CHRONIC SORROW IN MOTHERS OF ADULT CHILDREN WITH CEREBRAL PALSY: AN EXPLORATORY STUDY

by

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AN ABSTRACT OF A DISSERTATION

submitted in partial fulfillment of the requirements for the degree

DOCTOR OF PHILOSOPHY

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Abstract

Chronic sorrow has been defined as *a permanent and reoccurring experience of pervasive sadness and loss which underlies the life experience and which recurs over time for the parent of a child with developmental, medical, or behavior issues that prevent him from participating in society in a way previously anticipated by parents.* The functional question asked of the mothers was: "*Some parents have described a sadness that can occur when they think about their child with a disability. Parents can believe they are functioning well, but have times where they feel the loss for their child*." To date, little research has targeted chronic sorrow among parents of adult children who have a disability. Neither is it known how chronic sorrow exists and has changed over the years since the initial diagnosis for this specific sample.

This exploratory, qualitative study focused specifically on mothers of adult children with cerebral palsy. Snowball sampling was utilized to recruit six mothers in northeastern Kansas who were primary caregivers to their adult children with CP. Data were gathered with face-to-face mixed self-report surveys, including the Kendall Questionnaire on Chronic Sorrow; two surveys which assessed demographic, potential complications from cerebral palsy, and available resources; and a standard schedule open-ended interview targeting: personal experiences of chronic sorrow, chronic sorrow triggers (developmental milestones), and losses (including support, roles and responsibilities, and quality of life).

Two-coder analyses of interview responses were conducted within cases and comparisons were made across cases. Common themes identified in the narratives included sense of isolation, fear for the future, frustration, loss of hope, exhaustion, sadness, financial challenges, guilt, and anger. For example, isolation was another theme that changed over time depending on if the mothers were providing full-time care. Also, fear for the future was a universal theme when the children were much younger, but it changed into loss of hope for some of the mothers when the child was the age of an adult. The relevance of the findings was discussed, with particular focus being the subjective meanings of chronic sorrow for this sample. Recommendations for advancing research, practice, and policy are offered.

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Acknowledgements

I am grateful for the support of and encouragement from my family, peers, and KSU faculty during this journey.

Dedication

This is dedicated to all those mothers who have persevered through happy and sad days, through achievements and setbacks, and whose lives have been changed through their children.

CHAPTER 1 - PROBLEM IDENTIFICATION

Introduction: Statement of problem

"No one understands." Although that sounds like a statement a disgruntled teen might make, it is also a sentiment possibly felt by parents of children who have disabilities. When individuals have similar concerns or interests or share understanding, they find it easy to communicate. It is even more so for parents of children with disabilities as few others share similar backgrounds. Many parents may have loving concern expressed for the parent and family, but as helpful as this is, it is not the same as having a listening ear from someone who has similar concerns and experiences.

I know this. I live this every day. Our oldest child, Michael, has multiple disabilities. His chief diagnosis is autistic spectrum disorder (ASD), but he also has Attention Deficit Disorder (ADD), vision problems with near-vision tracking difficulties, a seizure disorder, and both fine and gross motor dyskinesia. According to a neurologist, he also has an undiagnosed syndrome because he has hyperextensible joints, a high arching palate, absent arch on his feet, an unusual hairline, scapular prominences, and has only a few muscle fibers loosely tacked into place. He has had chronic difficulties with digestion.

During early childhood, his immune system was less active than other children. He spent the majority of his first three years with illness including the usual childhood chickenpox and colds, but also ophthalmic staphylococcal infections. He also had a standing order for antibiotics because of recurrent pneumonia and bronchitis. Any increase in humidity would set off a respiratory infection. I am a Registered Nurse, so he was never hospitalized as I was comfortable caring for him at home. After I realized the connection between weather changes and rapid respiratory tract infection occurrence, I was grateful he never had to be in the hospital where one of the first things ordered might have been a croup tent which adds moisture to the air and would have made him worse. It was decided that not only were his skeletal muscles weak, but also that smooth muscle and the cilia which move mucous up the respiratory tract were weak.

Although he had received infant stimulation therapy beginning shortly after his first birthday, it was not enough for professionals to see significant progress. He began attending preschool a few days before his second birthday, unusual for the early 1980s. He sat if placed, but he did not yet walk or talk at that time and was projected to be moderately to severely

developmentally delayed with little hope of walking or speaking. I had been given exercises to do with him. (Amazingly enough, he still remembers 'The Price is Right' from all the passive muscle exercises I did with him at that young age!) He received diagnoses from Cerebral Palsy to 'we have no idea.'

He had a flat affect and did not respond to voices or surroundings. The therapists told me to talk to him always, verbalizing colors and surroundings. We also read to him a great deal. All of these were terrifically important as it turned out he retained it all. Before he could talk, he would scream to be pushed toward the Dairy Queen or the library, his two favorite places. He read words at a similar time he discovered how to talk. He remembered everything, and still does.

As he grew older, he had numerous problems with the school system, primarily because of lack of an appropriate diagnosis. At one point during an Individual Educational Plan (IEP) meeting, teachers argued where he should be placed as his physical disabilities and his inability to complete activities of daily living (ADLs) would have a better fit with the children with more severe disabilities, but the educators did not want him there as Michael could read. They believed it would be a disservice to him to not have adequate learning environment.

The educational system was not equipped to deal with Michael's particular set of disabilities. Early in the grade school system in the l980s, he was tested for autism without parental knowledge, but it was determined this was not a possibility because of his ability to speak. Shortly after this, we moved to another town, one that had been considered previously, but whose special education director at an earlier time refused to provide services. That person was no longer there and services were available. By now, his folder was becoming quite thick. No one reviewed his school folder, so he was placed in a classroom that was easiest to get to as those responsible for classroom placement believed he probably had a problem with ambulation since his file was so thick, although he did not. His teacher at that time was hostile to working with children with disabilities, but the years after were good ones. He worked on the advanced spelling list, took Spanish, and learned to write in cursive. Doors closed to his education as soon as grade school was over. Teachers did not want to make any accommodations in Spanish or to have him in a regular classroom.

A paraprofessional for required one-on-one help was not consistently available. He attended five schools in five years, not only because of his disabilities but also because of new

school construction. He then was exposed to some of the worst teachers known to the special education system, but was rescued because of a caring paraprofessional. It was not until years later that we discovered all the cruel things that had been said to him by one teacher. Michael has a great memory and could quote her word-for-word; the statements were later validated by other students and teachers in the regular education system who did not know what to do.

Health was not usually a problem, but he did have a badly broken leg as a result of a car running into him on a side street when he was 12. Once again, his disabilities were not considered. He was given only Tylenol for pain medication post-surgery as they were unsure of his ability to communicate whether he was in pain and wanted this response magnified to detect complications should they develop. Because of his very high pain threshold, this was not a huge problem; however, he knew clearly that he was not supposed to urinate in the bed and refused to use a urinal. With much encouragement, the nurse finally notified the physician that an order to get up to the commode was needed. His major pain issue was almost instantly resolved.

Health became a problem his last year in high school as he had continuous sinus infections with chronic nasal bleeding, although he had several courses of antibiotics that alleviated the problem only for a few weeks. Again, with insistence to the physician from me, a computerized tomogram (CT) scan was scheduled along with a consult with an ear, nose, and throat specialist. The radiologist and both physicians read the scan and believed surgery to remove the infection in the sinus cavities was necessary. He needed two doses of antihypertensive medication before surgery as his blood pressure was quite elevated. Surgery was complete, but the nasal bleeding was not resolving. The physician reviewed the CT scan again and was surprised to learn that a 6 cm tumor was present. In a few weeks, Michael experienced a grand mal seizure and three days later was semi-comatose. By that time, we knew the diagnosis: nasopharyngeal cancer, inoperable due to the location of the tumor and the crossing pathways of the cranial nerves. He had exceptional care from the physicians, nurses, and technicians in the radiation and oncology units. However, he still developed sepsis twice, had surgery to replace gastrointestinal feeding tubes and central lines, and experienced acute and then chronic kidney failure.

Because of the necessary antibiotics, contrast medium used for testing, infections, and the kidney failure with resulting severe edema, he also developed avascular necrosis of the joints. One joint was 100% necrotic with severe pain, so he needed a total hip replacement. He was not

a good surgical candidate, but the decision was made to have the surgery to improve his quality of life. He had reaction to medication and anesthesia and instead of staying overnight in the hospital, he was there 5 days, then spent another week at a rehabilitation unit and needed four units of blood. Other joints are believed to have regained circulation and the bones have repaired on their own.

The hip problem and the long cancer treatment led to the necessity of resigning from his job which he loved. He now works in a sheltered workshop during the day and still hopes to return to the job he had previous to the drama.

Throughout his life, we have had concerns about his vulnerability, if peers or adults would accept him, and what his future would bring. Sadly, not enough people are aware of his needs or of the needs of others with disabilities. Some can understand the disabilities associated with health problems such as cardiovascular problems or diabetes, but have no understanding of those who have intellectual along with physical disabilities.

Parents who have children with disabilities have few people with whom they can connect who have any conception of the fears and joys that occur with parenting these special children. Sharing about concerns or difficulties brings an attempt at understanding, but soon eyes glaze and explanations are seemingly incomprehensible. In contrast, when visiting with another parent who has a child no matter what age with congenital disabilities, it is possible to finish each other's sentences. The background for each is of enough similarity that understanding occurs rapidly. We can share the accomplishments we see that may mean little to others with typical children. Conversely, we can also share the fears and the ongoing sadness that is sometimes a sub-text of our lives.

Purpose of Research

In addition to giving a voice to those parents of adult children, this study will explore if and how chronic sorrow is experienced by parents of adult children with Cerebral Palsy (CP) and will begin a discussion about if and how chronic sorrow is expressed differently by parents of adult children over time.

This specific study will assess the presence of chronic sorrow. It will also be of use to professionals who work with parents as they need anticipatory guidance and information for

those years. It will be a beginning to the discussion of chronic sorrow in a specific population, but it is hoped that it will be a springboard to the understanding of additional populations.

The study will give voice to parents who still have a story to tell. Studies such as this can begin a discussion of how parenting this child has changed their lives, if they have advice for those aging parents of these adult children, and specifically, what parents of adults with disabilities can tell about how chronic sorrow changes over time. Their wisdom and approaches to the decisions they made for and about their child will potentially be of assistance to parents struggling with similar choices.

Background of the Problem

Parents who have a child with disabilities face many challenges in their lives that circle around their child. Immediate concerns may deal first with what is the precise reality, with whether or not their child will survive and for how long. Challenges encompass how they will manage day-to-day issues, how to tell family and friends, and will they have the stamina to be good parents in this new unanticipated situation. They then have concerns about the future, acceptance of their child into the community, what abilities and opportunities the child will have, and where and with whom the child will live when he is older. Day-to-day routines soon take over the long-term concerns as immediate needs replace future thinking. Parents and their child become a family where the child is integral to the family function and structure. The child with the disability becomes the centerpiece of the family, sometimes being noticed because he is not quite the same as other children and sometimes being admired as he strives through barriers. The child because of his existence and because of whatever specific disabilities he has may supplant other siblings, other family and individual goals, and may change living situations, socioeconomic status, and career choices. There may never be a more life-changing and perhaps life-affirming life circumstance for the family than the existence of this specific child.

Change comes to families as they meet others. For families with a child with disabilities, their circle changes from day one. Health care professionals seen for routine health care matters may also be seen frequently for concerns that could be life-threatening and will upset equilibrium in the family. Professionals do not need to refer to a medical chart as they become very familiar with the parents, usually the mother, and the child with the disability. Personal identity changes to ‘the mother or father or sibling of the disabled child’. At some point, health care providers

may listen to the parent describe what is happening physiologically and allow the mother to participate in health care decisions. If the child is able and services are available, the circle will expand enough to let in specialized therapists. Choices of who will do the therapy are few, but if the family is fortunate, the therapists have some knowledge and experience dealing with the particular disability of the child and will care for their child with objectivity, skill, and patience.

The location for school or the age at which the child will begin school cannot always be chosen by the parent as services available are intertwined to the educational system in early years. Changes can be made as the parents struggle to attain services they believe appropriate for their child by working with parent organizations, teachers, the school board, and if needed, the legal system. Uprooting the family to another city or state may become necessary for the child to receive needed services within the educational system. The diagnostic label may blur and may be different depending on how services are allocated within the system.

Life for all involved with the child can become almost routine when the child has educational services. The child has a variety of people with whom he associates, and his world expands depending on the interest of the educational system in providing enriching activities and preparation for the future. Those with whom he works know him well as do other peers without disabilities if the school provides an appropriate education in the least restrictive environment.

The family is faced with many obstacles as they advocate for their child with disabilities. Distress can and does occur because of the disabilities apart from typical family issues. Coping mechanisms may not be quite the same as those are for the typical family. Family members including spouses and siblings may not receive the time or quality of attention as does the child with the disability. The principle caregiver for the child may change career goals for either parent. The principle breadwinner may change in order to provide health insurance and community resources for the child. These changes may be viewed as beneficial for the entire family or they may be greeted with resentment.

Although paperwork may be initiated when the child is 14, transition services are not usually satisfactory when the child is ready to leave the educational system. If community placement for a job is not satisfactory at that time or if other events interfere with that placement, the child cannot go back to the school system and have job training again. Job coaches who know the child may not be available or suitable to train him for meaningful employment. Sheltered workshops may not be available in the community in which he resides, so

transportation could be an issue if the child prefers living at home rather than a group home. Because of automation and possibly the economy, keeping busy at the workshop may not be successful as contracts may be lost. Life at school was regimented as parents know the schedule of the school day, meet other parents at Parent-Teacher nights, and visit about the child with teachers, staff and therapists. Schedules change after the mandated years of school are completed. Meeting with other parents will rarely occur. Meeting with professionals is done on a scheduled yearly basis if the child receives services.

When the child leaves high school by graduation and ages out of the educational system, he has minimal contact with peers who do not have disabilities whom he knew through mainstreaming or lunchroom contact. If he attends church or synagogue, he will keep some contacts. If he has only placement in the sheltered workshop, those with whom he associates will be limited to others with disabilities and the supervisors. He may live at the home of his parents or in some type residential group home. He may experience many disabilities that do not allow him to do much more than be supervised and sit with others of similar extensive disabilities. His circle becomes contracted once again.

Parents can accept these realities and difficulties as part of their lives, but sometimes 'what if' surfaces. The chronicity of the disability may be quite similar to that of chronic disease as it does not change significantly. The disability cannot be overcome; it is always there. Sometimes it is in the background, but it never disappears. These episodes can be exacerbated if the child with a disability has a normally developing twin, a sibling that catches up to him in development, or relatives who have children of similar ages without disabilities. Early on, baby books documenting developmental milestones such as first social smiles, first time sitting up, and the times when walking and talking begin may be neglected or ignored in order to avoid the obvious: the child is not developing like other children. The grief the parent usually ignores and avoids may suddenly rise up, demanding expression during times of developmental, social, and educational milestones for other children. The parent may think that the disabilities are a part of the child and are being dealt with, but emotions are sneaky and just when the parent believes they are under control, will express themselves at the most inconvenient times.

Chronic sorrow is a term that applies to situations such as these. The parent may have advocated for her child for years, but sometimes small things can become more meaningful in a different context and the sadness felt because of some aspect of the disability thought accepted

can be overwhelming and must be expressed. The parent can get better at hiding the emotion, but it lurks under the surface, just waiting for the time her guard is let down to be in evidence.

Chronic sorrow may be more prevalent than thought. For instance, when parents of children with disabilities are asked how they are doing, unless the person asking has similar concerns, it is likely that the parents will answer in a positive manner to that they are viewed as a normal family and not as poor parents (Catlin, 2003). They then may give positive feedback depending on who is asking the questions.

Chronic sorrow is a sorrow that does not disappear with time because the basic situation itself does not disappear. Recently, I visited with another mother about our children: mine, who was 26 with multiple disabilities due to an unknown syndrome and the other child, aged 5 diagnosed with Down syndrome, and multiple associated disabilities. Both have intellectual disabilities. Although the ages of the children were different (one no longer was associated with the educational system and the other just beginning), the emotions felt by both of us were quite similar. Chronic sorrow was a term that made sense for us on multiple levels. This conversation came about when she asked about my research topic in general. She completely changed her demeanor when I talked briefly about chronic sorrow and the tenor of the conversation also changed.

Research has been completed including parents when their children are part of the educational system and receiving services. Unfortunately, that population is not easily accessible after the child completes high school. It is comparatively easy to access the parents of these children via parent support groups or through informal meetings associated with education. That may be why the majority of research dealing with stress, distress, positive life outlooks and coping strategies of the parent of the child with the disability is conducted on parents who have children in this age group. Few research studies document parenting views when the child with a disability is an adult (Blacher, Neece & Paczkowski, 2005).

Statement of the Problem

Research involving parents whose child has left the educational system is scant. As will be noted in the review of literature, research typically has focused on parents who have young children until the time they leave the school system. In the United States, it is difficult for those who might be interested in researching lives of parents or adults with intellectual disabilities to

obtain access to people to contact after the child exits formal school because of privacy concerns, although some access may be obtained through various support groups or organizations such as Special Olympics. Therefore, knowledge about this group of parents has been minimal. In addition, the majority of research literature viewed targeted parents who had children with diverse disabilities rather than focusing on one specific type of disability.

This, then, is the problem: Do parents of adult children with disabilities experience chronic sorrow, especially when intellectual disabilities are included? It is unknown if chronic sorrow has decreased for them over time. Professionals may also be unaware of the problems facing the parents. This research would be a step in addressing this problem as well.

The specific exploration of chronic sorrow for these parents is lacking as well. Only one study exists to chronicle the phenomenon in parents with adult children with disabilities and it did not include the interview questions or how the data were analyzed to support the stated findings (Blaska, 1998). Sorrow experienced by these parents or caregivers may be pervasive and enduring for the entire life of the child or parent/caregiver role.

Very little is known about parental emotions after their children reach the age of adulthood. As adult children with multiple disabilities live longer due to improved health care during childhood, it is important their parents be heard and their opinions and emotions valued. To begin this type discussion, the focus will be on parents of adult children with cerebral palsy.

It is imperative the voices of parents are heard in a different way by professionals. This study will focus on that neglected group of parents. Rather than focusing on all parents of adult children with multiple disabilities, this study will give voice to mothers of adult children with CP, an understudied group.

Parents live the problems inherent in parenting a child with disabilities every day. Sometimes professionals may need to listen with greater understanding. Professionals may not recognize the battles parents face every day, whether in caring for the child physically, worrying about whether the staff will recognize symptoms of a seizure or just his needing to use the bathroom, or wondering if the next trip to the emergency room may be the last.

Significance of the Study

This study will enlarge the body of literature about families who deal with their children who have disabilities. In particular, the study will enhance understanding of concerns of these

parents of *adult* children with disabilities, a period in the life span understudied both qualitatively and quantitatively. Few studies have addressed parental responses after transition from the educational system to community services. Studies involving chronic sorrow do not address, support, or acknowledge that parents continue to be parents of their children with disabilities. Their concerns may be significantly different than the concerns that occupied them when their child was younger. Family dynamics and structure have changed over time. Living arrangements may have changed. Ways of coping with the challenges and stresses in their lives because of the existence of the disabilities of their child may have evolved. Their perspective on life may have changed due to the passage of time. Numerous questions exist about parenting issues for adult children with disabilities. For example, what about their past lives do they value in relationship to their child with disabilities? What would the parents change? How have the stressors in their lives changed? How has this experience of parenting their child with disabilities been beneficial or detrimental in their lives or the lives of others in their family? Those who work with individuals who have disabilities may thus be able to add a unique perspective from the lived experience of other parents to aid in counseling and decision-making processes.

CHAPTER 2 - LITERATURE REVIEW

This chapter will review literature on chronic sorrow from its inception by Simon Olshanksy (1962) through key researchers past and most recent. By reviewing the research in the field of chronic sorrow, the reader will see specific domains of chronic sorrow as identified by the literature. This chapter will also give the reader understanding about the relationships of Cerebral Palsy (CP) to chronic sorrow after first providing the background as to why CP exists and the health problems associated with CP. After this discussion, this portion of the literature review will turn to methodologies used in past writings including types of surveys and questionnaires with associated difficulties and the advantages of each.

Chronic Sorrow

Chronic sorrow was first introduced as an observation by Simon Olshansky (1962) of a pervasive, never-ending and ongoing type of grief experienced by parents, particularly mothers, who have given birth to infants with identifiable congenital disabilities. Olshansky (1962) believed these feelings occurred whether the child lived with or away from the parents. Factors such as "parent's personality, ethnic group, religion, and social class" (Olshansky, 1962) were not related to how this sorrow was perceived. These emotions could occur with any disability, but they were more common among parents who have children who are "severely or moderately retarded – whose children would be considered retarded in any society and in any cultural group" (Olshansky, 1962, p. 191).

Current research about chronic sorrow experienced by parents of adult children who have congenital disabilities is missing. As children live longer with more severe disabilities and with a possible corresponding increase in the severity of intellectual disabilities, it is important to determine how chronic sorrow is recognized and whether it may be expressed differently.

Disagreement exists about what makes up chronic sorrow, especially about the role grief plays. Chronic sorrow may be considered as a type of grief, but chronic sorrow is different from grief. There are also some similarities as chronic sorrow embodies a specific type of grief. Grief in general goes by many different expressions and emotions. Parents of children with disabilities experience this grief on many levels. The specific type of grief of chronic sorrow may not be

shared with other parents unless they, too, have a similar situation. I come from such a background and have experienced the concept of chronic sorrow like other parents who have children with many types of disabilities, all of whom were relieved that their feelings might be legitimate and that those feelings had a name that made sense to them. I have spoken with mothers of children with multiple disabilities, with Down syndrome, with schizophrenia, and with cerebral palsy. All have been willing and perhaps even anxious to share their perspectives and feelings about their child. Most often, mothers mentioned the sorrow occurring at times of normative developmental milestones for other children of similar ages, particularly those developmental milestones that their child would never meet, or would meet much later, accomplishments which would not be recognized by others. These are recurrent losses.

Historical Viewpoints of Chronic Sorrow

Chronic sorrow as a term was introduced in the early 60s, but could have been formulated as a reaction to previous literature such as that by Bibring (1953) and by contemporaries such as Solnit and Stark (1961) and Bowlby (1962).

Simon Olshansky (1962) is credited as the first to discuss chronic sorrow. His purpose was two-fold: first, he advised professionals to avoid asking the parents to unequivocally 'accept' the child as 'mentally defective'; second, he urged professionals to recognize that parents experience chronic sorrow as a natural reaction to the role of parenting a child who is multiply-disabled.

Olshansky (1962) presented his view that the helping professions often urged parents to accept the reality of their child's disability. When parents did not behave as the professionals wished, he believed that professionals often responded by claiming that parents were denying reality and were neurotic. The difference between parents of typical children and parents of children with disabilities is that most parents of children without disabilities can anticipate a future when their child is self-sufficient. This is not always the case for parents of a child who is "mentally defective". The continued experience of chronic sorrow ends only with death of either the child or the parent. Olshansky (1962) asked counselors to allow more time for parents in counseling and to listen to the feelings of the parents in order to support emotions experienced during this time of adjustment, which may be long-term. He also advocated for respite care for the mother to assist her coping with the daily responsibilities.

The Olshansky essay (1962) included in a professional journal of social work may have been written to refute what may have been common thoughts and attitudes about the right thing for parents to do when they have a child with intellectual disabilities. These prevailing attitudes were paternalistic and denigrating in nature. He wrote this from the historical attitude of this time period when parents were encouraged to place their children with disabilities into an institution so the parents could go live their lives (Trent, 1994).

Controversy still exists as to if chronic sorrow is grief or depression, although the literature refutes correlation with depression (Kendall, 2005; Roos, 1994). Chronic sorrow is a type of grief, but it was initially considered depression. Bibring (1953) questioned whether an individual who refused to live in the present, but instead persisted in living as though the longed for object existed would not be at risk for depression. This idea can be seen later when the physician believed his role was to persuade the mother to accept the reality of the *deviant child* as soon as possible after the diagnosis because it might help her combat depression. The grief experienced by parents subsequent to the birth of the child with disabilities was considered to be *unresolved mourning* which could only be resolved when the child was removed from the family or died (Solnit & Stark, 1962).

It is important to view Olshansky's (1962) essay in view of the beliefs and culture of the time, which may have been best summarized by a contrasting article published the previous year (Solnit & Stark, 1961). The prevailing thought of the time was that parents should be informed it was best for all concerned to place the *deviant, defective*, *blighted*, *damaged*, or *retarded* child in an institution as soon as possible because the birth of an infant with congenital defects was extremely traumatic and parents would look at the child as a personal failure. Mothers would experience guilt because of the birth of the baby. The guilt would push the mother to dedicate herself to care for this child to the exclusion of all else which would damage the family. The mother would become injured herself as she took on the identity of being defective herself. She then may withdraw from society and her responsibilities for the rest of her family. The physician or social worker was to give the "verdict or reality" (Solnit & Stark, 1961, p. 531). The loss of the idealized child must be worked through so the parent could accept reality, the "retarded child" (Solnit & Stark, 1961, p. 533). "The process of mourning cannot be as effective when the retarded child survives" (Solnit & Stark, 1961, p. 533) and "when a person is mourning, their ability to recognize, evaluate, and adapt to reality is often significantly impaired" (Solnit &

Stark, 1961, p. 533). The physician was to discourage procrastination in accepting the *damaged* child because postponing a plan to initiate institutionalization would injure the mother and her family. If parents could not make plans that were appropriate (according to the physician and social worker), then other family members such as grandparents were to be brought into the planning situation to help the family conform.

The Solnit and Stark (1961) article has blatant *physician knows best* overtones. These writers did not accept the idea that a family could include a child with disabilities or that a families love their *deviant* children. Again, this article is an example of thinking at that time. However, it was of interest that these authors recognized that the mourning or grief does continue for parents when the child survives.

It is possible that families still face working with professionals that believe they know what is best for both parent and child. For example, a multiplicity of professionals will be working with the child after a delay in development or a congenital disability is professionally diagnosed. Children typically have at least one therapist and may have many providers of health care. Physical and occupational therapists, speech/language therapists, social workers, child psychologists, physicians, and nurses as well as paraprofessionals and case managers are involved in planning and evaluations throughout the lifetime of the child. The attitudes expressed openly or subtly by professionals can affect how the parents express their emotions of chronic sorrow.

Olshansky (1962) may have been influenced by his contemporary, Bowlby (1961), who advanced ideas about how attachment and loss was connected to grief, mourning, and sorrow. Bowlby (1961) viewed mourning as a behavioral sequence where variations occurred in complex expressions of behaviors and emotions. He considered grief to be the subjective part of mourning and that the process of grief included trying to recover whatever was lost. Bowlby (1961) believed that the outcome of mourning and grief would be realization that what (or whoever) was loved and was permanently gone. Bowlby (1961) discounted the idea that depression is a part of mourning or that guilt must be a part of that mourning process.

It is possible that the parent who is experiencing this type of grief and loss of the anticipated ideal child may initially deny the reality of the developmental problems for the newborn. Parents may not want or be able to deal with the reality of the situation at a particular time. Since Bowlby (1961) also believed that anger and hatred were a part of grief, this idea may

have influenced physicians who wanted babies with deformities to be whisked away before the mother could attach or bond with the baby so mothers would not have to suffer these emotions. Solnit & Stark (1961) provide the example of how physicians wanted babies not to bond with their mothers, but it is conjecture that Bowlby influenced physicians in this way. Again, the concept of loss of the anticipated ideal child is a refrain. At this time in the 1960s, children with disabilities died much earlier, so the ongoing realization of loss was not as long in time as it is today with improved medical care. No other journal articles about chronic sorrow were published until the 1970s and were written with only the parents of infants and young children in mind**.** It was believed that chronic sorrow would change and resolve when the death of the child born prematurely with congenital disabilities occurred (Fraley, 1986; Young, 1977).

It was not until the latter 1990s that literature addressed how chronic sorrow might be experienced by parents who have adult children with disabilities (Blaska, 1998). This particular study profiled parents who had adult children with a variety of diagnoses and assessed how parents remembered cyclical grieving as it occurred for them. It was found that support for grieving was needed for parents during times of health issues in the child, times when the child should have met typical developmental milestones, when experiencing lack of understanding of their situation by others, and concurrent with other events that may be insignificant to others. This can be viewed as loss of meeting developmental milestones and loss of aspects of the relationships with others.

Other disciplines have added to the literature on chronic sorrow. These include psychology, psychiatry, rehabilitation, and nursing. In one of the first articles referring to chronic sorrow in nursing journals, Young (1977) wrote of the difference between losing a child to death and losing the idealized child at birth because the child was different than the expected healthy or perfect child. A time of grieving this loss and adjusting to it may not have been a possibility as the parents have to deal with the very present demands of the birth defect. “Parents of a defective child experience distress as long as the child lives, and their response to having the child may be either adaptive or maladaptive. With the child’s death, parents complete the stages of acute grief and resolve their chronic sorrow” (Young, 1977, p. 39). Young wrote that the stages of chronic sorrow included denial, developing awareness, and restitution. Restitution was projected to last until the *defective child* died, at which point the parents would resolve this chronic sorrow experience.

In the 1970s, children with disabilities did not have typical life spans. Young (1977) summarized that a maladaptive response to the birth of a child with disabilities would include continual denial and an inability to function so that the mother might only be able to care for the child with the defect if their spouse or other children were ignored. The mother might also be unable to accept the child and would then designate daily cares to other relatives or an institution, although Young believed that institutionalization could be an adaptive response and should be considered on an individual basis. Whether or not institutionalization is considered positively or negatively, it is not currently an option for parents as state funding for care of virtually all of those with developmental disabilities has been re-directed to a community-based system.

Although the opinion that grief and loss would be mitigated by institutionalization might have been helpful for some parents in the 1970s, it could also have been psychologically uncomfortable for other parents if they did not want to place their child in an institution or if they expected that chronic sorrow would abate in specific stages. It is a simplistic notion to state that parents deny, accept, and then cope. Young (1977) viewed the parental response occurring on a maladaptive-adaptive continuum, one that the health care professional could support as continuing adaptation to the situation. She did not view chronic sorrow as a remitting-exacerbation process, but one that occurs in progressive stages. She introduced nurses to this concept of chronic sorrow, but her understanding was based on the stage progression of grief, not in the cyclic interpretation of sorrow that is defined in chronic sorrow literature. No information was included for parents whose child does not die, who deal with a lifetime of sorrow. Again, this could be because this article was written in the 1970s where many more children born with syndromes or congenital defects experienced a much shorter life expectancy than those with disabilities do three decades later.

Definitions of Chronic Sorrow

Olshansky's (1962) definition was the basis for the majority of the studies on chronic sorrow, but Lindgren, Burke, Hainsworth, and Eakes wrote individually and collectively about chronic sorrow as well and added more specificity to the term. Other definitions were coined by Senour, Phillips, Kearney and Lindgren writing with Connelly and Gaspar. The most current thoughts about chronic sorrow are by Kendall (2005).

Olshansky (1962), the pioneer in this literature, introduced the term chronic sorrow and defined it as a never-ending and ongoing grief experienced by parents who have a child with a disability. He did not give boundaries, such as how long it might last, if the emotions increased over time, if parents were able to resolve chronic sorrow over time, or if it is resolved with the death of the child.

Other pioneers in advancing understanding of this term were a group of nurses (Burke, Hainsworth, Eakes, & Lindgren, 1992). They added to the definition of chronic sorrow by contributing several research studies. They also formed a consortium to study this concept. Their studies were based on an unpublished doctoral dissertation by Burke (1989). She also introduced a questionnaire in that study which has been used and adapted since in studies of chronic sorrow.

The most current research is by Kendall (2005). Her definition included the chronicity of the sadness that recurs and how it is triggered arbitrarily. She identified other attributes as:

> The experience of profound sorrow, not unlike intense surges of grief and sadness felt at the time of the initial loss, the experience of invalidation, including social isolation, feelings of unfairness, and lack of voice, or the perception that one is not 'heard' by others; and the state of feeling physically overwhelmed, exhausted or vulnerable (Kendall, 2005, p. 47).

The sorrow occurs in response to a perceived loss with no predictable end, the "perception of an unresolved disparity, or incongruence, between the idealized or anticipated future reality or relationship and the actual one" (Kendall, 2005, p. 47) and events or situations that illuminate the perceived disparity (Kendall, 2005). She also used the term 'renormalization' that occurs after the intermittent chronic sorrow temporarily resolves. Kendall noted that depression is not identical to chronic sorrow (Kendall, 2005).

Definitions concerning chronic sorrow are inconsistent. The terminology of chronic sorrow is not well-known, so other writers have used either different or additional terms to describe similar or perhaps the same phenomenon such as regrieving (Vines, 1986), cyclic sadness (Burke et al.; Grant, Ramcharan, and Flynn, 2007; Lindgren, Burke, Hainsworth and Eakes, 1992; Phillips, 1991; Young, 1977), pathological grief or depression (Bibring, 1953; Kennedy, 1970), mourning (Solnit & Stark, 1961), grief-relief process (Bullock, 1981), and living loss (Roos, 1994). According to some, these emotions experienced by parents may be secondary to caregiver strain (Brannan, Heflinger, Bickman, 1997), be a part of depression

(Bibring, 1953; Solnit & Stark, 1961), be included in the process of bereavement (Copley & Bodensteiner, 1987), or result as a response to stress (Chimarusti, 2002), chronic illness (Grant, Ramcharan, and Flynn, 2007), or hopelessness (Kennedy, 1970; Young, 1977). Chronic sorrow is the term that should be used for consistency.

These terms all speak to the emotions experienced by parents when confronted with the reality of a child with disabilities. Consistent in the definitions are emotional response and pervasive sense of loss; however, specific inconsistencies exists about whether or not the sorrow is cyclic, increases or decrease with time; whether stages exist, or if specific developmental milestones trigger these emotions, and how each relates to parents' perceptions of loss.

Chronic sorrow discussion initially occurred with the understanding the child would die. Bullock (1981) viewed this as a grief-relief process where the emotional state of the parents vacillated according to whether the parents wished for the severely affected child to live or to die, especially in the case of a child who may not be aware of his surroundings. Parents may anticipate a loss through death that does not occur and may feel guilt for doing so. Parents who have children that continue to live with deficits may have life-long experiences with grief-relief that is not resolved until death of the child at whatever age (Bullock, 1981).

Others have noted how the perception of chronic sorrow cycles emotionally over time (Damrosch & Perry, 1989; Davis, 1987; Fraley, 1986; Vines, 1986; Wikler, Wasow, & Hatfield, 1981). Parents experience hope as well as hopelessness, but cyclical hopelessness may be a component (Kearney, 1994; Phillips, 1991) which will cause sorrow yet again. The diagnosis itself may be like bereavement (Lowes & Lyne, 2000) as it is a loss, but how that emotion changes over time is not well understood. Burke & Hainsworth et al. (1992) clearly differentiated chronic sorrow from pathological grief and depression. Pathological grief is an abnormal reaction; depression is a mental disorder; and chronic sorrow is a normal reaction.

These views of cycling emotions may again relate to Bowlby (1962) as Bowlby's idea of phase two and three of mourning as disorganization and reorganization occurred multiple times and was "experienced as a series of repeated and painful disappointments" (Bibring, 1953, in Bowlby, 1961, p. 334). This emphasized the chronicity of how mourning the loss can evolve without resolution and substantiates the foundation of chronic sorrow.

Chronic sorrow then can also be seen as evolving from Bowlby's ideas of loss and mourning. It is the result of many losses (Lindgren, Burke, Hainsworth and Eakes, 1992; Lowes

& Lyne, 2000; Senour, 1981) beginning with loss of the anticipated perfect child. Mothers are the traditional caregivers of children and may see their role differently as they become caregivers for a child that will never gain independence. That specific role may be quite different than she anticipated; therefore, the mother experiences the loss personified in the child with disabilities more keenly (Davis, 1987). She "lives the loss" (Roos, 1994) each day.

In addition to the perceived losses of anticipated role and of the idealized child, the element of time is different in chronic sorrow from other types of grief or bereavement. Grief is limited by time and occurs in response to one loss (Kennedy, 1970). Losses to a parent who has a child with disabilities are not all obvious at the time of diagnosis, but change as trigger events, such as meeting expected developmental milestones do not occur. The parent might not always know the extent of the disability at the time of the child's birth and, therefore, might experience additional losses as the physical, intellectual, or emotional disabilities become more apparent as the child grows older.

Time is one of the areas in the chronic sorrow definitions about which authors are inconsistent. Chronic sorrow is not bound by time but may vary over time (Bruce, Schultz, & Smyrnios, 1996; Hobdell, 1993; Kennedy, 1970; Lindgren et al., 1992). It may increase steadily (Burke, et al, 1992; Phillips, 1991, Young, 1977), or decrease over time (Blaska, 1998; Hobdell, 1993; Hobdell & Deatrick, 1996). The time element was included in the definition by some authors so that sorrow becomes chronic when it exists over 2-3 months (Hobdell, 1993, Kennedy, 1970) and varies in intensity (Hobdell & Deatrick, 1996). It may exist until death of the child (Olshansky, 1962). However, in another study, the variation in intensity took place over time as chronic sorrow decreased over time for both parents (Hobdell & Deatrick, 1996).

Other writers have included the element of time in their definitions of chronic sorrow, attempting to make sorrow as experienced by parents fit a specific progression, such as the stages proposed in the Kubler-Ross theory of death and dying. Stages of resolution and exacerbation were thought to occur at one time (Copley & Bodensteiner, 1987; Young, 1977), but this idea was refuted (Davis, 1987) as a societal construct. A specific stage progression indicates sorrow resolves; therefore, a progression of stages to be completed might be seen as delegitimizing the chronic sorrow felt by parents if their sorrow was not completed as expected. Phillips (1991) wrote of a mother who had a child with multiple anomalies, but who believed her child would develop normally. The study only encompassed a six week time period, so it is certainly possible

that the mother's view of the normalcy of the child was a coping mechanism. Six weeks may not be sufficient time to uncover the periodicity of chronic sorrow. The hope for the future that the mother had for her daughter may work for her for that short time period. The definition of chronic sorrow may need to be enlarged to include periods of hope in a cycle with hopelessness; however, it is possible that hopelessness does not exist for all who experience chronic sorrow.

Other definitions have included how the emotions of chronic sorrow are triggered. Sometimes specific and similar events may occur for parents that trigger this response either in developmental milestones or life transitions (Burke, 1989; Damrosch & Perry, 1989; Wikler, Wasow, & Hatfield, 1981). This facet of chronic sorrow has not been explored in the literature except to show how events elicit sorrow in parents of children with disabilities. It has not been determined if these emotions change over time in reaction to such milestones, or if parents become reconciled to these developmental differences as their child transitions to the age of an adult.

Research on Chronic Sorrow

Early research and essays about chronic sorrow involved parents of babies with obvious disabilities. Although Olshansky's (1962) essay was about his observations of parents with neonates who had congenital disabilities with significant intellectual disability, others applied his thinking to populations who were diagnosed with cerebral palsy (Chimarusti, 2002), intellectual disability (Roos, 1994), non-specific developmental disabilities such as Attention Deficit Disorder and some birth defects (Mallow & Bechtel, 1999), epilepsy (Hobdell, Grant, Valencia, Mare, Kothare, Legido, & Khurana, 2007), and neural tube disorder (Hobdell, 2004). Other studies included parents who had children who were born prematurely (Fraley, 1986), and a child who has "diagnosis of severe physical disability and the prediction of severe mental disability" (Bullock, 1981, p. 193). In addition, parents who had a child with a chronic disease of diabetes (Gallo, 1991) were noted to experience chronic sorrow.

Virtually all of the studies have focused on parents who have children, usually under the age of 21, with specific or general disabilities. Parents of children were usually selected according to availability of contact such as those from educational cooperatives in special education or parental support groups. Studies included mothers of children with disabilities (Dunning, 1999; Hobdell, Grant, Valencia, Mare, Kothare, Legido, & Khurana, 2007; Phillips,

1991; Young, 1977) and families who had children under the age of ten, primarily parents of children from 6 months to 6 years of age (Damrosch & Perry, 1989).

Several comparative studies have been completed as well. Some studies examined how chronic sorrow may differ between mothers and fathers (Damrosch & Perry, 1989; Hobdell & Deatrick, 1996; Mallow & Bechtel, 1999). Others included how chronic sorrow differed between parents who had a child with only physical disabilities and parents with a child who had associated intellectual disability (Vines, 1986), how chronic sorrow differed between mothers who had a child with an acute illness and mothers who had a child with a chronic illness were compared (Dunning, 1999), how chronic sorrow was demonstrated differently in mothers who had a child with chronic illness to those who had children with illness and/or congenital disabilities (Phillips, 1991), and how chronic sorrow increased for mothers who had children with intractable seizure disorder compared with mothers who had children with well-controlled seizures (Hobdell, Grant, Valencia, Mare, Kothare, Legido, & Khurana, 2007).

Additional research included caregivers and spouses as well as individuals themselves as they interpreted their experiences of chronic sorrow. Studies were completed on chronic sorrow as experienced by a spouse of a chronically mentally ill disabled husband (Hainsworth, Busch, Eakes, & Burke, 1995) and an adult child or a spouse of someone with Alzheimer's dementia (Lindgren, Connelly, & Gaspar, 1999; Mayer, 2001). Chronic sorrow was also reviewed as it occurred for individuals themselves with chronic diseases such as arthritis (Shea, 1986), catastrophic injuries (Dewar & Lee, 2000), multiple sclerosis (Isaksson, Gunnarsson & Ahlström, 2007; McKeown, Porter-Armstrong, & Baxter, 2003), and Parkinson's disease (Lindgren, 1996; Hobdell, 1996). All these studies determined that chronic sorrow occurred; however, the time element or if resolution of the chronic sorrow occurred was not emphasized.

It is of interest that memory loss or compromised cognition was not always seen as important by the individual, as one might have expected in studies of Parkinson's or Alzheimer's diseases. Instead, multiple losses were noted, such as loss of a future, which corresponds to the concept of chronic sorrow in parents of children with disabilities and the multiple losses they face. These results corresponded to findings of others who had experienced a loss similar to those losses, but who identified a different loss as being more significant than expected by the researcher (Kendall, 2005).

Domains of Chronic Sorrow

The four major areas of chronic sorrow as determined by review of the literature are loss of support, loss of quality of life, loss of roles and relationships, and recognition of loss through triggering events. Each of these has themes for which I will give some examples. Overlaps between and among the domains exist.

The first domain examines the professional support available to the mother including health care providers, therapists, and nonprofessional support, such as that from family and friends. It also includes social and informal support systems, such as those in faith groups. Spiritual support is discussed separately because of the diversity of meaning this conveys.

The second domain is loss of quality of life for the parents. Socioeconomic factors influence many aspects of life, including where a family resides. When a child is born with disabilities, families must consider if therapies or health care is available or if a Medical Card is the best option. Their health may be problematic or affected by the child's disability. Cultural backgrounds, family attitudes, and beliefs about disabilities will influence where they live, perhaps as much as socioeconomic factors. Their quality of life is affected by the balance between the care necessary for the child versus the amount of care parents have the ability to give as they age themselves. When a child has multiple disabilities, the situation influences quality of life.

The third domain, loss of roles and relationships, includes how the mothering role is perceived, how the care of the child is divided, and the change in relationships both social and familial because of the child's disability.

The fourth domain, how the loss is recognized through triggering events, differs among parents although lack of meeting developmental milestones is consistently expressed as a trigger in the literature. This includes events throughout the lifespan of the adult child, and the transitioning of the child from the educational system to the adult world. This domain is woven throughout the other domains.

There are other losses that do not neatly fit into one of these domains including how context of the loss varies among individuals as well as how the loss is perceived and how chronic sorrow changes in intensity over time. This area encompasses the definition of chronic sorrow in that it examines in more depth specific aspects, such as if and how the loss changes over time and includes other losses that do not neatly fit into other themes. They are either discussed in

literature or are known by the author. Again, some areas overlap, depending on the context of the loss.

In order to further understand these domains, they will be discussed separately and more thoroughly.

Loss of Support

Support systems can be both formal and informal. Formal systems consist of those professionals who work with the child. Informal systems consist of parents, other relatives, church families, and friends. Without an adequate support system, isolation is probable (Kendall, 2005).

The professionals who interact with the parents can be the beginnings of the formal support system. However, the term chronic sorrow is not found widely in professional literature and the concept is probably not recognized by those who work with parents of a child with developmental delays, which was the reason behind Olshansky's (1962) essay. Empathetic communication from professionals may be lacking when parents are informed about their child's disabilities (Chimarusti, 2002; Roos, 1994; Todd & Jones, 2003). This can color parental interaction with these professionals, especially as they look to someone for guidance during these times. Parents may feel communication is only one-way from the professional when they receive information about their child. Some parents have also voiced dissatisfaction with the quality of information given to them by health care providers. Information given by professionals has changed over time as parents have demanded greater voice in decisions.

The communication and information given to parents has changed since the 1960s because of prominent personalities writing and speaking about their children with disabilities. Historically, health care providers thought they knew what was best for the family and encouraged institutionalization as was apparent in Solnit and Stark (1961). In fact, during the 1950s and 1960s, institutions grew as they were pressured to accept babies as well as older children. Then in the latter 1960s, institutions began to be recognized as places of tragedy with inadequate training and staff, which fueled legislative efforts by parents to change the system (Minnesota Association for Retarded Children, 1969). Psychiatrists, who were responsible for state institutions, began to lose control over choices such as institutionalization as educators from universities began to conduct research on how best to serve these families in the school system.

Perhaps more significant in the 1960s, funding given by the Kennedy family and the book previously written by Dale Evans Rogers (Angel Unaware, 1953) helped fuel additional research. (I read this book as a child. I do not have the complete citation for that edition). These families brought forth topics of intellectual disabilities, education, and living situations separately from mental illnesses (Trent, 1994). Parents began to advocate for education for their children with intellectual disabilities. They then began to push for early intervention in preschool years. This began in Kansas in the mid-1980s. I had a role in the parental task force which successfully initiated earlier intervention. Once parents had a voice and became more involved, changes from institutionalization to community-based programs became common-place.

As early intervention became key in managing the disabilities of the children, it became important to identify those children who needed assistance before formal education began. Neighborhood or school district screenings became common in order to identify children who needed early intervention programs. These clinics included screeners such as educators and public health nurses. Parents who had not known of developmental problems or delays before the screening may then have attempted to access health care for more definitive answers. Parents continue to want information and support from health care providers. They want empathy. They want their child appreciated as a unique individual, not seen solely as a disability without seeing the person (Larson, 1998). Physicians or other professionals have not provided this support consistently (Jones & Passey, 2004: Roos, 1994; Sandler, 2001).

Parents may be the first to recognize disabilities exist (Glascoe & Dworkin, 1995) as they recognize the absence of developmental milestones. They then may seek out additional information and screening from professionals to answer their questions about their child's development. When parents attempt to access information, their first stop might be with physicians to seek answers to their concerns, but they may not receive the information or support they seek. Physicians may be loathe even to assign a diagnosis to an infant or child or to recommend appropriate services (Jones & Passey, 2004: Sandler, 2001), thus leaving the child out of important early intervention programs.

Parents can be significant resources to health care and can provide useful information if physicians will utilize parental observations in an organized fashion. Families believe that working in partnership with physicians can be useful, but do not always believe physicians see them as partners (Knox, Parmenter, Atkihson & Yazbeck, 2000). Parents may also find lack of

agreement among health care professions (Jones & Passey, 2004), which further adds to their feelings of frustration and isolation and does not decrease the loss associated with this lack of professional support.

Psychological support has been deemed necessary for mothers of children with disabilities. It is not clear which groups of parents might profit from this type support. For example, when parents of children of different ages with cerebral palsy were identified related to successful coping strategies, parents of younger children coped best compared to parents of adolescent and young adult children (Lin, 2000). This may have implications for support perceived by parents of children with other disabilities as well.

Professional support is not the only support lacking for families with children with disabilities. Everyday support might also be missing as the addition of the child with disabilities to the family life forces changes. Social deprivation and lack of social contact can lead to additional grief as life and personal routines of the parents and family members change because of the diagnosis. This can particularly occur for mothers of persons with intellectual disabilities (ID) because their time is spent caring for the child and thus they are socially deprived and isolated (Emerson, 2003; Heller, Hsieh, & Rowitz, 1997; Hirose & Ueda, 1990). Social isolation may occur for fathers as well (Spear, 2004), although the mothers believe they have the greater burden of caregiving (Heller, Hsieh, & Rowitz, 1997). Mothers relied on outside support and would seek outside help, although they did rely somewhat on husbands; however, fathers relied primarily on their spouses (Hirose & Ueda, 1990; Saloviita, Italinna and Leinonen, 2003). If parents do not perceive they are receiving support from each other, they may have even greater difficulties (Taanila, Syrjala, Kokkonen & Jarfelin, 2002).

Loss of social support may also occur if the mothers do not believe they or their child is accepted, particularly when a child is not accepted into play groups or in spontaneous neighborhood interactions (Green, 2003). Parents may not want to continually explain and instruct about the disability (Jones & Passey, 2004). Parents of peers may not invite the child with the disability to attend events apart from those at school. As the child grows older, it is also more difficult to integrate him into the life of the church, a problem when parents depend on spiritual support and participation. The spiritual aspect is discussed further in parental quality of life.

Parenting issues increase when caring for a child with disabilities compared to caring for a child without disabilities. Professionals may begin working with families with the assumption that parenting the child with disabilities can make a positive impact to family life, perhaps because of past experiences with other families, but this would not be of use to the many families who need additional social support (Hastings and Taunt, 2002). This lack of support systems for parents and children increases as children with disabilities grow older (Lin, 2000).

Isolation perceived by the mothers could be buffered by the level of social support from those outside the family (Christian, 2007; Dyson, 1997, Plant & Sanders, 2006). However, in reality, additional social support is usually not forthcoming. In addition to the underlying definitions from Olshansky (1962) and Burke (1989), Kendall (2005) also added that chronic sorrow included the "experience of invalidation, including social isolation, feelings of unfairness, and lack of voice, or the perception that one is not 'heard' by others" (Kendall, p. 47).

Since this research will focus on parents who have children with cerebral palsy, it is of interest to discover how support systems or feelings of isolation impact parents of children with CP. Support cannot stay the same as it existed before the child's disability, but should increase. According to one study (Brehault, Kohen, Raina, Walter, Russell, & Swinton, 2004) which primarily included parents of children with CP, chronic stress is almost doubled in parents with children with disabilities from the rate of stress found in the general population with similar support systems and contacts.

Social support may decrease inversely to the amount of time the mother has available to spend with those outside her immediate family. When she is the major caregiver, especially when health problems of the child are significant, her time is spent in addressing health problems as well as providing routine care. This occurs regardless of the primary diagnosis as mothers and families had significantly less spare time whether the child had CP, autism or intellectual disabilities. Social life then changed appreciably (McGilloway & Donnelly, 1995; Sen & Yurtsever, 2007). It is important for parents to receive social support from those not associated with family or friends. However, fifty to sixty percent of families with children with disabilities receive no assistance or very little assistance from friends or relatives (Jokinen & Brown, 2005).

Isolation is common among these families, especially as the children grow older. Unfortunately, support systems are primarily available to parents of younger children (Chimarusti, 2002), perhaps because of the obvious differences in attaining developmental

milestones during that time period, stress encountered by parents, and involvement of the educational system in working with both the child and the parents.

The sense of isolation could increase as parents also need to take time to navigate through the economic and health care fields. Case management for many parents is infrequent. Parents must learn to negotiate the maze and are responsible for learning how to do this on their own with occasional help from other parents who have had similar experiences. More help in the home is needed if persons are to live with family rather than an institutional setting as care is given to many children with disabling conditions every hour of every day for those who have greater physical disability (McGilloway & Donnelly, 1995), such as children with cerebral palsy who have multiple physical needs.

Friends and family may not be as closely involved because of the child's disability; family members and friends may even lose contact with parents of children with disabilities (Heiman, 2002). Parents need support other than that available from family and friends – or professionals. Therefore, additional formal support systems may be very helpful in connecting parents with other parents with similar circumstances (Taanila, Syrjala, Kokkonen & Jarfelin, 2002). In Kansas, Families Together is the parent training and information center. This organization provides a day or weekend for families and their children with childcare provided for all children with disabilities and their sibling, so parents can be informed of educational strategies and rights of their children. They have access to formal classes, a library and professionals, but the most important resource might be the contact with and support received from other parents. Families who coped best with new and long-standing demands have support systems that encompass both formal and informal systems (Taanila, Syrjala, Kokkonen & Jarfelin, 2002). Lack of social supports forecast burnout for the mother (Christian, 2007).

Loss of Roles and Relationships

One of the first roles that change after a diagnosis of disability for the child is that of parenting. Parents have an idealized view of the child, realizing that children may vary from the child anticipated. However, when the diagnosis of disability is given and associated health or behavior problems occur, the parenting role changes drastically as their dream of the ideal child is been shattered (Bowlby, 1961; Olshansky, 1962). One of the parents, usually the mother, will

have to assume the primary caregiving role (Heller, Hsieh, & Rowitz, 1997). The maternal role will change as the caregiving role changes (Grant, 1990; Sen & Yurtsever, 2007).

Relationships have the potential to fracture or become closer when the child is factored into the relationship. Parental relationships have the potential to alter as roles change (Taanila, Syrjala, Kokkonen & Jarfelin, 2002) as parents incorporate the needs of the child with disabilities into the family.

Relationships with family and friends may change completely (Heiman, 2002; Hobdell, Grant, Valencia, Mare, Kothare, Legido, & Khurana, 2007). Parents may have limited time for others outside their immediate family because of the child's health problems. For example, some children may have ongoing health needs resulting from oxygen deprivation as a consequence of uncontrolled seizure activity, leading to progressive decline in mental abilities. Family members may shy away from the responsibilities inherent in caring for a child with extensive health care needs as also might friends. Family or friends might prefer previous relationships that can no longer exist. Other adults and children in the community may have difficulty knowing how to relate to someone with disabilities and perhaps their parents as well, so stigmatization may occur for the family as well as the child (Green, 2003).The inherent difficulties when children do not meet developmental milestones are obvious when children cannot feed or toilet themselves or walk unassisted when expected. Family and friends may be able to help when the child is younger and can be carried, but as the child grows older, all these cares become problematic and maneuvering is more difficult. This leads to further isolation from family and friends as they no longer feed competent to help.

Culture has the potential to encompass roles and relationships as well as parental quality of life and availability of support systems. Culture is influenced by geographic locale, family practices over time, religious and spiritual backgrounds and defines what is assumed to be normal behavior and beliefs by a particular group of people. It is defined as a system of shared beliefs, values, practices and attitudes (MSN Encarta).

Although those with disabilities are not hidden away in the Midwest United States as they may be in other cultures, children with disabilities might not be welcomed in certain social or religious settings. Mothers learn that their role includes putting the well-being of the child first throughout his life at the expense of a career of their own or for care of the rest of the family. Some may feel that they 'should' take care of the child at home during his lifetime; others may

feel choices are limited and supports will be available only if the child is placed in a group home. Guilt about their decisions may follow them throughout their child's lifetime.

Although initially parents may look to health care providers for information and support, they soon discover they themselves may be the best and sometimes only advocate for their child. Support systems from school are no longer available after age 21 in the state of Kansas, although other states may include those with disabling conditions until age 25. Those supports available after the person is 21 give little choice in how an individual with disabilities spends his day.

Culture could also influence the attitudes in the Midwest, the site for this research. From my viewpoint according to this culture, the role of the parents is to adapt and carry on. Admonitions heard multiple times by me and other parents such as 'God doesn't give you more than you can handle', make it difficult for some parents to reach out to others who do not know what the parents deal with on an everyday basis. Family members may be well meaning, but unless they have similar problems, they have difficulty providing support and may not have the skills to deal with children and adults who are mentally and physically challenged. Comments such as 'You evidently didn't pray right', or 'Everything happens for a reason', and 'God has a plan' may be well-intentioned, but not supportive (comments other parents and I have discussed at length over the years)**.** One difference in the United States might be that parents do not always view their child with an intellectual disability as punishment (Gardner & Harmon, 2002), but they may feel others believe the child has the disability due to some fault of their parents or the parenting. Parents have a commonality that is a culture of their own apart from where they are located geographically (Davis, 1987).

Parents experience role confusion as sometimes they are in charge and sometimes not. They are expected to know when their child is developing typically or if the child is having a seizure without being educated. Health care and social service providers may inadvertently promulgate the idea that the parents are at fault for not recognizing their child has disabilities, and then parents are judged by those providers as to their quality of parenting (Todd & Jones, 2003). Blame for the disabilities occurring has been placed on mothers by their families, their husband's families and even husbands (Sen & Yurtsever, 2007). Mothers may receive mixed messages, such as educational professionals believing the education system should be in charge of education. However, the system does not provide needed interventions unless mothers advocate for them. Parents may also feel that somehow their child with disabilities is less valued

as health and educational services are more difficult to arrange for them. Problems can occur when the child is hospitalized, as parents are supposed to care for their complex medical needs at home, but are not necessarily considered a valuable part of the health care team if the child is hospitalized (Baumgardner, 1999; Clements, Copeland, & Loftus, 1990). Roles seem to change depending on expediency.

The surrounding culture does make a difference as to how the child is viewed – or how the parents of the child with disabilities are viewed – and the situations encountered in which the mother is placed through her own beliefs or disability of the child. A nursing student from Kenya spoke of how an aunt was ostracized for birthing a child with a disability, so much so that she was given a different home in which to live with the child and the husband took a second wife. He stated that it was believed the child was a product of witchcraft or punishment from God, beliefs substantiated by research into various cultures (von der Assen, 2006; Gona, 2004). Therefore, the role of the wife was eliminated and only the role of mother remained.

Another study (Hazmat & Mordi, 2007) pointed to another culture with similar beliefs. Two groups of caregivers in Nigeria of children age 6 months to 12 years were contrasted, one group who cared for children with cerebral palsy, one group who cared for children developing normally, comparing the health of each group. The group of children with cerebral palsy was also subdivided into divisions based on their gross motor function ability. The authors included the stigma of caring for a child with a disability as part of the emotional stress as that is a part of society in Nigeria. Mothers who have children with disabilities are believed to have incurred a curse or who did something wrong, so they are punished. The amount of care related to the severity of the child's disability also changed relationships (Hazmat & Mordi, 2007). One culture here in the United States is found in specific types of spiritual beliefs. The Latter Day Saints culture believes their children with disabilities have a special purpose and are a blessing from God (Marshall, Olsen, Mandleco, Dyches, Allred, & Sansom (2004).

Loss of Parental Quality of Life

Quality of life is impacted by balance in personal lives and rest and recreational opportunities which is inadequate for mothers caring for children with disabilities (Crowe & Florez, 2006). Although culture impacts quality of life as well as roles and relationships, parental quality of life is also impacted by how the child with disabilities affects health care needs of the

parents; how socioeconomic status changes, which may be determined by job and career options; if health care is available secondary to insurance or Medicaid; how overall health of parents decreases; how available childcare and expertise is, what the impact of multiple disabilities is including behavior problems if they exist, and what the parents' perspective is on positive and negative aspects of parenting.

One of the changes for parent quality of life is economic. Socioeconomic status of the family as well as the child's disability (Quine & Pahl, 1985) can contribute to additional problems in the family because of the lack of finances or a change to a lower socioeconomic status (McGilloway & Donnelly, 1995). Parents who cannot afford care for their children with disabilities are required to spend-down to a near poverty level to receive funding from governmental programs (Savage, 1998).

Families of children with intellectual disability (ID) were significantly economically disadvantaged when compared to families without children with ID (Emerson, 2003). Half of the mothers with children who had cerebral palsy reported needing financial help (Sen & Yurtsever, 2007) and the majority of these mothers may not be able to work outside the home (Hirose & Ueda, 1990).

Some parents may not have physicians who take children with medical cards (Medicaid), so those parents experience additional stress trying to find adequate health care for their child. Parents may have also experience difficulty getting physicians to make any diagnosis as a definitive diagnosis may come only from prescribing more diagnostic tests for which Medicaid or insurance may not pay (Sandler, 2001). An example of this occurred when I worked in a Women's, Infant, and Children (WIC) clinic. I visited with a mother who had concerns about her 18 month old child's development. She had a medical card for her child and took her to the physician for routine checks. She believed the child was delayed in development, but this was her first child and she was not assertive in asking, primarily because this physician was the only one in that area that would see children with a medical card. She looked intently at the nurse and asked, "Is it really OK if she doesn't sit up yet?" The chronological time for a child to begin sitting is 6-7 months of age, but no evaluations had been done.

Another example from personal experience is one when my son was assessed. The physician only thought the child was a bit behind, stated the child would catch up, and for me not to worry unduly. After I verbalized opposition to waiting for development to occur, the physician

referred my son to a pediatric neurologist who saw a good looking child with no apparent physical deformities. He scheduled a computerized axial tomography (CAT) scan and pronounced the year old child normal. Another physician was finally seen after I strongly requested another opinion. That physician stated the child was moderate to severely delayed (retarded was used at this point in time) in development, a diagnosis that proved to be correct. Without adequate insurance and advocacy, our family may not have been able to receive these additional professional opinions and evaluations.

Although educational levels achieved were similar to parents of children with other disabilities, variations in incomes in those caregivers of children with cerebral palsy exist (Brehault, Kohen, Raina, Walter, Russell, & Swinton, 2004). A reduction in socioeconomic status might result after the birth of the child because one or both parents may not be able to work as many hours or in specific careers if the child requires more care (Brehault, Kohen, Raina, Walter, Russell & Swinton, 2004; Todd & Jones, 2003). If the child lives with parents, it is unusual that mothers can work fulltime because of the increase in caregiver responsibilities, the lack of child care after school for children with disabilities, and the mother's lack of sleep. As the child approaches adulthood, mothers may also realize that the time for a career of their own may never occur (Birenbaum & Cohen, 1993; Green, 2004; Knox, Parmenter, Atkinson & Yazbeck, 2000) and that additional income will not be forthcoming.

Although the father may experience less social disruption than the mother as he is more likely to be in the workforce, he may bear the brunt of the socioeconomic burden (Sen &Yurtsever, 2007). Fathers may have to change jobs, refuse promotions, or otherwise alter employment in order to be of help to the child with cerebral palsy (Hirose & Ueda, 1990). Financial difficulties may also occur as health care policies do not cover residential care, so families either must fund these living arrangements privately or look to public programs (Green, 2004). Choices regarding where to live can be limited based on the educational and health care services available.

Not only do families have financial difficulties, but also costs borne by private insurance and the taxpayer increase when children have these type diagnoses. In addition to costs associated with daily care for the child with disabilities, medical costs for families with children with CP are much greater than the economic challenges presented for families by children in general. Children with chronic diseases such as cerebral palsy cost Medicaid from 2.5 to 20

times more than payments for children without these diagnoses (Ireys, Anderson, Shaffer, & Neff, 1997). In addition, as noted previously, families must survive on less income because one parent must be a caretaker as these children need care the majority, if not all, of the day. Caregivers outside the home are usually not willing to provide this level of care; therefore, the economic impact extends much farther (Sen &Yurtsever, 2007).

Insurance does not cover supplies such as large diapers for children who will never be toilet trained or formulas for children unable to be nourished totally by mouth, or for medical supplies such as ankle-foot orthotics for ankle plantar flexion or headrests for wheel chairs, all important, if not essential, supplies and devices for many children with CP. Vans and home modifications may be needed for wheelchair transport of the child (Birenbaum & Cohen, 1993). Because of the expense involved in caring for children with disabilities, families may have difficulty paying for health care costs even with insurance and might instead need to choose between jobs with insurance that do not cover the costs involved or a medical card so children can have some coverage. Thus, parents pay for these supplies and devices and may sacrifice retirement savings, entertainment with family, or school supplies for other siblings.

Parental quality of life and chronic sorrow is also affected by how healthy parents are and how they maintain their health. Their physical well-being may be affected, possibly connected to presence of stress and lack of sleep. One study in Canada (Brehault, Kohen, Raina, Walter, Russell, & Swinton, 2004) compared the physical health and psychological well-being of caregivers of children with cerebral palsy to that of parents in the general population. Data was retrieved from questionnaires completed by the caregiver from two large surveys, that of the National Population Health Survey and the National Longitudinal Study of Children and Youth. Numerous demographic and work-related variables were included.

The study (Brehault, Kohen, Raina, Walter, Russell, & Swinton, 2004) also assessed support systems and how families function as well as the levels of stress in their lives. The study then correlated these variables with chronic physical health issues, including pain. It was hypothesized that stress in caregivers might be manifested in the occurrence of these chronic health problems. No differences were found between men and women in terms of pain or emotional problems, although women did report more general health problems. Neither gender differences nor socioeconomic status in the two groups accounted for more health problems in the caregiver group. A primary finding was that the variable making the difference in chronic

health problems was caring for the child with the disabilities. These caregivers reported physical problems to a greater extent including back problems, migraine headaches, ulcers, asthma, arthritis/rheumatism and pain (Brehault, Kohen, Raina, Walter, Russell, & Swinton, 2004).

In addition to physical health, parents' emotional health can also be affected. If the child's disability was seen as a catastrophe, the level of stress for the parents was higher, which impacted mental health. For the mother, the situation was worse when the child demonstrated problem behaviors; for the father, the perception was worse when they believed the child would not be accepted socially (Saloviita, Italinna & Leinonen, 2003). Mental health of the mother can also be negatively impacted by the behaviors demonstrated by the child (McConkey, Truesdale-Kennedy, Chang, Jarrah, & Shukri, 2008). These may all exacerbate the emotions of chronic sorrow as well.

Studies are inconsistent in linking health of parents to the child's disability. In a study completed in Nigeria, no evidence was found to support the linking of the severity of the handicap with the general health of the caregiver. Distress scores as indicated by the General Health Questionnaire (GHQ) were higher in caregivers for children with cerebral palsy. Although stress can be a predictor of how well the immune system works, it is not known from this study how health of the caregivers was impacted (Hazmat & Mordi, 2007).

Fatigue and lack of energy can result when caring for a child with multiple disabilities. It was not apparent if the previous study (Hazmat & Mordi, 2007) considered the physical labor involved in caring for children with multiple disabilities which translates to fatigue and potential low back pain. Fatigue and loss of energy occurs from loss of sleep due to medical issues of the child such as seizures and illnesses. Both of these occur to a greater extent than they would if their child did not have the disability. The burden of caregiving can be quite challenging for those mothers who have children with disabilities (Summers, Poston, Turnbull, Marquis, Hoffman, Mannan, & Wang, 2005).

An additional study looked at mothers of children with CP as well and how stress affected their lives**.** Indian researchers (Vijesh, & Sukumaran, 2007) researched stress in mothers of children with CP and found that the level of dependence of the child on the parent for all activities of daily living corresponded with the amount of stress experienced by the mothers. The number of associated disabilities also raises stress levels. The majority of these mothers had moderate to severe stress which affected quality of their lives. The most stressful time was when

the mother learned of the diagnosis. Mothers' stress did not relate to whether they were Hindu, Christian or Muslim; whether their husbands had stayed with them or not, although all husbands were supporting the mother and child. Whether mothers lived in rural or urban areas, income levels did not influence stress.

Parental quality of life is closely related to availability of support systems, a domain examined previously. In Turkey, stress was considered to be secondary to inadequate or absent social support received from anyone other than family as no institutional care is available there (Sen & Yurtsever, 2007). In developing countries such as Bangladesh, social support and educational programs are not widely available (Mobarak, Khan, Munir, Zaman, & McConachie, 2000). Latina mothers in California have a greater risk for depression if they have a child with intellectual disability but this may be due to lack of social and family support related to possible immigrant status and separation from or rejection by husbands (Blacher, Lopez, Shapiro, & Fusco, 1997).

Coping from day-to-day could be difficult, especially when few people help with tasks relating to care of the child with disabilities. If parents need more coping mechanisms but have not developed them, chronic sorrow increases (Hobdell, Grant, Valencia, Mare, Kothare, Legido, & Khurana, 2007). Energy is also affected by the amount of time and effort it takes to deal with associated health and behavior problems. This can include losses perceived by the parent due to both intellectual and physical disabilities as well as possible co-existing behavior problems.

Diagnoses of multiple disabilities, especially for those children more severely affected, usually but not always include corresponding intellectual disabilities. The most current information available is that ~0.78% of all people in the United States have intellectual disabilities (ANCOR, 2007). These intellectual disabilities can result from genetic conditions, from maternal illnesses contracted during pregnancy, from injuries and low birth weight or prematurity. Some of the major diagnoses that have a direct relationship to intellectual disability are Down syndrome, Fragile X syndrome, autism spectrum disorders, and cerebral palsy.

Along with Down syndrome, cerebral palsy is one of the most common physical disabilities associated with intellectual disabilities. Those with intellectual disabilities do not necessarily have physical disabilities nor do persons with physical disabilities necessarily have lower intelligence; however, the more severe the physical defect, the more likely intellectual disability also occurs. If children have identifiable defects at birth, they are 27 times more likely

to also be diagnosed with intellectual disabilities by 7 years of age (Jelliffe-Pawlowski, Shaw, Nelson, & Harris, 2003).

When a child has more constant needs in physical care with a corresponding decrease in ability to learn, chronic sorrow may increase as the parents must come face-to-face with the limitations of the child each day (Phillips, 1991) as more and more developmental milestones become out-of-reach. Another study (Jelliffe-Pawlowski, Shaw, Nelson, & Harris, 2003) stated that the occurrence of mild intellectual disability is under-identified as some children whose syndromes are closely aligned with intellectual disability did not yet receive services. This occurred because physicians hesitate at times to make diagnoses unless the child has very obvious disabilities (Sandler, 2001).

Behavior also affects parental quality of life and was a major predictor of stress (Kersh, Hedvat, Hauser-Cram & Warfield, 2006; McConkey et al, 2008; Mobarak, Khan, Munir, Zaman, & McConachie, 2000). Certainly day-to-day activities affect parents' perception of their quality of life. For example, parental stress increases if behavioral problems co-exist with the disability (King, King, Rosenbaum, & Guffin, 1999; Plant & Sanders, 2006). Children included in this particular study were primarily those with a diagnosis of CP, although children with other disabilities were also included (King, King, Rosenbaum, & Guffin, 1999).

Fidler, Hodapp, & Dykens (2000) researched how stress levels varied for parents of children between 3 and 10 years of age who had one of three separate genetic syndromes. Stress in the parent did not vary according to income or the genetic syndrome, but again, problem behavior of the child contributed to perceived stress in the parent. Another international study reviewed how behavior affected quality of life of Taiwanese, Irish and Jordanian mothers (McConkey et al, 2008). Neither professional support nor coping strategies improved mental health, family functioning or decreased stress, primarily because of existing behavior problems. The authors generalized that universal problems for parents occurred across cultures arising from the behaviors in children with disabilities.

It takes energy to deal with the demands of parenting, but caregiving for children with disabilities becomes more difficult as the child grows older and grows physically. It is more difficult to secure children in transportation of any sort if they prefer not to go. Ordinary dressing, bathing, and grooming become greater challenges. Fatigue also arises from worry as parents become concerned about care for female children as they arrive at puberty. When they

care for children who cannot control elimination on their own, they find the beginning of menstruation complicates matters further.

As the child with disabilities ages, it becomes more difficult to find appropriate childcare when parents cannot or wish not to be present. For some parents, being able to have a social life or freedom to participate in hobbies or other activities adds interest and richness to life. Parents could need childcare to pursue additional schooling or to work longer hours. Childcare is more likely to be available when the child with the disabilities is younger. It is quite difficult to find a companion to essentially babysit an adult with disabilities, especially when the caregiver may need to provide personal care such as assistance with toileting. Respite care is occasionally available, but this must be set up in advance and precludes a spontaneous evening out by parents. Olshansky (1962) advocated for respite from care for the mother to assist her in managing her daily responsibilities.

One of the ways in which some parents may find solace, support, and an increase in the quality of their lives is through their spiritual beliefs and church affiliation (Scorgie & Sobsey, 2000; Speraw, 2006) as religious beliefs may be one of parents' major emotional supports (Abbott & Meredith, 1986; Strauss & Munton, 1985). Meditation and prayer may used to cope as well (Eakes, Burke, & Hainsworth, 1998) as some parents or those experiencing loss rely on spiritual comfort, meditation, or prayer to somehow get through each day. Ethnic or cultural beliefs may also provide a spiritual background that assists families in how parents frame their experiences when they have children with disabilities (Blacher & Baker, 2007). This is closely related to the culture of the family, which is related not only to parental quality of life, but also to relationships and roles that are changed when parenting a child with a disability.

Since beliefs about spirituality can influence how a family responds to various situations, it is another important facet to consider (Young, 1977). Spiritual support was identified as one of the primarily coping strategies used by parents of children with cerebral palsy (Lin, 2000). However, health care providers, clergy, and those in the faith community of the families ignored or were perceived to have ignored the spiritual needs of both the child with the disabilities and their parents. Some parents with whom I have visited have stated clearly that they have questioned why God has allowed their child to be in pain or have other difficulties in life related to his disability. Others have wondered what lesson God intended for them to learn by giving them their child. On the other hand, if parents found welcome from a spiritual place in a faith

tradition, “their assumptions about faith in action were affirmed, and their sense of peace and ability to cope were enhanced” (Speraw, 2006). Therefore, if parents do not believe they or their child are welcomed within a faith community, their faith may be challenged.

So far, primarily negative aspects of parenting and how the child’s disabilities could affect parental quality of life have been discussed. However, potential positive aspects of parenting a child with a disability should also be recognized. Medical professionals many times present the diagnosis in a negative manner. These professionals might be surprised to find that families can find positive attributes about their child and about the situation. Some could believe families are not realistic when they find a silver lining and therefore may be dysfunctional when the families do not emphasize the disability (Kearney & Griffin, 2001).

Although adjustments need to be made and sorrow may exist, parents may discover new and positive things about themselves and their families through dealing with the disabilities of the child (Stainton & Besser, 1998). Viewing the child with the disability in a positive way is one way parents deal with the ongoing circumstances that occur in caring for a child with disabilities (Hastings & Taunt, 2002). Positive themes identified by parents include were:

source of joy and happiness, source of increased sense of purpose and priorities, expanded personal and social networks, and community involvement, source of increased spirituality, source of family unity and closeness, source of increased tolerance and understanding, source of personal growth and strength, positive impacts on others/community and interaction with professionals and the service system (Stainton & Besser, 1998, 61).

Other positive aspects in parenting a child with disabilities were identified as key themes by other researchers:

1. Pleasure/satisfaction in providing care for the child
2. Child is a source of joy/happiness
3. Sense of accomplishment in having done one’s best for the child
4. Sharing love with the child
5. Child provides a challenge or opportunity to learn and develop
6. Strengthened family and/or marriage
7. Gives a new or increased sense of purpose in life
8. Has led to the development of new skills, abilities, or new career opportunities
9. Become a better person (more compassionate, less selfish, more tolerant)

10. Increased personal strength or confidence
11. Expanded social and community networks
12. Increased spirituality
13. Changed one's perspective on life (e.g., clarified what is important in life, more aware of the future)
14. Making the most of each day, living life at a slower pace" (Hastings & Taunt, 2002, p.118).

Many times, parents find joy in being a parent to their child (Kearney & Griffin, 2001). The parents can focus on positive aspects of parenting the child with the disability after they begin to accept the child with the disability (Sandler & Mistretta, 1998). They learn to advocate for their child and may become more confident in their approach to life's situations (Scorgie & Sobsey, 2000).

Parents discover who their friends are for better or for worse. Parents may believe their child has a purpose here on earth and therefore can then reframe the experience positively. They might find they were stronger than they thought initially and that they have attributes with which to deal with adversity. Parents have the opportunity to better understand who they were, what they stood for, and how they reacted to adversity.

Positive attitudes by parents should not be seen as denial of the disability, but rather another aspect of resilience. These attitudes do not negate the idea that adjustments and stresses have been present. Although these acknowledgements of the positive occurred, it is not known when these positive feelings arose as research has not dealt with when families may recognize these positive outcomes. Neither is it known if this is a universal outcome for families. This is an avenue for future research.

Quality of life will change over time as parents exist in a paradoxical universe, knowing the disability of the child all too well, but believing and hoping for something better for their child in the future (Larson, 1998). Their lives intersect with others they might have never met without having this special child. Their focus in life will change. For example, they might become active politically in order to fight for health care, education, and potential quality of life for the child and the opportunity for the child to live apart from them. Viewing life with their child and how it affects them in a positive manner gives balance to parents' lives and makes it

possible to carry on in the not-so-pleasant aspects of dealing with the disabilities and raising their beloved child.

Quality of life for the mother can be impacted by health of the child. In particular, the use of medical technologies can very much change quality of life. If the child with disabilities must have items such as a feeding tube to survive, the family tends to focus on those specific needs (Baumgardner, 1999). Provision of tasks such as this were once done by nursing staff, but families need to learn them and may not feel they can do it all while maintaining other parental roles (Baumgardner, 1999).

Recognition of Losses

The loss of the anticipated child becomes more apparent during times other typical children meet developmental milestones. In some cases, the parents do not need to deal with the disability and might not recognize the severity of the disability until those developmental milestones are not met (Glascoe & Dworkin, 1995). Chronic sorrow occurs commonly during the time when other children complete these developmental milestones and the child with the disability does not (Burke, 1989; Damrosch & Perry, 1989; Wikler, Wasow, & Hatfield, 1981).

When the child is of an age to assume adult roles, another time of crisis occurs. Parents will need to consider the best placement options for a child at this time (Green, 2004). Few articles have been published since the 1980s that examine experiences of parents as their children with disabilities leave the educational system and the decisions they make at this time (Hanley-Maxwell, Whitney-Thomas, & Pogoloff, 1995; Heller, Hsieh, & Rowitz, 1997; Hirose & Ueda, 1990; Quine & Pahl, 1989; Roos, 1994; Wikler, 1986). Services thus far have been received through the educational system and parents may not understand how and why services previously available for their child in the educational system are no longer available through adult services after school is over. When they do comprehend the lack of support services, parents have more concerns and less optimism for their child's future (Knox, Parmenter, Atkihson & Yazbeck, 2000).

Because of the increasing responsibilities involved in parenting, parents will experience changes in relationships, roles as parents or in their careers, and how they plan for their future. Disagreements because of these changes in roles and relationships are possible (Heiman, 2002; Sen & Yurtsever, 2007).

Mothers and fathers may need to change career goals and how they view who they are as individuals and family members. Siblings may also be needed to assist in caring for the child, changing their family responsibilities as well.

Transitioning begins in the educational system as planning begins for life after school. A time of reflection occurs during the time the child is projected to leave school, typically another developmental milestone. Many families see having the child with the disability become independent from them as a necessary progression (Hanley-Maxwell, et al., 1993). Other parents have concerns about their child moving on in the world, but also worry about what would happen if the child stays with them because they may be weary with the caregiving.

As the time of usual transition occurs and the child continues to need care with many life aspects, the parents might look at options for other living arrangements for the child. Parents are getting older and fatigued. They could be unable to continue to give necessary care (Green, 2004). If the child is not able to find adequate housing or a group home or if he continues to live at home, parents might experience further loss and frustration secondary to ongoing loss of freedom (Rapanaro, Bartu, & Lee, 2007). A group home or other residential living might be an option for their child, but their feelings of burden as a caregiver could include guilt if they have concerns about how and where their child is cared for (Heller, Hsieh, & Rowitz, 1997). Some children might return home to live (Jokinen & Brown; 2005) after placement in residential care is not viewed positively.

Some of the concerns voiced by parents have been how their child will adjust living apart from the family, how they will transition to a work experience, what options they will have for leisure and recreational activities, and if they will have friends and stay safe (Hanley-Maxwell, et al, 1995). Unfortunately, services for work or residential care are usually not available immediately after graduation because of waiting lists unless long-term planning has been completed or a need for emergency placement is realized. The children may have the opportunity to continue to participate in Special Olympics or church depending on the degree of disability and ability to participate, but their associations with peers not from the community of the disabled may consist only of paid caregivers and their families. Also, other parents or relatives might be the only sources of community outings other than those planned by the sheltered workshop.

Although the education system begins to initiate a plan of transition during the latter school years, parents have difficulty visualizing a time of separation because they have difficulty planning for the future. Parents may recognize the need for change in caregiving of the adult child with the disability and work toward out-of-home placement; however, they continue to worry about the child's well-being throughout his life. Although they may not have the hands-on day-to-day caregiving responsibilities (Heller, Hsieh, & Rowitz, 1997; Jokinen & Brown, 2005), mothers, in particular, continue to have concerns about the presence and quality of services received by the child. Some believe they do a better job caring for their child, regardless of his age, than would an outside service (Grant, 1990; Grant, Ramcharan, McGrath, Nolan & Keady, 1998; Heller, Hsieh, & Rowitz, 1997).

Options for placement are limited depending on the state in which the child lives. In Kansas, the child may not be placed in a geographic area in which he has lived thus far, depending on vacancies in group homes which offer the level of care needed. Waiting lists for services have lengthened because of the decline in current economic funding to those with disabilities.

Parents prefer placement with another family member rather than outside the family of origin if change needs to occur because of crisis or caregiver health problems, but other family members might not be able to care for the child, either. Crisis situations may predicate movement of the child with the disability outside the family home even when that placement was not planned by parents (Heller & Factor, 1993). Children with greater needs were more likely to change living situations after parents found the caregiving burden too severe or if they believed they would not be able to provide care in the near future (Heller, & Factor, 1993; Prosser, 1997). The majority of parents did not want the living situation of their child to change until after the parents die (Heller, & Factor, 1993). Some parents hope their child dies before they do (Grant, 1990). Although family members may be disinclined to make residential arrangements, they could potentially make some type financial provision for their relative (Prosser, 1997). Unfortunately, without knowledgeable legal counsel, the person with disability may have less service availability if they have money left to them at a parent's death.

Many families make no formal plans for the future (Grant, 1990; Heiman, 2002; Prosser, 1997). However, that does not negate their strong concern about the future for their relative. This is worrisome as both the population of adults with disabilities and their parents are growing

older. If these caregivers suddenly need services because of a decrease in their health, services may not always be immediately available (Grant, 1990; Prosser, 1997). It is possible parents might believe their adult child is safer at home and that others could not adhere to the high standards they had for their child's care (Grant, Ramcharan & Flynn, 2007).

As the child grows older, more losses are noted and thus, sorrow continues and is not resolved. Initially, times of family crisis occurred after the child was born and the parents did not know what was happening. Later times of crisis arise when parents first learn of the child's diagnosis as well as times of health changes and hospitalizations (Chimarusti, 2002; Clements, Copeland, & Loftus, 1990). Chronic sorrow is also manifested in parents when their child was under stress from chronic illness, inappropriate behaviors, and when developmental milestones are experienced by other children (Fraley, 1986). When considering their child's future, parents are concerned about how he will develop intellectually and what he will be able to do in his life (Strauss & Munton, 1985), but may not want to plan for future living arrangements.

Some families do not want to think about the future, whether the future is with or without their child with disabilities. One study viewed plans for the child's future and found that only 28% of those parents or relatives whose child is living with them have thought about future residential needs (Prosser, 1997). Elderly caregivers worry a great deal about what will happen to their adult children if they are not able to continue care, but "they find the subject too painful to broach and do not make any concrete plans until it becomes unavoidable" (Richardson & Ritchie, 1986, in Prosser, 1997). These findings were corroborated as parents whose children were approaching the end of their high school years were asked about changing plans for living arrangements (Green, 2004). Some had no plans for a change and wanted to postpone thinking about this for the indefinite future. Parents who do initiate a change in living situations continue to grieve but continue to believe this child must be considered as a part of their family (Krafft & Krafft, 1998).

Cerebral Palsy

This study will focus on mothers of adult children with cerebral palsy (CP) who also have intellectual and physical disabilities. This group was chosen because the researcher has known mothers of children with CP who have struggled with chronic sorrow alone. It was also selected

because those with this disability are not as recognized and utilized for research as those with Down syndrome, a common diagnosis which is connected to several disabilities.

It is of interest to note how frequently the more common disabilities occur. Some of the most common physical disabilities associated with intellectual disabilities are Down syndrome and cerebral palsy. More than 2 of every 1000 babies born have been diagnosed with cerebral palsy in the 1990s, up from previous decades, most likely due to higher survival of low birth weight and premature babies (United Cerebral Palsy, 2006). Of those who had mild intellectual disabilities, 34.3% were also diagnosed with cerebral palsy; of those with severe intellectual disabilities, 60.8% had cerebral palsy (Jelliffe-Pawlowski, Shaw, Nelson, & Harris, 2003). Children who have intellectual disabilities are not consistently identified earlier due to the reluctance of health care providers to assign a diagnosis to younger children (Sandler, 2001).

Information is kept on trends by the Center for Disease Control and Prevention (CDC, 2006) as is data for congenital anomalies, congenital malformations, and birth defects of any type. It should be noted that these previous terms are used interchangeably. Approximately 3% of all children born in the United States are diagnosed with some type defect, the primary one being cleft lip and/or palate (CDC, 2006). The one occurring second in diagnosis is Down syndrome, a congenital anomaly based in genetics. It occurs once in every 733 live births (CDC, 2006), or 13.0 per 10,000 live births (Besser, Shin, Kucik, & Correa, 2007). These data on birth defects are analyzed by the CDC from metropolitan Atlanta, Georgia which reflects overall incidence of congenital defects.

The incidence of Cerebral Palsy (CP), categorized as a developmental disorder although the damage to development usually occurs in the first trimester of pregnancy, is not included in the data as a separate category, but children with CP who have a concomitant birth defect are included under the specific congenital defect. The prevalence of cerebral palsy is estimated to be between 3.1 to 3.6 per 1000 (National Center on Birth Defects and Developmental Disabilities, 2004) or 31 to 33 per 10000. Approximately 60% have co-existing developmental disabilities (National Center on Birth Defects and Developmental Disabilities, 2004). The disabilities resulting from CP then are found to occur more frequently than do those from Down syndrome.

As stated previously, caregiving may be impacted by both physical and intellectual disabilities as complexity of the caregiving skills will increase for each difference perceived by the caregiver. For example, persons with cerebral palsy have many central nervous system

problems that result in secondary motor and sensory impairments which increase parental difficulties (Evenhuis, Henderson, Beange, Lennox, & Chicoine, 2000). These additional difficulties experienced by parents may be expressed as chronic sorrow.

Rationale for Use of This Population

Parents of adult children who have specific disabilities, including intellectual disability, have been neglected in research. Chronic sorrow has been studied in the past in populations of parents whose children have multiple disabilities. Some disabilities were not specified, others included parents of children who had neural tube disorders (Hobdell, 1993, 2004), epilepsy (Hobdell, Grant, Valencia, Mare, Kothare, Legido, & Khurana, 2007), prematurity (Fraley, 1990), Down syndrome (Damrosch & Perry, 1989), intellectual disability (Roos, 1994), CP (Chimarusti, 2002), severe physical disability with predicted intellectual disability (Bullock, 1981) or congenital disabilities in general (Blaska, 1998, Mallow & Bechtel, 1999, Phillips, 1991). One study only addresses 'cyclical grieving' in parents of adult children (Blaska, 1998) and did not use the terminology of chronic sorrow.

Two of the most well-known disabilities are Down syndrome (DS) and cerebral palsy. Although Down syndrome is more common diagnosis at birth, many of these individuals known to the author are employed and may live independently or semi-independently with fewer obvious physical disabilities. Also, because this syndrome has a higher incidence, these parents may have previously been subjects for research.

The literature is replete with studies done involving family members of the person with DS. Down syndrome is a genetic or chromosomal aberration and might be detected before birth from viewing nuchal fold thickness in an ultrasound, a test done quite routinely, and further investigated through maternal alpha-fetoprotein blood studies. CP is not diagnosed as rapidly nor is it a known diagnosis prior to birth.

This study is not intended to generalize to the population of parents who have adult children with intellectual disabilities from multiple etiologies although direction for further study may be implicated. A specific parent, the mother, was chosen as mothers provide the bulk of the caregiving. A specific diagnosis, cerebral palsy, was also chosen as children with CP may have both intellectual and physical disabilities. Parents can easily identify children as to whether or not they experience major restrictions in movement and in feeding ability, which will impact

their quality of life and life span negatively. It is posited that these mothers of adult children may experience chronic sorrow throughout the child's lifetime.

Classification for Cerebral Palsy

Cerebral palsy occurs after damage to some portion of the developing brain and cannot yet be diagnosed by a chromosomal test, but instead is diagnosed because of motor delays that result in delays in reaching age-appropriate developmental milestones. It is commonly diagnosed in the first three years of life. Specific risk facts are associated with CP such as prematurity, but not all premature babies will be diagnosed with CP.

CP only occurs after birth in approximately 10% of those diagnosed due to injuries such as those from child abuse such as shaken baby syndrome or other injuries and neonatal infections such as meningitis, so it predominantly occurs subsequent to an injury to the brain during some point in pregnancy that affects development of or oxygenation to the brain. Approximately 60% of those diagnosed with CP have other developmental disabilities such as intellectual disability (CDC, 2004).

Overall, the incidence of CP is increasing, but the causes are not always clear. Rubella vaccine, iodine supplementation, controlling hyperbilirubinemia in the neonate, and limiting or eliminating large bottom-feeder fish high in methyl mercury from the diet of expectant mothers are measures that have reduced the incidence of cerebral palsy. Incidence of CP should also decrease due to administration of antenatal steroids, which decreases the incidence of Respiratory Distress Syndrome (RDS) and other causes of morbidity and mortality for premature infants, but that is not the case as overall incidence of CP is basically unchanged and because premature birth of babies has continued (Nelson, 2003).

Rarely, birth injuries result in stroke, another related factor in the development of CP. No specific study to date has investigated if cesarean section delivery might decrease the incidence of stroke as it may prevent birth injuries to the infant, although it is known that cesarean delivery has increased to well over 30% in the United States (March of Dimes, 2007) and as high as 70% in Brazil (Hopkins, 2000). It is therefore unlikely that cesarean section delivery is a factor in decreasing the incidence of CP.

Parents continue to be parents and to have concerns about their children. Parents who have children with obvious physical or intellectual disabilities which preclude their child from

participating fully in community activities and in the workplace may have greater concerns, translating to the experience of chronic sorrow. Cerebral palsy is one of the disabilities to encompass both physical and intellectual difficulties. As such, it will be discussed and the parents of adults with cerebral palsy will have input.

History of Classification

To begin the discussion about chronic sorrow and cerebral palsy, it is important that the basics of cerebral palsy are addressed. First, how cerebral palsy is manifested and classified will be addressed. Then why cerebral palsy occurs will be discussed. Of particular importance will be the problems of CP associated with physical abilities, activities of daily living, and general health. These associated problems can lead to the specific morbidity of respiratory illnesses and even death. Knowledge of these ongoing possibilities relate to chronic sorrow as experienced by parents as well.

Ways of classification have evolved over time, although they have always included some type brain lesion or injury and associated clinical manifestation. Types of movement disorders as well as areas of paralysis have been used to classify CP as well as the amount and degree of muscle tone as well as specific overall motor disorders. Mental functioning has been included as part of classification (Bax, 2005; Little, 1843 in Morris, 2007; Minear, 1953 in Morris, 2007; Mutch, 1992; von Heine, 1860, in Morris, 2007; Wyllie, 1951, in Morris, 2007). "For practical purposes it is usual to exclude from cerebral palsy those disorders of posture and movement which are 1) of short duration, 2) due to progressive disease, or 2) due solely to mental deficiency" (Bax, Goldstein, Rosenbaum et al., 2005, p. 571-572).

Many definitions of CP have been listed over the years. The most recent one is that:

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

Controversy exists about the importance gross motor function is given in other definitions; however, because many of the developmental milestones relate directly and specifically to motor movement, this part of the definition was retained by these experts. One of

the first signs of CP could be feeding difficulties, which is not a part of gross motor development, so those with less obvious signs of CP may not have those gross motor problems in the first 12 to 18 months of life, although usually CP is manifested before or during this period of time (Bax et al.).

Currently, it is recommended that CP be classified in 4 different ways: motor abnormalities, associated impairments, anatomic and radiological findings, and causation and timing. Motor abnormalities include the observed motor disorder and exactly how the movement problems affect function in all areas (Bax, p. 575). The associated impairments include "whether or not associated non-motor neurodevelopmental or sensory problems, such as seizures, hearing or vision impairments, or attentional, behavioural, communicative, and/or cognitive deficits, and the extent to which impairments interact in individuals with CP" (Bax, p. 575). Anatomic and radiological findings include the specific areas of the body such as the trunk or extremities that are impaired as well as the findings from the computed tomography or magnetic resonance imaging, including "ventricular enlargement, white matter loss, or brain anomaly" (Bax, 2005, 575). This definition does not include how participation in society is affected by their lack of abilities, which these authors point out as a limitation in classification. (It is also of interest that the authors use *'participation restriction'* rather than handicap, terminology that seems more appropriate and less noxious.) The well-known authors prefer to use the "motor disorder and functional motor classification in both upper and lower extremities" (Bax, 2005, p. 576). Causative factors may never be known so are not included in usual classification unless the cause is obvious (Bax, 2005).

Indications of Cerebral Palsy

Motor problems may be one of the first indications of CP which can include how the muscle functions, how the individual can begin muscle movements, and how much help the person needs in muscle movement. The motor problems relate either to coordination or muscle tone regulation. Muscle or motor difficulties include seizure occurrence as well. At different points in the life of a person with CP, various motor problems such as seizure control or intellectual disabilities may create more problems than others (Bax, et al., 2005).

Seizure disorders occur in between 15% to 60% of children with cerebral palsy (Kwong, Wong, So, 1998). Seizure disorders occur of every seizure type. If seizures exist, consequences

and problems were far greater for the child (Vargha-Khadem, Isaacs, van der Werf, Robb, & Wilson, 1992). The seizure disorder itself may cause further motor impairment over time (Bax, et al., 2005).

The disturbances in the brain relate to the expected pattern of brain maturation and, therefore, influence neurological and motor functions. Motor ability directly affects the ability to eat which includes the ability to use fine motor for cutting and directing food to the mouth, and also for chewing and swallowing. This is crucial because feeding status affects the general health of the child and the prognosis for future development; therefore, in addition to gross motor movement, the general health of the individual with CP is affected by how the individual is nourished. This includes whether or not the child is independent in feeding, if he needs major or minor help, if in order to take in the calories needed that he also needs supplemental formula, or if the child uses a feeding tube as a primary source of nutrition.

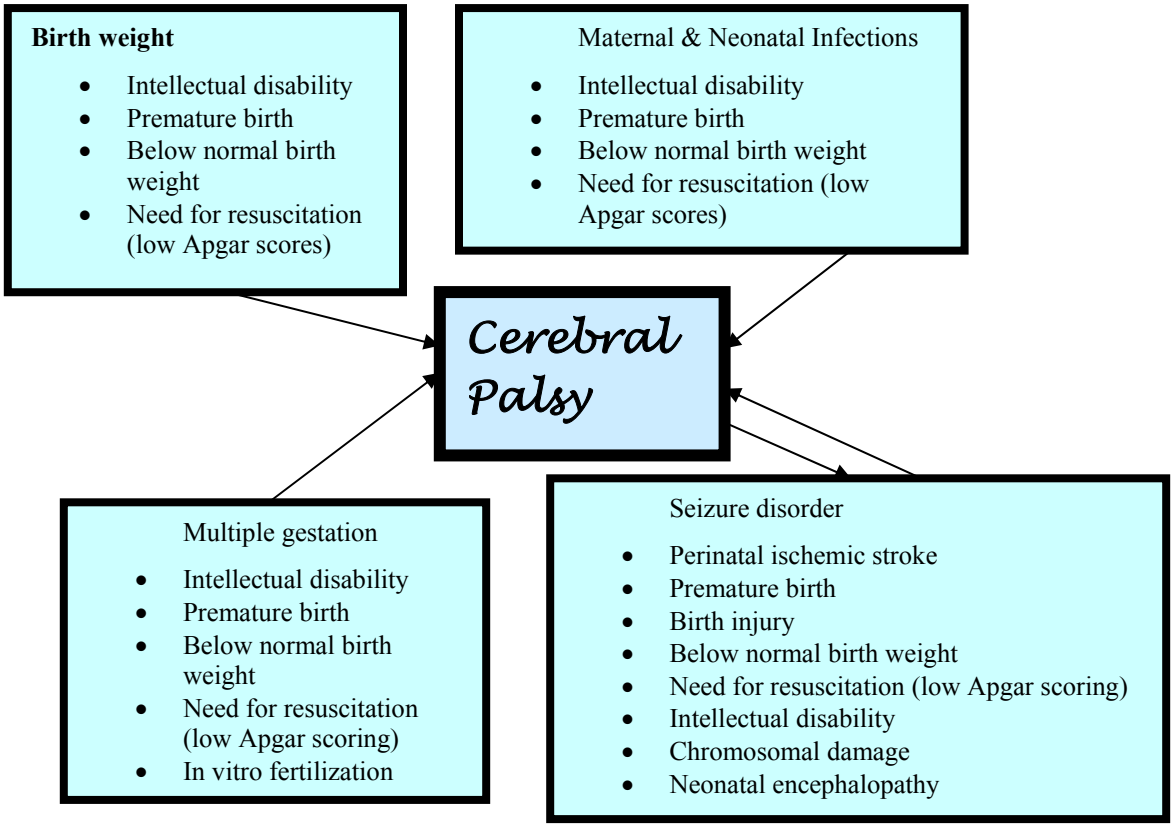
One study in particular illustrated the interrelationships among feeding ability and overall health status. It also added mobility and intellectual ability to the variables. This study was completed using The Gross Motor Function Classification System (GMFCS) and the Child Health Questionnaire (CHQ) for Pain, General Health, Physical Function, and Impact on Parents. (CHQ may not have face validity for all areas evaluated in this population as it was constructed to assess quality of life for children functioning at a higher level.) The sample population came from levels III, IV and V as measured by the GMFCS and was between 2 and 18 years of age. The particular levels were sorted by functional ability with III, IV, and V having decreased motor function. Children in Level V who used a feeding tube for nutrition took more medications than did children in other levels and were most frail. Of those, 43% experienced respiratory infections in the last year; 23% of those in Level V who did not utilize a feeding tube for nutrition experienced respiratory problems. Children in Level V who utilized a feeding tube had an estimated mental age of 1.9 years. Additional findings included that children born before 36 weeks had a mean age of 6 years, but those born after 36 weeks had a mean mental age of 3.9 years of age. Findings included “the worse the mobility, as judged by the GMFCS, the worse the nutritional status, and that the lower the mental age, the lower the mental health score” (Liptak, O’Donnell, Conaway, Chumlea, Worley, Henderson, Fung, Stallings, Samson-Fang, Calvert, Rosenbaum, & Stevenson, 2001, p. 368). With the feeding tube, the risk for respiratory problems doubles (Liptak, et al, 2001).

Malnutrition is one of the health problems identified which can inhibit the immune response, so it affects more than body composition. Nutrition could be equally important as movement in determining the amount of time parents spend in caretaking tasks, and the overall health of the child, all of which could relate to expression of chronic sorrow. These specific problems related to nutrition and movement will be discussed in greater detail later on.

The literature review indicated several relationships to the neurological damage present in CP, some of which will be discussed.

Conditions Associated with Cerebral Palsy

Figure 2.1 Conditions associated with CP



The previous chart illustrates the three primary conditions associated with CP which are low birth weight secondary to prematurity, infections including neonatal and maternal, and multiple gestations (Odding, Roebroeck & Stam, 2006). Also included on the chart are seizure disorders. These are frequently present in those with CP as either seizure disorders decrease

oxygenation to the brain resulting in neurological damage or the neurological damage is present due to other conditions and seizures result.

Other conditions include associated intellectual disability, low Apgar scores, chromosomal damage and birth defects, perinatal ischemic stroke, and birth injuries due to a prolonged second stage of labor. All of these contribute to CP because of the potential damage to the developing central nervous system. This damage results in the types of motor and posture impairments. The neurological damage has the potential to impact length of life; however, life expectancy approaches that in the general population unless severe impairments present, especially for those with severe motor impairment with intellectual disability (Koman, Smith, and Shilt, 2004).

Low Birth Weight

Low birth weight is one of three major risk factors for cerebral palsy (Odding, Roebroeck & Stam, 2006). Birth weights, particularly linked to preterm births, have been implicated consistently as a factor in the development of cerebral palsy. Babies born prematurely may also weigh less than appropriate for their gestational age. These birth weights are categorized according to low birth weight (LBW) (under 2500 grams) and very low birth weight (VLBW) (less than 1000 grams). LBW infant births have increased by 18% (7.9% of all births) in the United States. Prematurity occurred in 12.5% or 1 of 8 births during 2003-2004 (Martin, Hamilton, Menacker, Sutton, Mathews, 2005). Preterm births also "increased 2% in 2003 to 12.3 percent of all births. The preterm delivery rate has risen 16% since 1990 and by more than 30 percent since 1981" (Martin, Hamilton, Sutton, 2005, p. 2). These data relating prematurity and low birth weight point to the reason CP has not decreased in occurrence.

Birth weights classified as very low continue to increase. No change in incidence has been noted in babies born less than 1000 grams or in those born prior to 28 weeks gestation. As more babies classified as VLBW live, the incidence of cerebral palsy (CP) has increased. The four variables most strongly associated with the diagnosis of CP in these VLBW babies were maternal chorioamnionitis (an antepartum maternal infection), early neonatal sepsis, maternal primigravida status and the male gender of the baby (Costantine, How, Coppage, Maxwell, & Sibai, 2006). Other causative factors included "perinatal ischaemia, anoxia, perinatal infections, and the iatrogenic effects of drugs such as steroids in the postnatal period" (Hack & Costello,

2007, p. 7). US data may be worse as more babies are born of very low birth weight (Hack and Costello, 2007) and are counted in statistics, where they are not included in other countries when the babies do not survive.

Again, because of the strong relationship of prematurity to cerebral palsy, pregnancies resulting from in vitro fertilization were also studied because of corresponding early deliveries. The incidence of cerebral palsy was compared between populations of children with cerebral palsy born subsequent to in vitro fertilization and those not. When the results were adjusted for multiple variables including multiple gestations and prematurity, cerebral palsy was associated strongly with prematurity. Prematurity occurs more commonly as a result of in vitro fertilization (Strömberg, Dahlquist, Ericson, Finnström, Köster, Stjernqvist, 2002) whether multiple gestation occurs or not.

Not only do premature births occur more commonly from in vitro fertilization in multiple gestations. They also occur in singleton births resulting from in vitro fertilization. Those babies from these pregnancies who were born prematurely also had an increased risk of CP. In one study, 59% of children in this category were subsequently diagnosed with CP (Hvidtjorn, Grove, Schendel, Vaeth, 2006). Therefore, because of the propensity for a significantly higher number of preterm births, there is a concomitant increase in cerebral palsy.

The use of surfactant in extremely low birth weight babies is credited with helping to mature lungs and decrease mortality. One large center collected their data from births of VLBW babies in the 1990s before and after use of surfactant and found, although babies lived, they had greater incidence of sepsis, periventricular leukomalacia (white matter damage in the brain related to a decrease in blood flow to the brain), and chronic lung disease. This is of interest as all of these may contribute to the development of cerebral palsy. The increase in survival was coupled with an increase of significant neurological impairment which could later be attributed to an increased risk of cerebral palsy. The article questioned the routine resuscitation for infants from 750-1000 grams and pointed out the ethical issues in doing so as these infants were more likely to have the neurological problems and significant expenditure of resources keep them alive with the very real possibility they may have long-term disabilities (Wilson-Costello, Friedman, Minich, Fanaroff and Hack, 2005) such as CP.

Maternal Infections

Maternal infections are another of three major risk factors for cerebral palsy (Odding, Roebroeck & Stam, 2006). Two of the primary maternal infections associated with CP are chorioamnionitis and endometritis, both intra-amniotic infections, which may relate to as many as 11% of all CP diagnoses (Wu, Escobar, Grether, Croen, Greene & Newman, 2003). Other maternal infections causing increased risk to the fetus are neurotropic viruses such as toxoplasmosis, cytomegalovirus, the herpes viruses, and Epstein-Barr virus (Gibson, MacLennan, Goldwater, Haan, Priest, & Dekker, 2006; Guerina, Hsu, Meissner, Maguire, Lynfield, Stechenbwerg, Abroms, Pasternack, Hoff, Eaton, & Grady, 1994; Schendel, 2001). These are of particular significance as they can be transmitted to the fetus and will cause neurological damage if the infant is not treated. Group B strep causes infant infection if not treated in the mother prior to delivery. This bacterial infection is now rarely associated with cerebral palsy unless the mother is not screened before delivery and not treated in a timely manner (Hermansen & Hermansen, 2006).

Other variables increase the occurrence of CP when paired with maternal sepsis and VLBW babies such as early neonatal sepsis, maternal primigravida status and the male sex of the baby (Costantine, How, Coppage, Maxwell & Sibaiu, 2006). CP increased four times if the neonate also becomes infected in addition to maternal sepsis and VLBW (Wheater & Rennie, 2000). Maternal fever greater than 38 degrees Celsius in itself may injure the fetal brain (Nelson and Willoughby, 2000). Maternal infections were also associated with low Apgar scores (a measure of well-being in the neonate done immediately after birth to help determine need for resuscitation) below 6, the need for intubation and the occurrence of seizures in the neonatal period (Grether & Nelson, 1997), all of which relate to CP. Infection occurring before delivery may have the appearance of asphyxia at birth (Badawi, Kurinczuk, Keogh, Alessandri, O'Sullivan, Burton, Pemberton, & Stanley, 1999) so it is important to evaluate the newborn thoroughly. Maternal infections also may contribute to cerebral palsy as symptoms of maternal intrauterine infection also imitate birth asphyxia in the newborn (Nelson and Willoughby, 2000). Other variables that had an association with cerebral palsy were maternal age greater than 25 years, first baby and black ethnicity.

Multiple Gestations

The third of the major risk factors for cerebral palsy is multiple gestations (Odding, Roebroeck & Stam, 2006; Petterson, Nelson, Watson & Stanley, 1993). Many studies have amplified understanding of the phenomena. The more embryos and more fetuses, the higher the risk for cerebral palsy becomes. Risk for CP with multiple gestations increased substantially as the number of fetuses increase and was as high as 42% - 47% in triplet gestations. In these multiple births, the risk for infants who were born at less than 32 weeks gestation was 20 times greater than those who were born after 36 weeks gestation. In these multiple gestations, the risk increased as gestational age decreased, particularly in combination with asphyxia (Petterson, Nelson, Watson & Stanley, 1993; Yokoyama, Shimizu, & Havakawa, 1995). LBW increased the frequency of CP in those babies from multiple gestations (Petterson, Nelson, Watson & Stanley, 1993).

Much but not all of the increased risk of cerebral palsy is related to the tendency of twins and triplets to be of low birth weight. Rates of multiple births are rising because of increased use of treatments for infertility and a rise in births to older women. One study looked at cerebral palsy in twin births, twins of the same sex, and twins when one of the twins died before birth (Pharoah, Price & Plomin, 2002). If one twin died, the prevalence of CP increased in the surviving twin. When both twins lived, those of the same sex were more likely to have the diagnosis of CP than if they were different. Findings suggested that monochorionicity may be one reason for more CP diagnoses among same sex twins.

Other relationships exists among CP to intellectual disability, epilepsy, low Apgar score, chromosomal defects, birth injuries, neonatal encephalopathy, and perinatal arterial ischemic stroke.

Intellectual disability may be a predictor of cerebral palsy as impairments also occur during early brain development. A study done to assess multiple factors behind developmental disability (Decoufle, Boyle, Paulozzi and Lary, 2001) examined the prevalence ratio, the "prevalence of a developmental disability in children with 1 or more major birth defects divided by the prevalence of the same DD in children without major birth defects" (728). Developmental disabilities occur because of injuries during the process of early brain development. This comparative study found that intellectual disability was associated with birth defects in multiple organ systems such as those of cardiovascular, respiratory, gastrointestinal, reproductive,

urinary, and musculoskeletal as well as defects of the eye. Therefore, the authors suggested that intellectual disability does not occur because of the birth defects but is a part of the early embryonic development so that the development itself causes both the physical and intellectual defects.

Another study that viewed the relationship of cerebral palsy to severe mental retardation (Nicholson & Alberman, 1992) and found that 25% of children born at less than 1500 grams had severe mental retardation and that 37% of all children with cerebral palsy also have severe mental retardation without considering birthweight. Intellectual disabilities are associated with increased diagnosis of epilepsy (Carlsson, Hagberg, & Olsson, 2003), another problem associated with cerebral palsy.

In one study about developmental disabilities, cerebral palsy and epilepsy were two of the most serious outcomes (Decoufle, Boyle, Paulozzi and Lary, 2001). In another study, neonatal seizures were documented in up to 48% of children who were subsequently diagnosed with cerebral palsy (Bruck, Antoniuk, Spessatoo, deBern, Hausberger, & Pacheco, 2001). The Decoufle et al. findings concluded that the prevalence rate for developmental disability increased according to the number of identified birth defects, not necessarily the severity of one birth defect.

Swedish researchers computed the odds ratio (which needs to be greater than 1 to be significant) of various problems related to a low Apgar score. Premature infants were excluded as were those with chromosomal & severe malformations. A low score had the odds ratio of 31.4 for cerebral palsy. (FYI: The risk for low Apgar scores was higher in June, July, August, and December with significance truly found only in August.) One finding was an influence on the score if the baby was post-term, or after 40 weeks gestation, as "the risk was obvious in week 41 and very pronounced in week 43" (69). Low birth weight was also significant. If the Apgar is below 7, neurological impairments, mortality and morbidity increase (Thorngren-Jerneck and Herbst, 2001). The low Apgar scores were of greater significance when maternal infection was also present (Costantine, How, Coppage, Maxwell & Sibaiu, 2006).

Chromosomal fragility or defects also contribute to cerebral palsy (Kadatani, Watanabe, Sawano, Minatozaki, & Kadotani, 2001). Chromosomal abnormalities and continuous gene syndromes can also occur early in pregnancy during gametogenesis or early embryogenesis. This

can result in deletions, duplications, or translocations of genes (Menkes & Flores-Sarnat, 2006) which may lead to CP.

For many years, it was thought that birth difficulties subsequent to a prolonged second stage of labor contributed to the majority of cerebral palsy. It is now believed that this accounts for only 10% of the total CP incidence and instead results from one or a combination of several abnormalities, which could be developmental, metabolic, autoimmune defects, infection, or coagulation defects, all of which could lead to cerebral palsy and neonatal encephalopathy (American College of Obstetricians and Gynecologists, 2003; Menkes & Flores-Sarnat, 2006). Newborn encephalopathy does not occur because of intrapartum problems (Badawi, Kurinczuk, Keogh, Alessandri, O'Sullivan, Burton et al, 1998).

> Neonatal encephalopathy is a condition characterized by abnormal consciousness, poor muscle tone and reflexes, difficulty initiating or maintaining breathing, or seizures, and may result in permanent neurologic impairment. In contrast, cerebral palsy is a chronic developmental disability of the central nervous system recognized by uncontrollable movement and posture…If there is hypoxia during labor sufficient to cause cerebral palsy in later life, it would also have to be severe enough to cause neonatal encephalopathy in the first few days after birth" (American College of Obstetricians and Gynecologists, 2003).

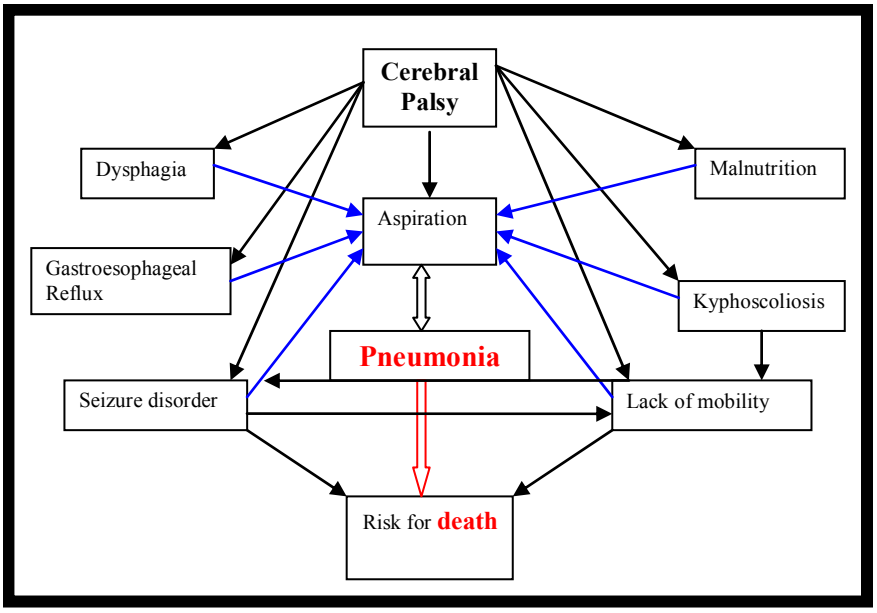
Another of the causes for cerebral palsy in the neonate is perinatal arterial ischemic stroke. It also could be mistaken for birth asphyxia as a causative factor for cerebral palsy as was maternal infection. Perinatal arterial ischemic stroke (PAS) is "defined as occurring between birth and 28 days postnatal age in term or near-term infants, with subsequent distinctions for premature infants" (Kirton & deVeber, 2006, 367). It is diagnosed by magnetic resonance imaging (MRI), which is preferred, or computerized tomography (CT). Because these tests have better sensitivity, neonatal stroke can be diagnosed much more accurately today than a few decades ago.

It is possible that some of the risk factors for stroke are similar to other risk factors for cerebral palsy. It is of strong interest that 17% of the babies from mothers using cocaine had a perinatal stroke (Heier, Carpanzano, Mast et al., 1991 in Kirton & deVeber, 2006). This study was done over 15 years ago. With advanced imaging technology in use today, more cases can be identified.

Cerebral palsy secondary to stroke has some differences compared to CP from other types of injury. In stroke, the other hemisphere is intact; however, other causes of injury do not leave areas of functioning nearly as well. In stroke, the affected side may also have areas untouched by damage. Due to the perceived plasticity of the brain, function can improve over time if the area of damage is identified and limited (Kirton & deVeber, 2006).

Health Problems

Figure 2.2 Health problems for those with CP



Numerous health problems exist for many individuals with CP. These health problems impact the life span of the affected individual and caregiving by the parent. These include respiratory infections such as pneumonias, gastroesophageal reflux, dysphagia, kyphoscoliosis, malnutrition, mobility difficulties, and seizure disorders. The pneumonias may be a result of other health problems. In particular, mobility and problems in nutrition may be of most impact to morbidity and mortality of the individual. Many of these health problems are interrelated, such as seizures contributing to aspiration and gastroesophageal reflux. Relationships exist in ability to eat and aspiration. Lack of mobility and skeletal deformities also contribute to respiratory infections.

Respiratory difficulties are one of the primary reasons for morbidity. Life expectancy among those with mild cerebral palsy is now similar to the general population; however, half of

those with severe cerebral palsy die soon after reaching adult age, most commonly from pneumonias and other respiratory infections (Braverman, 2001). Deaths of those with severe disabilities that were attributed to these types of respiratory problems range between 52-77% (Seddon & Khan, 2003). This may be related to aspiration, which can be obvious related to the individual choking, coughing or gagging; however, aspiration is usually silent and undetected.

During seizures, aspiration is very likely to occur in more than 40% of those with cerebral palsy as children. Those with greater motor involvement and spinal deformity are unable to cough forcefully and thus clear lungs from secretions. Also contributing is lack of physical exercise which results in atelectasis, an obstruction of the airways because of retained mucous plugs and then loss of function of that area of lung tissue. Risk factors for aspiration include dysphagia, gastroesophageal reflux in which stomach contents with acid proceed up into the esophagus thus eroding and irritating esophageal tissue with the comittent risk of inhaling this acidic content into the lungs (Braverman, 2001).

Gastroesophageal reflux is also quite common in this population and may occur in as high as 70% of those with severe disabilities (Abrahams and Burkitt, 1970) attributed to spasticity of the abdominal muscles or to poor muscular coordination between the stomach sphincters and the esophagus. Aspiration and reflux can lead to esophageal damage as acid inflames and erodes the membranes or to respiratory infections and subsequent damage to the airways. Aspiration may be controlled by changing the consistency of food and fluids to a more thickened state to improve the ability to be swallowed. Percutaneous esophageal gastrostomy (PEG) tubes may also be inserted for tube feeding, thus bypassing the oral area (Seddon & Khan, 2003) and perhaps decreasing risk of aspiration.

Gastroesophageal reflux and aspiration can be related to simple swallowing difficulties (dysphagia). Swallowing reflex is actually very complex in nature and occurs through reflexes among mouth, pharynx, larynx, esophagus, diaphragm, and tongue. If these muscles do not work together, aspiration of both food and fluids can occur multiple times (Seddon & Khan, 2003) and may be as high as 97% in children who have both CP and swallowing problems (Arvedson, Rogers, Buck, Smart, and Msall, 1994). Drooling and inability to swallow oral secretions and seizures also are risks for aspiration and pneumonia. Symptoms of respiratory illness include dyspnea, change in response, and decreased appetite as well as low grade temperature, coughing and an increase in secretions (Braverman, 2001).

Other respiratory difficulties also contribute to infections and death. Coughing is something done reflexively by those with normal neuromuscular reflexes. However, this activity either is not triggered effectively by those with cerebral palsy or is not sufficient to move respiratory secretions from the lungs. The respiratory muscles are also weak, leading to a barrel shaped chest as intercostal muscles are used much more than usual for exhaling (Seddon & Khan, 2003).

Kyphoscoliosis is another disorder common in those with CP that contributes to respiratory problems. (Kyphosis appears as a spinal curve forward of the middle spine because of muscle weakness. Scoliosis is a lateral curve, either C-shaped or S-shaped. This is of interest as lung expansion can be severely compromised on the affected side. Individuals may not be able to sit in an upright position as kyphoscoliosis progresses.) Scoliosis may continue to advance in CP. These individuals may not communicate verbally, so the caregiver may only know about the respiratory infection if he knows the person well and recognizes how he manifests symptoms (Seddon & Khan, 2003).

Although respiratory difficulties contribute to morbidity and mortality in those with CP, nutritional problems also take their toll. Ability to eat may be as significant as is cognitive and motor ability to overall health status of children with cerebral palsy. Problems in feeding were positively associated with the family's inability to participate in everyday activities. Some of the children who were primarily tube fed with severe feeding dysfunction had more hospital days and more days missed from school and other daytime programs because of illness; however, they experienced fewer episodes of respiratory illness than those not tube fed. Growth failure paralleled motor difficulties in that those children with more severe cerebral palsy experienced poor growth and depleted stores of fat. Feeding and health problems are more common for this population of those with cerebral palsy, even those who have less severe manifestations and muscle involvement (Fung, Samson-Fang, Stallings, Conaway, Liptak, Henderson, Worley, O'Donnell, Calvert, Rosenbaum, Chumlea & Stevenson, 2002).

Mobility is used as a one way to prognosticate future abilities. The poorer the mobility, the greater the risk for other health problems in the person with CP. Therapy and rehabilitation have the potential to improve function through adolescence; however, improvement in ability to walk does not occur after age 25. Those who use a wheel chair do not improve and have a substantially higher risk of dying. Those who have some ambulatory abilities can improve

through their teen years, but will level off in their 20s (Day, Wu, Strauss, Shavelle, & Reynolds, 2007).

Motor dysfunction occurs secondary to disturbances in the brain which relate to the expected pattern of brain maturation and, therefore, these disturbances also influence neuromotor functions which also include seizure disorders. Seizure disorders of every seizure type occur. The seizure disorder itself may cause further motor impairment over time (Bax, et al, 2005). As many as 30% (Zafeiriou, 1999) to 60% (Kwong, Wong, & So, 1998) of children with cerebral palsy have associated seizures. Seizures occurred before the child was 1 year for approximately 61% (Bruck, Antoniuk, Spessatoo, deBern, Hausberger, & Pacheco, 2001; Singhi, Jagirdar, Khandelwal, & Malhi, 2003) to 67% (Zafeiriou, 1999) and was strongly associated with motor and intellectual disabilities (Bruck, et al, 2001; Liptak, O'Donnell, Conaway, Chumlea, Worley, Henderson, Fung, Stallings, Samson-Fang, Calvert, Rosenbaum, & Stevenson, 2001).

As the person with CP ages, health problems will include pain, additional sensory problems, and decreased mobility and ability to self-feed. Pain occurs particularly in the cervical area. Epilepsy will worsen as well. Mobility influenced ambulation and the ability to self-feed. Most of those with CP will experience declines in mobility. All of these change general health and lead to increased risk for death.

Survival decreases primarily for two reasons: first, the decline in the ability to walk and balance independently leading to the complete inability to ambulate and second, the decline in the ability to feed leading to inability to self-feed and the necessity for tube feeding for nourishment. Those with minimal to no mobility rarely survive to age 60. These declines adversely affect muscle strength which influences posture negatively. Appropriate support for posture is extremely important to either prevent or limit spinal scoliosis as the absence of spinal support further contributes to respiratory difficulties (Strauss, Ojdana, Shavelle, & Rosenbloom, 2004), which also affects morbidity and mortality.

In addition to declines in mobility, inability to self-feed may lead to malnutrition, also strongly associated with cerebral palsy (Liptak, et al, 2001). "Mortality rates were much higher among those who required gastrostomy feeding than among those who did not" (p. 88) and "were strongly dependent on degree of mobility" (p. 88). Those with the least ability to lift their heads died four times more frequently compared to those who did have the ability to move independently in rolling or sitting (Strauss, Shavelle, Reynolds, Rosenbloom, & Day, 2007).

If those with CP are not able to feed themselves or if they have difficulty in chewing and swallowing food, tube feedings are an option to maintain sufficient calorie intake. Unfortunately, aspiration pneumonia with subsequent increase in morbidity and mortality is not uncommon for those who have these difficulties or those receiving tube feedings because of the frequency of gastroesophageal reflux (GERD). Aspiration pneumonias can be reduced if reduction in GERD can be facilitated. For some, fundoplication surgery may reduce this risk. Changes in fundoplication surgery done in order to reduce gastroesophageal reflux common in the population and an increased prevalence of tube feeding done to augment or to be the main source of nutrition are factors in the reduction of aspiration pneumonias. For those adults who are tube fed and the most severely affected by CP, the mortality rate fell by approximately 50% when GERD was reduced. "Children aged 10 years who are tube fed and do not lift their heads in prone are subject to roughly 500 times the mortality rates of the general population" (Strauss, Ojdana, Shavelle, & Rosenbloom, 2004, p. 91). It is not known if this change in mortality is accompanied by a corresponding improvement in quality of life with utilization of these methods done to reduce both GERD and aspiration pneumonias (Strauss, Ojdana, Shavelle, & Rosenbloom, 2004).

Studies of Chronic Sorrow Specific to Children with Cerebral Palsy

In addition to the chronic sorrow studies discussed previously, studies were also found which compared mothers of children with varying diagnoses including cerebral palsy. Phenomenological studies were also discovered. Comparison of experiences was drawn between mothers of adults with intellectual disability and mothers of adults with mental illness (Kim, Greenberg, Seltzer & Krauss, 2003). Both these groups worked with their children for the lifetime of the child, not only as a child but as an adult. Both sets of parents had to deal with deinstitutionalization for those with intellectual disabilities and with mental illnesses. The time difference in diagnosis differed in that parents of those with intellectual disabilities are typically diagnosed at birth or early childhood and parents of those with mental illness are typically diagnosed in late adolescence or early adulthood. Parents of those with ID have similar challenges over time as the ID level does not change; however, parents of those with mental illnesses may be working with acute versus chronic manifestations of the disease. Both groups of parents may experience chronic sorrow, but the time line is very different.

Family functioning, social support, and stress of parents of children with disabilities was compared to parents of children without (Dyson, 1997) and included 62 sets of parents from both Canada and the United States. This study applied to parents with younger children, not adult children. The researchers chose a short form of the Questionnaire on Resources and stress initially developed by Holroyd in 1974 and shortened by Friedrich, Greenberg and Crnic (1983) and may not apply for parents who have adult children. They found that family support and functioning was similar, but family stress was greater in parents of children with disabilities (Dyson, 1997).

There have been no specific phenomenological studies done about chronic sorrow experienced by parents of children with cerebral palsy. However, parents with children with disabilities in a phenomenological study about spiritual needs for their family and their child inevitably wanted the researcher to know about their child before they would answer questions (Speraw, 2006). This is important as it supports the idea of allowing parents time to talk about their child before asking specific questions in research.

Most studies about parents who have children with cerebral palsy have dealt with parents of younger children as opposed to adult children. These studies primarily have been about stress, anxiety and depression, or coping abilities, not about chronic sorrow.

Literature about parenting children with cerebral palsy, various stressors, coping processes used by parents, and how parents adapted to the changes in their lives was reviewed. It was found that physical limitations or disabilities of the child predicted more stress and perhaps depression in the mothers (Altindag, Iscan, Akcan, Köksal, Erçin & Ege, 2007; Rentinck, Ketelaar, Jongmans, & Gorter, 2006). Therefore, information about physical limitations should be collected for this study.

One longitudinal study interviewed parents who had children with cerebral palsy who were in their middle 20s in order to better understand their emotions about the initial diagnosis and how coping occurred (Hirose & Ueda, 1990). It was assumed in this study that chronic sorrow occurs during the adjustment to the diagnosis of cerebral palsy.

Review of Methods

Multiple methods have been used to determine experiences of chronic sorrow. Questionnaires or surveys have been completed related specifically to chronic sorrow. These

range from one of the earliest, the Direct Question (DQ) and some derivation of the Burke questionnaire to Mallow's (1999) instrument further defining chronic sorrow. Other instruments have also been used to determine if chronic sorrow is related to depression (it is not), if chronic sorrow is experienced differently by mothers compared to fathers, if chronic sorrow is present in individuals or spouses of those with chronic illnesses among others.

One method used was the Direct Question (DQ), initially developed by Wikler, Wasow, and Hatfield (1981) to measure the 'intensity dimension of chronic sorrow.' The question was:

"In the field of handicapped children, there's a phrase that's often used to describe how the parents of handicapped children feel chronic sorrow. Things can be going along just fine, and suddenly out of the blue you might begin to feel sad again. Sometimes it may be little things that set off those feelings… those moments may be trimming the Christmas tree, hearing a special piece of music, seeing your child outside playing … or it may be the big life changes that bring back strong feelings of sadness such as the beginning of school. To what extent do you experience chronic sorrow?"

This DQ was used in other studies as well (Damrosch & Perry, 1989; Hobdell, 1993). Content and concurrent validity for the DQ were established by Wikler et al. (1981) and Damrosch and Perry (1989). Global ratings of perception of a specific concept by single item indicators have been found to be a psychometrically sound method of measuring the intensity of a symptom of feeling (Youngblut & Casper, 1993 in Hobdell, 1996). By use of this question in this study, 86% of the participants indicated they had experienced chronic sorrow.

Questionnaires have also been used in many studies, but not all are currently available nor were the originals included in the journal articles. Two of the questionnaires were based from Burke (1989), the Chronic Sorrow Questionnaire (CSQ), which had 16 items, and a questionnaire with fewer questions, the Adapted Burke Questionnaire (ABQ).

The first was constructed by Burke (1989) and was also used by Mallow and Bechtel (1999). In addition, it was used by Hainsworth, Eakes and Burke (1994) in a study determining presence of chronic sorrow and coping for infertile couples, for individuals with long-term cancer, with Parkinson's disease, multiple sclerosis, and for spouses acting as caregivers. Findings included the presence of chronic sorrow in over 83% of all subjects and for 50% of the caregivers. These findings were determined by thematic identifications by two of the authors, who had interrater reliability of 1.00.

The Burke Questionnaire was developed to determine basic characteristics of chronic sorrow (Burke, Hainsworth, Eakes, and Lindgren, 1992). It was used to look at differences between the two parents in experiencing chronic sorrow (Mallow and Bechtel, 1999). In this study, the parents of child with developmental delays were given the questionnaire separately. It was found that the father and mother experienced chronic sorrow differently with father becoming resigned and mothers experiencing chronic sorrow more intensely. Responses from one question, "Is there anything you would tell nurses or other professionals about helping people like yourself?" were very dramatic (Mallow and Bechtel, 1999, p. 34). This study contacted families from a parent support organization with 19 mothers and 9 fathers electing to participate whose children had ADHD and a variety of birth defects or genetic problems. These authors believed the responses were very similar in nature and that specific types of disabilities did not need to be discussed. Specific events caused sorrow to occur over time, such as health crises of the child and the child not meeting societal expectations. The questionnaire was formulated in a dissertation by Burke when evaluating characteristics of chronic sorrow in parents of children with spina bifida where reliability and validity of the tool were established (1989).

The Burke Chronic Sorrow Questionnaire (BCSQ) has 16 questions. The Burke Questionnaire was subsequently reduced to an 8 item questionnaire and then called ABQ (Hobdell, 1993). This adaptation was most commonly used by researchers of this phenomenon of chronic sorrow. According to Hobdell, the Burke CSQ may be biased toward presence of chronic sorrow and was not objective enough, her justification for the adaptation. She used the ABQ in studies of parents who had children with neural tube defects, epilepsy, and in researching how parents might differ in their experiences with chronic sorrow (Hobdell, 1993; Hobdell, 2004; Hobdell & Deatrick, 1996; Hobdell, Grant, Valencia, Mare, Kothare, Legido, & Khurana, 2007).

The Adapted Burke Questionnaire (ABQ) was also used by researchers studying chronic sorrow by parents of children with neural tube defects (Hobdell, 2004), caregivers of those with Alzheimer's dementia (Mayer, 2001), women with chronically mentally disabled husbands (Hainsworth, Busch, Eakes, & Burke, 1995), spouses of those who have multiple sclerosis (Hainsworth, 1996), to differentiate between sorrow experienced by mothers and fathers (Hobdell & Deatrick, 1996), to discuss chronic sorrow as experienced by fathers (Spears, 2004), and with families who have children with epilepsy (Hobdell, Grant, Valencia, Mare, Kothare,

Legido, & Khurana, 2007). Spear (2004) also used ABQ to profile fathers' experiences with chronic sorrow.

Other permutations on the Burke Questionnaire included using both the BQ and the ABQ with the DQ. Hobdell adapted the original Burke Questionnaire to include the "most frequently reported mood states from the CSQ (grief, anger, shock, disbelief, sadness, hopelessness, fear, and guilt)" (Hobdell, 2004, p. 4, electronic version). Sixty-nine families who had children with neural tube defects of different types participated in the study. Parents rated these mood states on a 4 point Likert scale (3 = very intense, 2 = somewhat intense, 1 = not intense, 0 = absent). An intensity score was calculated by summarizing the eight item scores, for a possible range of 0-24: the higher the score, the greater the intensity of sorrow. Second, five questions were asked to measure the mood state, cyclical nature, and intensity dimension(s) of chronic sorrow. These five questions were:

1. What other feelings did you have that are not listed here? 2. Has there been a time when the feelings from the time of birth returned? 3. How do those feelings compare to the first time you had them? 4. Are there events that bring up these feelings? 5. Was the intensity for these events the same, less, or more intense than the first time you had them? Progression (of chronic sorrow over time) was not measured in this study" (p. 4).

The content reliability of the ABQ was determined previously with Cronbach's alpha being 0.72 of form A and 0.80 of form B. In this specific study, "Cronbach's alpha for the ABQA was 0.81 for fathers and 0.83 for mothers. Reliability for ABQB was 0.89 for fathers and 0.91 for mothers. Cronbach alpha readings using the ABQ were all above .72." The ABQA was given to ask how parents perceived chronic sorrow at the time of diagnosis, and the ABQB was how they perceived chronic sorrow at the present time. Hobdell and Deatrick recommended that the 8-item ABQ be continued in future studies (1996).

ABQ and 3 questions from the CSQ were both used in Hobdell & Deatrick's (1996) study of parental differences in perception of chronic sorrow with a child who had a neural tube defect. The 3 additional questions were:

1. What other emotions did you experience? 2. Thinking back to when you had those feelings about your child's diagnosis, has there been one time when you have had them? 3. Some

parents say that certain events tend to bring up those feelings again. Were there many events when you had those feelings? Describe the events (Hobdell & Deatrick, 1996, p. 61).

In this study, parents completed the same questionnaire combination twice, the first time to describe what they might have answered at the time of diagnosis, the second time to describe how they felt at the time of the study. "A total score was derived from the grid of mood states with a possible range of 0-24. Any score other than zero was indicative of chronic sorrow. Results from the second form (current time) … documented chronic sorrow" for both parents. This study sample included parents of children from 6 months to 6 years of age. Parents responded using a 4-point Likert scale, from 0 = never to 4 = most of the time. Continued use of ABQ was recommended.

The ABQ was again used by researchers studying chronic sorrow by caregivers of those with Alzheimer's dementia (Mayer, 2001), parents of children with neural tube defects (Hobdell, 2004), women with chronically mentally disabled husbands (Hainsworth, Busch, Eakes, & Burke, 1995), spouses of those who have multiple sclerosis (Hainsworth, 1996), to differentiate between sorrow experienced by mothers and fathers (Hobdell & Deatrick, 1996), and families with children who have epilepsy (Hobdell, Grant, Valencia, Mare, Kothare, Legido, & Khurana, 2007).

A recently developed questionnaire was devised by Kendall (2005). This questionnaire was developed because the author found no previous qualitative questionnaires to use for research, although she did discuss Hobdell's use of the ABQ. This questionnaire was developed for determining chronic sorrow in those who were caring for an individual with chronic disease or disability or chronic sorrow in the individual himself. It consisted of a Likert-type scale and was reduced to 18 items. Her panel of experts included parents of children who had disabilities, one person with multiple sclerosis, and people who have written about chronic sorrow: Mary Burke, Carol Lindgren, and Susan Roos, all of whom have published in the area of chronic sorrow. She used Olshanksy, Eakes, and Roos (1994) in her conceptual framework.

Kendall (2005) primarily looked at depression and well-being as she believed chronic sorrow and depression to be closely related positively and well-being negatively. Several of her statements on the questionnaire were deleted as they were considered as an effect rather than a component of chronic sorrow such as how life choices may be based on the perceived loss or the support system available. I disagree with this idea based on my perceptions of the definition of

chronic sorrow. She did determine that chronic sorrow can exist without symptoms of clinical depression and with a sense of positive well-being.

To establish validity and reliability, Kendall (2005) developed the Kendall Chronic Sorrow Instrument (KCSI) by purposeful convenience sampling and asked those older than 18 who self-identified as having experienced a loss due to a chronic condition or situation to complete the instrument. Support groups were targeted as well as other community organizations. Additional testing of an adapted instrument based on the first iteration was given to parents of children with special needs. The questionnaire began with 57 questions which were reduced in number to 18. A Likert-type scale was initially used for individual responses which ranged from strongly agree to strongly disagree. The final instrument asked for a rating according to time: "6, almost always; 5, frequently; 4, sometimes; 3, not sure; 2, usually not, and 1, infrequently" (Kendall, 2005, p. 126). Scores were determined by a total of added points: "0-38, No Chronic Sorrow Present; 39-82, Likely Chronic Sorrow Present; and 83 and over, Chronic Sorrow Present" (Kendall, 2005, p. 127). Those who scored 83 and over were currently undergoing chronic sorrow and those scoring 39-82 experienced chronic sorrow, but were not in the current phase. The instrument was either sent to self-selected participants by mail for their completion or given to them in person. It was noted that having a child with a disability was the most common perceived loss. It was suggested that the instrument be used in a variety of situations in future research. In addition, it was suggested that in some cases, this questionnaire would help professionals to correctly identify chronic sorrow as a diagnosis rather than depression.

Additional methods used in journal publications included the Texas Revised Inventory of Grief and Recurrent Sorrow (Teel, 1993), a Parents Questionnaire which was used to describe parental objective and subjective experiences in caring for children with disabilities in Ireland (McGilloway & Donnelly, 1995), case study or field research (Krafft & Krafft, 1998; Phillips, 1991; Roos, 1994), exploratory or phenomenological study (Johnsonius, 1996), and descriptive graphs (Damrosch & Perry, 1989; Wikler, Wasow, & Hatfield, 1981).

The Texas Revised Inventory of Grief and Recurrent Sorrow questionnaire was used by Teel (1993) to study recurrent or chronic sorrow as it relates to other variables experienced by parents who had younger children with cognitive difficulties. Because this attempted to study variables such as social support, spirituality, and depression in chronic sorrow, its use would

muddy the waters of the concept of chronic sorrow existing in parents who have older children with disabilities.

An unknown questionnaire (Blaska, 1998) was used as a basis for face-to-face interviews which were conducted with parents of adult children who had diagnoses including Down syndrome, autism, blindness, and cerebral palsy with severity ranging from mild to severe were interviewed using a total of nine questions. Nine questions were asked, but only question six was included in the text: "Think about the first five years with your child. Were there any times that some of these intense feelings came back?" This question was repeated with other time spans of elementary, adolescence, high school and post high school. It is not known how each diagnosis was represented as to percentage or severity. Parents had known of the diagnoses between 21 and 35 years. Notes were taken as some parents voiced discomfort with recording the interviews. These notes were transcribed within 48 hours of the interview. This questionnaire was not available from the author at the time of the dissertation proposal.

Blaska's study (1998) was the only known study completed for parents of children of adult age. This used an exploratory methodology which was done with a naturalistic approach utilizing face-to-face interviews by a master's level student who was trained by a researcher. The ages of the children ranged from 21-39 years. Interviewing was completed by 3 fathers and 7 mothers. A wide range of disabilities represented. Not all children lived at home. Because of the number of years, the interviewer asked the parent to consider the first five years of their child's life, then to focus on the elementary years, adolescence, high school, and post high school. Focusing on specific time-span helped parents recall events that were significant to them. Probes and cues were also used to elicit responses…The intent was to tape record the interviews. However, the majority of parents were uncomfortable with this procedure. Subsequently, notes were taken during the interviews and shared at the conclusion…the interviewer transcribed all notes within 48 hours of the interview. Follow-up calls were made to three participants to clarify data (Blaska, 1998, p. 7).

One case study was done by Krafft and Krafft (1998). They profiled two professionals (themselves) who described their feelings of chronic sorrow occurring over the life of their profoundly intellectually disabled son, disabled due to intractable seizures. They informed the reader that the family's lives have been forever altered when these disabilities occurred. Another second example of case study/field research was done in which three mothers were interviewed

for 2 hours each week for six weeks (Phillips, 1991) to develop theory at this point in time. Prognoses varied for children.

A phenomenological pilot study (Johnsonius, 1996) wrote of expanding the themes of chronic sorrow and pointed out that chronic sorrow was a phenomenon better understood by examining the lived experience. Her study was done to share descriptive stories about how families felt when living with a chronically ill child. Three mothers shared their experiences, including their feelings when told their child had a disability. No information about age of or diagnoses for the child was given. The investigator used bracketing, analyzing, intuiting, and describing in her phenomenological approach. The investigator bracketed 'chronic sorrow is present in parents of chronically ill children.' She then listed components of chronic sorrow which were "display of cyclic emotions of withdrawal, a loss of connectedness, and an outward appearance of sporadic happiness blended with the environment of continued pain and conflict" (p. 167). Intuiting allowed her to share understanding of the participants' stories. Describing included the use of objectivity. She recorded the interviews in one meeting, she transcribed them to text, and she did the data sorting to find shared descriptions. She then cited common meanings of phrases of the perceived reality for these three participants (Johnsonius, 1996). Two of the three mothers experienced some hopelessness over child's situation as they could not see how the child would improve.

Graphs drawn by parents or by the researchers were used to discover how parents believed their emotions changed over time in two studies. Wikler, Wasow, & Hatfield (1981) used graphs to document how chronic sorrow changed over time. They asked the DQ, and asked parents to draw a graph to represent intensity of emotional ups and downs. Damrosch & Perry (1989) also used graphs to show how chronic sorrow is cyclical and how parents recover from initial grief. Pictures of two graphs were shown to parents, one of which was a V which the right side's trajectory gradually increased to the level of the first side of the V, representing how emotions returned to a previous point before the child's diagnosis. The second graph showed a picture of a saw-toothed V, or a V shown multiple times. The first depicted how sadness resolved over time and the second graph showed how peaks and valleys occurred. Parents were asked to choose which graph most looked like their pattern of emotions after receiving the news of their child's diagnosis. These already drawn graphs were used as previous study (Wikler et al.) using graphs asked the parents to draw their own graphs, and parents were uncomfortable doing so.

Parents were chosen on the basis of their participation in a parent support group. Responses were collected from 18 fathers and 22 mothers. The mean age of the child was 6.59. This study involved parents of children with Down syndrome. Here, fathers were shown to recover, but mothers were the ones experiencing chronic sorrow and reported it occurring more frequently. Damrosch and Perry also asked the DQ, but did not ask it as a yes or no question. Instead, parents were asked to rate the intensity of the emotion on a scale of 0-4. In addition, Damrosch and Perry also utilized a Parental Coping Scale, an 81-item questionnaire. All questionnaires were received by mail. Intensity of chronic sorrow increased as the child grew older; however, only three of the children were older than age ten.

The questionnaire established face validity by experts in the area. Content validity was established by a panel of experts composed of academicians and clinicians. Burke, Hainsworth, Eakes, & Lindgren (1992) supported previous definitions of chronic sorrow as a "pervasive sadness that is permanent, periodic, and progressive" with no predictable end that intensified as time elapsed; however, a subsequent study did not clearly support the idea that chronic sorrow intensified over time.

Review of Reliability and Validity in Previous Studies

The first study to use the ABQ questionnaire which was derived from the BQ was by Hobdell and Deatrick (1996). For this study, content validity for the ABQ was determined by three clinical experts with 100% agreement of differences found between parental responses of chronic sorrow. Reliability was "determined in a survey of 26 parents of children with cancer, pulmonary, or neurologic disease. Seventeen parents were male, nine female. Reliability for the first form (Form A) demonstrated a Cronbach's alpha of 0.72; for the second form (Form B), and alpha of 0.90 was obtained. In the current sample reliability for Form A was .81(fathers), .83 (mothers); Form B .89 (fathers), .91 (mothers)" (Hobdell & Deatrick, 1996, p. 60).

"The ABQ consisted of a grid of eight mood states (grief, shock, anger, guilt, disbelief, sadness, hopelessness, fear) which were ranked for intensity on a 4-point Likert Scale (very intense, somewhat intense, not intense, absent). Parents were then asked in a questionnaire to respond to three questions derived from the CSQ that reflected the issues of the cyclical nature of chronic sorrow:

1. "What other emotions did you experience?

2. Thinking back to when you had those feelings about your child's diagnosis, has there been one time when you have had them?

3. Some parents say that certain events tend to bring up those feelings again. Were there many events when you had those feelings? Describe the events.

"Each parent was asked during the visit to complete the ABQ twice. First responses (Form A) to the ABQ indicated emotions at the time of diagnosis (birth or ultrasound), the second (Form B) was reflective of emotions at the time of the study. A strict sequence of instruments were (sic) presented to each parent. Few verbal cues were given. Specific questions were answered as they arose" (p. 60-61).

The mood states from the Likert scale were categorized from the three above questions. The responses of mothers' and fathers' were listed and summarized separately.

Hobdell (2004) built on her previous work with chronic sorrow to compare chronic sorrow and depression in parents with neural tube defect. "The ABQ was used and used 8 of the most commonly reported moods 'from the CSQ (grief, anger, shock, disbelief, sadness, hopelessness, fear, and guilt). More specifically, both parents were asked to indicate the intensity of these mood states on a 4-point Likert scale (3 = very intense, 2 = somewhat intense, 1 = not intense, and 0 = absent). An intensity score was calculated by summing the eight item scores, for a possible range of 0-24. The higher the score, the greater the intensity of sorrow was believed to be. Second, five questions were asked to measure the mood state, cyclical nature, and intensity dimension(s) of chronic sorrow. The questions were:

1. What other feelings did you have that are not listed here?
2. Has there been a time when the feelings from the time of birth returned?
3. How do those feelings compare to the first time you had them?
4. Are there events that bring up these feelings?
5. Was the intensity for these events the same, less, or more intense than the first time you had them? (Hobdell, 2004, p. 3-4).

It definitely appears that the content validity was used as obtained by the previous study as the number of experts was the same (3). The reliability was also exactly the same from the previous study (Hobdell and Deatrick, 1996) using the same pilot study. She stated that "in the present study, Cronbach's alpha for the ABQA was 0.81 for mothers. Reliability for the ABQB

was 0.89 for fathers and 0.91 for mothers" (4-5). Whether this previously used pilot study is sufficient is questioned if the population varies substantially from the population studied for Hobdell's research. For instance, do parents who have older children vary from the parents in Hobdell's research who had children from 6 months to 6 years of age?

Hobdell et al. (2007) used information from the ABQ in the 2004 study as a basis for her study looking at chronic sorrow in parents with children who have epilepsy. The children ranged in age from 18 months to 18 years and time of diagnosis was divided into greater or less than 2.5 years. "Content validity has been previously determined. Previous reliability has demonstrated a Cronbach's alpha of 0.90 for parents, 0.89 for fathers, and 0.91 for mothers (Hobdell, 2004). The Cronbach's alpha for this study was 0.935 for parents (p. 78).

Two other studies are important to include, those of Johnsonius and of Kraftt and Kraftt. Johnsonius (1996) completed a phenomenological study. Three parents were asked "Tell me a story that describes how you feel with a chronically ill child" (p. 167). The investigator bracketed 'chronic sorrow is present in parents of chronically ill children' (p. 167). Researcher did her own transcription of audio recordings. Dependability was achieved by an inquiry audit. "Credibility was established with peer debriefing and member checks" (p. 168). (Note to committee: The terminology is a bit different in this study as she used terms such as peer debriefing.) Krafft & Krafft (1998) completed a study in which they described their experience with chronic sorrow as parents of a child who developed intellectual disability as a result of long-term seizures. No reliability or validity was presented.

The study by Hainsworth, Eakes, & Burke (1994) used the BCSQ with validity and reliability having been established on the original questionnaire. "Face validity was provided by two experts in the field, and content validity was established by a panel of seven experts, three academicians, and four clinicians. In addition, 15 interviews of the original spina bifida sample were analyzed independently by two raters to determine the presence of chronic sorrow. An interrater reliability coefficient of 1.00 was obtained" (p. 62).

Kendall's (2005) entire study was to ascertain validity and reliability of the KSCI. Reliability testing included a Cronbach's alpha of .91 which strongly pointed toward internal consistence for the final product. Validity included that of construct which was determined during testing by administration of a depression and well-being scale. She was able to eliminate 30 of the initial 57-item questions by utilizing a one-factor solution "that explained 35% of the

instrument variance and a Cronbach's alpha of .96" (Kendall, 2005, abstract). She then was left with an 18-item instrument which is both valid and reliable to use to examine the occurrence of chronic sorrow.

Advances in Theory of Chronic Sorrow

The theory of chronic sorrow has evolved over time as researchers asked about how it might apply to situations other than that of parents dealing with their infants and young children with disabilities. Studies then sought to support ideas of chronic sorrow having an end point versus a cyclical pattern, how it occurred in stages, or how its experience became more intense over time. Those who wrote about chronic sorrow in parents of children with disabilities consistently looked at time of knowing a diagnosis of disability, whether at birth or later in infancy, and reaching developmental milestones later as being times when chronic sorrow intensified. However, these developmental milestones were shrouded in the parents' meanings of the significance and recognition of specific milestones and the loss associated with lack of typical development. These complications in how parents and those people surrounding them view the child's accomplishments over time might add to the perception of loss.

First, Bowlby (1961) introduced attachment and loss. In his studies, he notes that grief can be resolved if the person realizes that the loss is permanent, but that depression occurred when the planned-for and hoped-for object continues to exist and the loss therefore continues. He did not address how adults express loss, but how loss is viewed by a child. Depression may occur because of the conflict between hope and reality. Depression of this sort experienced by the mother can be prevented if the mother actually loses infant (Solnit & Stark, 1961). Placement of the infant in an institution was done so that the loss was final and resolution could occur. Depression is no longer viewed to correlate to chronic sorrow (Kendall, 2005).

Olshansky (1962) was the person who initially used the phrase 'chronic sorrow' to describe a pervasive, ongoing and recurring response by the parent in having a child with severe mental retardation and was also a normal response. Acceptance of the child's disabilities may never occur. The Wikler and Wasow (1981) study confirmed the cyclical nature of chronic sorrow, that it had no resolution as it might if this type sorrow resolved over time.

Another viewpoint looked at chronic sorrow occurring in stages, but viewed chronic sorrow from bereavement theory, noting that chronic sorrow began to resolve as parents

acknowledged the child's disabilities, which allowed them to be more realistic about their child's abilities as 'emotional turmoil' fades. This article was written to explain parental behavior during these stages. The cycles or phases occurred as parents vacillated between denial and reality. They used sorrow and bereavement in a similar fashion and believed that chronic sorrow occurs as a phase of bereavement. They note that parents who do not transition from one phase to another may be stuck in their grief and that parents must accept the handicaps of their child in order to complete phase I and experience closure. They do not deny that chronic sorrow might still exist, but they accept the reality of the child's existence and do not experience the 'emotional turmoil' (Copley & Bodensteiner, 1987).

Earlier, as expressed in the previous paragraph, chronic sorrow was thought to be a sorrow that had specific stages through which parents should advance in a linear fashion with the end result being that the acute grief resolved (Young, 1977). However, this research was not done for parents with older children, but to parents who experienced caring for a child with either congenital defects and/or chronic illness who died. She used the concept of chronic sorrow based from Olshansky (1962). Her article was based on her observations in 'field research.' In these cases, chronic sorrow was limited to the time the baby lived and resolved with the occurrence of grief with the child's death. Here, parents deny, accept, and then cope. She viewed the parental response occurring on a maladaptive-adaptive continuum, one that the health care professional can support to continue adaptation to the situation. She did not view chronic sorrow as a remitting-exacerbation process or cyclic, but only occurring in progressive stages.

Chronic sorrow is complicated by the expectation of society for parents. Parents may be expected to suppress this type of long-term sorrow. Society expects that grief be limited in time, that prolonged sorrow may be a flaw in being a good mother. This grief is to be hidden from view of mainstream society. How is it socially acceptable to continue to grieve? "…mothers of handicapped children characteristically describe themselves as having entered a community (usually invisible to others) of people who are permanently changed by suffering, by grief" (Davis, 1987, p. 357). Connections exist between these people who are changed in this way. The trigger in experiencing the loss is the diagnosis of the problem, but Davis stated that this is the loss of the anticipated relationship. It is possible that parents are expected to mourn during the initial diagnosis, but are expected to control grief after that period of time. Sorrow or grief experience is to be limited in time according to the expectations in our culture. Culture may not

allow chronic sorrow to be expressed, so it is hidden by these parents. The person with loss eventually may achieve 'emotional detachment', but perhaps not resolution (Davis, 1987).

Burke (1989) further researched the concept of chronic sorrow in her unpublished dissertation. She interviewed families who had a child with spina bifida to "refine and operationalize the concept of chronic sorrow" (p. 232). This is important as this is when the Burke Questionnaire was introduced. Additional work based on this questionnaire was done with reliability and validity having been established in this research.

Chronic sorrow may be expressed and felt differently by mothers and fathers. Initially, chronic sorrow was described in terms of its expression for mothers, probably because mothers are usually the primary caregivers for the child and thus find their role is different than what was anticipated. Fathers may bear more of the financial burdens while mothers may be limited in working outside the home as they assume responsibility in caring for the child with the disability. These roles may be what affect how both respond to the long-term responsibilities of caring for a child with disabilities (Damrosch & Perry, 1989; Hobdell, 1996; Mallow & Bechtel, 1999)

Teel further advanced the theory. She gave examples of critical developmental periods when it is more obvious how the child is different from other children or from the child for whom they had hoped. She clarified how chronic sorrow is different from bereavement – that death does not occur in this situation. She also added that understanding of the grief felt by parents was not improved by theories from bereavement literature. She compared and contrasted bereavement and chronic sorrow theories, primarily using Olshansky's (1962) definition. The definition of chronic sorrow included the idea that the sorrow was ongoing, initiated following a permanent loss other than death, that emotions varied over time, and that these feelings continued until the death of either the parent or the child without resolving. She questioned if consequences such as institutionalization of the child might occur in response to the pain experienced during chronic sorrow, whether illness or disease might contribute to immunological dysfunction where parents may become physically ill, and if parents might reframe the loss to distance themselves from the sorrow. She asked for research which would better describe chronic sorrow, "how long each occurrence…lasts, what affects the intensity and frequency of sorrow, and what the ramifications of chronic sorrow are over time" (p. 1317). She later completed research including both parents of children with disabilities, but used the Revised Texas

Inventory of Grief. The article utilizing that specific tool is not currently available, but the Revised Texas Inventory of Grief was found on-line.

Several authors noted how chronic sorrow could exacerbate with life occurrences or developmental milestones. Examples of some developmental milestones exacerbating chronic sorrow included critical periods in which sadness increases for the parents who have children with disabilities. Examples were when the child learns to walk or talk, is fitted for a wheelchair, has illnesses, behaviors or surgeries especially associated with the particular disability, begins special school or is the age to graduate from high school, and passes certain birthdays (Davis, 1987; Fraley, 1986; Teel, 1991).

Theory on chronic sorrow evolved greatly because of the work of Eakes, Burke, Hainsworth and Lindgren, who wrote about chronic sorrow in several articles (Eakes, Burke, & Hainsworth, 1998; Eakes, Burke, Hainsworth, & Lindgren, 1992; Hainsworth, 1996; Hainsworth, Busch, Eakes, & Burke, 1995; Hainsworth, Eakes, Burke, 1994; Lindgren, Connelly, & Gaspar, 1999). Realizing confusion existed in the definition of chronic sorrow as compared to other terms of pathological grief and depression, the authors compared these terms to chronic sorrow. As previously stated, Burke and Hainsworth (1992) believed chronic sorrow was separate and different from pathological grief and depression as chronic sorrow was a normal reaction.

Concept mapping of chronic sorrow was done by Eakes, Burke, and Hainsworth (1998) and later by Kendall (2005). Both visual depictions show a disparity between reality as anticipated and reality that actually existed, which is the trigger to chronic sorrow. The disparity is not resolved, nor will it be over time, as reality differs from the desired situation because reminders of the loss continue. Kendall (2005) includes three facets of chronic sorrow: "physical exhaustion, feelings of invalidation (isolation/alienation), and lack of voice" (Kendall, 2005, p 246). Kendall's (2005) model shows that between trigger events, the person living with the loss will adapt somewhat and uses the term 're-normalization' to indicate the emotion of well-being.

These studies were of value as they validated the existence of chronic sorrow and gave specific times when it was more likely to occur. All questions used in the questionnaire on chronic sorrow are included. At the point this article by Eakes, Burke, and Hainsworth was written, only 5 studies existed about chronic sorrow and those only described parents of children with physical and mental disabilities.

Initially, the definition of chronic sorrow included recurrent or cyclic sadness over time in a situation with no predictable end, which occurred because of either external and internal stimuli that gave rise to the feelings of loss, disappointment, and fear; and progression and intensification of the sadness or sorrow continued years after the initial disappointment or loss (Lindgren, Burke, Hainsworth & Eakes, 1992). These authors then added to the definition to include intensification of chronic sorrow over time. However, although one of the parts of the definition is that chronic sorrow increases over time, variables related to this progression are not always known. The support of the idea that chronic sorrow increases over time is not obvious in this study, so this aspect needs to be explored as well.

Burke & Hainsworth (1992) formed The Nursing Consortium for Research on Chronic Sorrow to study chronic sorrow across the lifespan for individuals with chronic illness and their caregivers, both of whom may experience chronic sorrow. They wrote about how depression and pathological grief differ from chronic sorrow. They state "chronic sorrow is at the descriptive level of theory development…refined and operationalized concept of chronic sorrow and validated its occurrence in parents… identified specific events and milestones at which this sorrow recurs" (p. 235). The article includes the caregiver version of the Burke Chronic Sorrow Questionnaire, a 16 question version, which was adapted from the original Burke Questionnaire.

Further clarification of chronic sorrow was that chronic sorrow is not a true phenomenon (Dunning, 1999) and that emotions of hopelessness and depression were not integral to chronic sorrow. Her study compared chronic sorrow experienced by mothers with a child who has either chronic illness or acute illness during hospitalization. This may be comparing different types of sorrow as parents who have a child with an acute illness do not live with the reality of the chronicity of a disability. It was difficult to see how this research advanced theoretical foundations of chronic sorrow.

Roos (1994), who wrote of her experiences in parenting a daughter with a disability, also noted that chronic sorrow is not pathological, is different from grief and because it does not resolve or have an end point, and thus becomes chronic and permanent. Grief has an opportunity to resolve when the object of grief is no longer present, but as the child continues to live, the sorrow is chronic and ongoing.

Hainsworth, Eakes, & Burke (1994) enlarged the theory of chronic sorrow further by completing a qualitative study including individuals with chronic or life threatening illnesses

such as infertile couples, individuals with long-term cancer, individuals diagnosed with Parkinson's disease or multiple sclerosis, and spouses who were caregivers for some of these individuals. In this study, Burke's Chronic Sorrow Questionnaire (BCSQ) was used. Data was collected either by audiotaping personal interviews or by interviewing the individual by telephone. The questionnaire as initially used by Burke (1989) was adapted to better fit circumstances of the individual being interviewed, although the content was not. It was not clear how infertile couples were considered as having a chronic illness, although it is understandable how they could feel chronic sorrow.

Lindgren, Burke, Hainsworth, and Eakes (1992) further expanded the theory of chronic sorrow in various stages of life to support that chronic sorrow occurred over the lifespan. They clarified that chronic sorrow differed from irresolvable grief and depression in that chronic sorrow is recurrent sadness and distress which does not permanently disappear. New losses arise and old losses are remembered. They stated critical components of chronic sorrow are: "1. There is a perception of sorrow or sadness over time in a situation that has no predictable end. 2. The sadness or sorrow is cyclic or recurrent. 3. The sorrow or sadness is triggered either internally or externally and brings to mind the person's losses, disappointments or fears. 4. The sadness or sorrow is progressive and can intensify even years after the initial sense of disappointment, loss or fear" (Lindgren et al., 1992, p. 31).

Chronic sorrow is different from prolonged grief or depression because "prolonged grief is a long-term reaction to one loss, and chronic sorrow is the reaction to multiple losses over time…Resolution is not achieved" (Lindgren et al., 1992, p. 32). Depression is a mood change that does not cycle as chronic sorrow does. Lindgren et al., (1992) further give antecedents for chronic sorrow as "1. The person experiencing chronic sorrow must be involved in a trajectory of chronic illness or disability, either as the one afflicted or as a caregiver. 2. The trajectory has an identifiable beginning such as the birth of an ill baby or a diagnosis of a chronic illness such as Multiple Sclerosis or Alzheimer's disease" and consequences of chronic sorrow as "1. The person is able to move into other phases of the chronic illness situation, having grieved losses of the previous phase. This is more likely if comfort and support have been received. 2. A depressive state or abnormal grief reaction may occur; this is more likely if the supportive network is inadequate" (p. 35). The conceptual framework of chronic sorrow is not yet complete as further exploration is needed as to how it occurs across the lifespan and in other populations.

Johnsonius (1996) wrote of expanding the themes of chronic sorrow and that chronic sorrow was a phenomenon better understood by examining the lived experience. This study did not seek to find commonalities in the children, but only themes by the involved parents. It did find recurrent sadness in the stories. Not knowing the similarities in the children, the ages, the types of disabilities or how the stories were elicited make it difficult to replicate the study. It was unclear in the results whether depression was linked to chronic sorrow. This was the only qualitative study that utilized bracketing and coding for themes.

Chronic sorrow was also viewed as grief-relief process as parents experience ambivalence about their child's diagnosis and his possible death as a consequence of necessary surgery or the severe mental disability as a prognosis (Bullock, 1981, p. 193). Grief begins after the child's diagnosis, but conflict occurs because sometimes the parent may consciously or subconsciously wish for child to die, and not know 'whether to pray for their child to live or to die" (Bullock, 1981, p. 194). They also may be coping with 'death without dying' for the child (p. 195). The parent may appear relieved when death occurs; however, the parents may experience guilt when the child dies. Professionals are asked to recognize conflict and turmoil that may occur in parents who have children with disabilities. Chronic sorrow has the opportunity of resolving only after the child dies (Young, 1977).

Burke, Hainsworth, Eakes, and Lindgren (1992) suggested more qualitative studies which would increase understanding of this phenomena and how it exists apart from stage-based theories that march toward a resolution. Their theory advancement postulated that sorrow increased when developmental milestones were not met as well as when health problems occurred. This occurred during the lifespan of the child because caregiving did not cease as the child grew older. Their long-term goal was to find appropriate interventions in a variety of those individuals affected by chronic sorrow.

Burke et al. (1992) suggested these 6 questions to guide future studies:

1. Does chronic sorrow occur in a variety of populations across the life span (e.g., affected individuals with diverse chronic or life-threatening conditions, caregivers)?
2. What are the characteristics of chronic sorrow in these populations?
3. How does the expression of chronic sorrow in these populations compare with the expression of chronic sorrow by parents of children with disabilities?
4. Is chronic sorrow an inherent phenomenon in chronic illness situations?

5. What are the major subconcepts of chronic sorrow theory?

6. How do these subconcepts relate to each other?

Qualitative studies were suggested as best so that:

documentation, analysis, and interpretation of the characteristics and meanings of the phenomenon of chronic sorrow can be observed. This would also build on current knowledge of chronic sorrow and add to this theory... A structured interview with open-ended questions allows for focused but unlimited responses on the part of subjects. The resulting data are fertile for the emergence of relevant themes that can be analyzed for classification and potential linkages (Burke, Hainsworth, Eakes, and Lindgren, 1992, p. 239).

The support of the idea that chronic sorrow increases over time is not obvious in one study (Lindgren et al., 1992), so this aspect needs to be explored as well.

Kendall (2005) was the most recent researcher to add to the concept of chronic sorrow. She believed that depression was sometimes identified when a better diagnosis would be chronic sorrow. She emphasized that sorrow of this type reoccurs with the trigger events and does not resolve. The loss is that perceived by the individual, not assigned by another. She agreed with others who have written about chronic sorrow that it is a sorrow with no predictable end or resolution, there is a disparity between reality as it exists and as it could have been, and specific triggers or developmental milestones trigger the sorrowful reaction, with a subsequent acceptance of the current situation as normal for the persons experiencing the loss.

Some of the issues in families dealing with chronic sorrow are invalidation, isolation, and a belief that others cannot or do not understand the specific situation. Although she lists physical exhaustion occurring before these feelings and lack of voice after, it is possible that no hierarchy is intended and that all three of these are components in chronic sorrow. Although depression was initially thought by the author to play a part in chronic sorrow, the use of this instrument determined that chronic sorrow is different from depression and that those affected by chronic sorrow may have a positive sense of well-being between the episodic sorrow cycles.

Specific Purpose

The preceding review of the scientific literature shows that while research has focused on chronic sorrow as well as cerebral palsy, few studies have targeted chronic sorrow among parents or, specifically, mothers of adult children with cerebral palsy.

The foregoing review also shows that the physical, psychological, social, and economic demands on these parents are likely to be high, perhaps exceeding their personal resources to meet their needs. Those with cerebral palsy who have difficulties in both mobility and in meeting nutritional needs have a high risk for increased morbidity and subsequent mortality. Hospitalizations will be more frequent for surgeries that help manage the contractures and musculoskeletal deformities and problems as well as feeding issues that might result in the need for feeding tube placements or aspiration pneumonias.

This study will explore the presence and components of chronic sorrow that may exist among these mothers. The primary conceptual definition of chronic sorrow is based on the work of Olshansky (1962). The definition that will be used in this study is that chronic sorrow is *a permanent and reoccurring experience of pervasive sadness and loss which underlies the life experience and which recurs over time for the parent of a child with developmental, medical, or behavior issues that prevent him from participating in society in a way previously anticipated by parents.*

Also, the four domains identified in existing research literature linked to the experience of chronic sorrow will also be examined. For present purposes, these can be described as 1) loss of support, 2) loss of roles and relationships 3) loss of quality of life, and 4) recognition of loss. These domains could be discussed for parents of adult children with other disabilities as well in the future.

Therefore, this research will explore these domains for selected mothers of adult children with cerebral palsy in order to extend knowledge about the chronic sorrow as it is defined by the mothers, the types and degree of support perceived by these mothers, the changes in relationships and roles, the perceived quality of life within this context, and how they experience the triggering events which initiate chronic sorrow.

CHAPTER 3 - Method

Introduction

Since chronic sorrow has not been studied in mothers of adult children who have cerebral palsy, this study explored the possible occurrence of this phenomenon in this special population and attempted to understand how it is experienced. In addition, environmental, familial, and personal factors surrounding and possibly affecting the occurrence and quality of chronic sorrow were explored. Despite the small number of overall cases to be studied, it was hoped that the collective case comparisons yielded an understanding not only of unique experiences of these mothers, but also afforded what Stake (1995) refers to as "petite generalizations" – that is, generalizations qualified by the contexts in which chronic sorrow may be found to occur. In addition, the interview method allowed the women to express their views in their own words.

This study utilized a qualitative collective case study design, using a semi-structured schedule interview as the primary data-gathering method. This was done as the case study strategy had capability of exploring "contemporary phenomena in depth" (Yin, 2008, p. 18), allowing the researcher to draw implications and propositions about the "how' and "what" about these phenomena (Gubrium and Holstein, 2002).

Sample and Sampling Strategy

The sampling frame for this study was constructed using snowball (sometimes called "cobweb") sampling, a recruitment technique utilizing social networks to produce potential research volunteers (Browne, 2005). Snowball sampling was the only possible way to access this population because of confidentiality issues related to the Health Insurance Portability and Accountability Act (HIPAA).

Snowball entrée points included friends from Families Together (a state parent support group for parents of children with disabilities) as well as personal acquaintances. I did not succeed in finding a large pool of mothers who had adult children with CP. I then informally explored some contacts with health care providers through which I got three other names, two of whom were eligible to participate. Three mothers declined to participate as they did not respond to several queries about potential participation. I received at least three names more than once.

Each mother had to meet the specific criteria for inclusion in the study:

1. The mother is currently or has been a primary caregiver and is less than 65 years old;

2. The adult child with CP is 25 or older.

In the beginning, twelve mothers were identified as potential participants. They were contacted through email or phone, depending on which was available to me or given to me by another contact. They were asked about participating in a research project about mothers who had adult children with disabilities. On further contact, I discovered one mother had a child just under age 25 years; another mother was older than age 65. Another failed to respond to repeated queries until after interviews concluded, one did not respond, and another was not the mother of the adult child, but was a sister-in-law. Another declined to participate. Therefore, the final number of participants totaled six (Appendix A: Sampling).

Characteristics of those comprising the final sample were diverse. The ages and sex of the child with CP varied as did the age of the mother, sibling configuration of the child, socioeconomic identifiers, parental employment, and the health status of the mother and of the child. Ethnicity and geographic areas were similar. Those mothers who participated were between 45 and 62 years of age; their children's ages ranged from 26-38 years old. The socioeconomic status of the mothers ranged from lower class to upper-middle class. The level of disability of their children ranged from *totally dependent on others for care* to *living and working independently*. One mother had chronic health problems. Four adult children experienced chronic health problems and two of these had been hospitalized, and two had no recent illnesses. Only one adult child did not have a sibling. All were Caucasian; all the mothers lived within 60 miles of Kansas State University.

Institutional Review Board Approval

As required by Federal Regulatory statutes governing research at Kansas State University, the research protocol and Statement of Informed Consent was submitted to the University Research Compliance Office for review. The IRB application and Statement of Informed Consent are found in Appendix B. Protections for confidentiality included de-identification of data in transcripts and in possible publications and professional presentations. The interview was recorded and transcribed as planned. Those interviewed were first identified by number and were later identified by pseudonyms of Allison, Beth, Carole, Darla, Ellie, and Fiona.

Research Tools

Tools used in the study included the Kendall Questionnaire on Chronic Sorrow, two surveys, and the interview questionnaire. The first survey determined demographic data as well as information about the mother and child including their health. The second survey asked about resources available. The Kendall Questionnaire and the two surveys were self-administered. The verbal answers to the interview questions were recorded and transcribed. These tools as well as the interview questionnaire were vetted by the dissertation committee. The literature review, personal experiences, experiences voiced during informal visits with mothers of children with disabilities in the past, and a pilot interview with a mother helped inform the specific content of the interview questions.

Kendall Chronic Sorrow Questionnaire

The Kendall Chronic Sorrow Questionnaire (Kendall, 2005) (Table 3.1) was administered to assess the presence of chronic sorrow. To date, reliability assessments are limited to internal consistency (Cronbach alpha). Kendall (2005) reported an alpha of .91 among the 18 items in this questionnaire. . The mother circled the number which most closely corresponded to frequency of the experience from 6 to 0 which was associated with *almost always* to *never*. The circled numbers were then totaled to determine the scoring. The highest score possible is108. Scoring of this questionnaire was "0-38 – no chronic sorrow present, 39-82 – likely chronic sorrow present, 83 and over – chronic sorrow present" (Kendall, 2005, p. 127). Findings are reported in data analysis.

Table 3-1 Kendall Chronic Sorrow Questionnaire

		Almost always	Frequently	Sometimes	Not sure	Usually not	Infrequently	Never
1.	I think about the loss as if it had just happened	6	5	4	3	2	1	0
2.	I feel saddened when I think of the loss	6	5	4	3	2	1	0
3.	I feel just as sad when I think of the loss as I did when the loss first happened	6	5	4	3	2	1	0
4.	I feel like crying when something reminds me of the loss	6	5	4	3	2	1	0
5.	I feel full of sorrow	6	5	4	3	2	1	0
6.	I feel sadness when I am reminded of the loss	6	5	4	3	2	1	0

7.	I feel saddened by things that other people see as unimportant or minor	6	5	4	3	2	1	0
8.	I feel full of sorrow when I think of what might or could have been if the loss had not happened	6	5	4	3	2	1	0
9.	I feel that the sadness related to the loss comes and goes	6	5	4	3	2	1	0
10.	I feel I have to give up things in my life because of the loss	6	5	4	3	2	1	0
11.	I feel I have control over my life situation	6	5	4	3	2	1	0
12.	I feel my life is not the same as I had hoped or dreamed it would be because of the loss	6	5	4	3	2	1	0
13.	I think of what my life might have or could have been when I am reminded of the loss	6	5	4	3	2	1	0
14.	I feel alone during the time I feel sadness related to the loss	6	5	4	3	2	1	0
15.	I feel that I have enough energy to deal with my life	6	5	4	3	2	1	0
16.	The changes in my life because of the losses are unfair	6	5	4	3	2	1	0
17.	I believe that life is unfair	6	5	4	3	2	1	0
18.	I feel older than my age because of the loss	6	5	4	3	2	1	0

Demographic and Survey Questions

The two sets of survey questions gave baseline information about the mother and her adult child. The mother completed these surveys after she completed the Kendall Questionnaire. Results of the Kendall Questionnaire and the two surveys will be included in Chapter 4.

Questions in the first survey (Table 3.2) included baseline information of the population, but also were formulated to begin exploration of the identified domains and losses inherent in chronic sorrow: the losses of support, roles and responsibilities, and quality of life. The experience of chronic sorrow could be influenced by where the adult child currently lived, maternal role, and quality of life. In addition, chronic sorrow could have changed if the mothers were not currently the primary caregiver for the child. Also, survey questions included also asked for maternal responses about some of the potential health care issues for both the mother and her adult child as they relate to roles and responsibilities as well as quality of life. These questions included information about the number of specific health, nutrition, and mobility issues for the adult child that have the potential to lead to significant morbidity and mortality as identified by literature.

Table 3-2 Survey Demographics and General Information

1.Your age: ___40-50 ___50-60 ___60-65
2. Employment of caregiver (partially addresses SEC of family) ___ Employed at home ___Employed outside the home
3.Do you consider your family to be (partially addresses SEC of family) ___ Higher socioeconomic class ___ Middle socioeconomic class ___ Lower socioeconomic class
4. Where does your child currently live ___ Lives with mother ___ Lives in group home ___ Lives independently ___ Other _____
5.Age of adult child ___ 25-30 ___30-35 ___35-40 ___ over 40 Age of siblings ___ 25-30 ___30-35 ___35-40 ___ over 40 Do any of these siblings have CP or another disability? If so, which ones? Rank of adult child with CP ___ oldest___ middle ___ youngest
6. Ability of movement of child (addresses **mobility** of child) ___ Walks independently ___ Walks independently with assistive device such as cane or walker ___ Walks with assistance with another person ___ Walks with assistance with another person and assistive device ___Moves independently using wheelchair ___ Moves only with assistance in transfers to and from chair ___ Dependent on others for transfers and movement from place-to-place
7. How does your child receives the majority of nourishment (addresses **nutritional status** of child) ___ Feeds self independently, able to swallow ___ Feeds self independently with someone else cutting, mashing, etc ___ Eats with someone feeding him/her ___ Eats, chews few bites only; supplemented with special formula ___ Unable to chew solid food, supplemented with special formula ___ Dependent on tube feedings for virtually all of nourishment
8. Has child experienced any of the following at any time: (addresses past **health issues/morbidity** of child) ___ Swallowing difficulties ___ Feeding tube placement ___ Seizures ___ Curvature of spine ___ Gastroesophageal Reflux Disease (GERD) ___ Aspiration without hospitalization ___ Other health issues _____
9. Health condition of your child: (addresses more recent **health issues/morbidity** of child) ___ Hospitalized ___ times this past year/two years/three years ___ Reason(s) for hospitalization ___ Aspiration ___ Pneumonia ___ Tube placement ___ Surgery ___ Seizure ___ Urinary tract infection ___ Other _____
9. Health condition of mother (addresses past **health issues/morbidity** of parent) ___ Back pain ___ Stress ___ Depression ___ Chronic illness ____Other _____
10. Health condition of mother (addresses past **health issues/morbidity** of parent) ___ Back pain ___ Stress ___ Depression ___ Chronic illness ___ Other _____
11. Ethnic background:___ Caucasian ___ Hispanic ___ Native American ___African American ___Other _____
12. Who helps (helped) you care for your child? Please rank in order 1-6 of most help to least: ___ Spouse ___ Other children ___ Friends ___ Paid caregivers ___ Grandparent(s) or extended family ___ Others (specify) _____ ___ No one
13. Which professionals provided helpful support? Please rank in order 1-9 of most help to least: ___ Family physician

___ Other physician or specialist
___ Physical therapist
___ Occupational therapist
___ Speech pathologist or therapist
___ School nurse
___ Social worker
___ School teacher
___ Other (specify) _____
___ No one

14. Who is responsible for coordinating health care and therapies for your child?

___ Physician
___ School
___ Community Disability Developmental Organization (CDDO)
___ Parent

The second survey (Table 3.3) targeted the mother's perception of resources and support. This survey was modified from the Chronic Illness Resources Survey (CIRS) (Glasgow, Toobert, Berrera, Jr. & Strycker, 2005). The following survey questions asked about a variety of different resources that people use to manage illness or disability and if these resources were present for them.

For each item, the mother selected the number that best indicates her experience with her adult child:

To what extent do these terms describe your experience:

Not at all	A little	A moderate amount	Quite a bit	A great deal
1	2	3	4	5

Table 3-3 Resources and Support

1. Has your doctor involved you as an equal partner in making decisions about your child's disability management strategies and goals?
2. Has your doctor or other health care advisor listened carefully to what you had to say about your child's disability?
3. Has your doctor or other health care provider thoroughly explained the results of your child's tests (e.g. EEGs, other laboratory tests?
4. Have you thought about or reviewed how you were doing in accomplishing your child's disability management goals?
5. Have you arranged your schedule so that you could more easily do the things you needed to do for your child?
6. Have you had health insurance that covered most of the costs of your child's medical needs including medicine, personal supplies, dietary supplements, and durable medical equipment (DME)?
7. Have you attended meetings (e.g. church groups, hospital programs, support groups) that supported you in managing your child's illness?
8. Have you had a flexible work schedule that you could adjust to meet your child's needs? (Leave blank if you don't work outside the home.)
9. Has your workplace had rules or policies that made it easier for you to manage your child's disability (such as time off work to exercise, to attend appointments with your child, or be

available for your child's disability related needs)? (Leave blank if you don't work outside the home.)
10. Have you had control over your job in terms of making decisions and setting priorities to manage your child's disability? (Leave blank if you don't work outside the home.)

(The previous 10 questions were adapted from Glasgow, Toobert, Berrera, Jr. & Strycker, 2005).

The Interview Instrument

The final tool used was the interview. Questions were structured to invite mothers to add additional or clarifying comments about the meaning of chronic sorrow for them and associated emotions, how chronic sorrow changed for them over time, and targeted the identified domains of loss. These domains included Loss of Developmental Milestones, Loss of Support, Loss of Roles and Responsibilities, and Loss of Quality of Life. Each question asked for examples or explanation of her response. For example, a question on hopes and dreams of the adult child or the mother was also included as those can change over time and also affect quality of life.

Specifically, the interview questions (Table 3.4) were selected based on the domains of chronic sorrow as reflected in the literature. They consisted of a mix of structured as well as open-ended questions. Questions 1 and 2 asked for their belief on whether or not they had experienced chronic sorrow and if it had increased, decreased, or stayed the same over the years. Question 3 asked about events that triggered chronic sorrow and narrowed the question to developmental milestones. Roles and responsibilities as well as childcare burden and quality of life were queried in question 4, 12, and 13. Questions 5 through 11 asked about types of support available through the adult child's lifespan. Quality of life issues were examined in questions 14 through 19. The final question allowed the mothers to ask questions, add information, and clarify their views. Each question here shows the area of research interest targeted by each question is highlighted and in parentheses.

To reiterate, in order to get to the information included in the domains of chronic sorrow, specific survey and interview questions were formulated that corresponded to the previously defined domains of chronic sorrow. These questions were identified to explore these domains and the experience of chronic sorrow as it occurred for these mothers. The questions were administered as standard scheduled structured items to each respondent. The participants answered each question as they wished which meant they spoke more at length about areas with

which they had more comments, experience, and emotions. This permitted discovery of themes that may not have been fully defined by the specific questions.

Additional discussion is summarized after table 3.4 for each domain.

Table 3-4 Interview Questionnaire

1. Some parents have described a sadness that can occur when they think about their child with a disability. Parents can believe they are functioning well, but have times where they feel the loss for their child. Do you experience chronic sorrow? (**Definition**) Yes _____ No _____
2. Has this experience changed for you as a mother since your child's diagnosis until now? Did chronic sorrow a) decrease, b) increase, c) remain about the same, or d) don't know – can't tell if it increased or decreased. (**Experience)**
3. Could you please describe examples of a time or specific events during where or when you experienced chronic sorrow? **(Loss of Developmental Milestones: Triggering Events**) ___ Birth to age 2 years (e.g. social smile, sitting, standing, walking) ___ Toddler to preschool 2-5 years (toilet trained, running, jumping, throwing, attending pre-school) _____ ___ Middle childhood 6-8 years (dress self, reading, tie shoes) ____ ___ Middle childhood 9-11 years (spending time with peers) _____ ___ Early adolescence 12-14 years (influenced by peers, strong sense of right and wrong, body image concerns) ___ Middle adolescence 15-17 years (considering career, driving, babysitting or other part-time jobs) __ ___ After high school 18 years and older (college, vocational training, career, marriage, living independently) _
4. Who helps (helped) you care for your child? (R**oles and Responsibilities; Quality of Life, Childcare**) ___ Spouse ___ Other children ___ Friends ___ Others ___ Paid caregivers ___ No one
5. Which professionals provided helpful support? Give example. ____ **(Support: Professional)** ___ Family physician ___ Other physician or specialist ___ School nurse ___ Social worker ___ School teacher ___ Therapist: physical, occupational, speech pathologist ___ No one
6. What nonprofessionals have provided helpful support? **(Support: Social)** ___ Church members or clergy ___ Social groups ___ No one
7. What anticipatory guidance would you give to mothers in similar circumstances? What guidance would have been useful for you? **(Social Support)**
8. Have your spiritual beliefs been useful in parenting your child? If so, how? ___Yes ___ No ___ Sometimes 9. How did attendance or participation change in your church/synagogue/social group/family after your child was born? **(Support: Spiritual)**
10. If spiritual beliefs or faith is or has been a part of your life, has it changed during parenting your child? If so, how? **(Support: Spiritual)**
11. How has your church/synagogue/social group/family accepted your child? **(Support: Spiritual)**
12. Who is responsible for coordinating health care and therapies for your child? Who has been helpful? (R**oles and Responsibilities)** ____ Physician ___School ___Parent
13. Are you able to continue participating in social or personal plans without your child as much as you would like? (R**oles and Responsibilities)** ___Yes ___No Has this changed as your child grew older? If so, how?
14. How has caring for your child impacted your family financially and emotionally? **(Quality of Life: Financial and Emotional)**
15. Has your child had or does your child currently have behavior problems? **(Quality of Life: Behavior of Child)**
16. When ___ was young, what plans did your child have for social & recreational, living arrangements, work environment, or educational opportunities? **(Quality of Life)**
17. Where is your child now living? What were your plans for ___ after completing high school?

Is this what is occurring? **(Quality of Life)**
18. Have you found any positive aspects in parenting ___? **(Quality of Life)**
19. Have you found any positive aspects in parenting ___? **(Quality of Life)**
20. Is there anything you would like to ask me at this point? Or "Now that you know what the research is about, is there anything that I should have asked but didn't?" (Rubin & Rubin, 1995).

Additional discussion is summarized below for each domain.

Chronic Sorrow Definition

The review of literature revealed that mothers of younger children with disabilities experience chronic sorrow. Burke et al. (1992) theorized that the intensity of chronic sorrow increases with time; however, few studies have been done to see if this was consistent in parents of older children with disabilities. Therefore, question 1 was asked to ascertain if chronic sorrow is experienced by the mother according to her point of view. Question 2 was asked to compare/contrast times chronic sorrow occurred for these mothers and how or if it changed over the years. For instance, sometimes chronic sorrow may not occur until other children or siblings pass the child with disabilities in development.

Loss of Developmental Milestones: Triggering Events

To ascertain if specific developmental milestones elicited such a response, interview question 3 asked directly about the expected developmental milestones for each age group. Were there specific developmental milestones that elicited chronic sorrow that were similar or different for the mothers?

Loss of Support

Questions 5 through 11 dealt with responses about available support. The first persons to whom parents might turn for answers or prognoses are those professionals in health care. These professionals have not been consistently supportive or knowledgeable. Parents themselves have done research and discovered information necessary to deal with the disability. This does not address the needs of parents who are not technologically savvy or who are not able to seek answers for themselves. It is not known to what extent resources and support can be consistently accessed by parents.

Social support can come from spouses, families, the community, or informal support groups. The literature noted that parents become isolated when dealing with a child with disabilities. How family or other support changes over time is not known.

Interview questions about spiritual support were also included. Anecdotal experiences from mothers through the years chronicled how church families did not know how to react to or involve the child with disabilities in religious, worship, or fellowship activities.

Loss of Roles and Relationships

Mothers anticipate their children maturing, leaving the home, and being contributing members of society. Instead, mothers who have children with disabilities may not always have that in their future. Mothers may change their focus of attention to what must be done immediately and as the child becomes older will still have to concentrate on unchanging day-to-day needs. Roles may not evolve as they do for mothers whose children do not have disabilities (Crowe & Florez, 2006). These concerns are addressed in questions 4, 12, and 13.

Loss of Quality of Life

The amount of time involved in childcare, health of mother or child, lack of options in living situations, and financial as well as emotional burdens impact the quality of life for the mother (Crowe & Florez, 2006; Donovan, VanLeit, Crowe, & Keefe, 2005; Emerson, 2003; McGilloway & Donnelly, 1995; Summers, Poston, Turnbull, Marquis, Hoffman, Mannan & Wang, 2005). These losses could also contribute to chronic sorrow. The interview assesses this in questions 14 through 19.

Interview Procedure

Organization of the research questions was done by specific domains previously identified in the literature; however, the analysis was needed to identify if these domains were indeed the significant issues (Stake, 2000). Results will be reported in data analysis.

The following procedure was followed with each mother:

1. Reviewed and signature approval of the Informed Consent;
2. Administered the Kendall Chronic Sorrow Questionnaire (Kendall, 2005);
3. Administered the demographic and other survey questions;
4. Administered second survey on available resources;

5. Administered the interview questions, which were audiotaped.

The self-administered surveys took approximately 20 minutes to one hour. I then began the audio recorder and asked the interview questions. Answers given by the mothers were through their contextual interpretation of their experiences. I thanked them for participating and informed them I would be contacting them after transcription was complete for feedback, to answer any questions that they may have had subsequent to the interviews, and for comments. They were also given contact information in case they had questions or comments before they received the transcripts.

All transcriptions were done the same day as the interview. Before transcribing, I first made a template of the interview questions. I then transcribed the interview using Voice Recognition software found in Vista where I listened to the audio recording and spoke into a microphone, then corrected for synonym errors for which the transcription could not adjust. All identifiers were then removed and line numbers were added. I then reviewed the transcript *in toto* in order to not eliminate the "connections between concepts and their context" (Bradley, Curry, & Devers, 2007 and wrote my overall perceptions of the interview.

Respondent validation

After all interviews were complete, each transcript of the recorded interview in its entirety was reviewed by the respondent for verification and elaboration, also called respondent validation. Transcripts were sent via email to the four mothers. Two were delivered in person with attached contact information for feedback if they wanted. Using the respondent as the co-interpreter of the information substantiated themes I took from their words. Each was asked, "Does this represent your thoughts at the time of the interview?" This step enhanced the subjective validity of the responses offered.

Four respondents indicated that the interview did accurately represent what they had shared. No telephone or email feedback was received from two other participants. Comments reflected appreciation of the opportunity to participate, that the session provided 'great moments of reflection', the interview 'definitely got my points across', 'I relived this again when I read it'. This process enhanced the subjective validity of the information gathered and reaffirmed that the transcription represented their intended meanings.

Data Analysis Method

First, all identifiers were removed from the transcript and the entirety of the transcript was reviewed for specific phrases that illustrated the specific domains previously identified. An example of a partial transcription is found in Table 3.5.

Table 3-5 Sample of Transcription of Interview

2. Could you please describe examples of a time or specific events during where or when you experienced chronic sorrow? **Birth to age 2 years (e.g. social smile, sitting, standing, walking)** Well, we didn't have sitting or standing or walking. We had social smiles, recognition of others, and that was about it. The 'not sitting', that was ... knowing that she should be saying mama, and knowing that she should be able to feed herself some, you know, lots of seizures at that time, lot of sickness at that time, lot of hospitalizations at that time, and I always went through all of that by myself 'cause her father was out of the picture so, it was just really hard.

The interview questions were visualized on a table as based on construct and themes of chronic sorrow as defined by the literature (Miles & Huberman, 2000).

The following steps describe the process.

Step 1: Organization of data

After the interviews were transcribed and the identifiers were removed, the process of bracketing began. To prepare for analysis, I carefully arranged the questions to reflect the subject matter so data inspection was organized related to previously identified themes from the literature review (Table 3.4) as suggested by Miles and Huberman (Miles & Huberman, 1994, in Denzin & Lincoln, 2000). In addition, the transcripts were reviewed *in toto* in order to not eliminate the "connections between concepts and their context" (Bradley, Curry, & Devers, 2007) and I then wrote a summary of the interview interaction.

Step 2: Inclusion of second coder

In order to enhance objectivity and to clarify the understanding of key phrases, a second coder was brought into the project. This was also done to increase the reliability of the information (Miles & Huberman, 1994, p. 64). The second coder had a background which somewhat differed from mine. She was a generation younger in age and was parenting a preschool-aged child. Backgrounds were similar as we both were employed at

the same workplace in similar occupations. However, she had no previous knowledge of chronic sorrow or of parenting a child with disabilities.

To train her in the content, I gave her the proposal and asked her to read 19 specific pages for an overall discussion of the facets of chronic sorrow. She completed required institutional training for IRB. She then met with me and was given the training sheets (Appendix C) which gave examples for each of the domains I wished to examine. The examples showed the exact quote with the line number so the second coder could find the context from which the quote was taken. The line number didn't always directly correspond to the question that was posed in the particular domain, but did illustrate the domain as defined. Random quotations from all of the respondents were used as exemplars in these training sheets. When she reviewed the pages on chronic sorrow and the training booklet, we were ready to proceed.

Step 3: Coding procedure

Simplistically, the steps we used in the coding procedure were these:

a. **Identification** of key phrases and statements

b. **Indexing** the domain of the previously identified phrases

c. **Interpretation** of meaning of the phrases

d. **Inspection** of the previous interpretation for essentials of phenomena

e. Definitions of the **recurrent features** of the phenomenon not previously recognized by us.

The following a. through e. illustrates and discusses *Step 3*:

a. **Identification**: Identification was done according to Denzin (1989) as described in Denzin & Lincoln (2000), which was to "locate … key phrases and statements, … interpret meaning of the phrases … inspect these meanings for what they reveal about the essential, recurring features of the phenomenon being studied, offer a tentative statement or definition of the phenomenon in terms of the essentially recurring features" (Janesick, 2000, p. 391). To begin this process, the two coders read through the transcribed interview. During a second reading, key phrases were marked, either by brackets ([and]) or by underlining the phrase.

b. **Indexing**: The second step was indexing in which losses were identified by the use of phrases or short descriptions of the text applied universally throughout the narratives of each case (Pope, Ziebland, & Mays, 2000). After bracketing, each coder then marked the domain the

phrase represented. These were indicated in this way: Chronic Sorrow defined (CS), Chronic Sorrow experience (CSE), triggering events (TE), Loss of Roles and Responsibilities (R&R), Loss of Support: Professional (Prof S), Loss of Support: Social (Soc S), Loss of Support: Spiritual (Spir), Loss of Quality of Life: Behavior (QoL Behavior), Loss of Quality of Life: Health of Mother (QoL Health of mom), Loss of Quality: Health of Child (QoL Health of chld), and Loss of Quality of Life: Emotional and Financial (QoL E&F). To determine if training was sufficient, we met to discuss the first interview to compare bracketing and we negotiated our path of understanding of the domains and significance of phrases or sections of the interview. When we were satisfied our understanding was similar, we both proceeded with additional interviews in order. This is further described in *Step 3*.

Coders individually identified key phrases by bracketing these phrases in the interviews and indicated the domain as described previously. We met several times over a period of weeks after we had bracketed the interviews separately and then compared and discussed our findings. An example of bracketing is in Table 3.5. After we bracketed the interview individually, I rearranged the phrases we identified as most important according to the domain we believed they represented. Those phrases both of us initially agreed upon as the most significant were changed to red. We then negotiated what other phrases to include in the final grouping. In this discussion, we considered whether they were helpful to meaning or to overall background for the interview. As can be seen by the variety in line numbers, not all the phrases were from the questions designated to give responses to that specific domain.

Table 3-6 Bracketing example

Loss of Role & Responsibilities
(responsibilities) fell mostly on me **(R&R)** (154); all fell on me **(R&R)** to do (therapy) (162); can't get a lot of things done when … (brothers) didn't have much time or involvement **(R&R)** from either their father or I (166-7); he (dad) couldn't bring himself to do it (exercises) so I was the bad guy (225-6); (coordinating care) Myself. Me. I. I did all of that **(R&R)** (361); I failed (referring to time with sons) (377-8); her dad did not come back (change in her role) (248)

The domain assignment of the phrases was done by the use of initials of the domains to show what we believed the phrases signified. In the following example (Table 3.6), the first coder's significant phrase is identified in purple, the second coder's in blue. Those phrases both identified are in red. Again, the coders negotiated which phrases were significant. Additional

sub-themes evidenced themselves with more in-depth review of the interview transcripts by the coders. Data continued to be organized and re-organized as themes presented themselves through coding. The following example is shown to note how we decided not all the phrases first bracketed were part of the chronic sorrow definition and experience. We believed the phrase "feeling that everyone else's kids were doing it by themselves" also belonged in the Loss of Developmental Milestones: Triggering Events.

Table 3-7 Bracketing example

CS Definition (as defined by mother including experience over time) and Experience (emotions expressed)
Fleeting coming and going (5); kind of comes and goes (7); hopefully decreased **(CS)** (12); not as often (14); acceptance **(CS)** (15); big sorrow time… 19-20); cried (28); feeling that everyone else's kids were doing it by themselves **(TE and CSE)** (28-29); fear (31); moments of sadness **(CSE)** (47); times, moments of feeling sad **(CSE)** (55); that was very hard; that was very, very hard **(CSE)** (61); Why did this have to happen? (113-4); concerns of how she will deal with that **(CSE)** (226)

c. **Interpretation**: The coder and I independently noted other themes that occurred apart from the domain in which the results were located. After we met and discussed our interpretations, I then re-organized these significant phrases according to the questions and themes they were thought to represent. The themes identified are in the left-hand column where purple is the first coder's identified theme and blue is the second coder's (Table 3.7). Again, what we both initially indicated significant was changed to red. We then discussed the themes from the other phrases and how we agreed or disagreed on themes represented by the previously identified phrases. As can be seen, we initially used phrases that were very similar in describing the phrases as *sad* is part of *sadness* and *fear* is part of *fear for the future*. This was very helpful as it indicated we were looking at similar understandings of the phrases. We then decided on the phrases to use to describe the themes.

Table 3-8 Identification of Themes Example

CS Definition (as defined by mother including experience over time) and Experience (emotions expressed)	
Fear for future Sadness Fear Sad	Fleeting coming and going (5); kind of comes and goes (7); hopefully decreased (12); not as often (14); acceptance (15); big sorrow time… 19-20); cried (28); feeling that everyone else's kids were doing it by themselves (28-29); fear (31); moments of sadness (47); times, moments of feeling sad (55); that was very hard; that was very, very hard (61); Why did this have to

	happen? (113-4); concerns of how she will deal with that (226)

d. **Inspection**: The second coder and I again met to revisit these phrases to see if other domains than those previously identified existed. Although we could comprehend how domains were addressed, we had some difficulty believing all domains had been completely addressed. We identified one other theme that seemed pervasive for the last respondent which was not addressed in the table or directly addressed in the interview questions.

e. **Recurrent features**: All mothers used the phrase *developmental milestones* when they spoke of triggering events. Another example was found in the experience of *sadness* which was also universal. Although these steps gave us useful information in describing the experience of chronic sorrow for this population, we were not satisfied that we had captured the essence of one of the threads that ran through individual interviews. We therefore met again to discuss words that would cover the impressions from phrases we believed important and added the theme of *loss of hope*. The coders looked at all phrases again to substantiate their convictions that the recurrent features of the phenomenon of chronic sorrow were clear. This added to the defining characteristics for the phenomena of chronic sorrow for this population. We were then satisfied that we had covered the domains of chronic sorrow. In this way, we approached the phenomenon from as many perspectives as we could to assess what the phrases revealed.

The analysis consisted of within case and among case contrasts. After each respondent's answers were summarized in an individual case report, I was then able to make between case and cross-case conclusions (Yin, 2008).

Step 4: Within-Case and Cross-Case Analysis

Specific themes from each separate interview were identified. Cross-case comparisons were conducted to identify similarities and contrasts across the women's reports.

Themes

Table 3.8 shows and example of the compilation of the various themes found by the coders as we looked at the bracketed phrases. The **purple** was what the researcher noted; the **blue** was noted by the second coder. All were done individually. We then met to discuss the themes and why they were chosen by each of us. We also looked to consolidate the themes if possible. For example, we both identified *fear*. We discovered that a better theme would be '*fear*

for the future' so that was used in the final table Appendix E about themes. It was decided that acceptance was not the same as '*loss of hope'*. 'Sad' was changed to '*Sadness*'. 'Depression' was seen only in Beth, so that theme was eliminated from the final grouping of themes. We looked closely at several themes and were surprised how often both of us wrote '*isolation*'. We also noted that some things such as 'developmental milestones' were very difficult to qualify other than in terms of loss, so we left them in those terms. *Loss of hope* was a new theme that developed during thematic discussions.

Table 3-9 Examples of Themes as identified by coders

Loss of roles / responsibil-ities	**Isolation**; questioning	**Isolation** **Anger** **Isolation**	**Isolation**; **fear for future**	**Isolation** Resignation / (acceptance); effect on sibling **Isolation**	**Isolation** **Failure in parenting other children** **Isolation** **Guilt in parenting / lack of time with siblings**	**Isolation** **Guilt r/t lack of time with siblings** **Frustration** **Guilt r/t other children**
Loss of support: Professional	**Isolation**	**Isolation** Decreased support over time	**Exhaustion**	**Challenges**	**Isolation** **Isolation** **Loss of hope**	**Frustration**
Loss of support: Social	**Isolation** **Isolation**	**Isolation** – need help **Anger** **Frustration** **Isolation** **Exhaustion** **Loss of hope**	**Isolation** **Isolation**	**Challenges** *even with emotional support*	Family doesn't understand – **Isolation** **Isolation**	**Isolation** as help decreased **Isolation**

The discussion on themes was conducted much the same as was the discussion of bracketing of phrases or sections of dialogue. It was a back-and-forth repartee. The second coder remembered exact phrases from the interviews, so both of us were well-versed in the content and context.

Some of the themes were not unanimous. They are shown in black italics. It did not mean they were not relevant, but they were not phrases we universally agreed upon as themes. We agreed on specific themes as shown in Appendix F in results. An example of Appendix F is shown here. The themes were color coded and arranged to find individual themes and to ascertain for how many mothers the various themes occurred. The results from all analyses will be further discussed in Chapter 4.

Table 3-10 Examples of Themes Summarized

Loss of Quality of Life: Childcare	**Fear** *and relief*	**Isolation** **Exhaustion** **Loss of hope**	**Isolation**	**Isolation** **Challenges** **Isolation** *for child*	**Isolation** **Exhaustion** **Guilt** *over time spent with child, not siblings*	**Isolation**

CHAPTER 4 - Results

The results of this exploratory qualitative study demonstrated the experiences of chronic sorrow for six mothers who have adult children with cerebral palsy. Each of the mother's responses will be presented with case summaries, predominant domains, and themes for each.

Review of Research Questions

The research questions included

1. What is chronic sorrow and how does it exist for those interviewed?
    a. How has chronic sorrow changed as years have gone by?
    b. Does chronic sorrow decrease, increase, or remain the same for mothers who now have an adult child with cerebral palsy?
2. How do the following affect the experience of chronic sorrow?
    a. Where the adult child lives
    b. Overall health of the adult child
    c. Abilities of the adult child
    d. Overall health of the mother
    e. Support
    f. Losses in quality of life of mother
    g. How has the mother's life been affected?

These questions guided both the survey and interview questions used in the study. These findings are discussed in Chapter 5.

Results of Within-Case Analyses

A within-case analysis was completed for all six interviews, including the health of mother and adult child, ages of the mother and adult child, and rank of the adult child with siblings. I first compiled the information from the survey questions, and then I looked at each interview and its overall characteristics. The interview explored whether or not the mother believed she has or is currently experiencing chronic sorrow and if it has changed over the years. It also asked her for specific triggering events for chronic sorrow as well as information about her support and quality of life. A summary and my overall impressions of the interview were

also included. An example of a portion of the interview is included for each mother. These responses from the interviews assisted in the narrative of the experiences of chronic sorrow for these mothers. From these responses, underlying themes were established.

The survey questions and the answers by the mother for each question are found in Appendix D. Discussion of these findings is found for each mother in the individual case study reports.

Allison

My overall impression was that Allison was at ease. She had a pleasant expression the majority of the interview. She is married to her children's father and her adult child with CP has an older sibling. Allison is employed outside the home and has been since her children were young. She is in her early 60s.

Allison spoke of the "fleeting coming and going" of chronic sorrow that has "hopefully decreased" for her over time, so she stated that she believed she did have chronic sorrow; however, her completed Kendall Questionnaire score of 28 did not indicate she did. Certainly she was clear that she experienced chronic sorrow when her adult child was young as that time was "a big sorrow time". Her son lives independently in his own home with support staff. He is the youngest child of two in the family. He has swallowing difficulties so he is unable to chew solid food. He also has curvature of the spine. He is dependent on others to move about.

Allison spoke of experiencing *fear for the future* and *sadness*, some of which she stated was expressed through crying at the time of the triggering event which included she believed "everyone else's kids were doing it by themselves." In the interview itself, she questioned, "Why did this have to happen?" She spoke of how difficult it was, especially when triggering events occurred, stating, "That was hard; that was very, very hard."

Table 4-1 Allison: Bracketing of Triggering Events and Themes

Fear of future; Developmental milestones	I think – yeah, but… (8); couldn't do the things they were doing (21); felt most when I had to ask for help (24); trying to get the teachers to do what they were supposed to do (37-38); he didn't fit (53); didn't know where he fit (55); wasn't doing that (56); it was in no way the same (57); back surgery (61); how fragile he could be (62-63); granddaughter afraid of wheelchair (221); concerns of how she will deal with that (226)

Triggering events were clustered around developmental milestones, especially when she saw another child moving forward in accomplishments and hers was not as he "didn't fit" and "wasn't doing that". She spoke particularly about difficulties in working with the school system, in trying to get teachers to work with her child. She stated she felt chronic sorrow most "when I had to ask for help." Although triggering events were not directly mentioned as frequently as her child grew older, they still existed. She noted how she was occasionally reminded of his fragility, especially when surgery was necessary. Although her immediate family is familiar with her child's disabilities, some were surprised when younger relatives unfamiliar with her son's wheelchair were afraid of it and therefore afraid of him because of the physical difference it made in their perception of him.

Allison's role and responsibilities changed over time as a mother because of her son's disabilities. The mother noted how her role as a mother changed for her other child because of demands related to this child. She changed her role over time and she stressed how she was no longer a provider of care, but a coordinator of care. Her son with CP has not lived with her and her husband for several years. Her view of herself as a coordinator of care may be quite significant in her adjustment to chronic sorrow and its decrease over time.

The score from the Satisfaction with Support Survey was 3.9, indicating she was satisfied 'Quite a bit' at the time she completed the survey. However, in the interview, she indicated she found support from a speech pathologist, but she cited little support and no help from health care providers. Professional support was inconsistent for her. Allison stated she "didn't get any outside help…"

Social support was lacking as well from those outside the family. She stated many people looked only at the outside appearance without trying to discover who her son is and his good qualities and "fail to see who he is."

Spiritual support was not an area of strong concern. She continues to question, but feels that she and her son have support in this area.

In most cases, her support existed because she worked hard to find it. The family support group, begun in 1982 (http://www.familiestogetherinc.org/aboutus.html) in Kansas, was instrumental in support for her, beginning when her son was probably in his early school years.

Neither she nor her adult child has significant health issues at this time, but she noted that his behavior is changing over time and beginning to impact his life and those around him. She

did not believe she had financial or emotional difficulties now, but she and her family financially coordinate all his care and his living situation. Her overall affect was pleasant. She smiled frequently when talking about her son and when she referred to how she was able to do so much more than she had planned when he was younger as she was "amazed when it was OK for him" not to live in close proximity to his nuclear family.

Beth

Beth is a lady in her 60s. She is married to the adult child's father who is her primary resource. When her child was still in the school system, she was able to work outside the home, but is no longer able to do so. Her adult child requires constant help and supervision. Although she is very close in age to Allison, she appears older.

Beth evidenced chronic sorrow as she spoke about her experience and related emotions over time. She said, "Oh, yes!" when asked if she experienced chronic sorrow and went on to say "it's lots more complicated … don't even know what normal is." Her score on the Kendall Questionnaire for Chronic Sorrow was 67, a score that indicated chronic sorrow was likely. She cited many emotions including how lonely and isolated she felt as well as her experience with guilt, sadness, and depression.

Beth's child lived at home with his parents. He had experienced aspiration and also been hospitalized in the recent past for aspiration, pneumonia, and seizures. He was dependent on others to move him about when in bed or in the wheel chair. He was nourished through tube feedings only. His mother reported back pain, stress, and depression. Her husband was the only current significant source of help other than paid caregivers coming to the home.

Isolation was a pervasive theme in her interview. Beth stated that she believed the chronic sorrow was worsening over time "because as he gets older … is having more complications" secondary to his CP. She said her adult child must always have first consideration. She couldn't escape from her responsibilities for him and she saw no end in sight. She did not look into the future, but spoke only of living day-to-day as the experience was "never-ending" and that she was "scared to death" about the future (*fear of the future*), not knowing "where is the end in all of this?"

Triggering events for her were developmental milestones, especially when she observed other children's accomplishments compared to her child's lack of accomplishments "any time

there are milestones." Beth continues to remember specific instances when another mother either intentionally or inadvertently compared their child to hers and her reaction to that and how hurt she felt. She wondered "what was going to happen after public school … either dump them somewhere…" She again noted how alone she felt and how she could not identify with mothers who had children without CP. The predominant theme underlying her discussion of the topic was *isolation*.

Beth's role changed after the birth of her child as she became a permanent caregiver for him. She stated she and her husband rarely spent time as a couple and that she did not feel like a couple. She felt isolated from her husband because they had to take turns doing things as individuals and as caregivers, but not usually as a couple. "If he goes somewhere, I stay home." One of her unanticipated roles brought on by necessity was her need for knowledge of the legal system during school years in particular, but also in maintaining care-giving for him before he turned 18. She took on the role of therapist also as therapy took up much of her time on a daily basis. Daily tasks such as repositioning him throughout the day and night every few hours also were not something she thought she would be doing as her child got older as Beth was "still trying to pull my son up in bed." *Isolation* was again an ongoing theme as she discussed her changes in responsibilities because of her role as the parent of a child with CP.

The satisfaction with support score was 2.75 the day Beth completed the survey. In years previous, support from professionals, especially those from the school system, was adequate in the pre-school years as she noted the teachers "did a really good job of integrating him into some regular classes for some things," but as he grew older, she found it fading. Beth wondered "What is going to happen when he turns 21?" again illustrating *fear for the future*. She stated she expected professional help, but did not receive it. She found some support from the school nurse and from his therapists. One of her examples of good support was experienced when her child attended an Easter Seals camp, although she said she sent an attendant with him.

Not only did support decrease over time in the school system, but Beth specifically noted how much less support exists after formal time in school is over. She had no overnight help from anyone at anytime: "That never, ever, ever happened". She believed that parents of other children did not want their children to associate with children like hers as "people grab their kids and move them away," but that the children of these parents were more accepting when given an opportunity. She stated that the best support came from parents' groups as they could understand

what parents are going through and "have better information for you and can give you resources." She cited how much she could have used some outside help. Again, the ongoing theme to her perceptions here again was *isolation*.

Beth spoke of how she wanted to understand why this happened. She described *anger* at God and her church family as she did not have the support she needed. She was not able to work in either her vocation or avocation because of her care-giving responsibilities and wondered why she would be given abilities by God and why God did not allow her to use them as she asked, "I'm not supposed to do anything??" She spoke about her longing for answers as she "couldn't accept the fact that the Lord allowed this to happen ... I wanted it fixed!" She felt isolated from other worshipers and from God.

Her quality of life has been significantly impacted as illustrated by Table 4.2. Not only is she experiencing *isolation*, but also *exhaustion*. Because of her son's needs, Beth or her husband must be on-call every hour of every day. She does not believe she can leave him with others for very long, although she will leave him in care of her husband. Her son's care is physically demanding due to his inability to move significantly on his own. She stated caring for him was "never-ending." Again, she verbalized *isolation* due to his needs and little belief that this would ever change and had no hope for any change in the future (*loss of hope*).

Table 4-2 Beth: Bracketing of Quality of Life and Themes

Isolation, exhaustion Fear for future Fatigue/ exhaustion, isolation	lawsuit against the school district (46); we had to go though great sacrifices (50-1); the alternatives are so bad (64); that was the only time (93); absolutely no break whatsoever. Ever (106); there's something that unusual that happened… if we hadn't come home, if we'd stayed for that dessert … would have had a problem (113-5); burden hasn't lessened any (189); you have just had it and you're gonna be up all night turning (referring to turning child) like I was … (203-4); this physical burden (226); I was not reliable (237); show me something I've indulged myself in (343-4); don't get to have lighter, happier time (352); need something besides the four walls to look at (353); he never had any plans (390); trying to pull his stuff together (398); what is going to happen when he turns 21? (401-2); we're in for the long haul (405); I have to be able to do something else (530)

Beth appeared very physically fit which could have been because of the physical demands of caring for her adult child; however, she stated how fatigued she was from having little uninterrupted sleep. She seldom smiled and her posture was slumped. The overall affect

was of someone who was beaten down. She stated his health was worsening and indicated seizures and pneumonias were some of his medical problems. Beth noted it was becoming more difficult to provide care as she grew older and that she had given medication management for her son over to her husband at this point. Her child's problem behaviors such as temper tantrums were becoming more frequent. Financial issues were an ongoing problem as she and her husband had paid caregivers with them to help with his care. She did not see how these problems were going to go away and asked, "Where is the end to this?" (*loss of hope*).

Carole

Carole is also in her early 60s. She has been divorced since her daughter was a baby. She has an older son who no longer lives close and is raising a family himself. Carole's daughter lived with her and has always done so, except for a brief break when she lived in a group home. Mother's health is good at this point. Carol appears very trim and physically fit, although she looks older than her stated age. Her child needs care and supervision every hour of the day. She works outside the home during the day while her daughter is supervised at the sheltered workshop. Her hours have been adjusted depending on when her daughter can have care. She has arranged for another person to provide this supervision in her home after the sheltered workshop is closed for the day.

Table 4-3 Carole: Bracketing of Chronic Sorrow Definition and Themes

Anger; frustration; fear for future – loss of hope Fear; loss of hope	Absolutely! Sure do (6); pretty much as stayed the same … decreased some. Has decreased a little (11); just really hard (20-1); ever going to climb this mountain? (27); sorrow came when she would just sit and look at us with kind of like a glare like, it just didn't connect (29-31); really hard time for me personally (reference to middle adolescence) (55); pretty well resolve the fact that none of those things are going to happen (after HS) (64); kind of hurt (response to TE) (75); very angry (to be by herself) (89); infuriated (169); we never looked that far ahead (313); Burns me the wrong way (347); feel like I'm playing guess what and I'm losing (353-4); we're doing funeral planning. For her (376-7); how long can I keep her home? (393)

The presence of chronic sorrow was acknowledged by Carole when she said, "Absolutely! Sure do". Her score on the Kendall Questionnaire was 79, a score which indicated it was likely she was experiencing chronic sorrow. She stated she believed it might have

"decreased over time," but that the experience was still really hard and harder at some times than others, and that nothing was ever going to change for the better (*loss of hope*).

Carole was "angry" and "infuriated" as she had to guess at what she should do throughout her daughter's life. The only planning for future was around funerals for each of them. She had no hope her life was going to change for the better; in fact, in light of funeral planning, her perception was that it would be worse, especially if she died before her daughter or was unable to care for her as she verbalized, "How long can I keep her home?" (*loss of hope*).

Triggering events initially were the lack of meeting developmental milestones. She told of how she tried to teach her daughter to play, but her daughter did not connect what she and the therapists were trying to have her do. She said, the "sorrow came when she would just sit and look at us with kind of like a glare like, it just didn't connect." She said she wondered, "Will she *ever* do anything?" Carole stated that middle adolescence was "a really hard time for me personally." Specific developmental milestones she mentioned were when she saw a neighbor girl "practicing cheerleading", when a niece was married, and when her "brother went off to college." Her daughter communicates to others by sounds and pitch of vocalizations, but not by words. The mother became noticeably sad (*sadness*) when she spoke of planning her daughter's funeral.

The father of the child left them because of the child's disability and has provided no support; therefore, Carole is the primary breadwinner. Years previously, she had wanted to go to school, but because of her responsibilities for her daughter never could go back. She has raised her older child to be independent and he no longer lives with her; he has a family as well. Her child with CP could not be independent and continues to need supervision and care for all personal needs. She is toilet trained during the day, but she needs her mom and continues to sit on her mother's lap, as she has since she was young.

The overall satisfaction with support scale for Carole was 4.4 on the day the survey was completed, indicating she was satisfied 'Quite a bit'. However, during the interview, she did not give information that indicated she was satisfied; in fact, she is not satisfied as she has not had good information about her legal rights nor does she have respite care. Several years ago, Carole attempted to find other living arrangements and tried a group home. This was initially successful, but did not work out because of possible lack of supervision for all the residents. She believed that a group home was not a good long-term solution for her daughter. She did not have access to

knowledge about legal ramifications of conservatorship and guardianship after her child was 18, so appropriate legal counseling was absent, leading to significant financial and emotional hardships to maintain custody of her daughter. With much effort on her part, Carole was able to get counseling about maintaining custody from an elected political official. She also was able to find a dentist who would help her care for oral injuries suffered by her child subsequent to seizure activity. Other than the dentist and legislator, she could not cite professionals who had been supportive.

Social support has not been forthcoming. Carole believes both she and her child are socially isolated (*isolation*). She has some paid caregivers and day care is provided by a local CDDO, but she has no other help at home. She works at a lower paying job and takes her daughter to day care services during that time, and then a caregiver supervises her until her working hours are over. She does not see how this will change. Her life revolves around her daughter's needs.

Carole feels she has much spiritual support as well as emotional and financial from her church family. She believes her faith has become stronger, especially as she sees "God has used (her child)". She needed money for her child's dental care after the oral injury and was very grateful to her church for helping her with that (dental care other than extraction is not available for children over 18 in Kansas).

The quality of life for her child is affected by her physical disabilities. Carole's child is non-verbal except for a few sounds; she has recurrent seizures. Because of this, she had a fall and needed dental surgery. She is unable to care for herself. She has been hit and injured by others. She also drools most of the time. She is able to walk, but needs help in eating and toileting. She cannot be trained to perform any kind of work.

Carole worries about the future for both her daughter and herself (*fear for future*). She does not know what would happen to her daughter without her being there to care for her. She is worried about the future for both of them. She has noticed that her daughter's behavior is getting worse as she grows older, although she gave positive reinforcement for good behavior during the interview. She stated she had started this when her daughter was very young because she was concerned that her daughter's behavior might be an issue at some point in the future.

Carole said she knew she should have gone back to school so as to better support her family, but it was not possible because of the responsibilities she had. She discovered how little

she knew about the legal system as she advocated for her daughter in the school system and had to proceed legally to maintain custody of her child. She found that dental care was not covered in the Medicaid system. She has had many out-of-pocket expenses for daily needs for her child as well as the medical and dental needs. Carole has needed second opinions, but found they were not covered, so she had to bear those associated expenses as well.

Darla

Darla is in her 50s, is married, and has an older daughter. Chronic sorrow has decreased over time because Darla believes she and her husband now know what her daughter needs. Quite a bit of chronic sorrow occurred after her daughter was born. The episodes of chronic sorrow have revolved around education, specifically teachers. Darla noted how concerns were never quite resolved and that negatives remain. She characterized the experiences as "frustrating" and "challenging". Some of the chronic sorrow was related to the long continuing process about her child's life and the unknowns about her future (*fear for future*). Her score on the Kendall Questionnaire was 46, a score indicating she likely is experiencing chronic sorrow.

Her daughter lives with Darla and her husband. The older daughter lives and goes to school out-of-state. Darla does not have chronic health problems, but has experienced flu and pneumonia this past year. Her daughter has had hospitalizations for seizures. She is mobile with the help of orthotics, but moves and completes usual daily activities very slowly, albeit independently. She does work part-time, but needs transportation as provided by parents.

Darla cited that the most sorrow occurred at the time of the initial diagnosis because of the grim prognosis at the time. At other times, it occurred during the toddler time period when others were meeting developmental milestones and her child was not, and during challenging times with schools and teachers as well as with other people as she aged. Times when challenges occurred in getting her the types of supports she needed were also times of chronic sorrow.

Darla's role has changed because of her child's disabilities. She verbalized worry about the child's future (*fear for future*) and what her daughter will be able to do on her own. At this point, her daughter works part-time. She and her husband cannot leave her for long stretches of time, but are able to run errands and perhaps leave her overnight. However, her adult child cannot live independently. Darla specifically stated how it was expected that children would grow up and become responsible as "with a typical child you relax in that responsibility and

separate more to some degree," but no separation or independence is happening as she matures and they "would have to support her throughout her adult life." There was not a thought that this would improve over the years. In fact, she stated, "Ongoing challenges … negatives aren't going away."

Darla's career has changed because of her daughter's disabilities. The mother also recounted the experiences her older child had and how the oldest child's life of necessity had to revolve around needs of the younger. The plan is that the older child will someday assume guardianship of her sibling.

Darla noted positive experiences with a nurse case manager, a pediatrician, an orthopedic surgeon, and some therapists, but cited challenges that occurred with teachers in the school system. Darla believed she has family support both emotionally and financially when needed, although those outside the family are not consistently supportive. The satisfaction with support scale for Darla was 3.7, indicating that she was satisfied with the professional support available 'Quite a bit'.

As seen in the Table 4.4, spiritual beliefs were strengthened due to this experience, but Darla said it had been a long process as personal beliefs about God were initially challenged.

Table 4-4 Darla: Bracketing of Loss of Spiritual Support and Themes

Challenges	my spiritual beliefs were challenged … they've evolved in a way that's been very helpful. Initially, it challenged to everything I believed, and how I believed ... long time in figuring out how it all made sense (131-4); how to justify a God that controlled everything, imposing these challenges on the child! Resolving that dilemma and understanding it, and helping put it in perspective … long process … helped me grow spiritually … one more thing that I was trying to justify and make sense out of (135-9); initially, we didn't have a church … or a connection with a pastor (150-1); we really connected with that pastor (149-50); our church group … were always pretty accepting (158-9)

Her child has been eligible for personal care attendants, but this has not always worked out. The prevailing problem over time has been transportation as public transportation is not available, so her daughter is dependent upon parents for transportation to employment or other daily activities. She also moves slowly, so is unable to keep up physically. She is independent in most activities of daily living, but substantial time must be allotted for most activities.

Early in her life, her daughter experienced seizures and continues to occasionally have periods of unusual seizures that have been difficult to treat. She has had pneumonia and has visual and cognitive problems. She has needed surgery as well. Complications secondary to CP have increased as she ages. The mother denies health problems for herself although stress may play a part in some of her health problems. The mother said that overall, it is easier to have her child live with them for now, especially since the law does not allow her to live with other persons if they are not family members in the way her daughter's care is now funded. Money has been a challenge since Darla's daughter was born. Darla stated they owed, "thousands of dollars, after the first NICU stay, but we paid it off over time." Finances are an ongoing issue and challenge as insurance does not cover the durable medical equipment she needs.

Ellie

Ellie is in her 50s. She works outside the home and has two other children. Ellie did not feel her experience with chronic sorrow had changed over time. She stated, "It doesn't go away." She had experienced anger, hurt, pain, betrayal, apprehension, grief, and emotional and physical exhaustion. It is difficult and she continues to feel sad. Her Kendall Questionnaire score was 42, indicating chronic sorrow was likely present. She is in good health. Her overall affect was tinged with sadness and made little eye contact until the end of the interview when she thanked me for being able to talk about things she seldom shares with others.

Ellie's daughter lives independently and drives a car. She is employed and has an advanced college degree. She has few health problems and ambulates with equipment or 'knee walks'.

Ellie reported that triggering events began with the initial diagnosis and continued as developmental milestones were not met. Events such as finding who would accept her in daycare because of her physical disabilities triggered chronic sorrow. Playground activities she had difficulty with, what she could wear, and being in Driver's Education were other triggering times. In addition, how others reacted to her physical characteristics and disabilities were also problematic. The hours of exercises as part of physical therapy she did with her daughter caused chronic sorrow as well.

Table 4-5 Ellie: Bracketing of Loss of Role & Responsibilities and Themes

Isolation	(responsibilities) fell mostly on me (154); all fell on me to do (therapy) (162);

Isolation Guilt	can't get a lot of things done when … (brothers) didn't have much time or involvement from either their father or I (166-7); he (dad) couldn't bring himself to do it (exercises) so I was the bad guy (225-6); (coordinating care) Myself. Me. I. I did all of that (361); I failed (referring to time with sons) (377-8); her dad did not come back (248); now I know more what to do for somebody that has a physical disability (447-8)

Ellie's parenting responsibilities were not as she expected. In addition to the usual roles and responsibilities inherent in being a mother, she had the responsibility of getting her daughter to therapies, coordinating her care with professionals, and doing the therapies at home with her daughter. Because of that, she had a lack of time to spend with her other children and felt a sense of failure and guilt in parenting those children. She believes her professional attitude has changed because of her experiences with her daughter and that she is more responsive to those with physical disabilities.

Several times Ellie mentioned the lack of professional support. However, the score from the satisfaction with support survey was 4.3, indicating 'Quite a bit'. This did not seem true in light of her other comments during the interview. She expected professionals in health care to be more involved. "Nobody from the hospital ever got involved in her case … nobody really talked to us about her, nobody talked to us about anything that could be wrong … except the neonatologist (who) told us she'd probably be a vegetable." and she had difficulty getting information. After several years, she noted that "not everybody knows what to do." She did receive good help from a physical therapist who referred her to a physician who did help. She also cited Vocational Rehabilitation as an agency that was helpful.

In addition to the perceived lack of professional support, she experienced *isolation*. She stated her family didn't understand and she had no help in coordinating care for her daughter. When asked about help she had or who was responsible for her daughter's care, she replied, "Myself. Me. I. I did all of that."

Spiritual support was not evident. She did not change her belief system and cited one church which did not behave as she felt Christians should when considering her daughter for preschool. Although she was not a church attendee, she continued to pray and 'bargained with God' so her daughter would be OK.

The quality of her life and that of her children was impacted by the child with the disability. Early on, she received some help from a friend with childcare, but she believed she

herself spent more time with the child with CP rather than the siblings and verbalized guilt about that. Currently, ambulation is her child's primary problem. She does drive. The mother has no health problems. Her adult child lives independently and is employed. Over the years, the mother found her health insurance to be very helpful and to cover the majority of associated costs.

Fiona

Fiona is in her 50s, is married and has two other children, one older and one younger. She works outside the home. Fiona's overall health is good.

Chronic sorrow was defined by Fiona as something that never goes away. She believed it has decreased, and that she experiences it differently now than when her son was younger. Fiona used to cry, but now she is 'just sad'. She did not want to give up all her hopes for him (*loss of hope*), but now she has had to do so. Chronic sorrow included having no balance in her life. Her Kendall Chronic Sorrow Questionnaire score was 67, indicating likely chronic sorrow. Her overall affect was sad, but she did smile on occasion.

Her son currently lives in a group home, but he lived with his mother and father until his 20s. Chronic health problems include curvature of the spine. He has been hospitalized for symptoms of dehydration, urinary tract infection, and nutritional malabsorption. He has a history of seizures, although those are not an issue at the present. He is dependent on tube feeding for nutrition and on others for movement in his wheel chair and any position changes.

Her triggering events included knowing the developmental milestones that should have occurred and seeing other children who were meeting those milestones. She stated, "It was a whole different world. We were trying to figure out who would change his diapers and feed him every day." Her son had no peer connections apart from school, so he had no social invitations. This may be because he does not speak, so others find it difficult to communicate with him.

Table 4-6 Fiona: Bracketing of Triggering Events and Themes

Sadness; heavyhearted; regretful	When (older brother) gets married, I knew (my son) will never get married and I feel that. When (my son) went through graduation and I knew he didn't understand what was going on and he would never go to college, it was very much a sorrow. It is those milestone moments that never go away (7-10); I would see other mothers with their babies, and I would actually cry (15-16); didn't do sitting, standing, walking. And so, I'd see other children his age of doing that (23-4); other children (with developmental disabilities) there who could walk and talk and feed themselves, and be toilet trained (28-29); He was in school, and

	obviously not going to be reading, but we were showing him words, thinking he was recognizing things … and working really hard on all that oral communication, which he didn't get (33-35); He wasn't in very many social groups, he didn't get invited to one birthday party in three years (42-43); trying to keep his body form getting so quirked up that he couldn't even move (47-8); graduation was supposed to be a really happy time and we went through it for (my son), but it wasn't very happy (60-1); he will never really travel, he will never have a mate or a relationship (68-69); when I look at his brother who's two years older (236); he loved heavy equipment; he loves horses, he loves music, and he could've gone any of those directions (240-1)

Comparing him to other siblings also brought on chronic sorrow, especially when they graduated and when her other son married as she knew her son with CP would never have those opportunities. "When (older brother) got married, I knew (son) will never get married and I feel that. When (son) went through graduation and I knew he didn't understand what was going on and he would never go to college, it was very much a sorrow." "It is those milestone moments that never go away." Another milestone for her son with CP was moving from his parent's home, but this was not necessarily perceived in a positive way as "This was it! He will never live anywhere else."

Responsibilities for her son were very different in that he needs help with basic movements, diapering, and feeding and will need this during his lifetime. Rather than attending events together as parents, choices had to be made and parents took turns to be with his siblings. Fiona believes this was hard on the siblings and could be the reason for some of their poor life choices as she was not as available for them. Caring for her son with CP meant that the quality of life for her family was not as good. She needed help for all the responsibilities associated with his care.

Fiona believed she was fortunate in that she had helpful physicians, therapists, and special education teacher; however, services that were needed were not consistently available. The satisfaction with support scale was 4.5 indicating 'Quite a bit'. Social support decreased as he grew older. It became more difficult for them to go out as caregivers for her son were not always available. His father and siblings cared for him as well as the mother, and they had excellent resources due to those they knew, but it was still difficult to find adequate help. The church has provided positive support. Spiritual beliefs have grown stronger.

Her son has had ongoing medical problems, especially when he was younger. The mother experienced several years of *exhaustion* when he was having sub-clinical seizures. Fiona had to change dreams for her child as well as the focus of her career. Problem behaviors have occurred secondary to health concerns. Finances were also a problem in that it was difficult to have enough financial resources at any time. Overall impression was that she seemed relaxed and at ease sharing her experiences with her child and family.

Cross-Case Comparison

Kendall Chronic Sorrow Questionnaire Results

Scores were 29, 67, 79, 46, 42, and 67. Scoring of this questionnaire is "0-38 – no chronic sorrow present, 39-82 – likely chronic sorrow present, 83 and over – chronic sorrow present" (Kendall, 2005, p. 127). According to Kendall's criteria, all scores but the first indicated likely chronic sorrow. The standard deviation for all was 18.9. All mothers verbalized they experienced chronic sorrow in the interview.

Demographic and Survey Results

Overall information

Three mothers were between the ages of 50-60; the other three were between ages of 60-65. All but one mother was employed outside the home. All but one considered themselves to be middle socioeconomic status. One believed she best fit into the lower socioeconomic classification. All mothers were Caucasian and lived in a similar area of the state. Three mothers had no identified health problems, although two experienced back pain and stress with one of those also citing depression. One noted high blood pressure. The mothers who noted two or more personal health issues had children who needed total supervision and care.

Four of the adult children lived with their mothers, one lived in a group home and one lived his own home with supports. Three of the adult children were 25-30; three were between 35-40 years of age. Only one adult child had no siblings. Others had one or two siblings ranging from 25-30 (3) to 30-35(1) with one having a sibling over 40. One had a sibling younger than 25. None had siblings with disabilities. The adult child with CP was the oldest in two cases, the youngest in three, the only child in one, and the middle child in one family.

Two adult children were dependent on others for all transfers. One walked independently but needed supervision, and three utilized an assistive device of some sort such as orthotics. Two fed themselves independently, one adult child needed assistance in mashing or cutting, one must have blended food, and two were dependent on tube feedings. None were able to feed themselves only after someone else mashed, pureed, or cut their food.

All but one child had current health issues. The one who did not have current issues experienced surgery years ago to lengthen her hamstrings. All but one experienced swallowing difficulties which would put them at risk for aspiration pneumonias, although only one was hospitalized for this specifically before the interviews occurred. Four had recurrent or past history of seizures, four had gastroesophageal reflux disease (GERD), three are experiencing curvature of the spine, and three have been hospitalized for seizures. One of these was hospitalized for pneumonias, aspiration, urinary tract infection (UTI), and seizures. Another was hospitalized for UTI, malabsorption of formula, and tachycardia, all of which are typical consequences of dehydration. Both of these children who were hospitalized were dependent on tube feedings for nourishment. Another was hospitalized related to uncontrolled seizures.

Professional support and resources

Some of the different resources that could be used to manage care of the adult child are described in Appendix D. The survey asked to what extent each was true on a scale of 1 to 5 with *Not at all* – 1, *A little* – 2, *A moderate amount* – 3, *Quite a bit* – 4, and *A great deal* – 5. Each mother was asked which professional provided helpful support and was asked to rank those they had in order of helpfulness; however, not all mothers provided rankings, but indicated only if the professional had been helpful. The family physician was listed as first once. Therapists were ranked in the top three by five mothers as providing helpful support. School teachers and school nurse were listed by three. Four mothers indicated they were included in their child's disability management strategies and goals, although one of these also circled 'not at all' which may have indicated a different experience with one or more physicians. One mother indicated her doctor had not involved her very much with decision-making. All indicated they were listened to carefully by health care professionals 'quite a bit' or 'a great deal', although one said aloud while marking the survey that she did not choose a physician unless she knew she could work with him. One was not sure this was done consistently; all others believed that the laboratory and

medical tests were explained quite a bit or a great deal. The mean value of these scores was 4.12. The mean for the mothers overall was included for each question. Also, the mean perceived support for each mother is shown. When mothers included two different scores, the lower one was used in the calculation. Beth perceived the least amount of support (2.75) overall and Ellie and Fiona the greatest (4.3 and 4.5).

Financial concerns

Health insurance was inconsistent in meeting the needs of the child. One found it did not meet needs, another that it met needs only partially, and others had the majority of needs met through health insurance. Through casual conversation, I learned that three have Medicaid at present, but I do not know what kind of insurance all have currently or did have. This is a question that should have been included.

Social support

Among married mothers (one was divorced), the spouse was most often indicated as the first person to help with the adult child. Paid caregivers were next, then siblings or other family members. Friends were cited only once and that source of support occurred only when the child was much younger. All mothers indicated they were the ones who coordinated health care and therapies for their child currently with one noting that she no longer did this since he had moved to a group home. All indicated they had thought about how to accomplish goals for their children. All except two have arranged their schedules to fit their children's needs. One who does not currently need to rearrange her schedule has a child who lives independently with support staff; another needed to rearrange her schedule in the past which was difficult at times, but her son now lived in a group home, so this is no longer a problem. Three mothers were either not aware of support groups in their geographic area or did not attend. Four have attended support groups in the past. One mother indicated both that she had attended and that she had not had an opportunity had moved from another state at some point, so it is possible that she had support at only one location. All but one mother had a flexible work schedule with one indicating there was no choice because flexibility was a 'must'. All five who worked outside the home indicated their workplace offered flexibility. When visiting informally, all took this question to mean flexible time for their child, not necessarily for them. The content in this question should have been emphasized in the questionnaire. One person changed jobs so as to have better

financial means to care for her child; however, she found it was very difficult to manage care for her child. Others had significant control of that facet and circled 'quite a bit'.

Interview Findings

Questions were arranged to answer the questions about chronic sorrow in this group of mothers. All responses were organized in order for easy reference across the interviews and were organized so that each question was separate from the others. Line numbers were also added for reference.

Chronic sorrow definition

The first question asked in the interview was whether or not the mother believed she experienced chronic sorrow. All six indicated they experienced chronic sorrow. Each described a 'coming and going' in similar words and stated 'it never goes away' with one mother asking, 'when will this all end?'

The differences in their experiences of chronic sorrow varied as far as whether chronic sorrow had increased, decreased, or remained the same. Four indicated that chronic sorrow had decreased over time; for one person, the experience was about the same over time; for another, it had increased over time. Three of the six used identical wording, speaking of how 'sad' they were. *Exhaustion* was mentioned by three mothers as they talked about chronic sorrow. Emotions listed were fear, despair, sadness, big sorrow, very difficult, very lonely, bitterness, much worse than I thought, scared, guilt, depression, can't get out, *frustration*, really hard, anger, incredulous, hurt, betrayal, shock, apprehension, disturbing, can't keep a balance, disturbing, slap in the face, a punch in the stomach. Many terms were used by more than one of those interviewed.

Triggering events

The triggering events that initiated chronic sorrow according to these mothers were described consistently as *developmental milestones*. The time of diagnosis was described by each of them as a triggering event, especially when their children had medical complications at birth or infancy, which all did. One comment that summarized the content for all of the mothers was "these milestone moments never really go away." The mothers compared how different their children were from other children of similar age or from siblings when present.

Differences in triggering events included how severe these moments of chronic sorrow were through the life span of the child. One mother stated this occurred when she had to ask for help, two more found it very severe at time of the initial diagnosis, two when events occurred for others in their families or with acquaintances that illustrated accomplishments for others such as weddings and graduations. Two mothers noted developmental delays where the other four commented how their children would never reach those developmental milestones. Whether the child lived independently, with the mother, or in a group home, the mothers experienced chronic sorrow. They commented how different things could have been. One mother whose child lived independently with support did not note sadness, but also surprise and relief that he could live without her nearby as it was more than she had thought was possible in earlier years. However, another mother was saddened that it was no longer possible to offer her child the kind of activities she had hoped to when he was younger and that it became necessary to move him into a group home. These events solidified her *loss of hope*.

Loss of Roles and Responsibilities

Losses were not solely found in inability to meet appropriate developmental milestones. One of the overriding changes was in either loss or change of the mother's roles and responsibilities. Similarities were that all had responsibility for the coordination of care. An ongoing theme seemed to be *isolation*, although it was mentioned in different contexts. Comments included "I do it all"; "Me. Myself. I. I do it all"; "I have been. Me"; "me"; "I do that"; and "I can't do it anymore." One mother stated, "With a typical child you relax in that responsibility and separate more to some degree." Overall, the losses in roles and responsibilities impacted the entire family including the extended family, including the roles of the mothers in caring for other children, in their social lives, in their lives with their spouses, and in their careers as well as in the roles of siblings.

Differences among mothers in losses of roles and responsibilities were the level of care their children needed. One mother noted how much different mothering skills were when other parents were trying to teach children to live independently and she was dealing with who would change adult diapers and who would do the tube feedings as well as ongoing medical challenges. Many differences existed in whether spouses helped or not with therapies, transportation, or basic coordination of the care needed. Some of the mothers had family members who could help

when the child was younger; however, this help dried up as the children grew older and needed help other children of similar ages did not. Again, methods of feeding and other activities of daily living necessitated training of others.

Sometimes these 'others' providing day-to-day care were siblings, which also illustrated how typical roles in the family change when a child has disabilities. Four mothers noted how their children were impacted. Two siblings had a chosen career that was no doubt influenced by caring for their brother or sister. Two other mothers reported feelings of guilt they had when acknowledging the time the child took from their other children and problems these siblings may have had due to lack of attention on the parent's parts and another mother questioned why I did not ask more questions about how the sibling was affected. Another stated she and her husband chose not to have another child because of the possible risk of having another child with developmental problems.

Mothers also noted how their roles as wives changed. One had to assume the role of breadwinner when her husband left as he did not want anything to do with the child with the disability. Another also was divorced, but had remarried. Roles in the community also changed. Two couples were active, going out either together or with friends. This changed as the couples either stayed at home more often as time went by because it was too difficult to find someone who could care for complex needs of their child or instead went out individually without their spouse.

I could not say with certainty, but it is quite possible that all of the mothers had different careers than what they would have had otherwise. One might have pursued more education which she verbalized as something she had planned earlier in her life. One was not allowed to pursue the career she had planned. Three had careers in which they worked directly or in a supervisory role with either an individual with disabilities or their families. Another was employed in health care.

Loss of Support: Professional

Not all parents felt they had adequate professional support. One parent cited only a speech therapist, that physicians and nurses had not been helpful. Another wondered why others did not do either a good job informing them or advocating for children such as hers as "parents cannot stay on top of doing all the daily grind" as she referred to learning about what options

they had in education, planning for the future, and in health care as she noted the limitations of the health care system.

When looking at health care support, one parent stated they only chose physicians based on how they could work with them and trusted their parental instincts. Another was not informed about her child's diagnosis until well after birth and did not know what the diagnosis meant as she initially thought it was something that could be cured. Two found specific physicians that were very helpful and three spoke of how helpful school nurses were in getting them information and being supportive. For example, one mother did not understand how tube feeding was done and thought that every time her child needed to fed, he would have a tube down his throat and she did not want that. The school nurse explained how a percutaneous feeding tube worked which was a huge relief to her and helped her make the decision to have this procedure done.

Other supportive professionals reported by mothers consistently included physical and occupational therapists as well as speech pathologists, depending on the needs of the child. Some children had the benefit of the therapists in the school system, but not all had treatment from the professionals themselves but instead received care from non-certified personnel. One mother in particular believed her son needed professionals with more experience in caring for those such as her son. The school system in general and Special Education teachers in particular were either vilified or extolled. One mother's son attended a specialized school at some time during his educational period which was seen as somewhat helpful, but this took the child from the rest of his peers in the community. Moving from place to place was also a problem as one mother and spouse would work with one school system and get things improved, and then have to begin the process again when they were transferred and the child was in another school system. There were no constants in the educational system. One mother probably summarized it for the other mothers when she stated, "not everybody knows what to do" as she spoke about the professionals with whom she had contact and their level of expertise.

Loss of Support: Social

Social support decreased for all as their children grew older. Because of the level of care their children required and the lack of respite hours, the mother's social lives contracted. They had some social support when their children were smaller from family and friends, but the ability of friends to care for their children decreased as their child grew older. They found some support

in the school system, but more from parenting groups. Two mothers were not aware of a parental support group where all four other mothers specifically mentioned the helpfulness of Families Together, a support group for parents who have children with disabilities in the Midwest. Support decreased more when their children were no longer within the school system. One mother stated, after "aging out of the school system, there's nothing there." Three mothers who worked outside the home when their children attended school either had to change the focus of their career (2) or work only from home.

For three mothers, some social life continued within the context of their church. However, that did not mean there were not challenging times as they struggled with the 'why' of their child's diagnosis. The acceptance of why this happened to their child and to them was different. Comments about their spiritual beliefs included "(it was a) long process … (but) helped me grow spiritually;" That's the only reason I got through … so it just made my beliefs stronger," "I did pray a lot … just let me get through." For two mothers, church attendance was not a part of their social life previous to the birth of the child and they did not make changes to incorporate the church into their lives afterwards. Another stated she found much support and meaning from her church and her faith grew stronger as she needed to lean on God more and found a purpose for her daughter as well. For yet another, church continued to be a part of her life, but she felt alone and isolated being there as she never understood and "couldn't accept the fact that the Lord allowed this to happen."

Quality of Life: Health of Child

The adult children with CP were similar in that all the children had significant health care needs at birth. The differences involved how long, to what extent, and how severe the health care needs were. As anticipated when I researched potential health care problems in those with CP, mobility and nutrition did predicate the degree of disability in the adult child. Those who were dependent on others for basic needs required much more attention in day-to-day supervision and experienced health problems whereas those two who could ambulate on their own had less morbidity.

Quality of Life: Mother's Health

The mother's health varied widely. The four mothers who had to physically move their child all appeared to be physically fit. Emotionally, one stated she had depression and two stated

they were currently under significant stress. Three others denied current health problems. However, it must be noted that all but one admitted *exhaustion* at some point. Two expressed worry about how long they could keep up the care needed for their child; two could no longer do all the daily caregiving tasks.

Quality of Life: Behavior of Child

There were no similarities on behavior of the child. Sometimes, the physical attributes could cause some frustration in the mother when the adult child could not keep up with others. Three adult children had some behavior problems such as temper exhibitions and stubbornness, some of which could be because of their mental capacities where self-injurious behavior was noted, or as their mothers stated, their behavior was changing as they aged and they did not adjust well to either change in everyday structure or in not getting what they preferred.

Quality of Life: Financial and Emotional

One mother specifically spoke about emotional strain. Four mothers indicated they had experienced or were currently experiencing financial challenges. One stated she had very few options financially. Another mother stated imploringly, "There aren't! There aren't enough resources, or of family's income." Another mother stated emphatically, "economically, it's been … tough, medications not always covered… no dental care covered … had to come out of my pocket." A third said, "money is a challenge; … thousands of dollars, after the first NICU stay, but we paid it off over time ... we basically support her." Another mother whose daughter had excellent insurance coverage at birth and during childhood wondered, "(I) don't know how parents get through." Only one mother stated she had adequate funding and financial support to ensure her son had what he needed; however, she stated she is coming across "people who don't believe that we should have all the services that we have … I think as times get tighter, we will probably hear more of that." Another's daughter is now self-supporting with minimal health care problems or financial needs at present.

Within-Case Themes

Themes were placed in a table (Table 4.7) for accessible referencing for both the within- and cross-case analyses.

Themes for Allison

The most common theme identified as part of chronic sorrow definition for both the coders was *fear.* In context, this was in response to thinking about the future; therefore, the theme was altered to be *fear for the future. Fear* was also a theme in triggering events for chronic sorrow and in quality of life as impacted by help with care of the child. *Fear for the future* was also found in quality of life related to behavior of the adult child. However, Allison expressed relief and surprise when thinking about the future as she expressed "amazed when it was OK" speaking of her son's current living location which negated the fear she had expressed previously. *Isolation* was also a theme of hers when speaking about the lack of professional help. This theme also was present somewhat with those from outside the family. Also, *isolation* existed because Allison coordinated all her son's care.

Themes for Beth

To reiterate, *isolation* was a predominant theme for Beth. This was expressed in her expression of her feelings about experiences of chronic sorrow when Beth stated she was "lonely, very lonely". A secondary theme identified in this definition of chronic sorrow was a *loss of hope* for her future. She spoke about "no end in sight", "loss of control" for future, "no closure" to the experience, and that it was a situation she found depressing and *frustrating*.

Isolation was again a theme in triggering events as she expressed how different she felt herself to be from other mothers who had children meeting their developmental milestones. Beth spoke of how she empathized with another in a situation where a person "couldn't get out".

Fear of the future was part of her experience of chronic sorrow as well as she wondered "what was going to happen after public school?"

Beth spoke of how her role as a wife was so different in that they could not be away from the home at the same time as one of the parents always had to stay with their son. Not only was this a problem currently, but it was an even greater problem when she and her son had to live elsewhere in order to have appropriate therapies. This further isolated Beth and her son from her husband. She found the quality of professional care inconsistent and at times inappropriate. Social support became less and less and perhaps negligible when he aged out of the school system. She noted how she has no respite, resulting in *exhaustion* for her. Beth voiced *frustration* with the lack of support throughout his life as she "never, ever had help", "you're on your own",

and that she and her husband do not "have a meal together which is very rare". This was summarized not only as *isolation* but also as *loss of hope*.

The theme of *isolation* also figured in the loss of spiritual support "everything that was preached about did not apply to me" and wondering "why don't You fix this?" She voiced *anger* at God for allowing this to happen. This did not refer only to her son, but also to herself and her lack of options in her life. Beth had similar thoughts about her changing roles and responsibilities in her life as she wondered what her role was supposed to be. She believed God had given her skills, but she was not able to use them. She believed she was trusting in God, but then He let her down. *Loss of hope* for what was happening was also a theme as she "wondered if (she) was supposed to do anything." Beth believed the spiritual family should be much more involved in supporting families such as hers, although she found an exception in one ministerial family who were "extremely accepting."

Loss of hope was also seen in the health status of the mother. She stated, "I just can't do it anymore." She was *exhausted* with the care and the "physical burden." She stated that both emotional and financial areas impacted their quality of life and "were a strain on both fronts."

Themes for Carole

Carole also described f*ear for the future*. She was fearful about what might happen in the future and she "never looks that far ahead." Carole said she "feels like I'm playing 'guess what' and I'm losing." She wondered how much longer she can care for her daughter at home. She stated "none of these things are ever going to change" which also illustrates the theme of *loss of hope*.

Sorrow and *sadness* was something expressed during triggering events when "she would just sit and look at us with kind of a glare like, it just didn't connect." The triggering events included more than lack of meeting developmental milestones as sickness and hospitalizations were noted as well. The mother expressed *fear for the future* and a *loss of hope* as well as a sense of *sadness* as what she saw happening with other children "didn't happen." She was alone with her daughter after her son left home. She is doing funeral planning for them both.

Carole has been alone or *isolated* in the physical and financial care for her daughter. She was afraid about the future (*fear for the future*) when her husband "chose to leave" when she was a year old. Carole was the primary breadwinner after that time, so her role changed of necessity.

She was the only one responsible for care. She had no support in this or in gaining knowledge about how to proceed. Carole recited how she had to "adopt (my) own daughter" as she had no help in knowing what the legal process was to maintain custody of her daughter after she turned 18. She was *exhausted* in attempting to remedy this situation.

Exhaustion and *isolation* also figured into her attempts to get support from professionals and social groups. She "always went through all … by myself." She has "paid caregivers and myself – that's it" when it comes to caring for her child. The *isolation* and *exhaustion* occurred because the mother talked about "no social or personal plans," and little to no time for herself as "the older she's got, the harder that it is."

She did not experience loss of spiritual support. She spoke at length about how helpful, both emotionally and financially, her church family had been and how she believed God had used her daughter in being a spiritual support to others as the daughter managed to push a Bible to someone who was grieving. She spoke of her faith becoming stronger and that it has "made it OK."

Worry and *fear for the future* were constant threads. The mother wondered "how long can I keep her home?" and "How long am I going to be physically able to keep her home?" when she spoke of her age (over 60).

Isolation for both of them was also a theme in her daughter's behavior as she was unable to proceed with plans if her daughter was having a bad day. Her daughter had medication to "keep her from being so intense", but "she's very strong-willed" so plans are canceled. The mother stated that "the older she's got, the harder it is."

She stated that she has few financial options and in order to care for her daughter, she's had to sell things "important to me". She can only afford so much in the way of dental and other health care. She realized they all would have been better off if she could have had more education, but she did not have that option. She has been *isolated* because of definite lack of options.

Themes for Darla

Fear of the unknown was a more distinct theme in early childhood, especially during the time of initial diagnosis. Once the "extent of the disability … became more apparent … it became easier." Darla spoke of "ongoing *challenges* … negatives aren't going away," "don't

know if those barriers will go away. She expressed *resignation* in that she is more used to the supports her daughter needs and the idea that her daughter must continue to live with them as that is the best option now. At this point in time, *loss of hope* is not recognized for this mother, although Darla stated the "negatives aren't going away."

The two terms used most frequently by this mother were *frustrations* and *challenges*. The challenges came initially because of her daughter's grim prognosis. As her daughter grew older, the challenges revolved around the school system. Her daughter also had situational health concerns that demanded attention. However, the mother stated her daughter isn't cognizant of all the challenges and may not advocate for herself. This again makes the responsibility and role of parenting more challenging. Darla spoke of *challenges* she and her daughter faced in professional and social areas and that the *challenges* "would be ongoing for the rest of her life." Initially, Darla spoke of spiritual *challenges*, but she believes those beliefs have evolved although it took some time to grow spiritually. Darla believed that finances will be a continuous *challenge*, especially because insurance will not cover some of her daughter's needs.

Darla spoke about how she and her daughter were initially *isolated* from others after she was born because Darla was told not to take her daughter to places for fear of illness as medical professionals indicated her daughter would not survive if she contracted pneumonia. The mother alluded that she also continues to be *isolated* as she is not able to change their daily routine spontaneously because of her daughter's needs or because her daughter takes longer to get ready. Her daughter is *isolated* as well as she is dependent on others for transportation.

Themes for Ellie

Exhaustion was something Ellie mentioned several times, especially when they found out her daughter had the diagnosis of cerebral palsy. She stated it was "like someone … slapped me in the face" and "it's never going to end … what a shock!" when they were told the diagnosis. From then on, Ellie was involved in her daughter's life as something more than she expected a mother to be as she assumed the role of coordinator of care and therapist for her. Ellie noted how others do not understand the "physical and emotional exhaustion that comes with caring for a child with a physical disability." The *exhaustio*n came because she had so many roles and responsibilities in taking her daughter to therapy and in being with her when she was hospitalized. She said she was "not able to get anything else done!" All her thoughts were "very

sad, very disturbing" as she cared for her daughter. The mother spent time with her daughter doing "hours of exercises ... and she (daughter) cried and screamed."

She felt *isolated* socially as well. She said she would have appreciated "having some time to have somebody to cry with" because, although her family knew the diagnosis, "they don't really understand." The responsibilities "fell mostly on me … all fell on me in accomplishing and arranging for therapies. When asked about who coordinated the care, she replied, "Myself. Me. I. I did all that." She discovered not everybody knows what to do. She highlighted the help one physical therapist gave her in referring her to a physician and how much one nurse taught her. The mother did not note support from the majority of the professional staff and stated, "Nobody talked to us about anything."

She was *frustrated* in trying to care for her and felt *guilty* and a sense of failure that she could not spend time with other children. She also felt disillusioned about Christian behavior as she believed some church members did not demonstrate those values when dealing with her daughter. However, she prayed a lot on her own and "bargained with God" "to make it so she's OK". She was thankful her daughter had "no horrific handicaps". She felt *isolation* from her other children as she spent many hours on exercises for her daughter and her sons "didn't have much time or involvement from … me."

Themes for Fiona

Fiona talked about not giving up hope, of planning for the future, being so worried and not very happy (*sadness*) until her son moved into a group home. It really struck her at that point that he would never move anywhere else, that this was it for him as his future was now his present. She stated, "We gave up on those dreams so long ago." She realized "he will never really travel; he will never have a mate or a relationship ... he will never live any place else." This illustrated *loss of hope* for his future. She essentially gave up on how much she wanted him to participate in the community as a whole as she realized that he would have a better quality of life in a group home than she could provide.

Isolation was another theme as she compared her child to those of others as they were meeting developmental milestones and hers was not. She was concerned about day-to-day tasks such as "trying to keep his body from getting so quirked up that he couldn't even move" … "trying to figure out who would change his diapers and feed him every day … a whole different

world!" She also voiced how she was *isolated* from her husband as they had to take turns attending other children's events so one of them could be with her son. She stated how very supportive her husband was, but that she was the one "from the very beginning" who made appointments and was in charge of insurance claims and anything else that needed coordination.

As time went by, they became more *isolated* from their friends. "People sort of eased away" over time and it "happened so slow that we kind of didn't think much about it." Some of this could have occurred because it "took such extraordinary efforts to get support." It was "too hard to get someone to take care of everything at home so we could go out … that wasn't a priority."

Cross-Case Themes

The most identified themes as summarized from the interviews were *isolation* (6), *fear for the future* (5 mothers), *frustration* (5), *loss of hope* (4), *exhaustion* (4), *sadness* (4), and *financial challenges* (4) as is seen in Appendix E. Other themes identified were guilt (3) and anger (3). All six mothers identified with the triggering events of chronic sorrow occurring in association with not meeting the *developmental milestones*, not only the ones as commonly occurring in toddlers but also those in adulthood such as the meaning behind high school graduation. For some, the child's inability to meet these milestones triggered *fear for the future* which led to *loss of hope*.

Some themes were not identified universally or as clearly. These included the loss of options, loss of self, resignation, acceptance, depression, relief, regret, loss of control, and loss of balance in personal life. Loss of options and loss of control could have been addressed as they occurred for two mothers and could have resulted from similar events. Another sub-theme to that could also be the perception of loss of self and loss of balance in one's personal life. Whether resignation and acceptance were similar was not explored. However, it was not the same as *loss of hope*, although either could lead to that. Regrets could have included guilt and *frustration*. Again, this was not clear-cut, so were not included in the themes identified by the coders. An example shows how the themes were arranged.

Table 4-7 Examples of Themes Summarized

	Allison	Beth	Carole	Darla	Ellie	Fiona

Chronic **sorrow**	**Fear for future** **Sadness**	**Isolation** *(loneliness)* **Fear for future** **Loss of hope** *Loss of control, no options* **Frustration** **guilt**	**Anger** **Frustration** **Fear for future** –> **Loss of hope**	**Fear for future** *ongoing Challenges*	Difficult emotional and physical **Exhaustion** **Physical pain** **Sadness** **Anger** *Apprehensive Overwhelmed*	**Physical pain** *no balance in life* **Loss of hope**
Triggering Events	**Fear for future** Developmental milestones	**Isolation** **Fear for future** Developmental milestones	**Isolation** **Sadness Fear for future** **Loss of hope** Developmental milestones	**Challenges** **Frustration** Developmental milestones	**Frustration** **Fear for future** **Anger**/*hurt* **Loss of hope** Developmental milestones **(***Couldn't participate in activities other children did)*	**Sadness** *heavyhearted regretful* **Fear for future** **Loss of hope** Developmental milestones

An elaboration of the overall findings about the experiences of these mothers is included in Chapter 5.

CHAPTER 5 - Discussion

In this chapter is a discussion the experiences of the mothers with chronic sorrow as they parented an adult child with cerebral palsy. The implications of the findings regarding these mothers are included. An overview of the study will be included as well as the discussion of the research questions and pertinent findings. References will be made to previous research and how this research relates and adds to that literature. Recommendations for health care providers and policy changes are also included. Limitations and suggestions for future research will also be addressed.

Overview of Study

This qualitative study explored the experiences of six mothers in their own words. Each mother was interviewed in a place of her choice. The meeting time including the interview process lasted from one hour to two and a half hours. Initially, they were asked to complete the Kendall Questionnaire, survey questions about basic demographics of the mother and adult child, and a survey about their perception of available resources. They then completed a recorded interview.

The Kendall Questionnaire was included and given before anything else to gather quantitative information about whether or not chronic sorrow existed for them and the extent. Mothers were not excluded if the numerical total did not indicate the mother experienced chronic sorrow as the tabulation was not done until the interview was completed. The demographic questions assessed socio-economic background, the age of the mother, child, siblings, specific health problems of the child including hospitalizations and specific health issues of the mother, and mobility and nutritional issues of the child. An additional survey was adapted to look at available support for the mother, although this was also addressed in the interview questions.

The interview questionnaire was structured to ascertain each of these domains and their relationship to the overall experience of chronic sorrow for these mothers. The interview was organized specifically to address losses identified in the literature review and included the domains of loss of support, loss of roles and responsibilities, and loss of quality of life. Losses of support included consideration of professional, social, and spiritual support available. Loss of

quality of life included questions about childcare, behavior of the child, health care needs of the child and mother, and financial and emotional impacts. Loss of roles and responsibilities included how the mother's role was impacted as both wife and mother and in career. Although not planned, information also was collected about sibling role changes as well.

The interview, which was audio-recorded, concentrated on exploration of chronic sorrow: If the mother believed she has experienced this, if it had changed in intensity over the years, and what triggered it. In addition, interview delved specifically into developmental areas, hopes and dreams, and positive and negative aspects of being a parent to this child.

A second coder was sought to lend objectivity to the process. She had no background in chronic sorrow; however, she had recently completed research as part of a Master's program. She was given training which included specific readings about chronic sorrow and a training guide for determining losses as they were identified in each domain. She also assisted in identifying predominant themes.

Each interview was transcribed with identifiers removed and coders reviewed them individually. After bracketing was done by both coders and agreement was reached on pertinent phrases, the coders also reviewed the interviews again to understand underlying threads or themes of these losses and to come to a greater understanding of the overall phenomenon. Agreement was negotiated and the predominant themes were identified for each mother.

Results were organized for Kendall Questionnaire, survey questions, and interview questionnaire. These results were analyzed individually as within-case and cross-case results. Specific areas of loss were noted in the categories of loss. Themes were also discussed with supportive quotations and findings included for each mother. Commonalities were identified as well as unique variations. Although literature review had identified common areas of perceived loss, additional themes were discovered for this population which will add a more firm foundation to understanding of chronic sorrow.

Purpose

The purpose of the study was to explore the meanings of chronic sorrow. While research has focused on chronic sorrow as well as cerebral palsy, few studies have targeted chronic sorrow among parents and none have researched chronic sorrow among mothers of adult children with cerebral palsy.

As stated previously, this period in the life span has been seriously understudied, both for parents of adult children with disabilities and the adult children themselves. Maternal concerns and adjustments to a long period in their lives spent caring for a child with disabilities which may or may not include intellectual disabilities have not been well addressed. Although more questions have presented during this study, this study begins to explore these maternal responses and concerns over this long period of time from birth to the present time, a period that included at least 26 years. This study will give a different perspective to those who provide care to this population as well as care for both the mothers and the adult children.

Few studies have addressed parental responses after transition from the educational system to community services. Studies involving chronic sorrow do not address, support, or acknowledge that parents continue to be parents of their children with disabilities. Their concerns may be significantly different than the concerns that occupied them when their child was younger. Family dynamics and structure have changed over time. Living arrangements may have changed. Ways of coping with the challenges and stresses in their lives because of the existence of the disabilities of their child may have evolved. Their perspective on life may have changed due to the passage of time.

Also as stated previously, this study was done specifically to better understand the chronic sorrow experience for mothers who have an adult child with cerebral palsy, a long-term disability, in order to see how chronic sorrow exists and has changed over the years since the initial diagnosis.

Summary of Findings

The findings of this study included within-case and cross-case descriptions of how chronic sorrow existed for these mothers. This included identification of similarities and differences as they were expressed by the mothers. Cross-case analysis revealed only two themes that were universal, but several themes were verbalized by the majority of mothers. Universal themes were *isolation* and *fear for the future*. More interesting was when these common themes were expressed. For example, all mothers expressed *fear for the future* when their children were younger, but this was not always expressed as occurring as the child was an adult. Developmental milestones were consistent triggers for chronic sorrow. Ellie's case was very important to overall findings because of the differences in both health status and living situation

of her child from the other adult children. Overall, this study informed the continued development of the phenomenon of chronic sorrow.

Discussion of Findings

This discussion will elaborate on the relevance of the findings of what constitutes chronic sorrow and how it is experienced. First, the definitions of chronic sorrow and questions arising from past studies will be re-examined. Next, the findings of this research as they relate to previous studies will be discussed. Then the subsequent findings and themes of the phenomenon as explored here will be discussed. In addition, how the findings answered the research questions will be included. The definition of chronic sorrow will be finalized for these mothers.

The definition of chronic sorrow used here was taken from Olshansky (1962) and is a permanent and reoccurring experience of pervasive sadness and loss which underlies the life experience and which recurs over time for the parent of a child with developmental, medical, or behavior issues. The review of literature gives samples of the extreme demands placed on parents who have children with disabilities. In particular, these children are at higher risk for morbidity and mortality secondary to their disabilities.

This study explored the presence and components of chronic sorrow that may exist among these mothers. The primary conceptual definition of chronic sorrow was based on the work of Olshansky (1962) which was modified from the original in that one phrase was not included, "*that prevent him from participating in society in a way previously anticipated by parents.* This definition as well as the review of literature helped shape the survey and interview questions. It is possible that this phrase should have been retained as this addresses the *fear for the future*.

One of the characteristics of chronic sorrow in the previously reviewed literature was that it changed over time (Bruce, Schultz, & Smyrnios, 1996; Hobdell, 1993; Kennedy, 1970; Lindgren et al., 1992). The person who coined the term 'chronic sorrow', Olshansky, (1962), stated as a whole that it did not resolve until after the child died. Then subsequent authors claimed that it increased or decreased over time (Blaska, 1998; Burke, et al, 1992; Hobdell, 1993; Hobdell & Deatrick, 1996, Phillips, 1991, Young, 1977).

One of the primary problems with this part of the definition of chronic sorrow was time used as a reference point for the mothers was not the same for each study. Instead, for example,

some studies looked at time for six weeks to two months (Hobdell, 1993; Phillips, 1991). The mothers or parents in the studies about chronic sorrow also dealt with children who were younger such as families who had children under the age of ten, primarily parents of children from 6 months to 6 years of age (Damrosch & Perry, 1989). Children in this current research are between 26 and 38 years of age. This is a quite different encapsulation of time. When chronic sorrow was first recognized, children with disabilities for the most part did not survive until the age of adulthood. Therefore, this study is one that is pioneering exploration of this longer period of time.

There was no consensus among mothers from this study on how chronic sorrow changed over time, only the idea that this experience did come and go. Initially, the mothers all completed the Kendall Questionnaire. Scoring of this questionnaire is "0-38 – no chronic sorrow present, 39-82 – likely chronic sorrow present, 83 and over – chronic sorrow present" (Kendall, 2005, p. 127). None of them scored in the 'chronic sorrow present' category as the highest score was 79 for one of the mothers, other scores being in the same range of 39-82 (42, 46, and two mothers with 67). In fact, when the first interview question was asked to one of the mothers, she indicated that with this definition of chronic sorrow, she agreed she had this experience, and her score was below 38 at 29. This may call into question the validity of the scores from this questionnaire for this population.

Olshansky's (1962) concept of chronic sorrow was that it occurred primarily in parents whose children were most severely disabled and who had intellectual disabilities. Chronic sorrow literature expanded to include how not only parents, but spouses and other caregivers of those with not only disabilities with or without associated intellectual disabilities experienced chronic sorrow. In addition, those caring for persons with specific diagnoses such as diabetes, multiple sclerosis, and Alzheimer's Dementia have also been studied regarding the experiences of chronic sorrow, (Isaksson, Gunnarsson & Ahlström, 2007; Lindgren, Connelly, & Gaspar, 1999; Mayer, 2001; Lowes and Lyne, 2000; McKeown, Porter-Armstrong, & Baxter**,** 2003). This study adds to that body in that not all mothers had children with intellectual disability; therefore, support continues for chronic sorrow not being exclusive to parents with children with intellectual disabilities.

Loss in Chronic Sorrow

All mothers needed no definition of chronic sorrow as it seemed they all understood instinctively what this was. They were given the definition but needed no further explanation of the phenomenon. All answered in the affirmative, although Kendall Chronic Sorrow Questionnaire did not substantiate this as a possibility for the one mother.

Loss of Developmental Milestones: Triggering Events

Triggering events were broken down by developmental milestones specific to individual groups with specific examples of each age given to the mothers. This information was very difficult to quantify, perhaps because five of the six adult children failed to meet an overwhelming majority of these milestones. All mothers used the term 'developmental milestones' and may have become familiar with the term during Individual Educational Plans or therapy sessions. Most mothers jumped ahead and continued to discuss the majority of these milestones together as "she never did any of that" and "never did sitting, standing, walking," "will never travel or get married." The mothers knew other children were accomplishing these things, but it was difficult for mothers to identify with the milestones at all when their day-to-day goals were so different. These mothers compared their children to others with developmental delays who were able to feed themselves as "other children his age there who could walk and talk and be toilet trained (Fiona)" and this seemed to trigger more isolation.

Routine developmental milestones were referred to altogether rather than separately as "it was in no way the same" (Beth) and "loss of her childhood (Ellie)," although some stated that chronic sorrow was worse around the time of diagnosis (Allison, Darla, Ellie). Mothers had a tendency to put the entire school experience together as well, perhaps because as their child aged, all but one child was in a Special Education classroom and may not have progressed from grade to grade. It is not known if this was a self-contained classroom for all of those five. This could have added to the sense of isolation. As Allison said, she was "pretty resolved to the fact that none of those things are going to happen" as she referred to some of the developmental milestones.

These triggering events also were seen in terms of loss, congruent with other literature, that the child has lost those milestones in development (Lindgren, Burke, Hainsworth and Eakes, 1992; Lowes & Lyne, 2000; Senour, 1981) which began with the diagnosis of cerebral palsy.

The loss of the achievement of attaining the typical developmental milestones as it contributes to chronic sorrow is described in the only article found that addressed chronic sorrow of mothers and their adult children with disabilities in general (Blaska, 1998). These type losses were cited by all mothers in this study. However, as stated by Roos (1994), the loss is lived everyday and includes much more than the lack of meeting developmental milestones alone.

Loss of Roles and Responsibilities

All the mothers noted how much responsibility they had for their children with CP. All also noted how exhausting this was for them, and talked about the changing of position and personal care needed by the child throughout all 24 hours, the therapies, the lack of time spent with siblings or the decision not to have other children. In addition, they were supposed to advocate for their child. Beth may have stated it most clearly when she stated, "parents cannot stay on top of doing all the daily grind." The role of spouse and mother changed from expectations the mother may have had before the diagnosis of CP. Beth noted how she was viewed more as her child's mother rather than her spouse's wife as they were not seen together. Darla spoke of how her child would continue to live with them as they would always need to support her. This supported Davis (1987) who wrote of the loss of the tradition role of being a mother as other unexpected tasks entered in that were different from raising the child to take on a responsible role in society. Again, this overall exhaustion, where it might not occur for all these mothers throughout the life span of their child, was spoken of by all, and was strongly emphasized by two of the mothers whose children were more severely affected.

Loss of Support

Loss of support consistently contained the theme of isolation. Mothers were surprised that physicians did not have all the answers and the mothers themselves were going to coordinate care, which these mothers learned to do. Ellie spoke of how "nobody talked to us about anything," another experience that was isolating, which supported previous literature findings (Jones & Passey, 2004: Sandler, 2001).

The *professional support and resources* survey asked for numerical values along a scale of 1 to 5 to indicate availability of resources. The mean value of these scores was 4.12, which should indicate they believed personal and professional management and resource strategies to deal with their child's disability were adequate. This was not borne out by the interview

questions later, but these responses could be more indicative of how they believed their support system was flourishing at the present time and not the overall period of time during which they cared for their child.

Similarities were found in the mother's perception of professional support, although the results were not identical. All had reconciled to the fact that they were the coordinator of care, whether or not they had support from a spouse. The one mother who was no longer responsible for this still had a voice in her son's care although it seemed to her so much less as he currently lives in a group home.

The specialty areas of professionals consistently cited as giving good support were therapists. It depended on which therapy was needed, but physical and occupational therapists as well as speech pathologists consistently were listed as helpful professionals. School nurses were also viewed as helpful and supportive.

It was difficult to tease out whether parents were satisfied or dissatisfied with teachers or school districts. One spoke of lawsuits against the district, another's son went to a specialized school, but all spoke of challenges trying to work with the school system and trying to get adequate services. At this point, mothers continued to want something, anything that would benefit their child. As Fiona stated, "We were showing him words, thinking he was recognizing things ... and working really hard on all that oral communication, which he didn't get." Again, this may be an additional example of how the mothers' role changed as they tried to work with their children on their own in addition to asking the schools to be of help as well. Looming for all was stated by one mother, "What is going to happen when he turns 21?" and even the school system was lost for support.

Social support was initially present. Nuclear families were very supportive, but not all had families to help in the immediate vicinity. Also, as stated by Darla, (some) "family members were more accepting than others." Carole had very little help as she was "left by myself." Allison perhaps had the most social support through the years, but she, together with other similar families, made that possible. Other families noted how their friends fell away though the years or they had no options to be apart from their child for any time (Beth, Fiona) or only for a limited amount of time (Darla). This supported the precept that families with children with disabilities receive no assistance or very little assistance from friends or relatives (Jokinen & Brown, 2005), that the assistance and support they received when the children were younger diminishes over

time (Chimarusti, 2002), and that social contact with friends erodes over time as well (Heiman, 2002). As found in the literature, this lack of social support forecasts burnout for the mother (Christian, 2007) and should continue to be a concern for those who care for these families.

Allison may have recognized how the loss of support could make a difference in her life and others like her, so she was instrumental in developing this type system earlier in the life of her child. Ellie was not aware of any formal or informal system as she stated, "It just would have been nice to have someone to cry with." This supports how important a more formal support system can be to these parents comprised of others with similar circumstances (Taanila, Syrjala, Kokkonen & Jarfelin, 2002), not only when children are younger, but throughout the life span.

Inconsistencies were found in how much support mothers received or wanted to receive spiritually. No common themes emerged regarding loss of spiritual support. Two mothers grew in faith, which may mean they had faith already. These mothers felt supported and strengthened by their faith. Another lost the meaning she wanted to have as she was angry, questioned God, and felt more isolated from her core beliefs. Another stated how disillusioned she was with religion, but that she "bargained with God … to make it so she's OK." Two other mothers noted how their children had found a supportive church home, different in how the children had been raised. Another found a community church after the child was born, but this occurrence was not spoken of as something the family needed to do as a consequence of her birth and diagnosis.

The lack of spiritual support was seen by one mother to contribute to her sense of isolation, but spiritual support alleviated isolation for two mothers. These findings somewhat supported the premise that if parents found welcome from a spiritual place in a faith tradition, "their assumptions about faith in action were affirmed, and their sense of peace and ability to cope were enhanced" (Speraw, 2006). Spiritual support was not seen as essential overall and therefore, cannot be considered a universal loss according to this study, but should be carefully considered according to individual needs.

Loss of Quality of Life

Quality of life was determined by support indirectly and was more directly seen by how much help they had in childcare. This was an area consistently lacking for all mothers. Carole stated, "I don't have much time for myself … always went through all ... by myself." Allison said, "didn't have any other help," when speaking of the time before her son moved out. Beth

looked so tired as she stated she had "absolutely no break whatsoever. Ever." All but one adult child qualified for personal care attendants, but as Darla said, personal care attendants have "been almost more challenging than helpful, but when it's working and we have a good one, it's helpful." Ellie noted how she "couldn't get a lot of things done" as so much of her time was taken up by either taking her daughter and the siblings to therapy or in doing home exercises herself when her child was younger. This definitely relates to social support available, but is more narrowly defined.

Several mentioned how rarely they were able to leave the home, whether for worry about what health catastrophe would happen when they were gone or because they had no one else to care for their child. As Fiona stated, "We hardly did anything social because it took such extraordinary efforts to get support." Just making sure someone was home to assist the child off the school bus took a great deal of planning for her.

Again, when the child was 21 and no longer in the school system, the lives of these mothers had to focus differently and return back to the minute-to-minute care. Fiona made the decision to place her son in a group home as "he needs a better quality of life than I can offer." Her experience has been positive thus far which did not support the premise that the mother experiences guilt when this type decision is made as Heller, Hsieh, & Rowitz (1997) suggested mothers might. However, Fiona's child had much greater needs, which did support the study which stated children with greater needs were more likely to change living situations after parents found the caregiving burden too severe (Heller, & Factor, 1993; Prosser, 1997). Both Beth and Carole made that decision as well for similar reasons, but it did not work out for diverse reasons as their child's health worsened after placement. Both brought their children home. In both cases, they noted frustration and spoke about how they could not plan their lives apart from that of their child, so the premise that further loss and frustration occurred because of the additional loss of freedom was supported (Rapanaro, Bartu, & Lee, 2007). Both these mothers had concerns about services received by their child in the group home and believed they did a better job of protecting them and keeping them safe, which supported findings by previous studies (Grant, 1990; Grant, Ramcharan, McGrath, Nolan & Keady, 1998; Heller, Hsieh, & Rowitz, 1997). Both Beth and Carole spoke of their concern that their children would outlive them, a topic found in Grant (1990).

Darla's adult daughter could perhaps live elsewhere, but because of transportation and other issues, she continues to live at home with nothing else foreseen as "it is easier for her to live with us for now." Staffing was arranged for another child to live independently with supports. Yet another child lives completely independently and is able to participate in society, has a career and available transportation with an adapted vehicle. Those children living at home have mothers who believe their adult child is safer at home and that others could not adhere to the high standards they had for their child's care, further supporting the premise in Grant, Ramcharan, & Flynn (2007).

Another problem that could decrease the quality of life for the mother is the behavior of the child. This was not validated by Ellie whose child was very high functioning; however, Allison, Beth, and Carole all noted behaviors that had worsened as their children aged. As Carole summarized, "The older she's got, the harder that it is." Darla noted how much more slowly her daughter moved than did others and how much time had to be allotted. Again, all parents but Ellie, who had the daughter highest functioning, experienced behavior problems of varying severity.

Personal health also impacts quality of life. It is a possibility that maternal health could be affected as stress affects the immune system. Caring for a child with multiple physical disabilities which demands much physical exertion by the caregiver is also a potential risk factor for maternal injury and pain. However, these findings were inconsistent here as they also were in a previous study (Brehault, Kohen, Raina, Walter, Russell, & Swinton, 2004). Two mothers (Beth, Carole) had some physical discomforts and one had some illness (Darla), but this cannot conclusively be linked to the expectation of either immune of physical problems for all mothers, although it stands to reason that those who must do physical manipulations in caring for their children could face more risk of pain and injury, especially as they age.

Concern about health care needs for a child can also impact quality of life. At the time of the interview, Beth, Carole, Darla, and Fiona had concerns about their child's health status. Although Allison's son has many risk factors for significant morbidity, he has not been ill to this point. Ellie's daughter does not have the major risk factors such as risk for aspiration pneumonia as do the other children because of the differences in nutrition and mobility. The occurrences of seizure activity as well as infections have been significant health concerns for the majority of the others.

Finances were not seen as major concerns for two mothers; however, they are and have been for the other four mothers. As Fiona stated, "I don't know anyone who can afford that! … There aren't enough resources or of a family's income!" Supplies needed for mobility, nutrition, or elimination are costly and must be paid for. Typical babysitters are not useful to 'babysit' an adult. Specialized caregivers cost more. If a mother wants her child to participate in the life of the community, it takes more time and more resources. Otherwise, the child and mother are both isolated. Allison stated that some people might not view the services her child receives in a positive way. This supports concerns voiced by Savage (1998) that children with disabilities may be viewed as "burdens and leeches on societal resources" (Savage, 1998, p. 58).

Quality of life issues and financial solvency also relate to career or job opportunities. The lack of career opportunities or the necessity of making career changes may be fueled by lack of finances or health insurance, or lack of caregiving assistance or respite case. Carole experienced chronic sorrow about her daughter's situation, but also was sad that she was not able to go to college as she had wanted to do. Beth had a career, but was not able to practice. Fiona made a career change with the help of her family, but after her son 'graduated', she would not have been able to continue unless his living situation changed. These mothers did not have options and have had to make difficult decisions, either to abandon their career dreams, change their career, or to change how or where their children would live. Therefore, some mothers have accepted that the time for a career of their own may never occur (Birenbaum & Cohen, 1993; Green, 2004; Knox, Parmenter, Atkinson & Yazbeck, 2000) or have changed their ideas of what their career or job is. Three mothers are currently in careers working with others who either had children with disabilities or with their parents. This may have occurred because their unique experience is valued and also because initially these careers were flexible (Klein & McCabe, 2007).

This study may be unusual in that at least three of the six mothers were working with either the parents of children with disabilities or directly with children who have disabilities. Two are working in health care. It is not known whether or not their choice of career was impacted by the experiences working with those in health care who worked with their daughters. Two of the mothers have other children who made their choice of career based on the experiences with their siblings with CP. Since no question directly asked how experiences with sibling impacted the life of the sibling(s) without CP or how the career choice changed for the mothers are other areas which need further exploration.

Themes

The major themes were isolation (6), fear for the future (5 mothers), and loss of hope (4). Themes of emotions and experiences also common were frustration (5), exhaustion (4), sadness (4), and financial challenges (4). Other themes identified were guilt (3) and anger (3).

Other themes discovered but not well explored were loss of options, loss of self, resignation, acceptance, depression, relief, regret, loss of control, and loss of balance in personal life. These were not universal themes, but had there been different questions, more information about these could have been forthcoming.

Isolation

Isolation was one of the themes pervasive throughout the interview topics. This occurred for all mothers when speaking of their loss or change in roles in responsibilities. Caring for children by default went to these women. However, it is also possible that if men had completed the same interview, they would believe similarly. There are so many responsibilities when parenting a child with numerous medical and physical problems that both parents could feel overwhelmed, exhausted, and that they were doing the majority of the work and assuming this type responsibility.

Isolation also occurred for several of the mothers socially. This also affected their quality of life as childcare was less and less available. According to their accounting, this became more evident as their child grew older and care was perhaps more complicated and complications more severe. This supported previous literature about how the demands of the day-to-day care led to isolation, although previous studies dealt with a much younger child population (Emerson, 2003; Heller, Hsieh, & Rowitz, 1997; Hirose & Ueda, 1990).

Behavior of the child also resulted in maternal isolation as socially the activities in which the mother could participate were necessarily fewer. For instance, behavior such as the adult child not understanding social boundaries and approaching strangers to hug or otherwise physically touch them could be seen as inappropriate for those who did not know the child or family. It might be easier for the mother and child to avoid this type confrontations altogether and further withdraw from the outside world. It is also very probable that this isolation for the child increased as well as age peers grew apart from the child.

Kendall (2005) included isolation as part of her definition. Her definition of chronic sorrow was:

> The experience of profound sorrow, not unlike intense surges of grief and sadness felt at the time of the initial loss, the experience of invalidation, including social isolation, feelings of unfairness, and lack of voice, or the perception that one is not 'heard' by others; and the state of feeling physically overwhelmed, exhausted or vulnerable (Kendall, 2005, p. 47).

From the responses of the mothers in this study, the part of the definition speaking to the "social isolation … lack of voice" as well as the "state of feeling physically overwhelmed, exhausted, or vulnerable" is well worth keeping and including in future definitions about chronic sorrow. These findings also support the idea that support systems decrease for both mothers and children as children age (Lin, 2000).

As Davis (1987) noted previously, the ongoing grief felt by these mothers is one withheld from the society at large. It may be easier and less isolating to spare others the pain and concerns that are so much a part of day-to-day life of the mothers of children, no matter what their ages may be. The emotional detachment society expects may be a façade built over the years. Again, as Davis (1987) stated, these mothers have entered "a community (usually invisible to others) of people who are permanently changed by suffering, by grief" (p. 357). It is an ongoing problem that families with children who have disabilities continue to be isolated from others in the community (Umberger, Stowe, &Turnbull III, 2005).

Exhaustion

Another common theme was *exhaustion*. This exhaustion may have been psychological as well as physical as they worked to understand why their "child had to suffer" (Beth). But it must also include the constant care these children required. As Ellie stated, "I was exhausted, pretty much all the time." Each mother spoke of the therapies they had to do in addition to other requirements for their child. For some mothers, the caregiving burden increased as their child grew older because they had to physically change his position, change adult diapers, and maneuver their child for transportation and feedings. Positioning an adult who cannot help himself into a wheelchair that may or may not fit the body contours is very difficult when no additional help is available. Lack of sleep was referred to by Beth and Fiona specifically.

Fear for the Future

Fear for the future threaded through several of the areas of loss. This was most evident during earlier childhood when mothers did not have a definite idea of the future and what the diagnosis of cerebral palsy meant to their child or to them. Ellie did not know what was wrong with her child, and when physicians eventually explained her child had cerebral palsy, she said "I literally just fell into the chair. I was so – oh my god! It's never going to end!" The fear for the future was found when mothers discussed the experiences of chronic sorrow, the triggering events, their roles and responsibilities now and over the years, and all aspects of quality of life including both their health and that of their child's as well as behavioral issues of their child and financial concerns. More notable was that no mother ever expressed excitement for her child's future and, in four of six interviews, no hope for her own future was noted.

Loss of Hope

Loss of hope appeared to arise from *fear for the future*, but experiencing fear for the future did not mean the mothers definitely experienced loss of hope. Past studies spoke of mothers achieving resignation, acceptance, or adapting (Young, 1977), but these terms do not mean loss of hope. Cyclical hopelessness was also viewed as a component of chronic sorrow (Kearney, 1994; Phillips, 1991), but this study did not show that all mothers experienced hopelessness or loss of hope. Some hopelessness was noted by Johnsonius (1996) in two of three study participants when the caregivers did not see how the health of their chronically ill child would improve; however, hopelessness at intervals is not the complete *loss of hope* found in this study in three of the participants.

It is not death or the final loss, but it is a type of death, the death of dreams and hopes. For some, loss of dreams will lead plans for the future in a different direction when options are available. In cases for some of these mothers, no further dream or option is available, which is what makes the sorrow in this situation so close to that of the grief in death, except it is ongoing as death of the individual has not occurred. Death can be anticipated, which is how Carole is viewing it, death can be an on-going concern as it is with Beth who worried if they left their child, something drastic would occur, or death could be ignored. Nonetheless, the loss of hope for the future was a theme strongly evident in three of the six mothers.

As stated previously, parents exist in a paradoxical universe, knowing the disability of the child all too well, but believing and hoping for something better for their child in the future (Larson, 1998). When that hope of – something or anything – better for the child is gone, the perspective of the losses is different. Loss of dreams for their child may have a relationship to the loss of hope. The ancient saying, 'where there's life, there's hope' by Cicero, is then no longer true. This should not be equated with sadness or depression, although components of either of these could be present. Although this sense of profound loss may lead to grief, it is also possible that it can give a sense of relief as the mother finally can do no more other than what she does routinely. It is far more intense than acceptance of the situation, and perhaps this is because the loss is seen as almost the final loss. This may be facet of chronic sorrow needing further exploration.

Research Questions

The research questions have begun to be answered. The definition of chronic sorrow has evolved to be not only a permanent and reoccurring experience of pervasive sadness and loss which underlies the life experience and which recurs over time for the parent of a child with developmental, medical, or behavior issues that prevent him from participating in society in a way previously anticipated by parents. It also includes the coming and going of exhaustion, sadness, isolation, fear for the future, and perhaps loss of hope. These mothers recognized chronic sorrow immediately when given the sentence beginning the interview: Some parents have described a sadness that can occur when they think about their child with a disability. Parents can believe they are functioning well, but have times where they feel the loss for their child. When I read this definition of chronic sorrow, I emphasized loss and saw instant understanding in the mother's eyes. Whether the phenomenon increases, decreases, or stays the same over time is an individual perspective. It is not yet clear what specifically influences how the experience changes over time. However, the phrase "that prevent him from participating in society in a way previously anticipated by parents" should be included as it addresses fear for the future, a common theme. Triggering events were universally times or occasions of perceived developmental milestones.

Where the adult child currently lived might affect chronic sorrow. For instance, perhaps as the caregiving duties decreases, chronic sorrow might as well. But it does not disappear.

Neither Ellie nor Fiona's child lived with them, but they both experienced chronic sorrow. One of the themes found for Beth, Carole, and Fiona was *loss of hope*. For these women, their children's living situation didn't decrease chronic sorrow. However, for Allison, the possibility existed that her child's living situation did make a difference for her. Her chronic sorrow score was lowest, and she evidenced relief that her adult child could live apart from her and had an adequate support system.

The overall health, behavior, and need for supervision of the adult child might also contribute to chronic sorrow. All but Ellie's child required some type of supervision the majority of the time if not constantly, although two of these adult children did not live with their mothers. Concern about their children can be exhausting emotionally and direct care can be exhausting physically. Certainly *exhaustion* was a theme encountered frequently. More in-depth information about the psychological and emotional issues with which these mothers deal would be of worth.

The health of the mother did not relate to chronic sorrow in this study. However, it is more probable that the age of the mother did. Two mothers verbalized concerns about how they were going to continue to care for their child as they aged and another made a decision to place her son in a group home.

Adequacy of support is another contributor to chronic sorrow. Only Allison stated her support was adequate; however, she was very active in a parents' support group and this group as well as family provided support either in the past or currently. Neither Carole nor Ellie was aware of any support group; Allison, Beth, Darla, and Fiona were. The primary support groups ended when the child no longer was in school. Parents might no longer know the other mothers after that time. The state-wide support group ends for parents when their child is 21 as well.

Professional support is one aspect that the mothers seem to develop as their child grows older. They learn which health care providers with whom they can work. These mothers learned they had to become the managers of their children's care.

These losses as discussed in the study did impact the overall quality of life for the mother. The individuality of the mother, the resources and support she had impacted her life experiences. The focus of her life centered on providing care for their child if the child lived at home. The focus changed if they were not responsible for direct care, but no relationship was found in this sample between that direct care provision and presence of chronic sorrow. Also,

looking back at the individual interviews, no mother ever voiced sorrow at being this child's mother, but all mothers found reasons and examples of how the experience was beneficial.

Unique Contributions

This is the first study to explore chronic sorrow for mothers of adult children with cerebral palsy. It confirmed findings of previous studies about chronic sorrow, but it also contributed new themes of *fear for the future* and *loss of hope* to overall understanding for these mothers. This study also included Ellie, a mother whose child functioned much higher than the other adult children as the child was living independently. Ellie believed she experienced chronic sorrow. This is important as her contribution illustrated that the adult child's functionality does not preclude mothers experiencing chronic sorrow. Beth and Carole were also unique in that both of them attempted placement of their children in a group home setting and both decided it was not in the best interest of their child to continue in that arrangement. Another unique contribution in the study was that the mothers looked at their experience being parents to their child over a much longer period of time than previously described in the literature for this population.

Study Strengths and Limitations

Study strengths included focusing on the mothers' personal experiences with chronic sorrow in their own words. Another strength of the study was the overview of the chronic sorrow experience over a length of time previously not described in the literature. Also, no previous studies have concentrated on mothers of adult children with cerebral palsy.

Limitations of this study are the lack of random sampling. Data obtained in the Midwest US could be significantly different than data obtained in other locations. It was planned that mothers interviewed would have been dissimilar in education, employment, and experiences with their child which was only partially the case. I also hoped to sample different ethnicities which did not occur. It may not be possible to replicate the analysis by others who have a different background (Bradley, et al.) as "overly mechanistic approaches or reliance on inexperienced qualitative analysts may dampen the insights from qualitative research" (Morgan 1997 in Bradley et al., 2007).

Both a strength and a weakness is the concentration of mothers of adult children from only one diagnostic group. Whether all adult children should have had an intellectual disability

to further add to homogeneity was a consideration; however, to have a variety of disabilities with the same overarching diagnosis could be a strength of the study as well. Another strength of the study was that the interviewer was also a mother of an adult child with multiple disabilities. This made it easier for these mothers to share information.

The general nature of qualitative research is also a strength and weakness. Data obtained from the surveys was only somewhat useful. The information from the interviews was richer and revealed more about what the individual mothering experience comprised. Themes could not have been identified otherwise.

Implications for Practice

One of the major findings in this study is that chronic sorrow continues, whether or not the adult child has associated health problems. It may be easier for providers of health care and friends to believe the mother has accepted her child's disabilities and the associated day-to-day details of life. In truth, this did not seem to be the case. They may be better at functioning for the public over time, but when asked, the majority of these mothers expressed concerns and fears they had through the years. Only one person spoke of planning for death for either her child or herself, but others wondered how they could continue to care for their child, either because of the child's physical or health problems or because of their advancing age and declining abilities. Mothers cited few options available, although one believed a sibling would be a guardian if needed.

Friends and family as well as professionals may need to be proactive in finding adequate care and funding. Mothers themselves may be approaching burnout and not always be able to advocate for better funding and care. Respite care for these mothers should be a priority, which will take legislative muscle. Considerations of how resources are distributed will be needed as well as reexamination about the worth of those who have multiple disabilities and their caregivers.

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Friends and family as well as professionals may need to be proactive in finding adequate care and funding. Mothers themselves may be approaching burnout and not always be able to advocate for better funding and care. Respite care for these mothers should be a priority, which will take legislative muscle. Considerations of how resources are distributed will be needed as well as reexamination about the worth of those who have multiple disabilities.

Parents

As the child comes to the end of his time in the educational system, parents may be caught off-guard as services to which they are accustomed are withdrawn. Services on a day-to-day basis may be gone completely depending on how early parents have accessed the system and how long is the waiting list for services.

Some parents may live in the here-and-now and have difficulty imagining a future for their child after contact with the education system is over and may not want to think what that future might be like. Parents do not understand how support will change after child is 21 and out of school. Because of this, the educational system should be in the forefront of guiding parents to understanding of how lives will change when the child exits this system. Before the network of support dissolves, it would be very helpful to offer opportunities for parent connections through the school system. They may not understand that not only the child, but also the parent will transition to a difference in daily activities, possible employment, or the need for additional childcare options. Visiting with parents whose children have left the educational system may be much more useful than educators informing parents of possibilities; however, educators could facilitate parents coming to give information about transition and their personal experiences. Support should be available for mothers after the school experience for the child is over. As Beth said, "I was always very concerned about what was going to happen after public school and it's been much worse than I ever thought."

Another possibility in finding future support for parents could be through support groups such as Families Together. These type organizations could ensure parents have some type

contact list of other parents in their geographic locale before this support is no more. Although these lists have been provided to participating parents in the past, it is possible that parents fail to understand the importance of keeping these contacts current. Emphasis must be provided as to why these contacts need to be continued. If a parent could be designated to provide periodic contact via email or social networking, it is possible that those who are not used to taking the initiative could remain in touch with other parents.

In addition, other networking opportunities can exist in social webs such as Facebook or in blogs. With this type social networking available, concerns and challenges could be shared frequently which could be an advantage and would increase social support and understanding, decreasing some of the perceived isolation. As it was noted in this research by Ellie, at times parents need someone with whom to cry. Beth also stated that she received the best information from parents who have been there.

Parents want to be good parents of all their children, but the child with the very emergent needs may take parental time away from attending events of other children or from undivided attention from parents. Both Ellie and Fiona expressed feelings of guilt and failure regarding the lack of time or energy available to spend with their other children. Experiences of other parents may be useful in helping understand how to schedule time or to continue to communicate with the siblings.

Families and those involved in caring for the child with the disability must understand the lack of options, the exhaustion and isolation, and the fear for the future inherent in family functioning. Recognizing symptoms of burn-out early could preserve these families. Friends, family, and professionals must be involved in advocating for their needs. This would lead to better delivery of services for those who live apart from parents and better options for those who parents can no longer do the really heavy lifting, emotionally and physically. Mothers cannot care for their children and advocate for services. As Beth said, “parents cannot stay on top of doing all the daily grind” and “I’m supposed to stay on top of, I’m supposed to go to the capital and advocate.” She was already exhausted and did not know how to do any more.

Policy

As funding for education decreases, school nurse positions have been eliminated. Both Fiona and Beth noted the help and useful information provided by school nurses experienced in caring for children similar to theirs. These positions are not optional. Children with CP

experience many health challenges. The school could be liable for not understanding symptoms of silent aspiration or various types of seizure activity. School nurses are invaluable resources and their positions in the school should be maintained. In addition, paraprofessionals and teachers need information about specific disabilities as well.

Training for community, whether volunteer or jobs, is important for these adults. This occurs as part of transition planning in the educational system, but if this training is not reinforced after time in school is over, the training may be underutilized or not used at all. If opportunities are not available, appropriate or possible, these adult children need supervision and care. At this time, the waiting list for services continues to grow each year. Those children finishing school may not have services available by the time they are needed (Ranney, 2010). Even when the services are available, they may be insufficient as they were for Beth, Carole, and Darla.

The training for professionals who will work with the parents and their *adult* children must be expanded to include professionals from multiple fields as adults transition to the community. Professionals must be able to work closely with the parents and recognize their unique contributions to the quality of life for the adult child. In addition, professionals need to acknowledge the parents as the people who know most how to work with the child and can identify the early signs and symptoms of health problems.

Mothers need more help coordinating care, especially during those first years of chronic sorrow. Ellie was not informed early on about her daughter's diagnosis and did not know her options. She spoke about the emotional and physical exhaustion that went with coordinating the therapies and then providing the therapy at home as well as the other cares her daughter needed.

Funding should be available for respite. This involves having someone who can care for the adult child at times both during the day, weekends, and evenings. They must be adequately trained and compensated. All mothers who provided direct care for their adult child noted how difficult it was to plan anything apart from their child.

Policies supporting mothers and families should be in place. In the state of Kansas, more than 5700 people with disabilities are on the waiting list for services, approximately 2000 of whom are receiving limited services and 3,800 who are on the waiting list for services (Ranney, 2010). Services now provided may not be the most appropriate and need to be provided

according to the needs of the individual and family. Problems existed with supervision and safety for both Beth and Carole and they removed their children from residential care.

Legislators must be given opportunities to be in closer contact with both parents and their children with disabilities. They must have a face and family with whom to connect when funding is challenged and they must develop priorities which include care for the most vulnerable in society. Ignorance about repercussions of their decisions must not be allowed. One legislator was informed in detail about the problem when he met with Carole. He was able to intervene on her behalf and learned first-hand about the system-wide difficulties this parent encountered.

Many adult children with disabilities have a Medical Card after they are 18 years of age. Some physicians do not have room in the schedule for someone who requires in-depth care such as those with multiple disabilities. In addition, their business practice may be full so that they no longer accept those with Medical Cards. Reimbursement to health care providers for care of those with fragile and complicated health conditions needs to improve. If this is not possible, special training for nurse practitioners would be very useful as typically, these advanced practice nurses can spend more time with individuals which is required for those who need in-depth assessments.

Practitioners

Students in university programs such as Family Life Education would benefit from learning about needs found in this population. Educational emphases may be quite different to prepare to work with parents such as these. Parents do not have time off, cannot sleep through the night consistently, nor do they escape from day-today responsibilities. Both physical and mental exhaustion occurs. Isolation and problems contending with thoughts about the future were common in the population in this study and should be investigated by practitioners before additional suggestions and demands are placed on their time. Tools and methods to combat these should be developed.

Because nurse practitioners can allow more assessment time, it may fall to them to provide care for those who have complex and challenging health care issues. Schools of Nursing preparing adult or family practitioners should include increased content in learning about parental concerns as well as adding to their baseline knowledge of congenital disabilities. Of utmost importance is learning about how the disabilities impact family life. Panels of parents may be helpful in providing a perspective to those in health care.

Chronic sorrow should not be ignored as if it does not exist. Instead, practitioners should recognize the struggles families face everyday and give them credit for battles in which they are involved. Practitioners should also keep up-to-date in treatments and subsequent potential effectiveness for specific populations and corresponding disabilities. Parents continue to look to health care professionals for options. According to results from this study, parents have been disappointed.

Those in health care must recognize that parents are the ones responsible for complex care on a daily basis. The parents usually know much more than the practitioner about methods or medications that are effective for their child and their input is invaluable. However, since they have been on-call for their child the majority of the hours in the day, burn-out could be anticipated. After additional research is completed about signs and symptoms of parental burnout, practitioners require further education to provide anticipatory guidance.

Planning for who will follow children with disabilities as they become older should be done because parents may not be sure who will provide medical and nursing care. The pediatrician may have been someone who knew the intricacies of caring for their child and arrangements which must be made to transition care to another practitioner. Arrangements should be investigated before the child becomes 18 as some practitioners may not be comfortable caring for an adult child with disabilities.

In addition, if the child has a Medical Card, it may be more difficult to transition care to other care providers as not all providers accept this method of payment. In particular, the majority of dentists do not accept Medical Cards. Dental care should be available to adults. Mothers cannot always pay in cash as Beth had to do. Nutrition is necessary for life and good oral health is imperative to the ability to eat (Masterson, 2004). This population is also at high risk for aspiration pneumonia, a condition with increased risk for those with poor dental hygiene (Cavallazzi, Vasu, & Marik, 2009**;** Scannapieco, 2006**).** This would help mothers such as Carole who scrambled to find cash for dental services to repair her daughter's teeth damaged by a seizure and subsequent fall.

Recommendations for Further Study

Numerous questions exist about parenting issues for children with disabilities. For example, what about their past lives do mothers value in relationship to their child with

disabilities? Another question that would have been useful would have been 'What help would have been or would be useful to you?' Ellie talked about how she did not understand what was going on with her daughter after she was born: "Nobody really talked to us about her, nobody talked to us about anything that could be wrong ... except the neonatologist told us that she'd probably be a vegetable." Ellie did not feel she had support from anyone other than the physical therapist and found that she was going to have to manage care for her child which surprised her.

The type of insurance each adult child had as well as whether the coverage was adequate to meet the child's needs was not included. This should have been added to the demographic information.

It was quite difficult to maintain control over the information in developmental milestones and the associated experiences of chronic sorrow. This sequencing of the interview questions may work for mothers of children whose disabilities are less severe. For this population, more information may have been gained about severity of triggering events if one of the categories of triggering events had been 'event or time of diagnosis of CP', a phrase recommended for future studies.

Again, it is possible that this study's results might have been quite different is the population had been comprised of those with less severe disabilities; however, it must be noted that one of the more disabled adult children was employed and living with supports and is employed part-time with supports, the least disabled had a career and post-college education, and another has a certification and is employed part-time.

This study does not address whether chronic sorrow is experienced by caregivers such as siblings or aunts. This would be an area for further research as well.

The major findings of loss of hope should be expanded. How does the loss of time with the child's siblings or the decision to not have additional children affect mothers? How did they arrive at their choices to have or not have another child? What would the parents change? How have the stressors in their lives changed? Although the interview questions included positive and negative aspects of parenting this child, little information was gained. Perhaps if the questions spoke more of the family, more information could be attained. For example, the question could have been "How has this experience affected your family?"

One of the drawbacks in the study was a lack of understanding about spirituality. I did not explain it well to the participants who seemed to take it as a church or denomination, not

their idea of the power behind their everyday lives that may cause illumination of the problems they work with. This merits better work and exploration of this idea alone. How or if loss of spiritual support is different from social support as it was initially conceptualized is unclear. Unless spiritual support has a better definition, it would be more helpful in the future to study it as a whole included with social support.

Another facet not examined directly in the research was how the diagnosis of cerebral palsy changed their life trajectory relating to career choice. No question specifically addressed the different paths that may have occurred for these mothers although at least four mothers changed career or education after their child was diagnosed.

It would have also been of interest to examine how the mothers saw themselves. Many mothers may feel they are identified as their child's mother and have little identity of their own as they raise children. One of the themes identified with one participant was 'lack or loss of self'; however, this was not replicated in other interviews or themes. This is a subject that could be better explored in a qualitative fashion in the future.

Cultural facets should also be explored. For instance, the idea that children with disabilities are a special gift from God as spoken of by one participant was linked to the specific religious culture of Latter Day Saints and borne out by Marshall, Olsen, Mandleco, Dyches, Allred, & Sansom (2004) in a fascinating research article about that culture and how children with disabilities are viewed. Other cultures within the United States would be of interest as well. How those with disabilities are viewed in different cultures was briefly examined in the review of literature; however, this population was based in the Midwest and so did not add to this knowledge. In addition, studies involving other ethnicities and locales could add to this to increase understanding of the phenomenon.

Studying the families of those who have children with disabilities is the foundation of future research. How family support, dynamics, and structures evolve due to the child's disability compared to those of typical families would give better insight to those working with families such as those included in this study.

It is important to recognize how families utilize support. What supports are available to them? Is there a point at which it is easier for families to remain isolated, and are families so used to social isolation they do not know how to ask for help, or are so used to having no help they cannot recognize when it is offered? What types of support would families accept if they

were available? As Darla noted, when home help was available and consistent, it was very helpful, but that was not the normative experience for her. Would families utilize group meetings or web-based contacts or would those be one more thing they could not take advantage of due to time restrictions?

Family functioning and patterning may of necessity be quite different depending on the needs of the child with the disability. The knowledge of how families change in roles and responsibilities over time would be useful for anticipatory guidance. Fiona stated her child's siblings helped care for her child as did Allison's and Darla's sibling. Little information was received about how Ellie's or Carole's children helped care for their siblings. How siblings are incorporated into care for their brother or sister and their responses to their increased responsibilities would be helpful to understand in order to again provide further anticipatory guidance to the family after initial diagnosis of a disability. How others can be incorporated into support for the family would be useful as well. If how this occurred was better understood, the family could be better prepared with supports already in place especially as the child's need increase.

How siblings react as they grow is also of interest and relevance. It is not known if their position or gender compared to the rank of the child with the disability differs. Many grow up with the expectation or necessity of them helping with care. Their perception of burden may cause behavior or scholastic problems. One older child's career choice was influenced by her sibling's disability; however, in this study, two mothers believed their lack of availability and attention influenced siblings in a negative way. Many years ago, a camp specifically for siblings of those with disabilities was organized, but was not continued. One year was not enough for these children to recognize the possible support and connections they could make with other children who had similar issues. Parenting is challenging in the best of circumstances. Parents of children with disabilities may need ideas on how best to contend with these and not lose connections with other children.

Parents may assume other siblings will continue to care for the child with disabilities if they are not able to do so. Darla mentioned that her other child would assume guardianship if the parents were no longer able to do so. Whether this knowledge is explicit or implicit merits further study. In addition, studies about sibling plans for care as they parents age or die would be

very important. This would include how daughters-in-law may become the caregiver when brothers are the available sibling.

Parents may pull together or pull apart. Carole's husband left the family because of the child's disability. Ellie's family also suffered a break-up. It is not known how completely relationships between significant others change. This vital support within families may be missing even if the relationship holds together on paper. If parents separate or divorce, did the advent of the disability influence the change in their status?

Behavior of the child with the disability could also affect family dynamics. Three of the mothers in this study indicated their children's behavior was more challenging as the adult child aged. Whether this is significant to parents of adult children with disabilities other than CP is not known. Also, it is not known if this behavior change is typical in adults with CP.

Future research on parental perceptions of transition from the educational system would be helpful to realistically base future program development. A longitudinal study would be best beginning with parental perceptions of how useful transition planning is and ending with their perceptions of how realistically it prepared them for their child's life after involvement in that system. Another option would be to complete multiple studies done at different points in those transitional years.

Implications for further study surround families who have children with disabilities. Parents have many other needs not otherwise addressed beginning while their children are in the educational system. Beth made it very clear that she believed the needs of the child were no longer considered after the child was no longer eligible to stay in the educational system. Education mandates that transition planning begin at age fourteen; however, planning for the future may not seem as if it is a priority. This transition planning may be addressed on paper, but it is not known how much parents understand of the impact transition planning should have. At this point, parents may not understand they must utilize the support within the school system to prepare for future realities. Parents may not understand how their support will change after the child leaves the educational system and may have so many responsibilities day-to-day that the future seems almost impossible to contemplate. How they respond to professionals working on planning for the future and how based in reality the parents perceive planning to be should be examined.

As children with disabilities live far longer than expected, research will need to be increased to deal with the different problems posed by those with disabilities. Instances exist where parents cannot maintain care of their child, which happened for Fiona. This could occur because of increased needs for the child with the disability, aging or health problems of the caretaking parent, or multiple other family concerns.

Families may become more and more exhausted and may not realize they can no longer care for themselves or their families until they burn out, an event that may have been demonstrated in Beth. This is a specific area that demands attention. How burnout manifests itself could vary widely; however, professionals in the healthcare system and in education need to recognize that it does occur. Those involved in family support such as friends and extended families also need guidelines to recognize burnout and so they can intervene. Unfortunately, families at this time have few options, even for short-term respite or care as respite funds continue to be cut or eliminated, group home options may not be available, and other residency possibilities are closed to new admissions.

Additional areas of recommended study include research to enlarge understanding of this phenomenon as it pertains to mothers and fathers of adult children with other disabilities such as autism and schizophrenia. Studies of both parents of adult children with disabilities whose children are between the age of transition from the educational system and age of 25 would also be beneficial. Also, the research has not addressed chronic sorrow for fathers in this age group. Neither have grandparents for children with disabilities of any age group been studied regarding their reaction and perceptions of the challenges facing the parents in raising a child with disabilities.

Practitioners

Research should be done to identify the baseline knowledge educators and health care practitioners have on caring for those with disabilities before additional demands are placed on their professional practice. Additional information should be gathered from parents outlining what they wished practitioners knew. When baseline assessments of what is currently known about what is taught is complete, then courses of study could incorporate additional foundational knowledge about disabilities and how to work with parents who have knowledge the practitioners do not.

How training of health care personnel could be improved is another area worthy of exploration. Parents who have experienced their children's hospitalization should be queried about what was helpful, what was not during these episodes. This would include how they involved in decision-making, if they wanted to be involved as well as their perceptions towards the professionals about knowledge of their child's diagnosis and understanding about appropriate care.

Again, knowledge about danger signs for parents and families should be expanded. Unless educators and health care practitioners have better information about signs and symptoms of burn-out, these symptoms can be missed. Therefore, research aimed at identifying these as they develop could be extremely beneficial, especially if the research is organized to address ways to alleviate these symptoms and methods identified that families have used successfully or unsuccessfully.

This study began to examine chronic sorrow in mothers of adult children. Allison, Ellie, and Fiona's children did not live with them, although living situations of the children were dissimilar. Allison's score from the Kendall Questionnaire were the lowest of the group, but she did indicate she experienced chronic sorrow. Ellie's and Fiona's scores were similar which indicated their sorrow was no less profound or significant when these mothers made decisions about their child's living situation that precluded staying with them. Follow-up studies are recommended to further compare how living situations impact chronic sorrow.

The current research added to previous studies of chronic sorrow. The definition of chronic sorrow according to these findings was adapted: a permanent and reoccurring experience of pervasive sadness and loss which underlies the life experience and which recurs over time for the parent of a child with developmental, medical, or behavior issues that prevent him from participating in society in a way previously anticipated by parents*, resulting in exhaustion, isolation, and potentially, loss of hope and dreams.*

Conclusion

Mothers may improve in hiding their experience with chronic sorrow. However, chronic sorrow continues as illustrated by these women. Triggering events continue as those the same age as their child graduate from college, get married, begin careers and they experience the losses for their child once again. They continue to manage care as they are the experts and the

persons most knowledgeable about their children. The mothers worry what will happen to their children if and when the mothers can no longer do all that is required of them. Adult children with disabilities including cerebral palsy are on the waiting list.

Mothers are waiting to be acknowledged and assisted as they experience chronic sorrow.

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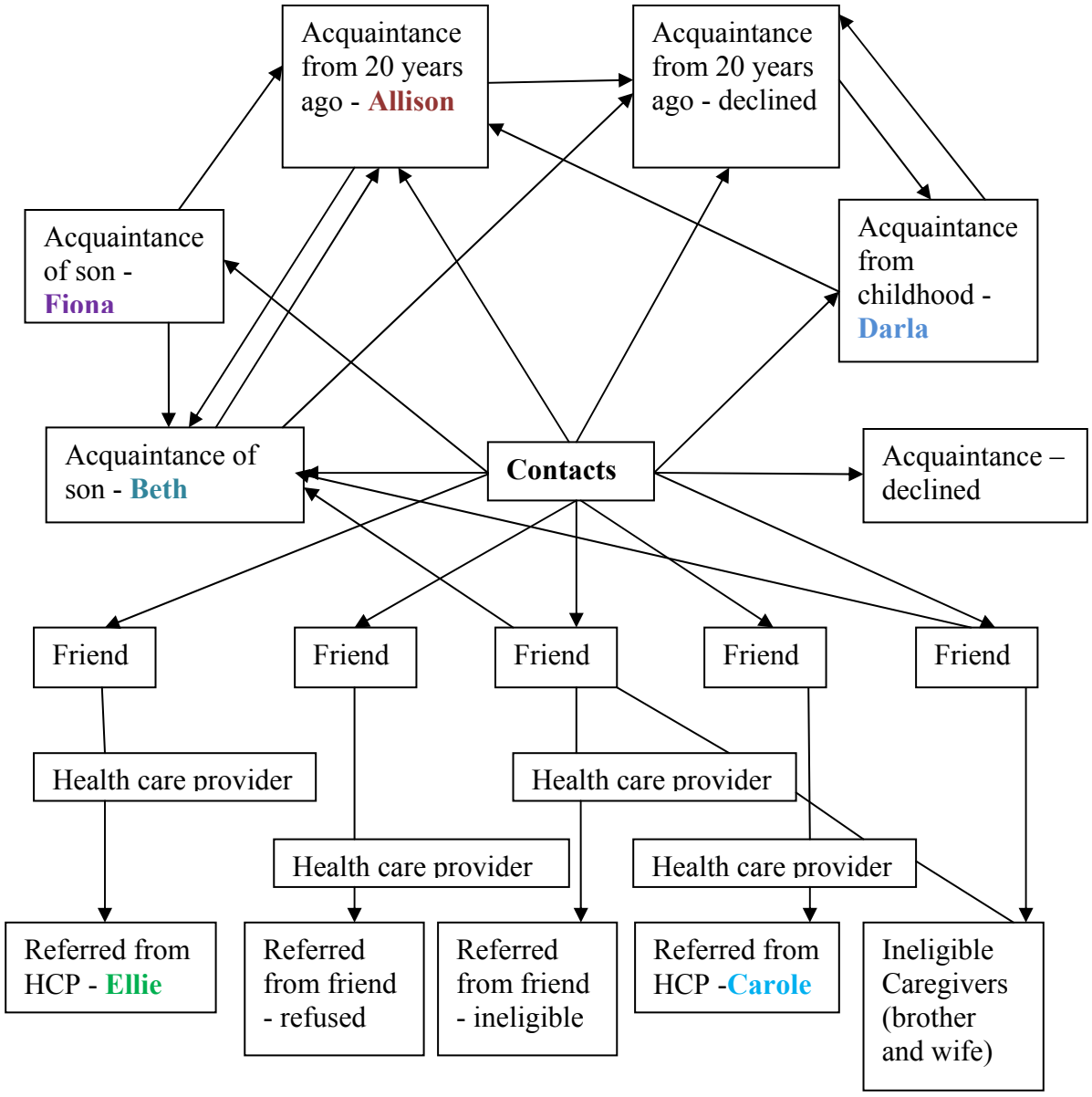
Appendix A - Sampling

Figure A.1 Review of Sampling



Appendix B - Training for Coder

Instructions to coder:

1. Complete KSU training.
2. Read through pages 35-54 of proposal for overall discussion of chronic sorrow.
3. Read through the interview overall.
4. Look at the questions again. Bracket the portion of the interview that specifically pertains to chronic sorrow.
5. Identify whether the bracketed portion addresses that domain (such as loss of support) and/or other domains of chronic sorrow and indicate in margin.
6. Meet with researcher to discuss findings, similarities and differences, of the first interview.
7. Proceed through remainder of interviews.
8. Meet with researcher for discussion after each.

Domains:

Chronic Sorrow (presence indicated by mother)

Chronic Sorrow Experience

Triggering Events (bringing about feelings of chronic sorrow)

Loss (or Changes) of Roles & Relationships

Loss of Support

Loss of Quality of Life

- Quality of Life: Availability of Childcare
- Quality of Life: Health of Child
- Quality of Life: Health of Mother
- Quality of Life: Behavior of Child

Financial and Emotional Loss

Miscellaneous

Examples of chronic sorrow found in interviews (on following page):

Themes for coding interviews: These themes begin on p. 35 of the proposal. It is discussed at length p. 35-53.

Chronic sorrow

Sadness that comes and goes. This definition is what the mother determines it to be and can include perception of actual or anticipated loss. This is not a depressive state, although depression could co-exist. It may change over time or remain the same. Key words are 'comes and goes'.

Loss of roles and relationships: Perception of mothering role, changes in roles & relationships

Mothering role usually involves assisting, facilitating, or otherwise guiding a child toward becoming independent and self-sufficient. Did this role change? Did relationships change with spouse or other siblings? Career aspirations and goals may also change in response to child's needs throughout life.

Recognition of loss through triggering events

Did the mother note specifics as to when she was sad or observed disparities between her child and another child in experiences or development? Triggering events may also include specific developmental milestones that usually occur as listed in the age groupings.

Loss of support

Professional support: Professional support is that support coming from people who are paid to help. Examples are physicians, PAs, NPs, RNs, PT, OT, ST (or SP), caseworkers such as those from a Community Developmental Disability Organization (CDDO), group home care providers, social service, school nurses, special education teachers.

Social and family support: Social support is support that comes from friends, church family or church members and associated groups such as Sunday School or women's groups, neighbors, parent organizations such as Families Together, school support groups, social sororities, specific developmental disability groups. Family is defined as parents, siblings, grandparents, aunts, uncles, cousins and those who may be considered part of the family such as very close friends. Isolation from family arises from statements of responsibility not shared by others, 'me', 'I', 'alone' 'lack of help', no one else, no one on whom to depend, by myself.

Spiritual support: This is not denomination, but how mother perceives relationship with God or spiritual life in general. It may be seen as questioning God or belief system, 'why me', why my child, change in prayer focus, change in relationship with God or importance of spiritual life.

Loss of quality of life: Health of child, health of mother: mental or physical, time needed to care for child, financial/economic

Health of the adult child may determine day-to-day activities and impacts health of mother. Is she able to do the physical care necessary such as changing position of child, feeding, dressing, toileting or other personal care needs? What is her energy level? Does she have chronic problems such as back pain, insomnia? How able is the child to perform own ADLs? Other examples include how activities are determined by specific needs of child. Other comments that allude to loss of quality of life would also include statements about family or friend's needs coming second to child's needs, day-to-day activities rarely change, future is determined by child's needs, do not think or perhaps want to think about future.

Was life path or career changed – for good, different, bad – primarily because of child's diagnosis, insurance, and/or needed care?

The family or mother's financial resources may have changed over time or may have changed drastically because of child's needs such as special formula, adult diapers, hospitalizations, doctor's and therapist visits, babysitter's or other caregivers, AFOs, and transportation.

Table B-1 Examples of Bracketing

General Domain: Chronic Sorrow	Line # with example and identification of respondant
1. Some parents have described a sadness that can occur when they think about their child with a disability. Parents can believe they are functioning well, but have times where they feel the loss for their child. Do you experience chronic sorrow?	5-7 A fleeting coming and going. I would not say - it just kind of comes and goes. (#1)
2. Has this experience changed for you as a mother since your child's diagnosis until now? Did chronic sorrow a) decrease, b) increase, c) remain about the same, or d) don't know – can't tell if	9 I think it's increased because as he gets older or having more complications. (#2)

it increased or decreased.	
Triggering events for Chronic Sorrow	
3. Could you please describe examples of a time or specific events during where or when you experienced chronic sorrow?	5-6 I think when I'm with friends who have a son ___'s age, it becomes apparent to me there is a big difference. (#1)
Birth to age 2 years (e.g. social smile, sitting, standing, walking)	34-36 Did I experience this? Oh yes, absolutely! Every milestone … it was very very difficult to not be seeing those and then just being told that you are not going to see any….. oh sure! Walking - all of those things… Oh, yeah anytime that there are milestones. (#2)
Toddler to preschool 2-5 years (toilet trained, running, jumping, throwing, attending pre-school)	26 thinking 'will she *ever* do anything'? (#3)
Middle childhood 6-8 years (dress self, reading, tie shoes)	29-32 (Pause) I think the sorrow came when she would just set and look at us with kind of like a glare like, it just didn't connect, 'I don't get what you are trying to teach me, I just don't understand, I don't understand red, blue, yellow; I don't understand one, two, three; you want me to do what with this dolly? I want to eat it.' (#3)
Middle childhood 9-11 years (spending time with peers)	43-51 But it was other people that presented the most problems in their dealings with her at this stage, so the most challenges around other people and how they interacted with her at that stage of the game and on through high school. Most had to do with her challenges that school. She had some health challenges during that time they were ongoing so those would be specific to her condition. She was 16 - her seizures started up again so she was hospitalized for two weeks and then another two weeks after that with really unusual seizures and that was a specially challenging because they couldn't find out how to stop them. We did Biactin and we were able to stop them but, yeah, that was a really challenging time. (#4)
Early adolescence 12-14 years (influenced by peers, strong sense of right and wrong, body image concerns)	42-44 Well, she still doesn't have any body image kinds of concerns, she doesn't care she has a red pants on, blue pants on or green with red dots, it doesn't matter to her. She doesn't understand to pick out a long sleeve shirt on a cool day, that's neither here nor there to her. (#3)
Middle adolescence 15-17 years (considering career, driving, babysitting or other part-time jobs)	54-55 Yeah. And we were trying to figure out who would change his diapers and feed him every day. Yeah. That was a whole different world. (#6)
After high school 18 years and older (college, vocational training, career, marriage, living independently)	61-63 and that was very hard. That, that was very, very hard. That was the first time he had had anything medical done and it brought back a lot of feelings - how fragile he could be. (#1)
Loss of Support	
4.Who helps (helped) you care for your child? ___ Spouse ___ Other children ___ Friends ___ Others	162-164 That is what I was there for, that's what I was, a mother, you know, so that was fine and so I think that's where the grief comes through, because you can't get a lot of things done when you're in the hospital (#5)

___ Paid caregivers ___ No one What type help does each provide?	
5.Which professionals provided helpful support? Give example. ___ Family physician ___ Other physician or specialist ___ School nurse ___ Social worker ___ School teacher ___ No one ___ Therapist: physical, occupational, speech pathologist	204-205 She only had a physical therapist. We never had a social worker, nobody from the hospital ever got involved in her case. (#5)
6.What nonprofessionals have provided helpful support? Give example: ___ Church members or clergy ___ Social groups ___ No one	106 Oh, dear. Outside of TARC? No. (#4)
8.Have your spiritual beliefs been useful in parenting your child? If so, how?	114-115 It is always very hard to understand why did this have to happen? (#1)
9.How did attendance or participation change in your church/synagogue/social group/family after your child was born?	130-133 Initially, my spiritual beliefs were challenged. And through the years, I think they've evolved in a way that's been very helpful. Initially, it challenged to everything I believed, and how I believed, and it was a long time in figuring out how it all made sense. You know, I wasn't necessarily angry but incredulous was more how I felt. (#4)
10.If spiritual beliefs or faith is or has been a part of your life, has it changed during parenting your child? If so, how?	193-195 I think sometimes that it's pretty easy to despair. You feel like you're, you know, when it's 2:00 AM and you just have had it, and you're gonna be up all night turning like I was last night, I'm thinking, OK Lord, where are you? I mean it's very, very lonely. (#2)
11. How has your church/synagogue/social group/family accepted your child?	147-148 People did kind of ease away and so, I don't know exactly, it happened so slow that we kind of didn't think much about it, but people sort of eased away. (#6)
Loss (or changes) of Roles & Relationships	
12.Who is responsible for coordinating health care and therapies for your child? Who has been helpful? ____ Physician ___School ___Parent	356 Myself. Me. I. I did all of that. (#5)
13.Are you able to continue participating in social or personal plans without your child as much as you would like? ___Yes ___No Has this changed as your child grew older? If so, how? ___ Easier ___Same ___More difficult	173-177 she still relies on us for transportation and that would be an everyday challenge, how she gets to work, what she does after work, where she goes. Most of the time we work it out and that's not a big deal. But that would primarily be the reason she impacts our daily routine, what we do or don't do for the most part. (#4)
14.When ___ was young, what plans did your child have for social & recreational, living arrangements, work	390-392 she wanted to be a baker or wanted to be a daycare provider. And she, she bakes at home, but she doesn't do it as a work because I don't think she'd be able to stand long

environment, or educational opportunities?	enough periods of time (#5)
17.Where is your child now living? What were your plans for ___ after completing high school? Is this what is occurring?	324-326 I realized she was becoming too dependent on me. So, like I said earlier, I put her in a group home situation, thinking we could sever ties so that we did for little while, but I had to bring her back home..(#3)
18. Have you found any positive aspects in parenting ___?	202-203 we've really tried to be forward thinking and not let the 'what ifs' dwell (#1)
19. What about negative aspects? What have these been for you?	366 You just don't do things you liked to do. (#3)
Loss of Quality of Life	
15.How has caring for your child impacted your family financially and emotionally?	192-194 Economic? Absolutely! Although, we've been pretty fortunate with medicine. We've got that hard, and we've had to pay, oh, thousands of dollars, after the first NICU stay, but we paid it off over time. But, you know, we basically support her…(#4)
Other	
20. Is there anything you would like to ask me at this point? Or "Now that you know what the research is about, is there anything that I should have asked but didn't?"	219-220 you didn't say very much about other children and the effect of that may or may not have had on them (#1) (This would also go under Question 14)
107 What anticipatory guidance would you give to mothers in similar circumstances? What guidance would have been useful for you?	122-123 to not lose yourself, to not be overwhelmed and grieving (#4)

Appendix C - Informed Consent

PROJECT TITLE: Chronic Sorrow in Mothers of Adult Children with Cerebral Palsy: An Exploratory Case Study

APPROVAL DATE OF PROJECT: _7/10/09_

EXPIRATION DATE OF PROJECT: _7/10/10_

PRINCIPAL INVESTIGATOR: Dr. Rick Scheidt

CO-INVESTIGATOR(S): Marilyn Masterson

CONTACT NAME AND PHONE FOR ANY PROBLEMS/QUESTIONS: Dr. Rick Scheidt, Justin Hall, rscheidt@humec.ksu.edu, 532-1483.

IRB CHAIR CONTACT/PHONE INFORMATION*:* Jerry Jaax, Associate Vice Provost for Research Compliance and University Veterinarian, 203 Fairchild Hall, Kansas State University, Manhattan, KS 66506, (785) 532-3224.

SPONSOR OF PROJECT: None

PURPOSE OF THE RESEARCH: As I have told you, my name is Marilyn Masterson. I am conducting research as part of my graduate requirement for the Ph.D. in Lifespan Human Development at Kansas State University. The purpose of this project is to learn how mothers of adult children with cerebral palsy deal on an *everyday and long-term basis* with the challenges this poses. I have selected mothers because they are often the people who assume major responsibility for the care of children with CP. Currently, there is very little information about this to guide professionals and families dealing with these issues. I would like to ask you about how parenting and care-giving experiences, including how these responsibilities and personal reactions may have changed over time. I am especially interested in the long-term sense of grief or loss – sometimes called 'chronic sorrow' - that often comes with these challenges and how you deal with it. Finally, I am interested in learning about your experiences with both formal and informal support systems and how well they have worked for you. The purpose of this project is to determine the existence of chronic sorrow for mothers of adult children with cerebral palsy, how and when it occurs, and if it has changed over time.

PROCEDURES OR METHODS TO BE USED: For screening purposes, I will start off by asking you to answer some questions regarding your possible experience with chronic sorrow. This will include some questions about your background as well. Then I would like to interview you about your experiences. The interview is composed of about two dozen questions that address these purposes. Most are 'open-ended' and allow us to talk in a conversational manner. At the end of the interview, I invite you to share with me any other important issues that we may NOT have discussed**.** With your permission, I would like to tape record the interview. This assures that we won't lose any information. I will transcribe the interview and put it into a

written format so I can more easily work with your answers. A trained coder and myself will then work together to summarize your responses to the various questions.

LENGTH OF STUDY: The interview will take approximately one hour. As part of the process, I would also like to return for a second and final follow-up visit with you. I will share with you the conclusions I draw from the interview and see if you believe these accurately represent your feelings. At that time, we can also discuss any other thoughts that may have occurred to you since the first interview, if any.

RISKS OR DISCOMFORTS ANTICIPATED: It is possible that some of the questions may deal with experiences or memories that are painful to you, are too personal, or may make you feel uncomfortable or sad. If this occurs, *just tell me you would **rather not answer** that question*. Of course, if you need to take a break at any time during the interview, please let me know and we can pause.

EXTENT OF CONFIDENTIALITY: I would like to share the experiences of the mothers in my study with appropriate professionals, perhaps at conferences or in published form. Please be confident that your identity will NOT be tied to your words and that and that all personally-identifiable information will be removed from the transcripts and reports that come from them. Once the interviews are transcribed, your name will not be attached to the written copy. The tapes will be destroyed following transcription.

Only I and one other trained coder will have access to your responses to my questions. All transcripts are maintained in locked cabinets in my possession. Again, your name will not be attached to the transcripts.

TERMS OF PARTICIPATION:

I understand this project is research, and that my participation is completely voluntary. I also understand that if I decide to participate in this study, I may withdraw my consent at any time, and stop participating at any time without explanation, penalty, or loss of benefits, or academic standing to which I may otherwise be entitled.

I verify that my signature below indicates that I have read and understand this consent form, and willingly agree to participate in this study under the terms described, and that my signature acknowledges that I have received a signed and dated copy of this consent form.

Participant Name: _____
Participant Signature: _____ **Date**: _____
Witness to Signature: (project staff) _____ Date: _____

Appendix D - Survey Questions and Satisfaction with Resources

Table D-1 Survey Questions

General information						
	Allison	Beth	Carole	Darla	Ellie	Fiona
Kendall score	29*	67	79	46	42	67
Maternal age	50-60	60-64	60-64	50-60	50-60	50-60
Employed outside /inside home	Outside	inside	Outside	Outside	Outside	Outside
SEC: higher middle lower	middle	middle	lower	middle	middle	middle
Child lives in/with	own home w/support	Mother	Mother	Mother	indepen-dent	group home
Child's age	35-40	35-40	35-40	25-30	25-30	25-30
Rank of adult child with CP	Oldest	Only	youngest	youngest	Oldest	middle
Race	Caucasian	Caucasian	Caucasian	Caucasian	Caucasian	Caucasian
	*Chronic sorrow not indicated by Kendall scoring					

Mobility of adult child	Allison	Beth	Carole	Darla	Ellie	Fiona
On own						
Assistive devices				X (orthos)	X	
Another person		X				
Another person and assistive device						
Own w/wh/ch						
W/assistance in movement & transfers			X			
Dependent on others	X					X

Nutritional status of adult child	Allison	Beth	Carole	Darla	Ellie	Fiona
Independent				X	X	
Feeds self; needs help w/mashing, cutting						
Eats with someone feeding			X			
Unable to chew solids; supplemented with blended food or formula	X					
Tube feedings		X				X

Morbidity of adult child	Allison	Beth	Carole	Darla	Ellie	Fiona
Swallowing difficulties	X	X	X	X		X
Seizure history		X	X	X		X
GERD		X	X	X		X
Aspiration w/o hospitalization		X				
Feeding tube placement		X				X

Curvature of spine	X			X		X
Orthopedic				X	X	

Hospitalizations of adult child	Allison	Beth	Carole	Darla	Ellie	Fiona
Aspiration		X				
Pneumonia		X				
Urinary tract infection						X
Seizure		X	X			
Dehydration						X

Health of Mother	Allison	Beth	Carole	Darla	Ellie	Fiona
Back pain		X	X			
Stress		X	X			
Depression		X				
Hypertension				X		
None identified	X				X	X

Help with childcare for adult child	Allison	Beth	Carole	Darla	Ellie	Fiona
Spouse	X	X		X	X (very little)	X
Paid caregivers	X	X	X	X		X
Grandparents				X (when young)		X (when young)
Siblings					X	X
Friend					X (very little)	

Professional support for mother	Allison	Beth	Carole	Darla	Ellie	Fiona
Physician	X	X	X	X	X	X
Speech pathologist		X	X	X		X
Physical therapist	X	X	X	X	X	X
Occupational therapist	X	X	X	X		X
School nurse		X		X		X
Teacher	X	X			X	X
Specialist physician			X			
Social worker			X	X		
Nurse case manager				X		

Coordinator of care of adult child	Allison	Beth	Carole	Darla	Ellie	Fiona
Physician						
Nurse						
Social Worker						
CDDO						X
Mother	X	X	X	X	X	X

	Allison	Beth	Carole	Darla	Ellie	Fiona	MEAN
Mother equal partner with physician	5	2	5	1 5	5	5	**4.67**
Physician listens carefully to mother	5	1	5	4	4	5	**4**
Physician explains tests well	5	4	3	4	3	5	**4**
Personally reviewed goals for child	5	5	5	4	5	5	**4.83**
Arranged personal schedule to accomplish things needed for child	2	1 5 Must	5	4	5	5	**4.5**
Health insurance covered needs of child	5	3	1	5	5	4	**3.83**
Meetings of support	5	1	5	1	2	5	**3.87**
Flexible work schedule	5	5	5	4	5	5	**4.83**
Work place policies allowed time off for child	1	Don't work outside home	5	5	4	4	**3.8**
Control over job in making decisions to manage child's disability	1	Don't work outside home	5	5	5	2	**3.6**
							4.12 (Mean)
MEAN	3.9	2.75	4.4	3.7	4.3	4.5	

Appendix E - Themes Summarized

Table E-1 Summary of Themes

	Allison	Beth	Carole	Darla	Ellie	Fiona
Chronic **sorrow**	**Fear for future** **Sadness**	**Isolation** *(loneliness)* **Fear for future** **Loss of hope** *Loss of control, no options* **Frustration** **guilt**	**Anger** **Frustration** **Fear for future** –> **Loss of hope**	**Fear for future** *ongoing Challenges*	Difficult emotional and physical **Exhaustion** **Physical pain** **Sadness** **Anger** *Apprehensive Overwhelmed*	**Physical pain** *no balance in life* **Loss of hope**
Triggering Events	**Fear for future** Developmental milestones	**Isolation** **Fear for future** Developmental milestones	**Isolation** **Sadness** **Fear for future** **Loss of hope** Developmental milestones	**Challenges** **Frustration** Developmental milestones	**Frustration** **Fear for future** **Anger**/*hurt* **Loss of hope** Developmental milestones **(***Couldn't participate in activities other children did)*	**Sadness** *heavyhearted regretful* **Fear for future** **Loss of hope** Developmental milestones
Loss of roles / responsibilities	**Isolation** *questioning*	**Isolation** **Anger**	**Isolation** **Fear for future**	**Isolation** *Resignation/ (acceptance) effect on sibling*	**Isolation** **Guilt** *in parenting / lack of time with siblings*	**Isolation** **Guilt** *r/t lack of time with siblings* **Frustration**
Loss of support: Professional	**Isolation**	**Isolation** *Decreased support over time*	**Exhaustion**	**Challenges**	**Isolation** **Loss of hope**	**Frustration**
Loss of support: Social	**Isolation**	**Isolation** **Frustration** **Exhaustion** **Loss of hope** **Anger**	**Isolation**	**Challenges** *even with emotional support*	**Isolation**	**Isolation**
Loss of support: Spiritual	**Questioning**	**Isolation** **Spiritual** **Loss of hope**	**Beliefs stronger** *Calmness in "Him"*	**Challenges** *to beliefs*	**Disillusionment** */Bargaining*	***Beliefs stronger*** *security? Spiritual is mother's strength/ Relief when talking about Religion/ spiritual support*
Loss of Quality of Life: Childcare	**Fear** *and relief*	**Isolation** **Exhaustion** **Loss of hope**	**Isolation**	**Isolation** **Challenges** **Isolation** *for child*	**Isolation** **Exhaustion** **Guilt** *over time spent with child, not siblings*	**Isolation**
Loss of Quality of Life: Health of child		**Isolation**	*Constant care*	**Isolation** **Challenges**		**Exhaustion** *Ongoing medical problems, esp.*

						when young
Loss of Quality of Life: Health of mother		**Exhaustion** **Loss of hope**	*Worry* **Fear for future**			**Exhaustion** **Loss of hope**
Loss of Quality of Life: Behavior of child	Worry/ **Fear for future**	**Challenges** *in behavior*	**Isolation**			**Exhaustion**
Loss of Quality of Life: Financial / Emotional		*Emotional &* **financial** *strain*	*Few* **financial** *options* **Isolation**	**Finances** **continuous** **Challenges**		**Financial** **Challenges** *Stressed overwhelmed*
Misc.	*Asked about effects on siblings*			*Lack of options* *Loss of self*/**Isolation**		