Quality of Life for Caregivers of Children with Sickle Cell Disease

by

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A thesis submitted in partial fulfillment
of the requirements for the degree of
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Date of Approval:
April 17, 2007

Keywords: Caring for chronic illness, caregiver perceptions, needs of caregivers, life satisfaction of caregivers, experience with medical professional, experiences with social support services, constructivist approach, strategies for enhancing life satisfaction

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ABSTRACT

Sickle cell disease is a chronic hereditary health condition that affects the red blood cells of its carriers. This disorder impacts its carriers in numerous ways including physically, emotionally, socially, and educationally. Responsibility for the day-to-day care and medication management typically falls to the parent(s). These parents endure significant hardships as a result of the daily provision of care and the financial strain. Caregiver stress has been associated with poorer quality family functioning, stressed parent-child interactions, and limited child development competencies.

The purpose of this study was to investigate the quality of life of parents of children with sickle cell disease and to determine what factors contributed to the overall quality of life of these parents. Further, the hierarchy of needs of parents of children with sickle cell disease was investigated.

Using a qualitative approach, this study employed a multiple case study design in order to investigate the notion of quality of life among participants. Descriptive data are provided for each of the four participants, including a presentation of their individual cases and thematic developments across interviews. Thematic developments across cases also are presented concentrating on similarities and differences across participants. Discussion includes an analysis of the subjective experience of the quality of life for participants, factors that impact their quality of life, ongoing challenges of these
participants, and specific needs of these parents. Strategies for professionals to support the needs of families coping with this disease are presented.
Chapter I

Introduction

More than 50,000 Americans are affected with Sickle Cell Disease (SCD) (Morse & Shine, 1998; Sickle Cell Disease Association of America, 2000) and the numbers continue to grow. According to the Sickle Cell Disease Association (2000), about 1,000 American babies are born with SCD each year. Additionally, one out of 400 African Americans has SCD (Charache, Lubin, & Reid, 1989; Ievers-Landis, 2001; Lemanek, Bucklo, Woods, & Butler, 1995; U.S. Government Publication, 1993). This painful and chronic disease is not limited to African Americans but can also be found in individuals of Mediterranean, Caribbean, South and Central American, Arabian, and East Indian descent (Charache et al., 1989). Sickle cell disease is not a rare disease. In fact, there are more people affected by SCD than by other common genetic conditions, such as cystic fibrosis, phenylketonueria (PKU), or hemophilia and there is currently no cure for SCD (Bonner, Gustafson, Shumacher, & Thompson, 1999).

Defining Sickle Cell Disease

Sickle cell disease (SCD) is a chronic hereditary disease, which affects the red blood cells of its carriers. People with SCD have red blood cells that contain mostly hemoglobin S, an abnormal type of hemoglobin. Sometimes these red blood cells become sickle-shaped (crescent shaped), which makes it difficult for them to pass through small blood vessels. These vessels become clogged making it difficult for oxygen to reach a
particular part of the body. Lack of sufficient oxygen restricts normal blood flow causing the complications of sickle cell disease.

The severity of the disease varies between individuals (Brent Sickle Cell & Thalassaemia Centre, 2002). In children, physical growth may be distorted or retarded. Some examples of physical distortions experienced by children with SCD include abnormal contact of the upper and lower teeth, arms and legs that are slender and elongated, and poor development. Puberty in children with SCD is usually delayed slightly (Morse & Shine, 1998). Other outcomes of SCD include damage to many of the bodily organs (as a result of frequent pain crises), leg ulcers, stroke and decreased resistance to infection (A.D.A.M., 2001). Some children affected by SCD often experience pain crises that lead to frequent hospitalizations and school absences. In addition, some children suffer from limited neurocognitive development due to stroke, which causes damage to the brain over time. Nettles (1994) found that children with SCD had poorer academic achievement in reading and mathematics than did a control group of children when age and race were held constant. Children with SCD also had the most absences from school than the control group.

It is evident that children affected by SCD require increased resources and supports to improve their quality of life. Although some support is provided within the community setting, much of the support received by children with chronic illnesses is provided by their family, friends or other non-professional caregivers (Lim & Zebrack, 2004; Martinez-Martin et al., 2005). This indicates that these informal support systems must bear all the stresses and other burdens or limitations that might come along with caring for those with chronic illness. Given that caregiver stress may have a negative
impact on children (Lim & Zebrack, 2004), it is essential that investigators examine what factors influence caregiver stress. Such investigation would help to determine the most effective ways to intervene and support these caregivers and their ill children. Whitten and Essien (1979) conducted interviews with 50 carriers of SCD and 50 parents of children with SCD. They found that these parents knew very little about the disease, some of which had SCD themselves for 20 to 30 years. These individuals were not able to cope effectively with the disease and may not have truly understood the necessity of seeking support services. Whitten and Essien also found that there had been few attempts to educate these parents and that it was difficult to get parents to attend educational sessions.

Single parents head many of these targeted homes. According to Tucker (1998), the provision and utilization of quality services is critical for single parents. Tucker notes that poverty is most highly pronounced for those children living in single-parent households headed by women. Her work revealed that children in one-parent families perform more poorly in school and their dropout rate is nearly twice as high as the overall average. In 1985, for example, 66% of Black children and over 70% of Hispanic children living in female-headed households lived in poverty. Given that some of the targeted families may share many of these characteristics (single-mother headed, poor, etc) the presence of such a chronic illness as SCD adds another threat to the psychological and emotional well being of caregivers and to poor outcomes for children (Hoare, Mann, & Dunn, 2001). According to a study by Martinez-Martín and colleagues (2005) female caregivers experience a significantly greater level of stress than do male caregivers as a direct result of a heavier workload.
It is very possible that the strain and additional stressors impact the quality of life for caregivers and families of those with chronic illnesses. The concept of quality of life is broad and has many facets. Many researchers agree that quality of life is defined as individuals’ perceptions of their physical, psychological and social functioning and is influenced by finances, spirituality, health, school, and work among others (Hofstede, 1984; Juniper, 1997; Paloutzian & Ellison, 1982; Rakib, White, Hedge, Newberry, Fakhoury, & Priebe, 2005; Sawyer et al., 2004; Theunissen, et al., 1998). The quality of life of individuals is directly related to their subjective experience of life. This means that their perceptions about their well being are very important and should be considered when determining their outcomes.

Quality of life may be measured objectively or subjectively (Badia et al., 2005; Devlin, Hansen, & Selai, 2004). There has been a tendency for researchers to measure the quality of life objectively. However, Dolan (2000) contends that qualitative data should illuminate the thoughts that respondents use in to order produce their particular responses allowing investigators to gain a more rich and in-depth understanding of why and how their comments differ; “rather than second-guessing respondents, the collection of qualitative data straight from the horse’s moth appears a more appropriate strategy in this context” (p. 1266). According to Dolan’s statement it is the analyses of the qualitative comments that allow one to read between the lines and understand what underlies the numbers reported on quantitative measures, thus adding depth to the data collected and the conclusions drawn. The ultimate goal of professional services is to improve the well being of those who they serve. In determining whether this improvement has taken place, both qualitative and quantitative methods of measurement have their place. It is essential
not to exclude patients’ perceptions about their experience of life prior to and after their services. Given that young children may not have the cognitive capacity to effectively communicate their life experiences, it may be necessary to use parents or caregivers as a proxy respondent (Coq, Boeke, Bezemer, Colland, & Eijk, 2001). Research indicates that parents of younger children (under nine years) tend to be more knowledgeable about their quality of life than the children (Jokovic, Locker, & Guyatt, 2004).

Investigators have investigated the quality of life of caregivers in various chronic illnesses (Lim & Zebrack, 2004; Mann & Dunn, 2001; Martinez-Martin et al., 2005, Quittner, Expelage, Opipari, Carter, Eid, & Eigen, 1998; Schulz & Quittner, 1998). Lim and Zebrack (2004) reviewed 19 studies that focused on the quality of life for families and caregivers of individuals with chronic illnesses. They found that characteristics of the patient and caregiver, stressors (i.e., caregiving demands, patient impairment), coping ability, and social support all impacted the quality of life of these caregivers. These results indicated the impact of caring for individuals with chronic illnesses on caregivers and the need for professional intervention. According to Quittner and colleagues (1998) families of children with chronic illness were more likely to experience greater marital discord and less marital satisfaction, as well as greater disruptions in daily routines when compared to families without a child with chronic illness. Quittner and colleagues (1998) included 62 married couples caring for a child with or without cystic fibrosis in a study to investigate the impact of such caregiving on marital satisfaction and to understand the specific stressors experienced by these caregivers and their strain on the family. Their hypotheses were confirmed in that they found that caregivers of children with cystic
fibrosis experienced greater marital role strain and had less time for social and recreational activities than those caring for a child without cystic fibrosis.

Shultz and Quittner (1998) are concerned that little attention has been given to individuals with chronic illness and the reciprocal impact they have with those providing care. Caregiving is not always a negative experience; however, there is evidence of a tendency towards negative outcomes. It is essential that investigators take a closer look into this issue due to the possibility of a transactional effect between the caregiver and the care recipient.

**Goals and Benefits of Current Project**

The goals of the current study were to take an exploratory approach to understanding the overall quality of life and the factors that influence the quality of life for caregivers of children with sickle cell disease. The outcomes of this project are expected to benefit families and the service and research communities. Families may indirectly benefit from the outcomes of this project. Findings from the current study will inform health professionals about the factors that promote satisfaction within families and that are likely to promote an improved quality of life. The service community may benefit from the availability of data that may enhance available services or from the knowledge of what factors impact the outcome of clients and families. This investigation serves as a pilot study to provide directions for future research. Specifically, the following research questions were addressed:

1) What is the overall quality of life for caregivers of children with sickle cell disease?
2) What factors influence the quality of life of caregivers of children with sickle cell disease? What do caregivers of children with sickle cell disease perceive as the interaction between these factors?

3) What is the hierarchy of needs of caregivers of children with sickle cell disease?
Chapter II

Literature Review

Sickle cell disease (SCD) is a global health problem that affects thousands of individuals (A.D.A.M., 2001; Brent Sickle Cell & Thalassemia Centre, 2002; Sickle Cell Disease Association of American, Inc., 2000). One out of every 400-600 African American babies born in the United States are affected by SCD (Brown, Armstrong, & Eckman, 1993; Charache et al., 1989; Ievers-Landis, 2001; Lemanek et al., 1995; Sickle Cell Disease Association of America, 2000; U.S. Department of Health and Policy Research, 1994). Although this chronic illness is found largely in the African American population, it also affects those of Mediterranean, Caribbean, South and Central American, Arabian, and East Indian descent. The illness also has been found in Belgium and the United Kingdom (Brent Sickle Cell and Thalassemia Centre, 2002; Charache et al., 1989; Ievers-Landis, 2001; Sickle Cell Disease Association of America, Inc., 2000). According to Morse and Shine (1998), in about 50% of the cases, the onset of SCD is between six months and one year of age. Sickle cell disease is not a rare disease, but affects more people than other common genetic conditions such as cystic fibrosis, phenylketonueria (PKU), or hemophilia. There is currently no cure for SCD (Bonner et al, 1999).

Definition of Sickle Cell Disease

Sickle cell disease is a chronic hereditary disease, which affects the red blood cells of its carriers. This disease results from the presence of large amounts of
hemoglobin S in the blood. Hemoglobin is a pigment that carries oxygen throughout the body. Abnormal forms of this pigment are called hemoglobin S. Individuals with SCD have red blood cells that contain mostly hemoglobin S. Morse and Shine (1998) believe that, in individuals with SCD, hemoglobin S accounts for approximately 95% of the hemoglobin produced rather than the normal hemoglobin (hemoglobin A). Normal hemoglobin are round, donut-shaped, with a smooth surface and are flexible. This flexibility allows them to flow easily through small blood vessels. As hemoglobin A releases oxygen (through a process called deoxygenation), it retains its smooth and flexible properties. Abnormal hemoglobin (hemoglobin S) reacts differently during deoxygenation. These red blood cells sometimes become sickle-shaped (crescent shaped), which makes it difficult for them to pass through small blood vessels. These cells become clogged making it difficult for oxygen to reach that part of the body. Lack of sufficient oxygen restricts normal blood flow causing the complications of SCD. When this sickling process happens repeatedly, causing the cells to clog vessels, red blood cells become permanently damaged, causing anemia (Morse & Shine, 1998).

There are three different types of SCD, sickle cell anemia (Hb SS), sickle hemoglobin C disease (Hb SC) and sickle beta thalassaemia disease (Hb SbThalassemia) (A.D.A.M., 2001; Brent Sickle Cell and Thalassaemia Centre, 2002; Morse & Shine, 1998). The type of genes a child receives from his/her parents determines the type of SCD a child develops. Each child receives a normal (A) or an abnormal (S, C, or b+) gene from each parent. Sickle cell anemia (Hb SS), the most common type of sickle cell disease, results when a child receives two abnormal (S) genes from his/her parents. A child inheriting hemoglobin S from one parent and another type of hemoglobin from the
other parent will have another form of SCD such as sickle hemoglobin C disease or sickle beta thalassaemia disease (Brent Sickle Cell and Thalassaemia Centre, 2002; Morse & Shine, 1998). A child may have sickle cell trait (inheriting one abnormal gene and one normal gene) and will typically experience no complications, except in unusual circumstances (Morse & Shine, 1998).

The likelihood of a child developing sickle cell disease varies based on the presence of SCD in parents. A child born to two carriers of the disease has a 100% chance of inheriting the disease. The chances decrease for those children for whom one or both parents do not have the disease. If neither parent has the disease, the child can not inherit SCD. The life expectancy for individuals with SCD has more than doubled over the past decade from approximately 20 years to 42 years for males and 48 years for women (Ievers-Landis, 2001; Morse & Shine, 1998).

Sickle cell disease impacts carriers and caregivers/families in various ways. More investigation is needed about the impact of sickle cell disease on caregivers. While additional research also is needed regarding the impact of SCD on children, below is a brief summary about what is known regarding the medical/cognitive, educational, and psychosocial impacts.

*Medical and Cognitive Impact on Children*

The severity of the disease varies between individuals (Brent Sickle Cell & Thalassaemia Centre, 2003). Barbarin, Whitten, Bond, and Conner-Warren (1999) contend that SCD causes severe physical challenges for children including fatigue, intense pain episodes, strokes, and leg ulcers. Most of the health problems experienced by
individuals with SCD result from problems in the red blood cells. As previously noted, these cells are typically round and smooth. When they become sickle-shaped, stiff and rigid, they began to clog red blood vessels causing damage. During this process of clogging, patients often experience severe pain episodes, which cannot be predicted. This pain is experienced in the part of the body where the clogging is taking place. Pain crises, as they are called, typically occur in the legs, arms, or the penis (in males). Pain crises in the penis are referred to as priapism, characterized by a lasting, painful erection (Brent Sickle Cell and Thalassemia Centre, 2002; Morse & Shine, 1998). Pain crises have varying durations between individuals. Pain episodes may last from 7 to 14 days and sometimes longer (Morse & Shine, 1998). Some individuals have episodes every few years (A.D.A.M., 2001). It is not uncommon for symptoms to be so severe that they require hospitalization. Other medical difficulties include fatigue, breathlessness, cough, rapid heart rates, delayed growth and puberty, increased susceptibility to infections, and ulcers on the lower legs. Jaundice, bone pain, attacks of abdominal pain, weakness, joint pain, fever, vomiting, excessive urination, excessive thirst, muscular pain, pallor, chest pain, decreased fertility, and poor eyesight/blindness characterize additional medical complications of SCD (A.D.A.M., 2001; Brown et al., 1993; Morse & Shine, 1998).

Another complication of SCD is stroke and brain infarcts. Approximately 9 percent of children from the ages of 6-12 are impacted by stroke (Adams et al., 2001). However, stroke recurs in 67% to 70% of patients with SCD (Adams et al., 2001). Strokes have been related to various educational and psychosocial difficulties, including changes in behavior, memory and personality. (Brown et al., 1993).
About 17 percent of children aged 2-16 demonstrate evidence of silent infarct (Adams et al., 2001). This information is of utmost importance because such experiences place children at increased risk for negative outcomes in various domains. According to Barbarin et al. (1999), the physical, social, and medical challenges faced by children with sickle cell disease may affect their psychological well being. This experience may lead to other complications and emotional, cognitive and neurological challenges. Chapar, Doctors, Radel, and Coupey (1986), found that children with SCD demonstrated deficits in fine motor control, visual short-term memory, and visual-motor integration. Additionally, lower scores were found on spelling and reading tests and lower global intelligence scores when compared to healthy siblings. These findings are important because they indicate that these children are at increased need for services and targeted, databased interventions to mediate the effects of these complications. It is important to note that many of the studies that have investigated these areas with this population have had their share of limitations including, small sample sizes, absence of a matched control group, and failure to confirm a diagnosis of SCD in patients (Brown et al., 1993).

*Educational Impact*

Many educational difficulties have been noted for children with SCD. Among the difficulties are increased absences from school, poor performance in reading, math, spelling, and science, and impaired memory resulting from stroke (Adams et al., 2001; Barbarin, Whitten, & Bond, 1994; Brown et al., 1993; Morse & Shine, 1998). Children with SCD often have high numbers of absences from school due to frequent hospitalizations (Morse & Shine, 1998). There has been little agreement among
investigators about the relationship of these absences to school performance (Brown et al., 1993). As noted by Brown and colleagues, studies looking at the relationship between school absenteeism and academic performance have indicated that neither school absenteeism nor frequent hospitalizations were related to academic outcome. Brown and colleagues further noted that studies published in this area show a variable pattern of behavioral and cognitive functioning in children diagnosed with SCD. Fowler, Whitt, Nash, Atkinson, Wells, and McMillan (1988) compared the academic performance of 28 school-aged children with SCD to a control group of 28 children without SCD. The groups were matched on age, sex, and socio-economic status. Their findings indicated that no significant difference existed between the performance of the control and experimental groups on tests of global intelligence such as the Woodcock-Johnson Tests of Cognitive Abilities. They did, however, find a significant difference between performance on reading and spelling tests, with the control group performing less well. Given the inconclusive findings regarding the relationship of school absenteeism and academic performance, further investigations need to be conducted controlling for school absenteeism and exploring other factors (e.g., frequency of occurrence of pain and fatigue) that might relate to poor academic performance among children with SCD. In spite of this variation, a large body of literature indicates that children with SCD are at increased risk for the development of learning problems.

Additional factors that may impact the academic functioning of the child include socioeconomic status, opportunities for learning and stimulation, cultural issues, and physical ability to perform tasks (Brown et al., 1993). Richard and Burlew (1997) compared the academic performance of two groups of children ages 7-11, one with SCD
and one without SCD. The groups were matched based on age, sex, and socioeconomic status. Richard and Burlew were interested in the groups’ outcomes on several variables: grade retention, grades in reading and mathematics, attendance in school, and outcomes of the California Achievement Test (CAT). Their findings indicated no significant differences in performance on any of the variables. The inclusion of a matched sample in this study was notable. Including matched controls in research looking at the impact of SCD on children is imperative, as it will allow the research and service communities to more accurately determine what outcomes are related specifically to SCD versus other variables. Socioeconomic status has been identified as a variable that moderately contributes to the academic and cognitive outcomes of children with SCD (Lemanek et al., 1995). Thus, socioeconomic status is implicated as an additional risk factor for poorer outcomes for children with SCD. Given that many factors may contribute to the outcome of children with SCD, more carefully designed and controlled studies will greatly add to the knowledge of the specific impact of SCD on the academic performance and outcome of affected children.

*Psychosocial Impact*

Gentry, Hayes, Dancer, and Davis (1997) have noted difficulties in the cognitive and linguistic domains for children and adolescents with SCD. Poor adjustment has been noted among children and adolescents affected by SCD, especially adolescents (Barbarin et al., 1999; Brown et al., 1993). Conyard, Krishnamurthy, and Dusik (1980) also have found that this population of children experience elevated rates of psychological dysfunction, excessive school absences, school dropouts, and social immaturity. Several
theories have been posed about why these difficulties exist within this population. These theories have been investigated but the findings have been mixed. One explanation for the inconclusive findings is that mediating factors may exist to buffer the impact of the disease on children and adolescents. Some examples of factors that might mediate the effects of SCD on individuals include severity of the disease, social supports, resources, and socioeconomic status. Failure of some investigators to control for these factors may lead to very different findings. It is imperative that investigators employ more qualitative measures and actively seek to understand the voice of the individuals and the experiences behind the numbers that are reported on their research protocols. The utilization of qualitative measures might provide richer data allowing investigators to identify specific psychosocial difficulties and factors contributing to the occurrence of these challenges for children with SCD. It is possible that individual children and adolescents possess certain resiliencies that help them to better cope with SCD and thus have a very different experience than others.

An overall delay in psychosocial functioning has been noted as a characteristic of children with SCD (Brown et al., 1993; Morse & Shine, 1998). Brown et al. hold that decreased psychosocial functioning may be presented in the form of behavior problems, impaired academic performance, and maladaptive family functioning. Additional research is needed that focuses specifically on psychosocial adjustment problems. This area is still understudied and also is characterized by inconclusive findings.

In males, delayed puberty has been a defined problem (Barbarin et al., 1999; Conyard et al., 1980; Morse & Shine, 1998). Hurtig and Parks found sexuality to be a
major stressor for females with SCD but not for males. They hypothesized that the developmental immaturity of males makes sexuality less of an issue for them compared to females. Delayed puberty in males might account for some of the social rejection by peers, teasing, social isolation, loneliness, and psychological dysfunction they experience (Barbarin et al., 1999; Conyard et al., 1980). Future research needs to compare and contrast the experiences of male and female SCD patients in schools and among their friends. To effectively intervene and support these students in the school or other social setting, it is imperative to understand their specific experiences and the factors that relate to those experiences.

Morgan and Jackson (1986) investigated body satisfaction, depression, and social withdrawal in 24 adolescents with SCD. They found that adolescents with SCD were less satisfied with their bodies. They further found that these youth experienced more symptoms of depression than their healthy peers and spent less time in activities, both social and non-social. These challenges might negatively impact the academic performance of these students. It is imperative that effective supports be put in place for these students.

Familial Impact

The families of children and adolescents with SCD must endure significant hardship as a result of the daily provision of care and financial strain. What has been presented above may not solely impact the ill child, but may influence the well being of the entire family, especially caregivers. In their provision of care, caregivers are likely to encounter many of these problems, as they are experienced by these youth. Many parents
must provide direct care and medication management for their children on a daily basis. Additionally, parents/caregivers must also interact with school personnel to ensure that their child is receiving the appropriate services and modifications that might be needed to support the child’s neurocognitive impairments (Barbarin et al., 1999; Ievers-Landis, 2001). Caregiver stress has been associated with poorer quality family functioning, stressed parent-child interactions, and limited child development competencies (Ievers-Landis, 2001). It is expected that caregivers of these children are faced with increased levels of stress due to the significant responsibilities they face. The author is interested in understanding if these factors are related to the psychological well being of the caregiver and if so, how?

It appears that children affected by SCD require increased resources and supports to improve their quality of life. Although some support is provided within the community setting, much of the support received by children with chronic illnesses is provided by the family, friends or other non-professional caregivers (Lim & Zebrack, 2004; Martinez-Martin et al., 2005). This indicates that these informal support systems must bear all the distresses and other limitations that might come along with caring for those with chronic illness. Given that caregiver stress may have a negative impact on children, it is essential that investigators examine what factors influence caregiver stress. Such investigation would help to determine the most effective ways to intervene and support these caregivers and their ill children. Whitten and Essien (1979) conducted interviews with 50 carriers of SCD and 50 parents of children with SCD. They found that these parents knew very little about the disease, some of which had SCD themselves for 20 to 30 years. These individuals were not able to cope effectively with the disease and may not have
truly understood the necessity of seeking support services. Whitten and Essein also found that there had been few attempts to educate these parents and that it was difficult to get parents to attend educational sessions.

Single parents head many of these targeted homes. According to Tucker (1998), the provision and utilization of quality services is critical for single parents. Tucker notes that poverty is most highly pronounced for those children living in single-parent households headed by women. Some interesting statistics reveal that children in one-parent families perform more poorly in school and their dropout rate is nearly twice as high as the overall average. In 1985, for example, 66% of Black children and over 70% of Hispanic children living in female-headed households lived in poverty. Given that the targeted families shared many of these characteristics (single-mother headed, poor, etc) the presence of such a chronic illness as SCD adds another threat to the psychological and emotional well-being of caregivers and to poor outcomes for children (Hoare et al., 2001). According to a study by Martinez-Martin and colleagues (2005) female caregivers experience a significantly greater level of stress than do male caregivers as a direct result of a heavier workload.

Quality of Life

It is very possible that the strain and additional stressors posed impact caregivers and families of those with chronic illnesses. The concept of quality of life is broad and has many facets. Many researchers agree that quality of life is a multifaceted concept defined as individuals’ perceptions of their physical, psychological and social functioning and is influenced by many different factors (Hofstede, 1984; Juniper, 1997; Paloutzian & Ellison, 1982; Rakib et al., 2005; Sawyer et al., 2004; Theunissen et al., 1998). This
definition reflects a broad definition of quality of life that was developed by comparing
definitions published by nine groups of investigators (Badia et al., 2005; Bernhard et al.,
Hoefstede, 1984; Juniper, 1997; Lim & Zebrack, 2004; Paloutzzian, 1982; Sawyer
et al., 2004; Tammura et al., 2004; Theunissen et al., 1998). Hofstede (1984) suggests
that individuals’ perceptions of their quality of life might also be related to their cultural
background. Based on his suggestion, it is possible that the experience of quality of life
might be very different from individual to individual even if they shared some common
characteristics. Hofstede introduced the idea that different cultures have different need
hierarchies, which might differ significantly to that proposed by Maslow. For example,
values that are more prevalent in an individualistic society may be very different from
those prevalent in a collectivistic society. Therefore, in quality of life research it is
essential to allow cultural influence (if any) to unfold and in practice to take into
consideration how one’s culture might dictate their expectations and/or their satisfaction.

Furthermore, Bernhard, Lowry, Mathys, Herrmann, and Hurny (2004) underlined
the importance of periodically assessing the quality of life for individuals. In their study
of 186 patients with colon cancer, they investigated whether the perceptions of quality of
life remained constant over time. They collected quality of life assessment data at several
timepoints and compared them accordingly. They found that the meaning of quality of
life for these patients changed over time. The experience of colon cancer is very different
from the experience of many other illnesses (Rakib et al., 2005). Therefore, it is not safe
to assume that these findings generalize to other illnesses. These findings do, however,
indicate the needs to investigate the notion of stability over time as it relates to the
perceptions of quality of life.
The quality of life of individuals is directly related to their subjective experience of life. This means that their perceptions about their well being are very important and should be considered when determining their outcomes. Quality of life may be measured objectively or subjectively (Badia et al., 2005; Devlin et al., 2004). There has been a tendency for researchers to measure the quality of life objectively. However, Dolan (2000) contends that “qualitative data should provide insights into the cognitive processes that respondents use in order to arrive at their responses; thus enabling researchers to get a better understanding of why valuations differ in addition to how they differ. Rather than second-guessing respondents, the collection of qualitative data straight from the horse’s mouth appears a more appropriate strategy in this context.” According to Dolan’s statement, it is the analyses of the qualitative comments that allow one to read between the lines and understand what underlies the numbers reported on quantitative measures, thus adding depth to the data collected and the conclusions drawn. The ultimate goal of professional services is to improve the well being of those who they serve. In determining whether this improvement has taken place, both qualitative and quantitative methods of measurement have their place. It is essential not to exclude patients’ perceptions about their experience of life prior to and after their services. Given that young children may not have the cognitive capacity to effectively communicate their life experiences, it may be necessary to use parents or caregivers as a proxy respondent. Research indicates that parents of younger children (under nine years) tend to be more knowledgeable about their quality of life than the children (Jokovic, Locker, & Guyatt, 2004).

Investigators have studied the quality of life of caregivers in various chronic illnesses (Hoare et al., 2001; Lim & Zebrack, 2004; Martinez-Martin et al., 2005; Quittner
et al., 1998; Schulz & Quittner, 1998). Lim and Zebrack (2004) reviewed 19 studies that focused on the quality of life for caregivers of individuals with chronic illnesses. They found that characteristics of the patient and caregiver, stressors (i.e., caregiving demands, patient impairment), coping ability, and social support all impacted the quality of life of these caregivers. These results indicated the impact of caring for individuals with chronic illnesses on caregivers and the need for professional intervention. According to Quittner et al. (1998) families of children with chronic illness were more likely to experience greater marital discord and less marital satisfaction, as well as greater disruptions in daily routines when compared to families without a child with chronic illness. Quittner and colleagues (1998) included 62 married couples caring for a child with or without cystic fibrosis in a study to investigate the impact of such caregiving on marital satisfaction and to understand the specific stressors experienced by these caregivers and their strain on the family. Their hypotheses were confirmed in that they found that caregivers of children cystic fibrosis experienced greater marital role strain and had less time for social and recreational activities than those caring for a child without cystic fibrosis.

The studies presented above comprise just a few of the studies that have attended to the impact of caring for an individual with chronic illness on caregivers. There are more studies that have examined the same topic; however, more attention to this topic is still needed. Shultz and Quittner (1998) is concerned that little attention have been given to individuals with chronic illness and the reciprocal impact they have with those providing care. Caregiving is not always a negative experience; however, there is evidence of a tendency towards negative outcomes. It is essential that investigators take a
closer look into this issue due to the possibility of a transactional effect between the caregiver and the care recipient.

The current study is concerned with the chronic health condition called sickle cell disease. The impact of caring for chronic illness is not limited to cystic fibrosis and other chronic illnesses. It is expected that caregivers in sickle cell disease experience similar problems. However, the quality of life for caregivers in sickle cell disease may or may not be impacted by the same factors. As previously presented, the physical/medical impacts of sickle cell disease vary between individuals; however, its impacts may be very chronic, painful, and profoundly limit the functioning of those affected. The current study investigated the overall quality of life for caregivers in sickle cell disease and factors impacting their quality of life through a qualitative approach.

*Maslow’s Hierarchy of Needs*

As previously referenced, Hofstede (1984) cited Maslow’s 1943 theory of the hierarchy of needs in his claim that importance of needs are influenced by cultural values. Abraham Maslow is best known for his 1943 theory of a hierarchy of needs (Envision Software, 2005; Gwynne, 1997). The theory of hierarchy of needs was based on Maslow’s belief that human beings are motivated by unsatisfied needs falling on one of five levels/domains; physiological, safety, love, esteem, and self-actualization needs. Maslow contended that an unmet need in one of these domains resulted in violence and other evils. Maslow further theorized that a fulfillment of needs in one domain always is followed by an emerging need a higher domain. Hofstede (1984) argues that Maslow’s theory has cultural limitations and that each level would be ranked very differently from culture to culture. Hofstede cited a study by Haire, Ghiselli, and Porter (1966), which
asked managers to rank Maslow’s category of needs based on their importance. They found that only rankings of managers in the United States were consistent with Maslow’s original ranking. It is important to highlight that the importance of the levels of needs in Maslow’s need hierarchy is influence by cultural studies, according to these investigators. This indicates that some factors are present, which moderates the perceptions of the importance of needs. The current study also is concerned with the specific hierarchy of needs of caregivers of children with SCD.

*Constructivism*

The research paradigm for this study is constructivism. There are several factors that distinguish constructivism from the other paradigms including methodology, logic, epistemology, axiology, ontology, and causal linkages. Constructivists use purely qualitative methods and inductive logic to answer researcher questions (Tashakkori & Teddlie, 1998). This means that constructivists study things in their natural settings, using various forms of data collection (i.e., interviews, observations, artifacts, etc.), and pull the data together to interpret phenomena or topics in terms of the meanings that people bring to them (Denzin & Lincoln, 2000). Constructivists are subjective in their epistemological orientations, meaning that the inquiry is bound in the perceptions of the respondents. Given this view, constructivists believe that it is not possible for one to separate him/her self from what is being studied (Creswell, 1998; Tashakkori & Teddlie, 1998). The knower and the known are inseparable; therefore, qualitative researchers must interact with those whom they are studying. Additionally, constructivists take a relativist ontological perspective; meaning that they believe that multiple, subjective realities exist. Each individual involved in the research has their view of reality and it is their
perspectives that construct realities over time (Creswell, 1998; Tashakkori & Teddlie, 1998). Furthermore, constructivists hold that it is impossible to determine causes and effects because of the interactional effects of entities (Tashakkori & Teddlie, 1998).

Goals and Benefits of Current Project

The goals of the current study were to take an exploratory approach to understanding the overall quality of life and the factors that influence the quality of life for caregivers in children with sickle cell disease. Findings from this project are expected to benefit families and the service and research communities. Families may indirectly benefit from the outcomes of this project. Findings from the current study will inform health professionals about the factors that promote satisfaction within families and that are likely to promote an improved quality of life. The service community may benefit from the availability of data that may enhance available services or from the knowledge of what factors impact the outcome of clients and families. This project serves as a pilot, which should result in directions for future research. Thus, investigators will benefit from the identification some quality of life issues for children and families impacted by sickle cell disease and from directions to for future research.

Summary

Sickle cell disease is a global health problem that affects thousands of individuals (A.D.A.M., 2001; Brent Sickle Cell & Thalassemia Centre, 2002; Sickle Cell Disease Association of America, Inc., 2000). This chronic illness has been implicated in numerous psychological, emotional, familial, and academic adjustment problems. The research presented within this chapter has demonstrated that children with SCD suffer
from many different medical, educational, and psychosocial difficulties do exist (A.D.A.M., 2001; Brown et al., 1993; Morse & Shine, 1998). In addition to the impact of SCD on children, of particular concern in the current study is the well being of caregivers. Various investigators have demonstrated that the issues surrounding SCD, from the perspective of the patients and families members, can be very complex. Some valuable literature exists, which helps individuals began to unravel some of the complexities that surround this topic. The information presented within this chapter on the impact of sickle cell disease on affected children and families has demonstrated the lack of sufficient research in this area and the fact that many of the findings are inconclusive. Much investigation is still needed to further understand the exact experiences of children and families affected by sickle cell disease as well as some of their specific needs. This literature review has specifically demonstrated the need for further research concentrating on the quality of life of caregivers in sickle cell disease and what factors influence their quality of life. The inclusion of more qualitative methods (i.e., open-ended, non- or semi-structured interviews) will help to identify the well being of this population and some specific factors that are related to their quality of life.

It is important to identify what specific struggles these caregivers experience in addition to what factors enhance or perpetuate those struggles in order to design an appropriate intervention. A thorough assessment of the quality of life of these caregivers will serve as a great catalyst to the design of such services.
Chapter III

Methods

This chapter provides a description of the methods used to address the research questions posed in Chapter I. The participants are described followed by a presentation of the instruments used for data collection. The chapter concludes with a detailed discussion of the study procedures.

Participants

This study involved four parents of children between the ages of 9 to 13 years old that have been diagnosed with sickle cell disease (SCD). Three female participants and one male participant were involved in this study. Participants included: Emily, a 39-year-old, African-American mother of five children (four in the home); Howard, a 43-year-old, African-American father of four; Wilma, a 40-year-old, African-American mother of five; and Zanine, a 36-year-old, African-American mother of two. Each participant had one child that has been diagnosed with SCD. Emily was married (spouse age 40-years) and lived in an upper class neighborhood with an annual family income of approximately 71-75 thousand dollars. She had three male children aged 5 (kindergarten), 5 (kindergarten), and 9 years (third years). Emily’s daughter, aged 11-years (6th grade) was diagnosed with SCD. Howard was married (spouse age 48-years) and lived in a lower class neighborhood with an approximate annual income of 26-36 thousand dollars. His children included two daughters ages 9 (4th grade, diagnosed with SCD) and 11 (6th grade) years. Wilma was married (spouse age 38 years), living in a lower-middle class neighborhood with an annual income of approximately 56-60 thousand dollars. Her
children included two boys (ages 12 and 7 year 6th and 2nd grade) and three girls (19 and 15 years/college and 10th grades respectively and one 6-month old). Zanine was a single mother of two boys ages 13 (7th grade/diagnosed with SCD) and 9 years (4th grade). Her annual family income was approximately 51-55 thousand dollars. Households of each participant include the parents and biological children. No extended family occupied their dwellings.

**Instruments**

Data for this project were collected through unstructured interviews lasting 60 to 90 minutes each. Informal interviews were conducted at the Children’s Cancer Center and/or at the home of each participant. Due to the unstructured nature of these interview sessions and consistent with the methodological approach of this study, no formal data collection instrument was used. The interviewer served as the primary data collection instrument as participants disclosed their experiences to the interviewer. The interviewer, through intimate interaction with the participants, in their environments, developed an “intimate familiarity” with the respondents and their worlds resulting in a level of understanding that surpasses what could be communicated to others in the absence of that experience (Denzin & Lincoln, 2000; Strauss & Corbin, 1997). Two questions were used to initiate conversation with each participant: 1) What does the term ‘quality of life’ mean to you? and 2) Please describe your current quality of life? Additional questions emerged as a result of immersion with and ongoing analyses of the data (Denzin & Lincoln, 2000; Glaser & Strauss, 1967; Strauss & Corbin, 1997). This type of approach is thought to provide a greater breath of data than other types of interviewing (Fontana & Frey, 1994).
Demographic data also were collected from participants. See Appendix A for a copy of the demographic form.

Participants were interviewed a minimum of two times. Additional interviews provided a higher level of information and served as a level of validation of the data. Follow-up interviews entailed seeking further understanding and clarification of the information shared during previous interviews. This process, called member checking, is a way of returning information back to the respondent and seeking feedback on findings and interpretations made to date. Member checking serves as a form of reliability in that reliability (in qualitative research) is grounded in the experiences of the people and is enhanced when respondents are allowed to verify that what is reported represents what they intended to communicate (Onwuegbuzie, 2002). Probing is another form of reliability employed in this study. The process of probing involves seeking clarification from respondents in an effort to enlarge one’s understanding of an experience or phenomenon. Implementation of these processes necessitated a third visits with one of the participants to further clarify and review data.

Design

The research paradigm for this study is constructivism. According to Tashakkori and Teddlie (1998), the constructivist paradigm supports the use of various forms of data collection in the natural setting, and data are inductively combined to make sense of a phenomenon. Additionally, Denzin and Lincoln (2000) hold that constructivism adopts a transactional epistemology, meaning that the knower and the known are inseparable. Under this paradigm, the text tends to be multi-voiced, allowing readers to hear the perspective of the participants as they have expressed them (Denzin & Lincoln, 2000).
This qualitative research study employed a multiple case study design. John Creswell (1998) defines qualitative research as “an inquiry process of understanding based on distinct methodological traditions of inquiry that explore a social or human problem. The research builds a complex, holistic picture, analyzes words, reports detailed views of informants, and conducts the study in a natural setting” (p.15). These data were collected to enable the investigator to take a broader look at the notion of quality of life through the lens of caretakers of children with SCD. The subjective nature of quality of life limits the extent to which it can be captured using a numerical value. It was the intention of the investigator to gain an in-depth look into this issue through the words and perceptions of the respondents.

A case study is a way to explore a particular topic with a single or multiple individuals. This study examined multiple individuals involved in the provision of primary care to a child with SCD in order to understand their overall quality of life. The paradigm used in this study is consistent with the grounded theory approach, which is used by researchers in an attempt to discover the underlying factors that interact to construct reality for the respondent (McCallin, 2003). Consistent with the methods of this study, constructivist grounded theorists acknowledge that the researcher creates the data and the analysis through repeated, intimate interaction with the respondent (Denzin & Lincoln, 2000; Glaser & Strauss, 1967; McCallin, 2003; Strauss & Corbin, 1997).

**Procedures**

The specific procedures of this study are outlined below beginning with a description of the methods used to recruit participants and secure a commitment to be involved in the study. Second, the specific procedures used to collect data for this project
Finally, this section ends with a discussion of the methods that were employed to analyze the data.

**Participant Recruitment.**

The participants for this study were selected using a combination of homogeneous and convenience sampling methods. Convenience sampling involves the selection of participants because they are available and are willing to be involved in the study. Following approval by the Institutional Review Board (IRB), the study was initiated and participant selection began. Participants for this study were recruited from the Hop-to-It program (a community-based program designed to support children and families impacted by SCD) that were willing to participate. These individuals were African American and the biological parent(s) of a child, aged 9 to 13 years, with SCD. Homogeneous sampling is appropriate due to the investigator’s specific interest in this population. Following approval by the Institutional Review Board (IRB), the study was initiated and participant selection began. The Executive Director of the Hop-to-It program, made initial contact with all participants and determined their interest and willingness to be contacted by the investigator. The Executive Director of the program generated a list of parents who met the inclusion criteria, were interested, and willing to participate in the study. A number drawing procedure from the list was utilized to randomly select five participants, including an extra individual for practice purposes.

Participants selected using the above procedures received a phone call from the investigator informing them that they were selected to participate in the study. An informed consent form was provided to all participants upon enrollment in the study (see Appendix B). This form provides detailed information about the study, why it is being
conducted, who will benefit and how, who are being asked to participate, the voluntary
nature of participation, and who to contact should concerns arise about research activities
or if the participant has any questions about the study.

The investigator verbally reviewed each section of the consent form with each
prospective participant and explained all data collection procedures. All participants
provided informed consent prior to the interview, which signified that they understood
the study in which they were taking part. A copy of the consent form is included in the
appendix.

*Interviewer Qualifications.*

The primary investigator was responsible for collecting all data. The investigator
has been trained at the graduate level in qualitative methods and has had three years of
field experience in qualitative studies. Additionally, this investigator also has had
extensive training in human relations, assessment, and non-biased data collection. To
further enhance the credibility of the data collected in this project, a practice interview
was conducted. A faculty member with a Ph.D. in Medical Sociology, a M.A. in Social
Work, and a M.A. in Public Health, and who has an extensive background in qualitative
data collection and analysis including greater than 30 years combined experience,
accompanied the interviewer on the first interview. Interviewing skills and style were
critiqued and constructive feedback provided following the interview. Feedback included
a discussion about the interviewing style, ability to listening and probe appropriately, and
the ability to establish rapport with the interviewee. Additionally, feedback centered on
the actual content of the interview and ways to begin to process the data collected during
the interview. The Supervision in the analysis of the data resulting from this practice
interview also was provided to the interviewer by this faculty member. This analysis was for purposes of practice and feedback only. The resulting data were not included in the results of this study.

Data Collection Procedures

Qualitative research methods were selected for this study because the quality of life and contributing factors were not known prior to the study and because the author desired to collect thick, rich data regarding the well-being of caregivers of children with sickle cell disease. Unstructured interviews with caregivers were the primary sources of data examined in this study. Interviews were tape-recorded. Tape-recording interviews served to stimulate recall and reflection and to generate a typed transcript of the session. The tape-recording served as a main source of data collection. In addition to tape-recording, the interviewer generated hand-written notes during interview sessions.

Although a two of the interviews took place at the site of the Hop-to-It program (Children’s Cancer Center), the majority of the interviews took place in the participants’ home at their request. Reasons for preferring to interview in the home included lack of childcare for children, distance from the home to the Cancer Center, travel expense (i.e., gas), and convenience of the participant. Upon meeting for the interview, the interviewer read the following preparatory statement to each parent: “I would like to thank you once again for your willingness to participate in this very important study. Your involvement is very valuable to this study and to the sickle cell disease community. We will begin by reviewing the informed consent form, where we will review information about the study, including a brief description, amount of time involved, and benefits and threats to participating in the study. We will then complete a brief demographic information sheet
and begin the interview with a few questions. Our interview will be tape recorded to capture our discussion today.” Upon obtaining informed consent from the respondents and thanking them for their interest and participation in this study, demographic data were collected followed by the initiation of the interview using the questions posed earlier (i.e., what does the term quality of life mean to you). Although the constructivist approach does not necessitate the use of a formal questioning instrument, several questions did surface during the interviews and were routinely posed to each participant. In addition to the two questions previously stated, participants routinely were asked the following questions: 1) What other factors seem to impact your quality of life? 2) How is parent (participant’s name used) right now? What one thing would you like others to know about caring for a child with sickle cell disease? Each interview lasted approximately 45 to 90 minutes. Following the interview, participants were thanked again for their involvement with the study and reminded that a follow-up interview would be necessary following the analysis of the data.

Upon meeting for the second interview, the participants were greeted with the following preparatory statement: “Thank you again for your involvement with this important study. I have had a chance to transcribe and analyze your data and would like to share it with you to verify that I have recorded your thoughts correctly and that I am understanding what you are trying to communicate. Then I have some questions for clarification of what we discussed the last time. I also will be recording this session to help me remember what we talked about.” The interviewer made a copy of each transcript available for participant viewing during each follow-up interview. Transcripts were referenced and reviewed in each interview with exception of the second interview
with Wilma. During Wilma’s follow-up interview, the transcript only was alluded to during the interview. Although her transcript was available at the follow-up interview, reference was made to specific quotes that had been taken from her transcript and included in her case summary for follow-up. In addition to the transcript being available, each participant received a typed summary of all analyses that had been completed. These summaries included descriptions of the data provided (i.e., restatement of their definitions, factors identified as contributing to quality of life, and a restatement of their recommendations for school staff and other influential figures) and a summary of researcher interpretations of their data. Researcher interpretations included thoughts and interpretations made by the researcher, summaries and categorizations of their data, as well as additional questions that arose from the analysis. Questions resulting from the analysis of interview data guided subsequent interviews. Although the actual transcript was used with only three of the participants, the summary of analyses was used in every follow-up interview. A sample summary of analyses may be viewed in Appendix D (all identifying information has been removed). This process proved to be valuable as participants were provided the responsibility of validating the data and analyses made. In several cases the review of such data impacted the participants in several ways. First, participants were able to identify information that was not consistent with what they intended to report. In one case, changes made to the data were critical as they substantially changed the meaning and implications of the data. Secondly, the participants used that opportunity to share additional experiences and enhance what they had originally reported. In the absence of this validating experience the reliability of these data would have been weak and questionable. Through these experiences, the interviewer
became greater informed and empowered to comprehend the specific needs of a population. Following the interview, the participant was thanked for his/her participation and informed that he/she may be contacted should additional questions arise during the analysis of the data.

Given the nature of the discussions that took place during the interviews, it was anticipated that participants might have experienced some emotional distress. In the event the need for emotional support or counseling did arise, Hop-to-It staff was available to provide such support. Participants also were forewarned that they had the right to refuse a reply to any questions that they were not comfortable answering. A few times during the interviews, the interviewer was asked to stop the recording due to the personal and sensitive nature of what was being shared. Discussions that took place during that period of time were neither hand- nor tape-recorded and were not included in the results of this study. Although the support staff was available through the Hop-to-It program, the need for such services did not arise.

The final interview session served as an opportunity for the participant to be made aware of any additional interpretations and findings from the data and offer additional feedback or clarifications. Following a review of the findings, feedback and interpretation, each participant engaged in a final debriefing with the investigator. Debriefing is the process of making participants aware of the researcher’s mission for the study. Although the mission was made clear from the beginning, the researcher again reviewed the purpose of the research activities. Additionally, the researcher explained the next steps in the process and solicited participants’ feedback about the experience of being involved in the study. This session served as an opportunity for the researcher to
gain feedback about his/her interactions with the families and any strengths or weaknesses that the families deemed important. This session also served as an opportunity for the participant to be made aware of any additional interpretations and findings from the data and offer additional feedback or clarifications. This awareness was achieved via the review of the Summary of Analysis and Interviewer Thoughts (see Appendix D), which was provided to each participant and used to guide the interview. Respondents were posed questions related to each section of the summary and allowed to provide feedback and make any changes, deletions, or additions to the data.

All data remained confidential and were viewed only by the investigator and the supervising committee when needed. Interview data remained in the locked office of the investigator. Additional security measures included the use of pseudonyms on interview forms. Each participant was given a code, which consisted of letters and numbers. This code was used instead of names on the participant interview form. The investigator, on a secure, electronic file, maintained a master code list. Participants were paid $10.00 for their participation in each session. The participant recruitment and data collection period took place over a period of six months. Participant recruitment lasted for five weeks allowing time for prospective participants to be identified and the selection process to take place. Each participant engaged in an interview (a minimum of two) at an average of six to nine weeks apart, until the researcher was satisfied with the clarity of data collected.

Data Analysis

Analysis of collected data was ongoing and analyzed at two levels: single case and cross-case. The first level involved a detailed descriptive analysis of each individual
interview and the generation of themes within each interview. Creswell (1998) refers to the analysis of themes within an individual case as within case analysis. According to Creswell (1998), description serves as the core of qualitative research, allowing the investigator to become the storyteller and engage the reader through a presentation of his/her experiences while in the field. The investigator first sets up a context for the presentation by providing a concrete description of the setting and events surrounding the experience, then carefully presents facts and ties together detail. Thus the end product entails a description of the experiences and challenges faced by caregivers of children with sickle cell disease. Participants’ voices were presented through the use of quotations.

The second level, called a cross-case analysis, involved a thematic analysis across the cases and an interpretation of the meaning of the cases. The analysis concluded with a documentation of the lessons learned from the case. Because the process of analyzing can be overwhelming (Anfara et al., 2002), the investigator enlisted the help of a colleague with an extensive background in qualitative research and data analysis, who simultaneously analyzed data resulting from the practice interview. This process allowed the researcher to obtain feedback about the way the data were being viewed and assess reliability. While subsequent interview data were not reviewed, this colleague intermittently provided assistance with data analyses throughout this process serving as a peer reviewer and challenging higher levels of data analysis.
Chapter IV

Results

This chapter provides a detailed overview of the study results. A description of each participant, including family demographics, is presented first, followed by results of the cross-case analysis. Results include a presentation of participant definitions of the term ‘quality of life,’ their quality of life before and after the birth of the child, factors influencing quality of life, prioritization of parent needs, and recommended strategies for promoting quality of life among parents of children with SCD. To maintain the confidentiality of the participants, each parent has been assigned a fictitious name. In each case, all discussion is based on participant report.

Definition of Quality of Life

In determining the quality of life of these parents, it was important to first understand how each of them conceptualized that term. Each participant was asked to describe what comes to mind when they hear the term ‘quality of life.’ The definitions provided were very different. Emily defines quality of life as living the “American Dream,” living in a beautiful and nice neighborhood, attending ‘A’ quality schools, having an enlightened education, having some measure of success, and attaining some prestige, privilege and power. Emily links prestige to education indicating that education is a means to prestige. Privilege she defined as being in a certain group, in a certain circle of friends. Power, she stated, is money. Additionally, Emily’s definition of quality of life includes having opportunities that were not afforded to her as a child, and setting the
stage to allow her daughter with SCD, later on, to continue the quality of life that she and her husband have given to her.

Howard views quality of life from a different perspective. He defines this term as having a fulfillment of life. Fulfillment of life, he further explained, is being biblically fulfilled (observing biblical principles) and having children. He further defined quality of life as happiness, being alive, and understanding that we are here for a certain time. Howard asserts that “any day above ground is a good day.” Wilma and Zanine provided very brief definitions. When asked to describe what comes to mind when she hears the term ‘quality of life,’ Wilma stated simply, “a way of life in general, a decent life.” She further explained that she does not require a million dollar mansion to have a quality of life but must live “decently.” Zanine defined quality of life as "both the parent and child having good health,” and "having money.” She explain that money plays a key role because one needs it to help pay bills.

To compare their perceptions of quality of life over time, each participant was asked to describe their quality of life prior to the birth of their child with SCD and in the present. Similar to their definitions, their descriptions also varied. Emily recounted her early experiences living in an inner-city, rat-infested community where her family owned their own home. Although her family owned their own home, it was located in a depressed community. In addition, this parent observed how the quality of the school and the education to which she was exposed differed significantly from that of her Caucasian counterparts. On the job as well, she observed economic and environmental differences between she and her Caucasian peers. These living conditions and the disparities that
existed between she and her peers led her to pursue success and “level the playing field” between she and her Caucasian counterparts.

Howard came from a spiritual home where his family attended church, bible study, and prayer meetings on a regular basis. His description of his quality of life prior to the birth of his child involved living in a stable family, observing biblical principles, pursuing success, having high expectations from his parents, being financially stable, disciplined, and determined. However, he stated that his life was not fulfilled until the birth of his children.

Wilma reported that her quality of life was “okay, fine.” She was a single parent with two children, had just gotten saved (in the church), and spent time going to church. There she met her husband, the father of her child with SCD. Zanine’s description related to her teenage years due to the birth to her child with SCD during her late teenage years. She further reported that she was pretty free because she had nothing to worry about. She lived at home with her mother.

Table 1

<table>
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<tr>
<th>Descriptions of quality of life since birth of child</th>
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<tbody>
<tr>
<td>Emily</td>
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<tr>
<td>Constant challenges</td>
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<td>Frustration</td>
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Table 1 displays a summary of participants’ descriptions of their quality of life since the birth of their children with SCD. When describing their current quality of life, all participants indicated that they had major challenges (i.e., exclusion from medical care).
decisions, attaining appropriate educational accommodations) in regards to their children with SCD. Although one parent refused to provide detail, each parent was forced to advocate for their children to get appropriate medical care. Participants described numerous experiences that involved medical professionals or residents making inappropriate and sometimes harmful decisions for their child. For example, upon learning that the knowledge of most doctors about SCD was limited, all participants resorted to conducting research to educate themselves about the disorder. By conducting research and observing other physicians throughout their children’s lives, these parents accumulated a wealth of knowledge about SCD and its treatment. Three parents reported that they had to fight/struggle to be included as a member of the team making medical decisions for their child. Two of the four parents shared specific experiences wherein their input about what their children needed was disregarded. They had to resort to being assertive and strictly demand what they wanted, against what the doctor/residents were attempting to do.

“And sometimes I have to say to them, its time for her to have a blood transfusion. They fight with me and say, no its not time. I say, yes its time. She’s deteriorating a lot. She needs a blood transfusion. And when they go check this, I mean okay Mrs. Emily we’ll go ahead. Or sometimes I have to revert to calling her old hematologist back in another state and share with him just over the phone and he’s not getting paid for this. But I guess because he’s so dedicated, he was such a wonderful doctor. I would describe to him what’s going on and he would say, Mrs. Emily tell them to transfuse her now. Exactly what I was telling them to do is exactly what he said to me.
And so it’s a struggle because I find some (doctors) are more knowledgeable than others.” (Emily)

Additionally, the parents had challenges finding doctors that appeared to genuinely care about the welfare of their children, who took time to talk to and hear them and their children, and who made him/herself available to them at any time. Zanine, when probed about her experiences with doctors, stated, “I won’t comment on that.” Wilma and Howard specifically related a lack of satisfaction with Doctors who did not ‘know them.’

Another common experience involved the realization that information available on SCD was limited. Each parent found it challenging to locate information that would educate them about the disease. When posing questions to doctors, three participants reported that the doctors seldom would take time to answer questions and would sometimes provide them a pamphlet. The pamphlets, they reported, “said nothing” (meaning the information was not very helpful and was limited). They resorted to other means such as purchasing books, attending conferences, and gathering any information they could find. These three parents also were forced to demand information about medical procedures/tests being completed on their children. Wilma reported how she demanded to know everything that was being done to her child and the purpose for the procedure. That was a way that she stored knowledge.

“And when it came to the hospital, when they were telling me at one time that my baby needed a spinal tap, I had enough sense to know he didn’t need a spinal tap. His hemoglobin is always going to be low. It’s things I could tell a doctor, I mean its things that I was telling residents. They couldn’t tell me because I read. And you know, I am not that parent, when my baby gets sick, rush him to the hospital and just stand back. I want
to know what you’re doing. I want to know his hemoglobin. I want to know what you are wanting to stick. I want to know everything because I educated myself” (Wilma).

Other descriptions of the current quality of life involved a direct rating comparing the formal (early years of child) and current quality. Two participants reported that their quality of life had improved greatly due to the improved health of their children. They reported that their children are not getting as sick as they previously did and that makes life much better. One of these parents related her improvement to increased resources. Earlier on, she did not have a car for transportation. Additionally, she reported that money and work was limited. She now has transportation and a better home. In terms of money, she says that she still is broke. A third parent, Howard, reported that his quality of life was good before and is still good now. He reported that he does not regret his experiences because he believes that all things happen for a reason and he enjoyed his experience raising a child with SCD. Emily reported challenges prior to the birth of her child, earlier on in her child’s life and currently. Unlike the other three participants, Emily’s child continues to experience frequent pain crises. These experiences are emotionally challenging for Emily, who has experienced bouts of depression as a result.

Table 2 presents a comparison of participants’ definitions of quality of life and the nature of their individual experiences. The nature of participants’ definitions and experiences represent the themes that surfaced in their definitions as they discussed their early experiences.
<table>
<thead>
<tr>
<th>Participant</th>
<th>Nature of Definition</th>
<th>Nature of Experiences</th>
</tr>
</thead>
<tbody>
<tr>
<td>Emily</td>
<td>Living the American Dream</td>
<td>Struggled for success</td>
</tr>
<tr>
<td></td>
<td>Nice homes</td>
<td>Desires education</td>
</tr>
<tr>
<td></td>
<td>Beautiful and nice neighborhoods</td>
<td>Sought nice home early</td>
</tr>
<tr>
<td></td>
<td>Quality education and schools</td>
<td>All advocating targeted better services and education</td>
</tr>
<tr>
<td></td>
<td>Some measure of success</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Attaining some of the Three P’s</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Better opportunities</td>
<td></td>
</tr>
<tr>
<td>Howard</td>
<td>Being biblically fulfilled</td>
<td>Bible stressed in family life</td>
</tr>
<tr>
<td></td>
<td>Happiness</td>
<td>Taught bible as child</td>
</tr>
<tr>
<td></td>
<td>Fulfillment of life</td>
<td>Expects challenges</td>
</tr>
<tr>
<td></td>
<td>Being alive</td>
<td>Stresses true understanding</td>
</tr>
<tr>
<td></td>
<td>Understanding of mortal limitations</td>
<td>Strives to keep child cheerful</td>
</tr>
<tr>
<td>Wilma</td>
<td>A way of life in general</td>
<td>Is happy with current life</td>
</tr>
<tr>
<td></td>
<td>A decent life</td>
<td>Desires more but is content</td>
</tr>
<tr>
<td>Zanine</td>
<td>Good health</td>
<td>Cried often due to health</td>
</tr>
<tr>
<td></td>
<td>Having money</td>
<td>Challenges with crisis</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Financial stress</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Limited work and resources</td>
</tr>
</tbody>
</table>
Contributing Factors

Each participant was probed about factors that were responsible for their perspective on and experience of quality of life. As participants discussed factors impacting their quality of life, it became apparent that some stressors led them to unhealthy reactions (such as depression, crying, stress, and worrying) while others tended to serve as factors that strengthened these parents during tough times. For example, all participants specifically stated that prayer/faith in God strengthened them. Based on these associations, the numerous factors identified by participants were grouped into two categories, positive and negative contributors to quality of life. These groupings were verified by participants.

Negative contributors. Negative contributors to the experience of quality of life are defined as those factors that tend to produce some negative impact on the individual or that tend to be negative in nature. Refer to Table 3 for a display of these factors communicated by each participant. Some of these factors led directly to negative reactions. For example, the health of the child led to bouts of depression and nights of crying for two parents. Challenges with medical professionals also subjected parents to fighting/struggling to get what their children needed.

Table 3

<table>
<thead>
<tr>
<th></th>
<th>Emily</th>
<th>Howard</th>
<th>Wilma</th>
<th>Zanine</th>
</tr>
</thead>
<tbody>
<tr>
<td>Guilt</td>
<td>Care for child</td>
<td>Health challenges</td>
<td>Health of child:</td>
<td></td>
</tr>
<tr>
<td></td>
<td>challenging during early years</td>
<td>during first two years of child’s life</td>
<td>Challenges with illness</td>
<td></td>
</tr>
<tr>
<td>Role of advocacy</td>
<td>Advocate for child</td>
<td>Advocating for appropriate healthcare</td>
<td>Limited work and money</td>
<td></td>
</tr>
<tr>
<td>-----------------------</td>
<td>------------------------</td>
<td>----------------------------------------</td>
<td>------------------------</td>
<td></td>
</tr>
<tr>
<td>Fighting wars</td>
<td>Fighting to be involved with healthcare decisions</td>
<td>Fighting to be involved with child’s medical decisions</td>
<td>No transportation early on</td>
<td></td>
</tr>
<tr>
<td>Ongoing challenges</td>
<td>Challenges with medical professionals/medical healthcare</td>
<td>Challenges with medical professionals: Quality of healthcare is being spoiled</td>
<td>Scarcity of doctors and hospitals</td>
<td></td>
</tr>
<tr>
<td>Scarcity of information</td>
<td>Scarcity of information available on SCD: Forced to educate self</td>
<td>Scarcity of information available on SCD: Forced to educate self</td>
<td>Scarcity of information available on SCD: Forced to educate self</td>
<td></td>
</tr>
<tr>
<td>Resentment</td>
<td>Limited knowledge of SCD among medical professionals</td>
<td>Quality of medical professionals</td>
<td>Emotional stress: Crying at night due to son’s condition</td>
<td></td>
</tr>
</tbody>
</table>

(minimized by love for child)
Several consistencies existed across participants as is evident in Table 3. Being eyewitnesses to the suffering of their children with SCD was one factor that resulting in negative feelings (such as depression and guilt) for three of the four participants. Howard is the one exception. He reported being impacted by the suffering of his child; however, due to his outlook on life, he appreciates the experience and believes that he received a measure of strength from experiencing this challenge. Scarcity of information available on SCD was another factor consistent across all four participants. Lacking information on
SCD and being unable to get questions answered by the medical doctors made the beginning years especially difficult for all participants. Another factor shared across three of the four participants is the quality of health care professionals. Lacking experiences with doctors who get to know their patients, at least their names, led to dissatisfaction with medical services and to fights with medical doctors.

*Positive contributors.* Positive contributors identified by each participant are presented in Table 4. The table contains a list of factors identified by participants as contributing to their quality of life or as having a positive impact on them. Numerous factors surfaced as having provided strength to get each participant through their challenging times. In reviewing these factors, several major themes were identified under which these positive contributing factors may be classified. In addition, the number of factors in this domain encouraged the grouping of them into smaller domains. While factors were taken directly from each transcript (verbatim), domains were labeled by the researcher.

The Self was identified as one domain. The Self refers to characteristics of the individual that directly influences or moderates their response to a stressor. Spirituality refers to any positive contributing factors that involved God, prayer, faith and belief or any relation to a greater, non-human power. Family refers to either characteristics of the family that provides encouragement to move forward in the face of challenges or hope in the future financial, educational, and medical success of the family. Education refers to self-empowerment through studying, conducting research, and knowledge present in participant’s repertoire that helped them to overcome their challenges. Culture/Upbringing refers to characteristics of participants’ own upbringing (the way in
which they were reared) or their family’s cultural beliefs. Environment refers to characteristics of participant’s physical environment. Resources refer to money and other necessities for daily living and survival. The Other category was reserved for other factors that did not easily fit into any of the other domains. Factors for each participant have been grouped according to these domains and are presented in the following tables. While factors were taken directly from each transcript (verbatim), domains were labeled by the researcher.

Table 4

<table>
<thead>
<tr>
<th>Factors contributing positively to quality of life</th>
</tr>
</thead>
<tbody>
<tr>
<td>Emily</td>
</tr>
<tr>
<td>The Self</td>
</tr>
<tr>
<td>Attitude</td>
</tr>
<tr>
<td>Outlook on life</td>
</tr>
<tr>
<td>Vision</td>
</tr>
<tr>
<td>Four D’s/Three P’s</td>
</tr>
<tr>
<td>Perseverance</td>
</tr>
<tr>
<td>Ability to reinvent</td>
</tr>
<tr>
<td>Adaptability</td>
</tr>
<tr>
<td>Organization</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Emily</th>
<th>Howard</th>
<th>Wilma</th>
<th>Zanine</th>
</tr>
</thead>
<tbody>
<tr>
<td>Attitude</td>
<td>Attitude</td>
<td>Approach</td>
<td>Motivated to</td>
</tr>
<tr>
<td>Outlook on life</td>
<td>Outlook on life</td>
<td>to/Outlook on life</td>
<td>educate self re: SCD</td>
</tr>
<tr>
<td>Vision</td>
<td>Self education</td>
<td>Love for her child</td>
<td>Did a lot of research</td>
</tr>
<tr>
<td>Four D’s/Three P’s</td>
<td>Structure/Discipline</td>
<td>Expectations for her son: No limits</td>
<td>on the internet</td>
</tr>
<tr>
<td>Perseverance</td>
<td>Marine Corps</td>
<td>son: No limits</td>
<td>Takes actions/</td>
</tr>
<tr>
<td>Ability to reinvent</td>
<td>Accepts things</td>
<td>.initiative to keep</td>
<td>son productive and</td>
</tr>
<tr>
<td>Adaptability</td>
<td></td>
<td></td>
<td>complication free</td>
</tr>
<tr>
<td>Organization</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Emily</td>
<td>Howard</td>
<td>Wilma</td>
<td>Zanine</td>
</tr>
<tr>
<td>-------</td>
<td>--------</td>
<td>-------</td>
<td>--------</td>
</tr>
<tr>
<td><strong>Spirituality</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Prayer</td>
<td>Church attendance</td>
<td>Faith</td>
<td>Prayed a lot</td>
</tr>
<tr>
<td>Faith</td>
<td>Attended prayer</td>
<td>Prayer</td>
<td></td>
</tr>
<tr>
<td>The LORD - Rock</td>
<td>meetings</td>
<td>Family prayer</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Biblical fulfillment</td>
<td>Reliance on God</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Biblical principles</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Learning the Bible</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Family Characteristics/Well-being</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Seeing child</td>
<td>Healthy of child</td>
<td>Child’s improved</td>
<td>Good health</td>
</tr>
<tr>
<td>potential reinforced</td>
<td>Closeness</td>
<td>health</td>
<td>Child’s needs being</td>
</tr>
<tr>
<td>Optimism for child</td>
<td>Wife</td>
<td>Work (financial)</td>
<td>met</td>
</tr>
<tr>
<td>Child’s health</td>
<td>Children’s</td>
<td>Money but not</td>
<td></td>
</tr>
<tr>
<td>Establishing QoL for child</td>
<td>happiness</td>
<td>directly</td>
<td></td>
</tr>
<tr>
<td>Financial security</td>
<td>Daughter’s response</td>
<td>Child’s strengths</td>
<td></td>
</tr>
<tr>
<td>Pulling potential out of child</td>
<td>to her upbringing</td>
<td>Child’s knowledge</td>
<td></td>
</tr>
<tr>
<td>Time with family</td>
<td>(Taking time out)</td>
<td>Togetherness</td>
<td></td>
</tr>
<tr>
<td>Measure of success</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Emily</td>
<td>Howard</td>
<td>Wilma</td>
</tr>
<tr>
<td>----------------</td>
<td>---------</td>
<td>--------</td>
<td>-----------</td>
</tr>
<tr>
<td><strong>Education</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Studied successful people</td>
<td></td>
<td></td>
<td>Self-education re: SCD</td>
</tr>
<tr>
<td>Taught herself (self-help)</td>
<td></td>
<td></td>
<td>Parent’s college education</td>
</tr>
<tr>
<td>Knowledge Enlightened education</td>
<td></td>
<td></td>
<td>Her level of knowledge re: helped her with advocacy</td>
</tr>
<tr>
<td><strong>Environment</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Quality of neighborhood</td>
<td></td>
<td></td>
<td>A better living place</td>
</tr>
<tr>
<td>Quality of schools attended</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Upbringing/Culture</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Success Expectations</td>
<td>Faith</td>
<td></td>
<td>Discipline Expectations</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Values/Self-respect</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>The way raised</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Successful</td>
</tr>
</tbody>
</table>
Numerous factors were identified as promoting a better quality of life. As with the negative contributing factors, several consistencies (discussed below) exist across the positive contributing factors. Each participant possessed personal characteristics that tended to help them overcome some of the negative experiences that they encountered. Additionally, spirituality was identified by each participant as playing a role in their lives. In terms of contrasts, some participants had a social network (extended family and friends) from which they could draw strength. Education also surfaced as a factor
contributing positively to the quality of life for all four participants. Having educated themselves about SCD, each participant was able to better advocate for the best medical care for their children. The positive effect of education also is apparent in the participants’ accounts of their experiences with medical doctors. For example, Emily recognized her daughter’s need for a blood transfusion when the doctors saw no need. After further consultation with a previous doctor and a review of the symptoms, an emergency transfusion did occur.

Present State of Participant: Quality of Life

Participants were asked the following question during the first interview: “how is (parent) right now?” with their name being inserted in place of parent. Responses ranged from simple to more detailed, from “satisfied” to “overwhelmed” to “not good.” A breakdown of the responses follows in Table 5.

Table 5

Parent descriptions of their present state

<table>
<thead>
<tr>
<th>Participant</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Emily</td>
<td>Currently feel good but recently a basket case: Hidden turmoil, deep depression, lots of crying, rage inside, cultural barriers</td>
</tr>
<tr>
<td></td>
<td>Accommodates self: Self-designed interventions</td>
</tr>
<tr>
<td></td>
<td>Children are her ministry</td>
</tr>
<tr>
<td></td>
<td>Angry at husband; Sees family as not normal</td>
</tr>
<tr>
<td></td>
<td>Unable to fulfill desire of completing degree</td>
</tr>
<tr>
<td></td>
<td>Gets overwhelmed: Challenges are taxing, CEO of her home</td>
</tr>
<tr>
<td></td>
<td>Currently not satisfied with life right now</td>
</tr>
</tbody>
</table>

54
<table>
<thead>
<tr>
<th>Participant</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Howard</td>
<td>Satisfied</td>
</tr>
<tr>
<td></td>
<td>Doing fine</td>
</tr>
<tr>
<td></td>
<td>Wants some things better for his children but they are out of his control</td>
</tr>
<tr>
<td></td>
<td>“Other than that I’m great”</td>
</tr>
<tr>
<td></td>
<td>I’m happy</td>
</tr>
<tr>
<td></td>
<td>I’m comfortable</td>
</tr>
<tr>
<td></td>
<td>Just leveled: Balanced: I’m right in the middle; Bubbles not floating either way, negative or positive</td>
</tr>
<tr>
<td>Wilma</td>
<td>I don’t have the best</td>
</tr>
<tr>
<td></td>
<td>I am not in a hundred thousand dollar house, but its fine</td>
</tr>
<tr>
<td></td>
<td>I feel overwhelmed</td>
</tr>
<tr>
<td></td>
<td>“I’ll kind of calm down once I get to lie down”</td>
</tr>
<tr>
<td></td>
<td>Okay right now – I am out of my environment</td>
</tr>
<tr>
<td></td>
<td>“I feel overwhelmed a lot.”</td>
</tr>
<tr>
<td>Zanine</td>
<td>Not good</td>
</tr>
<tr>
<td></td>
<td>Not good because my son is without a doctor to take care of him</td>
</tr>
</tbody>
</table>

The present state of the parents at the time of the interviews varied for various reasons. As is consistent with her definition of quality of life and the nature of her experiences, Zanine reported that she was not very happy (despite her better living environment and having transportation) because her son is without a doctor to take care
of him. Emily had just endured a personal crisis due to her daughter’s condition; however, she had managed to help herself through that time. She reports, however, that she currently was not satisfied because (as is consistent with her definition of quality of life and the nature of her experiences) her education had not been completed. She reported wanting to complete her degree but had not been able to, due to her excessive responsibilities. Emily like Wilma reported getting overwhelmed. Wilma reported that she was okay at the moment of the question because she was away from her environment (home); however, she reports that she feels “overwhelmed a lot.” Howard differed from the other three participants in that he (consistent with his definition of quality of life and the nature of his experiences) reported being “satisfied, doing fine, and just balanced.”

_Awareness of SCD_

Finally, participants were asked to share one thing that they would want others to know about SCD. Specifically, they were asked to state one thing they would say to an influential person (a person who had power to make a difference or make things happen) about SCD. Each participant provided a different response to this question. Emily would like an influential person to understand and communicate to society that SCD is not an African American disease. She feels that certain racial issues are associated with this disorder and she would like it to be viewed as a more common disease. Emily recounted challenges with several agencies that she felt were largely due to SCD being a disease that affects mostly African Americans. Zanine, likewise, felt that individuals with other diseases, like cancer, get more publicity and awareness. These experiences led the parents to conclude that a level of racism underlies their challenges, given that cancer largely impacts other races of people.
“You always hear things about children with cancer, but nothing about children with sickle cell disease. They do more things for them.” (Zanine)

Wilma, likewise, felt that people of influence could assist with increasing awareness of the disease. Every participant felt that SCD does not get enough attention. Howard and Wilma would like people to understand that SCD is not a hidden disease and that it is not going away. Wilma asserts that people should understand that there are parents out there who have children with life threatening diseases and that they really care about their children.

Wilma and Zanine asserted that parents affected by SCD need to go out and get more involved by increasing awareness themselves. Additionally, Howard felt like the depth of information available on SCD needs to be improved. He communicated that, in his personal opinion, some of the information available is outdated. Two parents offered very interesting responses to this question, “state one thing you would say to an influential person about SCD or what one thing would you want others to know about SCD?”

“Has Oprah Winfrey done anything about sickle cell anemia? Well, I would like for somebody to bring it to her attention because she has the ability to bring about that awareness because she reaches so many homes. I would love for somebody to call Ms. Oprah and say, Ms. Oprah here’s something and its not just indicative of African Americans. Sickle cell anemia affects Middle Easterners, which consists of Sicilians, Asians, and Indians and some Caucasians. There are different strands of sickle cell anemia. What could we do to make this become a household name? The woman has the
power and the compassion to do it. Why has anyone not thought about bringing it to her attention?” (Emily)

Emily believes that Oprah Winfrey has a heart for these sorts of challenges and that she is in a powerful position to promote awareness. She further explains why people need to be informed. “She has the power, but before she retires someone needs to bring it out there. You want this to get out there because people, especially Caucasians, ask me, what is sickle cell anemia?” (Emily)

Initially (during the first interview) Zanine gave this reply, “nothing” when asked what she would want influential people to know. Then she later added, “researchers come and get information but they don’t do nothing.” Due to past experiences with research and the perceived lack of follow-up, she felt that there was no recommendation to offer or that there was no use in offering one. Regarding this particular study, she says she really did not want to participate. “No reflection on you” she said to the researcher. She simply wanted to communicate that there is a lack of follow-up from researchers.

Experiences with Schools

As it relates to schools, experiences ranged from good to challenging. Wilma recalls good experiences with her son’s school because he always attended a private school where the staffed worked with her. By the term “worked with me,” she meant that the staff collaborated with her to ensure that her son’s needs were met. They allowed nurses from community agencies to come annually and educate staff and classes about SCD. Wilma appreciated how the school (prior to the beginning of each school year) ensured that her son had an updated physical examination and they consulted with a local organization about the most appropriate ways to support him in the school setting.
Additionally, “they got a picture of him in case he gets sick, to make sure that’s him.” (Wilma)

Howard also communicated that “they follow through” at his daughter’s current school. He struggled, however, with his daughter’s academic performance. She began, he says, with high performance, which then dropped due to absences from school. Zanine simply suggested that schools should bring in people to educate staff and students concerning SCD. Emily reported both positive and challenging experiences with schools. She found that she had to educate schools about SCD because staff, even some African American staff, was not aware of the disorder. Emily also has had a mixture of teachers who were very compassionate towards her daughter and some who were not. She discussed the teacher who made assumptions about her daughter’s economic background, resisted implementing needed accommodations, and was very insensitive. Additionally, she discussed how helpful it was to have educators who were familiar with the child and already understood her illness.

**Summary**

These parents each communicated their subjective experiences of quality of life and their perceptions of that term. Each parent presented a unique definition of the term quality of life, yet factors described as influencing their quality of life were largely consistent across interviews. These data seem to suggest that individuals will describe or define the term according to their subjective experiences; however, the same factors may interact to determine their quality of life.

These data also indicate that a myriad of factors exist to serve as sources of strength or resilience in the lives of these parents moderating the stress associated with
SCD. Embedded within the data from each case also are strategies that communicate ways that professionals could strengthen their practices to aid in improving the quality of life of those they serve. Chapter 5 will discuss the similarities and differences across participants and the implications in detail.
Chapter V

Discussion

The results of this study are discussed in this chapter. The following discussion includes many important findings that have implications for social service, educational, and medical professionals, as well as those within the research community. The following sections will review the questions that directed these research activities. Findings of the study will be discussed as they relate to each research question.

Research Questions

Research Question #1: What is the overall quality of life of caregivers of children with sickle cell disease?

The first research question concerned the overall quality of life of caregivers of children with SCD. In determining the perceptions of quality of life, it was important to determine how each participant conceptualized the term. In this study, conceptualizations differed across participants. These results are consistent with prior research indicating that the definition of quality of life differs vastly from individual to individual based on their experiences (Hofstede, 1984; Paloutzian & Ellison, 1982; Sawyer et al., 2004). Each definition provided by participants was distinctive from the next one. Interestingly, the nature of the definitions provided by each parent was consistent with the nature of their individual life experiences (i.e., their general approach to conflicts, their child-rearing practices, and the way in which they were impacted by different challenges in life). Researchers have found that individuals’ perceptions of their quality of life are based
heavily on their subjective experiences (Hofstede, 1984; Juniper, 1997; Paloutzian & Ellison, 1982; Rakib et al., 2005; Sawyer et al., 2004; Theunissen et al., 1998). Thus, it is conceivable that their definitions also would reflect that subjectivity. It is hypothesized that the individuals are likely to define the term quality of life based on their most salient life experiences. This does not suggest that their quality of life is not impacted by factors outside of those salient experiences but that these subjective experiences are so significant they stand out as the primary contributor to quality of life.

For example, Emily conceptualized the quality of life as living the American Dream and having access to top quality resources (i.e., homes, education, neighborhoods, etc.). Her descriptions of experiences encountered throughout life tended to involve the same types of themes/values that are embedded within her definition. She described how she lived among poor environmental conditions; attend poor quality schools; and struggled with the frequent health challenges of her daughter. With one exception, every type of conflict shared by this parent involved the pursuit of the best services or resources of some type (i.e., medical care, education, support resources, etc.). In addition, each participant without fail provided a description of their present state or satisfaction with life that was absolutely consistent with their definitions of quality of life and the nature of their experiences. What is apparent in comparing the definitions of these parents to their life experiences is that their conceptualizations of the term quality of life tended to be shaped by their individual experiences with life. Rather it is what they value most or what they tended to struggle with over time; there appears to be a definite relationship between these factors. These findings directly support previous empirical findings about the relationship between perceptions of quality of life and subjective experiences. Many
factors were identified as impacting quality of life in some form further supporting the individualized nature of the experience and reality of quality of life. Based on these observations, it may be hypothesized that critical factors exist in each individual’s life that moderate the effects of SCD on caregivers. This hypothesis is proposed despite the shared experiences, beliefs, or demographics of participants. Data from this study illustrates that each participant, prior to the birth of their child with SCD, developed different values (evident in their definitions), and pursued different types of goals (i.e., prestige, privilege, power/money, biblical fulfillment, education, discipline) for them and their children. What is intriguing, however, is that in spite of those differences, many of the same types of factors impacted their quality of life in some way.

Related directly to the first research question, each parent described their quality of life, as they currently perceived it. It appears that quality of life changed over time for two of the participants and changed somewhat for one other. According to Wilma, her quality of life changed “a great deal.” The change in quality of life appeared to be directly related to changes in the factors targeted in their definitions as well as other contributing factors. Howard did not indicate any changes in his quality of life (except the fulfillment of happiness after the birth of his children). Based on his definition, his perception of quality of life appears to have been consistent over time given that the factors embedded in his definition were instilled in him as a child and continue to be present in his life.

With the exception of Howard, these findings are consistent with the research of Bernhard, Lowry, Mathys, Herrman, and Hurny (2004). They concluded, based on their investigations, that the meaning of the term quality of life changed over time for patients.
with colon cancer. This suggests the necessity to periodically evaluate client’s perceptions as well as their satisfaction when attempting to measure quality of life. This is especially critical for research that is longitudinal in nature. It is possible that what is being measured at one instant might differ from what is measured over time due to the alteration of perspectives.

Many factors might explain the stability of Howard’s quality of life over time. These data, however, are not sufficient to make that determination. Another consideration is the fact that he is the only male. Again, while that determination cannot be made with these data, this notion of gender role has merit and should be explored with further research. Howard explained how his wife is excessively emotional regarding his daughter’s illness. Although this study targeted Howard, there is some merit to investigating how two parents, from the same family, exposed to illness/crises could have such different emotional responses. While the cause of Howard’s stability only could be speculated, it is certain that a complex interaction exists between health of the child, perspective/outlook on life, and personal and family characteristics to influence the quality of life.

Parents were asked to describe their current quality of life. Without exception, each description involved the status of the ill child. It should be noted that parents were not prompted to describe how the child’s health related to their quality of life. However, each parent included the child in their descriptions. This observation is indicative that parents may not be able to describe or view their quality of life outside of the child with SCD. In relation to the previous hypothesis, the consistent inclusion of the ill child in their definitions resulted from the idea that their experiences in raising this child were one...
of the most salient experiences in their lives. While the presence of SCD in their lives is not solely responsible for their quality of life, it appeared to have significant impact. Recall that two participants directly related their improved quality of life to the improvement in the health of their children (i.e., less crisis, child being able to care for self, etc.). Notice again how these experiences related directly to the definitions provided by each participant. Although in a state of distress a few months earlier, Emily stated “right now I feel good.” The only change was the recent ending of her daughter’s last crisis.

Another important notation is that these parents appear to possess certain resiliencies or personal strengths that help them to buffer the various stressors in their lives. Thus, it may not be obvious to others that these parents are confronted with such greater stressors because they are able to compensate well. High levels of stress may be hidden so well that their needs can easily go undetected. It is therefore imperative to be sensitive to parents in order to increase the likelihood of identifying high levels of stress, depression, or other internalized turmoil that they might have managed to conceal from others in their environment. As will be seen in a later section, two of the four parents stopped sharing their needs due to several factors (including a lack of trust). It is essential to build trust with these parents so that they will have an outlet for these feelings should the need arise.

Research Question #2: What factors influence the quality of life of caregivers of children with sickle cell disease? What do caregivers of children with sickle cell disease perceive as the interaction between these factors?
Lim and Zebrack (2004), in their review of numerous studies concentrating on the quality of life for caregivers of individuals with chronic illnesses, found that a myriad of factors accounted for their quality of life. Among the factors noted were patient and caregiver stressors, coping ability, and social support. These reports were broadly consistent with the reports of participants involved in this study. The next few sections will explain those findings and their implications.

Parents identified numerous factors that impacted their quality of life both negatively and positively. Every factor included in their definitions of quality of life were reiterated as contributing factors including quality homes and neighborhoods, having resources, the adherence to biblical principles, and good health, among others. Results found that a number of additional factors contributed to their quality of life over and above those included in their definitions. It appears that caregivers of children with SCD might define SCD based on their most salient experiences; however, a number of other factors appear to influence how they actually perceive or rate their quality of life.

Several factors were consistent across cases including prayer/spirituality, strengths/resilience of the parents, happiness of family, health of the child, and challenges associated with the provision of care to a child with sickle cell disease. Other factors surfaced as contributors to quality of life, but were not consistently identified by each parent. One major contributor identified by every parent was prayer/spirituality. These families appear to rely heavily on prayer. Three of the parents directly related the ability to survive stressful periods to the power of prayer in their lives. All of the families exhibited faith in God and a belief in applying biblical principles to their lives.
One future research study might investigate further the interplay of culture and spirituality or just spirituality, given that prior research identified spirituality as a strength among African American families (Briscoe, Joseph, Sengova, Smith, & McClain, 2000). Another study might investigate the contrast between spiritual and non-spiritual care providers of SCD.

Robert Hill (1999) investigated the experiences of African-American families and found that they were able to rebound from crises and major stresses and achieve a level of wellness or success. In studying this group, Hill analyzed some of the strengths that were consistently found among people of this culture. Among the factors identified as strengths of African-Americans were strong achievement orientation, strong kinship bonds, and strong religious orientation. These factors support the outcomes of this study given that each of these factors emerged as contributing positively to the quality of life of the African-American participants. Future investigations might analyze how these families handle the specific demands of SCD. Some of those factors have emerged from these data; however, the results of this study only highlight approaches relative to the participants of this study.

Apparently from the experiences of these participants, an enormous amount of SCD-related challenges exist and result in other emotional, social, and financial difficulties. In the midst of hardship, the notion of resilience permeates these parents’ discussions. The factors of resilience range from unique to common across participants, and illuminate the fact that some caregivers of children with SCD have personal factors that divert them from the extremes of associated stressors.
The personal attributes of these parents and their particular outlooks on life appeared to create in them a shelter in which they could be protected from the challenges they faced. Emily, Howard, and Wilma identified personal beliefs that had a direct impact on how they approached conflict in their lives. This suggests the possibility that personal beliefs or attitudes toward life moderate the responses of parents to major stress in their lives. Some examples of factors that might serve as moderators include vision, expectation (expecting challenges as a normal part of life), belief that better experiences are forthcoming, and focus (concentrating on the positive opposed to the negative). According to Emily, “if you focus on where you are at or the negative that you are dealing with, then you will never overcome it.” Investigators might study the relations between these beliefs and caregiver response to stress with a sample population. It is hypothesized that these more optimistic beliefs will result in a greater valuation of and satisfaction with life.

Outlook on life is very important. How you interpret life’s events appears to dictate your approach to them. This serves as another hypothesis that may be explored in future research. If a map of these participants’ lives was drawn, it would indicate a direct path between early experiences, definitions/perceptions of the term quality of life, and later approach to life. For example, Howard was raised with biblical principles, he defines quality of life as being biblically fulfilled, and now he applies these principles to his life. Clearly, perspectives will differ from parent to parent. It is essential to help guide parents towards a mode of thinking that will ensure the more positive responses to these events. This may be accomplished through formal interventions (counseling) or through
day-to-day habits among professionals of highlighting positive thinking, and challenging negative or unhealthy thoughts/expectations of parents.

Another component that served as a source of strength for each of these parents was their ability to educate themselves. In each case, these parents began with almost no knowledge of what SCD was and how to care for carriers of this disease. Initially each of these parents relied on professionals to educate them but that dependency was short-lived. These parents did research at the library, on the internet, asked questions, attended conferences, and observed their children to accumulate an enormous amount of knowledge about SCD. There exists a notion of ‘parent as expert’ as termed by the investigator. This knowledge allowed these parents to be active participants in decision-making for their children and it provided them a sense of security in terms of judging the quality of health care provided to their children. This point is worthy of further exploration. If all parents are not prone to educating themselves, then there may be some strengths that might be adapted from these parents and used as a tool to strengthen other parents. Their education and experiences with this disorder have led these parents to advocate for their children. Their knowledge and ability to effectively advocate for their children has proven to be a source or strength for them.

Happiness also was identified as a contributing factor, however not in isolation. Findings of this study suggest a possible interaction between happiness, family characteristics, and family cohesion. Recall that togetherness and happiness were specifically identified as reducing the stress level related to caring for the child with SCD. Based on the information shared by participants, togetherness is hypothesized to impact the happiness of the family. Further research might investigate the relationship of
family cohesion and other family characteristics to quality of life. By association, it may be hypothesized that the health status of the child may negatively impact the psychological, social, and emotional well-being of other family members due to the closeness that exists. The reality of living with SCD for family members remains another realm to be explored empirically.

Another area not targeted in this particular study is the role of marital status and impact of care on the marital relationship. Two participants discussed their marital relationships and alluded to some marital stress and marital cohesion. Carter and colleagues (1998) found that parents of children with chronic illness were more likely to experience marital discord and less satisfaction. Contrasting the experiences of study participants, it is possible that the quality of the marital relationship may be compromised due the added stress of providing care to an ill child. The impact, however, may be moderated or mediated by some unknown factors (i.e., individual goals, resilience, and outlook on life). The level of spousal involvement in care giving responsibilities, for example, may serve as a significant contributor to the health and happiness of the marital relationship. Sufficient data are not provided in this study to discuss the impact; however, this is an important route for future research. It is hypothesized that the families providing care to a child with SCD do not necessarily experience greater stress and less satisfaction, although the likelihood increases. It is hypothesized that the provision of care to a child with SCD in the absence of certain resiliencies and positive contributors will lead to marital discord and less satisfaction. Therefore, findings from this research suggest that Carter and colleagues’ position may be expanded to more accurately reflect the reality of care giving and marital health.
The health of the child without doubt impacts care giving in a number of ways. Its specific impact is dependent on several factors such as those presented in the results. Based on experiences of three participants, it is hypothesized that quality of life changes as a function of the health of the child. For example, several parents described how their quality of life was not as good when the child was younger due to the greater frequency of health complications. It is interesting though, that with the exception of one parent, health was not directly implicated in the definitions provided. In considering quality of life of caregivers, though, it is important to use caution. While the presence of this illness does impact the quality of life, it has been established that other factors may interact to moderate the impact of child health. Thus, health alone may not directly or solely change the quality of life, but it may have a significant impact.

One significant factor, challenges with professionals, shared across participants, deserves further attention and should not go unmentioned. An investigation into the prevalence of such challenges is imperative. In a society where parent involvement in child intervention teams is encouraged more and more, being excluded and having to contend to be heard is unacceptable. Although three of the four participants shared this experience, this study lacks the power to make any generalizations to other caregivers in SCD. However, it is likely that such problems exist with others. A related investigation should involve knowledge of health care professionals about SCD and their level of confidence or experience in treating children with this disease. It appears, based on the data in this study that there are few doctors who are knowledgeable of SCD. It is not certain if these parents simply are unfortunate in locating doctors or if there exists a real
scarcity of medical doctors to treat SCD. Perhaps a needs assessment among health care professionals is in order.

Other challenges involved teachers and other school staff. Three of the four parents had negative experiences with school personnel. Sources of difficulties involved preconceptions made regarding the ill child, failure to follow-through on parent requests, and lack of receptiveness to ideas from the parents. These experiences suggest that school staff should frequently evaluate their professional practices to ensure that parents are feeling welcomed, valued, and that their children are receiving appropriate attention. Additionally, given that needs vary from family to family, periodic needs assessment (as they relate to what reasonably could be provided in the school environment) or a simple satisfaction survey may be conducted. When a parent expresses dissatisfaction, it is essential that staff further question parents to identify the problem and employ the appropriate problem solving activities. These same suggestions are in order for social services staff.

Other areas that warrant research attention include the relationship between marital status and age of caregivers in SCD and quality of life. One participant, who represented a single family, shared a definition and experiences which were very different in nature from the other three participants. Research by Tucker (1998) supports the indications that marital status may have direct implications for the stress experienced by parents in the provision of care. Possible factors include financial well-being, greater stress levels, and lack of care giving relief, among others.

Age of the caregiver in SCD may indirectly influence the quality of life of caregivers. Participants involved in this study all were between 40 and 45 years of age
with the exception of Zanine, who was 36-years old. A future investigation might explore whether age or age interacting with other factors (such as experience) correlate with quality of life or parental stress levels.

Informal and formal supports were implicated in the quality of life of caregivers of children with SCD. Family members and friends provided support for these participants. However, one mother did not utilize those resources due to the failure of supporters to maintain confidentiality, to show empathy and genuine interest, and failure to follow through on promises. Although this experience was limited to one of four participants, this topic also is worthy of follow-up in future research. The identification of factors that prevent parents from accessing/utilizing needed support is critical in instituting systems to increase access to care.

Culture played a role in two out of four of the families. This finding is consistent with the research of Hofstede (1984) who discovered a relationship between culture and quality of life. It is critical therefore, for professionals to consider the cultural background of individuals when providing services, and consider how that background might influence their practices. Emily explained at length how she experienced cognitive dissonance because her culture does not wholeheartedly endorse the use of services provided by psychologists or psychiatrists or the use of medication for psychological disorders.

Research Question #3: What is the hierarchy of needs of caregivers with sickle cell disease?

Participants identified a myriad of needs; however, not all needs were central to their quality of life. This study partially was aimed at determining if the needs of these
parents were consistent with those identified by Maslow in his theory of hierarchy of needs and if the same order of needs existed for these families. Some support existed for Hofstede’s (1984) and Haire, Ghiselli, and Porter’s (1966) position that culture might impact the relative importance or ranking of these needs. However, rather than ranking or re-ranking needs, participants consistently added a sixth need to the hierarchy. Based on parent report, there are certain needs that would be added to fit their individual situations. However, for every family involved in this study, prayer and faith in God were foundational needs to survival, fulfillment, happiness and all of the other factors identified as contributing to their quality of life. Wilma specifically stated that her survival/success was due only to prayer.

As it relates to their specific situations, education is another need of parents of children with SCD. They quickly learned the value of education after learning of their children’s diagnoses. Each parent struggled to access sufficient information about SCD. In some cases information was distributed by the doctors but was limited in terms of the scope of what it provided. In other cases, it was difficult to find doctors willing take time to answer questions. Thus, education became very valuable and essential in supporting and advocating for their children. However, education does not appear in Maslow’s theory to be a central need. This may be related to the premise on which his hierarchy was built, targeting drive needs for survival. It is hypothesized that these needs changed with the addition of a chronic illness in one’s family.

*Realities of Living with Sickle Cell Disease*

Throughout the course of this study, the investigator was able to get a glimpse inside the lives of these families and understand that there are certain realities about
which the average person may not be cognizant. One reality is regarding the significant level of challenge confronted by these families. A second reality of living with SCD is the extreme impact that this disease has on individuals and families. This study was prolonged due to several of these realities. An interview with Emily, for example, was delayed for more than three months due to frequent crises related to SCD. Her daughter had been hospitalized four times in three months, resulting in hip replacement surgery at the age of 12-years. An interview with Zanine was postponed for months because her major concern was finding a doctor who could care for her son. The final reality for these parents is after all of these experiences, fights, challenges, and tears, the disorder of SCD does not go away.

**Limitations**

This study documents the experiences of quality of life for four parents of children with SCD. The results of this study, however, should be interpreted with caution. Due to the qualitative, non-controlled nature of this study, as well as the limited sample size, the results of this study can not be generalized to other caregivers of children with SCD. The findings of this study are related to the subjective experiences of these particular parents and might not apply equally to other parents. This study serves as a pilot study to highlights important issues for inquiry.

**Delimitations**

Each participant involved in the study has verified all data presented within this manuscript. The information presented in Chapter 4 provides the greatest representation of participant voice given that it is a summary of information obtained directly from the participants without interpretation. Chapter 5 includes a discussion of how those data
relate to the research questions and purpose of the study; it also includes the investigator’s perceptions about those data. At follow-up interviews, transcripts along with a summary of interviewer thoughts and interpretations were presented to the parents for verification and clarification. Additional visits to the field allowed the interviewer to solicit feedback from each participant, have data verified, and ask additional follow-up questions.

*Implications for Educators and School Personnel*

Although the data presented are based on the subjective experiences of four parents, they represent real experiences of families caring for a child with a chronic and often painful disease and may be helpful to service providers. These families communicated the importance of developing trust (Maslow’s first stage), being proactive, conferencing with parents, involving parents, emphasizing cultural competence in collaboration, and focusing on the strengths of the child.

The challenges experienced by several of the parents in this study involved a lack of trust for school personnel. Their experiences left them well aware of the necessity of following through with the school and being persistent to get results. Their experiences, however, left them skeptical about whether their children’s needs were being met. These types of parent-school relationships might be avoided through proactive and early intervention by staff. School staff should make every effort to help build a positive and successful relationship and communicate with all parents. One reality for some of these parents that has been constructed through their prior experiences with schools is that staff lack a genuine interest in what they have to share. Thus a simple recommendation is to listen to parents and validate their concerns. Consulting with the parent to answer
questions is critical in the development of trust. Parents want to be included and heard; parent consultation is a great means to fulfilling those desires.

Another recommendation is to involve parents in all decision-making related to their child. One constant theme that emerged through these data was the notion of fighting (for involvement with medical staff and with schools). According to Brown (1997), involving parents in decision making is critical to building trust; involving parents includes listening to them and respecting their input. Parents hold a wealth of information about their children and their medical care as a result of their history with the child. They should be seen as chief historians in their child’s lives and as important contributors to assessments and decisions. Brown (1997) contends that a successful consultation relationship between the school and family is dependent on the establishment of a working relationship with parents, identification of the problems they experience, and helping them identify and implement acceptable solutions. School professionals serve as consultants to help guide families in the implementation of effective skills to facilitate the success of their child (Brown, 1997). Information is critical, especially since many myths exist regarding this disease. These myths must be dispelled and replaced by evidence-based knowledge.

In addition, when talking with parents, using the name of the child is important. Using the child’s name helps to make the relationship more personal and demonstrates that the staff member has taken a personal interest in the child. When conferencing with parents, developing a Care Plan (a written plan documenting the problem/need of the child, what will be done to address it, and how it will be evaluated) is another way to facilitate the development of trust and assurance in the school. The care plan should
include specific plans to respond in the case of a crisis, a sign that the student is in crisis, and the do’s and do not’s of caring for the student. All staff members that could potentially interact with this student should be made aware of this plan. Additionally, it is essential that all conferences with parents focus on the strengths of the child. Although less positive topics may need to be discussed, a great strategy involves initiating conversations with the positives.

Finally, staff should make every effort to emphasize cultural competence in all family interactions. For example, these parents rely heavily on God for their strength and on prayer for guidance. These issues might surface in relations with schools and should be respected. A parent might report for a meeting accompanied by a clergyman and desire to pray prior to the meeting. These desires (as is appropriate) should be respected. It is not necessary to initiate these types of actions, however, parents should not be prohibited if they feel the necessity to do so. Another example involves making recommendations for outside services. A parent who comes from a culture like Emily’s might not be as receptive to a recommendation for counseling for her or her child and might even be offended. Talking with the parents in efforts to avoid assumptions is a great opportunity to expand one’s understanding of their culture and the types of support that work for them.

In summary, school personnel should engage in a problem-solving process to provide support for children with SCD and their families. In order to engage in this process, educators must be knowledgeable of SCD and must take into account the needs, culture, and experiences of the family.
Implications for Social Services Professionals

Given the data that emerged as a result of this research, some recommendations are in order for social services professionals. The notion of early intervention is consistent with the emergent themes in these data. Parents consistently reported that the demands of SCD and the challenges associated with it were significantly more intense and severe during the early years of the child. As their level of knowledge and understanding of the child increased so did their comfort and coping. The demands of SCD on the parent were more severe during the child’s early years for each of the participants. The need for early intervention, beginning within the first year of the child’s life with caregivers of children with SCD is warranted based on these data. The need for education, support, counseling, and an ear appear to be great at this stage of these parents’ experiences. Reaching them early and guiding them through these experiences, answering questions and working with others in their lives (i.e., schools, churches, etc.) to understanding their experiences may help tremendously to buffer the impact of the caregiving demands. The parents involved in this study missed these experiences during the early years of the illness and developed animosity towards medical, social services, and in some cases educational professionals. This animosity might have been avoided to a certain degree through early intervention.

It also is recommended that staff take time and get to know the parents and the child. In managing or assisting those managing chronic illness, it is difficult to treat what you do not understand. Spending time with these families will allow all types of professionals to develop and intimacy with these families. As a result, professionals will become better informed and empowered to intervene appropriately and more effectively.
Implications for Medical Professionals

Implications discussed in the context of the school relate equally to medical professionals. Parents specifically discussed the need for doctors who took time to listen, got to know them, answered their questions, and who did not rush them through their appointments. These practices are critical to the quality of life of these parents, especially since they accounted for a major part of the challenges associated with medical staff. These data suggest the need for doctors to become humanized (more empathetic and sensitive to the needs of their patients) and adapt a more holistic approach of meeting the needs of the families. Treating the whole person should be key; the whole individual is not limited to the medical/physiological needs but includes the emotional self as well. Additionally, parents must be regarded as an important informant for the medical team as they are the chief historians of the child and have a more intimate understanding of that child than anyone on the team. Parents must be made active in the care of their children.

Implications for Future Research

Through repeated interactions with these families in their natural environments important data have emerged with implications for investigators. This research has demonstrated the fact that there is a great deal for professionals to learn about these families. This suggests the need to be willing to understand the reality experiences of these families. All professionals must see themselves as early interventionists and consistently explore ways to make the caregiving experience more positive. One focus of future research might be to analyze ways to prepare parents to begin to release their children as they began to reach adolescence and independence. One question to be asked is when do caregivers of children with sickle cell disease relinquish the medical
management role to the child? Another question might be when do they begin to see the child as independent and then relinquish the idea that they have to protect the children? Answers to these questions will inform intervention services to prepare parents early for these challenges by providing them a long range vision of how these kids will fair in childhood.

One important direction for research in this domain is to explore ways to facilitate the humanization (becoming kind, gentle, and sensitive to the needs of patients) of medical professionals. The goal for everyone is to have high levels of wellness in their lives. The way to facilitate this is be open to intimacy (getting to know one) and treating the whole person. The quality of life of siblings of children with SCD might also be explored in future research. The nature and demands of the illness (SCD) are internal to the family. Investigators might explore how siblings cope with such demands.

It is recommended that this study be replicated and expanded to a greater population to compare and contrast the current findings. As stated earlier, quality of life research is lacking among this population and its value is critical. Future research also should concentrate on the relationship of gender to the experience of quality of life. Some interesting differences surfaced in the current research; however, findings were limited due to the small sample size and the uncontrolled nature of this study.

In conducting research of this nature it is imperative to balance the role of being an “insider” with that of being an “outsider.” Investigators must possess the ability to maintain a level of intimacy and not contaminate the data collected. Suggestions for maintaining professional distance include the following: 1) remain mindful of your research goal (an a priori understanding); 2) frequently remove yourself from the study
environment; and 3) avoid the nurturing role. Researchers must understand their purpose for going into these environments and remind themselves of these goals prior to each entry. In this study the researcher constantly was mindful that the professional goal was to understand the experiences of daily living by immersing the self in participants' lives and absorbing from them an understanding of what it is like to manage a chronic disease. Being an insider/outsider enhanced maintaining professional distance in this study. The investigator became an insider by joining these families in their natural environments and an outsider by leaving that environment and returning to her professional world and role. Researchers might be tempted to provide nurturance due to their roles as helpers. This should be avoided by remembering the purpose of the study and leaving the family intact.

Conclusions

The quality of life of caregivers of children with SCD is an important area that warrants quality research. The findings from this type of research can be used to improve the practices of school psychologists, medical and research physicians, education and social service professional, and the quality of life for parents of children with SCD.

The activities associated with this study have resulted in valuable information. These data have highlighted the needs of caregivers of children with SCD and provided several implications for practice and research. Firstly, these data demonstrated that the concept of quality of life is multi-faceted and is defined based on the subjective experience of participants. Further, there are numerous factors that impact the quality of life of individuals in both a negative and positive manner. Clinical and research professionals should understand that these families must be treated holistically (as a whole person) and their various needs met. Additionally, these parents must be seen as
the key historian of the child and as valuable to any decision-making teams regarding their children. Through repeated interaction with these families in their natural environments, these valuable data have emerged. These data demonstrated the need for informed practice and further research.
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Appendices
Appendix A

Quality of Life of Caregivers of Sickle Cell Disease

Demographic Data Sheet

Participant Code: ____________________

Marital Status: ____________    Age of Participant: _____  Age of Spouse: _____

Sex:    Male   /    Female

Participant Occupation:  ________________  Spouse Occupation: ________________

Number of Children in Home: _____  Number of Children with SCD: _____

Sex/Age/Grade of Child with SCD: _____/_____/_____  Sex/Age of Siblings: ___/___  ___/___  ___/___  ___/___  ___/___  ___/___

Grade(s) of Siblings:  ___    ___    ___    ___    ___    ___    ___    ___ (respectively)

Any Children with Other Chronic Illness? Yes / No

If Yes, how many and which illness?  _____  _________________________________
                                                                                   _______________________________________________________________________
                                                                                   _______________________________________________________________________  

Type of Neighborhood:  _______________________________________________________

Income Range of Family:  (16-20K; 31-35k; etc.)  ________________________________

Race/Ethnicity/Cultural Background:  ___________________________________________

Family Composition:  ___________________________________________________________
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MHC 2218
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Tampa, FL 33612-3899

Dear Ms. Perry:

I wholeheartedly endorse your project, *An Investigation of the Quality of Life for Caregivers in Sickle Cell Disease*. At the Children’s Cancer Center, we understand that sickle cell disease is a very chronic and complicated disease that has a tremendous impact on affected children and families, resulting in a need for increased support. For this cause we offer opportunities for ongoing support and resources to affected children and their families including parent training and support groups. Our services are geared towards providing these families with the emotional and educational support necessary to cope with their life-threatening illnesses. We gladly endorse any project that shares our burden for this population.

We understand that the purpose of your study is twofold. First, you intend to determine the quality of life for biological parents of children with sickle cell disease and what factors influence their quality of life. Secondly, you intend to determine the hierarchy of needs of caregivers of children with sickle cell disease.

A major component of our program is geared towards parents of children with sickle cell disease. We aim to provide emotional and educational support through support groups, educational sessions, parent newsletters, and the provision of educational materials concerning sickle cell disease and treatment methods. Findings from your study may help us to improve our services to these parents by identifying what specific factors impact their overall experience and satisfaction with life and specifically as it relates to caring for young children with sickle cell disease.

On behalf of the Children’s Cancer Center, I offer our support for your study in the area of Sickle Cell Disease. We will support your project by making initial contacts with parents concerning involvement with your study, and by offering the use of our facilities for the purpose of interviewing. We also continue to be available to provide emotional support to parents should the need arise. We commend you in your efforts to undertake this valuable and much needed study.

Sincerely,

Mary Ann Massolo, Executive Director
Children’s Cancer Center

“Because kids should fly kites, not fight cancer”
Appendix C

Institutional Review Board Informed Consent

Informed Consent
Social and Behavioral Sciences
University of South Florida

Information for People Who Take Part in Research Studies

The following information is being presented to help you decide whether or not you want to take part in a minimal risk research study. Please read this carefully. If you do not understand anything, ask the person in charge of the study.

Title of Study: An Investigation of the Quality of Life for Caregivers in Sickle Cell Disease

Principal Investigator: Angela Perry, M.A.

Study Location(s): Study will be conducted in Tampa, Florida.
You are being asked to participate because you are an African American and a biological parent of a child between the ages of 9 and 13 who has been diagnosed with sickle cell disease.

General Information about the Research Study
The purpose of this research study is to learn about overall quality of life for parents of children with sickle cell disease and what types of things influence their quality of life. Quality of life refers to your overall satisfaction with life. In addition to learning about your quality of life, another purpose of this study is to understanding what needs are important to these parents and why. Based on the perceptions of parents, this study is aimed at learning about what things are necessary for parents to have a good quality of life and how important each of those things are.

Plan of Study
As a participant in this study, you will be asked to participate in two interviews, each lasting between 1 to 1.5 hours. You will meet individually with the investigator and discuss your quality of life and what things are important to you. These sessions will involve only conversation and no surveys will need to be completed. During the first
Appendix C (continued)

interview, you will be asked to some basic demographic questions about your age, sex, marital status, and the age, sex, and grade of your child(ren) with sickle cell disease.

You will be asked to participate in a third session along with three other parents who have participated in the study. During this session you will be presented with the information that the researcher have recorded from the study and any interpretations that the researcher have made. You will be allowed to add any additional information or make clarifications that you feel may be necessary. This last session is expected to last for approximately one hour and marks the end of the study. Each session will be tape recorded to help ensure validity of data.

**Payment for Participation**
As a way of saying thank you for your participation, you will be given $10.00 in United States cash immediately following each interview and the final debriefing session. If you decide to withdraw from the study at any time, you will not be penalized. You will be compensated for each session that you have participated in.

**Benefits of Being a Part of this Research Study**
Although there are no direct and immediate benefits to taking part in this study, this study is expected to have some long-term and indirect benefits. Results from this study will help to bring much needed attention to the population of people affected by sickle cell disease through publication and presentation at national conferences and in the community. Findings from this study will also help those who offer support services for families by indicating what types of things directly increase parents’ quality of life. These findings are also expected to indicate important directions for future research. Additionally, all participants will have access to the findings from this study.

**Risks of Being a Part of this Research Study**
Although there are no known or major risks associated with being involved with this study, it is possible that you may experience some emotional discomfort due to the nature of the discussions that will take place. Should you experience a level of emotional distress that you feel it necessary for some counseling or emotional support, such service will immediately available to you through the Children’s Cancer Center.

**Confidentiality of Your Records**
Your privacy and research records will be kept confidential to the extent of the law. Authorized research personnel, employees of the Department of Health and Human Services, and the USF Institutional Review Board may inspect the records from this research project. The results of this study may be published. However, the data obtained from you will be combined with data from others in the publication. The published
Appendix C (continued)

results will not include your name or any other information that would personally identify you in any way.

Your name will not appear on any transcripts or printed documents resulting from this study. With the exception of the informed consent form, a pseudonym (made up of letters and numbers), will be used in the stead of your name. No one will access to any data that you provide with the exception of the investigator and members or her supervising committee. All information that you share, including recorded tapes and typed transcripts, will be kept in a locked file cabinet in the office of the investigator.

Volunteering to Be Part of this Research Study
Your decision to participate in this research study is completely voluntary. You are free to participate in this research study or to withdraw at any time. There will be no penalty or loss of benefits you are entitled to receive, if you stop taking part in the study.

Questions and Contacts

• If you have any questions about this research study, contact Dr. Kathy Bradley-Klug, Supervising Faculty Member at the University of South Florida at (813) 974-9486.

• If you have questions about your rights as a person who is taking part in a research study, you may contact the Division of Research Compliance of the University of South Florida at (813) 974-5638.

Consent to Take Part in This Research Study

By signing this form I agree that:

• I have fully read or have had read and explained to me this informed consent form describing this research project.

• I have had the opportunity to question one of the persons in charge of this research and have received satisfactory answers.

• I understand that I am being asked to participate in research. I understand the risks and benefits, and I freely give my consent to participate in the research project outlined in this form, under the conditions indicated in it.

• I have been given a signed copy of this informed consent form, which is mine to keep.

_________________________ _________________________          __________
Signature of Participant Printed Name of Participant Date
Investigator Statement

I have carefully explained to the subject the nature of the above research study. I hereby certify that to the best of my knowledge the subject signing this consent form understands the nature, demands, risks, and benefits involved in participating in this study.

_________________________ _________________________         ____________
Signature of Investigator Printed Name of Investigator Date
Or authorized research investigator designated by the Principal Investigator
Appendix D

Summary of Case Analysis and Interview Notes

Sample Follow-Up Form/Summary
HP2005

INTERVIEW NOTES:

What does the term Quality of Life mean to you?
Good health
Have money

Before child with SCD?
Late teenager when child was born
I was pretty free
Nothing to worry about
Lived with mom

After child with SCD:
• Now good quality of life
• For him— Not getting sick compared to other children with the same illness
• When he was younger – sick more frequently
• Had no car
• Had to take the bus
• Cried some nights
• Not a lot of money
• Work was limited

• Still broke
• Better living place
• Health
• Car

What one thing would you tell influential people?
• Nothing
• You always hear things about children with cancer but none about children with sickle cell disease.
• They do more things for them (children with cancer)
What has your experience been with doctors?
I won’t comment on that

Other things?
- The parents should go out
- About research – they come and get information but they don’t do anything.

THEMES
1. Good health and money important
   - but money may not directly change QoL
2. Life good prior to birth and good after birth in spite of struggles
3. Things that made it good now
   - Child not getting sick
   - Has a car (Transportation)
   - Has a better living place

INFLUENCES
1. Money (not directly)
2. Health
3. Living place better
4. Transportation

MY NOTES (Memos):
• Quality of life changed as a function of child’s health
• No more depression (crying at night)
• Less stress
• Money not necessarily or directly a determinant of QoL

FOLLOW-UP QUESTIONS

A) You said during the early years of your son’s life it was challenging (you mentioned him being sick a lot and you crying some nights).
- How did you get through that?
- What helped you?
B) Was there any one thing or things in particular that influenced your QoL and made it better?
   - You said that it was good then and it is good now.
C) What was responsible for you making it through your son’s early years? (Same as question A)
D) What would you say to school teachers, principals, nurses and other personnel? You identified some challenges early on with some professionals. What strategies or things would you recommend them in order to make parent’s experiences more positive and satisfying? (Anything you can think of)
E) You were talking about people with authority and how they do more for or how you see more things about children with cancer and none about those with SCD. What does that do for you – what is your response? How does that influence you (if at all)?

F) You said you cried some nights. What caused that? (During your son’s younger life?)

G) How would you rate your QoL during his early years? Would you look at it the same way? (Really how would it be defined then? Would you have defined it the same way then? What about when you were a teenager? Do you think you would have said the same thing? Why or why not?

**My Conclusions from Interview One**

- Quality of life changed as a function of child’s health
- No more depressed moods (crying at night)
- Less stress
- *Money not necessarily or directly a determinant of QoL but important and makes a different*

*These are my conclusions from Interview #1 – what do you think about them?*

*** From the interview, I gathered that some of your needs were the following? (Things important to you.

- Health
- Money
- Home
- Transportation
- Peace of mind
- Support (social-agency)
- Education (re: SCD)
- Happiness of your children

*Do you agree that those are some things that are important to you and are considered some of your central needs?*

Are there any others?

<table>
<thead>
<tr>
<th>Needs</th>
<th>Type</th>
</tr>
</thead>
<tbody>
<tr>
<td>Health</td>
<td>Physiological</td>
</tr>
<tr>
<td>Money</td>
<td></td>
</tr>
<tr>
<td>Transportation</td>
<td></td>
</tr>
<tr>
<td>Peace of mind</td>
<td></td>
</tr>
<tr>
<td>Support (social/agency)</td>
<td>Esteem needs</td>
</tr>
<tr>
<td>Education (re: SCD)</td>
<td>Self-Actualization</td>
</tr>
<tr>
<td>Happiness of your children</td>
<td>Esteem needs</td>
</tr>
</tbody>
</table>
MORE QUESTIONS
1. You defined Quality of Life as having good health and money. Will you please describe how these influence Quality of Life or how they relate to Quality of Life?
2. Why do you see QoL as good health and having money (How do those relate to your QoL? (Alternative approach to Question 1)
3. You said the parents should go out. Will you please tell me more about that? About what you meant by that?
4. You mentioned your son being sick a lot during his early years and that you cried a lot. Will you please explain how that impacted you?
   i. How did you get through that?
   ii. What helped you?
5. You were talking about people with authority or who can do something to help parents/children with sickle cell disease and said that they do more for children with cancer and that you see a lot of things about cancer children but none about those with sickle cell disease. Does that influence you at all?
   i. If so, how?
   ii. How do you respond to that? Describe how that makes you feel?
6. During your son’s early years, how would you rate your Quality of Life then? Was it the same or different than now and before he was born?
   i. Why or why not? (Do you think you would have given the same definition for Quality of Life at that time?)
7. From the first interview, I gathered these things as some of your family’s needs. (By needs I mean things very important to you and your family.)

   Health
   Money
   Home
   Transportation
   Peace of Mind
   Support (social support and support from agencies)
   Education about sickle cell disease
   Happiness of your children

   Do you agree that these are some things that are important to you and are considered some of your central needs? (Feel free to make any changes or remove any of the above.)

   Are there any others that you would add as central needs for you and your family?
8. You shared a lot of knowledge about SCD. How did you learn so much about sickle cell disease?
9. How is (parent) right now?