, including the nature of their children's deaths, their

levels of grief or coping styles, or whether they participated in or found useful the social supports available through bereavement groups for parents.

Utilization of support groups. In 1995, Schwab compared bereaved parents who sought involvement with a self-help group with parents who did not choose to participate in a group following the death of their children. The parents in her study who participated in bereavement support groups completed written questionnaires about their involvement in such groups. The parents in her study who did not participate in support groups answered open-ended questions during telephone interviews. Schwab reported that most parents who sought membership in a support group had children who died suddenly due to an accident or a catastrophic illness that was short in duration, whereas most parents whose children died after a prolonged illness or disabling condition did not join a support group. The participants who joined a support group reported doing so due to a lack of perceived support from others, including family and friends (Schwab, 1995). Upon entry into the support group, most parents reported that they had joined because they needed a place to share their grief with other bereaved parents, because they wanted to talk with other bereaved parents, and because they were encouraged to join a support group by their family and friends. Parents who did not join a group reported their reasons for not joining included a preference for more informal networks of support, through family, friends, and others who had been involved with the child's life and care prior to death. The parents who did not participate in support groups indicated that they had a desire to talk with other bereaved parents, but with those who had experienced a similar history and loss.

Toller (2005) examined how bereaved parents experience communication processes with other people in their formal and informal social networks. She conducted semi-structured interviews exploring perceived communication interactions with 16 parents who attended support groups after the deaths of their infant to adult children in the previous 29 years. The cause of death for the deceased children ranged from illness and disability to accident and suicide. Toller concluded that the bereaved parents in this study experienced two dialectical contradictions. Specifically, she said that parents experienced a contradiction between the physical absence of the child and the continuing presence or connection of an emotional bond with the deceased child, and she said that there was a contradiction between being “open or closed” when deciding whether to talk about the deceased child to others, based on how they were feeling and the history and experiences of the listener (Toller, 2005, p. 53).

For the parents in Toller’s (2005) study, talking about their dead children to others was often reported as a “double-edged sword” (p.53). The bereaved parents reported a desire to share their feelings of grief and loss as well as stories about the deceased child with friends and family. At the same time, however, most of these parents reported a hesitancy to be open about their feelings as they were afraid of the potentially negative reactions of others who might not understand or accept their grief. Toller also said that the parents in her study reported difficulty in articulating to others their ongoing sense of connection to and bond with their deceased child. To manage these contradictions, parents reported being selective in their communication style with others, and a style of taking control of communicative interactions with others when speaking about their grief or deceased children (Toller, 2005).

Support from Professionals

Two studies were found for this review that explored the role of professionals who were involved in the care of a child before death and the support of their bereaved parents (See Appendix H). The participants in both of these studies were primarily solicited through hospital records, but one study also employed media outreach campaigns for solicitation (Segal, Fletcher, & Meekison, 1986). One study involved interviews and field notes with 12 parents whose children had died in the previous 9 to 18 months as infants through adulthood as a result of trauma or disease (Macdonald et al., 2005). The other study involved interviews and self-report questionnaires with 61 Canadian families who had been bereaved for 5 to 40 years, and whose children died between birth and 7 years of age as a result of illness or trauma, including cancer, chronic disease, SIDS, and accidents (Segal et al., 1986).

The researchers in both of these studies stated that professional support – before a child’s death and during the bereavement period – is perceived as helpful and desired by families (Macdonald et al., 2005; Segal et al., 1986). Parents in both of these studies reported feeling a desired sense of connection to their child’s life as a result of ongoing contact with the multidisciplinary professionals who were involved with the care needs of their children before death. Families said that they valued personal contact, such as occasional visits, telephone calls, and notes or cards. They also said that they highly valued and appreciated the presence of the professionals who were involved in their children’s care at funerals and memorial services.

Segal et al. (1986) reported that all of the families interviewed in this study reported that they desired some type of support after the death of their child. However,

50% of the parents in their study said that they did not receive adequate support of any nature following the deaths of their children, nor had they received information about what to expect during bereavement or where to seek support if needed. The families in this study rated various sources of support as either *helpful* or *harmful* during the early period of bereavement (i.e., the first week) and a later period of bereavement (i.e., 1 year after the death of a child). According to the researchers, these ratings indicated that information from professionals was helpful, but the judgments and clichés professionals often offered were harmful. Specific examples of harmful supports were statements such as:

- “Don’t look!” when a child was bleeding or dying;
- “Why was this child skiing anyway?” after an accident;
- “You should have expected this,” following a prolonged illness; and,
- “Don’t cry” or “be strong” in front of a spouse or the deceased child’s siblings.

Parents in this study also stated that it was hurtful to them when professionals avoided parents around the time of a child’s death and just after the death of the child (Segal et al., 1986). Additionally, 80% of the families interviewed reported that the information they received about bereavement and the counseling they sought on their own was perceived as inadequate. Overall, parents report that their preferred source of support also varies depending on how and when their children died, and depending on the stage of grief they felt they were experiencing.

After their interviews with 12 parents whose children of any age had died from a trauma or disease, Macdonald et al. (2005) reported that three themes emerged regarding parental perceptions of their interactions with professionals around the time of their

children's deaths. First, parents said they placed great importance on the memorial service that took place at a hospital and on staff members' presence at the service. Second, parents said they found it difficult to return to the hospital after the child's death, but that they all attended the memorial service and found some closure in their return to a place that was significant to their child's life. And third, parents said they appreciated receiving cards and greatly valued professionals' and staff members' efforts to telephone or visit the parents, and to attend the child's funeral (Macdonald et al., 2005). Months and years after their children's deaths, parents said they still remembered positively which staff members engaged in which activities. On the other hand, parents said they were saddened and disappointed when professionals and staff members who were very involved with their children's lives did not engage in these activities, or were absent from memorial and funeral services.

Limitations of Studies Related to Parental Bereavement

This review of research clearly shows that parents exhibit a variety of grief responses and report feeling many different intense reactions associated with the loss of a child. These responses and feelings include guilt, anger, sadness, frustration, hopelessness, remorse, and a greater than typical need for the support and understanding of others. Some bereaved parents report a great sense of prolonged loss, and a tendency to remain identified with and connected to their deceased child. Others report a sense of loss, but also a conscious decision to move forward in life, and an effort to integrate the life and death of their child into a new and hopeful future, although it is often a difficult and lengthy process. Most parents report a need to share stories about their children, and to find meaning in the life and death of their child.

The results of this review provide important insights for multidisciplinary providers who work with children and families. However, although the results support many theories related to bereavement and suggest that certain types of child deaths may be correlated with particular grieving and coping responses, these studies are not without their limitations. The most common limitation across all of the studies relates to subject selection, and thus, generalization and transferability. Other limitations that will be discussed include instrumentation and specific assumptions made by researchers based on individual study results.

Sampling from Bereavement Support Groups

Unfortunately, sampling is an issue in sensitive research such as this, resulting in potential threats to both the internal and external validity of each descriptive study, and decreasing the credibility and transferability of each qualitative study. It is essential that solicitation for participation in parental bereavement research be done in a non-threatening, non-invasive manner, particularly due to the highly emotional subject matter being explored. Although some authors attempted to randomize subject selection by choosing every third or fifth parent and couple from a large group of individuals expressing interest in a study (Schwab, 1995), most of the subject pools are accumulated through the inclusion of all who respond to advertisements in large member-led, self-help bereavement support groups for parents, or through newsletters associated with such groups.

As surmised by both Drenovsky (1994) and Wheeler (1994), it is possible that the grief process of bereaved parents may be affected by involvement of some sort in a self-help support group, or that certain types of individuals are more or less likely to seek or

accept support from a group. Furthermore, it is possible that couples who participate in a support group and who participate in research related to marital issues following bereavement may actually be a select group of individuals, whose responses to questionnaires may be very different from parents and couples who do not reach out and share their grief experiences. Thus, studies using participants from support groups may actually exclude two extremes of bereaved parents—those who are having great difficulty coping and do not reach out for peer or bereavement support, and those who have put the loss behind them and do not wish to revisit their issues of grieving.

When participants are recruited via other sampling means (e.g., mailing lists generated from hospital records or newspaper death notices), those parents who choose to respond to an invitation to participate in bereavement research may represent a select group of individuals who are more able and/or willing to share their grief experiences (Kreicbergs et al., 2004; Papadatou et al., 1996). Such samples still may not be representative of all bereaved parents, and still leave out representation of families who do not choose to attend support groups, and whose children may have died at home after a long illness or disabling condition. These factors further limit the results of studies.

Other Sampling and Participant Issues

Other limitations related to subject selection include attrition rates in some of the studies, and the number of bereaved parents who either declined the invitation to participate in a study or who could not be contacted for some reason after beginning the study. The researchers of several studies reported difficulties in recruiting or retaining bereaved parents who were willing to participate in grief research (deJong-Berg & Kane, 2006; Meert et al., 2005; Seecharan et al., 2004; Thuen, 1995). In one study, fewer than

25% of the parents invited to be a part of the research chose to participate in the study (deJong-Berg & Kane, 2006). Therefore, although self-selection may be one of the few ways to recruit participants for this type of research, it must always be considered as an issue that threatens the validity of sampling procedures in studies.

Generalization and Transferability

In addition to limitations based on the source of subject recruitment, there are limitations based on the subject demographics and sample sizes. Such variables present a potential threat to the external validity or to the transferability of the results of these studies. More specifically, when demographics were included, the majority of the parents who participated in the studies included in this review were reported to be White, middle class citizens (Drenovsky, 1994; Nelson & Frantz, 1996; Reif et al., 1995; Riley et al., 2007); most of them were female (Arnold et al., 2005; Leahy, 1993; Milo, 1997; Riley et al., 2007; Talbot, 1996); a large portion of them were married or married couples (Alexy, 1982; Carroll & Shaefer, 1994; Goodenough et al., 2004; Miles & Demi, 1992); and when specified, most of them were from a Christian religious denomination (Bohannon, 1991b; Ponzetti, 1992; Wheeler, 1994).

Other limitations based on the subjects in these studies relate to ages and causes of death of the children in these studies, and the effects of length of bereavement on grief and coping strategies. The researchers of three studies conducted to assess the grief responses of parents, spouses, and bereaved others, compared individuals whose loved one died at any time from infancy to 70 and 85 years (Hogan et al., 1996; Middleton et al., 1998; Reif et al., 1995). The researchers of many of the studies comparing the grief reactions of bereaved parents compiled and compared data from parents whose children

died anytime from birth to 49 years of age (Carroll & Shaefer, 1994; Schwab, 1995; Talbot, 1996). None of these researchers discussed the possible effects of age or developmental differences on the results.

Some researchers compared the responses of bereaved parents whose adult children died as a result of accidents or suicide to the responses of bereaved parents of infants who died due to a congenital birth anomaly (Alexy, 1982; Arnold et al., 2005; Brabant, et al., 1995; Drenovsky, 1994; Seecharan et al., 2004). Other researchers reported on the intensity of grief responses by comparing parents who had been bereaved for short time with individuals who had been bereaved for decades (e.g., Brotherson, 1999; Thuen, 1995; Toller, 1995). In a few studies, the researchers compiled grief responses of parents who had been bereaved only 1 to 3 months with responses of parents who had been bereaved for 40 years (Devine, 1993; Wheeler, 1994, 2001).

In general, although bereavement studies tend to be quite heterogeneous with respect to recency of death, nature of death, and age of child at death, they simultaneously tend to be far too homogeneous with respect to race, ethnicity, gender, socioeconomic and marital status, religion, and other participant demographics. The result of such variability in subject characteristics, yet limitations in range of sources for participant recruitment, is a decreased ability to make generalized or transferable conclusions about the results of valuable bereavement research, which is necessary for both practical and scientific research.

Instrumentation

Although many researchers used reliable and valid instruments with psychometrically-sound properties, the method of implementation varied across studies

with some researchers relying on open-ended interviews (Brabant et al., 1995) and other researchers relying on written responses mailed from participants (Wheeler, 1994). In one study, one group of participants (i.e., those who did not join a bereavement support group) were interviewed by telephone with open-ended questions, whereas the data from the comparison group of participants (i.e., those who did choose to join a bereavement support group) were gathered from specific questions and checklist data reported on their group membership applications filled out up to 4 years prior to the commencement of the study (Schwab, 1995). In other studies, the researchers created instruments for data collection without reporting on reliability or validity of the measure (Arnold et al., 2005; Kreichbergs et al., 2004). In some studies, reliable and valid instruments were used, but the normative data for these instruments were gathered from undergraduate, occupational, prison, or religious order populations (Devine, 1993; Wheeler, 1994).

Even when authors reported the use of standardized instruments by trained researchers, questions regarding the validity and credibility of the results arise in most studies, as the information is ascertained by self-report and retrospectively, sometimes years or even decades after the death of a child (Leahy, 1993; Wheeler, 1994). This can be especially limiting in studies in which the researchers attempt to compare pre-loss information on family, personal, or marital functioning with similar at-time-of-loss or post-loss bereavement data, and it is all ascertained on a single measure and at a single point in time (Rando, 1983). Other researchers did not attempt to tease out how grief and marriage may affect each other, and thus, made conclusions about the effects of grief on a marriage without gathering information about the nature of the marriage and relations before the death of a child (Nelson & Frantz, 1996). The researchers of only 1 of the 47

studies included in this review reported any verification of data based on a method other than what was reported by the participants. Macdonald et al. (2005) compared observation field notes to the data obtained from their interviews with 12 parents whose children died in a hospital setting, as they explored perceived supports available for parents around the time of a child's death in a hospital setting.

Limited Assumptions Based on Methodology

Many of the researchers in this review acknowledged limitations with respect to sampling. However, most made conclusive assumptions based on their data as well. Some of these conclusions were in concurrence with earlier studies that were cited in the authors' reviews of the literature (Drenovsky, 1994), but some of the findings did not support earlier research (Brabant, et al., 1995). Although all of these authors' conclusions are potentially useful in both practical and scientific terms, caution must be used in accepting some of the assumptions made without further clarification or research. Examples of such assumptions include conclusive statements made about: initial grief responses (e.g., anger, guilt, denial); grief responses based on the nature of the child's death (i.e., sudden versus anticipated); gender differences among bereaved parents (i.e., mothers versus fathers); parent and family functioning after the death of a child (e.g., factors that may hurt or help functioning such as financial stress or religiosity); meaning reconstruction (e.g., self-identity, connection to the child); and, social supports (e.g., bereavement groups, contact with a child's professionals) that bereaved families seek as they cope with loss and journey towards finding new meaning in life.

Grief responses. Traditionally, researchers who have studied the grief responses of bereaved individuals have focused on the negative consequences of loss (Lindemann,

1944; Parkes, 2002). Consistent with this approach, the researchers of the six studies in this review who compared bereaved spouses, parents, siblings, and adult children overwhelmingly reported findings that detailed aspects of stress, depression, and other negative reactions solicited from and reported by participants in their studies. For example, Middleton et al. (1998) analyzed bereavement questionnaires completed by 124 parents, adult children, and spouses whose children, parents, and spouses had died at the ages of 6 months to 72 years. Although the participants in this study completed questionnaires that assessed a spectrum of emotional responses 4 times across 13 months, the researchers' conclusions were about the intensity and negative characteristics of parental bereavement compared to other bereaved individuals, but little was said about coping, helpful supports, or growth of parents or others in this study.

This style was also true for researchers who were comparing the grief responses reported by bereaved parents whose children died from various conditions and causes; the majority of findings were focused on negative outcomes such as anger and retribution (Drenovsky, 1994) and crisis of meaning for bereaved parents (Wheeler, 1994). The researchers who specifically explored the grief of parents who anticipated the death of a child due to illness or disability tended to report on anxiety, depression, and somatic complaints (Aho et al., 2006; Goodenough et al., 2004; Kreicbergs et al., 2004). Only a few researchers exploring the grief of parents after an anticipated loss reported on findings that detailed growth, perceived supports, and finding meaning in loss (Aho et al., 2006; Lister, 2005; Papadatou et al., 1996).

The studies in the current review did explore the context and familial relationships of the participants to the deceased, which was lacking in early grief literature (Bowlby,

1969; Davies, 2004, Hogan et al., 1996). Exploring within or across comparative samples of individuals who have lost children, parents, spouses, or other loved ones is important to scientific inquiry. So, too, is an in-depth understanding of the grief of parents whose children have died due to a specific cause or who have been bereaved for various periods of time. As Rubin and Malkinson (2001) observed, there are no significant deaths that are not in and of themselves risk factors, because permanent loss of a loved one has the potential to “derail a life trajectory” (p. 232) and to impair psychological and physiological functioning for survivors. However, investigating the unique bereavement experiences of various individuals should be a process that includes more than a focus on pathological responses and outcomes. Knowing what bereaved parents report about helpful supports and about finding meaning in loss is equally important to the expansion of literature related to grief.

Nature of death. In 1944, Lindemann published a paper detailing the reactions of adults who lost adult family members suddenly in a fire. According to a review by Gudmundsdottir and Chesla (2006), although Lindemann reported on abnormal responses related to the course of bereavement, he did not discuss how the circumstances and suddenness of the death may have interacted with the pathological reactions he identified. Since this early report, a number of investigators have conducted studies that have compared the grief of individuals who are bereaved suddenly with those who are bereaved following an anticipatory period.

In the current review, six researchers compared grief responses of parents whose children died either suddenly or following an anticipatory period. The researchers in four of these six studies reported that suddenness of death and extreme trauma (i.e., suicide)

were associated with more intense grief reactions and more negative bereavement outcomes (Drenovsky, 1994; Miles & Demi, 1992; Seecharan et al., 2004; Wheeler, 1994). For example, Drenovsky reported that the sudden death of a child may lead to more parental anger and/or a desire to retribute the loss by the bereaved parents. Her assumptions were based on theoretical support from earlier studies, stating that with a sudden death, parents have less time to rationalize the event or assign meaning to the death. Also, because human error is a legitimate cause of many accidents that result in a substantial portion of sudden deaths, many parents' anger may lead to feelings of desired retribution towards the individual who cause the child's death, even unintentionally.

Other researchers in the current review reported that anticipating a child's death is highly associated with intense psychological and physiological grief responses (Aho et al., 2006; Gillis et al., 1997; Kreichbergs et al., 2004), and that these parents often reported feeling a dual loss—the first being the loss of a healthy or typical child during the child's lifetime, and the second being the loss of the child permanently to death (Lister, 2005; Milo, 1997; Wood & Milo, 2001). Furthermore, many parents who participated in research exploring the grief related to the loss of a child following an anticipatory period reported that the timing of their children's death came as a shock to them, in spite of knowing that a child had a devastating diagnosis (Aho et al., 2006; Chomicki et al., 1995; Rando, 1983). The parents in these studies also reported feeling that their loss was not validated by other friends, by professionals, or by other bereaved parents, due to the child's health and/or developmental challenges and needs (Milo, 1997).

The conflicting views on whether parental grief is more intense and pathological based on the nature of a child's death is even further complicated by the fact that a

number of researchers comparing parents bereaved suddenly or following an anticipatory period found few or no differences at all between these groups (Arnold et al., 2005; Brotherson, 1999; Wood & Milo, 2001). The researchers in a number of studies in the current review reported that parental grief is intense and lasting no matter how a child dies, and that parental grief and preferences for sources of support vary more across the phases of bereavement than across the nature of the child's death (Alexy, 1982; deCinque et al., 2006; Reif et al., 1995). Rando (1983) reported that an ideal amount of anticipatory time for a parent to prepare for a child's death is about 18 months and up to 2 years—less than that does not allow adequate time to prepare for the death of a child with a terminal condition, and more than that may lead to parental denial that a child might actually die since they manage to live so long with a potentially terminal condition. But, her results, which offered longitudinal types of information were based on a cross-sectional analysis of parents, thereby limiting the strength of her conclusions. Rando's findings though, were consistent with what the fathers in the study by Aho et al. (2006) reported—that they alternated between hope and despair for so long during their children's lives as they battled to keep them alive in spite of a life-threatening condition, and in the end, found themselves clinging to hope even when there was little or no chance for survival.

Clearly, a number of variables can interact with the intensity of parental grief responses, such as the child's age, the length of time since a child's death, and the sudden versus anticipated nature of a child's death. Although the current available research yields conflicting results regarding exactly which group of parents is more or less likely to report more intense or enduring symptoms of grief, it can be concluded that undeniably, the death of a child due to any cause and after any period of time is a

devastating experience. To better understand the unique aspects of grieving parents, research is needed within specific groups of parents that examines the unique experiences and needs of parents who lose their children to specific conditions.

Gender differences. Riches and Dawson (2000) theorized that numerous social and cultural variables including one's relationship to the deceased, one's family-role, and one's gender role can affect how individuals grieve the loss of a child. In other words, people in the same family can grieve the loss of the same individual in very different ways. Therefore, mothers and fathers may exhibit different grief responses, and rely on different methods of coping. In the current review, many researchers concluded that mothers generally reported higher levels of grief responses than fathers, including depression, guilt, anger, despair, hopelessness, and somatic symptoms (Bohannon, 1991b; Leahy, 1993; Schwab, 1996). Goodenough et al. (2004) stated that fathers reported more depression and anxiety when their child died in a hospital, but in general, mothers reported more intense grief responses than fathers. Other researchers offered varying claims though. For example, Drenovsky (1994) stated that mothers reported feeling more anger than fathers, but she also wrote that fathers reported feeling more of a desire for restitution than mothers. Also, Seecharan et al. (2004) reported that mothers and fathers generally scored similar levels on various measures of grief.

The researchers of two studies with parents whose children died after an anticipatory period reported that mothers and fathers were both able to find meaning and benefit in the lives and the deaths of their children (Milo, 1997; Wood & Milo, 2001). Wood and Milo (2001) said that bereaved fathers of children with disabilities reported having consistency in their self-identity and their world view, and that this influenced their

ways of grieving and healing. This was in contrast to the mothers in this study though, who reported feeling that there were significant changes in their identity and in their world view following the deaths of their children.

Based on the results of their study of 8 fathers whose very young children with various disabilities died, Aho et al. (2006) concluded that fathers expressed very intense feelings of grief that included weeping, shouting, rage, and extreme physical work and activity. However, these researchers also said that the fathers in their study reported showing these expressions of grief only when they were alone. Like the fathers in Bohannon's (1991b) study of meaning reconstruction and in Wood and Milo's (2001) study of fathers whose children with disabilities died, the fathers in the study by Aho et al. reported that they felt isolated after their children died, and that they had to grieve privately and be strong or stoic for their spouses and surviving children. Some of the fathers in the study conducted by Aho et al. reported an ability to express some feelings of grief in the presence of their spouses, but typically, they reported choosing to repress their feelings and conceal them from other people until they felt they were alone or had the right opportunity to express their grief openly.

Traditional grief theories suggest that marital relationships and levels of intimacy may deteriorate following the death of a child, as bereaved mothers and fathers struggle to communicate and express their grief in conflicting different gender-related ways (Riches & Dawson, 1996). However, the researchers whose studies were included in this review offered results that are in conflict with this view. Instead, these researchers report that marital relationships tend to continue on the path of intimacy, conflict, or closeness that was the norm before the death of a child. For example, the researchers of two studies

reported that marital relationship interactions before a child's death—including levels of intimacy and conflict—were positively correlated with interactions, intimacy, and conflict levels after a child's death (Bohannon, 1991a; Devine, 1993)

It is important to understand the unique needs and preferences for coping of parents grieving the loss of a child, including differences that may exist between mothers and fathers. However, the results of the current review cannot be accepted without considering the limitations of the studies and the methodology. Most participants in research exploring parental bereavement are female. Only two studies looked specifically at the grief of fathers (Aho et al., 2006; Wood & Milo, 2001). The 8 fathers in each of these studies reported intense grief reactions, but their deceased children all had life-long disabilities or degenerative health conditions. It is not known whether the specific grief responses of fathers whose children died from other causes would be similar or different when compared to the fathers in other situations. Furthermore, the fathers in a number of studies reported choosing stoicism and concealing their real feelings of grief to protect the feelings of their spouses, surviving children, and others in their social networks (Aho et al., 2006; Bohannon, 1991b; Wood & Milo, 2001). Therefore, it is unclear whether results of other gender-related studies are really reflecting differences in grief reactions or in the demonstrative expressions of grief and response styles between genders due to cultural expectations and norms. Riches and Dawson (2000) caution if fathers feel they cannot grieve openly because it is not culturally appropriate, that resentment, isolation, and misunderstandings may arise and complicate bereavement and have an impact on a marriage.

Additionally, the conclusions of many researchers who report on gender-related studies that examine levels of intimacy are the result of comparisons of the grief and coping responses of married participants or married couples (Bohannon, 1991a; Devine, 1993; Schwab, 1996). Basing gender differences primarily on the responses of intact couples may not be representative of all bereaved parents, and thus, doing so limits the strength of these assumptions. It is possible that couples who choose to participate in bereavement research (which is made up largely of couples who choose to join a bereavement support group) have stronger marriages to begin with, before the loss of the child, which may influence grief reactions and coping strategies, and the findings of related grief research.

Family functioning. This review of the literature indicates that the death of a child is not only devastating during the initial time period following the death, but that the death of a child also produces *aftershocks* which are both individual and particular for parents as they cope with their loss (Brabant et al., 1995). For example, a parent who has moved through several typical stages (e.g, shock, anger, denial) of grief may revisit previous stages when realizing for the first time since death the vast array of subsequent losses related to the death of the child (e.g., not being able to send a child off for their first day of a new school year). Although secondary to the actual death of the child, these aftershocks are an important consideration in the grieving process. Still, when making conclusions about personal, marital, or family functioning and the process of coping after the death of a child, it is important to not overlook variables that may have an effect on the coping strategies throughout what may be prolonged bereavement process.

In 1983, Rando evaluated the experiences of 54 parents whose children had died due to cancer during the previous 2 months to 3 years, and concluded that there seemed to be a gradual decrease in the intensity of parental grief responses across the 2 years following a child's death. She also reported that there was a subsequent increase in the intensity of grief responses during the third year after a child's death. It is important to understand the nature and duration of grief related to the death of a child. However, the results of this study were based on a cross-sectional sample of participants, whereas the conclusions offered are longitudinal in nature. It is not known whether the parents who reported such high levels of grief in the third year would have also reported high levels during the first months or first year following the death of a child.

In Talbot's studies (1996, 1997a, 1997b), she reported that the mothers in what she called the *survivor* group mostly had intact marriages and middle to high income levels. She said that these mothers reported a positive life attitude and the ability to ask for and receive supports necessary for coping after losing their only child to death. However, when she discussed the mothers she called *perpetually bereaved* and who she said focused on feeling and defining the loss of their only child, there was no demographic data included regarding this group's income or marital status. When reviewing the data on means and ranges of participants' socioeconomic status, it is clear that a portion of Talbot's (1996, 1997a, 1997b) subjects were below middle income, and did not have intact marriages. Although this is not discussed in her study, it is possible that the perpetually bereaved mothers were also the ones with lower incomes, and may have been the participants whose marriages or partnerships had been disrupted as a result of the child's death. Cause and effect can not be concluded, but certainly, one might

consider that these variables could be correlated. If this is the case, then such variables may confound and limit statements about the effects of being able to integrate the role of motherhood into other life aspects, which Talbot said is necessary for being a survivor of child loss. It also limits the ability to make conclusions about the relationship between social activities and survivorship.

The results of the study conducted by Papadatou et al. (1996) also raise questions about variables that may complicate conclusions about the effects of bereavement on personal and family functioning. These authors reported that mothers who chose to care for their children who were dying of cancer at home relied heavily on strong family networks for support. They wrote that mothers in this study who chose to care for their children dying of cancer in the hospital did so due to the availability of professional and peer support (i.e., other parents of children with serious illnesses). Perhaps though, the mothers who chose a hospital setting also lacked social supports at home and did not have a strong family network upon which they could rely. Or perhaps, the mothers who chose to care for their children at home had more education, or professional support that lived in close proximity. These issues are not addressed in the study.

Goodenough et al. (2004) also discussed the effect of a child dying in the hospital versus at home following a prolonged illness. They concluded that fathers whose children die in a hospital experience more depression, anxiety, and stress than fathers whose children die at home. However, these researchers also reported that the children who died in hospitals lived an average of 218 or more miles from the hospital, whereas the children who died at home lived an average of 80 or fewer miles from the hospital. There is no discussion about the potential impact of the physical distance of a father from the hospital

setting, and therefore the physical distance between various family members. The reported depression, anxiety, and stress levels and the resulting impact on family functioning could very well be associated with altered or disrupted caregiving roles due to the child's illness, due to the absence of the mother who may be staying at the hospital with the child, or due to financial issues related to the long-term costs of the child's life-threatening condition.

The researchers of one study in this review specifically examined the long-term financial issues related to the death of a child with a chronic condition, and the resulting impact on family functioning. In 2002, Corden et al. reported that it is not uncommon for families whose children have chronic conditions or disabilities to receive supplement income from the federal government to meet the financial demands of caring for a child who needs specialized equipment or support services. This source of income becomes relied on by these families, who often choose to stay at home to meet the complicated needs of their children who have disabilities. This choice limits or eliminates their ability to be employed. These researchers concluded that when a child with a chronic condition dies and the family loses this monthly financial supplement, there can be a resulting financial strain that affects family functioning for years after the child's death (Corden et al., 2002). Undeniably, after spending years caring for a child with a disability, both emotional issues (e.g., the fathers in Aho and colleagues' 2006 study reported a marked decrease in concentration and motivation related to work after their children with disabilities died) and logistical issues (e.g., the parent's work skills are not up to date with technology; no recent education that makes one employable) can impact a parent's ability to return to work soon after the loss. However, Corden et al. did not discuss a number of

variables that could have affected the findings of their study. For example, they did not discuss the nature of these parents' previous work experience or education, the number of other young children in a family who needed care and attention, family dynamics prior to the death of a child, or other issues which may also interact with financial decisions, stress, and family functioning.

A number of families in the reviewed studies reported that spirituality and religiosity were an important part of coping with the death of a child, both around the time of the child's death (Meert et al., 2005) and in the years following the child's death (Brotherson & Soderquist, 2002). Bohannon (1991b), Meert et al. (2005), and Robinson et al. (2006) all wrote that parents reported intense spiritual needs surrounding the time of their children's deaths, and that both the rituals of religion and the availability of clergy are reported as very supportive during the time following their children's deaths. The researchers of two studies (Brotherson & Sonderquist, 2002; Robinson et al., 2006) also reported that parents felt religiosity and spirituality helped them feel connected to their deceased child, which has been reported by families in other studies to be important during parental bereavement (Brotherson, 1999; Fletcher, 2002, Wheeler, 2001).

However, when participant demographics were reported, the researchers of all of these studies based their conclusions on parents who were predominantly White and members of a Christian religion. Therefore, little can be said about other parents, who are not White or whose rituals and beliefs are based on memberships in other religions or no religious affiliation at all. Additionally, this information about what is helpful for family functioning after the death of child is based only on participants who chose to be a part of research; this leaves many questions about the functioning and coping styles of families

who do not choose to participate in grief research, such as the 50 percent of those parents who were invited but did not choose to participate in the study that was conducted by Meert et al. (2005) to explore meaning reconstruction and parental bereavement.

According to Bohannon (1991b), church attendance in her sample was correlated with lower levels of despair, loss of control, anger, and guilt. She wrote that these findings are consistent with previous literature in which researchers theorized that people who have a high degree of religiosity have less fear of death. However, Bohannon also states that “because forgiveness is a major tenet of most religions, it seems reasonable that anger and guilt about a child's death would be less acceptable for church attenders” (p. 157) than for other bereaved parents. Bohannon reported that she factored out social desirability as a covariate, and thus, she was able to conclude that religious denominations were not an issue in her study. Still, it seems plausible that due to denominational expectations of both behavioral responses and philosophical views related to particular religious beliefs, frequent church attending parents may be less apt to express despair and loss of control since they may be inconsistent with church beliefs. These parents may actually experience these strong reactions but choose not to express. In addition, parents who regularly attend church may have an advantage in the grieving process compared to parents who do not attend church, in that they may be less likely to suffer from social isolation which is often associated with the loss of a child (Schwab, 1995). Still, parents who attend church may also have a disadvantage, because they may choose to inhibit or conceal their grief reactions due to the cultural norms and expectations of their religious affiliation.

Another concern regarding assumptions made about family functioning is that the researchers of the studies in this review often make claims based on data ascertained months, years, and decades after the death of a child. Additionally, they make claims based on self-reported data and without discussing participant data that may also have had an effect on or interaction with variables being discussed. Few of the researchers in this review reported retrospective data on family functioning before the death of the child. Therefore, one can only speculate such a variable, and the potential impact on the findings. The interaction of bereavement and pre-existing family relations, functioning, and cohesion before the death of a child (particularly in cases in which the parents go through an anticipatory grief period) is worth considering in research, as such variables may further complicate family functioning and grief, and yet help explain parental grieving and coping processes.

Meaning reconstruction. Traditional theories of grief and bereavement emphasize the need to let go of one's emotional relationship with a deceased loved one (Bowlby, 1969; Rubin, 1996). Klass and Goss (2003) offered a more current theory though, in which parents seek to hold on to their relationships with their deceased children, and that this act is associated with meaning reconstruction, with better coping strategies, and with more positive outcomes following bereavement. The studies in this review were generally consistent with Klass' theory, and the researchers in the reviewed studies offered conclusions about the various ways that parents make sense of their children's deaths and integrate this intense loss into their new life without the physical presence of their children. Maintaining some type of a continuing psychological or emotional bond with one's deceased child was overwhelmingly reported as being associated with positive

outcomes, rather than as an indication of problematic grieving. However, a variety of sampling, instrumentation, and other methodological issues must be considered with respect to these assumptions.

Nearly all of the researchers in the current review conclude that grieving parents have a crisis in life (Arnold et al., 2005; Braun & Berg, 1994; Chomicki et al., 1995; Fletcher, 2002; Lister, 2005; Wheeler, 1994; 2001). In 2001, Wheeler reported on the findings of her study with 176 parents that explored meaning reconstruction and perceived supports. She said that an important facilitator of meaning reconstruction associated with parental bereavement is the connections a parent has or develops with other people who understand the loss (e.g., professionals who were involved in the child's care before death; other parents whose children have died from similar causes or at similar ages). Wheeler's study clearly contained methodological flaws though. For example, all of the participants in her study were members of bereavement support groups. In addition, she did not factor out potential interaction effects of variables such as losing a child at birth versus at age 48, or having lost a child in the previous month versus 40 years earlier. However, the information offered by Wheeler as a result of her study supports the conceptualization of parental bereavement as a crisis of meaning, and suggests that a bereaved parent's search for reconstructed meanings is central to the process of readjustment after the death of a child.

Based on the findings in their study of meaning reconstruction with 10 bereaved mothers, Braun and Berg (1994) suggested that the *meaning of life and death structures* parents have before the death of a child are correlated with meaning structures they reconstruct following the death a child. Furthermore, these researchers said that such

meaning reconstruction grows from adjusting to the discontinuity and disorientation that parents experience in their grief. In other words, the very crisis of meaning can lead to growth and improved reconstruction of earlier meanings. Although understandings of parental bereavement such as this are important to consider, it must be noted that the methodology of this study may limit the credibility of such findings. Other than that their children died suddenly, Braun and Berg (1994) provide very little demographic information about their parent participants, including the ages of the children who died or the length of time the parents in the study were bereaved.

In a study of 8 mothers whose children with various disabilities and chronic health conditions died, Milo (1997) reported that using cognitive coping strategies helped grieving parents find meaning and benefit in the lives and deaths of their children, and thus, were able to continue seeing the world as *benevolent* and *purposeful*. Riley et al. (2007) wrote that mothers who scored as *optimistic* in their study also reported less intense grief levels and the ability to seek the supports they felt necessary for coping with their loss. Gudmundsdottir and Chesla (2006) wrote that traditional mourning rituals and memorials are helpful to grieving parents as they begin the long process of meaning reconstruction; so, too, are new rituals such as visiting the child's grave, and maintaining memory connections such as displayed photos or artwork related to the child in the home. Brotherson (1999) concluded that parents find meaning and connection to their deceased children by sharing stories of their children's lives and deaths and their own grief responses, and also that the loss of one's child and story sharing is related to an increased feeling of compassion toward other bereaved parents. Fletcher (2002), who conducted case studies with two Hispanic families—one whose infant died due to an illness and one

whose teenager died due to an accident—reported that for meaning reconstruction to occur, families need communication outlets and opportunities to talk about their feelings and grief. Again, although these researchers offer information that may be useful to professionals and programs involved in the support of grieving parents, the results are based only on the responses of parents who have chosen to be involved with bereavement support groups. No conclusions can be made about how parents who are not involved with support groups reconstruct meanings in life and seek or maintain connections with their deceased children. Additionally, Toller (2005) wrote that some parents reported that talking about a deceased child can be a double-edged sword. She said that the 16 bereaved parents in her study, whose children died either suddenly or following an anticipatory period, all expressed a desire to share stories and feelings about their loss and to seek meaning and connection through such communication. However, they also expressed concerns about the reactions and feelings of others, including criticism they have received for talking about the deceased child or having such intense feelings of loss.

According to Lister (2005), meaning reconstruction takes years, and this complicated task of meaning reconstruction may begin long before the death of a child, when a parent first learns that a child has been diagnosed with a life-threatening condition. Her conclusions were based on interviews with 16 bereaved parents who answered questions about meaning reconstruction, and they are consistent with the conclusions of other researchers. Gudmundsdottir and Chesla (2006) reported that the number of *structures of meaning* a deceased individual had participated in with a survivor was positively correlated with the level of *crisis in meaning* and feelings of disconnection for the survivor when that person died. Clearly, even though parental grief and

bereavement are complex and painful issues, researchers have offered evidence indicating that bereavement can result in positive outcomes. It is also clear though, that more research is needed, that addresses methodological flaws and that continues the exploration of various characteristics that may affect or interact with grief and positive outcomes.

Social supports. In her review of the literature, Lister (2005) wrote that the concept of *social support* has been studied since the 1970s, and that it is generally defined as having other people who are available, and on whom an individual can rely on to feel that he or she is cared about or valued. She surmised that the basic definitions of *social support* underscored two basic elements: that there are sufficient people available to turn to in a time of need, and that whatever it is that individuals receive from those people is evaluated in a satisfactory way. Lister also wrote that bereavement is not a solitary experience, but one that is shared with others who may or may not provide the types of social support that are correlated with positive outcomes. When a child dies, appropriate supports may or may not be available from other family members, friends, peers, coworkers, other bereaved parents, the professionals involved with the child's care, and other individuals in the social network of the bereaved parent.

In the current review, a number of researchers studied parent perspectives about their need for and ratings of available social supports related to the death of a child. Based on her study with 16 parents whose children died from catastrophic illnesses, Lister (2005) wrote that parents reported perceiving more social support from friends who were not intimately involved in a child's life and death than from their own family members. Offering a different perspective, Brabant et al. (1995) interviewed 14 parents who participated in a bereavement support group and wrote that more than half of the families

in their study reported a perceived lack of support from their own family and friends. They also said that most of these parents reported that they had no long-term support from anyone, and that the support they did receive came mostly from coworkers and clergy. Based on their interviews with 21 parents who attended a support group at the hospital where their children died, deJong-Berg and Kane (2006) concluded that families who received information about participating in support groups and then utilized these groups found them helpful. All of these studies though, are based on the responses of parents who chose to attend bereavement support groups. Thus, the assumptions made based on these studies are limited. Additionally, the participants in deJong-Berg and Kane's (2006) study represent only 25% of the parents who were invited to participate in their research. There is no available information about the other 75% of invited parents, including whether they received any information about support groups, whether they attended any such groups, and whether they perceived such groups to be helpful or not.

It cannot be denied that some bereaved parents choose to participate in bereavement support groups and to participate in bereavement research up to 40 and 50 years following the death of a child (Brotherson, 1999; Devine, 1993; Wheeler, 1994, 2001). However, there are parents who have expressed concerns about sharing stories about their deceased child and grief in social settings (Toller, 2005). The bereaved fathers who were a part of two studies generally agreed that many people in social settings, even other bereaved parents, did not understand how they could love their children with disabilities so deeply, and then intensely grieve the loss of these children especially after an anticipated period (Aho et al., 2006; Wood & Milo, 2001).

These findings are consistent with Schwab's (1995) conclusion that most families who choose to attend bereavement support groups are ones who lost a child due to a sudden trauma or catastrophic illness, whereas most families who do not choose to attend such groups lost a child due to a chronic condition and following a prolonged period of anticipation. However, Schwab (1995) concluded that the reason these parents did not go to bereavement groups was because they reported having adequate informal support. This is not consistent with the findings of other researchers who specifically explored the bereavement of parents whose children died following a prolonged anticipatory period (Aho et al., 2006; Chomicki et al., 1995; Milo, 1997; Wood & Milo, 2001). Schwab does not probe or explore the nature of the reported informal supports, or even whether parents were hesitant to admit a lack of support lest they be judged by others (Toller, 2005). The fathers in the studies by Aho et al. (2006) and Wood and Milo (2001) reported that they consciously withdrew from human relations and experienced an unwilling isolation because they felt that it was better to grieve privately, rather than be judged by others or let others down with their expressions of grief.

A number of researchers in the current review commented on the role of professionals who were once involved in the care of a child who died, with respect to the social support needed by bereaved parents. These professionals might include physicians, nurses, educators, advocates, clergy, social workers, and support staff members who were somehow a part of a child's care team. Meert et al. (2005) wrote that compassionate professionals have 'beneficial effects' on parental bereavement. They and other researchers (Chomicki et al., 1995; Clerici et al., 2006; deCinque et al., 2006; Macdonald, et al., 2005; Robinson et al., 2006; Segal et al., 1986) report that caring professionals who

foster the connections many bereaved parents seek with their deceased children make a positive difference. These authors also agree that it does not take a lot of time for professionals to maintain intermittent contact with a family through an occasional phone call, card, or visit, but it makes a tremendous difference and is remembered as valuable by bereaved parents. This is consistent with the emerging theories that bereaved parents need some ongoing connection to their deceased children (Klass, 1996). None of the parents in the reviewed studies who desired contact with professionals after the death of their child sought to complain. Furthermore, although some parents reported that while it might be painful for them to return to a hospital where their child died, or to a school that their child attended, they said they still sought the opportunity to visit these places and the people they knew in them, as a source of solace and a connection with the past and with their child (Clerici et al., 2006).

Although one of the greatest limitations of the studies in this review is the fact that the research participants were solicited primarily from member-led, self-help bereavement groups, the numerous positive outcomes of many parents and couples in these studies also demonstrate the reality of the support available to bereaved families through such networks. Such findings illustrate the practical implications of a nonjudgmental ear, and the appreciated willingness of others who are able to share in the bereavement process of parents and family members. For whatever reason, there is a paucity of information related to the support needs of bereaved families who do not attend support groups. Understanding and support can have a considerable impact on coping and wellness. Therefore, additional research is needed to explore the support needs of all families, especially those who are not represented in bereavement groups.

Summary

Despite the methodological limitations of these studies and the researchers' assumptions, this research offers important findings that can support professionals in their work. In addition, it can clearly be concluded that parental grief is complex. Parental grief may persist at high levels for many years following the death of a child, regardless of the timing or nature of the death, the role of the deceased to the bereaved, the quality of the relationships, or the availability of social supports. As Wheeler (1994) reported, for most parents, the death of a child:

is unnatural and untimely, reversing the expected order of life events. A child holds multiple meanings for a parent: a connection with the past, investment in the future, and an extension of the self. When a child dies the meanings and purposes associated with the child are often shaken. The bereaved parent may experience a loss of previous assumptions about the meaning and purpose of life (pp. 261-262).

Although it is clear that the death of a child can create an intense and long-lasting crisis of meaning for the bereaved parent, there are also indications that recovery from such a crisis is possible, especially when parents receive some sort of formal or informal support. Social support can come from family and friends, from professionals and care providers, from co-workers and religious organizations, and/or from support networks of bereaved parents. All efforts to study and understand parental bereavement have practical implications, as researchers seek to identify factors that might explain why some bereaved parents experience interpersonal growth, and others struggle with intense loss and feelings of despair for prolonged periods of time. The results of such efforts can be

useful for future research, and for practitioners who work in all fields of human service, including education, health, and advocacy organizations.

CHAPTER III METHODOLOGY

This chapter begins with an explanation of qualitative inquiry and how this scientific approach is appropriate for exploring sensitive phenomenological issues of parental bereavement. After presenting the research questions for the current study, a detailed description of the methodology is offered. This description includes the methodology for participant criterion and recruitment, for data collection and the interview process, and for data analyses. Finally, ethical and personal considerations related to qualitative research and to this particular study are discussed.

Qualitative Methodology

Two major traditions of scientific research methods exist: quantitative and qualitative (Bogdan & Biklen, 1998; Isaac & Michael, 1997; Strauss & Corbin, 1998). Quantitative research methods typically involve objective measures for data collection. The data can be counted, or quantified, and then systematically and rigorously controlled and analyzed. The results produce information that allows the researcher to make claims about causal factors, to make statistical predictions, and to generalize the findings to other sample populations that did not actually participate in the research (Bogdan & Biklen, 1998). Qualitative, or *naturalistic* research, also involves systematic and rigorous data collection. However, rather than numeric quantities, human behavior is explored in natural and unique contexts and settings. Propositional knowledge and data are collected through observation, narrative form, and intuition that reflect the value patterns of the researcher (Isaac & Michael, 1997; Strauss & Corbin, 1998).

The information gathered through qualitative methods is informal yet personal, is rich in verbal description, and is based on definitions that evolve as the study progresses rather than predetermined hypotheses (Isaac & Michael, 1997). Quantitative methods, often based on hypothesis testing, produce statistically significant predictions or conclusions. Qualitative research methods result in the discovery of themes and the generation of hypotheses (Center for the Advancement of Health, 2004). Researchers conducting qualitative studies seek to discover, explore, and understand phenomenon through an inductive process, and from the perspective of the individuals experiencing the phenomenon (Bogdan & Biklen, 1998; Lincoln & Guba, 1985). Qualitative inquiry is “ideographic in its outlook” (Isaac & Michael, 1997, p. 218). Therefore, qualitative methods are excellent for discovering emerging categories, themes, and relationships that result from a particular phenomenon. These categories, themes, and relationships can later be tested and validated with quantitative methods (Bogdan & Biklen, 1998; Creswell, 2003).

According to Isaac and Michael (1997), qualitative inquiry leads to multiple realities as “the world as seen through the eyes of more than one beholder” (p. 219) unfolds. This method of scientific inquiry relies heavily on human perception, and the primary instrument for data collection is the human observer. Conducted in natural settings for a real-world context, qualitative research often involves purposeful sampling to increase the likelihood of uncovering multiple realities and to maximize the researcher’s ability to account for the nature of conditions and interactions and values that will be useful in assessing the transferability of findings.

Neutrality of the investigator and any prejudgments that might affect the data are preserved by the very nature of the grounded theory that emerges from the data collection process, and from the researcher-participant interaction that is without a priori hypotheses (Isaac & Michael, 1997). The research outcomes are the result of negotiations between the researcher and the human sources yielding the data, which allows the theoretical construction of themes. According to Isaac and Michael, confidence in the results of qualitative inquiry comes from credibility (believable and convincing findings); transferability (to other contextually similar settings); dependability (findings are consistent with other available reports); and, confirmability (the process and product of the data collection and analysis can be audited by others).

Parental Bereavement and Qualitative Inquiry

Grief and bereavement associated with the loss of a significant person or loved one are complex issues (Parkes, 2002). Furthermore, the grief and bereavement experienced by parents following the death of a child has been described as particularly intense, complicated, and prolonged in duration (Rando, 1985). Although there is a growing body of literature in which multidisciplinary professionals describe the unique grief experiences and coping styles of bereaved parents, there has been little consideration of the experiences of parents whose children die as a result of a chronic, degenerative, and life-threatening disability. As a result, little is known about the perceived support needs of this group of families, whose children are almost always eligible for early intervention and special education services under IDEA. An exploration and understanding of the specific experiences and needs of these families is essential, and such information must unfold through sound scientific inquiry.

According to Sandelowski (1994), individuals often make sense of life and life's events by telling the stories about those events. Polkinghorne (1995) wrote that lives and phenomenon can be understood, revealed, and transformed in stories, and by the very act of storytelling. Furthermore, an in-depth exploration of an individual's experience through the stories they choose to share can allow researchers to gain insight into the way various individuals understand their lives with respect to the phenomenon being explored. Therefore, an appropriate way to begin exploring and understanding the experiences of parents whose children die following a progressive degenerative disability would be through qualitative inquiry. By gathering stories of personal experiences and exploring the description-rich perceptions of bereaved parents whose children have died due to a degenerative disability, emerging categories, themes, and relationships can be explored. This process will lead to a better understanding of the phenomenon. The new understanding, acquired through grounded theory and inductive analysis of these bereaved parents' narrative contexts can provide a framework for approaching families' support needs. It can also offer valuable insight to teachers, advocates, and other professionals who work with these children and families.

Although exploring grief and bereavement associated with the loss of a child is a sensitive issue, researchers have found that most grieving parents welcome the opportunity to share stories about their deceased children, and that parents find the experience therapeutic (Dyregrov, 2004). According to Dyregrov, bereaved parents report that the interview process in which they partake during grief research is perceived as helpful. She said that bereaved parents have reported that sharing grief experiences through narratives, stories, and anecdotal information about their children's lives and

deaths is beneficial to them. Parents have also reported that offering this information, and feeling that it may be beneficial to professionals and other bereaved parents, helps them find meaning in their own loss (Dyregrov, 2004). Some families whose children with a developmental disability or chronic condition died have even reported that they find it easier to share these stories with professional researchers, rather than family members or friends or other bereaved parents whose healthy children died suddenly, because they do not feel like they are being judged by peers for their intense feelings and experiences of loss (Aho et al., 2006; Chomicki et al., 1995; Rando, 1993). Qualitative inquiry allows for such intimate expressions, as the researcher and participants engage in dialogue with the implicit goal of gaining a better understanding of human behavior and experiences, and seeking “to grasp the processes by which people construct meaning and to describe what those meanings are” (Bogdan & Biklen, 1998, p. 38).

Research Questions

Although qualitative research is conducted with a bottom up approach that does not involve a priori judgments or hypotheses, it is important for the qualitative researcher to bring general questions to the study because they give focus to both the data collection and the data analysis (Bogdan & Biklen, 1998; Miles & Huberman, 1994). Research questions state what the investigator seeks to understand, and help guide definitions for data collection such as: who should serve as the sample participants, how and where data should be gathered, and what type of data should be of focus. The initial questions in qualitative research tend to be general and based on real-world observations and quandaries as noted by the researcher’s experiences, theories, and scholarly interests (Marshall & Rossman, 1995). As the research inquiry progresses, the research questions

can be refined and made more specific with the discovery of emerging themes during data collection and ongoing data analysis (Maxwell, 1996).

Based on the real-world observations, experiences, and scholarly interests of the researcher conducting the current study, the following three broad research questions were created to guide this qualitative inquiry:

1. What are the subjective experiences of parents whose children have died due to a degenerative disability
 - a. Around the time their children are diagnosed with a degenerative, life-threatening disability?
 - b. During their children's lives?
 - c. Around the time of their children's deaths?
 - d. Since the time of their children's deaths?
2. What do parents of children who died from degenerative disabilities perceive as needs related to supporting their children and coping with loss?
3. When a child with a degenerative disability dies, what can professionals in education, health, and advocacy organizations say or do that might be most supportive?

Procedures

As recommended for studies using an exploratory qualitative design, a small group of bereaved parents was used to elicit common shared meanings and experiences, as this can lead to the development of emerging themes (Bogdan & Biklen, 1998; Isaac & Michael, 1997). The power of this purposeful sampling lies in selecting information-rich cases for study, and choosing participants who can provide information central to the

purpose of the evaluation and the needs of decision-makers (Isaac & Michael, 1997). Because many different types of life-threatening and degenerative disabilities exist that are associated with childhood mortality, one particular category of degenerative disability was the focus of this study. This procedure increased the likelihood of discovering emerging and common themes associated with this type of parental bereavement, and can maximize transferability of findings (Isaac & Michael, 1997). Due to the personal experiences, professional involvement, and academic interests of the researcher conducting this study, childhood neuromuscular disease was chosen as the diagnostic category for the inquiry. The key informants were a purposeful sample of bereaved parents whose children died due to complications of childhood onset neuromuscular disease. Other informants for this study included providers who worked directly with one or more of the participating families during the child's lifetime. These providers were recommended for inclusion by the parent participants because they had been seen as particularly supportive and helpful to the parents in this study.

Sampling Source

For more than 50 years, the MDA has provided numerous diagnostic, research, advocacy, and support services in health, education, social, and recreational domains to children and adults diagnosed with any of the 43 neuromuscular diseases that are a focus of this national voluntary health organization. The services provided by MDA are free to children and adults diagnosed with neuromuscular disease and their families, and include:

- Technical assistance (e.g., information specialists, publications, website);
- Nationwide medical clinics (e.g., diagnostic work, consultations, respiratory

- and mobility clinics, flu shots);
- Assistance with the purchase or lending of necessary medical or mobility equipment (e.g., leg braces, wheelchairs);
 - Support groups (e.g., online chats, parent groups, spouse and caregiver groups);
 - Recreation programs (e.g., summer camp, teen groups, art programs);
 - Advocacy services (e.g., representation during IFSP and IEP meetings, lobbying for improved laws related to disability);
 - Scientific and clinical research (e.g., search for treatments and cures for neuromuscular disease);
 - Public awareness campaigns (e.g., professional and public health education regarding the needs of people with disabilities and neuromuscular disease);
- and,
- Fundraising efforts to meet the financial demands of the multidisciplinary medical, support, research, and advocacy programs (MDA, 2007).

Although the child or adult with a neuromuscular disease is supported within a family context throughout the individual's lifespan, there are currently no formal support services related to parental grief and bereavement following the death of a child.

The researcher of the current study has been affiliated with the MDA since 1992, at which time she was diagnosed with an adult onset progressive neuromuscular disease. When her four children were subsequently diagnosed with a fatal childhood onset form of the same disease, her level of involvement with the organization increased. The first three children died during early childhood due to complications of the disease. The youngest child lived to be almost 14 years of age and served as the

National Goodwill Ambassador for MDA during his final 3 years of life. Since 2004, the researcher has served in the voluntary role of MDA National Vice President. MDA Vice Presidents provide counsel, support, and advocacy in their area of expertise, and assist with various programs and activities that are a part of the MDA (MDA, 2007).

Sampling Strategy

A number of purposeful sampling strategies are particularly appropriate to qualitative inquiry. However, due to the sensitivity of the subject matter being explored (i.e., grief and bereavement associated with the death of a child), soliciting and recruiting participants for this study was a challenging issue. A particular dilemma for participant recruitment in this study was the fact that due to the deaths of their children, the parents being sought for interviews were no longer likely to be formally affiliated with the education and advocacy organizations that once served their children. Furthermore, existing research in the area of parental grief and bereavement has shown that parents whose children die after a prolonged condition or degenerative disability are under-represented or absent from member-led self-help groups for bereaved parents, from which most participants for bereavement research are solicited.

The MDA works with individuals diagnosed with a neuromuscular disease and their families. Although there are no program services or formal supports available for parents following the death of a child who was diagnosed with a neuromuscular disease, parents remain on MDA national mailing lists until a request is made by a family to have its name removed. Families may also have some informal contact with their local MDA representatives who were involved with services and provided care to a family member before death. For the current study, the researcher recruited a

purposeful sample of participants through the MDA. It was hoped that through ongoing informal connections with this organization, parents who might not otherwise receive research invitations would become aware of the current study. In addition, because of the researcher's high profile in, and long-standing involvement with, the organization, it was hoped that parents who may not have considered participating in bereavement research would choose to become a part of this study. Approval from an institutional review board was sought prior to the beginning of the proposed study, and procedures to protect participants and their confidentiality were strictly followed.

A criterion sampling strategy was chosen to recruit parents through the MDA to create a purposeful sample for this study. With criterion sampling, the researcher studies all cases that meet some predetermined criteria of importance to gather information that may support the research questions (Isaac & Michael, 1997). The conditions selected for the criterion sampling in this study were chosen to maximize the chances that information gathered would be relevant to early interventionists, special educators, and other education and health professionals working with young children and their families. Due to the symptoms associated with life-threatening and degenerative neuromuscular diseases, nearly all children who are diagnosed with one of these diseases during infancy or early childhood are eligible for special education services under IDEA, and most require frequent interactions with health professionals. The participant criteria included parents whose children were: diagnosed with a neuromuscular disease before age 8 years, lived with the condition for more than two years, received special education under IDEA at some point during life, and died before age 21 years. Because the specific characteristics and support needs of this category of parents has not been explicitly

studied, only a small number of participants was needed to explore a ground-breaking area (Bogdan & Biklen, 1998; Creswell, 2003). A minimum of five parents was sought for participation in this study.

Participant Recruitment

The researcher placed a parent recruitment advertisement in the magazine that is mailed by the national MDA office every other month to all families who have a member diagnosed with a neuromuscular disease. After the death of a family member with neuromuscular disease, MDA continues sending these free, informational and educational magazines to the household, unless a family member requests that MDA terminate the subscription. The advertisement stated the purpose of the research (i.e., to learn more about the support needs of parents whose children have died due to a neuromuscular disease), invited interested parents to participate in this research, and offered both telephone and e-mail contact information for interested participants (Appendix I).

The researcher also asked each parent who participated in the study to recommend one or more professional service providers who had been particularly supportive to them during their child's life or since their child's death. If parents felt comfortable, they were asked to contact the recommended professional and invite them to participate in the current study. Providers who expressed interest were given the researcher's contact information. Once a provider contacted the researcher, information about the study and IRB approval was offered, and a consent form was sent to interested providers by mail or fax. A minimum of two providers was sought for inclusion in this study. The role of the providers in the study was to gather additional information related to the experiences and support needs of families whose children were diagnosed with and died from childhood

neuromuscular disease for the purpose of data verification and triangulation by gathering data from multiple sources. This issue is further discussed later in this chapter.

Participant response to parent invitation. Parents who responded to the invitation to participate in this research study were contacted by the researcher in the same way they initiated their first contact (i.e., if they responded by e-mail, an initial e-mail response was sent; if they initiated contact by telephone, the researcher contacted them by telephone). Parents were thanked for contacting the researcher and offered general information about the study, including: the purpose of the study (i.e., to better understand the support needs of families whose children with a diagnosis of neuromuscular disease die); the process of the study (i.e., several hours of audiotaped telephone interviews); that participation was voluntary and they could withdraw from participation at any time; and, that all information would be kept strictly confidential. Basic demographic information was acquired, including: the parent's name and contact information, the child's name, the child's diagnosis, the child's age at diagnosis, the child's age at death, and the best time and method of contacting the parent.

It was anticipated that not all parents who responded to the invitation to participate in this research would meet the criteria established for participation in the proposed study (i.e., the child was diagnosed after age 8, lived fewer than two years after diagnosis, or died after age 21). Because of the sensitive nature of the subject matter being discussed, and because a review of the literature indicated that sharing stories about their children's lives and deaths matters greatly to most bereaved parents, all parents who responded to the research invitation were offered an opportunity to share thoughts about the subject matter with the researcher in some way.

Interested parents who did not meet the criteria for selection. Parents who responded to the invitation to participate in the current study but who did not meet the selection criteria (e.g., their child was diagnosed after age 8; their child died after age 21; their child has a life-threatening degenerative form of neuromuscular disease but is living; their child died from a condition other than neuromuscular disease) were contacted and told about the selection criteria for the current study. An explanation was offered about the guidelines for academic research, and why they did not meet the criteria. However, they were also offered the opportunity to share their stories for a different project on which the researcher is working that does not have such limiting participant criteria. Parents thus had an opportunity to share stories about their child in an interview format even if they did not meet the criteria set for the current study.

Interested parents who did meet the criteria for selection. Parents who responded to the invitation to participate and met the criteria for selection were contacted by the researcher and thanked for their interest. Parents were offered general information about the study and told that participation was voluntary, that they could choose to withdraw from the study at any time, and that all identifying information about them or shared by them during the study would be kept strictly confidential. Parents were told that the audiotapes of all interviews would be transcribed, that pseudonyms would be given to all participants, that the tapes would then be destroyed, and that all transcript contents would be kept secure and confidential. Parents who met the criteria and became participants in the current study were also encouraged to contact the researcher at any point during the study if they had any questions or concerns.

Interview Setting

Isaac and Michael (1997) suggest a natural and real-world context as the goal for the setting in qualitative research. For most parents, a natural setting is the home. However, finding families whose children have died after being diagnosed with a neuromuscular disease may be particularly challenging. These parents are no longer formally affiliated with the health, education, or disability advocacy systems with which they may have collaborated during the child's life. Also, research has shown that these parents are not likely to be represented in bereavement support groups for families whose children have died (Schwab, 1995). Therefore, the participant solicitation for the current study was nationwide.

As a result of the nationwide scope of participant solicitation, it was not logistically feasible for the interviewer to travel to the homes of all the parents who were selected for participation. Additionally, the researcher, who uses a wheelchair due to the physical limitations of a diagnosed neuromuscular disease, might not have been able to enter all of the homes of the parent participants because of accessibility issues. Therefore, all initial interviews for the current study were conducted by telephone. Subsequent interviews were conducted by telephone and/or e-mail contact. Ongoing contact by e-mail was maintained with the participants during the study.

Methods of Data Collection

Data collection in qualitative inquiry involves interrelated activities resulting in accumulated information; this information allows the researcher to formulate emerging theories and answer research questions (Creswell, 2003). In-depth, open-ended

interviews are one of the most important data collection methods used in qualitative inquiry. According to Bogdan and Biklen (1998), an interview is a conversation that has a purpose, and the purpose of a conversation in qualitative research is for the interviewer to gather information from one or more participants with whom the interview takes place. Interviews can serve as the dominant strategy for data collection in qualitative inquiry. As the researcher gathers conversational narratives and stories from the participants, insights about how the participants view the world and their experiences can be ascertained through the rich and descriptive data that emerges from the participants' own words.

Interviews for qualitative inquiry should not be considered formal question-and-answer sessions with a pre-arranged outline that details every specific query (Eisner & Peshkin, 1990). Instead, they should proceed as loosely structured, non-directive, and flexible conversations, and rely heavily on open-ended questions (Bogdan & Biklen, 1998; Maxwell, 1996). Being flexible and asking open-ended questions during an interview session does not mean that there is a complete lack of structure, however. Rather, this process allows the participants in the study to respond to topical questions from their own frame of reference and to freely express their own thoughts as they share stories about their experiences and recollections and perceptions.

The source of data for the current study was in-depth open-ended interviews with parents who met the selection criteria, who chose to participate in the study, and who returned signed consent forms. All initial interviews were audiotaped and conducted via telephone, by the researcher who has experience in qualitative methodology and the interview process. The goal of the first interview was to gather stories and narratives about the experiences of bereaved parents. These stories were to gather insights and

understanding about the perceptions and support needs of parents whose children were diagnosed with and died from a childhood onset neuromuscular disease. The follow-up interviews included verification of the collected data through member check, and the gathering of additional information from the participating parents based on emerging patterns and themes that were noted during ongoing data analysis. Most of the follow-up interviews were conducted by telephone, but a few of them were conducted by e-mail correspondence due to parent request. During the follow-up interviews, parents also had the opportunity to share additional thoughts and stories that they had considered since the initial interview. During all interviews and e-mail correspondence, parents were invited to share thoughts on the interview process and experience.

During qualitative interviews, the researcher does not rigidly control the content being explored, but allows the participants to share their stories in their own words (Bogdan & Biklen, 1998; Marshall & Rossman, 1995). The role of the interviewer for the current study was therefore to communicate sincere interest and attention, and to listen to what was being said by the participants—who are the experts on their stories—rather than to do much of the speaking (Bogdan & Biklen, 1998; Creswell, 2003). Informed, signed consent was obtained from participants prior to interviews. All audiotapes of telephone interviews were transcribed verbatim by a professional transcriber within a week of the interview so that data analysis was ongoing in the study.

Initial Interview Process

The researcher contacted each parent who expressed interest and met the selection criteria for participating in the current study and answered any questions these parents had. She also explained the written informed consent process, that the initial interviews

would be audiotaped for accurate transcription, and that all information and identities would be kept strictly confidential. No real names were used during data analysis or presentation. All written and audio materials were stored in a locked file cabinet in the researcher's home, and all computer files were password protected. The parents were encouraged to contact the investigator with any questions, concerns, or additional thoughts they had related to this research at any point during the study. The written consent forms were then mailed or faxed to each participant according to their preference. Once the consent form was signed and returned to the researcher, the researcher contacted the parent to schedule a convenient time to conduct the initial interview.

Rapport. During the interview process, the participants should feel at ease and be able to talk freely about their points of view and personal experiences. Therefore, building researcher-participant rapport is important to the interview process and to the collection of narrative data (Isaac & Michael, 1997; Whyte, 1984). Prolonged engagement, or spending sufficient time with participants, is an important part of building rapport during qualitative inquiry (Miles & Huberman, 1994). The rapport between the researcher and participants in the current study began at least from the first point of contact, and continued to develop throughout the in-depth interviews. All parents who participated in the current study said that they recognized the researcher from her role in the MDA, and that because of this, they felt like they already had some connection to her. They said that this increased their comfort level in sharing experiences and stories for the current study. Also, in addition to being an empathic and good listener, researcher-participant trust and rapport can be developed through the very type of questions and conversational style that are used during the interviews. Therefore, although the role of

the researcher was to be an instrument of data collection through empathic listening, she also used conversational reflection with the parents to build rapport throughout the interviews.

Conversational style. To “produce rich data filled with words that reveal the respondents’ perspectives” (Bogdan & Biklen, 1998, p. 95), the interviewer in qualitative inquiry should communicate personal interest and attention through head nods and appropriate facial expression. Because the interviews for the current study were by telephone, the researcher encouraged participants to elaborate on various points that were relevant to the research questions guiding the interview through brief remarks that indicated both listening and understanding. Bogdan and Biklen (1998) said that when necessary, the interviewer can ask for clarification of information through phrases such as, “Could you please explain that?” or “I’m not sure I am following you.” However, only a few comments about the interviewer’s perspective or experiences should be offered as a part of the interview process and content, and only when they are relevant and offered as a part of building rapport, connection, and trust.

The interviewer can probe the participant about the past with prompting questions or comments, and even ask them to quote things that they remember from particular times and events. However, such prompts and questions should be for clarification and expansion of data rather than as a challenge to the participant. Unless the participant is spending a considerable amount of time on an unrelated topic (e.g., local sports or weather), it is inappropriate for the interviewer to interrupt the participant while he or she is talking, or to change to direction of the conversation.

Initial interview questions. Bogdan and Biklen (1998) wrote that “information in the qualitative interview is cumulative” (p. 95), with each interaction building on and connecting to previous ones. To help establish rapport during the initial interview, the researcher began with a few minutes of small talk that led to a conversational style and relationship with the participant. Then, the researcher began asking questions that were related to the literature review and to the research questions guiding this qualitative study (Bogdan & Biklen, 1998; Marshall & Rossman, 1995; Spradley, 1979). The answers to these questions were then probed to gain more insights and a better understanding of the parents’ personal perceptions and experiences.

In the current study, the in-depth interview format incorporated six open-ended descriptive questions that were chosen to gather personal reflections about the unique experiences and perceived support needs of the parent participants. These questions solicited data in narrative form that are both experiential and descriptive (Spradley, 1979). They were developed from the research questions and the literature review guiding this study (Appendix J).

As suggested by Bussell, Matsey, Reiss, and Hetherington (1995), because the study focused on an extremely sensitive subject, parents were debriefed about the purpose of this research before and after every interview. They were also offered opportunities to share their reactions to the interview process after each interview. In addition, parents were encouraged to contact the researcher at any point if they had any questions or concerns about the study.

Follow-up Interviews

To clarify and build on the narratives offered by parents during the initial interviews, follow-up interviews were conducted by the researcher with the participating parents. The researcher contacted each parent about a week after the initial interview to inquire about their reactions to that interview. About a month after the initial interview, the researcher contacted parents to verify data and to discuss emerging themes. Several parents sought numerous contacts by phone or e-mail throughout the study. This ongoing contact helped build rapport, and provided ongoing information related to the emerging themes that came from ongoing data analysis. Field notes were taken on all formal and informal conversations between the researcher and the participants, and records of all communications were kept.

The questions that guided the follow-up conversations emerged from the data gathered during the initial interviews. Verification that accurate data were obtained was an important part of this process, but parents were also invited to share supplementary information based on the emerging patterns and themes in the data. Additionally, parents were asked to share their thoughts on several related issues, including:

- Previous or current participation in any type of support group or advocacy organization related to their children's condition;
- Their feelings about participating in the current study; and,
- Suggestions for future research directions.

Methods of Data Analysis

In qualitative inquiry, data collection and data analysis occur concurrently. Data analysis begins immediately after completing each interview, and brings structure and organization to the immense amount of narrative data that are collected (Lincoln & Guba, 1985). When a specific issue is the focus of the research, analytical induction is often used to develop a descriptive model that explains and supports all cases of the phenomenon being studied (Bogdan & Biklen, 1998). This analytical induction continues throughout the conduction of the study, even after data are no longer being collected from participants. The researcher is guided by the literature review and resulting research questions, but concepts and themes emerge and change as the data are collected, transcribed, reviewed, coded, and analyzed. The result is the identification of grounded categories, themes, and theories that become the basis of future research. The purpose of the current study was to explore a specific phenomenological issue within a purposeful sample of bereaved parents. Therefore, the narrative content obtained during the interviews was analyzed using an inductive approach that allowed patterns and themes to emerge.

Narrative Analysis

Narrative analysis was used to explore the participating parents' shared stories about the loss of a child due to a neuromuscular disease, including their experiences of grief and perceived needs for supports. Narrative analysis was also used to explore and code the responses of the providers who participated in this study. Although there are various suggestions regarding how narrative analysis might be conducted, there is no

absolute binding theory of how interpretation must take place (Sandelowski, 1991). Polkinghorne (1995) suggested that the researcher inductively identify patterns that lead to categories and core themes that emerge from the data. According to Strauss and Corbin (1998), the grounded theory approach to narrative analysis involves reading and re-reading a transcribed database. Then, the researcher inductively labels patterns, or recurring concepts, expressions, or references. These patterns can then lead the researcher to discover themes, or sets of patterns. These emerging themes can then be coded, and compared to patterns and themes in other narrative transcripts to produce theories related to the phenomenon being explored.

For the current study, each interview session was transcribed verbatim by a professional transcriber within a week of the actual interview. The researcher also made field notes and personal observations during and after each interview that became a part of the overall volume of data. Once available, the interview transcriptions were checked for accuracy by the researcher against the original recordings. Each transcript was reviewed in entirety to gain an overall understanding of the data. The researcher then reviewed each transcript line by line, looking for and marking key or recurrent words, phrases, and patterns in the participants' narratives.

All field notes and interview transcripts were coded, and this coding began as soon as the first interview session was transcribed. Coding involved reviewing, sorting, and categorizing the collected data so that patterns could be noted. To search for emerging patterns in the similarities and differences across interviews, the researcher developed visual displays of the data during coding (Miles & Huberman, 1994). Themes and sub-themes were developed based on emerging patterns in the data. When a theme

was identified, it was color-coded, labeled, and indexed for each transcript. These themes were reviewed with each additional transcript so that emerging categories were continually created or collapsed during the ongoing task of data analysis.

Computer files were created for each participant. The patterns, themes, and categories that emerged from each transcript were then compared, contrasted, expanded, and refined with data files from every other participant, as new data were transcribed and analyzed during the study. This process was continued until all major themes were identified and indexed. As suggested by Strauss and Corbin (1998), after the themes were synthesized into a core set of categories, narrative explanations for these themes within participants were developed. These narratives were then compared to and synthesized with those of other participants. The final narrative explanation of the phenomenon being explored led to the results, and the discussion of developing theories based on the data.

Verification of the Data

It was anticipated that the participant recruitment and selection for the proposed study would result in a very small sample size. However, the information in this new area of qualitative inquiry is rich in description, and can lead to scientific and grounded understandings of the personal grief experiences and support needs of parents whose children are diagnosed with life-threatening neuromuscular diseases. The parents who participated in this study volunteered to do so, and they represent a group of parents who are absent or under-represented in most grief literature that is currently available and used to guide decision-making and best practice in the special education system.

The grounded theory that emerges from data collection and analysis is a trademark of qualitative methodology (Isaac & Michael, 1997). The trustworthiness of

these data therefore involves special criteria common to this type of scientific inquiry, that ensures that the findings are credible (i.e., believable and convincing), transferable (i.e., to other contextually similar populations and settings), dependable (i.e., consistent with other similar studies), and confirmable (i.e., the process and product of the data collection can be audited and verified through an outside party). The accuracy and trustworthiness of the data in the current study were verified through three techniques commonly used to establish credibility in qualitative research: member checks, triangulation, and peer debriefing (Bogdan & Biklen, 1998; Isaac & Michael, 1997; Lincoln & Guba, 1985).

Member checks. Only the providers of narrative information can verify the authenticity of data and the associated meanings and interpretations that were intended (Isaac & Michael, 1997). Therefore, member checks are a crucial technique in establishing credibility in qualitative inquiry because they involve the participants from whom data were originally obtained. Member checks are a process of checking back with participants about the accuracy of data, the interpretations made during data analysis, and conclusions drawn from this analysis (Bogdan & Biklen, 1998; Isaac & Michael, 1997; Maxwell, 1996). This method of validation reduces the possibility that data were transcribed incorrectly or that misinterpretations of participants' perspectives were made. For the current study, member checks occurred throughout the data collection process. The researcher checked the accuracy of her understanding the participants' narratives during each interview through the use of paraphrasing and summary techniques. In addition, member checks formally occurred as a part of the follow-up interviews, and as a

part of other ongoing informal conversations that took place between the researcher and the participants.

Triangulation. According to Isaac and Michael (1998), triangulation is a process that corroborates a researcher's findings by arriving at the results from different directions. In other words, information is gathered through different methods, data sources, or settings during triangulation, which increases the credibility of the research findings. In the current study, the key informants were bereaved parents whose children died due to childhood neuromuscular disease. For purposes of triangulation, data were also gathered from other informant sources. These other informants were service providers who were recommended as being very supportive by the parent participants. After returning the signed consent form, each provider participant was interviewed at least one time. These interviews were in-depth, conducted via telephone, and based on the open-ended questions that were posed to the parent participants (Appendix K). This process allowed the researcher to double-check findings that emerge from the parent data. Interviews with providers were conducted after all the initial interviews with parents were completed. Narrative analysis was used to code all data gathered during these interviews.

Peer debriefing. In peer debriefing, the researcher invites feedback related to the study from neutral peers or colleagues (Bodgan & Biklen, 1998; Lincoln & Guba, 1985). The researcher offers these peers information and details about the study and solicits questions and comments about various issues, including methodology, content, strengths and weaknesses of the study, data collection and analysis, and ethical considerations. For the current study, the researcher invited two colleagues to serve as peer debriefers. One of these individuals works as a director for advocacy in a national disability organization.

The other individual is a doctoral candidate in Early Childhood Special Education, an experienced qualitative investigator, and has published literature related to parental grief and bereavement. Neither of the peer debriefers had direct involvement with participant recruitment or interviews. The researcher also discussed the research and emerging themes with members of her dissertation committee.

Ethical Considerations

Ethical principles are essential in scientific inquiry. The design and method in which data collection and analysis are carried out in qualitative research must be done with consideration of the ethical obligations of the researcher (Bogdan & Biklen, 1998). These obligations are to ensure that the rights, needs, and values of the participants are protected at all times throughout the study. Bereaved parents who participate in grief research could be considered a particularly vulnerable population because of the sensitive nature of the issues being explored. However, Dyregrov (2004) stated that all the parents who participated in her study reported that their research experience was beneficial to them, and that none of the parents in her study reported any regrets regarding their participation. This is consistent with findings reported by Aho et al. (2006), who interviewed bereaved fathers whose children had died due to various disabilities. The fathers in this study reported that participating in bereavement research was a positive experience, and that they liked knowing that their experiences may help other people.

For the current study, the researcher attended to ethical considerations in a number of ways. She communicated the purpose of the research with all participants, obtained written consent from each participant prior to beginning any interview, and made all participants aware that their participation was voluntary and that they could

choose to withdraw from the study at any time. The researcher also established a system for ensuring confidentiality, including a locked filing cabinet for materials and password protection for computer files. No real names or identities were used at any time during data analysis or presentation. Transcripts and written interpretations of the data were made available to all participants. Finally, no specific information shared by any participant was discussed with any other participants in the study.

Personal Reflections

Qualitative methodology reflects the nature of researcher-participant interactions. It also reflects the biases and judgments that each individual brings to a study, including perceptions and values of the researcher (Isaac & Michael, 1997). In qualitative inquiry, the researcher is the instrument of data collection, and information is mediated through this subjective instrument rather than through inventories, questionnaires, or other quantitative methods of data collection (Bogdan & Biklen, 1998; Marshall & Rossman, 1995).

Qualitative inquiry yields rich and personal data. Although the researcher does not come to a study with prejudgments or a priori hypotheses, each researcher does come to a study with his or her real-world observations, personal experiences, and specific scholarly interests. It is essential for the researcher to admit and explore these issues, and to reflect and report on personal values and biases. In doing so, the neutrality of the researcher and the scientific integrity of the methodology is preserved (Bogdan & Biklen, 1998; Isaac & Michael, 1997).

The researcher of the current study entered this scientific inquiry as a bereaved parent, an adult with a neuromuscular disease, and a published professional in the field of

disability and grief. She had both an academic understanding of the topic being explored, and personal experiences and judgments due to her own life experiences. This undoubtedly would have some influence on her approach to the current investigation. However, through personal reflection, these subjective and preconceived understandings based on personal experiences of disability, grief, and bereavement can become helpful tools in qualitative inquiry. To clarify her own biases and subjective experiences, the researcher was interviewed using the parent participant questions (Appendix J) before conversing with the study participants. The following is a personal reflection from the researcher, written prior to beginning the study:

The proposed study represents a combination of my personal and professional interests in supporting families and professionals who care for children with disabilities. Before I gave birth to my children, I had been accepted into a doctoral program and was excited about my goal of becoming a clinical child psychologist. However, the decision to enter my current doctoral program and shift my focus to a program in early childhood special education was influenced by personal experiences that occurred as I cared for my own children who were born with life-threatening disabilities.

All four of my children were born with a rare form of neuromuscular disease. From birth, each of the children required a variety of medical and developmental interventions. However, the disease and subsequent prognosis was not correctly diagnosed in any of my children until after the birth of my youngest child. When my youngest child was almost two years old, I began experiencing unusual physical symptoms that affected my strength and coordination. I was diagnosed

with an adult onset neuromuscular disease that has since resulted in my reliance on a power wheelchair for mobility, and a machine that provides part-time respiratory support. Soon after my diagnosis, my children were given their own diagnosis of this disease. However, they each had inherited a fatal infant onset form of the neuromuscular disease that I did not even know I had while giving birth to them. I was told that my children would not survive beyond infancy or early childhood.

As a parent of four children diagnosed with a rare form of childhood neuromuscular disease, I spent nearly 20 years coordinating and tending to my children's medical, educational, social, emotional, and various health and developmental needs. Although this was often a very stressful experience—both physically and emotionally—these years were also filled with the joy that I felt in every moment of being a 'mommy' to my children. Throughout these years, I had opportunities to experience a variety of formal and informal supports, both in group and individual formats. None of these opportunities changed the reality that my children had severe disabilities and life-threatening medical conditions. However, many of the social supports that I experienced had a beneficial effect on how I perceived these stresses, and therefore on how I was able to cope with the atypical and intense demands that had become my typical and daily life. This is true for the supports that I received from other parents of children with disabilities, and also the informal supports that I received from professionals who were somehow involved with my children's various health, education, and advocacy needs.

Before my personal family experiences, I chose to become a professional who worked with children and families in a helping profession. My specific career goals shifted as I raised my own children, but the desire to support other families and the professionals caring for them simply grew stronger. Therefore, in addition to having opportunities to offer and receive social supports as a family member, I also had professional opportunities to provide supports to others as a leader in disability-related groups, and as an individual provider of family support. This combination of personal and professional support experiences helped shape my academic curiosity and research interests.

My first three children died during early childhood. The grief I experienced after these losses was intense, and seemingly unrelenting. After each of their deaths, a number of health, education, and advocacy professionals who had been a part of my children's care teams suggested that I attend a local support group for bereaved parents. Because of the positive experience and beneficial outcomes I had perceived related to participation in group supports prior to my children's deaths, I anticipated similar experiences and benefits would result from these groups. Instead, I felt like an outsider when attending these groups, even among my own peers—other bereaved parents. I noticed that most of the other bereaved parents in these settings had lost typically developing or previously healthy children to some catastrophic illness or trauma. I could not pinpoint why I felt like my experiences and stories were not a good fit with these other parents, but after several tries in several different groups, I stopped seeking this type of social

support. The supports I found most helpful were informal supports that came in the form of telephone calls and occasional personal interactions with other parents whose children with prolonged or degenerative disabilities had died, and with several of the professionals who had been involved in my children's care prior to death.

During informal networking with other bereaved parents whose children had died from severe or degenerative disabilities, I began to realize that I was not alone in my perceptions of the bereavement support that is generally available (or lacking) for families with these life experiences. Most other parents with whom I spoke had also received recommendations from caring professionals, suggesting that they join a bereavement support group. But, most of these parents said they did not feel that bereavement support groups were a helpful source of support for them, even though many of these parents had been long-time members in disability support groups prior to their children's deaths.

Being a curious professional and working in an academic environment, I began to review scientific literature related to parental bereavement. Interestingly, I observed that parents whose children die as a result of life-long, severe, or degenerative disabilities were under-represented in research. They were also under-represented in the typical bereavement support groups from which most parental bereavement research participants are solicited. This fit with my personal experiences and observations. I was also unable to find any studies that explored parent accounts of the unique and personal grief experiences related to the loss of

a child with a degenerative disability. Nor was I able to find any research exploring the perceived supportive needs of these families who coped with intense and enduring stress and loss both before and after their children's deaths.

My youngest child died about 3 years ago, just before his fourteenth birthday. He was well-known by people around the world because of his bestselling books of poetry and his frequent appearances on television. And, he was well-respected by many people because of his advocacy and ambassador work in areas of disability and peacemaking. Even though the suggestion was made to me by a number of professionals and friends, I did not consider joining a local bereavement support group in spite of the intense grief I experienced after my only surviving child died. Instead, I spent time talking about the nature of loss and the process of grieving the death of a child with a disability or chronic condition with a few close friends and colleagues. Additionally, I accepted a voluntary leadership position with the MDA, which offered me opportunities to network with other parents and professionals whose typical and daily life are shaped by the atypical and intense demands of caring for children with progressive disabilities. Now, as a doctoral candidate preparing my dissertation proposal, I have chosen to combine my personal and professional experiences, observations, and academic interests, and create a set of research questions related to these unique and perplexing issues.

Reflecting on these personal and professional experiences is an important task prior to beginning any qualitative inquiry. Because of my high-profile in the MDA, I know that it is likely that there may be parents who are willing to participate in this study because they recognize my name, and because they may have personal feelings about my youngest son. They may even feel a sense of rapport and connection that is critical to good qualitative inquiry, even before the interviews begin (Bogdan & Biklen, 1998; Isaac & Michael, 1997). Because my personal experiences are generally public knowledge, the parents who choose to participate in the proposed study may also be more willing to share their own personal stories, knowing that the listener is a 'peer' of sorts, who has a shared experience (Brotherson, 1999; Wheeler, 2001). Trust, friendliness, and rapport between the researcher and participants in a qualitative study are essential (Isaac & Micheal, 1997). However, I understand that a line must be established that distinguishes the researcher as an empathic and knowledgeable listener, rather than simply another participant who is gathering or exchanging information about a similar experience (Bogdan & Biklen, 1998).

I come to this study aware of my personal experiences and professional interests in this sensitive topic area. However, I am equally aware that preconceived perceptions and personal experiences should not interfere with research observations or process. My role as a researcher is to listen, to observe, and to describe what happens during the interviews and throughout the study. I also know that I should not use my personal knowledge and experiences to change the flow of any conversation during an interview, or to influence the emergence of

patterns and themes during data analysis. To monitor my personal perceptions and judgments, I will keep reflective notes throughout the study so that an observable chain of evidence is available that will more objectively ascertain that such biases do not affect the data collection or analysis. Finally, I will use data triangulation, member checking, and peer debriefing as specific strategies to verify the data and to strengthen the credibility of the findings.

CHAPTER IV

FINDINGS

This chapter begins with a description of the participants in this study. Due to the low incidence of the particular neuromuscular diseases discussed by the participants, specific demographic information is summarized in general terms (e.g., ethnic identity, nature of neuromuscular disease) to maintain confidentiality. Other information that is more general in nature (e.g., age of child at diagnosis, time since death) is summarized in Table 1. Descriptions of the providers who served as other key informants for the purpose of gathering information from multiple sources is also presented. This information is summarized in Table 2. Following the participant descriptions, there is an exploration of the themes that emerged from data analysis. These themes are presented as they relate to the three research questions:

1. What are the subjective experiences of parents whose children have died due to a degenerative disability
 - a. Around the time their children are diagnosed with a degenerative, life-threatening disability?
 - b. During their children's lives?
 - c. Around the time of their children's deaths?
 - d. Since the time of their children's deaths?
2. What do parents of children who died from degenerative disabilities perceive as needs related to supporting their children and coping with loss?
3. When a child with a degenerative disability dies, what can professionals in

education, health, and advocacy organizations say or do that might be most supportive?

Participants

Nineteen parents of children diagnosed with childhood onset neuromuscular disease responded to the recruitment advertisement for this study. Of those, 7 parents both met the criteria for inclusion, and signed and returned the consent form to begin participation. Two additional parents met the selection criteria and expressed interest in participation, but did not respond to attempts to obtain written consent. The other 10 respondents did not meet the eligibility criteria for the study based on the following exclusions: two had living children diagnosed with neuromuscular disease; three had children who died from neuromuscular disease prior to the age of 18 months; and, five had children who died from neuromuscular disease after the age of 21 years. Therefore, the results presented in this chapter are based on the prolonged contact and communication through telephone interviews and e-mail correspondence with the 7 parents who both met the eligibility criteria and returned the consent forms. The results also include responses from four other key informants, who were recommended by the parent participants as being very supportive providers. These 4 professionals provided information that offered insights into the research questions from a different perspective.

Parent Participants

The parent participants included 6 mothers and 1 father. Four parents were divorced from the child's other parent during the child's life, and 3 parents were still married to the child's other parent during the course of the study. The parents described

their ethnic or racial identity as African-American (n=1), Caucasian (n=2), or of multiple ethnic origin (n=4). The multiple ethnic origins included the child having 1 parent from an Asian, mid-Eastern, or Native American origin, and the child's other parent being from a European-American descent. Three parents lived in major metropolitan areas on the west coast of the United States, and four parents lived in major metropolitan areas in the mid-Atlantic or Northeast regions of the United States.

The children discussed by these parents included 3 girls and 4 boys. Their first symptoms appeared during infancy or preschool years, and the diagnosis of a degenerative neuromuscular disease was made during infancy or early childhood. Three children were diagnosed with rapidly progressive diseases that typically result in death during infancy or preschool years. Three children were diagnosed with fairly progressive diseases that typically result in death during adolescence or early adulthood. One child was diagnosed with a progressive neuromuscular disease that can be variable in severity. Depending on severity, death may result anytime from infancy through adulthood; however, the earlier the diagnosis is made the earlier death is likely to occur. Six children had complex health issues, were eligible for home nursing, and required breathing machines, feeding tubes, frequent hospitalizations, and other medical supports.

The children's physical abilities were limited (n=3) or severely limited (n=4), and all of these children needed mobility assistance. The 6 children who were diagnosed or symptomatic during infancy received some type of early intervention or therapeutic services prior to age three, and had transition plans in place for education services under Part B of IDEA that were to begin when the child turned 3 years of age. Two children had a sudden change in medical status and died before those services began. The seventh

child, who was not diagnosed until age 4, received education accommodations under Section 504 of the Rehabilitation Act of 1973 (United States Department of Health and Human Services, 2008) until sometime during elementary school, at which point the child began receiving services under Part B of IDEA.

Due to the low incidence of several of the diagnosed neuromuscular conditions, to maintain confidentiality only general information is being specifically matched with each participant. This information includes: the number of other children in the family, whether other children were affected with the disease, ages of symptom onset and diagnosis for each child, ages at death, and the amount of time since each parent's child died. This information is summarized in Table 1. Four parents lost their only child, 2 parents had more than one child affected with the same disease, and 1 parent had other children not affected by the disease. The children died between 3 and 20 years of age, and the parents were bereaved from 3 months to 5 years at the start of the initial interviews.

Table 1: Parent Participant Information

Parent	Child	Other children	First symptoms	Age at diagnosis	Age at Death	Time bereaved
Christie	Noel	None	3 months	6 months	3 years	4 years
Tim	Christopher	3 (1 not affected, 2 affected and also deceased)	3 months	6 months	3 years	5 years
Laura	Justina	None	3 months	6 months	4 years	2 years
Bev	Caleb	None	Birth	6 years	8 years	3 months
Haley	Melissa	1 (also affected)	3 months	11 months	12 years	10 months
Diane	Annie	None	3 months	7 months	15 years	3 years
Karen	Ethan	2 (not affected)	2 years	4 years	20 years	7 months

Provider Participants

Five parents recommended providers they considered particularly supportive for participation in this study. Two parents recommended the same provider, so a total of 4 providers were recommended. All 4 providers agreed to participation, and signed and returned the consent forms. These providers included a pediatric critical care physician, a pediatric physical and occupational therapist, a neuromuscular disease case manager, and an early childhood special educator. These providers had served in their professional roles for the previous 5 to 30 years, and worked in major cities in the eastern or western United States. Basic information about these providers is summarized in Table 2.

Table 2: Provider Participant Information

Provider	Professional role	Typical population served	Typical environment
Andrew	Physician	Pediatric critical care (birth-21)	Hospital-based
Betty Ann	Therapist (OT/PT)	Early childhood	School-based or child's home
Molly	EC Special Educator	Early childhood	School-based or child's home
Sally	Case manager/ Advocate	All ages (infancy-adult with diagnosis of a neuromuscular disease)	Medical clinic and community-based

Themes

The themes that emerged from the data are presented below, as they relate to the following research questions:

Research Question 1: What are the subjective experiences of parents whose children have died due to a degenerative disability around the time their children are diagnosed, during their children's lives, around the time of their children's deaths, and since the time of their children's deaths?

Understanding of the experiences of parents whose children die from degenerative disabilities is crucial to providing for and meeting the perceived support needs of these parents. Each of the parent participants in this study spent many hours sharing stories and personal memories about their experiences: with their children; with medical, educational, and other service providers; and with formal and informal support systems. They described: their children's early development and the time surrounding diagnosis; their children's progression through the disease, including how they learned about and provided for the various care needs associated with the condition; and, the time surrounding their children's death and their grief experiences since that time. They also described many of their interactions with professionals and service systems across these various periods associated with their children's lives.

In general, parents were able to recall and share rich details about experiences that were perceived as particularly stressful or negative, and about experiences that were perceived as particularly supportive or positive. Parents reported that it was more challenging for them to recall details of experiences that they considered "more routine" or that did not stand out as being particularly stressful. For example, 5 of the 6 parents whose children were diagnosed with a degenerative condition during infancy reported that their children received some type of early intervention or therapy services and that they began shortly after the diagnosis was made. However, none of these 5 parents remembered the details about how or when these services began, but they each said that they remember that it was a "helpful" or "good experience" that came during a very difficult time in their lives.

Three major themes emerged from the detailed experiences that the 7 parents shared about their children's lives and deaths, and from the detailed experiences that they shared about their interactions with service providers and service systems. Those themes focus on: the various stresses that are a part of parenting and caring for a child who is diagnosed with a degenerative disability; the ongoing struggles with seeking validation as a parent who is raising and loving a child with a degenerative disability; and, the various supports that make a positive difference for parents whose children die as a result of a degenerative disability. These three themes – stress, validation, and support – along with subthemes that emerged for each of these themes, are discussed in detail below.

A Journey Abundant with Stress

When a child is diagnosed with any type of illness or disability, the ensuing experiences for a parent and family will reflect stress that is associated with that reality. All of the participants agreed that there is a certain amount of *inevitable stress* when parenting a child with a progressive disability. Sally, a disability case manager, said families “have to deal with the reality of the diagnosis. Then they have to deal with all of the progressive changes, the medical needs, the logistic issues, and also the emotional challenges of coping with it all.” However, all participants also agreed that there are many *unnecessary stresses* that become a part of a parent's journey. Haley, whose daughter Melissa died when she was 12 years old, said, “In so many ways, I have felt like my entire life with my daughter was a continuous battle, with added stress. With stress that was not just a part of ‘my child has a disability.’”

All of the participants agreed that inevitable stress included: learning about their children's condition; addressing complex medical, educational, and social needs related

to their children's condition; and, coping with the inevitable progressions and ultimate deaths of their children. Participants also agreed that unnecessary stresses included: being judged by professionals and peers; having to battle for information, services, and quality providers; and, the social isolation that is frequently a part of the journey with a child whose medical needs limit typical activities. Christie, whose son died nearly 3 years after being diagnosed, talked about the journey being abundant with stress. She said that once she acclimated to his disability, her son's:

...condition changes because it is a degenerative condition. So, then you need new equipment, and new care routines. And inevitably, you have to battle with the unnecessary stresses yet again... That was our journey, always trying to just prevent the next crisis, the next heartbreak, the next battle... And it is the same journey, but it is so very different all the time. And sometimes you just feel like you can't navigate, especially when it's something stressful that was easily avoidable. You are tired and sad, and you try to focus on the positive and the moment, but it's always something.

The experiences of these participants clearly illustrate that parenting a child with a degenerative disability is a journey abundant with both necessary and unnecessary stress. Five subthemes emerged as categories related to both the necessary and unnecessary stresses that were experienced by parents throughout their journeys: dissonance, exhaustion, chronic changes, unanticipated shock, and profound grief. These five subthemes are summarized in Table 3, and are discussed in the sections below.

Table 3: Typical Stressors Experienced by Parents of Children with Degenerative Diseases

A Series of Dissonant Events	<ul style="list-style-type: none"> • Mismatch of expectations and reality • Mismatch of concerns and confirmations • Mismatch of what is known and what is observed • Mismatch of what is wanted and what is needed • Mismatch of what is needed and what is available
Exhaustion is a Part of Daily Life	<ul style="list-style-type: none"> • Cognitively learning about the diagnosis and care • Physically providing the child's care • Emotionally coping and 'living on the edge' • 'Battle fatigue' from conflicts with service systems
Chronic and Progressive Changes	<ul style="list-style-type: none"> • Physical and medical progressions of the disease • Changes in routines and equipment • Changes in services and providers
Loss is an Unanticipated Shock	<ul style="list-style-type: none"> • Not when or how expected • Child had <i>beaten odds</i> repeatedly across years
Grief is Profound	<ul style="list-style-type: none"> • Intense • Complex (other losses due to genetics of disease) • Enduring • Feelings of disconnection • Coping with validation issues

A Series of Dissonant Events

The parents shared stories about how they first noticed that something did not seem typical about their child's development, and about receiving the news that their child had a degenerative disability. They described these experiences as being a series of dissonant events, in which details they were seeing or hearing about their child did not match up with what they expected or what they knew. All parents said that this dissonance was stressful.

All 7 parents said that they had no expectation of a problem with their child's health early on, and they all looked forward to the birth of a healthy child. Only 1 of the 7 parents reported prenatal warning signs that there might be some health problem before the child's birth. Bev, the mother of Caleb who died at 8 years of age, said that her son had an abnormal growth on his spine that appeared during an ultrasound. She also said that because this growth diminished during the course of the pregnancy, she was not expecting any severe life-long issues to be a part of her son's life. The other 6 parents said that their children were born with no apparent symptoms or problems. For example, Diane, the mother of Annie who was diagnosed at 7 months of age and who died at age 15 years, said, "When she was born, she was a perfect little angel. She was just vibrant, smiled all the time. She was a little, fat, healthy baby." Haley talked about her daughter Melissa who was diagnosed at 6 months being "a great baby. I was just a proud mother, doing everything with her that any other parent would do with their infant."

Six parents said that in the months following their children's births, they began to notice subtle signs that did not seem to fit with normal child development. However, when they spoke with their pediatricians, all six parents were initially reassured that there was no real problem with their child. Haley began to notice that Melissa was not doing the same things as other infants her age, but when she told her pediatrician "something is wrong," she was told that babies "all develop at their own rate, nothing is wrong. Then when she was 11 months old, she was officially diagnosed." Christie said that she had concerns about her infant son, Noel, who seemed to choke a lot, have very weak muscles, and perspired more than typical. She, too, was reassured that what she was reporting to pediatricians was no reason for concern. It was not until their third visit that the

pediatrician “finally said something is not right, and sent us to the neurologist.” Before the results of neurological testing were available, Christie’s son went into a medical crisis at age 6 months. Only then was a diagnosis of a degenerative disability confirmed. This mismatch of what they were expecting and what they were seeing, and then the mismatch of what they were reporting as concerns to providers and those providers’ lack of confirmation that they should have concerns, were very stressful experiences for these parents.

Five of the parents whose children were diagnosed during infancy said that even more stressful than getting the diagnosis was the distress they experienced with “how” they received this information. They said that the challenging emotional content of what they were being told did not fit with the experience, which they described using words such as “cold,” “lacking compassion,” “matter of fact,” “horrible,” and “strange.”

Christie, the mother of Noel, said:

When we got the official news, how we got it was horrible. I will never forget it. Because Noel had a respiratory crisis before we knew what was wrong with him, there were many doctors already involved. They had a conference meeting. We walked into this huge, very blank, cold room, with nothing on the walls, a big long table with numerous, numerous, so many people sitting all around the table. Physicians from all different specialties, plus social workers, the chaplain, the interns, it was like the whole crew. And all that was on the table were boxes of tissue. That was all. A blank room, dozens of faces staring at us, and boxes of tissues. We sat down and they just basically said your son has (a progressive and deadly neuromuscular disease). He won’t live another 6 months, and you should

set your affairs in order. Boom. I just couldn't believe it.

Once their child's diagnosis was confirmed, stressful dissonance continued. When Tim's son Christopher was diagnosed at age 6 months, Tim was told that his child would die before his first birthday. Laura, too, was told that her six-month-old daughter would not survive past the next few months. Both parents were shocked and devastated by such news, but said that what they were hearing did not fit with what they were seeing. Tim said that despite being in shock, "It didn't just register because the baby didn't look ill." Laura was overwhelmed with the devastating information that her daughter would probably die very soon, but said, "Justina was happy, needing to be fed, needing her diaper changed. She was like, Hello! I am here! What is going on? Will you please feed me? So life had to continue in spite of the shock."

Sally, the case manager, agreed that parents go through these dissonant events and that they can be stressful:

Usually, when a baby or young child is diagnosed, they are not needing a wheelchair or a ventilator or the equipment and resources that come later.

Sometimes later is a few weeks to months away, and sometimes later is a few months to years away. But parents usually know something is wrong. Then they get this diagnosis, but their child still just looks like a pretty typical child with a little something that is not quite right.

Sally, like the other providers and parents, said that dissonance does not end after a child is diagnosed. Throughout the journey, parents struggle with mismatches between what they want and what they need to best care for their children, as well as mismatches between what is needed and what is available in the way of services and supports for their

children. For example, 2 parents referred to home nursing for their children as a “necessary inconvenience,” at least when a child first begins needing medical technology such as feeding tubes and breathing machines to improve or prolong life. Another parent, Bev, whose son Caleb had a tracheostomy tube and relied on a ventilator for breathing said, “We really didn’t want nursing. Some person in your house that you all of a sudden have to trust, with your child, your privacy, your life. But we needed some rest, so we used some of the night nursing.”

Another parent, Laura, said that she did not want home nursing but was told that her daughter would not be released from the hospital until such services had been secured. Due to a nursing shortage in her area, it took nearly 2 months to line up 8 hours of nursing, 5 nights a week, for her daughter. As a result, her daughter spent longer in the hospital than necessary:

She could have gone home 2 months before she did, but there were no available home nurses, so she had to stay all that time in the hospital ... She ended up spending her first birthday in the ICU, when we didn’t even know how many birthdays she might have.

Andrew, a pediatric critical care physician, said that this type of dissonance is typical, and can be very stressful for families. He said sometimes families “will get home nursing, but depending on where you live and what specific needs your child has, you are not really guaranteed that this will be available, or even that it will be quality care.”

Exhaustion is a Part of Daily Life

All 7 parents said that exhaustion was another stressor that they experienced during their children’s lives, and that different types of exhaustion were simply a part of

their daily lives. Molly, an early childhood special educator, said:

Time and energy are usually in short supply. The time needed to gather and process all the information about the diagnosis, to schedule and keep up with all the appointments, to provide the child's care which is often very complex and time-consuming, to deal with other family issues, and just trying to maintain any type of outside social contacts, those things just exhaust parents. And time for themselves is just not in the equation.

The specific types of exhaustion the parents discussed include:

- Cognitively learning about the diagnosis, care needs, and decision-making;
- Physically providing the child's care which often involves medical technology;
- Emotionally coping with the reality of the child's condition, with other family stressors, and with "living on the edge" regarding their child's health status; and,
- "Battle fatigue" that results from frequent conflicts with providers and service systems related to their child's condition and care needs.

Cognitive exhaustion. Learning about their child's diagnosis and care needs and thinking about important decisions was "mentally tiring" to the parents. They said cognitive exhaustion began at the time of diagnosis, when many of them were told there was "no hope" for their child's survival, that their child "would be dead soon," or that they should "make burial arrangements immediately." The parents said they immediately began seeking information and options that might prolong their child's life, but that this

was often challenging. Tim asked the professional sharing Christopher's diagnosis if there was any chance his son might live longer than a few months. He said the professional's response was, "there is nothing that can change it. Well, if you want to keep him on machines like a vegetable or something, sure."

Parents said they also experienced cognitive stress related to decisions they had to make about their children's lives and deaths throughout their journeys. Laura said:

We ended up deciding to have her trached. That, again, was a difficult decision. Knowing that she would likely not be able to eat or vocalize (because of the trach)... Yet at the same time as she was sitting there with the intubation tube, propped up in her chair, playing and smiling and doing all this stuff, it was like, how can we not do this?

Parents also experienced mental stress related to the amount of information and training they had to learn to provide for their children's needs at home. Diane, the mother of Annie, said:

We learned how to suction her trach, change her trach, manage and clean her breathing and feeding tubes and machines... manage all of her medications, respond to crises... and so many things. We had to do all those things for her properly at home, or she could die.

Because many childhood onset neuromuscular diseases have a genetic component, all 7 parents said they had to make decisions about whether or not to have additional children, and whether or not to have the child's siblings tested. Two parents were already expecting or had already given birth to other children at the time of the first child's diagnosis. Haley said that an additional stress was feeling judged for her decision-

making related to additional children:

I chose to have another baby. I wasn't trying to have another baby, but I got pregnant and that was that. I thought no matter what happens I would have that child anyway. I didn't do any of the (prenatal) testing, because it would not have changed anything. And people judged me for that, especially when my second child was also affected (by the disease).

According to Sally, the disability case manager:

Families have to face major decisions... about their children's care, their children's future. But also, some parents may have to make a decision about whether to quit working or not, to provide care at home for the child who often has significant support needs. Also, because of the genetic component with of these childhood neuromuscular diseases, families often have to make decisions about whether or not they will have additional children ... All these decisions can be very, very stressful for families.

Physical exhaustion. All 7 parents experienced physical exhaustion related to their child's care needs. Six children had frequent hospitalizations; because of their use of medical technology and breathing machines, they received hospital care in the Intensive Care Unit (ICU). As a result, most parents found themselves sleeping on the floor or in a straight-backed chair because there were no accommodations for parents to rest in this setting. However, these parents felt the need to be with their children, even when they were physically exhausted, and even when hospital rules disallowed it. One mother said:

It didn't really matter if we were really allowed to stay or not... our son was in the ICU, and we were going to be with him, for many reasons... So in the 3 years

that we lived in and out of the ICU, my (spouse) and I took turns sleeping on the floor of his room. Hundreds of days, and it was so exhausting, but it didn't matter.

Bev, the mother of Caleb, said:

I stayed by Caleb's side, at his ICU bedside for over 8 months. There were no comfortable chairs, no recliners. No place to shower. We were hungry and exhausted, but I needed to be with him, especially if there was the chance he might die. And if he was going to improve and I was taking him home, I needed to know how to care for him. His needs and condition were constantly changing. I needed to know how to provide his care.

Two parents said that due to work, their spouses traveled hundreds or thousands of miles weekly to juggle job expectations and being with their families. One parent said:

I was on one side of the country and (my spouse) was on the other side of the country all week working. Just before (our child) was born, we started our own company. You can't just quit or take a leave of absence. So for 6 months, I stayed with (our child in the hospital) round the clock. Then (my spouse) would catch a red eye flight on Friday night, cross the country, handle the 3 hour time change, catch up on everything that had gone on, relieve me on one of the weekend days, and then fly back out on Sunday.

Once their children were released from the hospital, parents said that providing for the medical, therapeutic, nutritional, education, social, and other needs of their children resulted in ongoing exhaustion. Tim, the father of Christopher, said, "We had to provide 24 hour care for him with no relief. We tried hard to get respite or nursing, but it was just my wife and me, taking turns between our jobs. It was a difficult 2 years."

Christie also talked Noel's care needs:

I spent time alone with him without respite or nursing. Sometimes he was so sick and I worried because he would often choke. I was there by myself, exhausted out of my mind trying to care for him around the clock, and I was worried too worried to sleep.

When her son, Caleb, who had a tracheostomy and ventilator was very ill with a respiratory virus, Deb said she didn't want her 6 year old son to have to go through the stress of another hospitalization, so she chose to go through the exhaustion of caring for him at home:

We avoided the hospital for 6 weeks. We killed ourselves to do that, providing 24/7 care so he didn't have to go in. We didn't mind providing the care. We would do anything rather than have him stressed out in the hospital, and where we lose control as his parents.

These are not unique experiences according to the providers. Sally, the case manager said:

If a child needs a nurse for a parent to take a break, even a shower, or get some real sleep, and that nurse doesn't show up or shows up and isn't really qualified to care for the child alone, the parent has no choice but to fill in the gap... And the same with therapists and teachers. If someone cancels, the parent really has to take over. So a parent may have worked all day on a job or caring for the child, and the night nurse calls in, the parent has to care for the child that night. So much stress, and add all that to the fact the parent knows that their child's condition is going to shorten their lifespan, it's overwhelming.

Emotional exhaustion. All 7 parents said that emotional exhaustion was a part of their journey. The emotional stresses they discussed included: differences in coping styles across parents and the effects of the disability on family dynamics and socialization; feelings of guilt related to their child's distress, anxiety, pain, or inability to "live a typical life"; and the stress of frequently "living on the edge" because of their child's chronic and acute medical fragility. None of the 4 parents who became divorced during their child's life reported that this separation was directly related to the child's disability. Instead, they all cited differences in personality, but said that these differences led to emotional stress related to decision-making and caring for their children. For example, 1 parent said that due to personality style, the ex-spouse "made a big deal out of things, and just didn't respect the disability. And so, (the ex-spouse) didn't provide real support even when providing care during visitation."

Many parents initially had the physical and emotional support of extended family or friends, but this diminished across time. According to Betty Ann, a pediatric occupational and physical therapist, in addition to the natural dynamics particular to any family, it is not unusual for parents whose children have degenerative conditions to become physically, emotionally, and socially isolated. "When a child has a life-long degenerative disability, the routine care needs are too intense, frightening, or long-term for most people. Then parents are faced with emotional isolation, in addition to the physical and mental stress and exhaustion that is already there."

All 7 parents frequently felt emotionally stressed about what their children had to experience due to their neuromuscular disease. The 6 parents whose children required frequent hospitalizations talked about what it felt like to watch their child go through

painful tests and procedures. Diane, the mother of Annie, said, “It felt like torture to me, watching her having to go through all those needles and pain.” Tim, the father of

Christopher said:

It was hard to watch... a helpless feeling to try to get the fear out of him, and help him get a little bit of the peaceful happiness that he had before each hospitalization... after each time he would return home, it was like he would just gaze, rather than be engaged.

Haley, whose daughter was in and out of hospital ICUs across her entire 12 years of life, said:

We spent a lot of time in the hospital. We spent a lot of time seeing other kids dying, from a car accident, cancer, infection, or disability. And they die. It’s not a typical life. You don’t leave that experience behind when you leave the hospital. It comes home with you, and your child takes that to school, to playgroup, to therapy, to camp, wherever.

The 6 parents whose children were diagnosed during infancy and who were medically fragile also talked about the emotionally stressful experience of repeated crises that occurred chronically with their children across almost the entire lifespan. Two parents referred to it as an “emotional roller coaster,” with the child either having repeated illnesses that “could lead to sudden death,” or with the child having repeated acute crises that “almost resulted in death.” Five parents talked about multiple cardiac and/or respiratory arrests that occurred with their children, and repeated episodes in which the parent had to administer some form of cardiopulmonary resuscitation (CPR). Christie’s son, Noel, went into an arrest “four or five times across the 3 years he lived.”

Tim's son, Christopher, arrested 20 times across the last 2 years of his life. What was especially stressful was that no one ever figured out why this was happening. Tim said, "sometimes he would go into a crisis when he was afraid, in a panic, but sometimes he arrested without any noticeable trigger." Laura, Justina's mother, recalled, "One minute she would be perfectly fine and a few seconds later she would be in serious trouble. You had to be attentive and you had to be aware of all of it, without being insane about it."

Like other parents, Diane said she lived being "prepared for the next crisis" for 15 years:

We needed at least two people, (more) was helpful. Everybody had a job or their role in what to do... All I could think about was saving her life. In the middle of that crisis, I couldn't be upset, I couldn't cry, I couldn't do anything but just start calling for help and take control. I looked so in control. But I would be sick as a dog the next day. But she would be fine. I would get through it, but this happened many times. Literally saving your child's life, and emotionally looking so detached, but really being so attached. It was so stressful, and emotionally and physically exhausting to keep going through that.

Conflict exhaustion. One of the most frustrating types of exhaustion was what 4 parents called "battle fatigue." All 7 parents reported conflicts with hospital, school, and community providers who were a part of support systems they needed for their children. One parent said:

If you don't jump every hoop, you will never get... the medical support you need for your child... or the public school system to come to the home after your child turns three. That kind of stuff frustrated me. I would have to go, 'Okay, here comes the battle warrior parent again.' I don't want to fight with other people. ...

And it takes so much energy to jump the hurdles that are a part of everyday life with these diseases. Why are the people and places meant to help, why are they putting additional hurdles out for us to jump?

Another parent said dealing with the “occasional rude or arrogant professional” was frustrating:

It took many, many months to get the education and respite services that our child was eligible for. (We were told) he wasn't eligible for education services because he seemed cognitively okay, even though he had this diagnosis of a degenerative muscle condition... We ran into so much opposition. Maybe if I was getting any kind of rest I could have handled it a little quicker, but not with the obstacles like (providers who do) nothing for weeks because it was always the responsibility of someone else.

Diane, whose daughter was diagnosed during infancy and died at age 15, talked about a disagreement she had with a doctor in the hospital:

One time, they wanted to give her a preventative drug, and I disagreed. It was just an antacid type of thing, but before they could give it to her, I wanted to be sure it would not be hurtful to her disease. When I said I didn't want them to give this antacid at that time, they wrote on her chart (that) Mom refused treatment for child. That was just wrong!

Conflicts with medical providers sometimes continued in the home setting. Christie talked about her struggle to find quality nursing care for her son at home:

The first home nurse had a very thick accent and you could not understand her at all. She also was a bit old, in her sixties. By this time, our son was very heavy,

toddler age, and he was very floppy. You had to lift and carry him everywhere, and she said she did not do lifting. So, that would be a problem. The next lady they sent was 65 and retired. We had a two-story house and Noel's room was upstairs. She not only didn't do lifting, she also did no stair climbing. I am like, 'Then what are you here for?' After a while, I stopped looking and provided all the home medical care myself, even though it was difficult.

All 7 parents also talked about frustrating conflicts with the special education system. Five of the six parents whose children received early intervention services said they were "generally," "very," or "extremely" satisfied with those experiences. However, all six parents described the process of preparing for or transitioning their children to Part B services when they turned 3 years of age as "challenging," "nightmarish," "negative," "frustrating," and/or "painful." The parents said they were a very active part of their child's early intervention team, and that they had good communication and collaboration with the providers, but this changed because of a birthday. Bev, the mother of Caleb, said:

In early intervention, we were a part of the team. Our input mattered and our follow-up work with him mattered. Whereas with preschool, you are not supposed to be there. Once he transitioned, once he simply turned 3 years of age, you are not allowed to be a part of his education plan. They tell what you should agree to. They consider you in the way. You are impeding your child's progress. To me, that just doesn't make any sense.

Christie said that due to her son's fragile medical condition, he needed his education and therapy services to take place in the home, even after he turned 3. She said:

It became a big deal, because they wanted him to come to them. They didn't know enough about (his disease) and that it could be life-threatening if he was exposed to something, and that he had these choking or respiratory crises all the time, with no warning. I really tried to insist about this, and there wasn't a lot of opportunity for services then. A lot of providers just weren't allowed or willing to come to the home.

Most parents said that the quality of education services "depended on the provider." Diane's daughter received all of her education and therapy services at home across 15 years. She said that there were "wonderful" teachers, but also "horrible" teachers who:

...judged us and tried to give input on things that were not related to their service. For example, when Annie was about 6 or 7, (she) was a typical kid who had this progressive disease and all this medical stuff. So when she would get a little defiant, this teacher didn't know how to handle her emotionally. She would tell her that she couldn't watch television that night if she didn't cooperate. I can tell my daughter that, but no teacher, just because she comes to our home to provide education, should be deciding a punishment for my child that extends beyond school hours.

Laura's daughter, Justina, needed a nurse with her to attend the public school where she received her preschool special education services. However, the school system was unable to coordinate this requirement with Justina's need for a bus with a lift for her wheelchair. She said:

At first they wanted to have her at school and not send the bus for the chair. But I

said 'No, she needs her independence!' ... After a long battle, it ended up where I would drive her to school and the nurse would meet us there. But because we didn't have a van with a lift for her chair, (the school system) would send a bus to pick up her chair and take it to school. This kind of defeated the purpose of transportation being an entitled service.

Karen's son, Ethan, was diagnosed at age 4 with a progressive disability. She said that even though he didn't begin using a wheelchair until he was in seventh grade, he had significant physical weakness and motor impairments that prevented him from running, or even from walking without falling frequently:

Some of the teachers in school, especially the PE teachers, never understood Ethan's disability. They were always telling him try harder ... and you can run, you have to build up your muscles. Even if I asked them if they understood about (a progressive neuromuscular disease) and they said they did, they really didn't. He had an IEP, but that was mostly for handwriting and classroom type things. It was like they totally didn't have a clue about how (his condition) affected him outside of those few specific things written on a piece of paper. It was very frustrating, and very tiring because I kept having to go to the school and try to explain things to this person and then that person.

Sally, the disability case manager, attends IEP meetings with parents as an advocate. She said:

I'm appalled by the (geographical) variance. Some schools and providers are just outstanding ... But then there are other schools that just don't get it. They don't respond to the physical... or emotional... needs of the child. And they don't

always recognize the role of the family in the child's life. There is a horrible lack of communication and collaboration. And that... can interfere with the coordination and delivery of services.

In addition to conflicts with medical and education providers, parents said they routinely engaged in battles to secure respite, insurance authorization, financial assistance related to disability, and more. In summarizing her thought on conflict, Haley said:

I could give thousands of examples of added, and in my opinion, unnecessary stress, that came from each service system that was there to provide support. But if the providers were just more informed, or if they were more inclined to do their jobs well, or actually accept the responsibility that some particular task is in fact a part of their job and not mine or some other provider's job, well, if that were the case, I could tell you how challenging it is to raise a child with neuromuscular disease, but I wouldn't have as many horror stories. I would have more 'in spite of disability, this was wonderful' stories.

Seeking Typical Amid Chronic and Progressive Changes

All 7 parents said that due to neuromuscular disease, their children had atypical medical, educational, mobility, and therapeutic support needs that required the use of atypical equipment, care routines, and services. All parents cited orthopedic accommodations such as: foot, leg, or body braces; hospital-style beds; wheelchairs, ramps, and vehicles with wheelchair lifts; bath chairs and bathroom accommodations; and, other atypical pieces of equipment such as standers for weight-bearing exercises. Six parents cited the need for medical technology that included: breathing machines (3 children were connected to these machines via tracheostomy tubes), suction and cough

assist machines, tubing for these machines, oxygen, and other respiratory supplies; feeding tubes and pumps, special formulas, and nutrition supplies; and, numerous medications and other supplies. Several children also used adaptive communication devices.

Parents reported that typical providers for their children, many of them providing services in the home environment, included: physicians, hospital nurses, and home nurses; special educators and educational aides; care coordinators and case managers; physical, occupational, and speech therapists; respiratory therapists and equipment specialists; and, respite providers. Meetings or interactions with these providers were routine, as was time-consuming medical care and responding to crises. Yet, in spite of these atypical experiences, all 7 parents said that it mattered to them to provide their child and family some “sense of normalcy.” However, they said that this was often a stressful endeavor, because the nature of a progressive disease is such that “things are always changing.” One parent said:

The baselines, the child's needs, the child's challenges, they all change. Some of the progressive neuromuscular diseases literally lead to rapid changes that happen across a day, a week, or a month. If a parent is really lucky, they measure the degenerative changes each year... When you think that you have finally gotten used to the new equipment, routines, and baselines that are now are part of your life, there are changes in providers or in service systems. It is so stressful, and amid the chronic changes, you are just trying to find some sense of a typical life for your child, your family.

Karen, the mother of Ethan who was diagnosed at age four, said, “Every time you figure

out a solution for one problem, there is a progression. So, we handle that, and find another solution... but then there is another change needing another solution. That is how you have to live.” Bev, the mother of Caleb who had medical problems from birth until his death at age 8, said:

Equipment, routines, people, it all changes throughout the child's life. Their body becomes weaker, the disease progresses, and ‘normal’ is constantly changing as the child is getting worse. It is so stressful constantly having to adjust to changes. The child is stressed, too. You are both trying to cope with reality of it all... It takes a toll.

Sally, the disability case manager, agreed with “change” being a stressor for these families:

Parents watch their children’s condition progress. They oscillate between chronic needs, then acute needs and crises, then back to chronic needs, and sometimes chronic acute needs. But the condition is always changing, back and forth, across months, or years.

Still, the parents said that they did “whatever possible” to “enhance typical,” and even to access community activities for their children, when their children’s health permitted it. Six parents said that other than the neuromuscular disease, their children were “typical,” “normal,” “healthy,” and “extremely smart and happy” children. One parent said that her child had “significant sensory issues” and “mild developmental delays” but that this was still a “witty, happy, child.” All parents agreed that “seeking typical” peers, environments, and activities were important efforts to them.

A few parents said that church and a spiritual community mattered to them.

Several parents enrolled their children in recreational programs. Most parents tried to access community library programs or go for walks in their neighborhoods, and 2 parents said that their children attended summer camp programs for children with neuromuscular diseases. All 7 parents said that their children enjoyed these social activities, and that it was “worth whatever challenges” were necessary to help their children have opportunities for “a typical life” and “be with other kids.” However, these activities were very limited, and it was difficult for parents to logistically leave the house without another person due to their children’s heavy and cumbersome equipment, and because it was “intimidating” to be away from home if a medical crisis arose. Many parents said that they ended up needing to withdraw their children from community programs due to health concerns related to the progression of their neuromuscular diseases.

All parents said that beyond the stress of their children’s condition changing, there was also the stress of unexpected changes in providers or service systems. Several families said that their health insurance companies made decisions that a particular hospital or professional was no longer a part of their plan. Laura’s daughter, Justina, had surgery for the placement of a tracheostomy tube in one hospital, and while she was recovering in the ICU, her insurance company notified her that they would no longer financially cover care provided in that hospital. She said this was stressful because, “We didn’t have the nursing in place to bring her home, but she can’t stay in the hospital where she just had surgery. We had to transfer to another hospital and develop relationships with a whole new team.” There were other challenges with changes in providers as well. Laura said Justina had a “fantastic physical therapist” who worked with her until she turned 3, but “unfortunately, we couldn’t continue with her. I was never very

happy with the therapy that we got from (the new providers). People were nice but it just didn't seem like they were very creative or doing very much."

Karen, the mother of Ethan, said that coping with the physical progressions was challenging, but that not all of the changes in equipment were necessarily "bad." She said:

He wrote an essay about (beginning to use a wheelchair when he was 12). It was actually a good thing, and not a bad thing, because he likes to do stuff. Before getting the chair, if we went to the mall, he would walk not far at all and then have to sit down and rest. Then there was always the danger of falling down. So, actually having a wheelchair gave him great freedom because he could go where he wanted to when he wanted to and not worry. It gave him more freedom. It wasn't a terrible thing. But it was stressful to know that this was a good thing because his disease had progressed to that point.

Laura summarized the stressful experience of chronic, progressive change in this way:

Every day life for a child like mine and a parent like me, well, it would be an absurd life for someone else. Or even for us before the diagnosis. But once you get that diagnosis, the whole concept of what is normal, what is typical, even what is crazy and absurd, that all just changes. You have to find normal, and then accept that this is it... And then, as things keep changing, you just try and develop an ongoing sense of normalcy for the craziness. It was just routine. Okay, she can't breathe. Turn on the suction machine ... Use the (resuscitation) bag ... So many crazy, not normal things just became our routine.

Death is an Unanticipated Shock

Five parents were told when their child was an infant that an early death was inevitable. They were told that death would occur within hours, weeks, or a few months. Two of these parents later found out that their children had been misdiagnosed, and that their child actually had a *fairly progressive* opposed to a *rapidly progressive* degenerative neuromuscular disease. These 5 children died between 3 and 15 years of age. The other 2 parents were told that their children would likely live to become young adults. One of those children was diagnosed during infancy, and one was diagnosed at age 4. These two children died at ages 12 and 20. Despite knowing for at least 3 and up to 16 years that their children had degenerative, life-threatening disabilities, all 7 parents said they experienced “shock” when their children died. All 7 parents also said that “how” and “when” their child died was unexpected, and they all shared very detailed stories about their children’s final days and hours, and about the stress of the experience.

Tim, said that his son, Christopher, had gone into an arrest and almost died 19 times in the 2 years before his son actually died. When he left for work the day Christopher died, “I thought it was another ordinary day. He was fine. It was so sudden. I heard he had another arrest, and 911 was called. I rushed home, but expected it to be just another arrest. Those were frightening, but it was ordinary for him.” Two other parents said their children attended school the day before “everything changed.” Laura said that her almost 4-year-old daughter, Justina, was happy when she came home from school one day, but became ill the next:

For a few hours, I tried to do what I could at home and finally realized that she was rapidly getting worse. I took her into the hospital. She was fussy, and not

feeling well, but nobody thought she was in danger of dying. She passed away a day and half later. It was very, very quick. And she didn't die from the respiratory problems that I had been warned about during her whole life. That's what I was expecting. But instead, some not diagnosable virus or something occurred and all of her systems suddenly shut down, her brain swelled, and that was it. She was all of a sudden gone, from who knows what.

Haley shared a similar experience. Her daughter, 12-year-old Melissa, called her from the nurse's office at school saying that she wasn't feeling well. Haley said that night was "very rough" and that she was "by her bed every minute taking care of her. It was very scary." By the next morning, Melissa seemed much better, and the doctor she had been communicating with by phone said that "the crisis had passed." She had a night nurse, so she slept in her own bed, but in the middle of the night she "heard alarms and ran to her room. The nurse was not with her, and Melissa was gray... We did CPR, and she woke up ... but she died the next day."

Karen said that her son, 20-year-old Ethan, was home from college on a break. She said he was a "little tired" when she left for work in the morning, but "otherwise fine." She also said that he had recently had a routine visit with a doctor and that there was no indication that anything was specifically wrong or that he was about to die. She got a call at work later that day saying that Ethan had been rushed to the hospital. She said, "I left work immediately, but by time I got there, he was almost gone. His heart had just stopped. They revived him, but he was really gone. So we had to let him go the next day."

Diane said that she and her daughter, 15-year-old Annie, were singing, dancing, and watching movies together during a weekend evening. Her child had “lived with a trach, a ventilator... and had been through repeated crises and arrests for 15 years” but she was “happy, fine, when I told her good night. She was very healthy for a child with this disease.” The next morning, Diane said she went to wake her daughter, and she had died in her sleep:

All the machines are still running. There were no alarms. You could hear the breathing. Something didn't look right, but I had no clue she was gone. But she had a funny color on one side of her face. Then I touched her, and just let out a scream.

Christie said that her almost 3-year-old son, Noel, was in the hospital because he “was having routine respiratory problems.” Things changed quickly:

He was fine, watching television, being Noel. But he was dehydrated and his secretions were really thick... I kept saying to the doctors and nurses that I was concerned, because I was having a hard time suctioning the thick secretions. They kept saying he was fine. Then all of sudden he choked on a secretion, and he arrested. He was fine one minute, and arresting the next. They did CPR, and his heart started again, but he was no longer there. For a month, he lay there with machines keeping him alive, but his brain had died. He was gone. So then we had to make the hardest decision of all... (after) almost 3 years doing everything in the world to keep him alive... It went against everything we believed in, and his passing was nothing like what we had been prepared for.

Bev was the only parent who said that her son, 8-year-old Caleb, received hospice care

before death. She said he had “lived on the edge since birth,” but did not receive hospice services until the last few days of his life. She recounted in detail the 2 years prior to Caleb’s death, with a litany of chronic crises, life-threatening infections and seizures, prolonged hospitalizations, and many “close calls.” But she said that even though she knew her son was slowly dying, that:

... no professional, and not us, no one thought that he would come home from the hospital and be gone 3 days later. We knew we had run out of options, but we all thought he had many months left to live. The hospice nurse came on day one of him being home, and asked him if she could come back and visit again. Caleb said no, and we all laughed because that was so like him! When the nurse was there 2 days later, she checked him and told us she would see us in a couple of days... he died that afternoon.

In addition to the “suddenness” of loss and the cause of death not being what they were expecting, most parents also experienced “incredible stress” related to other “tragic” aspects of their children’s deaths. Only 1 parent referred to the child’s death as “peaceful” even though it was sudden. The other parents shared stories about “painful memories” that “haunt” or “stress” them still. For example, Bev said that her son was enrolled in hospice services so that “he could legally die at home.” But when he died, the nurse was not there, so:

The hardest thing was that we had to leave the ventilator on him until the hospice nurse could come and be sure he was really gone. We couldn’t just take him off so, we had to listen to this machine breathing inside of him, expanding his lungs, when we knew he wasn’t there. That was really hard. It took almost an hour from

the time we knew he wasn't there. We talked to his doctor. We all knew he was gone. But we couldn't turn his machine off because it was against the law... a professional had to validate (his death)

Sally, the case manager, said that many parents are not prepared for when or how a child dies:

We are talking about young people, children, dying. I think there is such a tendency for everybody to want to do everything ... But there comes a time when there may not be more that can be done. Many of these children die unexpectedly. They get a cold that goes into pneumonia, and in a day or so, they are gone. Or they have an unexpected heart attack or some other sudden crisis. And this comes months or years after having this progressive condition, but somehow always managing to be healthy, or to get back to good health after a scare. So that is shocking for parents, even if they knew that their child's years would be limited. But there are also cases when there just is nothing else that can be done... but the professionals can't seem to bring themselves to tell the family just how bleak things are... Yes, the prognosis was known, but the child's death is not really expected. This child has outlived expectations, and then still, suddenly, dies.

Andrew, the pediatric critical care physician, agreed that "shock" might be a part of the stressful experience for parents when their children with neuromuscular disease die:

I think parents whose children die from degenerative conditions might be expected to be more prepared than parents whose children die suddenly, but I don't think they are more ready for it... They go through the same grief afterwards. And when you know the child 'might' die, for years and years and

years, you really lose that sense of being prepared. Of believing that death might really occur. A parent can't keep anticipating death, for years and years, and so when it suddenly happens, it is a shock. And it is very stressful.

Grief is Profound

The parents had been dealing with the deaths of the children anywhere from 3 months to 5 years prior to the start of the first interview. Three parents had been bereaved for less than one year, and the other 4 parents' children had died in the previous 3 to 5 years. All 7 parents described their grief experience as being "profound," "intense," "complex," "enduring," and with stress related to "guilt." These parents also said that they have felt very challenged by feelings of "disconnection" and of feeling "non-validated" in their grief.

Intense. All parents said that their grief experience has been "intense," and that it began with feelings of shock and denial. Christie, the mother of Noel who died at age 3, said:

It is especially difficult to handle grief when a child (with a prolonged disability) dies, because you are so exhausted already. Grief is exhausting for anyone. But I spent 3 years on hospital floors and without home nursing and battling to meet his needs and keep him healthy and happy. I had no physical energy to deal with the emotional issues of grief.

Diane said that when her 15-year-old daughter, Annie, died:

I was in complete denial that she was gone, which made it difficult for me to move on. I didn't want to come home every day because she wasn't here... I would stay out until it was time for me to go to bed. I would go somewhere.

Anywhere. And do nothing. I did not want anyone to know how bad the pain was. At work, I would literally just shuffle papers on my desk. I was ineffective. I would just close my office door and sob, and then clean my face, open the door, and act like everything was fine. I didn't want to share my pain, and I didn't want to go to a group and listen to someone else's.

Haley, the mother of Melissa who died at age 12, said:

I'm the type of person who can do anything... I can handle the exhaustion and challenges and battle with providers and systems and logistics and more. But when your child dies, it doesn't make any sense. Nothing makes sense. I can live with a kid in a wheelchair, who might die. I can take anything. I cannot live with this. My child actually dying.

Complex. Six parents said that in the year before or after their children's death, there were other major losses or deaths in their family as well which made their grieving more difficult. Also, 2 of the 7 parents said that when their child died, they had to deal with other issues of grief as well. When Tim's son died at age 3, he said that his grief was complicated:

(My second child's) death occurred while we were caring for our first child... You couldn't stop and grieve for him because you still had to care for Christopher. So then once Christopher was gone, it was like the both of them hit you. Then (my daughter) died, and it is wonderful but very difficult to just celebrate her (healthy) twin brother.

Haley also had another child who was affected by the same disease that led to her daughter Melissa's death. She said her 11-year-old son with the same disease was not

getting the care that he would have gotten “if my daughter had not died. I am exhausted. I am sad. And he is just a little boy. Not only did he lose his sister, but I am nowhere near who I was as a mother.”

Enduring. Most parents described the first year of grief as “being in shock” and “denial.” The 4 parents whose children had died 3 or more years prior to this study said that in the ensuing years, their grief “got worse.” Several hit a “breaking point” and “finally sought help,” but that although they are “coping” better, the grief has not decreased in intensity. Tim, who lost 3 of his 4 children to neuromuscular disease, said even though “it has been 3 years since (my daughter died), 5 since we lost Christopher, and 7 since we lost (another son), those might sound like long periods of time to some people, but I find that I am still just haunted.” Tim added, “I think about them many times each day and I don’t think there is a support for that.”

Christie’s son Noel died 4 years before the study began. She said, “He was like a rag doll. I had him on my right shoulder for 3 years. That is what I miss the most.” She added, “I feel like I walk crooked a little, because... he was 3 years old, and he couldn’t walk and I carried him everywhere... I always had him on my right shoulder. And I still feel such a hole there.” Diane, whose daughter died 3 years before the study began said, “As each New Year came, I was devastated, I couldn’t imagine entering another year without her.” It wasn’t until the third year that she “finally broke down and tried to get some help. What I didn’t know was that my family was watching, and knew I wasn’t coping, but they just didn’t know what to say.”

Guilt. Several parents discussed feelings of guilt related to their final words or interactions with their child, saying they wished they had “said something more loving,

said goodbye.” These parents said that because the death was so unexpected, they have to “live forever” with their final words. One parent said that the last words spoken to her child before an unexpected arrest were, “You’re being so glum, and you’re bringing me down.” She said she had no idea that her child did not feel well, and was about to die.

Other parents experienced guilt wondering if they could have said or done something differently in their child’s final days or hours that may have prevented the death. Some parents said that they felt guilty over having “feelings of relief” for their children who experienced much pain and anxiety during life. These parents have said that it “goes back to the dissonance” experience. They do not want their children to suffer, but they would also rather have them “here, alive again.” One parent said:

No matter what the circumstances, when a child dies, parents feel responsibility.

A bit of guilt ... That is what is so horrible about the loss of a child versus a mother, a father, a sister or brother, whatever. Any loss is sad, but you are not responsible for them per se. (This) is not the natural path of humanity. You are not supposed to outlive your child. Even though everyone will tell you it wasn’t your fault you did everything you could, as a parent, there is always that element of responsibility, which turns to guilt.

Disconnected. All 7 parents talked about feeling “disconnected” from their child’s routines and medical equipment, from the providers who had been “like family” for years, from many extended family members and friends, and even from “other bereaved parents.” Parents said that after years of “the disability being a way of life,” they felt at a loss for what to say or do, and with whom they should say or do anything. One parent said:

When my child died, suddenly, after all these years, they are no longer a patient in the hospital so you don't belong there, they are no longer a student in the school system so you don't belong there, and you are no longer a parent with a living child, so you don't belong with the people who have become your friends because the kids are the same age.

Another parent said:

I did all the things everybody does as a mother. Plus I did all these medical things, too... You bathe them, feed them, teach them. You do their... therapy... coordinate and attend meetings... You drive them everywhere because their friends' cars can't fit the wheelchair ... You create normal, typical, in this life that is anything but that. You sleep on the floor by their beds because there isn't a home nurse that night or they are sick. You even resuscitate them... But then, one day, they (die)... And it just goes away.

A few parents said that providers who were very involved with their children's care maintained some level of connection with them since their children's death, and that it has been "very helpful" and "welcome." But 1 parent, who has not had any ongoing connections said:

We spent so much time with professionals, they were like family. You know these people. You spent holidays with these people. You have lost teeth with these people. You get excited over little milestones your kid reaches with these people. Sometimes, you've even shared a meal with them... And it is so intense sometimes because of the child's needs and the support we give, together. They know you and your child. And then your child dies, and you don't see them. It is

weird. It is lonely. It is like, where is my child and all the people I know and all the routines I am supposed to be doing each day?

Betty Ann, the pediatric occupational and physical therapist, said that when a child with a chronic or progressive, long-term disability dies, she is a link to the child that most parents “do not want to lose. I have been told that I bring their child to life! While flattering, it is incredibly scary to hear something like that. I feel so responsible to keep those memories alive for them.” Sally, the case manager, had a slightly different view of connections with parents:

We don't mention the child's name, or share our memories, because we might be afraid that parents will hurt as they hear such things. But that is not healthy... As a professional, we work for an organization or an agency or a system. But as a human, our journeys have crossed. And that goes both ways. I have affected the families, but they have affected me as well... Oftentimes, I'll be going through a typical day at work, and something will happen and I'll think, 'Wow. That reminds me of (a particular child). That would have been so up his alley and down his street!' It makes me smile. So I'll call the family, and share that with them. Families need to know that others still remember... their children.

Most parents also felt disconnected from other bereaved parents. Many parents tried community support groups for parents who had lost a child, but they said they found these groups to be “unhealthy” or “unhelpful” or even “hurtful.” Several parents said they sought to “move forward with the grief” but felt the parents in these groups seemed to be “stuck in the grief” years or decades after their child died, “just retelling the story” and “going nowhere.” Several parents also said that many “parents” were grieving the loss of

an “adult child” or the loss of a child “who died suddenly” or “after a shorter duration illness.” Tim said:

We were all in the same place physically to try and deal with our losses. So at that level, we could all connect. But the life experiences were just very, very different. To have a supportive connection, there has to be some shared experience beyond simply the grief of losing a child. For parents like me, whose child had an entire life filled with disability, stress, that experience is not shared often by even other parents whose children die.

Even more challenging was that parents in this study said that other parents in support groups, like friends and members of the community, could “not understand how I could intensely grieve the loss of a child who really never had too much of a chance to grow up anyway.” Sally, the case manager, said that she has “routinely offered” families information about community bereavement support groups. However, she has not found that to be helpful. She said, “It is not really a good fit for the parents I work with. For whatever reason, these families may go once or twice, if at all, but from what they have said to me, there is just not a good match.”

Non-validated grief. The parents said that often, there were things that other people --- family members, friends, providers, and other parents whose children died more suddenly --- said that made them feel like their grief experience was *non-validated*. Parents said that around the time of their child’s death, many “well-intentioned people” offered “words of support” that were “hurtful” or “angering.” For example, parents said that they did not want to hear phrases such as: “you’ll get over it”; “God took the child for a reason”; “God doesn’t give you more than you can handle”; and, “I know how you

feel.” These parents said: “I don’t want to get over my child”; “Don’t tire me with Bible clichés”; and, “You don’t know how I feel because it was not your child.” Hearing these phrases made them feel like people were “minimizing” their grief. One phrase that was very hurtful to most parents was, “The child is happy now.” One parent said, “Even if that is true, it’s hurtful. I worked hard to be sure my child was happy here.”

Several parents also said that their grief was so intense, enduring, and lacking validation that they felt “isolated” and “questioned the worth of living.” One parent said, “I never, never felt like I wanted to end my own life. I just can’t figure out how to go on alone. It’s like you don’t want to die, but you don’t want to live, either.” Another parent said, “I don’t see any good that comes from a child’s death ... There is no more suffering ... But after each crisis, there was no suffering... so that can’t become an excuse, a meaning for the death of a child.”

Ongoing Struggles with Validation

The first theme that emerged from data analysis exploring the experiences of parents whose children died from childhood onset neuromuscular diseases was that their journey is abundant with stress. Some of the stress is unavoidable, due to the very fact that their children live with, and then die from, progressive diseases that typically necessitate atypical and complex medical care, educational accommodations, and other services and supports. However, some of the stress was referred to by both parents and providers as unnecessary, resulting from “excessive red tape,” “judgmental attitudes” or “lack of disability-specific knowledge” on the part of providers, and “service systems and regulations that hurt” in addition to helping families. The second theme that emerged

from data analysis is closely related: throughout this stressful journey, parents report ongoing struggles with validation.

All 7 parents said that much of the unnecessary, or avoidable, stress that they experienced grew from feelings of “not being validated” by professionals and by other people in general throughout their journey. These feelings began around the time of their child’s diagnosis, when they first began having experiences of dissonance. This struggle with validation continued during their years of caring for their child and working with multiple service systems and providers, and even into the experience of losing and grieving for their child. One parent said, “If my kid didn’t have this condition, there are so many things that wouldn’t be questioned. They’d just get this or that.” Another parent said that “medical people seemed skeptical” if parents described:

...experiences that didn’t match what their textbooks said should be happening. Then, when we said we felt overwhelmed, we were told we were doing fine. From day one, to this day, years into the grief, what we have observed and felt on the journey has not seemed to match what others think we should be observing or feeling. And what matters to us most – what’s best for our child – doesn’t seem to matter so much to others since our child never really had a chance to make it from the start.

This ongoing struggle with validation was discussed in three categories:

- Observations and concerns (i.e., What I observed and reported about my child or my child’s condition was not perceived by providers to be real causes for concern);
- Feelings (i.e., What I shared about feelings related to caring for my child was not acknowledged as significant); and,

- Priorities and values (i.e., What I expressed as preferences regarding my child's service and support needs and my role as a parent were not recognized by providers in ways that indicated my child mattered as much as children without degenerative conditions).

Non-validated Observations and Concerns

All 7 parents experienced repeated occasions during which professionals said “there was no reason for alarm” in response to concerns or observations they expressed about their child. Frequently, across the next minutes, hours, or days, these parents said that what they had observed and reported turned into critical situations. This experience happened in both medical and educational systems, although the consequences were “more dire” when it was a medical professional who did not follow-up or respond to a parent's concern. Diane's 11-year-old daughter, Annie, was in a hospital ICU for spinal surgery:

She kept saying, ‘Mommy, I can't breathe, I can't breathe!’ even though she was on the ventilator... I was concerned and asked if she could have a chest x-ray. He kept saying she was just congested. He didn't even pull out his stethoscope...

Later, our home nurse visited, and when she said something was wrong, they did the chest x-ray. It turned out she had so much fluid in her lungs that they had to put a chest tube in to drain it. She could have died, and they are acting like I am just seeing things that are not real.

The physician agreed that parent expertise and observations are not always respected:

I think it is tougher for professionals to feel comfortable working with families whose children have chronic and degenerative disorders because the parents really

know their child's disorder. They don't know anything about the rest of medicine, but they know everything about that disorder and about their child. They are clearly the expert. And I don't know that all professionals are comfortable with that, with sharing the medical part but accepting, with validating, the parent expertise part.

Non-validated Feelings

All 7 parents said that they have not always felt they could honestly share their feelings with providers, or with friends and other family members. They felt their overwhelming feelings of stress were not recognized by others because their children seemed happy or were not actively in a crisis. They also said when they took an active role in their child's care or became advocates, that they were labeled as "one of those parents" that providers should avoid. These parents said that other people, both professionals and peers, were not able to understand or respect their intense feelings of love and of loss related to their children with degenerative conditions.

Bev, the mother of Caleb who lived for 8 years with a degenerative disability, said that she did not say what she needed to say to providers even though she "felt scared, worried, that something was wrong with my child." She said that if her son was not in a crisis, "they made me feel like I was overreacting." Because Caleb's condition was poorly understood, "if he looked okay to them... they considered him fine. And he wasn't. And they made me feel like I was just looking for problems. They never validated how I really felt." Melissa's mother, Haley, said:

I tended then, even now, not to tell people how overwhelmed I really am, because it does not really seem to get me any place. It doesn't get me help. It doesn't get

me compassion. It might get me pity, but I never want that. I don't want people to feel sorry for us. I just want them to understand what this feels like and what we need.

Annie's mother, Diane, said both medical and educational professionals tended to comment about whether she was "reacting appropriately" to different stressful experiences or crises that occurred during her daughter's life. She said, "What exactly is the appropriate response to being in an IEP meeting and none of the professionals have given your daughter any consideration before they walked through that door?" She also said that during medical crises, "If you are hysterical... you can't be helpful to the providers. But if you are... giving information, people act shocked, like if I really loved my daughter I would be crying uncontrollably." She added, "It's like there is no appropriate response, and you are judged anyway." Sally, the case manager, said:

... even though they know that they know their child best, (parents) don't always feel comfortable or welcome or respected in sharing what they know... And sometimes, the professionals say or do things that reinforce that feeling of intimidation in parents. They don't indicate that they respect the parents' role as an expert, and then they don't indicate that what the parents are feeling about the experience really matters that much either.

Priorities and Values

The parents in this study said that they did not always feel like "what mattered most" to them was respected, or validated, by many professionals. Most stories that parents shared about these feelings were related to the following, which are discussed below:

- Not being offered the “hope” they sought that their child could have a “quality life” in spite of disability;
- Not being recognized as an essential part of the medical team, especially during repeated and lengthy experiences in hospital ICUs;
- Not being recognized as an ongoing and essential part of the educational team, especially when their children transitioned from early intervention to preschool services; and,
- Their children not being recognized as “worthy” of all the same professional time and attention, and grief, that “any other healthy child would be worth.”

My child is worth hope. Christie said from the time Noel was diagnosed, she was told there was “no hope” he would live more than a few weeks. She said:

I had no other vision but hope for my son... I couldn't understand no one else had this same vision of hope ... I was in such great distress, and was told there were no treatment options, no hope, no research anywhere in the world, no support connections, that might make a difference in my child's life. And then I find out that if any professional had just done a simple internet search on this disease, they would have seen there was a study right here in the United States, and that my son was eligible and it could save his life.

My child is worth a typical childhood. Caleb's mother, Bev, said she “wanted to treat him like a regular kid.” However, she felt providers treated Caleb “like a special needs kid. Like they would never let him cry. Sometimes it is okay to have to learn, and to cry.” She said, “We had different philosophies and I felt like I was constantly having to

force that, force my philosophy. I felt like what I wanted for my child wasn't valid. Wasn't respected."

My child is worth my time, expertise, and nurturing. Six parents said their child spent a considerable amount of time in hospital Pediatric ICUs. They said parents were allowed to be with their children 24 hours a day, 7 days a week in the Neonatal ICU and in all other units of care. However, in the Pediatric ICU, they said they were not welcome to stay with their children during the night, when the doctors were "making rounds" and discussing their own children, when nurses were changing shifts, or when the unit leaders felt that there was some crisis and that parents should not be there. These parents said that they were "afraid to go get a drink of water or use the bathroom" because if they left the unit, they "might not be allowed back in." Parents also said that they felt like professionals often took the opportunity of a parent not being around to try something new with their child, or to initiate a stressful procedure. One parent said:

In the ICU, they don't prevent crises from happening really, they just respond to them. I was there to do what I could to help prevent the crises from happening... What was really challenging was that it seemed like they really did respect my expertise on (this disease), but they did not seem to respect my role as his mommy. That I needed to be with him for a million different reasons. To protect him, advocate for him, and just to nurture him.

My child is worth professional time and expertise. All 7 parents felt like their children were not always given the best services, providers, or intervention options, simply because their child had a condition that was constantly changing, that was degenerative, and that would ultimately end in early death. One parent said:

The principal decided to talk on the cell phone to her husband rather than run the IEP meeting, not all of the providers involved were there on time, and none of the providers had my child's file with them. They said it was lost. They didn't have anything prepared.

Another parent summarized thoughts on this matter, and said:

Sometimes, there seem to be certain people who will deliberately stonewall you, especially if your child's condition is terminal. It's like they know that the longer they put you off, the greater the chance that they won't have to really do anything for you. For your child. In our case... there were even people that admitted doing this. Every child should be afforded the same expert care, regardless of the anticipated length of life.

Molly, an early childhood special educator, said that what these parents are reporting fits with the reality she has experienced when teaching a child with a degenerative disability.

She said:

When (a child) was about five, I was having a challenging time teaching him to identify letters, learn the alphabet. I really believed he was capable, and he loved books, so reading would give him something to do that didn't require energy, or moving. When I asked some of my colleagues if they had suggestions, the initial response was why are you bothering to teach him to read? He's not supposed to live too long, so is it really important? And I'd say, 'Yeah, to him it is.' And it was to me and his family as well.

My child is worth grieving. All 7 parents believed their children lived a "good quality" of life, and that their children were happy and knew they were loved despite their

ongoing challenges related to neuromuscular disease. However, all 7 parents also made references to feeling “penalized” by providers, peers, and society in general, for having a child with a poorly understood or not well-recognized disability. They said their intense grief related to losing a child with such complex and prolonged challenges was not validated. Karen said that when Ethan died, 16 years after being diagnosed, a friend remarked, “I heard your son finally died.” She said, “People act like ever since we heard the diagnosis we have just been waiting... for him to die. No, we were helping him live, and we loved doing that and miss it very much.” Haley said that after Melissa died, she went to a bereavement support group for parents and:

... someone said the death of a child who couldn't walk was a blessing. A child's death is not a blessing, and being in a wheelchair... does not necessarily mean that your life is not valuable... My daughter did so much. Cheerleading, shopping, great grades, vacations... She was confident and happy, and all the while, yes, she happened to be in a wheelchair with a progressive disability. But her death is not a blessing, for her, or me.

Andrew, the pediatric critical care physician, said:

I think that when a child dies from an acute car accident, or a sudden illness, society in general – your neighbors, your family, everybody else – there is devastation, shock, upset, everybody gets... how terrible the loss is. I think that when you have a child that has a degenerative or chronic illness, a lot of people sort of say you knew this was coming, why are you so upset?... that type of death must be very challenging for parents because society just doesn't get that this was a loss. A significant loss for the family.

Molly, the early childhood special educator, agreed with this thought. She said in this country:

There is a different response... to the death of a child with a degenerative disability, compared to the death of a child who was healthy most of their lifetime... People say things to these parents like... (you) had longer than expected as if that is supposed to be of comfort. It's never okay when a child dies, even if they outlive a predicted timeline.

In summarizing her thoughts on validating parents, Sally, the disability case manager said:

If 'get your affairs in order' is the emphasis professionals are suggesting to families, if 'this child can't survive so we won't really be doing anything for them' is the emphasis, that takes away the 3 months or 7 months or 4 or 20 years or whatever that a family might have with their child... The child matters regardless of the length of life.

Support Matters and It Really Makes a Difference

The first two themes that emerged from data analysis focused on the stressful journey that became the families' daily lives, and on the struggles these families had with feeling validated throughout those journeys. The third theme that emerged reflected the importance of social support. Support matters, and it really makes a difference. All 7 parents agreed that although support cannot change the reality of a child's diagnosis or death, what people say or do can change "how" parents are able to "navigate the journey," "celebrate the journey," and "survive the journey." Three types of supports

were discussed: formal supports, informal supports, and bereavement supports. Table 4 summarizes these sub-themes, which are discussed below.

Table 4: Support Makes a Difference

Formal Supports	<ul style="list-style-type: none"> • Compassionate, competent, and expert professionals • Available, coordinated, and collaborative services
Informal Supports	<ul style="list-style-type: none"> • Presence ('extra set of hands' and emotional support) • Experiential information from other parents • Logistics (meals, chores, place to sleep in hospital) • Social opportunities for child and parent • Empathetic listening and positive attitudes • Spirituality
Bereavement Supports	<ul style="list-style-type: none"> • Presence (during death and memorial service) • Connections to providers and others who knew child • Community supports • Continuing child's memory through activities, contacts

Formal Supports

All 7 parents provided detailed accounts of very stressful aspects of their journeys, and of their ongoing struggles with validation. They were also able to offer detailed accounts of specific people, services, and supports that “really made a difference” to them, and that helped them cope better. When discussing formal supports (i.e., providers and services that were a part of a formally organized system of care), parents said that what really helped was positive interactions and collaborative experiences with professionals who were both compassionate and competent, and with professionals who were experts in the area of their child's specific disability. They also said that “available” and “coordinated” services and providers were extremely helpful.

Compassionate, competent, and expert professionals. Both parents and providers agreed that “how” professionals talk to families is as important as “what they have to say.” One parent said that due to the “abrupt, negative way” she was told of her child's

diagnosis, she “didn’t really trust or want to talk with other professionals for a long time.” Most parents said that “how” they were told about their child’s degenerative, life-threatening condition made an already devastating experience “traumatic.” However, across time they found that some other providers were very compassionate and competent. This led to partnerships that were very supportive for them, and their children. One parent said there was a provider who was “just wonderful... he was our main ‘go to’ guy. From the moment he came on the scene... if we needed any kind of help or advice or in some cases machines, he would do what he could for us.” Parents also talked about the helpful interactions they had with disability-specific experts. One parent said, “We had several professionals who were competent providers, compassionate humans, and experts in the field of (this particular disability). That was a gift for my son and me.”

Several parents talked about the importance of “trust,” and of the importance of professionals respecting their child as a “unique human being” with “unique feelings and fears.” Bev said that one of Caleb’s doctors looked at him uniquely, and “thought creatively... He listened to us. And he listened to our son. He respected that our son had fears that another child might not have.” Ethan’s mother, Karen said:

A lot of times when the doctors or teachers come in to a meeting, they have got a student with them, someone who is learning. And they just talk among each other and do the measurements or the whatever and they don’t really even look at you. But there was this one doctor, he was really good. I always felt like he really cared. We didn’t feel like a statistic, that would end in some chart. He talked to me, to my child. He asked questions and listened to our answers, and he listened to our questions and answered them.

Sally, the disability case manager, said that how providers interact with families really matters:

How a diagnosis, how any information, is shared with a family does not change the news, but it does set the tone for how to live with a progressive, and often life-threatening, disability. It sets the tone for the sense of community that is available for the family... Even in what is a very difficult time or challenging time, there can be a sense of hope.

Available, coordinated, and collaborative services. In addition to good providers, parents talked about services that they considered “outstanding” and “extremely helpful.” According to the parents, services felt supportive when they were “quality and appropriate” for their child, and when they were readily available, coordinated, and collaborative in nature. A few parents talked about being able to take their children annually to a free neuromuscular disease clinic, where services were offered “in an assembly line” method. One parent said that getting so much information about their child’s progression and needs from specialists in neurology, nutrition, pulmonology, physical therapy, occupational therapy, speech therapy, social work, and case management across a few hours was “overwhelming,” but “very welcome and needed information” that could be “digested later, or with follow-up phone calls.”

Several parents said that their children’s pediatricians or other medical professionals made home visits so their children on breathing machines would not have to go to the hospital or to a medical office where the child might be exposed to germs or viruses. All 6 parents whose children received early intervention services prior to age 3 years talked about how supportive it was to have providers coming to their homes to

deliver services. Bev's son Caleb received almost all of his education and therapy services at home for 8 years. She said:

I liked that when they came into your home, you were part of the process the whole time. You could see what they were doing. They included the parent completely in everything... Sometimes, the OT and the speech therapist would work together, like on the swing and doing speech. They were fantastic. One of the therapists even met me at the (community gym program) when he first began there.

Christie said that various education providers came to her house on different days. She said:

(Noel) was getting brighter and brighter. It definitely helped. The providers taught me great ideas about how to keep him moving, and also they tapped into his strengths and helped him do so many things. And the PT we had... was just up on the latest of everything. She just was above and beyond most therapists that I had encountered.

Christie said she was concerned though when she found out that once a child turns 3, education services are no longer routinely provided at home. She said that due to Noel's fragile health condition and neuromuscular disease, "going to school" could be dangerous for him:

I set up a meeting, and I got the principal, the child psychologist, I had everybody that would have anything to do with Noel's education and therapy together. And we had this great meeting ... They were willing to (continue providing) public schooling in our home.

In addition to quality, coordinated, and collaborative services, parents said it was “extremely helpful” when providers or service systems helped them access the medical and educational equipment needed by their children, without them having to battle for it. Tim said an advocacy organization “got us (an orthopedic stroller) for Christopher. But even better than just getting it was, if you needed anything adjusted on it, they would come and do it for you... without us having to beg.” Laura said that Justina’s wheelchair sat higher than the tables in her preschool so she couldn’t always participate in group activities alongside other children. However, the school was getting a different chair “so that she could sit at the level with the other kids ... I liked that they were figuring out ways to help Justina interact and be at the same level as the other kids in the classroom.” Annie’s mother, Diane, said that anytime services “went as planned” or someone “just did their job” or “went above and beyond in services” it made “an already stressful experience easier to handle.”

Informal Supports

Parents shared experiences they considered supportive that came from sources outside of formal support systems. Informal supports discussed by parents included: presence of family or friends, experiential information from parents whose children had similar conditions, logistical supports, social opportunities, empathetic listening and positive attitudes, and spirituality.

Presence. Several parents said that they did not have much informal support from extended family or friends, either because extended family lived too far away or because the experience of meeting the prolonged and progressive needs of the child became “too enduring” or “too overwhelming.” But parents who did have the help of extended family

or friends reported that this became an “extraordinary” source of support for them. Parents said that this informal support system provided them “an extra set of hands,” and often provided them with much needed “respite” or “physical relief” so that they could do chores, organize their child’s services and supplies, talk with professionals privately, or even just to rest.

These parents said that their relatives or friends were willing to come to their homes or to the hospital, and learn the child’s care. They also said that these people provided emotional support for them, because they “knew (this person) really cared” and would not leave the child unattended, and that they would “make sure the child was happy and felt loved.” Two parents said that they had to quit their jobs to provide their child’s care at home, and that extended family also became a temporary or intermittent source of financial support. One parent shared the story of a friend traveling with her so that she could safely take her children on vacation.

Experiential information. Not all parents were comfortable participating in parent support groups, but all seven said that information they received from other “experienced parents” whose children had the same or similar disabilities was “invaluable.” In addition to group settings, parents gathered “first-hand” information through e-mail and Internet chats and by telephone conversations with other parents. One parent said:

We talked about what works and what doesn’t. We talked about our kids and we prayed for our kids...We really supported each other. If somebody’s kid is having surgery, we all make meals for that family. It was one of the most supportive things for me. And when (my child) passed away, every single one of those people was at his service.

Logistics. All parents said that *logistical supports* were very helpful to them. Several parents talked about friends, church groups, or even home service providers bringing meals to the hospital during a crisis, or to the home when “crisis was the ongoing norm.” Parents said that eating in the hospital cafeteria was expensive, and that oftentimes the cafeteria hours did not fit with the times they felt like they could leave their child alone for a while. One parent said “I hadn’t had a real, full, home-cooked meal in years” and that when the church sent the first of several hot meals to her house, she called it “the best food I had ever tasted.” Parents also talked about how helpful it was when people would do basic chores – mow the lawn, shop for groceries, clean the house – during particularly intense or prolonged periods of stress. One parent said that friends and members of the church shared “airline miles” to help support the expense of travel for a spouse to visit a child hospitalized great distance from home for 6 months.

Social opportunities. Parents said that regardless of whether social opportunities grew out of formal support organization (e.g., disability-specific organizations) or occurred more naturally in community settings, they found these activities to be very supportive and a “great stress relief.” Several parents talked about recreational activities, such as holiday parties, trips to the zoo, teen groups, or summer camp programs that were a part of neuromuscular disease organizations. One parent said that “even a fundraising event became a social opportunity,” where there was informal networking with both providers and other parents.

Most parents said that they tried to take part in local community activities as well, where their children could interact with non-disabled peers and they could chat with other adults who were “leading more typical lives.” One parent referred to this as a “reality

check.” Laura said that she enrolled her daughter in a “Mommy and Me” type playgroup while Justina was still an infant. She said this was a great opportunity, and that “because the (other) kids basically grew up with her, it wasn’t odd or weird or whatever that she eventually was in the wheelchair, that she had a trach or suction machine.” Bev said that when Caleb, was a toddler:

... (his) trach came out while he was at the gymnastics program. The instructor just came over and helped me put it back in. I was just shocked... She could have (said) you know, this is really not a good thing to have at our program. But... she was just glad he was okay... Even the other parents there encouraged their toddlers to give Caleb extra time to get through the tunnels with all of his tubing.

Diane talked about how “wonderful” it was when Annie went on her first “sleep over”:

Annie had never spent the night at anybody else’s house because of all her care needs. Most kids of elementary age and older are doing that. It wasn’t really feasible for Annie. But when she was 11 or 12, she had a sleepover at (the nurse’s) house with her daughter. It was a big decision for me to let her go, and I’m so glad I did. They had a blast!

Empathetic listening and positive attitudes. Parents said that having someone with both an “empathic ear” and a “positive attitude” was very helpful. When they received the support of someone who could “listen to venting” and “understand the sadness” but also “help celebrate the joy” of their child, they felt more able to cope with the daily stresses of their children’s diseases. One parent said, “I only surrounded myself with positive people,” and another said that “can do” attitudes really helped. Other parents talked about cards and packages they and their children received across the years, and

how supportive it felt “to feel less alone.” One parent said:

The (cards) from my family and close friends were nice, but it was the ones I received from past co-workers or acquaintances or people from the school or my church that I didn’t even know that were just so beautiful. They wrote me really inspiring and encouraging words, and they always talked about how wonderful my son was.

Spirituality. Three parents said that their spirituality and church involvement was “the most supportive” part of their experience during their children’s lives, and since their children’s death. One parent said the church the family belonged to created a special class for children with disabilities, and a support group for parents whose children had disabilities. Another parent said that there was a “24 hour prayer chain going for my child, all over the country” when the diagnosis was first made; this parent said that when the child died at home, “so many of those same people just showed up at the house, and formed a prayer circle.” Yet another parent said that when she first was told that her infant had a devastating neuromuscular disease:

I walked out and the first thing I did was went down to the hospital chapel. I am a very spiritual person. Praying helps me cope, and find strength, and answers.

Later when (my child) was dying, I was able to convince a professional to let (the child) die in that same chapel, rather that in the ICU. I’ve heard that other parents are now offered that option.

Bereavement Supports

Parents said the experience of benefiting from formal and informal supports did not end around the time of their child’s death, or in the months or years since their child’s

death. Three parents described the moments surrounding their child's death as "traumatic" or "chaotic." However, four parents said that in spite of the "overwhelming sadness" of their child's final moments, there was also "beauty," "grace," "dignity," or "peace." Two of these children died at home, and two died in the hospital; but all four of these parents said that "witnessing so many people" be present "with reverence" and react with "love" and "sincere grief" in response to their child's death was very meaningful, and helped them cope with their "sudden loss." One parent said that as she was leaving the hospital, "one of the nurses said that she would stay (with my child). I have no idea for how long or what she did after we left, but I left knowing that my (child) was not alone." Another parent, whose child died at home, said:

One of (my child's) doctors had given us information about what death might look like... What was said was very sad and awful, but at least we were prepared so that we were not so shocked, so afraid. We were under the impression that death was still several weeks or months away, not in just a couple of days, so we were still shocked at the timing. But we can't thank that doctor enough for... preparing us for what we were about to go through.

Presence during the memorial service. It "mattered greatly" to parents that "many, many people" – family, friends, and service providers – attended their child's funeral or memorial service. Three parents expressed disappointment that "significant" or "long-time" service providers did not attend their child's services. All parents said such presence conveys "how much my child mattered" or was "loved," "respected," or "appreciated." Several parents said that service providers gave eulogies or spoke at their children's memorial services. Bev said:

They all came to (Caleb's) service. All of his teachers and therapists from the last six or so years, from when he was a toddler, all of them, which shocked me... It was just amazing. My son really mattered to them. His teacher spoke at his service... the one he had had since he was 4 at home. So many people only knew his disability, or only saw him when he was so sick. This teacher was able to share stories about who he was as a little boy, as an incredibly witty and wonderful child. It was very special.

Ongoing connections. Other experiences parents said were "extremely helpful" were intermittent, ongoing contacts with one or more providers who were "very involved" or "very close" to the child or family before death, as well as ongoing connections to other parents of children with similar conditions. One parent said she initially did not respond to attempts from a service provider to contact her after her child's death, but "I was glad the calls kept coming, and I was finally sane enough to return the call." Other parents said either they or a provider initiated phone or e-mail contact, and that this communication was meaningful because it is a "connection of sorts" to the child and also to someone that mattered during the child's life. Two parents said that they have "gone out for coffee" or "a movie" with former service providers, and that the relationship has "grown beyond" serving the child, but includes a "shared memory" of the child. All parents and providers who said that there was some level of ongoing communication or connection reported this to be mutually "healthy" and "helpful." One provider said:

I get to love these families across time, and they matter to me. If I ever stopped feeling my feelings when someone I work closely with dies, then it is time for me

to leave my position. I go to a child's funeral for all the reasons another family member or family friend would choose to go. Because I want the family to know how much that child mattered to me, and to recognize how much I know that child mattered to the family.

Community supports. Several parents said they had “no interest” in attending a general support group for bereaved parents. They said they were “not group people” or that the thought of supporting another parent's grief was too overwhelming to consider as they tried to cope with their own intense grief. The parents who did attend these community support groups said that they “could be helpful to some parents” but that they did “not feel the support” they were seeking. One parent who “tried going” to a bereavement support group said:

I found it helpful to know other parents who have lost children. But really, it has been a challenge because many of them don't share the medical issues... I dealt with. What we share is the fact that our children have passed... We don't really share the typical things that go on in a child's life. Outside of tragedy, we don't have things in common.

The parents who went to these groups said they stopped attending after one or two meetings. Some parents felt like they had to “defend my child's quality of life” to other bereaved parents, and most felt like they had to “defend” their right to deeply grieve the loss of their child with a degenerative condition. They said that the groups were run “by other parents who had also lost a child,” but that it felt like these leaders “knew the experience of loss” but did not have adequate training in “how to effectively run a group and support all families” and “prevent hurtful things” from being said. Parents said that

“more helpful than these general groups” was their continuing, informal connections with providers and with other parents of children with similar conditions “who understood the child’s worth” and the depth of the loss and grief. A few parents also saw an individual counselor with specific training in grief and bereavement. They said this was very helpful, and that they felt “less judged” and “more sane.”

Continuing the child’s memory. All parents in this study liked talking about their child, remembering their child, and hearing and saying their child’s name. Every parent said that sometimes, talking about their child made them feel sad, but that “sadness is a part of grief” and that talking about their children more often made them feel happy. One parent said she had worked hard to “make it okay” for people to say her child’s name. Another parent said that her deceased child “still brings me so much joy... When people share their personal memories, I am still learning about my daughter, even years after she passed.”

Parents said they “welcome opportunities” to participate in activities that were meaningful to their child, and to share stories about their child and journey. They said sharing these stories “brings meaning” to them, and that it is “especially rewarding” when sharing stories about their child and journey “brings meaning to other people” – providers or other parents. Most parents said they still support fundraising activities for research toward cures or for social activities for children and families with neuromuscular diseases. One parent said, “It feels good to know that my child is still making a difference in life.” Another parent said an organization:

...was going to do a publicity story on him, and how well he was doing and living with (neuromuscular disease)... Then, he very suddenly had this choking episode,

and died. They were going to cancel the story. I said, ‘No, absolutely not’... They were baffled because I don’t think they had ever done a story on someone who had passed. All I could think of in my mind was that it was still a great opportunity to bring awareness to the disease for other people... and how wonderful life can be in spite of it ... So, they did the story... (and it) was all about the hope that is so much a part of the journey.

All 7 parents also said that participating in this research study was a “great” or “unique opportunity” to share their journey in a “meaningful” and “productive” way. They said although there are great providers and services available to meet the needs of children with disabilities, they felt that children with degenerative, life-threatening conditions “often don’t benefit from” or “have available to them” the full spectrum of these supports. They expressed hope that by sharing their stories for this study, “attitudes and understandings” of both providers and society in general “might open up” and “improve how” information and support are offered to parents whose children have degenerative disabilities. One parent said:

I am thrilled to do (this research). I would hate for anybody else to go through any of this in the same way my child and I went through it. That is what motivated me to participate. That, and knowing that I am sharing this whole experience with a researcher who understands it all, first-hand. Someone who I know gets what it is like to value and love a child with such limitations due to a progressive disease, and who I know gets what it is like to so intensely grieve the loss of that child. The journey with my child was incredible. And it was painful. But I wouldn’t give up that journey with my child for any other child in the world. But to have to the

opportunity to share my experiences with someone who is going to help change how parents go through the journey, improve how that experience and journey unfolds, well, that is a great opportunity for me.

Research Question 2: What do parents of children who died from degenerative disabilities perceive as needs related to supporting their children and coping with loss?

Parents shared detailed stories about the “journey” of caring for, and losing, a child with a degenerative disability. Based on their personal experiences, these parents also shared what they believed were “basic needs” related to supporting their children and to coping with their children’s deaths. Seven themes emerged for this research question: hope, information, resources, helpful networks, healthy partnerships, choices, and validation. These themes and subthemes are summarized in Table 5, and are explored in the sections below.

I Need Hope

The first theme that emerged related to the needs of parents whose children die due to degenerative conditions was the need for hope. Parents said that from the moment of diagnosis, they needed hope. Although professionals told them that there was “no hope” for long-term survival or for any “real quality of life,” they sought, and found, both hope and a meaningful quality of life for their children, and for themselves. They also needed hope that their child could live a “good,” “quality,” or “meaningful” life, and that they could be happy despite disability.

Table 5: Perceived Needs of Parents of Children with Progressive Neuromuscular

Diseases

Hope	<ul style="list-style-type: none"> • Child might outlive expectations • Child can have a meaningful life
Accurate Information	<ul style="list-style-type: none"> • Related to child development • Related to the child's disability • Related to transitions • Related to coping and support
Useful Resources	<ul style="list-style-type: none"> • Appropriate and quality • Accessible and timely
Helpful Networks	<ul style="list-style-type: none"> • Competent providers • Experts in the field • Experienced parents
Healthy Partnerships	<ul style="list-style-type: none"> • Mutual respect and trust • Communication and collaboration • Reliability and continuity • Mutually beneficial
Choices	<ul style="list-style-type: none"> • For treatment options • For resources • For supports and support systems
Validation	<ul style="list-style-type: none"> • "This is real" • "I am a good parent" • "My child matters" • "I made good decisions" • "My child lived a worthy life" • "I am not alone"

Only 1 of the 6 parents was told that there was hope for their child's survival. This parent said that a doctor told her to "start saving money" for the child's college tuition. She said:

... that is how I lived for all those years. With hope. With a positive attitude, that's how I lived, so that's how (my child) lived. We lived believing from day one that college was a possibility, because a doctor told me that was possible. And even though (my child) died, I do not regret for one moment that gift of hope that was a part of our journey.

The other 5 parents whose children were diagnosed during infancy said they were told their children would “not live” to or beyond their first birthdays. They were told there were “no options,” “no research,” “no treatments” that were “consistent with a good quality of life.” Laura, the mother of Justina who died at age four, said:

I was just kind of sitting there, completely stunned, needing something to be said other than, ‘She will die soon.’ I needed hope, even for a miracle. I now know that many kids with (this disease) do live past age one. And maybe, they will find treatments or cures by time she reaches that milestone, so what can I do to keep her healthy until then? I needed some type of hope, and all I got was ‘there is none.’

Caleb’s mother, Bev, noted that “Sometimes doctors give a very bleak prognosis when the reality is, they really just don’t know, especially when the diagnosis is one that a doctor isn’t familiar with. Children are so good at healing, even amazing with miraculous milestones.” She said that “by denying parents hope, you take away so many possibilities for the children and the families.”

Diane shared a story about her daughter, Annie’s, quality of life, despite predictions:

When she was an infant, one of her main doctors and I bumped heads... He wanted me to put her on a (Do Not Resuscitate) order. I said, ‘Absolutely not!’ He said what quality of life are you giving her? ... I told him, ‘As long as God is going to give her one breath, I will give her two.’ He just threw up his hands and walked away... We ran into that same doctor 4 years later. He was amazed, even told me I had done a good job... There she was, smiling and talking to him, and loving life, even with all that equipment.

Haley talked about all the things her child enjoyed in life, and said:

The limitations are going to be there whether I look at them or not... But I just can't focus on them, or I would never make it ... I don't think I live in denial, I think I just look differently. I see the possibilities... My child can enjoy going to car show even if driving is not in the future. You can enjoy the Indy 500 without being a race car driver, right?

The 4 providers agreed that parents of children with even the most devastating disabilities need hope. Betty Ann, the pediatric therapist, said, "A certain amount of denial is the same thing as having hope. It just depends if you are looking at the glass half full or half empty." According to Sally, the disability case manager, telling a family "nothing can be done" is inaccurate:

... There really is hope. The disease may ultimately result in death, but... there are routine ways to prolong a child's life if that is what a family wants, and there are routine ways to slow the progression of many of the diseases, and there are routine ways to... enhance the quality of life for the child and family. Even if a parent says, 'I don't want my child living on machines,' there are so many supports that can be offered that are not necessarily life-sustaining, but they can be life-prolonging, and... improve quality of life.

I Need Accurate Information

Having "accurate," "up to date," and "unbiased" information was the second theme that emerged related to parents' needs. According to Sally, the case manager:

Parents do need information, and they need it presented in manageable ways, and more than once... Some people want all the information in the world right from

the start. They want to talk with other parents, they want to know everything about this condition and what it is like and what might be their future. But other people do not want that. They want time to absorb it, time to discuss it with family. Professionals need to follow the family's cue, and also follow-up repeating the same information and offering more.

Most parents said that much of the information they did access about their child's condition they gathered independently by consulting the Internet or with other parents whose children had the same condition. Christopher's father, Tim, said:

Much of the information I got from providers was inaccurate, or biased against my son. Even phone numbers I got were often no longer working... And when I would finally reach someone, often I was given wrong information. Like that my son was not eligible for (early intervention) services because even though he really couldn't move his body at all, he was smart. That's not accurate information.

The types of information parents needed included general child development from the time of birth, disability-specific information including options for treatments and services, preparation for both medical and educational transitions, and support options or referrals for coping with issues related to the child's degenerative condition.

Child Development and Disability-Specific Information

The children discussed in this study were either "first-born" or "only" children. Parents said they "did not really know what to expect" with respect to general infant or toddler development. Therefore, parents said that when they first began to "notice signs" or "have concerns" that their child was not developing "like other children the same age,"

as pediatricians re-assured them that “things were fine” they did not know to think differently since their children were “happy” or “otherwise healthy-looking.” As a result, the 6 parents whose children were diagnosed during infancy said they “lost valuable time” in seeking or implementing treatments and supports that could prolong or enhance life for their children. One parent talked about how helpful a professional was in sharing information about a disability-specific organization:

He said that they were the most reliable source of information. He also said that there are some websites that are not very reliable sources of information... The Internet is a good place to start, but because it is not always controlled, you don't really know who is putting the information out there, and you might get misinformed. So you really need a professional to anchor the information, or at least to point you towards the right people or websites where you can get the reliable information you need about the disability.

Transitions

Parents said that they would have liked information about “transitions” during their child's life. One transition that parents said was very challenging was going from the hospital to home with new medical equipment and little or no support in the home for meeting the child's complex and time-consuming needs. Several parents said that even though social workers referred them for community services, there was no follow-up to ensure the services were available or appropriate, and therefore, their children lacked these supports.

Another transition that most parents said they were unprepared for was when their children “aged out” of early intervention services and moved to Part B education services

under IDEA. These parents did not know that they would have to “battle” or “struggle to prove” that their child’s medically-fragile health condition made school-based services too risky. One parent said that her child lived “pretty much isolated” for 3 years, and that suddenly putting him into the preschool setting with 10 to 12 other children “was overwhelming.” She had to withdraw the child from services until home services could be approved and begun. The 2 parents whose children transitioned to high school special education services also reported not being prepared for the “logistic challenges” of that change.

The final type of transition that several parents mentioned was related to their child’s transition to death. Although all 7 parents knew that their children had life-threatening, degenerative disabilities, only 1 parent said that any professional said anything about “what the death process might look like,” and that was “just a couple of days” before death occurred. Another parent said that as her child was suddenly dying, professionals did talk with her:

They didn’t sugar coat things, but they were also very compassionate in how they explained things... It was matter of fact with compassion. That was very helpful to me, because then I could trust them, and believe them, and also manage the information.

Coping and Support

Parents said being offered information about how other parents cope, and about support options for coping with their child’s disabilities and subsequent death was either “helpful” when offered, or “much needed” if not offered. One parent who was not offered information said:

When they say to me, ‘You are the parent, you know your child best,’ that is true, but I wouldn’t be asking for information or support if I knew everything. I was a good parent, but I could only know what I was told, or what I had read, or what I had learned by experience. So when I said, ‘I need information. I need support,’ and I was told that it was either unavailable or that I didn’t really need it, I get so angry.

I Need Useful Resources

The third theme that emerged in analyzing the data about what parents need was useful resources. Every participant emphasized the importance of having appropriate and quality resources that were accessible and timely. The range of resources that the participants said were needed included healthcare, education, therapy, equipment, respite, financial, recreation, social, spiritual services, providers, and supports. All parents said that at some point, they had medical or educational professionals who were not qualified to provide the needed services. They said that unless the resource was “useful,” it took “time,” “energy,” or “patience” from them that “was better spent” on the child. One parent said:

I needed resources. I needed a building that had ramps and adaptive chairs and someplace that could show me a bicycle that (my child) could ride, and a physical therapist that would come to the house... I needed resources that were easy to use. That weren’t ‘more trouble than they are worth’ to access. No battles. No incompetence. No ‘can we afford this’ or ‘are we eligible’ or ‘is it worth the effort.’ I just needed resources there that helped me help my kid live as normal a life as possible.

Sally, the disability case manager, said, “There are so many practical issues that need to be considered, and families need to know about these resources, and the resources really need to be available and affordable and accessible for families.” She added, “Sadly, unfortunately, many families find it challenging to know about or find the right resources, or to get linked up with things that would really be beneficial.”

Appropriate and Quality

All parents were able to cite “outstanding” services that were “wonderful” for their children. However, they were also able to cite “extremely frustrating” experiences that came from “not having the resources” that their children were eligible for and needed. Tim said:

We wanted some way to help him learn and... interact with his environment... He was very bright, but very limited in movement. We knew other parents that had interactive computer systems for kids with (this disease who) were able to communicate using very simple toggles. They could make choices with these systems. (We asked for) a program to go onto our computer so (he) could communicate. Instead, the teacher and physical therapist decided he needed to learn to paint. We asked for a communication tool, and they gave us paint and a brush for a kid who couldn't move his arms.

Laura talked about choosing “between two not-quite-right options.” She said when Justina first went to preschool, “they put her in a class that was primarily for kids with developmental disabilities, like autism, rather than a class for kids with physical issues. She had no cognitive or social challenges.” Laura said that Justina was transferred to a different school “with kids who were very social... and (she) had a great time.”

However, Laura said it was a “trade-off” because the teacher in the first school was “much better” but socialization “was a priority.” Bev talked about how “great things go” when resources “fit with” the child’s needs:

In the home we had a floor time therapist, and also a teacher from the school...

He was 5 or 6, and started talking for the first time. He learned how to play a little bit... He really flourished ... He just needed the right environment, the right services and supports.

Molly, the early childhood special educator, said:

Sometimes, what individual children need is very different from what other children of the same age or condition need. But sometimes, it is a challenge for parents and even providers to get those things recognized as needed resources.

Some systems are very helpful, but not all systems work well with families, and this can be a challenge.

Accessible and Timely

Parents also talked about useful resources needing to be accessible and timely for their children. Most parents talked about the challenges of finding “truly accessible” informal supports and community programs for their children. Most parents talked about difficulties they had with many of the formal supports that their children needed, that they were “not available” or “took way too long to get hold of.” Bev talked about therapy services for her son, Caleb:

He began receiving early intervention services as soon as he came home from the hospital. He was 6 months old. At first, we couldn’t get PT for him, because the school system just didn’t have someone available. So he didn’t end up getting PT

until he was almost 2 years old, even though that was one of his biggest needs.

Laura talked about how long it took to get a much-needed wheelchair for, Justina:

We had to wait 6 months for her chair once it was approved. That's a long time for anyone, but especially for a child with a condition that is progressive... She has grown, she has changed. She had to be refitted, which took more time. Once she finally got the chair... she was so happy, and she was mischievous...She finally got to just... be a kid.

The providers in this study said that accessing resources in a timely and affordable way is truly a challenge for most families. Betty Ann, a pediatric therapist, said:

Many organizations have equipment that would be useful to families, but they do not want to share used equipment because they are worried about liability.

Families need equipment immediately and the process is much too slow and long for the children who need a wheelchair, a bath chair, or an adaptive car seat. It's just so frustrating.

Andrew, a pediatric critical care physician, said:

What insurance does tend to cover is very basic, and not really always what is appropriate for the child ... Seating that will help prevent pressure sores is not considered a necessity, but really, it is. Parents have to learn how to navigate a system to fight for their child's right to have equipment fitting specifically for them, and that is just another stress.

I Need Helpful Networks

The fourth theme that emerged in exploring the needs of parents whose children have neuromuscular diseases was helpful networks. Parents desired a network of

competent providers “who know and do their jobs well,” of professionals who have “expert information or training” related to the child’s specific disability, and of other parents and families who have “first-hand knowledge and experience” of meeting the needs and coping with the losses related to their children with similar degenerative conditions. Sally, the disability case manager, said:

Some families have teachers... in the school system who really support the child and parents. Some families have a doctor or nurse that takes on that role. Some families have extended family or friends that become strong advocates. And for some parents, it is simply another parent who has already been through that part of the journey with their own child. The support they get depends on their networks, who they are connected to.

Competent Providers

Parents said “being nice” was a good attribute for service providers, but that “just being nice” was not sufficient for meeting their child’s needs. In addition, “inexperience” or a “lack of knowledge” about their children’s unique needs and strengths was not helpful, but a “frequent challenge.” Parents said it was very difficult for them when they asked for a specific intervention, such as how to best position a child to use a communication device, and the provider “didn’t seem to have a clue.” Most parents said they simply “wanted providers to know their jobs, and do them right.” One parent said a social worker “thought she was helping, but she wasn’t helpful at all. She would just sit there and... look at me with pity. I didn’t want pity.” This parent wanted “information and support and the best possible resources and care.” She said:

I wanted to say, ‘Don’t just look at me. Talk to me. Ask me how I am doing.

Support me. Ask me if I want a cup of coffee. Offer me a parking pass. A meal pass. Connect me with someone who has answers. But she just watched me as I went through all the painful meetings about where I was being told what would happen to my child.

A parent whose child needed an aide at school said, “He fell a lot, and his aide was a woman who couldn’t lift him. So she would leave him there and go get someone else to help.” Another parent said home nurses who are unfamiliar with medical equipment were not helpful, even if they were nice. “Home nurses don’t usually know critical care, and night nurses often fall asleep. I need to know where the good nurses are.” The disability case manager said:

Home health providers are not usually registered nurses... and the (school) aides... tend to be people who trying to pick up some extra money. They’re retired or they’re mothers whose children are now in school. They are not people who are physically able to pick up a child who has fallen, or to help a boy, or a young man in high school, use the bathroom. They may be very nice people, but they are not competent in the job... When you have a good match between the child, the providers, and the family, it’s great. But sometimes, that takes time. For some families, the time that these challenges take up is... sacred time.

Experts in the Field

The parents also talked about networking with “expert professionals” who did research related to their children’s disability, who had training specific to meeting the health or education needs of a child with a specific condition, or who had advanced training with some type of intervention or equipment that would be beneficial to their

children. Laura said she needed to be “connected with specialists that were more aware of the bigger picture, as opposed to the acute incident that may be happening right now. The acute need must be addressed, but it needs to fit into the big puzzle” of neuromuscular disease. Christopher’s father, Tim, said:

The people we ran into there either knew about (my son’s neuromuscular disease) or had no clue. It was kind of an either/or deal, which surprised me because it was a teaching hospital ... I was able to network with an expert though, and we exchanged quite a few emails and phone calls, across the country... It was good to be able to share and brainstorm with an expert who also cared about what was happening to my son.

Several parents also talked about the importance of having professionals who were “experts in grief” rather than just seeking help from “a generic counselor” who may not understand the unique issues a parent faces when losing a child. Haley said:

The death of a child is so unnatural that any way or spectrum of things that you could possibly think is okay... This bereavement specialist ... is one of the things I have found useful... No matter what I feel, as long as I am not hurting anybody including myself, it’s all right ... It is good to have an expert... help me feel less alone, less insane, in grieving.

Experienced Parents

Having connections to other parents whose children were living with or died from similar conditions was described as part of a helpful network. Parents said they received both emotional and informational support from other parents in their local communities and across the country. One parent said the shared knowledge that “came from the

trenches was invaluable.” Another parent said that in addition to practical advice and support, “experienced parents provided much needed validation” about what they were experiencing and needing related to a child’s disability.

Several parents also talked about the importance of having “peer networks” for their child. One parent said children need to know that they are “not the only kid in a wheelchair, with a trach, with a ventilator.” Parents said it was as important for their children to have opportunities to share their feelings with “other kids who would really get it” as it was for them to have those opportunities with other parents. The disability case manager said:

When the family is living as typical a life as possible considering the child’s disability and intervention and care needs, what families need is... connections with other families who are going through, or who have recently been through, similar experiences. Similar challenges... And it’s important for the kids, especially as they get older, 10 or 12 years old or so, for them to have other kids to talk with... about the progression of the disease.

I Need Healthy Partnerships

The fifth theme that emerged was healthy partnerships. In addition to having information, resources, and a supportive network of providers and peers, parents needed to have “healthy relationships” with the people with whom they worked to meet their child’s needs. They described healthy partnerships as having characteristics such as: mutual respect, collaboration and communication, reliability and continuity, and being mutually beneficial.

Mutual Respect and Trust

Participants said “parents need to trust professionals,” but that professionals “also need to trust the parents.” Parents said that they needed providers to respect that parents “have expert information about our child’s specific disability,” and that they “also have specific preferences and priorities” about how their child’s care needs should be met. Parents shared stories about healthy partnerships that “exemplified trust.” However, parents also shared stories about feeling “not trusted” and “not respected” by professionals, and that these experiences sometimes negatively affected other partnerships and experiences. One parent said:

At first, we just trusted everything the professionals said ... Then we found out that not all professionals share all the information, or they are hesitant to tell you the whole truth because you may make a decision that they don’t agree with. Also, not all professionals have all the answers, and they don’t want to admit it, so they just say what sounds good, or reasonable in the moment... I need professionals to be honest with me, and to help me feel empowered to care for my son. I need to trust them, and I need them to trust me.

In addition to building a relationship of trust, parents said that mutual respect is an important part of a healthy partnership. Caleb’s mother, Bev, said:

We tried to tell the professionals who provided services in our home, ‘These are the things that are your job’ and ‘these are aspects of parenting that are not your job’... Sometimes, they would even ask us, ‘Where do you want us to work with him?’ and ‘What do you want our role to be?’ And that sounds great. But they didn’t really follow what came from those discussions... If they would just do

their job... and be respectful of... our roles, and our preferences ... I needed to work with, not against, them.

Parents also talked about the importance of trust and respect between the providers and their children. One parent said that her child had “extreme anxiety over even the littlest things,” but providers often didn’t respect that this “was how (the child) was really feeling.” She said:

Providers need to see the child as a person with feelings, concerns, and rights... Realize that even if they can't talk or communicate well, they still have fears, things that bother or worry or scare them, and things they really like, things they get excited about... Be willing to do some things differently than you might normally to meet the needs of a specific child. Remember everyone is unique, and children are not little adults.

Molly, the early childhood special educator, said that mutual respect and trust are “essential”:

Most providers just don’t know much about neuromuscular diseases... But it really is a professional’s job to be prepared, to find out what they can... Parents are really the best sources of information about most aspects of their child’s care, and even about the disability after some period of time... They also know their child’s temperament and coping, the child’s medical and typical routines, things like that... In many cases, we can also learn from the child. Some children are able to tell you about their equipment or routines, and that provides the information you need, and it also builds rapport.

Collaboration and Communication

Collaboration and communication between parents and providers was also cited as an important aspect of a healthy partnership by the parents and providers in this study. Most parents said that their children's conditions were associated with atypical needs, such as unusual nutrition needs. It was often "challenging" when providers would "not listen" to what they were saying, or when providers would "not work with" other providers who had expert information about such atypical needs, often because of "political hierarchy." One parent said:

(A neuromuscular disease expert) explained our child's unique nutrition needs to us, and we also found literature on it. We tried hard to explain this to the doctors when (our child) was hospitalized in the ICU, but they wouldn't bend their protocol.... that no child in their ICU got fed for the first 24 to 48 hours ... That goes against everything that children with this disease need nutritionally. It actually... makes them weaker... They weren't even willing to talk with the experts on this disease.

Another parent described working with providers who did listen to parents and communicate with other professionals, and how much that helped. She said, "Hearing names of other doctors around the country helped... If the (local hospital) doctors we were working with weren't familiar (with the disability), we could get them to talk to people that were more familiar." One parent described the collaboration between her child's special and regular education providers:

The physical therapist worked in conjunction with the (local preschool my child attended in addition to the special education preschool) and made sure that

whatever was needed, was there in the classroom. Things like an adaptive chair, so that my child could come out of the wheelchair and sit in at one of the small preschool tables. The providers collaborated with each other, across systems, and that helped my child. It was great.

Sally, the disability case manager, said that collaboration and communication between and among parents and providers and children is very much needed, and that it is important to medical and education professionals to “see the child, and the family, from more than one angle.” She said teachers need to know academic things, “but also how medical things will have an impact on academic and social learning. And medical people need to know about the treatment and medical management, but also about how these kids can learn and play and be social.” She added that providers need to move past assumptions related to:

...what a disease is, and also about what it is not. What’s funny is that many of these professionals who don’t want you telling them how to do their job, they are telling the parent how to do their job with that child, beyond just education or health.

Reliability and Continuity

Parents said that having “reliable providers” and “continuity” was an important part of a healthy partnership. When this need was not met, trust became a “threatened” issue and challenged collaboration. One parent said that “after ongoing challenges” related to finding reliable and long-term providers with whom there was mutual trust and respect, “I just acted like I didn’t even need any support... I didn’t want people just coming and going in our lives. I needed support, and a good relationship with providers,

but acted like I needed nothing.”

Another parent talked about the challenges of “constantly changing” providers:

This was a teaching hospital and... different providers gave... conflicting bits of information. And you might have 3 or 4 respiratory therapists in a few days. For a child with (this disability) a good respiratory therapist is the key to survival...

Some of them were great but some of them just didn't have the knack. And so of course, that feeds into us never wanting to leave our child alone for a moment in that environment.

Parents reported that having reliable relationships with other parents, and relationships that continued past their child's death was important. All parents who were involved with a disability-specific organization prior to their child's death said that they still had some ongoing connection with this group, and that this was helpful to them. One parent “began to pull away” from this organization, because she wanted her child to experience “a typical life.” She said she “realized this was a mistake” later, and that she needed to be around “people who understood the experience of really living with a disability, a progressive disability like this.” She added:

While I wanted (my child) to believe in the future, I realized that this had to be done with the disability being a part of the reality... Part of that is being connected to other parents and kids who are going through, or have been through, the same experiences. Disability was part of our life, and so is loss. We can do more typical things, but that ongoing connection, during life and even after death, is an important part of the overall network.

Another parent talked about the helpfulness of “still being... connected... with other families we met” through a disability-specific organization. “We still go out with the families... do a couple of fundraisers with them each year... We are in touch otherwise by e-mail, phone.”

Mutually Beneficial

The last sub-theme that emerged in the category of healthy partnerships was “mutually beneficial” relationships. Most parents felt that at one or more times during their journey, they either had to “put aside their own needs” while trying to seek support, or they had to “go without support” because it was not beneficial to all people involved. For example, many parents said that to get the “peer support” they needed typically began with attending a support group, and that having to be in a group was sometimes “very difficult.” These parents said that it “could be scary” to be in a support group with other parents whose children were “much older” or “far more progressed” in the disability. They “didn’t always want to see that future so vividly.” Other parents said that after their own children died, they “didn’t want to frighten” or “cause discomfort with” other parents whose children were still living, so they chose “not to attend” fundraisers, parties, support groups, or other social events even though they “really needed that connection.” One parent described a support group she attended while her child was still alive. Another parent whose child had died from the same condition was there and she thought:

‘Oh, that could be me.’ And it was sinking, scary feeling. That parent had every right to be there, and needed to be there... the same as me. But it was very hard

for me. I can't do that to another parent... I can't have (support) at the cost of another person's comfort.

These feelings of "lacking mutual benefit" were frequently discussed by the parents who attended a general community support group for bereaved parents. Because they "didn't share the same life experiences" prior to death, parents often felt like they "had to defend" their child and their grief, which was "not beneficial." Parents also said that if the support group did not "have good leadership," it did not offer the same benefits to all parents. One parent said that if a particular parent "monopolizes the time getting their needs met, then how do the other parents get what they need?" Another parent said that group facilitators should have more training:

... the facilitator should try to steer people away from saying judgmental things, or things that are real to them but hurtful to another parent. But... once it's already out there, it's too late. Even the best leader can't anticipate what somebody is going to say. So I choose not to go (because)... then it's not a 'support' group that benefits everyone.

Andrew, the pediatric critical care physician, said that networking among parents is helpful, but only if it is "a healthy relationship" that develops "organically, naturally" from a shared experience or interest, and offers "mutual benefit." He said:

There can be certain emotional dangers to doing linking parents together without ensuring that the support will be mutual... So if a provider encourages a connection between parents, and one of those children dies, then a parent who still needs support is kind of put in the position of having to provide all the support to this other parent.

Sally, the disability case manager, said that it is a complicated issue:

Families need formal supports and informal supports ... And with both, it comes down to the person or system providing support, providing it in a way that is beneficial to all the families involved. Not just in a way that they think or feel the families should appreciate.

I Need Choices

Having choices for treatment options, resources, and support emerged as the sixth theme during data analysis. Parents said that as important as having choices for services and supports, was “having respect for the choices I make.” Early in the journey with their children, parents were “not offered” many, or any, choices about treatment options. As they began to gather their own information about their child’s condition and then express “specific opinions” about what they did or did not want for their child, they “met opposition.” Some parents were told their child “had to have a tracheostomy” or “had to have a permanent feeding tube,” and that there “were no options” for treatment otherwise. These same parents said that when felt strongly about a treatment option that was not consistent with what a professional recommended, they felt “judged” and were told why they were “wrong” in their priorities.

The parents also talked about not being offered choices with respect to “much needed resources” that may be available to their children. For example, 1 parent was told that there “were no options appealing decisions about (the child’s) education.” This information was inaccurate, and once an appeal was made the decision was reversed, “but I had to find out that I had an option, a way to appeal, all on my own.”

All parents needed options for supports that foster coping with their children’s

degenerative condition and the eventual loss of their children. One parent said:

I think no matter what the name of the neuromuscular disease is, no matter how it progresses, no matter how any child dies, and no matter how long a parent has to prepare for loss, how each parent deals with all this could be the same or different as how the next parent deals with it ... It may look the same or very different as another person's journey, another person's grief. But... each person might need very different things or supports to deal with their journey and their grief, no matter what the experience of disability or loss was. There just needs to be different types of supports there so people can get what they need, and not just try to need what happens to be there.

All providers in this study agreed that parents need choices . One said parents need to know:

... what choices they have to make, what options are available to support them... and support in... following through with the choices that they make. I think that is a major deficiency in our systems. We tend to tell parents the choice that we want them to make, rather than offer options. Many parents are not even told about the choices available to them. And if they are, they are not always supported in the options they choose.

I Need Validation

The seventh theme that emerged in exploring parents' needs was the "ongoing need for validation." All parents said that "not feeling or being validated" in their experiences or in what they perceived as needs throughout their journeys was a particular challenge, and was a "significant part of the unnecessary stress" that was a part of "nearly

every aspect of the journey.” Parents said they needed to “hear” and “know” that: their experiences and feelings were real; they were good parents; their children mattered to others, especially to care providers; they made good decisions for their children; their child lived a good life in spite of disability; and, they were not alone in their experiences, feelings, or needs. One parent said:

I don't know if other families have gone through the kind of feelings, experiences, even the nonsense that we have. Am I alone? Are we the exception? Or do other families also feel like this is surreal? That there is so much stress? And so much unnecessary stress?

This Is Real

All parents said that when they first learned that their child's diagnosis would result in early death they were “shocked” and “overwhelmed.” One parent said that she felt like it had to be “a bad dream” and wondered if what she was hearing “could be real.” Parents also said that often felt like other people “did not believe” or “acknowledge just how traumatic” the situation could be, which made them question whether their own feelings and experiences were “real.” Providers agreed that parents need to be validated in their feelings, experiences, observations, concerns, and experiences, but that “this is not always the reality.” The pediatric therapist said:

I have heard other therapists say that some parents exaggerate the child's needs to get more services or to gain more sympathy... I do not agree with this... I encourage those therapists to be more supportive and to use that information to guide them... meanwhile, the family is not being validated, and wondering if their

observations, concerns, are real.

One parent talked about how challenging it was when other people did not recognize how “real” and “challenging” the effects of the degenerative condition were on the child or family:

People don’t seem to understand how hard this is, because his disability and needs become normal ... They didn’t notice the progressions, and because... we kept our heads above water and did some typical things ... nobody noticed how hard it was for us.

Another parent talked about how supportive it was when validation of experiences was provided:

If it wasn’t in the text book, (most providers) couldn’t acknowledge or believe that it was happening. But it was... and it was good to have a couple of people who seemed keenly interested in anything new or unusual regarding what we were really experiencing.

I am a Good Parent

Another type of validation parents talked about was the need to know they were good parents for their child. Parents said they often felt “guilt” or “concern” about whether they were “doing a good job” and ensuring that their children were “happy” and “content.” Instead of feeling like they were “in the way” or “annoying,” they needed to know that “being a strong advocate” for their child was “ultimately helpful.” Caleb’s mother, Bev, said:

Some of the professionals acted like if you were questioning something that they said or recommended, you were a difficult parent. And especially early on, I was

scared to be that person. I wasn't comfortable with... terminology and... the care... Only if a provider validated a concern was I like 'Okay, maybe I am right.' I was too... inexperienced in the disability world to know better, to know that I was being a good parent, not a pain.

Diane felt "good" when a provider told her she was doing a "good job:"

The care coordinator... was leaving the apartment one day, and she grabbed my hand and said, she is such a special baby and you are a special mom. I really wish the best for you guys. She had tears in her eyes. Hearing her compliment the support system and care we had for our child, that just made me feel so good as a parent. That really mattered.

Haley needed validation during her daughter's life and after her death. She wondered if feeling "overwhelmed" during life was okay, and if being "relieved" that a child was not suffering anymore but also feeling "horribly sad and wishing they were still here" was okay. She said:

How is a mother supposed to feel when she wants to be with this one kid who has died, but that means leaving another kid back here who is still alive? It is a horrible feeling. It is torture. When a professional finally said, no, you are a good parent, this is all normal, I felt so much better. For the first time, I felt like I was not crazy.

My Child Matters

All of the parents felt like there were professionals who did not "do their best" when providing services or support to their children. Parents felt like this was because their child "had a degenerative condition" and that professionals seemed to have a "why

bother” attitude. Noel’s mother, Christie needed providers to know “my son was worth their best effort.” She said:

I needed people to actually come to a meeting... having done as much research or exploring into meeting my child’s needs as they would for any other child who didn’t have life-threatening condition. I needed people that recognized how much my son mattered... Why would agencies provide people who weren’t qualified? If it wasn’t quality services, it wasn’t worth the time. His time was limited.

The providers all had witnessed times when professionals did “not prepare” or “give the same effort” when addressing the needs of a child with a degenerative condition. One said:

I have seen education professionals come to... meetings unprepared. They may have academic information in front of them, and they are ready to make recommendations... but they don’t really know about neuromuscular disease or how that impacts education, or even other aspects related to the child being in school ... And it’s not so much that they didn’t know the name of a disease. It’s that they make assumptions. Like, oh, well he must be slow, or have mental retardation. I’ve heard, he’s going to die so there’s really no use in worrying about whether he’s doing his homework. Even if we know he... is definitely going to die ... make sure he’s doing his homework because he’s here now.

I Made Good Decisions

Parents needed to know and hear that they had made good decisions during their children’s lives, and said they had struggled with “issues of guilt” related to one or more decisions they made. It was important for them to know during the child’s life that they

were being good advocates, and it was also important for them to know as or after their child died that they made good decisions for their children. Sometimes, those decisions were not directly related to a child's care, such as a parent's decision to be with their children and "sleep on the floor in the ICU even when it was against the rules." Parents also said they "agonized over decisions" they made that may have become a factor in "when" or "how" their child died. One parent said:

Not a day goes by that I am not tormented with the thought, 'What if I had just demanded that a doctor see (my child) that day, rather than accept an over the phone judgment that everything was fine.' Clearly everything was not fine. If I was a good parent, making the best decisions at all times maybe (my child) would still be alive today. I'll never know.

In summarizing her thoughts on this theme, one parent said:

I needed professionals to tell me if they think I have done the right things during my child's life, and if I am still doing the right things when my child is dying. I need to know that I (was) a good parent, and that the professionals know I love my child.

My Child Lived a Worthy Life

All parents said they needed but often lacked validation that their child "lived a worthy life in spite of" neuromuscular disease. One parent said:

People just somehow don't seem to get that even though (a child)... has a disability that will progress, that you can still have... a great life. Many successes. Happiness. Hope. It's like... oh, well, this child might die, so let's not spend our time and energy because it won't matter. It does matter. And then when the child

dies, people are like, oh, what a relief. I needed people to know that my child had a good life... I am very proud, and miss (my child) who was an absolutely amazing person with a wonderful, wonderful life... We wouldn't have traded our child... for anything. I feel guilty about ever telling anyone about the challenges we faced, because then death implies relief.

Another parent talked about this lack of validation continuing after the child's death:

Somebody else's kid died in a motorcycle accident. She said every time (she) looked at the motorcycle, (she) was worried he was going to wind up crippled and in a wheelchair. Meanwhile she doesn't know about my life (and) what a great life my child had ... Again, you are trying to convince people about the worth of your child... and tell them, 'No, it wasn't all suffering... and I miss it as much as you miss your life with your child.'

Yet another parent said:

It seems people in our society love saga, they love tragedy. They slow down to look at a car wreck. They dwell on some well-known adult who died. But isn't it so sad, that when a child with a lifelong progressive disease passes, nobody can discuss it. Recognize the reality. Or acknowledge how wonderful that child was, even though death happened.

I am Not Alone

The final type of validation parents discussed was feeling or knowing that they were "not alone." They said it was overwhelming not knowing if they were the only person who had the experiences or feelings that were a part of their journeys. They also said that it was difficult for them to feel like they were the only person who

“remembered” their child and “felt comfortable talking about” their child. Finally, they said they needed to know if other people – other parents or providers who cared for children with degenerative disabilities – had the same intense feelings related to loss and grief after such a challenging journey.

Other people remember my child. Parents said it might be sad for them to talk about their children, but they want to do so. Karen had “a hard time not crying when I think of Ethan, but I like thinking about and talking about him.” She felt “blessed and really lucky that he was mine” and wished “other people could miss him in the way I miss him. For being a great person, not just disabled.” Laura shared her struggle with helping other people feel “more comfortable” saying her daughter’s name and sharing memories about her. She said people are “afraid that they are going to say something, and that I will get upset” because of what they said. However, she said “I am upset because my child died and I miss her. I am really glad that (someone is) talking about her and that I don’t have to be alone with this.” Noel’s mother, Christie, said:

People seem to feel comfortable saying, he is here in spirit, but then they can’t talk about him. If his spirit is with us, why do we have to close the chapter on him? Why do we have to put the spirit away? I feel so alone sometimes in remembering him.

Providers agreed that a lack of validation that “other people do remember” or “you are not alone” can be hard for parents. The pediatric therapist said when a child dies, professionals “have the control to either run, or stick by this family.” She said” :

My services are over and weekly visits will not continue. But they have developed this relationship with me... I know families do not want to burden me with their

grief, but we have a connection that is different than any other. I think it helps to share with them things about their child that I thought were unique and special. I think sharing what I learned from them and how that has helped me as a professional, as a mother, and as a person can bring them comfort.

Other people understand my grief. All of the parents had feelings of being “alone” in their grief. Some parents said they “still feel very isolated” in their feelings, and that other people, including close family members, “don’t seem to understand” the depth of their grief related to the loss of a child with such intense needs. Annie’s mother, Diane, said:

I had spent 15 years caring for her. Keeping her alive and making sure she was happy. Then she passed away. So all I did was work. It was just so much time on my hands. And people knew this, but nobody ever said, ‘You’ve got all this time on your hands after all this time, it must be hard.’ Nobody did that. Nobody recognized how empty my time was.

Diane also said she needed “validation that my grief was normal.” She did not want to tell her family “who I love and who loves me, that they can’t fill the void. That no matter... how wonderful they are to me, I will still miss my daughter.” She wanted someone who could listen to her and recognize how difficult it was to live without her child and say, “Yes, it is clear you love your family, but you’re right, nobody ever takes the place of her.”

Haley said after her daughter died, she was worried she was “going crazy, insane. I have these... terrible, tortured thoughts that I can’t put out of my mind. Thoughts about watching her die. Thoughts about the people who didn’t do their jobs right the night she

died.” When she “finally found” a counselor she could trust, she realized:

... that everything, every thought, is okay when your child has died. There is nothing even to say really. It is just to get through... You are not crazy. The experience is crazy. So it is okay to feel crazy. I needed to know if other parents go through what I have gone through and then feel the things I am feeling? ... Do they want to live, not just survive, but they don't know how? Do they actually miss the medical and therapy routines and the wheelchair and everything about the disability? I miss my child, and all of those things that were a part of her life. I sometimes still sleep on her bedroom floor... Is that crazy?

Sally, the disability case manager, said parents need to know they are not alone and that “there is still a place for them in the organizations and service systems and with the people that were a part of their life, or their child's life, for many months or years.” She said parents also need to know that there are people who do understand what they are going through, and that “if they are willing, they could be a helpful resource for families who are coming after them. That they have much to offer other parents, emotionally and practically.” According to Sally, “the greatest gift we can give a parent is to validate that they are not alone, and that their child has a special place in other people's lives... that their child mattered, and matters still.”

Research Question 3: When a child with a degenerative disability dies, what can professionals in education, health, and advocacy organizations say or do that might be most supportive?

The first two research questions guiding this study explored the subjective experiences and perceived needs of parents whose children were diagnosed with and

died from childhood onset degenerative neuromuscular diseases. The third and final research question focused on what multidisciplinary professionals might be able to say or do that would be supportive, or make some positive difference, for parents like the ones in this study. Based on the stories and information shared by the parents and providers in this study, three themes emerged during data analysis for this question: understand the experiences of parents whose children are diagnosed with degenerative disabilities; respond to the needs of these parents; and, provide ongoing validation for these parents from the point of diagnosis, throughout the lifespan of the child, and during and beyond the time of the child's death.

Understand the Experiences

According to all of the participants, supporting parents through the death of a child with a degenerative condition “begins around the time of diagnosis.” One provider said that “how” the diagnosis is shared “sets the tone” for how families and providers “begin and travel the journey.” This provider said that from the moment of diagnosis, there needs to be a “sense of the community that is available for the family,” and the understanding that professionals and families can form beneficial and supportive partnerships as the child's and parent's needs are met “throughout the journey.” The parents said that although a child's diagnosis and death can be marked with a particular time and date, there is “no specific dividing line” that separates their role as “a parent” on any part of the journey. One said:

Loving and caring for a child does not change with a devastating diagnosis, or even with the death of that child. The only thing that changes are the specific experiences, and the unique needs that are a part of loving and caring for the

child.

Another parent said that support around the time of a child's death "is not really something that begins all of a sudden." This parent said that people can say or do things that are helpful or hurtful in a given moment, "but the real, real support, the stuff that really makes a difference, well, that kind of grows from the people and the experiences that are a part of your life for the months or years before death occurs."

All parents and providers agreed that "understanding the experiences" of parents whose children are diagnosed with degenerative conditions before the child's moment of death can lead to a more supportive experience around the time of death. These experiences include the many stresses that are a part of the journey, the ongoing struggles for validation, and the types of formal and informal support that "made a difference" to them during their children's lives. Parents said that the providers who had been "most supportive" during the child's life were the same providers who were supportive around the time of their child's death, and since that time. One parent said:

The providers who got it during his life, they were the ones who got it around the time of his death. Maybe they weren't there witnessing it, but because they understood his life, and how much he mattered, and how much I did to take care of him, well, they understood the tragedy of his loss because they understood the triumph of his life.

In considering what any professional might do or say that would feel supportive around the time of a child's death, one parent summarized:

The most helpful thing that a professional could do at any point in this journey

is to really stop, and understand what we go through... Not just what a particular provider sees during their little glimpse of our journey. Not just the snapshot they get during a home teaching visit. Not just the image they get when we bring (the child) to the hospital in a crisis... But the whole overall set of experiences... Consider what it is like to be living this life... to be so exhausted, but to still have energy to battle for every single thing.. because this child... matters so much. Then that professional would get what we are experiencing when that child passes, and that alone is support.

The providers agreed that understanding parents' experiences across the lifespan of a child – including the inevitable and avoidable stresses – can make a difference in supporting parents when their children die. One provider said:

It's really up to professionals – in organizations, in schools, in hospitals, in all settings and systems – to not only support families in their necessary stress, but also to not impose the unnecessary stresses on them. If we could just open-mindedly recognize the experiences that these families go through, and then do our jobs well for the months or years that we work with these families, it wouldn't make the death of a child any easier to accept, but it could make it less lonely because... we understand the experience of loss.

Respond to the Needs

The first theme regarding professional support around the time of a child's death focused on awareness and recognition of the experiences that were a part of the parent's journey long before death. The second theme is similar, in that the support parents needed around the time of death were not very different from the needs they had while the child

was living with a degenerative disability. Parents said that in addition to understanding the experiences they go through while caring for their child, “acknowledging and responding to” their needs throughout their child’s lifespan would also make a difference around the time of death. In the immediate time surrounding their children’s deaths, parents “didn’t always know exactly what was needed.” However, they knew their needs at this “very challenging time” were “really no different in nature” than the needs they had for support throughout their child’s life. These needs included:

- Hope (e.g., that the child “is not suffering,” that the death “process is not prolonged,” and that “there is life beyond death”);
- Information and resources (e.g., “what death might look like,” “funeral homes,” “financial assistance,” “making meals or phone calls,” and “coping with loss”);
- Helpful networks and healthy partnerships (e.g., “presence” of providers or other people who “loved the child,” and “ongoing connections” with people who knew the child);
- Choices (e.g., “being with” the child at time of death, deciding “where” the child dies, and “types of grief support”); and,
- Validation (e.g., that the child “was loved” and “cared for,” that the parent “made good choices,” that the loss of the child “is significant” and that the “child’s life had worth,” and that the “child won’t be forgotten”).

Haley said there are “so many needs” when raising a child with a degenerative disability, but people do not always understand what is needed or why. “Then when (our children) die, the needs are not really any different, but having the needs go unrecognized because people still don’t understand what matters and why, well, just seems to be the

next part of the journey.”

Providers also said that support preferences vary from person to person. If parents have not already indicated the type of support they prefer (e.g., to be alone with their child during death versus having a professional present), it is always best to offer options, and ask parents what they need or want in the way of support. The providers agreed that it is important to understand and respond to the variable and ongoing needs of parents around the time of a child’s death. One provider said professionals cannot say a child will not die, but they “can let a family know, ‘You... are not alone... and we will try to support (you) in whatever way is beneficial.’”

The providers also said that it is important for professionals to understand that “a child is part of a family system.” Therefore, when a child dies, the entire family system “is shaken.” They said death may be “especially challenging” for parents and families who lose children to degenerative conditions, because even though there is some “expectation that death might occur at some point,” due to the “chronic crises” that are a part of the child’s life, “death is actually an unanticipated shock.” Sally, the disability case manager, said:

I think it is a gift, it is helpful, when the professionals can be truthful with a family about a child’s impending death. It’s not about giving up hope, or not continuing to provide the best care, the best intervention for the child. But while that is still happening, parents have time to say good bye somehow. They need time to prepare. To not be in such shock, when their child who has had this condition for months or years, really does die.

Molly, the early childhood special educator, said she knew a child she was

teaching “might die,” but she “had no clue it would be that day, that month, or even that year.” She said that if a provider “has any clue” that a child might die at any point due to a diagnosed condition:

It’s important to do things with the child that make memories for the parents.

Someone suggested this to me while I was working with (a particular child), but I was so sure (the child) had more time, that I focused on other lessons, other learning. In the future, I will make handprints, or memory books, or take photographs. I’ll do what I can to make lasting memories, whether the child has days or years, because you really never know.

Betty Ann, the pediatric therapist, talked about how she supports parents after a child dies:

It’s important to let the family know that just because their child has passed, that I will not disappear... I have learned that most families want to talk to me because I know personally what their child has been through.

Three of the four of the providers said the system or organization in which they work does not have “formal guidelines” for supporting families when a child dies. One provider said:

We have informal guidelines for what to do if a co-worker passes, or if there is a loss in the immediate family of a co-worker. But somehow, even though we work with families whose children might die, we don’t have any guidelines for supporting that family, or even supports for our own grief, which is very real as well. No guidelines that I know of.

Even though there were few or no guidelines for providing support to parents after the

loss of a child, the providers said that there are specific things that they have “learned through experience.” Examples that the providers offered of such support included:

- Offer parents empathy, not sympathy or pity;
- Offer “presence” to parents by visiting the home and by attending the child’s funeral or memorial service;
- Offer specific supports such as making phone calls or meals rather than saying, “Call me if I can do anything;”
- Avoid clichés such as, “At least the child’s no longer suffering” or “I know what you are going through;”
- Share stories and personal memories of the child with the parents;
- Listen to parents share their memories, and know that this may include sadness, frustration, anger, joy, pride, shock, guilt, and doubts about decisions they made;
- Answer questions parents may ask with honesty, including, “I don’t know, but I could try to find out” if that is the truth; and,
- Be open to some level of intermittent, ongoing contact with the parents if there was a strong partnership or connection prior to the death of the child.

With respect to maintaining ongoing contact with parents, one provider said:

I don’t think it’s under anybody’s control to not become emotionally involved, at some level, with the children we serve. Of course we’re told not to get involved, not to care that much, but how can you work with a child for years and not get attached? It’s human. And if we don’t feel and act human, then why are we in the field of human services?

The providers said “additional training” at both preservice and inservice levels were necessary for professionals who had any role in working with children who have illnesses, conditions, or disabilities that may lead to early death. They said having “current information” about the “specific experiences and support needs” of families who are coping with various disabilities and life-threatening conditions would be very helpful. They also said they would “welcome information” about being prepared to deal with their “own feelings of loss and grief” related to the deaths of children with whom they work. The pediatric critical care physician, said:

I thought I was prepared to interact with families when I became a doctor. But I have learned a whole lot since then, so now I think maybe I wasn't so prepared... I had more training for the medical aspects ... Lab tests. Treatments. Diagnoses. Even the ‘how to share bad news with a family’ training. But when you... walk in and tell the family this bad news, and they ask you 50 questions and... you have no idea how to answer them, well, that's pretty difficult... And it is painful... to not be able to keep a child alive.

Andrew also talked about how technological and medical advancements across recent decades have “shifted the population of children we work with today,” and how that affects providers’ understanding and comfort with meeting the unique needs of their families. He said in previous decades, ICU professionals “generally did what they had to do: fixed the problem, or not, and then moved on.” He said that now, children with chronic and degenerative conditions have to be in the ICU due to the medical technology that supports or prolongs life, but “they are not in comas, or dying in that moment. They are children and they have families. You can't fix it, and you can't move on.” He said

some of the problem is that providers “can’t get past their personal discomfort” to do what the families need them to do:

We can sit and talk with other professionals about the condition and the treatments and the prognosis and even the death, but when it comes to the actual practice of talking to families and talking to the children who are our patients, of meeting their support needs, that is not what we really want to do. But things are changing. (In the ICU) we are seeing children living longer and awake and being kids, and their parents needing to be there. It’s not what many critical care professionals signed up to do. And even for home nurses, and the teachers and other providers who work with these children and families, it’s not what people expected when they began training. But it’s now the reality, and we need to learn to deal with this, to be more comfortable... being with children and families.

Provide Ongoing Validation

The third theme that emerged for this research question about how multidisciplinary providers might best support parents during the time surrounding their children’s deaths is to “provide ongoing validation.” Like the first two themes, this final theme for supporting parents grows from the subjective experiences and perceived needs that the parents described as being a part of the “continuous journey.” Parents said their struggles with validation began around the time their child first “showed early symptoms” which led to a diagnosis of a progressive neuromuscular disease. They said needing and seeking validation continued throughout their child’s life, and was “a stressful part of the ongoing changes” and “the chronic crises.” Parents also said their need for validation “did not end with death,” and that it has

continued to be a need during the grieving process.

One parent said that validation issues begin at the moment of diagnosis, and can have a “ripple effect” on subsequent feelings and experiences:

If you are validated in your role as a parent from the very beginning, that you have concerns and questions and hopes and goals for this child’s life, that really has an impact on the types of... partnerships that are formed in the coming months and years. How you learn about your child’s diagnosis can affect how you interact with providers for a very long time, which can even affect the time surrounding a child’s death.

Providers agreed that early interactions between parents and professional that validate parents’ roles and goals have an impact on subsequent partnerships and experiences. One provider said that validating parents from the point of diagnosis can “alleviate or avoid a push/pull sort of situation” during critical times, such as end-of-life. All parents said that the “best validation” they received throughout their children’s lives and around the time of their children’s deaths was when they were provided information, services, care, or support “without having to beg” or “battle” for it. One parent said:

We all knew (my child) had a progressive and life-threatening condition, so why did people act like each change or crisis wasn’t real? Why was I made to feel like a bad parent who couldn’t accurately observe and report things about my own child? But when a professional would say, yes, you are right, and these are the things we can try to do in response to my concerns, it didn’t change that (my child) was getting worse, but it helped how I felt about being a good parent.

The parents talked about the ongoing need for validation around the time of their children's deaths, and during their "intense" and "enduring" grieving process. Most parents said that it would be supportive to them if providers were available to "answer questions" that might help them "feel more assured" that they had made good decisions and been a good advocate for their children. Finally, they said that it would be helpful if there were additional options for bereavement support since most of the "currently available community supports" were attended by parents whose children died "more suddenly" or "were healthy at some point." The parents said that because "life experiences prior to loss" were so different, it was difficult for other parents to understand and therefore validate their children's worth, or the depth of their grief.

In summarizing the experiences, needs, and supports that are a part of parenting a child with a degenerative condition, one parent said that all parents of all children:

... struggle with validating their child's needs and rights and seeking what is best, and seeking to validate their own needs and experiences. That is part of being a parent. But I think that the struggles we have as parents of a child with a progressive disability, when a child is alert and aware and learning but is physically getting weaker and weaker, the amount of advocating and battling and frustration just seems out of balance.

Another parent said:

There is no book. There is no manual to tell me what to do that is the absolute right thing for my child. Part of that is because this is so atypical, and each child's progression is unique. It ends the same way, but the journey is unique. Still, I think that the whole journey can be a little easier, if providers and other people

understood what it is like day to day, year after year. If people in general could just understand that these children matter, and they live good lives, even though life might be all too short.

Summary

Themes that emerged from the three research questions that guided this qualitative inquiry were explored in this chapter. These questions focused on the experiences and needs of parents whose children died from degenerative neuromuscular diseases, both during the lifetime of a child and during the time of death and bereavement. Parents described their “journey of stress,” ongoing struggles with validation, and beneficial supports that “don’t change the reality,” but that “really make a difference” throughout the journey. They said that their experiences and needs around the time of their child’s death were “not really different” from their experiences and needs during their child’s life. These themes are explored further in the next chapter.

CHAPTER V

DISCUSSION

In this study, the experiences and needs of parents whose children died from degenerative neuromuscular diseases was explored. Conclusions about the results are discussed in this chapter, as well as an examination of how these results compare to previous research related to the experiences and grief of parents whose children died due to other causes. An exploration of the significance of these findings and practical implications is also offered. Finally, limitations of the current study and suggestions for future research are presented.

Conclusions

Brotherson (1999) and Fletcher (2002) reported that no matter how or when a child dies, bereaved parents seek to share the story of their journey with other people. This was clearly the case for the parents who participated in this study. These parents shared rich and detailed memories of many aspects of their children's lives and deaths – both prideful and painful – as well as their ongoing experiences related to grief and bereavement. The themes that emerged based on data analysis were essentially the same across all parents. In fact, regardless of a child's specific neuromuscular diagnosis, the age of a child at the time of diagnosis or death, ethnic identity, geographical location, or the length of time since each parent was bereaved prior to this study, there were very few differences in the themes parents described.

The parents in this study all discussed their experiences of stress, of seeking validation, and of the formal and informal supports that made a difference throughout

their journeys. The stress reported was described as both *necessary* and *unnecessary* in nature, but always difficult to handle. Necessary stress was related to coping with the mental, physical, and emotional challenges of caring for a child diagnosed with a degenerative disability. Although inevitable, this type of stress was exhausting due to the progressive nature of their children's disabilities, and the chronic crises that resulted in parents feeling like they were "living on the edge" for months or years at a time. On the other hand, unnecessary stress was described as "avoidable" and "frustrating" by parents. This type of stress included parents' frequent "conflicts" and "battles" with professionals and service systems that did not "work as intended" or meet the needs or "rights" of their children. Ongoing struggles with validation both before and after their child's death was another source of unnecessary stress. When needs were met and validation was available in both formal and informal ways, parents felt supported. Parents did not perceive support when their needs related to coping with and providing for their children's degenerative disabilities were not met, or when they had to actively seek validation. This made their journey feel even more stressful.

Confirmation of Previous Grief Theory and Research

In a variety of ways, the results of this study complement previous research related to the grief experiences and support needs of bereaved parents. For example, other researchers have reported that parental bereavement is intense and pervasive (Leahy, 1993; Middleton et al., 1998), that parents have different preferences for what is perceived as supportive during bereavement (Alexy, 1982), and that the perceived helpfulness of others was found to be related to perceptions of coping (Reif et al., 1995). Consistent with previous findings, the parents in the current study reported intense and

enduring grief, and indicated the desire for choices in the formal and informal supports both during their children's lives, and during their grieving.

Another similarity between this study and previous research is the parent comments related to marital status. Bohannon (1991a) and Devine (1993) concluded that pre-death marital satisfaction was the greatest predictor of post-death satisfaction, and that a child's death was not reported to be the cause of parental divorce in that study. Four parents in this study said that they became divorced from the child's other parent before the child died, and that these separations were due to personality differences and not directly related to the child's disability.

Religion as a support for bereaved parents was also similar for the parents in this study. Brotherson and Soderquist (2002), Meert et al. (2005), and Robinson et al. (2006) all concluded that religious rituals and feelings of spirituality were supportive to parents around the time of a child's death, and helped parents feel connected to their children during the grieving process. Three parents in the current study reported that religion or spirituality were an important part of their system of support during their child's life and beyond death. However, all parents felt a spiritual bond with their deceased child, and this was strengthened through ongoing connections with both people and activities that were a significant or meaningful part of their child's life.

Earlier research has resulted in mixed conclusions regarding grief characteristics expressed by parents based on the cause or recency of a child's death. For example, there are researchers who have reported that the suddenness of a child's death was positively correlated with anger (Drenovsky, 1994) and with intensity of grief (Seecharan et al., 2004). However, Arnold et al. (2005) and Hogan et al. (1996) reported that anticipating

the death of a loved one does not ameliorate or foreshorten the intensity or duration of grief, or lessen any grief responses such as anger. Other researchers have said that parents are never really prepared for their children's deaths even when loss is anticipated (Chomicki et al., 1995), and especially if they have more than 18 months to consider the possible death of their child (Rando, 1983).

In the current study, all parents reported intense and enduring feelings of grief. These feelings included anger, sadness, guilt, and a crisis of meaning. Even though all parents knew for 3 to 16 years that their children had progressive, life-threatening disabilities, they all felt "shock" when their children died after years of oscillating between the possibility and probability of early death. This finding is consistent with Rando's (1983) conclusion following a study of parental grieving related to the loss of a child with cancer. She said that increased parental involvement with atypical physical or medical care needs of a child that lasts more than 18 months to 2 years before an anticipated loss is associated with the denial of the possibility of a child's death. Rando said that this is especially true when the child survives the life-threatening condition against statistical odds for a prolonged period of time. The parents in the current study reported that their children had "beaten the odds" and lived "on the edge" for prolonged periods of time. For several parents, this experience included their children surviving multiple near-death events. Consistent with Rando's (1983) theory, the prolonged care of these children with neuromuscular disease, coupled with their survival beyond statistical odds, resulted in "unanticipated shock" for parents at the time of their child's death. Therefore, although the loss experience of these parents would be classified in previous research as *anticipated* in nature, these parents were not prepared for when or how their

children died, and said their child's death, which had been a "possibility" for years, was *sudden* in nature.

Rando (1983) also reported that parental grief can be enduring and increase across time rather than diminish in a linear manner, especially when a parent provided for a child's atypical care needs for a prolonged period of time. She said parent grief subsides across the first 2 years and intensifies in the third year of bereavement. The parents in the current study who had been bereaved more than 2 years also reported that their grief was enduring in nature. They did not report a lessening of grief across the first 2 years though. Instead, their feelings of grief increased in intensity across the first 2 years, and continued to increase in the third year and beyond.

Most parents in the current study felt that the intensity and endurance of their grief were related to a lack of validation from other people. This is similar to statements made by parents in previous studies, who discussed grief related to losing children who had severe or life-long disabilities (Aho et al., 2006; Milo, 1997; Wood & Milo, 2002). Parents in those studies said other people, including other bereaved parents, were not able to understand the depth of their grief related to a child who had significant care needs and who was never really healthy from a very young age. They also felt that other people did not understand the worth of a child with such significant disabilities, or how such a child could be loved so unconditionally.

Numerous researchers have previously reported that ongoing connections to providers and other people who knew a child with a disability or life-threatening illness has been reported as a helpful source of support to bereaved parents (Clerici et al., 2006; deCinque et al., 2006; MacDonald et al., 2005; Wheeler, 2001). The parents in the current

study also indicated their desire for these ongoing connections with significant others who “knew the child as a person” beyond the disability. Like parents in previous studies, parents in the current study said that once a child who has lived an atypical life dies, there is a feeling of loneliness and isolation from typical sources of support. For months or years, their child was a part of medical, special education, and disability-specific organizations and systems. In addition to losing their child, parents struggled with the reality of losing connections to systems of support that were atypical for most families, but had become typical for them. The prolonged duration of the child’s disability and atypical care had limited typical or community supports parents had engaged prior to the birth of their child. Therefore, ongoing connections with providers that were a part of their typical interactions during their children’s lives were especially supportive and welcome.

Finally, consistent with emerging theories related to parental bereavement as a process rather than a task to be accomplished (Davies, 2004; Klass & Goss, 2003), parents in the current study reported the desire to continue with activities that were meaningful to their children. Parents said that maintaining some level of connection with their deceased child was a source of support. In addition, redefining roles and bonds with their child was an ongoing process that did not end in the months or years following a child’s death.

Emerging Grief Theory and Research

Even though the grief experiences of the parents in this study reflect similar experiences discussed by other bereaved parents, there are several distinctive issues related to the experiences and needs of the parents whose children have a degenerative

disability that are not found in previous parental grief research. Parents in the current study reported that their experiences and needs around the time of their children's deaths and during bereavement were largely a continuation of the experiences and needs that were a part of the journey with their child during life. These parents reported a number of unique experiences that may be different from parenting a child with a non-progressive disability or from parenting a child during a catastrophic illness. These distinctive aspects of parenting are discussed below and include: the progressive changes that are a part of living with a degenerative disability, the role of parental bereavement support groups, and the ongoing struggles with validation during the child's life as well as in grief.

Chronic and progressive change. Many researchers have concluded that parents of children with disability or illness report higher levels of both emotional and physical stress than parents whose children are healthy (Carnevale et al., 2006; Dellve et al., 2006). Carnevale et al. (2006) conducted a study in Canada about the experiences and needs of parents whose children who are technology-dependent (i.e., rely on ventilators or breathing machines due to disability) and who live at home. They concluded that caring for children with extremely complex needs at home is a stressful and overwhelming experience for parents. They also said that despite this ongoing stress, families in their study sought *normalcy* and developed routines that became a daily part of living with a medical disability. Parents in the current study also reported a journey abundant with stress and a desire for normalcy in spite of atypical equipment and routines. However, the parents in the current study said that both of these experiences were complicated by the chronic changes and progressive nature of their child's disability. Parents said that even in a life filled with inevitable stresses related to

parenting a child with a disability, it was the ongoing *changes* that became a distinct challenge for them. According to the *Double ABCX Model* of family adversity and adaptation (McCubbin & Patterson, 1983), this ongoing change could contribute to cumulative adversity that may have a negative impact on families.

The role of bereavement support groups. In 2004, the National Institutes of Health hosted a summit during which 10 years of international research was synthesized and presented in an effort to determine what constitutes state-of-the-science care for end of life. One of the five guiding questions was: What defines the transition to end of life? (National Institutes of Health, 2004). Nearly all of the studies reviewed for this summit that were related to the care of children were based on populations who were diagnosed with cancer, a condition with numerous scientific trajectories and statistical odds related to chances of survival. However, the panel leading this summit reported that there is no road map specifying exact beginning or end points for end of life care or for bereavement. Instead, they said end of life is usually defined and limited by the regulatory environment rather than by scientific data. Moreover, determining when to begin considering end of life care for children is most challenging since children tend to be resilient and families and providers tend to hold out hope for defying statistical odds.

Erby, Rushton, and Geller (2006) reported similar findings. They said parents whose children were living with neuromuscular disease recognized the importance of advanced care planning related to end of life issues for their children. However, such end of life care was not an issue professionals typically discussed with parents whose children had chronically progressing and life-threatening disabilities, yet lived lives that were typical in nature despite the disability. Furthermore, it was an issue the parents said they

were aware of, yet tended to avoid. Avoidance was cited partly due to the time-consuming experiences of coping with the intense care needs of their children, partly due to focusing on the successes of the present and keeping hope for their children's future, and partly due to the lack of professionals' openness or willingness to initiate discussions with these parents related to advance care planning.

All parents in the current study knew for 3 to 16 years that their children had an incurable, degenerative, and life-shortening diagnosis. Five parents were told that their children would not survive more than a few weeks or months beyond the point of diagnosis, but those children lived another 3 to 15 years. Only 1 parent reported that advance care planning regarding end of life was discussed during a child's 8 years of "living on the edge," and that discussion took place only days before the child's death occurred. Also, all parents reported that in spite of being aware that their child might die before adulthood, they had feelings of "unanticipated shock" related to their child's deaths. They said their children had "beaten the odds" so many times, and their children lived "healthy," "typical," and "quality" lives in spite of the degenerative conditions. Therefore, they felt unprepared for how and when their children died. This reality puts these parents in a distinct, and awkward, position when seeking support for their intense and enduring feelings related to the loss of their children. Community bereavement support groups are typically attended by and reported as being helpful to parents who either lost a healthy child suddenly to a traumatic event such as a traffic accident, or parents whose previously healthy child died due to a catastrophic illness such as cancer. Parents in the current study said their children's deaths were not unexpected, but they were also not anticipated.

Researchers of earlier studies have reported on the important role of support groups for bereaved parents. Some researchers have found that community member-led groups for parents whose children have died are reported as helpful to many parents, especially parents whose children died suddenly or after a brief traumatic illness (deJong-Berg & Kane, 2006; Thuen, 1995). Like parents in other studies (Brabant et al., 1995), most parents in the current study reported a perceived lack of understanding and support from friends and family members related to the loss of their child. In 1995, Schwab reported that parents whose children die after an anticipatory period are underrepresented in community bereavement support groups. However, she said parents in her study did not feel the need for groups because they had other informal sources of support. Most parents in the current study said that they because they needed support related to grief, they had attended a community support group at some point. However, none of the parents found these groups to be particularly “healthy,” “beneficial,” or “supportive” to them.

Parents in this study felt judged by other parents in bereavement support groups for deeply grieving the loss of a child who had significant care needs for a prolonged period of time. They felt hurt by judgmental statements other parents made regarding the “worth of life” when a child had a degenerative disability or had no independent mobility without the use of a wheelchair. It was also difficult for parents in the current study to listen to and support the grief experiences of other bereaved parents because of their own intense grief following so many years of challenging experiences. They said that beyond the tragedy of a deceased child, they did not share similar pre-loss experiences typical of parents in support groups. This is consistent with Toller’s (2005) finding that talking

about a child's death can cause discomfort for other people, even other bereaved parents whose child died from different causes.

Unlike the parents in Schwab's (1995) study, the parents in the current study reported that they chose not to continue attending these bereavement support groups, even though they had little or no alternate informal supports available to them from other family members, friends, or society in general. One of the providers who participated in the current study reported that even though she had routinely recommended these community groups for parents whose children died due to neuromuscular disease, she had more recently realized that these parents did not attend these groups routinely, and that they "did not seem to be a good match" for parents whose children lived such full lives for so many years with such atypical needs. This is a critical result to note because this finding does not lend strength to the assumption that bereavement support is generically available through these groups to all parents who lose a child and seek social support.

Importance of validation throughout the journey. For parents whose children were diagnosed with life-threatening conditions, researchers have reported that bereaved parents' attempts to make meaning of their children's lives and deaths began with the diagnosis, rather than in the time surrounding a child's death (Aho et al., 2006; Braun & Berg, 1994; Lister, 2005). Aho et al. (2006) said when a child is diagnosed with a disability, anticipatory feelings and experiences related to the child's condition are correlated with parents' grief responses following the child's death. Consistent with these findings, parents in the current study reported that experiences and needs around the time of their child's death and during bereavement were "not really any different" than the experiences and needs they perceived throughout their child's lifespan. Throughout the

stressful but rewarding journey with their child, parents needed tangible supports (e.g., information, resources, competent providers), and they needed intangible supports (e.g., hope and validation). They needed these same supports during the time of loss and grief.

Parents detailed their challenging experiences of dissonance, which included a mismatch of information, feelings, observations, and/or support needs or preferences. They said that this mismatch began before their child's diagnosis, continued throughout their child's life, and did not end with their child's death. Furthermore, they said this dissonance became a part of the ongoing struggle for validation that was a distinct aspect of the journey with their child. In fact, ongoing validation struggles emerged as a primary theme for all three research questions guiding this study. Clearly, this group of parents experienced a need for and a lack of validation during their child's life, and the desire for validation continued even after the death of their child.

These findings are consistent with previous research exploring the experiences and needs of parents whose children have complex medical needs (Carnevale et al., 2006) and whose children are diagnosed with rare conditions (Dellve et al., 2006). Both of these groups of researchers reported that families who have children with complex, rare, or poorly understood conditions often do not feel validated by providers or by society in general about the worth of their children. These researchers also said that the constant physical and emotional demands and stress that are placed on parents who raise their children with complex care needs and medical technology at home are not fully understood by the health and education professionals who play a role in providing for the care needs of these children. This is due to a lack of communication and collaboration across service systems, and the result is even more stress and a greater need for validation

on the part of the parents. What is important to note about the findings of the current study is that these parents said that due to unpredictable yet chronic changes, it was the ongoing struggles regarding their need for validation related to observations, concerns, feelings, priorities, and experiences that made coping and caring for their children even more challenging. Furthermore, needing yet lacking validation continued past the time of their child's death.

Discussion and Recommendations

The experience of stress is a common theme for most parents whose children are diagnosed with any type of disability or illness. Additionally, intense and enduring grief is a part of parental bereavement, regardless of whether a child dies suddenly or after an anticipated period of time. Therefore, the experiences and needs of parents whose children are diagnosed with and die from degenerative conditions are in some ways similar to the experiences and needs of other parents whose children have non-progressive or other rare disabilities, and of parents whose previously healthy children die due to traumatic events or catastrophic conditions. However, the experiences and needs of parents whose children have degenerative conditions also have some distinctive aspects, such as progressive changes, chronically "living on the edge," the lack of a good match for community bereavement support, and an ongoing need for validation. All of this further complicates the challenging journey for these parents and children.

In sharing their experiences, parents in this study illustrated a journey of stress marked by dissonance, exhaustion, chronic changes, unanticipated shock, and profound grief. These stresses began around the time of a child's diagnosis, but parents said they are not really linear in order, and that each of these stressful experiences recurs at

different points and during the many crises and changes that mark the journey. They also said these stressful experiences continue after their child's death. Finally, parents said that what makes the entire journey of *inevitable stress* so extraordinarily challenging is the ongoing struggle for validation and the constant and *avoidable stress* of ongoing conflicts with service systems and providers related to care needs and support.

Experiences shape the reality of a person's life. According to McCubbin and Patterson's (1983) *Double ABCX Model* of family stress and adaptation to cumulative adversity, the *pile-up* of pre-crisis and post-crisis stressors that interact with the availability of existing and new resources that support a family in responding to adversity can impede family adaptation, coping, and functioning. Until cures are found for all degenerative disabilities, the inevitable journey of stress that becomes a part of a parent's experience when caring for a child with a progressive disease cannot be changed. Direct service providers – teachers, therapists, pediatric physicians, disability advocates – cannot change the fact of a degenerative disability. Nor can they change that parents deeply love and worry about their children, that they seek the best care and resources for their children with devastating life-threatening conditions, or even the reality of intense and enduring grief that parents experience when a child dies. However, it is possible for many of the unnecessary or avoidable stresses to be mediated, or altogether eliminated, for these families.

Previous researchers have concluded that although professionals cannot change the stressful reality of a child's condition, they can have a positive impact on how that reality is experienced and on the amount of perceived support that assists parents in coping (Bailey & Bruder, 2005; Beckman, 2002; Bruder & Dunst, 2005; Seligman &

Darling, 2007). Dellve et al. (2006) suggested that parents' knowledge about their children's conditions and the availability of appropriate supports that meet families' needs could be positively impacted by multidisciplinary providers. These researchers report that professionals cannot change stressful or even devastating realities, but they can foster resiliency, which improves a parent's ability to cope with and meet the demanding experiences of an adverse reality. This understanding can be beneficial for parents like the ones in the current study: In other words, when providers support parents by meeting the need for supports such as hope, information, resources, helpful networks, and healthy partnerships, parents are better able meet the needs of their children, and cope with the parenting and losing a child to a degenerative disability.

Much of the stress experienced by parents in this study was inevitable and directly related to the reality that their child was diagnosed with a degenerative and devastating condition. However, parents were also frequently challenged by unnecessary and avoidable stress; these additional challenges had a negative impact on their experiences, their levels of exhaustion, their available supports, and their coping abilities. Unnecessary stresses grew from what parents considered avoidable conflicts with service systems and providers, and from feeling that their child's needs and worth as well as their own roles and priorities as a parent were not being validated throughout their journey. Parents were able to describe providers and services that were supportive during their stressful journey. However, as parents tried to cope with the dissonance, exhaustion, and chronic change that were inevitable and distinctive aspects of their journey, they were overwhelmed by judgmental attitudes, incompetence, and a lack of compassion and respect from many others that were also a part of their experience. Providers who participated in this study

agreed that parents whose children's conditions are devastating and/or poorly understood often face avoidable stress and lack validation from both professionals and society in general regarding the worth of a child with complex needs related to a currently incurable condition.

Although providers cannot change the reality of a child's condition, many of them do have ongoing opportunities to foster parents' resiliency by providing them with validation and meeting support needs throughout their journeys. Therefore, it is important for professionals in health, education, and disability organizations to be aware of and understand the experiences of parents like the ones who participated in this study. Understanding the distinctive aspects of stress related to caring for a child with a degenerative disability, such as chronic change and the ongoing struggles with validation, can offer insights about experiences that occur beyond a professional's personal interactions or role with a family.

It is equally important for providers to understand the unique opportunity they have to mediate many of the avoidable stresses that are a part of these families' journeys, rather than exacerbate the stress through unnecessary conflict and a lack of validation. If, as the parents in this study said, professionals in multidisciplinary systems provide services with both competence and compassion, the reality of parenting a child with a degenerative condition would not change, but the experiences would include fewer avoidable stresses, and parents meeting their child's needs would be less challenging. As one parent said, "thousands of examples" could be given about both inevitable and avoidable stresses related to parenting a child with a degenerative disability. But if providers "know their jobs" and "do them well," there would be "more 'in spite of

disability, this was wonderful' stories." Indeed, understanding the stressful nature of the journey, providing validation, and meeting the support needs of parents whose children are diagnosed with degenerative conditions can improve the experiences of these families.

Practical Implications

Despite similarities across families, responding to the stress of caring for a child with a disability and personal reactions to grief are unique experiences. Grief comes in different intensities, for different amounts of time, and has different effects on different bereaved individuals and on those around them (Arnold et al., 2005; Drenovsky, 1994; Kreicbergs et al., 2004; Leahy, 1993; Miles & Demi, 1992; Wheeler, 1994). The results of research have shown that parental bereavement has no clear endpoint, and that many bereaved parents grieve the loss of their deceased children for the rest of their lives (Hogan et al., 1996; Leahy, 1993; Lister, 2005; Rando, 1983). The parents in the current study described this as well.

Nelson and Frantz (1996) concluded that their study of bereaved family members provided no evidence at all to support the cliché that "time heals all things." Measures of family functioning and cohesiveness did not differ based on the amount of time that had passed since the death of a child, nor did they differ based on the cause of death. However, there was evidence suggesting that family cohesion before the death of a child was correlated with family functioning and coping after the death. The grief process appeared to be more difficult for those families who had more stress and conflict and less cohesiveness. Other researchers also offer evidence that supports and parental resiliency

prior to the death of a child are beneficial during parental bereavement (Meert et al., 2005; Robinson et al., 2006).

Grieving is a normal reaction to loss and its function is to restore the ability to love, which was impaired by the trauma of the loss (Nelson & Frantz, 1996). With adequate support that begins before the loss of a child with a disability, bereaved parents can shift their roles and relationships to compensate for the loss. Additionally, parents and family members feel supported by having someone with whom they can honestly share feelings, concerns, memories, and various grief reactions including guilt and anger. Such nonjudgmental support can be a source of strength to individuals, couples, and families (Papadatou et al., 1996; Talbot, 1996).

When professionals and providers are aware of the overall experience of parenting a child with a degenerative disability, they can help parents with whom they work become aware of what is typical in this atypical life event. Researchers have reported that this type of information from professionals is desired by parents (deCinque et al., 2006; Segal et al., 1986). The parents in the current study expressed this as a need as well. In addition to being supportive during the child's life, it can be a source of comfort and support to bereaved parents who may feel embarrassed, alone, or bereft of support. Professionals and other support personnel can help parents explore and understand their individual grief reactions. Normalization of grief reactions, especially feelings of guilt, anger, hopelessness, and despair is important. By empathically listening to parents and providing appropriate information and emotional support, professionals can help parents as they cope with feelings of grief and facilitate an understanding that these feelings are not necessarily pathological (Miles & Demi, 1992). This would also

meet the need for validation that parents in the current study sought before and after the death of their child.

Professionals can also anticipate specific responses that may be associated with gender, with the age of a child, and with the nature of the child's death, and help parents understand their own and their partner's and family's coping patterns. This fosters a mutually supportive environment, which is correlated with positive family outcomes (Nelson & Frantz, 1996; Riley et al., 2007; Talbot, 1996). Individuals who support bereaved parents can help them know that feelings of anger and retribution are not abnormal (Drenovsky, 1994). Also, professionals can support parents in integrating their role as a *mother* or a *father* in new life patterns. They can help them to understand that this does not mean they are forgetting or denying their child's existence which is a common fear among bereaved parents (Talbot, 1996, 1997a, 1997b). A more integrated identity acknowledges the child's death, but also preserves the child's memory and honors the parents' past life as a mother or father to the child.

Training

In a review of the literature on bereavement and grief research, the factors that influence change in multidisciplinary services and systems were considered by the Center for the Advancement of Health (2004). According to the authors, although formal and planned change is initiated at an organizational level, actual changes in practice begin at the level of the individual providers. These and other researchers representing multidisciplinary fields have also reported a need for increased preservice and inservice training of professionals in health, education, and advocacy organizations related to the care and support needs of individuals who have life-threatening conditions or who are

dealing with grief and bereavement (Field & Behrman, 2003; Gudmundsdottir, 2000; Lazenby, 2006; Perrin et al., 2007). All of the providers who participated in the current study discussed an ongoing need for training in their disciplines, so that they could better meet the unique needs of the children, parents, and families with whom they work. These providers expressed the need for training related to:

- Working with families whose children have chronic and life-threatening conditions;
- Information about disability-specific degenerative conditions;
- Understanding the overall experiences of families (i.e., beyond discipline specific);
- Understanding the specific support needs of parents during a child's life, and also during loss and bereavement;
- Collaborating with other service systems and providers; and,
- Being prepared to cope with personal feelings of grief related to the death of a child.

This training is often a part of higher education coursework and fieldwork. However, the providers said that preservice training is often limited in scope, and that it is not until professionals are “on the job” that they realize how much more training is needed to be both competent and compassionate in working with families. Therefore, ongoing inservice training is also necessary for providers to best work with and support the children and families they serve. Moreover, training programs may be beneficial not only to the children and families who rely on these service providers, but also to the professionals who may not currently understand the overall experiences of these families,

and who may not be aware of the “very real” and “positive difference” they can in fact make with families in spite a child’s disability and death.

Support

All of the parents in the current study reported that formal and informal supports made a difference during the stressful journey with their child, and also during their time of loss and bereavement. They said that *how* they received information, services, and support mattered as much to them as *what* was actually provided. However, all of these parents also discussed a frequent lack of appropriate and available supports that would best meet their needs and validate their experiences. Consistent with recommendations by experts in the field of family support (Bailey & Bruder, 2005; Dunst et al., 1996; Trivette & Dunst, 2004), these parents said they sought to normalize the stressful and atypical experiences that were a part of their journey, and that having validation and support through healthy and mutually-respectful partnerships with the professionals who were involved in their children’s care mattered greatly.

One of the important sources of support that parents in this study said was lacking was appropriate bereavement support, in which they could talk with other parents who shared similar pre-loss experiences rather than just the tragic experience of a child’s death. Parents reported that they liked the idea of groups being led by parents who understood “first hand” the experience of loss. However, they also said that these parents tended to lack appropriate training related to leading groups and to meeting the needs of all parents. They also said that the membership of these groups was not a good match with their personal experiences or needs.

Many researchers have documented the important reality of how the shared acknowledgment of loss can decrease feelings of social isolation and improve positive outcomes for bereaved parents (Aho et al., 2006; Bohannon, 1991; Brabant, et al., 1995; Schwab, 1995). Research findings are consistent with the theoretical concept that individuals who are able to express feelings in an accepting and supportive atmosphere move through the grieving process in a healthier manner than people who keep feelings inside (Nelson & Frantz, 1996). However, parents in the current study reported that without a shared experience prior to loss, typical grief support groups were not helpful, and were often perceived as hurtful.

In addition, a number of parents in this study said that their own personal loss was so overwhelming that they did not feel that they could participate in a support group at all. They felt unable to provide the “mutual benefit” and support which is assumed in a support group. Therefore, in addition to considering alternate sources of group support in which bereaved parents have more similar pre-loss experiences, it is important to consider alternate sources of bereavement support altogether for parents who have lost children due to a degenerative disability. Parents in the current study suggested Internet chats, phone support, and individual counseling provided by specialists trained in parental loss and grief.

Limitations of the Current Study and Future Research

Although efforts were made to verify the data obtained for the current study, there are three major limitations to this study. These limitations are related to the participants of the study, to the methodology of the study, and to the researcher who conducted the

study. Future research can address these limitations, and expand the findings and implications of the current study.

Participants

The parents who participated in this study represented a diverse group of people. They are from major cities on both the east and west coasts of the United States. The children they discussed represent diverse ethnic backgrounds. However, all of these parents' children were diagnosed with a childhood onset neuromuscular disease, and therefore represent only one of many different types of degenerative disabilities. Additionally, more than half (n=4) of this small group of parents lost their only child. Of the 3 parents who had other children, two of them had one or more of their other children also affected by childhood onset neuromuscular disease. Therefore, only 1 parent in this study had only one child affected by the disease and other healthy siblings not affected by the disease. According to Wheeler (1994) and Talbot (1996), losing an only child has been correlated with intense grief and a *crisis of meaning* for parents. All parents in the current study reported intense grief and most reported a crisis of meaning. These participants mostly represent a group of parents who lost their only child, or who have more than one child affected by or deceased due to a life-threatening neuromuscular disease. Future research should explore the experiences of families who have healthy siblings in addition to a child with a neuromuscular disease.

Methodology

Because this was a new population for qualitative exploration that had a national scope, all interviews were conducted by telephone rather than face to face. Also, due to

the researcher's disability and physical limitations, nationwide travel was not feasible. Nor was the certainty of accessible entrance into all participants' homes for interviews in that setting. Therefore, the chosen methodology was sound for logistic reasons, but qualitative inquiry is typically conducted in person and in natural settings, where the richness of each interaction can be more accurately recorded. Although there was prolonged contact and ongoing telephone and e-mail interactions between the investigator and the participants, the lack of personal contact may have some limitations on what parents chose to say, and thus have an impact on the findings. Future research should include face to face contact between the researcher and the participants.

Researcher

Finally, a potential limitation of the current study may be due to the personal nature of qualitative inquiry. Specifically, the researcher serves as the instrument for observation and data collection. As a result, the values, biases, and perceptions of the researcher conducting this inquiry may have influenced the data collection and analysis. Numerous strategies were used in this study to avoid this possibility, including: specific questions to guide the initial parent interviews, member check, the use of two different peer debriefers, and ongoing journal reflections made by the researcher following each interview.

As discussed in the methodology section, the researcher is a bereaved parent who lost four children to neuromuscular disease. Furthermore, she is well-known as a disability advocate, and serves as a National Vice President for the MDA. The parents in this study were solicited for participation through the MDA, and as a result, all of the participants had previous knowledge of the researcher's status as a bereaved parent. The

parents did not seek personal information about the researcher or the researcher's experiences as a parent during the interviews. Most parents did not even mention their knowledge of the researcher's personal loss until the end of the initial interview, when they were asked to share thoughts and reactions to participating in the current study. At that time, all parents said that their incentive to participate in the current study was due to their knowledge of the researcher's personal losses. They made comments such as "I knew you would understand my experience," "I knew you would not judge me," and "I feel like I know you in some way, so it was easier to talk about this."

The researcher-participant interactions were based on the interview questions that were approved by a dissertation committee prior to the commencement of the study (Appendices J and K). Because this study was qualitative in nature though, the researcher followed the conversational lead of the participants rather than rigidly adhering to the order of the proposed questions. However, the researcher was careful not to ask any leading questions, and to use summarizing statements and reflection during the interviews. In addition, the researcher checked with parent participants about the accuracy of emerging themes during follow-up interviews. There was only one major theme that parents suggested modifying. Parents said that the emerging theme of *seeking typical* as a source of stress was due to the *progressive changes* that complicated the matter of seeking typical. As a result of parent input, this theme was modified.

To document personal biases, prior to her interactions with participants, the researcher was interviewed by a colleague using the proposed interview questions. Finally, the researcher met with two different peer debriefers throughout the course of the study. In addition to discussing the transcripts and emerging themes from participant

interviews, these meetings included discussions about the researcher's field notes and reflective statements that were recorded during and after each interview.

Before beginning this study, the researcher clearly stated her academic interests that grew from personal experience: she sought to gather information about the experiences and needs of bereaved parents whose children died due to degenerative or prolonged disabilities because these parents are under-represented in bereavement research. Samples for bereavement research are largely drawn from community bereavement support groups, and these groups tend to consist of parents whose previously healthy child died due to a traumatic event or catastrophic illness. The researcher wanted to understand why parents who lose children to life-long disabilities are not in these groups. During her personal interview prior to the commencement of the current study, she discussed her own feelings of grief not being recognized by other bereaved parents. She said other people did not seem to understand the depth of grief when a child's death was anticipated for so long, and especially when a child had a significant disability or suffered much during life. During data analysis, whenever a parent comment was made that was similar to an expressed thought or experience mentioned by the researcher during her own interview prior to this study, the researcher carefully reviewed the transcript to ensure that her questions or reflective comments prior to the participants' responses were not leading in nature. She also specifically discussed these comments and transcript sections with a peer debriefer to increase objectivity.

In her field notes taken throughout the study, the researcher commented frequently on the tragic circumstances of the parent experiences shared during the interviews. She wrote that she thought her own "experience was uniquely unfortunate,

but that does not seem to be so. Instead, each of these parents is sharing a personal, yet collectively similar, tragic story.” During her own interview, the researcher talked about not feeling “validated” by other bereaved parents in support groups. In her journal reflections, she wrote that she was “not expecting the parents in this study to share such detailed experiences about a lack of validation that extended back to the point of diagnosis.” Although many of the themes that emerged were “not surprising” to the researcher, she wrote that she was “truly amazed at some of the emerging themes. I would never have expected *progressive change* or *needing hope* or *unanticipated shock* to be in the results section, but they do make perfect sense.” She wrote that she would not have been surprised to find that “the therapeutic aspects of storytelling in bereavement support groups are different for parents who had already told the story again and again to so many professionals.” What emerged instead was that “these parents are saying it’s not the same story. It’s not a shared pre-loss experience. Moreover, it’s too painful for some parents, who have lived their own tragic story for years, to listen to and support other grieving parents.” The researcher also reflected:

Occasionally, a parent has asked me, ‘Am I crazy to think that?’ or ‘Am I alone?’ or ‘Did that ever happen to you?’ Personally, I have the opportunity to validate this parent. I can say, ‘No, what you are saying is very similar to what I have been hearing from other parents,’ or ‘Yes, I do understand how that might feel.’ But I am very much aware that my goal is to personally validate this grieving parent as a professional who is conducting research. I am very careful, and scrutinizing the transcripts, to ensure that I am not seeking validation for my own experiences or my research interests.

Future Research Directions

Researching and explaining experiences of parental grief are difficult tasks. Experiences leading up to the loss of a child, the nature of grief, and subsequent responses are intense, complex, and multifaceted. Parents lose their unique relationship with their child, and also they lose the part of themselves that the child represents. In addition, parents may not have available, at least temporarily, typical sources of social support (i.e., the child's other parent, family members, friends) as they cope with this intense loss. With the death of a child who had a prolonged or degenerative disability, many parents also lose the network of providers and disability-related friends with whom they had weekly, or even daily, contact. It is therefore essential that professionals and providers working with children who have life-threatening conditions be aware of current literature that may help them, as they strive to support parents and family members who are anticipating or coping with the loss of a child.

In spite of a growing body of literature, there remains a lack of reliable and credible research that investigates the effects of demographic and situational variables on parental bereavement. Many of the earlier studies are far too heterogeneous with respect to the age of the deceased child at death, the number of years the parents and family members have been bereaved, and the nature of the child's death itself. On the other hand, most of these studies are far too homogeneous with respect to the source of participants (i.e., primarily solicited from bereavement support groups), and with respect to personal demographics such as race, ethnicity, marital status, and socioeconomic status.

Although many of the previous studies related to parental bereavement have limitations, the results do support the existence of relationships between parental bereavement and various aspects of coping, including: meaning reconstruction, seeking purpose in life, positive coping strategies, and appropriate and available social supports. However, ongoing research is necessary to gather more information about specific grief responses, coping strategies, and support needs of bereaved family members. This is especially true for under-represented populations such as the parents in the current study, and other populations of parents who are not typically reported as bereavement support group members (e.g., parents of children with other degenerative conditions or prolonged severe disabilities that began during infancy or early childhood). Recruiting participants for parental bereavement research is a sensitive and complicated process. Yet, research is needed with groups of parents and family members who are not members of bereavement self-help groups. Although such groups provide distinct and beneficial support to family members, the results may not generalize or transfer to parents who are unable, unwilling, or choose not to attend a bereavement support group.

Researchers exploring parental bereavement sometimes make conclusive assumptions based on information gathered from parents who represent many different situations and variables. Grief is personal. So, too, are the experiences and support needs of parents whose children die from a variety of causes. More studies exploring specific variables, such as the diagnosis of a particular degenerative disability, are needed to explore and explain a particular phenomenon. To date, there has been relatively little research exploring the experiences of parents whose children have died following a life-long disability or life-threatening health condition. More information is needed about the

specific responses and support needs of parents whose children die from severe disabilities and degenerative disabilities.

The researcher of this study explored the experiences and support needs of bereaved parents whose children were diagnosed with a degenerative disability through in-depth qualitative interviews. The findings offer an increased knowledge base for professionals who work with these children and their families in various education, health, and advocacy systems. Although the themes that emerged represent the views of all participants in the current study, additional research is needed with larger samples of parents and providers whose responses represent experiences related to other conditions. These samples might include parents whose children are diagnosed with other degenerative or rare disabilities, as well as parents whose children live for many years with chronic healthcare conditions that result in early death. In addition, research conducted with parents whose children are still living with these conditions would provide insights into real time needs and experiences, rather than a retrospective exploration of experiences and what would have been supportive. Future research should also explore the experiences and needs of parents whose children with life-threatening disabilities are not cognitively or socially typical as was the case in the current study. Additional research might also include focus groups that bring parents and providers together in discussion, rather than comparing individually gathered responses of these participants.

The parents in the current study said that their experiences and needs related to the loss of their child were a continuation of the experiences and needs that were a part of their journey with the child beginning around the time of diagnosis. Therefore, in

addition to research in the area of parental bereavement associated with the death of a child due to a life-threatening disability, studies are needed that explore practical and helpful ways to meet the support and validation needs of parents whose children have life-threatening disabilities. According to researchers who have explored the characteristics and effects of resiliency, providers who work with children and families can access information and tools that can help foster resilience during adverse situations (e.g., Grotberg, 1997; Heiman, 2002; Henderson, Bernard, & Sharp-Light, 2006; Luthar, Cicchetti, & Becker, 2000). Grotberg (1997) said that fostering resilience, or the ability to “prevent, minimize, or overcome the damaging effects of adversity” (p.1), will not change a challenging situation, but it can improve coping strategies. Furthermore, resilience can decrease adverse responses to stresses that are related to difficult situations, such as caring for a child with a degenerative disability, and increase a sense of capability in facing ongoing or future stressful events. Grotberg also said that resiliency grows from feeling connected (e.g., to helpful networks and healthy partnerships), of feeling competent (e.g., having information to make good choices and cope with stress), and of feeling validated regarding personal contributions in spite of adversity and stress. Henderson et al. (2006) said that resilience does not occur by chance; rather, it is nurtured through effort and the ongoing support of providers that interact with a child and family. Future research can explore effective ways of fostering resilience with families who have children with life-threatening disabilities, and increase understanding of how such resilience may correlate with the validation that parents in the current study reported was needed and beneficial.

Changing how parents experience the journey of caring for their children with degenerative and life-threatening disabilities is an important endeavor. So, too, is the endeavor of increasing that availability of appropriate supports for these families. However, to be successful in achieving goals such as providing validation, fostering resiliency, and ensuring useful resources for parents facing and coping with inevitable adversity, considering the approach for change becomes a crucial issue. Oftentimes, policies and guidelines related to change grow from a problem-solving approach based on knowledge and data gathered from theory, research, and practice. Although problem-solving methods can be very effective in health, education, and disability service systems, this approach may not be the best choice for considering how to improve the subjective experiences and perceived support needs of parents whose children have progressive and currently incurable conditions. An alternate approach to change – in which organizations and providers seek not to solve a problem, but to build on and improve services and aspects of care that are perceived as supportive by parents – is more realistic.

For the past decade, the concept of *appreciative inquiry* has been explored and studied as a positive approach to creating change in health (e.g., Farrell, Wallis, & Evans, 2007; Moody, Horten-Deutsch, & Pesut, 2007), education (e.g., Ainscow, 2007; Doveston & Keenaghan, 2006), disability (Jo, Brazil, Lofeld, & Willison, 2007), and other service systems (e.g., Busche & Kassam, 2005; Cooperrider, Whitney, & Stavros, 2003; Losada & Frederickson, 2005). According to Seel (2008), appreciative inquiry is a collaborative method of bringing about desired change, in which previous successes become the foundation for growth and improvement in service providers and systems. Rather than focusing simply on the elimination of deficits and problems, this model

applies an *appreciation* for what is working to the *anticipatory principle* of creating a desirable outcome. Future research can explore this approach for training professionals who work with children who have life-threatening disabilities and their families, and changing perspectives related to working with adverse situations in which problem-solving can be a challenge.

Finally, now that the experiences and perceived needs of parents whose children die from degenerative disabilities have been documented, future research can explore appropriate and innovative sources of social support for these families who have distinct needs. This would benefit parents like the ones in this study who said, "There just needs to be different types of supports there so people can get what they need, and not just try to need what happens to be there." Clearly, support groups benefit many parents whose children have disabilities or whose children die. However, these groups do not meet the disability- or grief-related support needs of all parents, such as the parents in the current study. Future research endeavors can explore alternate sources of support for parents, such as the telephone or Internet chat groups suggested by the parents in this study.

The words of one parent in this study summarize the need for ongoing training, for improvements in available sources of support, and for future research related to the experiences and needs of parents whose children are diagnosed with and die from degenerative disabilities:

There is no book. There is no manual to tell me what to do that is the absolute right thing for my child. Part of that is because this is so atypical, and each child's progression is unique. It ends the same way, but the journey is unique. Still, I think that the whole journey can be a little easier, if providers and other people

understood what it is like day to day, year after year. If people in general could just understand that these children matter, and they live good lives, even though life might be all too short.

Appendix A

Summary of Studies on Parental Bereavement: Grief Responses Across Bereaved Individuals

Author(s)	Subjects/ Source	Years Bereaved	Age/Cause Death	Measurement	Limitations	Findings
Hogan et al. (1996)	N=34 adults (22 parents, 9 adult children, 3 siblings) -Support groups	6 mos – 37 years	-2 to 85 years -Violence, AIDS, suicide, sudden illness, chronic illness	-Telephone open-ended interviews	-Selection -No information re: relationships of decease to survivors – Varying length of bereavement	-Grief follows a pattern regardless of cause of death, timeliness, or relationship to deceased -Anticipated death does not lead to ameliorated or foreshortened grief
Leahy (1993)	N=255 widows, mothers, daughters ("mothers n" = 58) -Support groups	1 month - 2 years	-Ages not specified -Illness, accident, "other"	-Written - <i>BDI</i> short form	-Selection -Variable age/cause	-Bereaved mothers reported more depression than widows, daughters -Mothers: more social withdrawal, sadness, guilt, hopelessness
Middleton et al. (1998)	N = (44 spouses, 40 adult children, 36 parents) - Australian study -Hospital referrals	No info	-6 months to 70 years -Sudden, illness, trauma, accident	-Bereavement questionnaire created for study; done 4x across 13 months	-Variable age/cause within groups -Missing participant information	-Bereaved parents had most intense grief responses (followed by spouses, then adult children)
Nelson & Frantz (1996)	N=80 (41 parents, 39 adolescent sibs) -Support groups; newspaper ads	Mean = 4 years	-Not specified -36%=suicide, 5%=accident, 29%=illness	-Written "interaction" instruments	-Selection -Generalization -Missing information	-Family conflicts correlated with "distance" among family members -Siblings reported more conflict than parent; closer to fathers after death
Ponzetti (1992)	N=64 (15 parent couples, 6 mothers, 20 grandmothers, 8 grandfathers) (n=21 deceased children) -Support groups	Not specified	- 1 month to 30 years -30% cancer -28% heart disease -42% other causes	-Self-report questionnaire	-Selection -Generalization	-Parents' grief focused on deceased child vs. grandparents' grief focused on their child (parent of deceased) -Parents treated siblings different after death of a child
Reif et al., (1995)	N=158 (140 parent, 3 children, 10 sibs, 5 grandchildren) -Support group	1 month to 17 years	-Newborn to 72 years -Various causes	-Descriptive questionnaires	-Generalization -Varying ages, causes, length of bereavement	-Time since death was strongest indicator of severe distress -Perceived helpfulness of others was indicator of coping

Appendix B

Summary of Studies on Parental Bereavement: Grief Responses Across Type of Childhood Death

Author(s)	Subjects/Source	Years Bereaved	Age/Cause Death	Measurement	Limitations	Findings
Alexy (1982)	N=42 parents (25 mothers, 17 fathers) -Support group	1 – 9 yrs	-6 months to 28 years -43% cancer, illness -57% sudden, trauma	-Interviews; self-report rating scales	-Selection -Generalization	-Bereaved parents prefer different types/sources of support during different phases of grieving
Arnold et al. (2005)	N=74 (Nursing alumni who lost a child) -Solicitation letters to all alumni	1 – 62 years	-Infancy to adulthood -Trauma, illness, disease, SIDS, other	-Quantitative measures created for this study	Instrumentation -Selection -Varying ages, causes, length of bereavement	-Parental grief is intense and lasting, no matter how or when a child dies -25% reported feeling ignored by others as a parent after child's death -Supports varied (family, friends, groups) but no data re: by type of loss
Drenovsky (1994)	N=39 couples (78 participants) -Support groups	-Not specified	-Ages not specified -76% sudden death (SIDS, accident, suicide)	-Written grief and depression instruments	-Selection -Generalization -Missing participant information	-Suddenness of death correlated with anger -Mothers express more anger; fathers express more desire for retribution
Miles & Demi (1992)	N=132 parents -Support groups	2 mos. - 7 yrs.	-1 to 18 years 62=suicide, 32= accident, 38=illness	-Written, open-ended questions re: stress, guilt	-Selection -Generalization -Varying ages	-Suicide survivors express more guilt
Seecharan et al. (2004)	N=79 parents or guardians of 59 children (30% of invited) -Hospital records	7 mos to 3 years	-Birth to >18 years -Traumatic, illness, neonatal problems, infections, disease	-Interviews, questionnaires - <i>Texas Grief Inventory (Revised)</i>	-Generalization -Varying ages, causes	Fathers/mothers had similar grief -Mothers of sudden children who died suddenly showed more grief than mothers of whose children died after anticipatory period
Wheeler (1994)	N=203 parents (73% mothers) -Support groups	1 month - 40 yrs.	-Birth to 48 years -Accident, disease, murder, suicide	-Written <i>GEI, Purpose of Life</i> tests	-Selection -Generalization Instrumentation -Variable age/cause	-Lower purpose in life correlated w/ recency of death, suicide, and loss of only child or multiple -'Crisis of meaning' reported

Appendix C

Summary of Studies on Parental Bereavement: Grief Responses Within Type of Childhood Death

Author(s)	Subjects/ Source	Years Bereaved	Age/Cause Death	Measurement	Limitations	Findings
Aho et al. (2006)	N=8 fathers -Internet support group	2 mos – 2 years	-Newborn to 2 years -Birth defect or chronic heart defects	-Open-ended questionnaires -f/u interviews by telephone, or face-to-face	-One father lost four children; others lost one child or only child -Selection	-Fathers' anticipatory feelings include fear, uncertainty, lack of knowledge, powerless to help child -Anticipatory feelings correlated with grief responses (disbelief, despair, self-blame, relief of child's pain) -Long-term stress of disability 'inhibited' grieving after death -Felt they had to grieve privately to protect others
Chomicki et al. (1995)	N=3 parents (2 mothers, 1 father) -Not specified	Not specified	-3 to 15 years -Severe or life- long disability	-Case study -Interviews	-Transferability -Missing participant information	-Parents are not prepared for death, even when anticipated -Chronic sorrow persists beyond death
Clerici et al. (2006)	N=17 families interviewed (chosen from 22 families who sought contact with professionals) -Hospital records	Approx 1 to 2 years	-Ages not specified -Cancer	-Semi-structured phone interviews	-Missing participant information -Transferability	-More than 50% of bereaved families sought contact with professionals who cared for child before death (for support and connection to child, not to complain)
Corden et al. (2002)	N=16 families (12 two-parent; 4 single mothers) -Children's hospice	Fewer than 2 years	-Infant to 17 years -Metabolic diseases, progressive diseases, cancer	-Semi-structured interviews	-Selection -Transferability	-All parents lost child's social security benefits (up to 72% of income) -Re-engagement with employment difficult (time since training and experience; grief time) -Negative financial impact found for families of severely disabled children can extend for years

Appendix C (continued)

Summary of Studies on Parental Bereavement: Grief Responses Within Type of Childhood Death

Author(s)	Subjects/Source	Years Bereaved	Age/Cause Death	Measurement	Limitations	Findings
deCinque et al. (2006)	N=9 parents (6 mothers, 3 fathers) -Australian hospital based support group	About 7 years	-No information -Cancer	-Narrative inquiry	-Transferability -Lacking participant information	-Parents desired more supportive contact with professionals both before and after their children's deaths -Sought practical and emotional information -Desired formal supports for siblings
Gillis et al. (1997)	N=97 bereaved parents who were already in another study (56 mothers, 41 fathers)	2 years	-1 month to 17 years -Cancer	-Self-report - <i>Symptom Checklist-90-Revised</i>	-Self report of symptoms -Generalization	-Parents reported higher somatic than behavioral and affective distress related to grief
Goodenough et al. (2004)	N=25 mother-father Australian dyads (total 50 parents) -Not specified	1 to 5 years	-Mean: 7 to 10 years -Cancer	-Self-report questionnaires, check-lists	-Generalization -Theoretical assumptions	-Fathers: more depression, anxiety, stress when child died in a hospital -Mothers: more intense grieving regardless of place of death
Kreicbergs et al. (2004)	N=449 Swedish parents (80% of all contacted by mail) N=457 non-bereaved parents (69% of all contacted by mail) -National mailing	4 to 9 years	-Age not specified -Cancer	-Developed for this study -Written questionnaires assessing: anxiety, depression, psychological well-being, quality of life	-Instrumentation -Lacking participant information -Theoretical assumptions	-Increased risk of anxiety/depression during first 4 to 6 years of grief -Bereaved mothers showed more psychological distress than non-bereaved mothers -Bereaved fathers showed more distress than non-bereaved fathers if child was over 9 years of age
Lister (2005)	N=16 (13 mothers, 3 fathers) -Support groups, mailings, personal invitations, etc...	6 months to 18 years	-1 to 22 years -Illness that lasted more than 6 mos	-Interviews	-Transferability -Varying ages, length of bereavement	-Trying to make meaning of loss began with diagnosis, not death -Friends provided more support than family members during bereavement -Meaning reconstruction takes years

Appendix C (continued)

Summary of Studies on Parental Bereavement: Grief Responses Within Type of Childhood Death

Author(s)	Subjects/Source	Years Bereaved	Age/Cause Death	Measurement	Limitations	Findings
Milo (1997)	N=8 mothers -From disability support groups before child's death	1 – 7 years	-10 months to 37 years -Various severe disabilities and health conditions	- <i>GEI</i> -Semi-structured interviews	-Selection -Varying ages	-Mothers felt their loss was not validated due to child's disability -Felt dual loss (disability and death) -Cognitive coping strategies can help mothers find meaning in pain of child disability and death
Papadatou et al. (1996)	N=15 mothers from Greece -20% lost only child -Hospital records	6 months – 3 yrs.	- 2 years to 16 years - Cancer	-Interviews -Medical records - <i>GEI</i>	-Selection -Generalization	-Decision to care for dying child at home vs. hospital based on family network, and availability of preferred supports -Grief is influenced by culture
Rando (1983)	N=54 parents -Support groups	2 months – 3 years	-Various ages -Cancer	-Grief scales, questionnaires	-Selection -Theoretical assumptions	-Best length of time to prepare for child's death: 18 months to 2 years -Grief subsides across first two years after death, then increases in third year
Wood & Milo (2001)	N=8 fathers -From disability support groups before child's death	No info	- 7 months to 16 years -Various severe disabilities and health conditions	- <i>GEI</i> -Semi-structure interviews	-Selection -Varying ages -Missing participant information	-Fathers who lose a child with a disability do not differ from other bereaved fathers on grief scales -Fathers who lost a child with a disability report a <i>double loss</i> -Fathers choose stoicism and activity over social support for coping

Appendix D

Summary of Studies on Parental Bereavement: Grief Responses Across Bereaved Parents by Gender

Author(s)	Subjects/Source	Years Bereaved	Age/Cause Death	Measurement	Limitations	Findings
Bohannon (1991a)	N=33 husbands and wives -Subset of previous study participants -Support groups	2 months - 5 years	-Newborn to adult -Various	- <i>GEL</i> 3x across 1 year	-Selection -Generalization -Varying age/cause	-Negative marital feelings before death correlated with high grief responses at death -This effect not present one year later for fathers, non-significant for mothers
Devine (1993)	N=109 parents (84 mothers, 25 fathers) -Support groups (for bereaved or mental health) -12 participants were divorced	3 months -40 years	-Birth to 39 years -Accident, suicide, traumatic illness, SIDS, stillbirth, homicide	-Self-report questionnaires - <i>COPE</i> , <i>PSS</i> , marital scale	-Selection -Instrumentation -Generalization	-Pre-death marital satisfaction is greatest predictor of post-death marital status and satisfaction -Low divorce rate in this sample
Schwab (1996)	N=35 couples -Support groups -Obituaries	No info	-Newborn to 40 yrs. -Cancer, accident, suicide, AIDS, SIDS, stillborn, illness	- <i>GEL</i> scales	-Instrumentation -Lacking participant information	-Mothers scored higher on most grief responses (despair, guilt, somatic) -No difference in denial, isolation, death anxiety, loss of appetite

Appendix E

Summary of Studies on Parental Bereavement: Grief Responses --- Loss of Only Child

Author(s)	Subjects/Source	Years Bereaved	Age/Cause Death	Measurement	Limitations	Findings
Talbot (1996)	N=80 mothers who lost an only child -Bereavement newsletter mailing list	Mean = 9 years (68%= 5-13 years)	-77% were 14-21 years (range= 3-21 years) -73% accident, 27% illness	-Interviews -Life attitude, well-being measures	-Selection -Generalization -Varying age/cause	-75% classified as <i>survivors</i> , 25% classified as <i>perpetually bereaved</i> -Positive life attitude, asking for and accepting support, social activities were positively correlated with coping
Talbot (1997a)	N=80 mothers who lost only child -Bereavement newsletter mailing list	Mean = 9 years 68%= 5-13 years)	-77% were 14-21 years (range= 3-21 yrs) -73% accident, 27% illness	-Interviews -Life attitude, well-being measures	-Selection -Generalization -Varying age/cause	- <i>Survivor</i> mothers see change in self and how approach life; integrate loss - <i>Perpetually bereaved</i> mothers focus on feeling and defining their loss
Talbot (1997b)	N=80 mothers who lost only child -Bereavement newsletter mailing list	Mean = 9 years (68%= 5-13 years)	-77% were 14-21 years (range= 3-21 yrs) -73% accident, 27% illness	-Interviews -Life attitude, well-being measures	-Selection -Generalization -Varying age/cause	-Motherhood becomes integral part of the self; coping is not relinquishing role, but integrating mothering identity in other ways

Appendix F

Summary of Studies on Parental Bereavement: Meaning Reconstruction in Parental Grief

Author(s)	Subjects/ Source	Years Bereaved	Age/Cause Death	Measurement	Limitations	Findings
Bohannon (1991b)	N=272 participants (143 mothers, 129 fathers) -Support groups	8 - 18 months	-Newborn to adult -Various	-Written <i>GEI</i> and religiosity instruments	-Selection -Generalization -Varying causes of death	-Church attendance correlated with levels of despair, loss of control (mothers), and anger/guilt (all parents) -Mothers > fathers on all grief measures except social isolation.
Braun & Berg (1994)	N=10 mothers -Support groups	No info	- No information -Sudden loss	-Interviews	-Lacks information re: participants, deceased children	-Life's meaning structures before and after loss are highly correlated -Meaning reconstruction grows from discontinuity, disorientation, and adjustment
Brotherson (1999)	N=19 (13 mothers, 6 fathers; all different families) -Support groups and personal invitation	2 to 49 years	-18 months to 25 years -Catastrophic illness, trauma, accident	-Semi-structured interviews	-Transferability -Variable age/cause	-Loss by illness or trauma has lasting impact, and parents seek to share story -Parents seek <i>connection</i> to deceased -Parents experience loss of hope; loss of sense of control; increased compassion to other bereaved parents
Brotherson & Soderquist (2002)	N=19 parents (13 mothers, 6 fathers) -Support groups and 'snowballing'	Minimum 2 years; No upper limit	-18 months to 25 years -Accident or cancer	-In-depth interviews	-Varying age, cause, time -Transferability	-Spirituality helps bereaved parents maintain <i>connection</i> to child, and offers beneficial ritual/clergy support
Fletcher (2002)	N=2 Hispanic families -Support group	7 months to 1 year	-5 months (illness) - 17 years (accident)	-Case study -Interviews	-Transferability -Variable age/cause -Theoretical assumptions	-Loss of a child by illness or accident can result in <i>identity crisis</i> for family -Families need communication outlets regarding their experiences and grief

Appendix F (continued)

Summary of Studies on Parental Bereavement: Meaning Reconstruction in Parental Grief

Author(s)	Subjects/Source	Years Bereaved	Age/Cause Death	Measurement	Limitations	Findings
Meert et al. (2005)	N=33 parents of 26 children (50% of those invited) -Hospital ICU records	2 years	- 3 days to 24 years -Accident, chronic illness, acute illness, malignancy	-Semi-structured interviews	-Transferrability -Varying age, cause	-Bereaved parents have intense spiritual needs -Parents need connection with child before (involvement), during (presence), and following death of child (memories, keepsakes, sharing memories, organ donation) -Caring professionals who foster such connections make a positive difference
Riley et al. (2007)	N=35 mothers -Support or therapy groups	Mean = 12 years	- 2 to 30 months -Accidents or neonatal deaths	-Likert scales, questionnaires	-Generalization -Varying cause/age	-More optimistic mothers reported less intense grief reactions/distress -Active coping, support seeking correlated with lower grief responses
Robinson et al. (2006)	N=56 parents whose child died in PICU -Hospital records	1 to 4 years	-Newborn – 18 years -Withdrawn from life-support equipment -Various causes	-Open-ended questionnaires	-Generalization	-73% parents found spirituality helpful at end of child's life and after death (rituals, clergy support, transcendent beliefs of future re-unification)
Wheeler (2001)	N=176 parents from a larger study -Support groups in 4 parts of U.S.	1 mos to 40 years	- Birth to 48 years -Sudden death, catastrophic illness, murder, suicide	-Open-ended questionnaires	-Transferability -Varying ages, causes, length of bereavement	-Death of child precipitates severe <i>crisis of meaning</i> ; need new purpose -Meaning found via: connections with others involved with child or similar loss; activities/objects related to child

Appendix G

Summary of Studies on Parental Bereavement: Supports from Parent Bereavement Groups

Author(s)	Subjects/Source	Years Bereaved	Age/Cause Death	Measurement	Limitations	Findings
Brabant et al. (1995)	N=14 participants (from 9 families) -Support groups	"More than one year"	-Newborn to 29 years -Accident, illness, congenital disability	-Interviews -4 open-ended questions -Grief measure	-Selection -Variable age; type of death -Generalization	-More than 50% perceived lack of support from family, friends -Most support from coworkers, clergy -Most reported no long-term support
deJong-Berg & Kane (2006)	N=21 of the 81 families invited -Hospital records (hospital where child died was source of support groups)	Less than 3 years	-Birth to 16 years -Illness, trauma, congenital diseases	-Telephone interviews -Survey created for the study	-Selection -Attrition -Instrumentation	-Families who receive information re: bereavement and participate in groups find them helpful
Schwab (1995)	n=85 (43 support group participants, 42 non-participants) -Death notices -Support group	1 to 4 years	-Newborn to 43 years -"Sudden" or "anticipated"	-Non-group= phone survey -Group= written survey	-Instrumentation -Generalization -Varying ages, cause of death	-Most support group participants lost child suddenly; most non-participants lost child after anticipatory grief period -Participants lacked other supports -Non-part's sought informal supports
Thuen (1995)	N=164 participants (45% of invited) (46% widow, 47% parent, 7% sib/other) -Norwegian bereavement project	1 to 24 years	-Newborn to geriatric -Illness, accident, suicide, stillbirth	-Questionnaire	-Generalization -Theoretical assumptions -Varying ages, causes, relationship to deceased	-Group participants found groups helpful -Bereaved parents (vs. widows) and those whose loss was <i>sudden</i> were more likely to attend groups
Toller (2005)	N=16 parents (12 mothers, 4 fathers) -Support group	6 months to 29 years	5 months to 35 years -Illness, suicide, accident	-Semi-structured interviews	-Transferability -Varying ages, causes	-Talking about deceased child can be <i>double-edged sword</i> -Desire to keep memories and seek meaning, but concern with discomfort and criticism from others

Appendix H

Summary of Studies on Parental Bereavement: Support from Professionals Involved with Child

Author(s)	Subjects/Source	Years Bereaved	Age/Cause Death	Measurement	Limitations	Findings
Macdonald et al. (2005)	N=12 parents -Hospital ICU records	9 to 18 months	-Infant to >18 years -Trauma, disease	-Interviews, observation field notes	-Varying age, cause -Generalization	-Families valued contact, support, kindness from professionals after child's death (e.g., attending memorial, sending notes r cards, occasional phone calls)
Segal et al. (1986)	N=61 families -Canadian professional records -News media	5 to 40 years	-Birth to 7 years (>50% over 1 year) -Sudden, cancer, chronic disease, SIDS	-Interviews -Questionnaire	-Varying causes -Theoretical assumptions -Missing information	-80% reported grief information and available counseling to be inadequate -50% reported receiving no support or information related to grieving -Preferred support source varies

Appendix I

Advertisement for Participant Recruitment

Parents Wanted for Grief Support Research

Parents who have lost a child due to neuromuscular disease have an opportunity to participate in research aimed at improving grief support services. The research is being conducted by MDA National Vice President Jeni Stepanek. She is a student researcher and doctoral candidate at the University of Maryland. The research will explore the types of supports families find most helpful when raising a child with a life-threatening neuromuscular disease, and also the types of supports families find most helpful after the deaths of their children. To learn more about this study or to learn about participating in the telephone interviews, please e-mail Jeni Stepanek at potatosaladclub@aol.com or call 301-405-6476. Thank you.

Appendix J

INTERVIEW QUESTIONS FOR PARENT PARTICIPANTS

1. Tell me a little about your child and family.
 - a. When was your child diagnosed?
 - b. What were some of the issues you and your family had to deal with because of this diagnosis?
2. Thinking back to time when (child's name) was diagnosed, what was that like for you?
 - a. What helped you and your family most during that time?
 - b. What was not helpful to you during that time?
3. What would you like to share about the time surrounding (child's name) death?
 - a. What helped you and your family during that time?
 - b. What was not helpful to you during that time?
4. Thinking about the time since (child's name) died, what has that been like for you?
 - a. What has helped you and you family during this time?
 - b. What has not been helpful to you during this time?
5. Are there any types of support that you wish would have been available to you during your child's life?
 - a. Is there any type of support you would like to have, that is not available right now?
 - b. What types of support are least helpful to you?
6. Are there any suggestions you might offer to professionals who work with children who have disabilities and their families (health, education, advocacy organizations)?
 - a. Is there anything you would like professionals to know about things that are needed, or that are not helpful, for families who have a child with a neuromuscular disease?

- b. Is there anything you would like other parents who might be living with or facing a similar loss to know?

Appendix K

INTERVIEW QUESTIONS FOR KEY PERSONNEL

1. Tell me about how you work with children and families.
 - a. Once a parent receives his or her child's diagnosis of neuromuscular disease, when do you meet the families and begin working with them?
 - b. What are some of the issues families typically have to deal with because of this diagnosis?
2. Thinking about the time just after a child is diagnosed, what is that like for parents?
 - a. What is most helpful to parents during that time?
 - b. What is not helpful to parents during that time?
3. When a child dies, what is your involvement with parents like around that time?
 - a. What is most helpful to parents during that time?
 - b. What is not helpful to parents during that time?
4. In the months and years after a child's death, what is your typical involvement with parents like during that time?
 - a. What is most helpful to parents during that time?
 - b. What is not helpful to parents during that time?
5. Is there any type of support that you wish could be available for parents whose children are diagnosed with neuromuscular disease, but is not?
 - a. Is there any type of support that you think would be helpful to parents during the time after their children's deaths that is not typically available to them?
 - b. Is there any type of support that is typically offered to these parents that you think is not helpful?
6. Are there any suggestions you might offer to other professionals who work with children who have disabilities and their families (health, education, advocacy organizations)?

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