

Running head: QUALITY OF LIFE

1

The Quality of Life of Families of Children with Cerebral Palsy

Jill Wippermann

A Senior Thesis submitted in partial fulfillment
of the requirements for graduation
in the Honors Program
Liberty University
Spring 2013

Acceptance of Senior Honors Thesis

This Senior Honors Thesis is accepted in partial fulfillment of the requirements for graduation from the Honors Program of Liberty University.

Kimberly Little, Ph.D.
Thesis Chair

Cynthia Goodrich, Ed.D.
Committee Member

Mark Foreman, Ph.D.
Committee Member

James H. Nutter, D.A.
Honors Director

Date

Abstract

Cerebral palsy, the most common cause of physical childhood disability, is a non-progressive disorder that results from an anoxic brain injury to the fetal or newborn brain. Because this disorder can cause disability, ranging from mild to severe effects on motor and cognitive functioning, the diagnosis can vary from one child to another, causing family stress due to vague and unknown predicted outcomes of the disorder. Because the diagnosis of cerebral palsy affects families in different ways depending on coping mechanisms, support systems, and the age and level of functioning of the child, among other factors, it is important to take an individualistic approach to care. Family-centered care has been shown to be beneficial in approaching the care needs of these families. To promote overall quality of life, efforts should be made to evaluate specific family member needs and include the entire family in the education, care planning, and implementation processes.

The Quality of Life of Families of Children with Cerebral Palsy

Cerebral palsy is a non-progressive but permanent disorder that results from damage to the fetal or developing brain, leading to partial losses of motor and cognitive functioning (Shelly et al., 2008; Varni et al., 2005). Occurring in two of every one hundred births, it is the most common cause of physical disability in children (White-Koning et al., 2007). There are many factors influencing the quality of life of both children with cerebral palsy and their families, including the child's level of disability, environmental and social influences, stressors, and level of support. Although quality of life can be explained in many ways, it can be defined as the individual's personal perspective of overall well-being and contentment in life, which includes both psychosocial and physical or health-related domains (Majnemer, Shevell, Law, Poulin, & Rosenbaum, 2008). It is important to distinguish between health-related quality of life, which assesses quality of life as affected by disease processes, conditions, and disorders, and an overall quality of life, which is a more encompassing and generalized well-being that takes into account factors other than health (such as support, spirituality, and social and emotional wellness). Much of the following discussion will focus on quality of life as it relates to overall wellbeing (Majnemer et al., 2008).

When assessing the quality of life of children with cerebral palsy, researchers and health care providers must also take into account the quality of life of the parents and siblings of the child as well, which can greatly impact the child's quality of life and the wellbeing of the family in general. The importance of family centered care, rather than just patient-centered care, is becoming realized and increasingly researched as studies

have continued to show its effectiveness. Current research considerations concerning families of children with cerebral palsy include comparison of proxy and child reports regarding quality of life, the self-reports of the child, adolescent, and parent quality of life, and the nature of family-centered care. The best way health care providers can ensure appropriate care to the entire family is to assess the coping mechanisms and quality of life of the individual family members and the family as a whole and to collaborate with the family in planning and providing care (Majnemer, 2008).

Proxy Report and Comparison between Child and Parent Quality of Life Ratings

To set the stage for the discussion of the quality of life of children with cerebral palsy, the advantages and disadvantages of proxy-report of a child's quality of life should be addressed. Ratings on children's quality of life have traditionally been given through proxy-report from caregivers, but researchers are now encouraging self-report when possible due to the higher degree of validity and decreased chance of other factors affecting the rating (parental stress, for example) (Davis, Mackinnon, & Waters, 2011). Often, the quality of life reports of both the parents and child are compared to determine the degree of agreement between the two regarding the child's quality of life. One study that compared child and proxy reports suggested the stress on the parents impacted their view of the child's quality of life, and found that 29-57% of the parent participants in the study rated the child's quality of life lower than the child did. This same study also found that, although children tended to rate their quality of life higher than their parents did, they rated it lower with regards to pain, and similarly in the emotional sphere. In general, parents tend to rate their child's quality of life as lower than the child does (White-

Koning et al., 2007). Although the relationship is weak, a correlation has also been shown between maternal depression and a lower proxy-report of the quality of life of the stressed parent's child with cerebral palsy (Davis et al., 2011). Taking this into account, more consideration should be given to self-report than proxy-report.

Proxy reports are used when the child is not able to give his or her own report, which allows for a report of the child's quality of life that could not be acquired another way. But studies have shown that sole dependence on proxy report can give an incomplete view of the child's quality of life, as seen by the differences in parent and child reports. The results of a study on self-report showed that almost 50% of children (ages 5-18 in the sample) with cerebral palsy can give a self-report of their health-related quality of life. The authors concluded that both parents and healthcare providers should not rely solely on proxy-report if the child is able to give a self-report (Varni et al., 2005). One group of researchers found their results questioned the accuracy of proxy-reports of health-related quality of life especially in the emotional and social domains (Maher et al., 2008). Due to differences in quality of life rating, self-report should always be taken if possible, but proxy report may still be used. Although quality of life related to functioning is an important aspect of a child's overall quality of life, the main focus of the current discussion will be on self-reported quality of life in the psychosocial and emotional spheres of a child's life as well as the effects of pain on quality of life (Davis et al., 2011; Maher et al., 2008; White-Koning et al., 2007).

Quality of Life of Children with Cerebral Palsy

The relationship between the quality of life of children with cerebral palsy and their disability has been debated, and different studies have come to different conclusions regarding the impact of cerebral palsy on the well-being of these children. Although the damage does not progress over time, it can be accompanied by other co-morbidities, including seizure disorders and alterations in cognition, communication, and sensation that further impact health (Davis et al., 2011). In the past, the quality of life of children with cerebral palsy had often been related to their level of functioning, but more recent studies have shown that these children can have a good quality of life (even in comparison to children without a physical handicap) (Shelly et al., 2008). In accordance with other studies, the authors of a study on the self-reported quality of life of children with cerebral palsy found that the quality of life of these children was more influenced by social and environmental factors than by their disability (Dickenson et al., 2007).

Health-Related Quality of Life

A study on child self-report found that there is only a weak correlation between level of functioning and quality of life, and the authors of this study suggested that children with disabilities adapt to their disability. Because they do not know any other physical state in life, they often rate their quality of life as good. This is known as the disability paradox, a phenomenon in which those with disabilities can have a good quality of life with a proper understanding of their disability and strong social support and relationships (Shelly et al., 2008). Comparisons of health-related quality of life and overall quality of life and a discussion of the factors influencing quality of life will be

addressed, as well as factors that can be taken into consideration while providing health care as a medical professional. It is important for health care providers to understand the child's view of his or her quality of life in order to provide individualized and appropriate care (Davis et al., 2011; Maher et al., 2008).

Contrary to what most people may believe, children with cerebral palsy often rate their quality of life as similar to that of children without a physical disability. As noted, in years past, quality of life was associated with the degree of a child's functioning. According to one study, there has been a recent change in the perception of quality of life, which was once thought to be more connected to physical functioning than well-being, as it is today (Davis et al., 2008). The study goes on to assert that the correlation between functioning and psychosocial health is of little consequence (Davis et al., 2008). A different study confirmed these results by finding that the perception of quality of life in children with cerebral palsy shows very few differences in self-concept and no differences in self-esteem in comparison to the ratings of children without cerebral palsy (Russo, Miller, Haan, Cameron, & Crotty, 2008). Of course, this finding does not always appear to be true. A different study discovered that the relationship between degree of functioning and health-related quality of life was notable and influenced greatly by degree of physical activity (Maher et al., 2008). Another group of researchers found that only certain spheres of quality of life were impacted by physical functioning, namely physical participation and health and feelings about disability. Emotional and social quality of life were less notably linked to degree of functioning (as has been already argued) (Shelly et al., 2008). Understandably, there are differences between the

questionnaires used in these various studies, which may be causing the differences in results. All studies addressed quality of life, though varied in focus between comprehensive well-being and degree of functioning. This would seem to suggest that although certain domains of emotional, as well as social, quality of life can be unaffected by disability, quality of life related to feelings about limitations and reduced physical participation is impacted by degree of functioning, as one would think. Regardless, it is important to evaluate each child individually to determine his or her degree of coping and specific quality of life. A health care provider should not just assume that a child has a lesser quality of life due to disability, but should still be aware of this very real possibility while determining how best to provide care (Davis et al., 2008; Maher et al., 2008; Russo et al., 2008; Shelly et al., 2008).

The main factor influencing health-related quality of life that will be discussed is the pain, which one might think would be a commonly addressed issue. In a study on children with mild hemiplegic cerebral palsy (hemiplegic referring to decreased motor functioning on the side of the body controlled by the affected hemisphere), researchers found that almost half of the children interviewed (out of 107 children with an average age of 9 years old) experienced a chronic, aching pain, usually on the palsy-affected side of their body. Massage and rest were found to be the most commonly used methods of relief. However, researchers questioned why analgesics were not used more often, and suggested that this become a more prominent care consideration in the medical field (Russo et al., 2008). Another study found that while not always statistically significant, there was a lower reported quality of life in participants who had pain in the week prior to

taking the survey (pain was also associated with lower self-appreciation) (Dickenson et al., 2007). In order for a child's pain to be better controlled, this study suggested that parents need education regarding the nature of the pain their child is experiencing and the methods for reducing the pain, including the appropriate use of analgesics, such as acetaminophen. As shown, pain is not just present in children with severe cerebral palsy, but in children with mild cerebral palsy as well. There is currently research indicating that pain is not well controlled in the adult population with cerebral palsy, and it appears that this is true for the pediatric population as well (Bjornson, Belza, Kartin, Logsdon & McLaughlin, 2008). It is especially important nurses take this into consideration when caring for a child with cerebral palsy, whether in the hospital or clinic setting, and take measures to ensure adequate treatment of pain for this population in order to improve their quality of life. The presence, characteristics, and quality of the pain these children are experiencing should also be assessed more frequently by parents as well to counter it more effectively, and this should be a teaching point that healthcare providers address. A possible cause suggested for the inadequate treatment of pain was that children and parents believed this was simply part of life with cerebral palsy. Increased patient and parent education concerning this belief and the reason for treatment of pain needs to be a care priority (Bjornson et al., 2008; Dickenson et al., 2007; Russo et al., 2008).

Self-Reported Overall Quality of Life

The specific factors influencing the well-being of both young children and adolescents with cerebral palsy will now be discussed. Younger children with cerebral palsy tend to self-report a higher quality of life than adolescents with the same physical

disability. This higher quality of life rating can be in part explained through the disability paradox, in which individuals with a disability can report a good quality of life because their disability is all that they have ever known and they have come to accept it. This is especially true in children with strong relationships with family and friends (Shelly et al., 2008). Although this phenomenon can certainly be true in adolescents as well, due to their increased awareness of self and peers, they may begin to struggle more with acceptance of the disability while in their teen years (Bjornson et al., 2008). Interestingly, in a study comparing the self-generated domains relating to quality of life for children ages 6-12 with and without cerebral palsy, the domain pertaining to physical health and needs was identified as influential more often in children without a disability than in children with cerebral palsy. Similarly, the domain of physical activity was identified as significant more often by children with cerebral palsy than by children with typical development. This finding suggests that children tend to take certain spheres of their quality of life, such as physical functioning, for granted, leading to differences in perceived importance among various domains (Vinson, Shank, Dixon Thomas, & Warschausky, 2010). For younger children, their disability was found to be unrelated to their level of quality of life in six categories pertaining to finances, self-perception, social and psychological well-being, school atmosphere, and social acceptance (Dickenson et al., 2007). Their quality of life was found to affect physical and emotional well-being and relationships with parents when the disability caused trouble walking, cognitive impairment, and speech difficulty respectively (Dickenson et al., 2007). This study found there was no strong relationship between emotional health and the degree of impairment,

which would seem to suggest that children with cerebral palsy should be treated with the same considerations in this area as children without physical disabilities. Although overall quality of life may not be strongly correlated to degree of functioning, according to the Livingston et al. study, studies have shown that health-related quality of life is lower in those with decreased motor functioning (as cited in Vinson et al., 2010). Assessing the child's quality of life, understanding their goals and feelings, and also seeking the parents' input on the child's well-being will help the healthcare provider know how best to plan care interventions that are appropriate and individualized (Dickenson et al., 2007; Vinson et al., 2010).

When determining how to best provide care interventions for young children with disabilities, it is important to assess what activities the child is motivated to perform. The authors of a study, conducted on the leisure activities of children ages 6-12 with cerebral palsy, state that parents should encourage participation in recreational activities because this is important in promoting health and engagement with peers, developing skills, and increasing enjoyment of life in general (Majnemer et al., 2009). The King et al. study from 2002 (as cited in Almasri et al., 2007) promotes increased participation in social and leisure activities as the primary goal of rehabilitation for children with cerebral palsy. The Majnemer et al. study found that children preferred social activities over recreation and tasks related to self-improvement (2009). Findings indicate a higher rate of desire to participate in an activity (whether physical or social) than a rate of actual participation among children with cerebral palsy. In light of this finding, encouraging a child to overcome their fears and failures and teaching them to learn from their failures will help

ensure a higher rate of actual participation (Majnemer et al., 2009). Identifying those obstacles, whether personal or environmental, will help those providing rehabilitation services foster intrinsic motivation in children (Majnemer et al., 2009, p. 172).

Studies have shown that in adolescents with physical disabilities, there is a decrease in the rating of health-related quality of life between childhood and adolescence (as noted earlier), and a lower reported quality of life in physical and psychosocial spheres for girls when compared to boys (Maher et al., 2008). It is important to take note of the new challenges that will be affecting the quality of life of adolescents, especially those pertaining to relationships, sexuality, independence, and transitioning, when addressing parent education and while providing family-centered care as a health care professional (Davis et al., 2008). When planning care, taking into account the child's age and developmental stage will help determine the more age-specific struggles they may have. This approach will help address both those usual developmental concerns and the more individual concerns related to cerebral palsy. For example, adolescents are more aware of peer groups and "fitting in" than younger children are, and involvement in physical therapy activities in groups with peers was suggested by some researchers in order to help increase socialization and participation (Bjornson et al., 2008). One study found that, unlike the interviews conducted with younger children, interviews with adolescents addressed the topic of acceptance of the handicap (Davis et al., 2008). Acceptance of the disability resulting from cerebral palsy plays a significant role in development in the adolescent years because these children are in a period during which they begin to develop their identity and transition into adulthood (Ball, Bindler, &

Cowen, 2012). A 15-year-old with cerebral palsy said during an interview that she hated it when people referred to her as the girl in the wheelchair because she wanted to be defined by who she was as a person, not by her disability (Davis et al., 2008, 196). It may be for some adolescents that the image the physical impairments create has a greater impact on self-perception than their limited mobility does. Like every other teen, they are looking for acceptance, but quality interaction with peers and others, who may feel uncomfortable around them, may be more difficult because of their disability.

Additionally, physical limitations can impair participation in social events. Addressing psychosocial and emotional struggles of adolescents with cerebral palsy can help form a strong patient-care provider relationship and increase the quality of individualized care. Teens with cerebral palsy are going through the same struggles as adolescents without physical impairments, but they have additional challenges that should not be overlooked while providing care. As with younger children, discovering those activities that an adolescent desires to participate in and helping them overcome the barriers they may have to successfully complete those activities will encourage effective rehabilitation and participation in life (Ball et al., 2012).

Quality relationships and strong support systems play a large role in the quality of life of both adolescents and younger children. To help support the child, care providers must also support the family members and encourage them so that they can be strong for the child. As one adolescent commented in an interview, “They’re [family] really important. You can’t cope with anything in life if you don’t have their support. And they drive you on and make you a better person” (Davis et al., 2008, p. 196). Promoting

interaction with family and friends, including family in planning care, and encouraging socialization can improve the social and overall emotional wellbeing of these children (Davis et al., 2008; Shelly et al., 2008).

Although children with cerebral palsy can report a good quality of life in social and emotional domains (especially with strong family and friend support systems), their limited degree of functioning does negatively impact other parts of their quality of life, including physical participation, health (especially regarding pain), and feelings about their disability. Because pain does have a significant effect on quality of life, it should be adequately controlled and addressed during care. As discussed, support and assistance with coping, especially with older children, are also important aspects of care, but these children also struggle with the same things as other children their age, and they desire to be treated the same way. As one study on the quality of life of young children with cerebral palsy encouraged, promoting more overall participation in life and recognizing that most of these children generally have the same experience of life as those without a disability should be the focus in providing care (Dickenson et al., 2007).

The Quality of Life of Siblings of Children with Cerebral Palsy

There is very little research on the quality of life of siblings of children with disabilities, and research on the quality of life of siblings of children with cerebral palsy is almost nonexistent. In a literature review conducted by Stoneman (2005), it was shown that throughout various studies, there were no differences in perception of self or ability between siblings of children with and without disabilities respectively. The study also found that relationships between the siblings were generally positive and supportive,

possibly more so than those of the comparison siblings (Stoneman, 2005). Burton and Parks (as cited in Stoneman, 2005) found that the college-age siblings of children with disabilities had increased internal control when compared with peers who did not have siblings with a disability and that having a sibling with a disability was actually beneficial to the participants in the study. Despite these positive findings, the diagnosis of the disability of a sibling can be very hard on the child's brothers and sisters, stirring up emotions such as anger, resentment, and guilt that they may have been responsible for their sibling's diagnosis (Moore, Howard, & McLaughlin, 2002). A study comparing the self-concept of handicapped children and a sibling nearest their age with a non-handicapped comparison group found that the handicapped child had decreased self-worth and more anxiety and their sibling also had a lower self-concept, though to a lesser degree (Harvey & Greenway, 1984). It must be taken into account though that self-esteem is only one aspect of the broad concept of quality of life, which this study did not explore fully. Despite the differences in conclusions among researchers, the effect of disability on a child's siblings has been shown to have both negative and positive consequences. Although the advantages of good sibling relationships and increased internal control are significant, the confusing feelings that siblings have to sort through, especially at a young age, needs to be addressed by parents as well as health care providers, to a lesser degree, in order to help the child accept and cope with their sibling's disability (Moore et al., 2002; Stoneman, 2005).

Knowing how effectively siblings are coping can help the healthcare provider give more comprehensive and personalized family care. As one study suggested, by

encouraging open communication within the family, especially between children and parents, the health care provider can help the family foster good sibling relationships and counteract stress. In addition, this study said that one of the most significant predictors of a child's acceptance of their sibling's disability is the parents' attitude toward the disability because children tend to look to their parents for how to respond to a situation (Moore et al., 2002). Because the knowledge level regarding cerebral palsy and attitude of the parents is so important in helping siblings cope effectively, education regarding this phenomenon should be addressed during health care appointments or hospitalizations to promote overall family health (Moore et al., 2002).

The reaction and coping abilities of a sibling with a brother or sister with a disability range and vary depending on the age of the sibling. Younger children may accept disability while older children may have more feelings of embarrassment regarding their sibling's disability (Moore et al., 2002). Even younger children may begin to help care for their sibling with a disability, which can also cause increased stress. The impact of their sibling's disability on their lives is also reflected in the career paths they eventually choose, often including professions that focus on helping others. Regardless of the degree of disability that a child has, it has been shown that the relationships amongst siblings and the family are really no different than those of families of children without disabilities (Moore et al., 2002). Care providers should address the struggles and feelings siblings may have regarding their sibling's disability, but they should not initially assume, as with the quality of life of children with cerebral palsy, that the ramifications of disability decrease the siblings' quality of life (Moore et al., 2002).

The Quality of Life of Parents of Children with Cerebral Palsy

The disability of children with cerebral palsy is understood to affect their quality of life, but the parents of children with cerebral palsy are also severely affected by their child's condition. It has been shown that parents of children with cerebral palsy experience more stress than parents of children without disabilities. Due to the nature of the physical disability and possible intellectual disability associated with cerebral palsy, the stressors on the life of a parent range significantly from challenges regarding finances to detrimental effects on physical health and time commitment to other relationships and activities. As one study recommended, the idea of care-giving as a career helps put the lives of these parents into perspective (Raina et al., 2005). The authors went on to write that as with any career, there are stages of development, including preparation for the role, execution of the role, and retirement from the role. But unlike a chosen career, care-giving for a child with cerebral palsy has much less time for role preparation and can be very long term, possibly for the lifetime of the child (Raina et al., 2005). Because the parents are usually the main caregivers for a child with cerebral palsy and the ones who implement care on a daily basis, proper family support and education is crucial to maintaining a good quality of life for both the parents and the child (Raina et al., 2005).

A study on the stressors in the lives of mothers of children with cerebral palsy found that role restriction, feelings of isolation, and poor support from a spouse were the top stressors, while another study on both parents found that additional stressors included limited time and freedom, stress on marital relationship, hardships in maintaining social relationships, sleep disruption, and financial burden (Davis et al., 2009; Glenn,

Cunningham, Poole, Reeves, & Weindling, 2008). Parents of children with cerebral palsy often face significant financial stress because the medical cost of caring for a child with disabilities is about two to two and a half times the cost of caring for a child without disabilities. In addition, due to the nature of the care the child often requires, the mother may not be able to work, further decreasing availability of financial resources (Brehaut et al., 2004). A low family income has been found to be associated with a higher need for locating resources related to funding services such as transportation, babysitting, and therapy as well as adaptive equipment and modifications in the home (Almasri et al., 2011). It is important for primary healthcare providers to take into account a family's financial status when planning care to ensure the family can actually afford the care that is planned. This may mean being creative and innovative to best provide for the family's needs. Because there are so many factors related to care-giving that could negatively affect a parent's quality of life, it is important to pinpoint the specific things impacting individual parents, making differentiations between mother and father as well, in order to adequately assess quality of life (Davis et al., 2009).

A study conducted in Canada comparing the quality of life of caregivers of children with cerebral palsy with the quality of life of caregivers without a child with disability found that the former group had increased incidence of chronic health problems (such as ulcers and migraine headaches). These health problems were possibly correlated with increased stress levels (though correlation of the results with stress were inclusive at best) (Brehaut, 2004). Another stressor influencing physical health includes interrupted sleep due to caring for a child during the night (Davis et al., 2009). Despite the

inconclusiveness regarding exact effects on health-related quality of life, it is apparent that a mother may sacrifice her own quality of life in an effort to improve her child's quality of life (Ones, Yilmaz, Cetinkaya, & Caglar, 2005). Attention to caregiver strain and stressors is an important consideration for healthcare providers because this affects not only the parents' quality of life but the child's quality of life as well. Education regarding local caregiver respite opportunities may be very beneficial for improving the physical health of primary caregivers by providing an opportunity for stress relief and rest (Ones et al., 2005).

Although mothers of children with cerebral palsy did not have a higher amount of symptoms of anxiety than mothers of children without disabilities, they did have a greater prevalence of depression related to the long-term nature of cerebral palsy (Ones et al., 2005). A review by Knussen and Sloper found that parents with higher stress levels have decreased or possibly harmful coping methods and lower support, indicated by financial and marital stresses, and adverse life circumstances (as cited in Glenn et al., 2008). Interestingly, it has been shown in multiple studies that the degree of parental stress is not related to the level of their child's degree of functioning, but rather is affected by their access to resources and support and the nature of the family environment (Glenn et al., 2008; Ones et al., 2005). Because of the unknown outcomes and prognosis of cerebral palsy once diagnosed, parents may need to develop several different strategies for coping (Rentinck, Ketellar, Jongmans, & Gorter, 2006). Parents may not have the necessary family coping mechanisms and ability to adapt when the diagnosis of cerebral palsy is made, and for this reason may experience a decreased quality of life. As a health care

provider, time should be spent determining the family's coping mechanisms in order to increase the health of parents and the child as well. If health care providers can determine whether a family is having trouble adapting, they can customize their care to those services that would best address this issue (Retinck et al., 2006).

Another study has shown that coping is better in families of children who are adolescents than in families of younger school-age children, finding that the effect of cerebral palsy is greater in the earlier years of the diagnosis (Davis et al., 2009). The Ellis et al. study (cited in Almasri et al., 2011) confirmed this conclusion, finding that families of older children had fewer needs than families of younger children due to the coping mechanisms they developed over the years. This is another important phenomenon to have in mind while determining how best to provide individualized family care.

Although financial, physical and mental health, and stress-related factors have a significant effect on a caregiver's quality of life, family environment and child behavior also greatly impact quality of life. An interesting finding throughout several studies is that child behavior has a greater impact on the quality of life of parents than the degree of the disability of their child. A study of mothers of preschool-age children in the United Kingdom with cerebral palsy found that the three areas that most contributed to stress included increased family needs, decreased adaptability, and the presence of decreased cognitive functioning in the child (Glenn et al., 2008). In this same study, it was found that the top stressors characterized a demanding and less cooperative child, more characteristic of temperament than degree of disability (Glenn et al., 2008). Although higher levels of stress were seen to correlate with higher levels of cognitive impairment,

this level of stress was also affected by other factors (such as other stressful life events and poor family support) beyond simply the level of the child's impairment (Glenn et al., 2008). The authors of a similar study recommended that teaching parents ways to combat child behavior through both cognitive and behavioral methods could increase caregiver quality of life (Raina et al., 2005). This is an important characteristic to consider when providing care, because as seen in children with cerebral palsy, it is not the degree of disability, but rather the environment and coping strategies of the individual and family that have a greater effect on quality of life (Shelly et al., 2008). The Davis et al. study found that unlike prior studies, there were no readily distinguishable differences in the stressors among parents of children with varying degrees of impairment (2009). Rather than simply focusing assessment on the degree of the child's functioning as it relates to parental quality of life, health care providers need to also assess how the child's behavior and the family environment is affecting family quality of life.

Although stress was high among most of the parents in the Davis et al. study, many still reported a good quality of life and reported positive benefits, such as support from other families of disabled children and inspiration from their child (2009). This finding was also true in the Glenn et al. study of mothers of children with cerebral palsy, which found that the participants, most of whom were coping adequately, viewed their children as rewarding and were able to maintain a strong relationship with them (2008). Many parents also use religion and faith as a method of coping (to be addressed), and spirituality has been shown to be a source of strength and purpose for both the family members of disabled people and persons with disabilities (Poston & Turnbull, 2004).

Although stress may be expected in a family of a child with cerebral palsy, a health care provider should not initially assume that the family is coping poorly. The Brehaut et al. study found through literature review that the psychological stress factors in the lives of caregivers can be decreased by productive coping strategies, positive social and family support, a feeling of control and good self-esteem, and access to various supportive services (2004). Allowing time to discover the level of coping of individual families will greatly assist health-care providers in giving their patients personalized care.

Taking into account both the positive and negative aspects of caring for a child with cerebral palsy in each individual family will help health care providers with providing the proper support. Noting the beneficial coping mechanisms of certain families may be beneficial as well if these mechanisms can be taught to other families. Although stress is not a guarantee in families of children with disabilities, because they are at a higher risk for stress, they need adequate resources and support at their disposal (Glenn et al., 2008).

Family Centered Care

As has been shown, taking a family-centered approach to care is important to address not only the individual needs of the disabled child but those of his or her family. A family centered approach to care can be defined as a holistic approach that takes into consideration the family's role in caring for the disabled child. Over the last three decades, the importance of approaching care with the whole family in consideration has been shown to be valuable. This type of care should encourage families to be the source of support and should promote their individual strengths (Poston & Turnbull, 2004).

Family centered care should include care of psychosocial health and support of the family as a whole, as well the integration of the parents' understanding of their child's health, needs, and functioning into care planning because parents are experts on their children (King, Teplicky, King, & Rosenbaum, 2004).

Care interventions that address both the child and the parents allows the parents to then address their child's individual needs in a way that lessens the effect of the disability on the quality of life of both the child and family (Raina et al., 2005). A literature review of family-centered service found that benefits of family-centered care included increased psychological well-being of mothers and increased parental knowledge, participation, sense of control and competency; several studies also showed decreased anxiety and depression (King et al., 2004). Almasri et al. confirmed in their study regarding the needs of families of children with cerebral palsy that family centered care is associated with increased access to and easier coordination of services, which can greatly reduce the stress placed on a family of a child with a disability (Almasri et al., 2011). The family members, especially the parents of a child with cerebral palsy, are the ones who care for the child regularly. They should be included in care because of this crucial role. Due to the nature of cerebral palsy, children with this condition need a multidisciplinary approach, with care from pediatricians, occupational, physical, and speech therapists, neurologists, and social workers among others (Ones et al., 2005). This approach to care can be overwhelming to families trying to figure out what care their individual child needs. It is important for health-care providers to strive for continuity of care for these families. The approach to care may also need to change over time due to dynamic family

functioning and the different stages of development that the child experiences. The degree of physical functioning of the child certainly affects the family's quality of life, but as one study found, the child's ability to communicate with others and express individual needs is also a predictor of family needs. The study went on to say that children who are unable to communicate effectively may have a greater need for consideration of ways to improve social participation and family interaction (Almasri et al., 2011). These unique concerns should be explored with families and time should be taken to discern in what areas the family feels the most stress related to providing care (Jeglinsky, Autti-Ramo, & Brogren Carlburg, 2011; King et al., 2004).

Although families of children with cerebral palsy tend to have a higher number of stressors than families without a disabled child, the quality of life of parents and child is often reported as good and impacted by strong relationships and support. Family centered care has been shown to be effective and beneficial to families as a whole, but there are still several factors, including family coping and functioning, that have yet to be fully explored (King et al., 2004). One study contrasting the views of families and health-care providers pertaining to family centered care found that written educational material regarding the child's disorder and its progression as well as information regarding available therapies, support groups, and community services were seen as lacking by both parents and health care professionals (Jeglinsky et al., 2011). These implications for further research could prove to be very beneficial in providing more individualized care for families. Health care providers should strive, not only to improve upon the services

already in place, but to also think of other new and creative ways to assist their patients (Davis et al., 2009).

Practical examples of how family centered care can be improved include providing access to services designed to help families during transition stages, such as when the child is diagnosed, begins primary or secondary school, or transitions into the adult stage of life (Davis et al., 2009). It is during these transition stages that stress can be more prominent, and by providing services, such as access to counseling, early intervention, and support groups, health care providers can significantly improve the quality of life of their patients (Davis et al., 2009). Two of the most important characteristics of family centered care are working with the family as a partner and providing continuity of care among the multiple disciplines involved. Providing the families with adequate education regarding the child's diagnosis and prognosis will help the parents to be knowledgeable and make more effective contributions to care planning. Education can also increase caregiver wellbeing by decreasing the stress related to unknowns and misunderstood information. Providing continuity of care is a collaborative effort between multiple disciplines, but if all healthcare providers have the same goal in mind, and all take the time to find out specific family needs, care will have more consistency (Davis et al., 2009).

Spirituality of Families of Children with Cerebral Palsy

The spirituality of families of children with disabilities is often overlooked when providing holistic family care. According to Larson and Larson (as cited in Parker, Mandelco, Roper, Freeborn, & Dyches, 2011), health care providers need to determine

the individual beliefs and cultural and family values that shape each family and plan care with these characteristics in mind. During an interview regarding the spirituality of parents of children with disabilities, one mother remarked, “It is interesting. No nurse ever asked me about this (disability and spirituality), or even asked me if I was doing OK for that matter, but faith is important. Tell nurses that. Faith is so important. They need to ask. Please” (Speraw, 2006, p. 223). Although health care providers strive to provide holistic care to their patients, studies have shown that nurses and other health care providers tend to either neglect to assess patient’s spiritual wellness or struggle to incorporate spiritual assessment into practice (Speraw, 2006). The importance of faith to family strength and coping, as well as marital wellness, has been shown, as in the study of a group of predominantly Church of Latter Day Saints parents. This study found that for both mothers and fathers of children with disabilities, satisfaction with marriage was lower in general but increased with increased spirituality (Parker et al., 2011). Because of the long-term nature of cerebral palsy and the toll it can take on the mental health of families, assessment of spiritual well-being is imperative for health care providers to perform in order to provide quality patient care. During a study on the spirituality of the parents of children with cerebral palsy, parents expressed that having faith helped them to sort through the meaning of difficult life events and provided a source of strength (Poston & Turnbull, 2004). Taking into account the ways that parents cope with stress, including through faith, is important when assessing the overall health of a family. According to the Speraw study, the failure of the health provider to realize the importance of spirituality to family health was actually harmful to those parents raising a child with a disability

(2006). Nurses and other health providers can provide resources that will help parents incorporate their public religiosity with their child's disability, which often can prove to be a hindrance to attending church among other things, and give them options for various support groups they could attend (Parker et al., 2006).

Conclusions

Although the diagnosis of cerebral palsy can have devastating effects on a family as a whole, the quality of life of the family members can be high if the proper support and perspective, coping strategies, and individualized family care are present. Children, if able, should give a report of their own quality of life, sharing the activities they would like to participate in and the nature of their pain so that appropriate care can be given. The parents' quality of life also should be addressed during hospital or clinic appointments, because their quality of life impacts their child's wellbeing and is the most influential factor in the overall family quality of life. There is very little research on the quality of life of siblings of children with disabilities in general. Although much research has shown that their quality of life does not differ from that of siblings of children without disabilities, they are affected by their parents' and siblings' qualities of life and also help provide care for their disabled sibling. Their quality of life should also be addressed while providing family centered care.

It is the responsibility of health care providers to be aware of the personal needs of families, and to provide care and the love of Christ through a family-centered perspective. As one author wrote, "It is the role of nursing to protect and advocate for those who are the weakest among us. . . Nurses have the knowledge and power to make a

difference. That power needs to be exercised” (Speraw, 2006, p. 229). It is not only the responsibility of the health care provider to assess and promote quality of life and encourage the family to express their needs and concerns, but it is a privilege as well.

References

- Almasri, N.A., Palisano, R.J., Dunst, C.J., Chiarello, L.A., O'Neil, M.E. & Polansky, M. (2011). Determinants of needs of families of children and youth with cerebral palsy. *Children's Health Care*, 40, 130-154. doi:10.1080/02739615.2011.564568.
- Ball, J.W., Bindler, R.C., and Cowen, K.J. (2012). *Principles of pediatric nursing: Caring for children* (5th ed.). Upper Saddle River, NJ: Pearson Education, Inc.
- Bjornson, K.F., Belza, B., Kartin, D., Logsdon, R.G., & McLaughlin, J. (2008). Self-reported health status and quality of life in youth with cerebral palsy and typically developing youth. *Archives of Physical Medicine and Rehabilitation*, 89, p. 121-127. doi:10.1016/j.apmr.2007.09.016.
- Brehaut, J.C., Kohen, D.E., Raina, P., Walter, S.D., Russell, D.J., Swinton, M., O'Donnell, M., & Rosenbaum, P. (2004). The health of primary caregivers of children with cerebral palsy: How does it compare with that of other Canadian caregivers? *Pediatrics*, 114, e182-e191.
- Davis, E., Mackinnon, A., & Waters, E. (2011). Parent proxy-reported quality of life for children with cerebral palsy: Is it related to parental psychosocial distress? *Child: Care, Health and Development*, 38, 553-560. doi: 10.1111/j.1365-2214.2011.01267.x.
- Davis, E., Shelly, A., Waters, E., Mackinnon, A., Reddihough, D., Boyd, R., & Kerr Graham, H. (2008). Quality of life of adolescents with cerebral palsy: Perspectives of adolescents and parents. *Developmental Medicine & Child Neurology*, 51, 193-199. doi: 10.1111/j.1469-8749.2008.03194.x.

- Davis, E., Shelly, A., Waters, E., Boyd, R., Cook, K., & Davern, M. (2009). The impact of caring for a child with cerebral palsy: Quality of life for mothers and fathers. *Child: Care, Health, and Development*, *36*, 63-73. doi:10.1111/j.1365-2214.2009.00989.x.
- Dickenson, H. O., Parkinson, K. N., Ravens-Sieberer, U., Schirripa, G., Thyen, U., Arnaud, C., Beckung, E., Fauconnier, J., McManus, V., Michelsen, S.I., Parkes, J., & Colver, A.F (2007). Self-reported quality of life of 8–12-year-old children with cerebral palsy: A cross-sectional European study. *Lancet*, *369*, 2171–2178.
- Glenn, S., Cunningham, C., Poole, H., Reeves, D. & Weindling, M. (2008). Maternal parenting stress and its correlates in families with a young child with cerebral palsy. *Child: Care, Health and Development*, *35*, 71–78. doi:10.1111/j.1365-2214.2008.00891.x.
- Harvey, D.H.P. & Greenway, A.P. (1984). The self-concept of physically handicapped children and their non-handicapped siblings: An empirical investigation. *Journal of Child Psychology and Psychiatry*, *25*, 273-284.
- Jeglinsky, I., Autti-Ramo, I., & Brogren Carlberg, E. (2011). Two sides of the mirror: Parent's and service providers' view on the family-centeredness of care for children with cerebral palsy. *Child: Care, Health and Development*, *38*, 79-86. doi:10.1111/j.1365-2214.2011.01305.x.

- King, S., Teplicky, R., King, G., & Rosenbaum, P. (2004). Family-centered service for children with cerebral palsy and their families: A review of the literature. *Seminars in Pediatric Neurology, 11*, 78-86. doi:10.1016/j.spen.2004.01.009.
- Maher, C.A., Olds, T., Williams, M.T., & Lane, A.E. (2008). Self-reported quality of life in adolescents with cerebral palsy. *Physical & Occupational Therapy in Pediatrics, 28*, 41-57. doi:10.1300/J006v28n01_04.
- Majnemer, A., Shevell, M., Law, M., Poulin, C., & Rosenbaum, P. (2008). Reliability in the ratings of quality of life between parents and their children of school age with cerebral palsy. *Quality of Life Research, 17*, 1163-1171. doi 10.1007/sl 1136-008-9394-6.
- Moore, M.L., Howard, V.F., & McLaughlin, T.F. (2002). Siblings of children with disabilities: A review and analysis. *International Journal of Special Education, 17*, 49-64.
- Ones, K., Yilmaz, E., Cetinkaya, B., & Caglar, N. (2005). Assessment of the quality of life of mothers of children with cerebral palsy (primary caregivers). *Neurorehabilitation and Neural Repair, 29*, 232-237. doi 10.1177/1545968305278857.
- Parker, J.A., Mendleco, B., Olsen Roper, S., Freeborn, D. & Taylor Dyches, T. (2011). Religiosity, spirituality, and marital relationships of parents raising a typically developing child or a child with a disability. *Journal of Family Nursing, 17*, 82-104. doi: 10.1177/1074840710394856.

- Poston, D.J. & Turnbull, A.P. (2004). Role of spirituality and religion in family quality of life for families of children with disabilities. *Education and Training in Developmental Disabilities, 39*, 95-108.
- Raina, P., O'Donnell, M., Rosenbaum, P., Brehaut, J., Walter, S.D., Russel, D., Swinton, M., Zhu, B. & Wood, E. (2005). The health and well-being of caregivers of children with cerebral palsy. *Pediatrics, 115*, e626-e636.
doi:10.1542/peds.2004-1689.
- Retinck, I.C.M., Ketelaar, M., Jongmans, M.J., & Gorter, J.W. (2006). Parents of children with cerebral palsy: A review of factors related to the process of adaptation. *Child: Care, Health and Development, 32*, 161-169. doi:10.1111/j.1365-2214.2006.00643.x.
- Russo, R.N., Miller, M.D., Haan, E., Cameron, I.D., & Crotty, M. (2008). Pain characteristics and their association with quality of life and self-concept in children with hemiplegic cerebral palsy identified from a population register. *The Clinical Journal of Pain, 24*, 335-342. doi: 10.1097/AJP.0b013e318162eae0.
- Shelly, A., Davis, E., Waters, E., Mackinnon, A., Reddihough, D., Boyd, R., Reid, S., & Graham, H.K. (2008). The relationship between quality of life and functioning for children with cerebral palsy. *Developmental Medicine & Child Neurology, 50*, 199-203. doi: 10.1111/j.1469-8749.2008.02031.x.
- Speraw, S. (2006). Spiritual experiences of parents and caregivers who have children with disabilities or special needs. *Issues in Mental Health Nursing, 27*, 213-230.
doi:10.1080/01612840500436974.

- Stoneman, Z. (2005). Siblings of children with disabilities: Research themes. *American Association on Mental Retardation, 43*, 339-350.
- Varni, J.W., Burwinkle, T.M., Sherman, S.A., Hanna, K., Berrin, S.J., Malcarne, V.L., & Chambers, H.G. (2005). Health-related quality of children and adolescents with cerebral palsy: Hearing the voices of the children. *Developmental Medicine & Child Neurology, 47*, 592-597.
- Vinson, J., Shank, L., Dixon Thomas, P., & Warschausky, S. (2010). Self-generated domains of quality of life in children with and without cerebral palsy. *Journal of Developmental and Physical Disabilities, 22*, 497-508. doi 10.1007/s10882-010-9187-z.
- White-Koning, M., Arnaud, C., Dickinson, H.O., Thyen, U., Bechung, E., Fauconnier, J., McManus, V., Michelsen, S.I., Parkes, J., Parkinson, K., Schirripa, G., Colver, A. (2007). Determinants of child-parent agreement in quality-of-life reports: A European study of children with cerebral palsy. *Pediatrics, 120*, e804-14. doi: 10.1542/peds.2006-3272.