Hearing His Story: A Qualitative Study of Fathers of Pediatric Stroke Survivors

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Hearing His Story: A Qualitative Study of Fathers of Pediatric Stroke Survivors

Abstract

Stroke is seen as a condition that only happens within the elderly community; however, this is not accurate. Most people are unaware that infants, children, and young adults can and do suffer from strokes. According to various researchers, pediatric stroke affects 25 in 100,000 newborns and 12 in 100,000 children younger than 18 years of age. Most pediatric stroke survivors will be left with some physical, behavioral, and/or cognitive impairment. While child rearing has traditionally been viewed as the mother’s forte, many fathers wish to be involved in sharing the responsibility of raising their son or daughter. Fathers of children with disabilities are rarely researched. This qualitative study inquired into the experiences of fathers of pediatric stroke survivors including their reactions and ways of coping.

In-depth interviews were conducted with 13 fathers whose children are part of the Pediatric Stroke Program at the Children’s Hospital of Philadelphia. Findings include the impact on the life of the fathers; the fathers’ use of various support systems; the need for the fathers to make meaning out of the devastating event; finding gratitude; and, the effect of their religious and/or spiritual beliefs in coping with their child’s stroke. Fathers also shared their advice for professionals who work with children with special needs and for other fathers facing a similar situation.

Included is a discussion of how the significant findings of the study compared to previous research, theories, and the Stress, Appraisal, and Coping framework of Folkman and Lazarus. Some additional relevant theories are also evaluated in regards to understanding the reactions and coping abilities of the fathers. Clinical implications for working with fathers of children with special health care needs and/or disabilities, limitations of the study, and suggestions for needed research in the future are also presented.

Degree Type
Dissertation

Degree Name
Doctor of Social Work (DSW)

First Advisor
Joretha Bourjolly, Ph.D.

Second Advisor
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Third Advisor
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Keywords
qualitative study, fathers, pediatric stroke, children with special needs, coping strategies, Folkman and Lazarus

Subject Categories
Social and Behavioral Sciences | Social Work

This dissertation is available at ScholarlyCommons: http://repository.upenn.edu/edissertations_sp2/51
HEARING HIS STORY: A QUALITATIVE STUDY OF FATHERS OF PEDIATRIC STROKE SURVIVORS

Lois Robbins

A DISSERTATION

in

Social Work

Presented to the Faculties of the University of Pennsylvania

in

Partial Fulfillment of the Requirements for the

Degree of Doctor of Social Work

2014

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Hearing His Story

Abstract

Hearing His Story:

A Qualitative Study of Fathers of Pediatric Stroke Survivors

Stroke is seen as a condition that only happens within the elderly community; however, this is not accurate. Most people are unaware that infants, children, and young adults can and do suffer from strokes. According to various researchers, pediatric stroke affects 25 in 100,000 newborns and 12 in 100,000 children younger than 18 years of age. Most pediatric stroke survivors will be left with some physical, behavioral, and/or cognitive impairment. While child rearing has traditionally been viewed as the mother’s forte, many fathers wish to be involved in sharing the responsibility of raising their son or daughter. Fathers of children with disabilities are rarely researched. This qualitative study inquired into the experiences of fathers of pediatric stroke survivors including their reactions and ways of coping.

In-depth interviews were conducted with 13 fathers whose children are part of the Pediatric Stroke Program at the Children’s Hospital of Philadelphia. Findings include the impact on the life of the fathers; the fathers’ use of various support systems; the need for the fathers to make meaning out of the devastating event; finding gratitude; and, the effect of their religious and/or spiritual beliefs in coping with their child’s stroke. Fathers also shared their advice for professionals who work with children with special needs and for other fathers facing a similar situation.
Hearing His Story

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Dedication

Candance Alexandra Garner, a true jewel

Indra's Net

Far away in the heavenly abode of the great god Indra, there is a wonderful net that has been hung by some cunning artificer in such a manner that it stretches out infinitely in all directions. In accordance with the extravagant tastes of deities, the artificer has hung a single glittering jewel in each "eye" of the net, and since the net itself is infinite in all dimensions, the jewels are infinite in number. There hang the jewels, glittering like stars of the first magnitude, a wonderful sight to behold. If we now arbitrarily select one of these jewels for inspection and look closely at it, we will discover that in its polished surface there are reflected all the other jewels in the net, infinite in number. Not only that, but each of the jewels reflected in this one jewel is also reflecting all the other jewels, so that there is an infinite reflecting process occurring. (Cook, 1977, p.2)
Acknowledgments

There have been many people who have been instrumental in guiding me gently and supportively throughout the process. My dissertation chair, Joretha Bourjolly, Ph.D. has provided continuing direction, suggestions, and friendship. She was reassuring when I needed it the most. Roberta Sands, Ph.D. has given so generously of her valuable time and was always available to read, edit, reread, edit, reread, and answer my concerns. I will be forever indebted to her for all her assistance. Robert Naseef, Ph.D. has spurred me to learn about the special issues that may have an impact on fathers. As a leader in the field of helping families of children with special needs, I am truly grateful for all his knowledge and his support of my learning.

The DSW program has truly been one of the most rewarding, if challenging, times of my life. From Lina Hartocollis, Ph.D., to all the professors who instructed the cohort members so brilliantly, to Jeff Curry, who made sure we were fed, nurtured, and assisted with our requests, I am so thankful. And to my fellow cohort members, I could not have persevered without all of your support and encouragement. Our membership in the group has created a bond that will never end.

I also owe a great deal to the members of the stroke team at the Children’s Hospital of Philadelphia. Your support and encouragement will always be remembered. And to Lauren Krivitzky, Ph.D. who quickly agreed to serve as my Primary Investigator, I thank you for sharing in the journey. To Caitlin Rice, L.S.W. and Lisa Mullikin, L.S.W., my social work neurology colleagues, I so appreciate all the time you both spent reading and commenting on parts of my work and for prodding me through the program.
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Lastly to my family and friends I need to say a heartfelt thank you. Sofia Pham, a special friend, former student, and now my teacher has provided outstanding editing guidance and feedback as well as continuing support and friendship. My family and longtime friends have also done an incredible job in standing by me throughout the past years. They share that they are all so proud of my accomplishments. While I too am proud of being a member of the DSW community, I am also looking forward to spend more time in my favorite role, that of Grammy.
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Preface

As a group, fathers are often an underrepresented population in research. To add insult to injury, some researchers rely on the mother when gathering information on how the father is doing. Many of the fathers I have worked with in the Pediatric Stroke Program at Children’s Hospital of Philadelphia (CHOP) are shocked when they are told that their previously healthy precious child had a stroke, a condition they thought happened only to people of their grandparents’ generation. Thinking about the experience and perspective of fathers coping with this kind of life-changing event sparks many questions: How, as a father, do you begin to deal with what has happened? What are the implications for you and your family? How can and do you make sense out of what has happened? Where do you turn? What do you do?

These were some of the questions I wanted to ask a diverse sample of the fathers of children treated in the Pediatric Stroke Program at the Children’s Hospital. As the social worker for this program, I could not find any information on fathers, or for that matter mothers, of pediatric stroke survivors. There are a few books about and by survivors of strokes and other types of brain injuries. Jill Bolte Taylor, Ph.D. authored the bestselling book entitled, My Stroke of Insight-A Brain Scientist’s Personal Journey. In her book Dr. Taylor described her stroke, the devastating impairments, and her long journey to recovery. Lee and Bob Woodward wrote, In an Instant, a book about the impact of Bob’s brain injury, which was caused by an improvised explosive device (IED) that went off when he was embedded with the military in Iraq in 2006. The Woodwards told of the impact of the stroke not only on Mr. Woodward but also on his wife, their children, their extended family, their friends, and their various communities. Former
Congresswoman Gabrielle Giffords, her husband Mark Kelly, and Jeffrey Zaslow authored, *Gabby: A Story of Courage and Hope*, which was the result of an assassination attempt. In this book the couple shares their dream of having a child that will now not be fulfilled, the intensity of surviving a situation that began with Gabrielle hovering between life and death and her extensive rehabilitation experiences.

When reading each of these books I found alarming similarities between their experiences and those of my patients and their families. Most glaringly were the shock and unexpectedness of the event, the nature of the brain injuries and resulting impairments, the life altering/goal (dream) altering realities, and the plain, hard work required of patients in their therapies on the road to recovery. However, in each of these books the survivor was an adult, not a child. Children in this country are often protected in many ways by their parents, resources, and family units; yet neither fathers nor mothers could protect their children from suffering a stroke.

There were many questions that I wanted to ask in order to understand the experiences of fathers of pediatric stroke survivors. The primary research question was how do fathers describe the impact of a child’s stroke on their lives? Specific research questions were as follows:

- How, if at all, have their identities and/or roles as fathers been impacted?
- How have the fathers’ significant relationships been impacted by the child’s stroke?
- How, if at all, did the child’s stroke affect the fathers’ spirituality?
- What has helped fathers cope with having a child who has suffered from a stroke?
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- To what extent have the fathers been able to accept what has happened? How do they describe the process of acceptance?
- Do fathers identify instances of personal growth that may not have occurred if their child had not had a stroke? If so, how do they describe them?
- What would they like others to know about raising a child with a medical diagnosis and/or disability?

When I began this study, I considered a number of topics that I wanted to examine in order to gain perspective and learn more about the experiences of the fathers of pediatric stroke survivors. Many of these topics are presented in the chapters of this dissertation, which I will briefly outline in this introduction. In this qualitative study of 13 fathers of pediatric stroke survivors, none of the participants had ever heard of children being diagnosed with a stroke. While pediatric stroke is not common, it is far more prevalent than people would imagine. Chapter I provides information about the frequency of strokes in children, descriptions of the most common types of strokes, the medical, social, and financial implications of a pediatric stroke, and the challenges for the child, parents, siblings, educational and medical systems, and the community at large.

As there is so little information about pediatric stroke survivors, I determined that it was important to look at other populations of children with special health care needs and/or disabilities. Chapter II looks at the challenges for parents raising a son or daughter with special needs. Parents of pediatric stroke survivors face similar issues from parental PTSD to the physical, emotional, and financial tolls of parenting a child with special
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needs. This chapter also examines the changing stereotypes of fathers as caregivers and the lack of research in this area.

Chapter III looks at both positive and negative influences of religion and spirituality from the perspectives of Christianity, Judaism, Buddhist, and Islamic teachings. The effect of growing up male in American society with the pressure to adhere to specific gender roles and the implications of such are presented in Chapter IV. Also described in this chapter are the differential rates of suicide and the ways men, in contrast to women, may react to sadness and depression. As many men do not seek traditional psychological therapy to address feelings of sadness and depression, alternative outlets and resources of support for men are discussed.

A brief review of the Stress, Appraisal, and Coping theory of Folkman and Lazarus is presented in Chapter V along with a number of well-regarded theories in social work practice. For many fathers, their understanding of the way the world fundamentally works came into question when their child suffered a stroke. Therefore Janoff-Bulman’s work and understanding of the concept of the assumptive world is an important part of the framework of this topic. Kubler-Ross’ stage theory of loss is contrasted with Olshanky’s theory of chronic sorrow. I also reviewed Boss’ theory of ambiguous loss and Calhoun and Tedeschi’s concept of posttraumatic growth that may occur after a struggle with a challenging situation.

A description of the methods employed in this qualitative study is found in Chapter VI. This chapter includes the recruitment and sampling procedures, the measures taken to protect the fathers, the procedure for the analysis of data, and descriptions of both the participants and their children.
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In Chapter VII I present the findings of the interviews. Themes that emerged are related to the reaction to the diagnosis, the effect on the life of the father and on the lives of his family members, coping strategies, and the impact of spirituality and religion. Self-identified concerns and challenges along with areas of personal and/or family growth are highlighted. The fathers’ advice to other fathers facing a similar situation, along with advice to professionals and those in the general community are presented. The findings in conjunction with previous research literature and the theoretical framework of Folkman and Lazarus along with the analysis of the responses of the participating fathers are found in the discussion chapter (VIII). Chapter VIII also includes clinical implications for social workers, limitations of the study, and ideas for future research.

I have learned a great deal about the personal and collective experiences of a diverse group of fathers dealing with pediatric stroke. The goal of this dissertation is to share some of their stories and to raise awareness and insight into the experience of fathers and families who have faced life-altering challenges due to their child’s stroke. And finally, an objective is to explore what is helpful and healing for families finding their way, often with a new perspective on what is most important and precious about living life.
Chapter I

Pediatric Stroke 101

Prevalence

Stroke is seen as a condition that only happens within the elderly community, but this is not accurate. Most people are unaware that infants, children, and young adults can and do suffer from strokes. Strokes can even occur in utero and, if fetal imaging is obtained, can be detected before the child is even born. The risk of stroke in children is greatest during the first year of life with increased prevalence during the perinatal period. Stroke occurs in about one of every 4,000 live births (AHA/ASA Facts, 2010); 1,000 infants a year have a stroke during the newborn period or before birth (Neergaard, 2005). While the statistics may vary slightly depending on the source, stroke is clearly a condition that affects not only the elderly but the youngest members of our society as well. The American Heart Association/American Stroke Association reports that the risk of stroke from birth through age 18 is nearly 11 per 100,000 children per year (AHA/ASA Facts, 2010). According to other researchers, pediatric stroke affects 25 in 100,000 newborns and 12 in 100,000 children younger than 18 years of age (CHASA, 2010; CHOP, 2010; Phend, 2008; Stanley, 2010); for children through 14 years of age the incidence is 2.52 to 3.5/100,000 (Gabis, Yangala, & Lenn, 2002); every year five out of every two hundred thousand children have a stroke (SAFE, 2010); 3,000 to 5,000 children have a stroke from age 1 month to 18 years (Neergaard, 2005).
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Some researchers believe there is an increase in the number of pediatric strokes although it is unclear why the frequency appears to be on the rise (Children’s Hospital of Pittsburgh, 2010) and the frequency of strokes may be greater than previously thought (Phend, 2008). Although still extremely rare, according to a retrospective cohort study, strokes in children and teens may be more common than most doctors believe. Previous studies using hospital diagnostic codes have estimated the annualized rate of pediatric stroke to be 0.54 to 1.2 per 100,000 U.S. children. But when investigators searched radiology reports as well as diagnostic codes in a single health system, the pediatric rate was 2.4 per 100,000 person-years (Neale, 2009). Two possible reasons for the increase in the numbers of cases of pediatric stroke include a result of increased survival in conditions that might be a risk factor for stroke (Gabis et al., 2002) and, according to E. Steve Roach, M.D., although better imaging technology has helped in diagnosing pediatric strokes, the primary reasons for the increase in numbers is because physicians are aware of the possibility that children can have strokes (Phend, 2008).

Although there has been a dramatic reduction in fatalities, strokes can still cause death. Recent reports indicate that stroke is the sixth leading cause of death in children (CHOP, 2010); one of the top 10 cause of death for children (AHA/ASA Facts, 2010). In either case, between 20% and 40% of children die after a stroke (AHA/ASA Facts, 2010; Phend, 2008); between 10% and 25% of pediatric stroke patients die (Neergaard, 2005).

**Issues Around Prompt and Accurate Diagnosis**
Children are not merely little adults when it comes to stroke risk factors, symptoms, and treatment. There are enough age-specific differences that caution needs to be taken when attempting to apply knowledge about stroke in adults to children (Phend, 2008). Children and adolescents with strokes may have remarkable differences in presentation when compared with older patients. The type of stroke also varies according to age (Phend, 2008; Roach et al., 2008). Neonatal strokes often present as seizures, typically involving only an arm or leg. If a seizure is not noted during the first few days of life it may be months before possible evidence of a neonatal stroke is noticed. This usually occurs when a parent notices that the baby of four to six months of age does not move his or her limbs in the same manner, illustrating a weakness on one side. In young children delays in gross motor development, tightness or restricted movement in legs or arms, and/or language delays can be symptoms of pediatric stroke. However, delays in crawling and walking may be wrongly ascribed to “lateness” and normal cognitive functioning often masks other developmental delays (CHASA, 2010).

Adult risk factors such as hypertension and atherosclerosis do not play a part in pediatric strokes. Risk factors for pediatric stroke are much different than the risk factors for adults. More than one hundred risk factors for stroke in newborns and children have been identified. The most common risk factors for pediatric stroke include:

- Head and neck infections
- Systemic conditions, such as inflammatory bowel disease and autoimmune disorders
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- Head trauma
- Dehydration
- Maternal history of infertility
- Maternal infection in the fluid surrounding an unborn baby (chorioamnionitis)
- Premature rupture of membranes during pregnancy
- Maternal preeclampsia

(Children’s Hospital of Pittsburgh, 2010)

About half of children who have a stroke have a previously identified risk factor. Sickle cell disease and heart disease, whether congenital or acquired, are the most common underlying risk factors (AHA/ASA Facts, 2010). While half of strokes have a known risk factor, it leaves the remaining half with no known risk factors or causes. This is extremely alarming to both the parents and patients. Literally, a child may be perfectly healthy one second and suffer from the life altering effects of stroke, or even die, the next. In normally healthy children and parents of newborns and children with medical conditions that may be associated with risk factors for stroke, there is a great sense of angst with the diagnosis with the uniform response being, “My child had a WHAT?” For those children who survive, the immediate concern expressed by families is for the possibility of another stroke occurring. For if the cause is not known, what can stop additional strokes? In reality, recurrent strokes do occur in 6% to 15% (Phend, 2008) in children; 20% according to the American Heart Association/American Stroke Association (AHA/ASA Facts, 2010). Due to the possibility of a recurrent stroke,
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assessing, and if possible, addressing underlying risk factors is particularly important to survival and quality of life (AHA/ASA Facts, 2010).

Signs and symptoms of stroke in children include:

- Sudden collapse
- Sudden loss of consciousness
- Onset of lethargy or difficulty walking
- Seizure
- Sudden loss of movement or weakness of face, arm or leg
- Numbness or tingling
- Difficulty talking

(Children’s Hospital of Pittsburgh, 2010)

Child caregivers, both parents and school professionals, have difficulty in recognizing the urgency of various symptoms most likely because they are not aware of the possibility of childhood stroke. The initial symptom can be a common complaint, such as a headache or fatigue. The child might not be able to or might not complain about the symptom. In children signs might be difficult to recognize. For example, aphasia may occur in a child who had not yet mastered language. There may also be new deficits in a child with developmental delay or previous neurologic impairments. An additional barrier to early diagnosis is children’s difficulty in describing a symptom and conveying the severity and acuteness to someone else. “Even an older child with appropriate verbal skills will have difficulty describing sensory or cerebellar symptoms, and without an appropriate description, a physician will be less likely to elicit various
abnormalities on examination and to appreciate the full significance of the event” (Gabis et al., 2002, p. 927).

**Types of Strokes and Specific Related Conditions**

There are different types of strokes in children. The three most prevalent are:

1. **Arterial Ischemic Stroke (AIS)**, which occurs because of a blockage in an artery, usually by a blood clot that has formed at the site of blockage or that has formed somewhere “upstream” in the arterial tree, has broken off, and been carried “downstream” in the blood flow through progressively smaller branches in the arterial tree, until it enters a vessel too small to fit through, plugging it closed. This type of floating blood clot (embolus) often forms within the heart or one of the larger arteries leading away from it, then breaks off and travels to the brain or another organ (SAFE, 2010).

2. **Hemorrhagic Stroke** occurs when a blood vessel in the brain breaks open or develops a hole in its wall through which blood begins to leak directly into brain tissue or into the clear fluid which surrounds the brain and fills its central cavities (ventricles) (SAFE, 2010). Hemorrhagic stroke accounts for 15 percent of strokes in adults and 50 percent in children (Moyer, 2006).

3. **Cerebral Venous Sinus Thrombosis (CVST)** occurs due to an occlusion in the cerebral venous system and can cause altered mental status and acute neurologic symptoms and elevated intracranial pressure (CHOP, 2010)
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Moyamoya Disease is also known to cause stroke in children. This condition was first described in Japan. (Moyamoya means puffs of smoke in Japanese as that is what the effects of the disease in the brain can resemble.) Moyamoya syndrome has now been seen throughout the world and affects individuals of many ethnic backgrounds. There is an increasing detection of this disease in American and European populations. In Japan, moyamoya is the most prevalent pediatric cerebrovascular disease, affecting girls almost twice as often as boys (Phend, 2008). While genetic factors play a major role, other risks factors include Down syndrome, radiation, and sickle cell disease.

Stroke can be seen in older children as well. The disorders causing stroke in toddlers and school-aged children may still produce stroke in adolescents. However, an increasing percentage of strokes, of both ischemic and hemorrhagic types, occur in relation to drug use. Common drugs causing stroke are cocaine and amphetamines and any type of illicit drug injected into the bloodstream (SAFE, 2010). Strokes can also occur through dissection (tear in the artery) that sometimes occurs as a result of participation in active sports such as wrestling or hockey.

**Ethnic and Gender Considerations**

There are ethnic and gender differences in the incidence of pediatric stroke. While ethnic and gender disparities for risk of stroke are well documented in adults, only limited information regarding the ethnicity and gender of pediatric stroke exists. While population-based studies are not able to determine gender or ethnic differences due to insufficient numbers of cases (Fullerton, Wu, Zhao, &
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Johnston, 2003), by analyzing discharges from a California hospital, researchers found that boys were at a higher risk than girls and African American children were at a higher risk than white and Asian children even after adjusting for trauma and the presence of sickle cell disease (Phend, 2008). Hispanic children had a lower risk of stroke (Fullerton et al., 2003). The numbers of strokes in the adult population mirror this finding with men and African Americans suffering a disproportionate incidence of strokes. However, the similar findings of gender and ethnic differences are not thought to have a similar basis in terms of risk factors. In adults these findings have often been attributed to ethnic and gender differences in terms of controlling risk factors such as hypertension, diabetes, and smoking. These factors do not play a significant role in children.

A study using administrative data found that African American children in the United States were at a higher risk of death from all stroke types than white children and boys were at a higher risk of hemorrhagic stroke death than girls (Fullerton et al., 2003). In the study analyzing admission for childhood stroke in California, trauma was assessed as a potential cause for the gender discrepancy in stroke risk. Boys were more likely to have a secondary diagnosis of trauma. Boys were shown to be at greater risk for ischemic stroke and hemorrhagic stroke even when cases with trauma were excluded (Fullerton et al., 2003). Sickle cell disease was a coexisting diagnosis in almost 7% of the overall number of those diagnosed with ischemic stroke and in over 38% of African American children. Only a small number of children with sickle cell disease were seen with hemorrhagic strokes. Excluding cases of children with sickle cell disease, African American children
continued to have a higher risk of ischemic stroke than white children. Moreover, African American children aged birth to four, without sickle cell disease had a higher risk of ischemic stroke than similarly aged white children (Fullerton et al., 2003). While the research in this study has only African American children as being seen with sickle cell disease, other ethnic groups including those with ancestors from countries near the Mediterranean and the Caribbean have small proportions of people with sickle cell disease. It may be that the only children in the California study who had both sickle cell disease and stroke were African American. It should also be noted that certain types of sickle cell disease are much more prone to cause strokes.

**Awareness of Pediatric Stroke (or lack thereof)**

Awareness or lack thereof, of the possibility of pediatric stroke is a huge factor for the general public, especially parents, school officials, first responders, and physicians. Very few people are aware that children, let alone babies, can suffer from strokes. The public does not realize that children can have strokes with devastating and permanent neurological damage. Therefore, parents and others who are involved in the day-to-day care of children are not necessarily attuned to the warning signs (Children’s Hospital of Pittsburgh, 2010).

If symptoms alert the caregiver to the need for medical attention, emergency medical personnel may be notified. However, for the emergency medical technician it is difficult for the symptoms of a possible stroke to be recognized, as there are many conditions that have similar symptoms. While the signs of stroke are similar in children and adults, according to Rebecca Ichord, M.D., children have other nonspecific signs that can distract medical personnel.
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“Stroke needs to be considered by first-line pediatric caregivers who encounter a patient with suspicious neurological symptoms, such as difficulty walking or using an arm” (ScienceDaily, 2/17/06). “Because an initial stroke is often the first sign of a problem in a child, preventing a first childhood stroke can be difficult” (AHA/ASA Facts, 2010).

Dr. Ichord, Director of the Pediatric Stroke Program at the Children’s Hospital of Philadelphia, stresses that neurologists must increase awareness about pediatric stroke among front-line providers and primary care physicians. There must be a concerted push for stroke to be on the list of possible causes of sudden neurological symptoms in children; stroke should be considered until ruled otherwise (Dienst, 2010). Pediatric stroke is off the radar screen in the emergency department and therefore children with stroke symptoms are often misdiagnosed or there is a delay in the diagnosis (Moyer, 2006). “Emergency medicine staff members are far more aware of the possibility of stroke among adult patients than they are among children who are brought to the hospital” (ScienceDaily, 2/17/06). Ichord found that children come to the emergency department hours and sometimes even days after the first onset of symptoms. These providers need prompt and well-informed advice from the consulting neurologist (Moyer, 2006).

Additional factors can create a delay or an incorrect diagnosis in the emergency room. Symptoms of pediatric stroke can resolve temporarily and children are discharged without a correct diagnosis. Sometimes there is a disbelief of symptoms due to assuming that other factors are involved. There have been cases where a teen with sickle cell disease may be thought to be seeking pain
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reduction medication as well as physicians who believe symptoms are due to illicit drug use in teens. Some facilities do not have imaging equipment readily available that is needed to confirm a diagnosis of stroke. As the imaging is costly, even those physicians with the diagnostic imaging available may be reluctant to order the tests. Clearly more lay and medical professionals need to have the possibility of pediatric stroke on the radar screen as quick diagnosis leads to quick treatment that can lessen the damage a pediatric stroke can cause. As soon as the diagnosis is made, patients need be placed on a stroke protocol as quickly as possible to help prevent further neurological damage.

Stroke protocols are extremely important as the sooner pediatric stroke is diagnosed and treatment starts, the better the potential outcome for the patient (Children’s Hospital of Pittsburgh, 2010). “The first treatment involves neuroprotective measures, which include maintaining adequate blood pressure, and supplying fluids and appropriate medication” (ScienceDaily, 2/17/06). However, pediatric stroke is often not promptly identified. Stroke in children is rarely diagnosed in the time frame of 3 to 6 hours (Gabis et al., 2002) which is time frame needed for the administration of tPA, a clot-busting drug administered to adults diagnosed with an ischemic stroke. Occasionally, some physicians with National Institutes of Health (NIH) approval will administer tPA if the time frame and certain other conditions are met. If a massive hemorrhage occurs in a child, the symptoms are overt and dramatic. This prompts immediate medical attention (Gabis et al., 2002).
Looking at the time lag in diagnosing stroke in children, time records of 24 children were investigated. Time from clinical onset to first medical contact averaged 28.5 hours, and the time of stroke diagnosis averaged 35.7 hours. In another single-center study the median interval from symptom-onset to arrival was 5.6 hours, with a range from 30 minutes to five days. The median time from onset to stroke-specific treatment was 23 hours. A median of 36 hours lapsed before the children received specific imaging that confirmed the stroke diagnosis (Moyer, 2006). As a comparison, adults’ time records showed the average time from symptom onset to ED arrival was 2.6 hours, time to initial imaging was 1.1 hour, and the total delay time (symptom onset until imaging completion) was 4 hours (Gabis et al., 2002). Promptness in treatment affects outcomes for both pediatric and adult stroke sufferers. A child with a stroke-related disability will have problems in school and will need various types of rehabilitative therapies for a long time. Preventing a disability caused by a stroke by treating it promptly could reduce the hardships on the child, family, educational systems, and society in general.

It is important for those involved with pediatric stroke to get the word out that children, even babies, do have strokes. While relatively small in number, the effects of stroke can lead to dramatic and debilitating consequences not only for the patient, but for the family and community as well. Awareness by the general public and medical community can lead to a faster diagnosis that can limit the devastating effect of the stroke and perhaps prevent a fatality. Everyone needs to realize that strokes not only happen to the 85-year old grandparent, but can
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happen to the grandchild as well. Just as in the elderly, stroke often leads to physical and cognitive impairments, which in turn affect not only the stroke victim but also the family members who will need to care for them.

**Caring for a Pediatric Stroke Survivor**

After the family has been given the often unheard of diagnosis of pediatric stroke, the focus is merely on whether the child will live or die. Families at this point can only deal with the current medical situation. They are numb to the future or anything not concerning the present time and present space. They have not “crashed” yet as they must be at attention to hear and try to comprehend all that is going on around them. Parental center of attention has a singular lens. After the child is out of mortal danger, parents can give thanks that their child is alive and the “now what” phase begins.

The impact of stroke can vary greatly along the continuum from no or minimal effects to complete and total destruction of previous abilities with little hope for regaining skills or learning new ones. When predicting functional outcomes for pediatric stroke survivors and their families many factors are considered. In children and in adults, deficits caused by the stroke depend on the size of the stroke and the specific affected area(s) of the brain. Different parts of the brain are responsible for different functions and the usually larger the stroke the greater the damage. The list of possible deficits due to damage in a particular area is as long for children as it is for adults. For example, paralysis of affected limbs and subsequent development of spasticity in those limbs can occur if motor areas are affected. Balance mechanisms are impaired if the cerebellum or its
related structures are involved. Language deficits (aphasia) occur if language
areas are involved (SAFE, 2010). Damage to the left temporal parietal lobe affects
a person’s understanding of speech and the ability to make sense of the thoughts
that are spoken. Part of the brainstem is the pons. Disruption to this area can cause
a complete loss of ability to coordinate and control body movements (Lash,
McMorrow, Tyler, & Antionette, 2004). In addition, many children face the old or
new problem of comorbidity of one or more medical complications that may have
contributed to or have occurred as a result of the stroke.

Even after compiling the lists of determinants and predicting general
potential for a full or partial recovery, medical staff is wrong a fair amount of the
time. Children that were not supposed to make great recoveries do so, while
others with much better assumed rehabilitative capacities fail to reach the mark.
Personal drive and supportive family and friends certainly do play a part. Current
research has shown that between 50% and 80% of surviving children have
neurological effects, the most common of which is hemiparesis (Phend, 2008).

**Following the Hospital Progression- From Intensive Care to Rehabilitation**

At the Children’s Hospital of Philadelphia, patients with strokes usually
follow a progression of care pathway. Most often patients are brought in by
helicopter or ambulance from an outside hospital and admitted to the Pediatric
Intensive Care Unit (PICU). This is the time for critical medical life and death
decisions. Patients are placed on a stroke protocol to limit the damage of the
stroke and lessen the chances for subsequent strokes. Typically, patients spend
less than a week in the PICU before they are moved to the regular hospital floor
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caring for patients with neurological problems. When the child is medically stable
he or she is usually transferred to the rehabilitation section of the hospital. Even
though occupational, physical, and speech and language therapies are usually
begun in the PICU, therapy intensifies in the rehabilitation unit with most of the
day involving one therapy or another. When it is felt the child no longer needs the
intensive therapy schedule or the insurance will not approve a continued stay, the
child often attends day hospital where he or she may stay at home at nights and
weekends, but comes to the hospital during the weekdays to continue with
therapies. Finally, the stroke survivor may only need therapies a few times a week
and can receive needed therapies on an outpatient basis. Each one of the moves
involves new sets of medical providers, insurance issues, therapy hours, and
parental commitment.

**Plasticity of the Child’s Brain**

The pediatric stroke community bases a degree of hope for good
recoveries because many specialists believe that a child’s brain is much more
‘plastic’ than the brain of an adult. In other words, healthy parts of the brain are
more likely to reroute themselves around damage. This plasticity in the brain of a
child means that the areas of the brain have not yet been ‘locked’ into their
lifelong function. Thus other areas of the brain can take over and assume some of
the function of the destroyed parts of the brain. Clinical lore states that children
who have strokes do “well.” This impression seems to be based to some degree on
good motor outcomes along with the general impression that children’s brains
have greater plasticity than adults. Because of this plasticity, many believe
children can recover to a somewhat greater degree than occurs in adults and the younger the child at the time of stroke, the greater this tendency (SAFE, 2010). However, there is much debate on this belief. Specialists once thought that most survivors eventually would recover, but research shows more than half of such patients will have permanent motor or cognitive disabilities (Neergaard, 2005). Although evidence of cortical reorganization in stroke recovery has been documented, the concept of pediatric brain ‘plasticity’ is probably overstated, especially in reference to children who have an onset of a stroke beyond the first few years of life. Functional outcome assessment in this group produced mixed results (Hurvitz, Warschausky, Berg, & Tsai, 2004).

**Implications for the Future**

In reality there is little information about the future implications for pediatric stroke survivors. Hurvitz, Warschausky, Berg, and Tsai (2004) looked at the long-term functional, psychosocial, and medical outcomes. They concluded that children who have stroke generally do well, with better recovery than seen in the adult population. However, this conclusion seems to be based on limited information. Most studies have focused on etiology and have only given a rough indication of functional outcome with little detailed information about post stroke abilities and disabilities. Many times, outcome is defined as survival versus death or presence of deficit versus no deficit. Some researchers do provide data concerning functioning for pediatric stroke survivors. For example, Gordon, Ganesan, Towell, and Kirkham (2002) reviewed the outcome of 90 children with a history of ischemic stroke and found that about 60% of the patients needed help
in some area of daily skills; 74% had motor deficits; and, 43% had speech and language difficulties. White, Salorio, Schatz, and DeBaun (2000) described deficits found in children with stroke after sickle cell crisis. These included cognitive impairments such as deficits in general intelligence, attention, language, visuospatial ability, short-term memory, and motor deficits. While most children were able to ambulate, the use of orthotics and assistive devices was fairly common. Functional performance in other areas, including activities of daily living (ADL), communication, and socialization, was less than satisfactory for many patients. Approximately 44% of pediatric stroke survivors needed special education. When looking at the beginning ages of adulthood, researchers found a fairly high rate of employment and college attendance; this was combined with a fairly low rate of financial independence and independent living (Hurvitz et al., 2009).

Although children and adolescents may have better outcomes compared to adults, it is important to remember that this is in part related to the high rates of comorbidities and mortality in the adult stroke populations where stroke is often a symptom of a larger syndrome. It is important to have a realistic view of the deficits that occur after a pediatric stroke in order to prepare families, schools, and community systems and agencies to be helpful and resourceful. One must remember that the adult stroke patient is working to regain lost skills, but pediatric stroke also affects the child’s ability to acquire new, age-appropriate skills.

**Barriers to Care**
Generally there are two types of barriers to the best appropriate services for the pediatric stroke survivor. These are the lack of financial resources and the lack of qualified therapists. The availability of rehabilitative services of physiatrists, occupational therapists, physical therapists, and speech and language pathologists play a crucial role in the successful recovery. While few therapists are specifically knowledgeable about pediatric stroke, some families do not have access to pediatric therapists or even therapists in general. For optimal recovery, it is most important for children to receive prompt and intensive therapies. There are often waiting lists for occupational therapists, physical therapists, and especially speech and language pathologists who not only assist with articulation issues but also with strategies to help the patient with difficulties in higher level cognitive functioning.

Looking at rehabilitative stays for those with acquired brain injuries, which include most stroke survivors, Keutzer et al. (2005) have expressed concern that rehabilitation lengths of stay are decreasing, especially with reduced reimbursement from managed care companies and Health Maintenance Organizations (HMOs). Shortened hospital stays necessitate a greater in-hospital focus on physical and functional goals and fewer opportunities for rehabilitation staff to address the full spectrum of survivors’ and family members’ needs. (p.535) Shorter rehabilitation stays do not permit optimal time for neurobehavioral therapy and recovery. Strokes can lead to emotional difficulties caused by the
brain damage in addition to depression and difficulty adjusting to the person who has changed from the child they were before the stroke.

The other huge barrier is the financial costs. Often, there needs to be one parent whose unpaid job becomes taking care of the child with the stroke. There is considerable “financial strain on families when mothers cease employment to care for the child, as well as the cost of specialist therapy service” (Dowling, 2007, p. 35). While Dowling reports on the mother needing to leave her job, occasionally it is the father who becomes the primary caregiver. Most survivors have multiple therapy and doctor appointments. Many children require medication and special adaptive equipment. Some qualify for government programs which require extensive paperwork before approval can be granted. Keeping track of all the necessary items and meeting all the needs of the child may become more than a full time job.

While the exact costs of childhood stroke to families and society are unknown, one study found that the average cost of medical care in the first year after childhood stroke is nearly $43,000, and the subsequent health care needs of these children can last decades, even far into adulthood. Another study found that the financial burden of strokes in infants and children is both substantial and long-term, with the five-year health costs for children with strokes is 15 times higher than children of the same age without strokes (AHA/ASA Facts, 2010). The costs to families and society extend beyond the direct medical costs which include not only insurance payments, co-pays, adaptive equipment, and the like but also the added expenses of gas and parking for needed services. Familial and societal
impacts also include altered family relationships and home life, lost income and productivity, and educational costs such as the need for special services and placement (AHA/ASA Facts, 2010). “Young stroke survivors often experience decades of weekly therapy session, seizure and spasticity medications, orthotics, orthopedic surgery, behavioral interventions, and special education in the school system, resulting in loss of work time for parents” (CHASA, 2010).

In general, children with any special health care need experience higher health care utilization and expenditures than the average pediatric population. Families incur a broad range of expenses associated with a special health care need (SHCN) for a child’s health care. Some costs incurred might include added electricity, equipment, food, other drugs, and expenses associated with medical appointments. The burden of these costs is magnified when care for the child means a loss in parental income due to missed work, not being able to work regular hours, not being able to work additional hours or overtime, having to change shifts with loss of pay differential, or quitting their job (Lindley & Mark, 2010).

Approximately 40% of families with SHCN children experience financial-related burden due to their child’s health condition. Financial burden often emerges as a significant concern at a time when families are already consumed with the child’s health challenges (Lindley & Mark, 2010). In Sweden “families of children with a (learning) disability receive state financial support that aims to address the impact of additional costs and loss of income” (Dowling, 2007, p. 36). In this article by an Irish nurse, a learning disability is comparable to a disability
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diagnosed at birth in the United States. Similar to hearing the diagnosis of stroke, “the news that a child has, or is at risk of having learning disability is often one of the most frightening and confusing pieces of information a parent will receive. At diagnosis, parents often describe a state of shock, denial, numbness, confusion and sorrow” (Dowling, 2007, p. 35). As an aside, one of the consequences of a neonatal stroke is an increase of 15% -20% for a future diagnosis of the American definition of a learning disability and a 30% chance of developing attention deficit hyperactivity disorder (ADHD). 

Access to needed health care due to limited insurance can lead to added financial difficulty and loss of needed therapies and medical care. Many families have difficulty affording the co-pays that are needed for medical and therapy appointments. Common barriers include:

- Losing dependent insurance coverage due to marriage or reaching adulthood;
- Managed insurance plans with ‘gatekeepers’ may make it more difficult for patients to gain access to needed specialty and rehabilitation care, resulting in possibly suboptimal care; and
- Increasingly, insurance plans are imposing annual or lifetime limits on needed medical care, such as rehabilitation services (AHA/ASA Facts, 2010)

**Becoming a Person with a Disability**

In addition to the economic and provider barriers, patient and families are left with a host of other issues. Strokes often lead to “invisible disabilities.”
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Patients may or may not need a wheelchair, a cane, or other devices that would signal an obvious disability. While the general public has inched a small way in being respectful of those with a disability, acceptance is much more difficult when the disability is unseen. Many pediatric stroke survivors are left with cognitive and emotional deficits. Immediate and extended family members also experience difficulty when a person, adult or child, is diagnosed with a stroke. In the adult stroke world, “stroke brings about a crisis in family systems as well as in patients themselves due to its sudden onsets. Stroke results in physical and cognitive impairments, communication deficits, and depression for the patient” (Kim & Moon, 2007, p. 82). Siblings of pediatric stroke survivors are affected on a daily basis. They not only have to cope with the changes caused by a stroke to their brother or sister, they must also adapt to the now unequal distribution of their parents’ time and resources. “Throughout their lives, brothers and sisters share most of the experiences that parents of children with special needs describe including isolation, a need for information, concerns about the future, and caregiving demands. Brothers and sisters also face issues that are uniquely theirs, including resentment, peer issues, embarrassment and pressure to achieve” (Conway & Meyer, 2008, p. 113).

Parents, as well, need to deal with a myriad of new challenges. Both mothers and fathers are overwhelmed when given the diagnosis. There are very few places to turn for support or information. No books are written about pediatric stroke for the family of a pediatric stroke survivor. Therefore, at this time, one can only look at evidence of support for families in similar, though not identical,
situations and attempt to learn from their experiences. Many families with children with chronic medical issues and/or disabilities turn to others with a similar diagnosis for support. Others turn to the internet, which can provide support but also incorrect information. Some parents cannot read stories on one particular website as they feel they are too intensive and depressing.

“A stroke is a devastating event, perhaps even more so in the pediatric population, since affected youngsters may require medical assistance the rest of their lives. Adding insult to injury is the fact that many victims of pediatric stroke already suffer from a chronic disease” (Nield, Brunner, Scott, & Jaynes, 2006). The impact on families of pediatric stroke survivors include issues with medical insurance and obtaining therapies; deciding what advice to follow; educational changes; emotional labiality; change in family structure; dealing with a condition that almost no one has even heard about; dreams altered/dreams denied; searching for the “cure;” hypervigilance; and, deciding who can or should know. But most of all, the question remains, what will the future bring for my child?

Unfortunately, most parents of pediatric stroke survivors must confront the challenges of raising a child with at least one disabling condition. The next chapter focuses on the issues and implications facing parents of children with special health care needs and/or disabilities. In this chapter special attention is given to the role of the father as caregiver.
Chapter II

Raising a Child with Special Health Care Needs and/or Disability

Parenting

It is often difficult to delineate the distinctions of raising a pediatric stroke survivor with those of parenting a typically developing child or a child with specific needs. For a child who is blind, certain tasks and alternate strategies he or she needs to learn are known. However, children with a history of stroke run the gamut of abilities and disabilities. Therefore it is important to look at raising a child with cognitive, physical, medical and behavioral health care needs as many parents may be faced with some or all of these concerns. For these parents, and to a lesser extent for all parents, the apprehension and uncertainty of a child’s future is often paramount. Parents of stroke victims do face added stress especially because it is unclear what the future holds and what issues the adult survivor of pediatric stroke may face. In reality the hopes and plans once held may now need to be changed for both the stroke survivor and his or her family.

Nearly 9.4 million children in the United States under the age of 18 are believed to have a chronic condition requiring special health care services for physical, developmental, behavioral, and/or emotional concerns (Gordon, 2009). Canadian 1992 statistics show that 7 percent of children younger than 15 years of age have a disability that limits their daily activities (King, Stewart, King, & Law, 2000). Burden and Thomas (1986) wrote that

Giving birth to and rearing a handicapped child can thus be seen as a series of transitions, e.g. at the time of birth and diagnosis, coming to
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terms with the news, searching for help of various kinds, entry into the education system and so on. Each of these transitions can be seen as involving certain potentially critical life events, each of which give rise to individual and family needs. (p. 168)

**Stressors**

Parents and other caregivers of children with a special health care need and/or disability are vulnerable to many stressors in trying to meet the scheduling challenges of numerous therapy and doctor appointments, fighting to obtain correct school services and placements, keeping current with the latest information about the child’s condition and possible remedies, financial burdens caused by needed care, and the ongoing concerns about future functioning abilities of the child in terms of the best quality of life possible. Unsettling feelings about the loss of the “perfect” child the parents anticipated are another source of stress and feelings of helplessness for families. These stressors happen in tandem with other stressors of typical American family members creating a volcano of pressure for many families with children with special needs. The combination of both sets of stressors impact the lives of the child with a chronic health care need and/or disability, the siblings, other family members, as well as the community at large.

Many children and families face issues of acceptance and normalization to a situation that is not normal. While many parents of children with special needs do identify positive aspects and experiences in raising their child, Western society can contribute to the stress faced by the family. Western society rarely values
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adults with disabilities and holds low expectations for parents raising children with impairments. Western societal norms view dependency as limited to the years of childhood with progression to independence reached in adulthood determined by being financially independent, productive, and functioning self-sufficiently. Society views parents as being emotionally and financially burdened when raising a child who may or may not reach societal views of independence (Green, 2007).

In taking care of a child with a disability and/or special health care needs, parents talk about the stress and burden in their everyday lives. Worry, fatigue, and limited social relationships are all related to stress. Many parents attribute their feelings of depression to work overload which left little time for themselves (Dowling, 2007). Burnout is one of the most widely studied aspects of stress-related psychological exhaustion. Norberg (2007) states that

The burnout syndrome, a constellation of symptoms including physical, emotional and cognitive exhaustion, is a consequence of longstanding stress exposure. Originally regarded as exclusively an effect of work stress, burnout may follow long-term stress irrespective of its source. For example, it has been seen among parents with an excessive parenting burden due to a child’s chronic illness. (p. 131)

Parents and caregivers need to take care of themselves. Unarguably, this is much easier said than done.

**Parental PTSD**
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Usually pediatric stroke patients who are above the age of admission to a Neonatal Intensive Care Unit (NICU) will initially be admitted to the Pediatric Intensive Care Unit (PICU). The admission of a child to this unit is a major stressful event for parents and little is known about the long-term psychological consequences for parents subsequent to their child suffering a critical illness. The posttraumatic stress model acknowledges the direct threat to life and provides a framework for conceptualizing and treating ongoing stress. According to this model, PTSD can develop after one or more stressful events. Although historically PTSD has been connected to survivors of war and severe disasters, PTSD has recently been acknowledged as a patient-reported outcome following injury and illness. Bronner et al., (2008) found that PTSD can persist for months or even years, resulting in serious impairment in occupational, social, and relational areas when not properly diagnosed and treated. Although research on PTSD in parents after a child’s admission to a PICU is scarce, studies have identified PTSD in approximately 18%-48% of the parents. (p. 181)

A study of a large number of parents of previously healthy children admitted to the PICU found evidence of distinct symptoms of PTSD. The authors noted that researchers focused mainly on stress experienced by mothers with a child in the PICU, while there is a lack of research on the experiences of fathers with critically ill children. If researchers are to understand the impact of pediatric intensive care treatment on parents, then both mothers and fathers must be included (Bronner et al., 2007).
Specific Diagnoses, Special Challenges

Stroke, while being a comorbid condition most frequently paired with cardiac or hematological disorders such as sickle cell disease, can also be caused by surgery from excess blood flow to the brain or the blockage of blood flow. Unfortunately a number of pediatric cancer patients also suffer from strokes. Working in Sweden, Norberg (2007) presented information concerning the emotional factors for parents of pediatric cancer patients that may be helpful for the current research. Most parents experience a crisis when a child is diagnosed with cancer. This is similar to the crises experienced by parents finding out that their child has suffered a stroke. Cancer, like stroke, has been “assumed to be a period of chronic stress for the parents” and “parents of children surviving brain tumours are likely to experience long-term strain related to the child’s disease. Negative consequences of chronic stress can be serious” (Norberg, 2007, p. 130).

Depending on the site of the stroke many survivors are left with impulsivity, intense emotional mood swings and/or depression. “Erickson (1968), Miller and Keirn (1978) reported higher levels of stress in parents of children with behavioral problems than in parents of cognitively impaired children” (Gupta, 2007, p. 418). Many survivors of pediatric stroke are left with both behavioral problems and cognitive deficits. In addition, stroke increases the chances of attention deficit hyperactivity disorder (ADHD). Gupta (2007) found that while the level of parenting stress is “determined by the overall nature of the disorder, parents of children with ADHD and developmental disorders reported higher levels of parenting stress than children with HIV infection, asthma, and healthy
controls” (Gupta, 2007, p. 417). Also, “parents of children with disruptive behaviors (ADHD) and parents of children with developmental disabilities (DD) reported higher total stress than parents of children with chronic medical conditions such as HIV-infection and asthma and typically developing children” (Gupta, 2007, p. 422). Some stroke victims must deal with behavioral, developmental and chronic medical needs. While Gupta (2007) found that parents had a more difficult time accepting a child with a visible disability, a difficulty for some stroke victims and their families is that the child “looks normal” and therefore people expect the child to be able to function in an age appropriate way.

**Mothers as Caregivers**

While both mothers and fathers of chronically ill children have to manage to cope with a variety of stressors related to the child’s care, several researchers believe that mothers as the traditional and primary caregivers are more heavily burdened both socially and psychologically than fathers of children with chronic illness (Florian & Krulik, 1991). In addition to coping each day with the child’s needs, mothers are often the parent responsible for the day-to-day requirements of the family, whether or not the mother works outside the house as well. The prolonged care of the child with special needs has been shown to have adverse effects on her physical, emotional and social well-being. Depression, guilt, distress, and high levels of worry have been documented in mothers caring for a child with a chronic illness. Mothers with fewer social resources reported a greater sense of burden and loneliness from being the child’s primary caregiver (Florian & Krulik, 1991). Florian and Krulik (1991) note that
a possible explanation for greater loneliness among mothers of chronically ill children can be related to the concept of situational loneliness.

Situational loneliness may occur in individuals whose social relationships were satisfying until some specific change, stressful in nature, happened in their emotional and physical milieu and changed their needs and desires for social contact. Raising a child with a chronic illness can represent a stressful change in the mother’s life. (p. 1295)

Similar to cancer, sickle cell disease is another condition with unpredictable medical implications thereby causing stressful lives for mothers caring for their children. Never knowing when the child with sickle cell disease will go into crisis, mothers are not able to plan for travel and activities for the future. This may increase the mother’s sense of isolation and depression. Mothers of children with sickle cell disease (SCD) expressed sadness about the lack of control they felt (Burnes, Antle, Williams, & Cook, 2008). In a study of Canadian mothers of African and Caribbean descent, Burnes et al. found that “mothers commonly reported several daily coping challenges: fear of their children’s death, separation anxiety, loss of control over life, helplessness, and loneliness/isolation, SCD stigma interacted with racism, contributed to social isolation, and prevented families from organizing as a group” (p. 211). In addition to sickle cell disease being a risk factor for pediatric stroke, many parents of stroke victims feel the same sense of not knowing if and when their child might have another stroke or seizure. While another stroke is usually uncommon, the threat and worry is always hovering right below the surface. Feelings of isolation can occur as no one
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in most circles of friends and family has ever heard of or understands the ramifications of pediatric stroke.

Mothers reported emotions of shock, sadness, anger, frustration, loss, disbelief, and guilt as well as feelings of isolation when they became a parent of a child with special needs. Even after many years, mothers could vividly describe the emotions they felt when given the diagnosis. For many mothers these feelings associated with the initial diagnosis changed over the years (Cameron, Snowdon, & Orr, 1992). While family and friends are not considered as supportive as they might, this may be because many people have had little contact with a child with developmental disabilities. Families of pediatric stroke survivors might feel a similar experience since virtually no one has heard of children having strokes.

Cameron, Snowdon, and Orr (1992) reported mothers’ sense of loss of the “normal” child similar to experiencing the death of a child. Some mothers felt it was necessary to distance themselves from the child in order to grieve their loss, but could not have this space due to the demands of caring for the child. As the child grew older, mothers reported being reminded on a daily basis of their child’s limitations when compared with other children of the same age. A new sense of sadness emerged as the child was not able to achieve developmental milestones. Mothers also felt anger and frustration as the child grew older; these feelings were usually associated with specific situations related to the family’s lifestyle and activities of daily living. Mothers of these children also described feelings of anger relative to the behaviors and attitudes people in the community had to their children. Although mothers felt anger and frustration, many were able to move
feelings of resolve and acceptance yet “others described their experience in terms of life-long stresses that may not ever resolve or reach a final stage of acceptance” (Cameron et al., 1992, p. 100). Out of necessity, some mothers of children with disabilities have become experts in navigating the health care and social service systems and, in turn, have become the “go to” people within their families. Mothers also felt an increased awareness of what is truly important; focusing on what has meaning to them and strengthening relationships with family and friends (Green, 2007).

Although most research focuses on mothers within two-parent families, Levine (2009) used a resiliency framework to study single mothers of children with disabilities. The purpose of this longitudinal Canadian study was to identify the factors of resiliency found in individuals and families within their social and environmental systems “with a view toward enacting policy changes and practice initiatives that will enable families to manage the care of their children in positive, respectful, and empowering ways” (Levine, 2009, p. 403). While the study did not include mothers of children with multiple or severe disabilities or whose children were medically fragile or technologically dependent, four overarching themes emerged in this study of single mothers of children with more mild disabilities. Levine (2009) described these themes as:

- use of individual thoughtful and responsive strategies of personal agency;
- the experiences of transforming the position of ‘child as disabled’ to one of ‘disability as normal’;
- the ability to use available resources and/or developing new resources; and, “moving from the position of ‘knowing’
through listening to other to ‘knowing’ developed in context of listening to self. (p. 411)

Although many pediatric stroke survivors are left with a range of disabilities, both mothers and fathers can develop these ways of resiliency for raising their children.

**Fathers as Caregivers**

Most research looks at mothers as caregivers, but what about the fathers of children with special needs? Only recently has there been attention to the inclusion of fathers in social work practice; however, there continues to be a significant lack of research relative to mothers. Research including fathers as participants is also a relative rarity even though fathers report wanting a greater role in the parenting process (Shapiro & Krysik, 2010). As Carpenter and Towers (2008) wrote,

in families of children with disabilities, mothers and fathers can react differently to the news that their child has a disability or special need. Emotional reactions by fathers to the birth of their child with a disability vary. The birth brings about life-transforming experiences. For some fathers, it is a challenge that allows them to display aspects of their personality not previously acknowledged. (pp. 118-9)

**Changing stereotypes.** Conventional attitudes in all known societies suggest that adult heterosexual men function as fathers to their wives’ children and providers and protectors for their partners and children (McNeill, 2007) with limited roles in actual child rearing. However there is a growing volume of
research that shows fathers who assume an active role in raising their children enhance and facilitate their child’s growth and development. The quality and quantity of father and child interactions may lead to “positive social developments, fewer behavioral problems, greater emotional self-regulation, increased language development, and enhanced cognitive functioning for young children” (Dyer, McBride, & Santos, 2009, p. 265). Many fathers reject the stereotypes and see themselves as going far beyond the masculine stereotypes to become an important and intimate part in the lives of their children. “The tender ways that fathers related to their children provides evidence of a richer involvement than popular images of fathers might suggest” (McNeill, 2007, p. 418). Many fathers in McNeill’s (2007) study saw themselves embracing a more holistic gender identity. Also looking at fathers’ involvement with their children, Jones and Mosher (2013) mined data from a sample of almost 4,000 fathers aged 15-44 who had participated in the 2006-2010 National Survey of Family Growth (NSFG). In this large and nationally representative sample, the researchers found that involvement of fathers was both complex and multidimensional. They found statistically significant differences on the frequency of involvement with regard to whether the father lived with or apart from the children. Differences were also noted in variables of age, marital or cohabiting status, level of education, and ethnicity.

Regardless of the level of father involvement, there is a belief that both mothers and fathers play a vital part with each gender bringing different contributions to raising children. Although many fathers agreed with the belief
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that differences “between mothers and fathers are ‘natural,’ their identity and behavior transcended what might be considered traditional masculinity” (McNeill, 2007, p. 421). For many men, their sense of masculine identity is important in defining themselves as parents. Fathers who had a more flexible gender identity engaged in a wide range of parenting behaviors. While unclear if caring behaviors shaped fathers’ views about gender or vice versa, fathers did feel the importance of engaging with their children because they believed that their sons and daughters needed them (McNeill, 2007).

**Fathers of children with special needs.** Fathers of children with a chronic health condition often transcend the “traditional male stereotype and embrace the opportunity for a more intimate and involved style of parenting” (McNeill, 2007, p. 409). These dads reported being deeply affected by their child’s diagnosis and needs. Fathers reported feelings of guilt, sadness, anger, and anxiety. Many adopted a protective stance of both their child and the child’s mother and were more meaningfully involved with the child and family (McNeill, 2007).

**Specific diagnosis.** Researchers of Canadian fathers of children with cancer found experiences of isolation and increased sadness. Yet these fathers reported discovering newfound meanings in reconciling the presence of pediatric cancer within the life of the family after the diagnosis. Fatherly roles in supporting their families included providing sufficient (financial) resources and helping to maintain a stable family life. Fathers demonstrated “a commitment to family integration, healthy personal lifestyle and attitudes, support seeking,
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spirituality, and reframing of priorities” (Nicholas et al., 2009, p. 260). Fathers’ experiences were found to be qualitatively different than those of the mothers. The research found that mothers reportedly “focus on the child’s everyday care needs and nurture for themselves supportive connections, fathers appear focused on the longer term impacts of the child’s illness and may rely on self-support strategies, particularly during times of hood in high stress” (Nicholas et al., 2009, p. 261). The researchers noted that like most studies of parental responses to childhood illness, the focus is frequently only on the maternal perspectives.

Fathers of children with an intellectual disability are also a neglected group in family research even though supports could be made available by understanding the fathers’ needs in adjusting to living with children with an intellectual disability. MacDonald and Hastings (2010) found data suggesting that these fathers are considerably less involved in their children’s care even when the mothers are employed outside the home. Some fathers tend to withdraw from being involved with their children with developmental disabilities or delays. The reason for this is unclear (Dyer et al., 2009). As it has been found higher “developmental outcomes for children with involved fathers, and the fact that mothers may experience less stress if they are more satisfied with their male partner’s contribution to child care, understanding father involvement is an important focus for researchers” (MacDonald & Hastings, 2010, p. 236). Several studies conducted in Italy suggest that, especially in children with intellectual disabilities (ID), parental stimulation and support are the crucial factors for the child’s development (de Falco, Esposito, Venuit, & Bornstein, 2008).
Fathers’ stress. Chronic and severe stress has been shown to contribute to poor health outcomes in men (Schneiderman, 2004). A study on fathers of healthy children and fathers of children with a chronic illness (Katz & Krulik, 1999) revealed that fathers of children with a chronic illness experienced a greater number of stressful life events, family events, and lower self-esteem than did fathers of healthy children. Fathers of children with special health care needs and/or disabilities have many, many worries. Not only do they worry about the effect on their child and his or her future, fathers need to be concerned about the effect on the healthy siblings. These concerns usually revolve around the loss of parental attention due to the need to be available for the affected child as well as less financial resources for the family. Some siblings are hesitant to discuss feelings and concerns with their parents, as they do not want to increase the stress already felt by their parents. Siblings of brothers and sisters with special needs have their own unique needs.

Fathers also worry about their wife or partner and her ability to cope and manage the needs of the child. Some fathers identified worry and stress revolving around practical and financial needs of the family. Intense stress sometimes results in difficulties maintaining attention and concentration at work and thereby being productive to sustain employment at work. “Most fathers described extensive costs and lost income as a result of the illness. Several fathers described personal physical symptoms, including stress and anxiety, dry throat, decreased sleep, and interrupted appetite” (Nicholas et al., 2009, p. 265).
**Being the stepfather.** With the number of remarriages and different types of new unions, the role of a stepfather needs to be addressed. Those who function in the role of father, whether legally married to the child’s mother or not deserve special consideration. It may be difficult for the stepparent to adjust to parenting a child with chronic illness, particularly in early-remarried years (Zarelli, 2009). There are experiences of both exclusion and isolation due to the inadequate legal and medical resources as well as social support (Mason, Harrison-Jay, Svare & Wolfinger, 2002). It may be difficult for stepfathers to understand their role in the child’s life and therefore incorporate a sense of hope and wellbeing within the family structure. Feelings of hope have been associated with adaptation and effective functioning while loss of hope can lead to unhealthy adaptations and ineffective functioning (Zarelli, 2009). “Caring for children with a chronic illness may produce challenges to fulfilling stepfather roles. Barriers to fulfilling the role of the stepfather may entail role ambiguity, role conflict, role incongruity, and role overload” (Zarelli, 2009, p. 93). Medical and other professionals may be leery of involving stepfathers for both legal and emotional reasons. Stepfathers, somewhat like many biological fathers, see their roles as financially supporting the family and supporting their wives during periods of stress. Going to work can also be a coping strategy for both fathers and stepfathers of children with special needs (Zarelli, 2009).

**Redefining expectations.** Fathers in America are now expected to be more involved in everyday parenting when compared to previous generations (Cornille, Barlow, & Cleveland, 2006). Carpenter and Towers (2008) found that
men wanted to be part of the daily experiences of their children and be included in the decisions affecting their lives. Fathers wanted to provide opportunities for their child’s learning and development. Some men looked for job flexibility in order to have more time and energy for their children. It was important for most fathers to be considered as equal partners and be acknowledged for their contributions to the lives of their family (Carpenter & Towers, 2008). While men are increasing their active involvement in the lives of their children and the literature reporting the positive effects for their children in regards to self-esteem, intellectual growth and social skills, fatherly involvement can be tested when a child has a disability or chronic illness. It may be difficult for the fathers to deal with letting go or changing the dreams the men had for their child in terms of family lineage and the father’s ego and pride for their child’s academic, athletic and vocational achievements (May, 1992).

In order to limit fathers’ negative emotions and experiences, fathers in one study used resistance strategies. These cognitive held, action-oriented strategies included: “(1) family integration and stabilization; (2) healthy lifestyle and attitude; (3) support; and (4) hope and spirituality” (Nicholas et al., 2009, p. 267). A high degree of mutual attunement was found when fathers and children with Down syndrome spent time playing together. This play interaction successfully enhanced the child’s level of play. Fathers were seen as an essential resource for their child’s development and an important support for the mothers (de Falco et al., 2008).
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In a poster presentation at the American Public Health Association on November 4, 2007, Bridges presented an ecological systems framework of selected protective and risk factors of African American fathers of children with special needs. While most research has looked from a deficit perspective, Bridges found recurring strengths in pride of their children’s accomplishments and an increased knowledge of ways to promote children’s development. Fathers also reported on concrete needs including a male caregivers’ support group (Bridges, 2007). The DADS Family Project seeks to assist dads in their understanding of the important role that fathers have in the lives of their children. In a setting with only fathers present, the DADS project has served as a tool to support fathers in developing their own voice (Cornille et al., 2006).

**Implications for supporting fathers.** Fathers of children with special needs perceive few available systems of supports. Being the father of a child with special needs can leave a man feeling powerless, depressed, weak, and guilty. If the father is not available, the entire role of child rearing needs to fall on others. It is usually the mother who is forced to become the child’s full-time caregiver. The mothers become the “expert” about the child’s needs with the fathers losing optimal involvement. When a man can push past these negative feelings he can develop ways of improving his life, his child’s life, and the life of the family. Positive results of father involvement are seemingly endless for everyone. With the involvement of the father, all family members feel less stressed, fatigued, isolated and depressed. Families can learn to rebalance themselves in constructive and healthy ways to develop ongoing beneficial traditions (May, 1992).
Lack of Research with Minority Populations and Fathers

Although there is an increasing level of research of fathers, the overwhelming majority of studies focus on mothers. Britain’s national family policy recognizes the important contribution fathers make in the lives of all family members. The policy promotes an understanding of the roles of both the father and the mother. However, support services are primarily focused on the needs of the mothers with services provided predominantly by women (Carpenter & Towers, 2008). There is limited literature highlighting parental suggestions for assisting the family, with the majority of information being provided by professionals (Burden & Thomas, 1986). “Despite an increase in father-focused research over the past two decades, there continues to be a significant lack of research examining fathers relative to mothers, as well as research that includes fathers as participants” (Shapiro & Krysik, 2010, p.1). While little is known about fathers there is even less research focusing on fathers from diverse backgrounds especially low-income, gay and ethnic minority fathers (Shapiro & Krysik, 2010).

Research that does look at the considerable influence of the father on a child’s development usually focuses on children without developmental delays. Dyer et al. (2009) concludes that the dearth of research concerning fathers’ involvement with their developmental delays has been unfortunate because paternal participation may have an important impact with these children because of the higher levels of parental stress and depression found in families of children with developmental delays. (p. 266)
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In studies looking at the experiences faced by parents whose children are in the Neonatal Intensive Care Unit, most studies focus on the mother. Though the importance of the father-child bond is well recognized, little is “known about the effect on this relationship when the infant is in the neonatal intensive care” (Deeney, Lohan, Parkes, & Spence, 2009, p. 45). Even when studies look at the fathers of high-risk infants as a side area of interest, conclusions are drawn from interviews with the mother only or with both parents together (Deeney et al., 2009). Most of the studies looking at parenting stress have used middle class Caucasian families. There is little representation of minority families in such studies and, as a group, minorities with disabilities have fewer resources and less knowledge of potential resources than those in the racial majority (Gupta, 2007).

This lack of attention to fathers, and in particular minority fathers and fathers of children with special health care needs and/or disabilities, is inconsistent with social work practice frameworks such as the ecological theory and family systems perspectives (Shapiro & Krysik, 2010). It is consistent with National Association of Social Workers Code of Ethics that social work research and practice and policy include fathers of all races, ethnicities, economic statuses and sexual orientation parenting children with and without special needs (NASW Code of Ethics, 2008).

Families of children with special needs, regardless of race, ethnicity, sexual orientation, religious, or economic status, need to adapt and adjust to their new situation. For some patients and their families, religion and/or spirituality may provide some level of assistance with an existential understanding and
provide a mechanism for coping and acceptance. The following chapter will examine the role of religion and spirituality. Both the positive and negative influences of religion and spirituality from the perspectives of Christianity, Judaism, Buddhist, and Islamic teachings are also presented in this chapter.
Chapter III

The Role of Religion and Spirituality

Of all the ways that people commonly deal with suffering—denial, rationalization, spiritualization, substitution—few are places of refuge. Most will disconnect us from the very life we hope to bless and serve and may defeat us in fulfilling the purpose of our lives. The sad part of this is that we can never hide from suffering. Suffering is a part of being alive. Hiding ourselves means only that we will have to suffer alone. (Remen, 2000, p. 137)

Reconciling Beliefs

Fairly soon after the diagnosis of pediatric stroke is made, parents must begin to reconcile their beliefs of why things happened and deal with numerous tensions and changes that will be occurring for them and their families. According to Kearney and Griffin (2001) parents in similar situations reported confusing and conflicting emotions, information and advice; ambiguous prognosis; of their own observations being in conflict with the information they were being given; of not knowing what to expect and sometimes, of simply not knowing what to expect and sometimes, of simply not knowing what to do. They had entered a world in which they had no experience and no knowledge, and there were no signposts or maps. They were torn by joy in the survival of their children but, at the same time, questioned the cost.
They recognized the children were lucky to be alive but, in the same breath, expressed their sorrow at what they were missing out on. Some grieved for the loss of the children as they knew them and, at the same time, felt unjustified in their grief as these children continued to exist. (p. 586)

Many parents and family members must now additionally deal with their opinion and societal views of people with special needs. Depending on the age of their children many of their children were, before the stroke, excelling in academic, sports, friendships, and so on. Many parents, like those in the general public, had limited or no experience with people who were like the children they now might be raising. Parents now have to face the pain and discomfort derived from societal values of people who do not fit the criteria for the ideal. Today’s Western success-oriented society places value on intelligence, beauty and youth (Kearney & Griffin, 2001). Looking back to medieval times, the major tenets of Christianity, Judaism and the Islam “saw disease and disability as the scourges of God, as punishment for sin, or as disciplines to be endured” (Seligman, 1991, p. 7). Even today people with disabilities are generally not viewed positively; they may still be looked upon as burdens to society, which generally views the “presence of a child with a disability as a tragedy from which the family may never recover” (Kearney & Griffin, 2001, p. 582). Yet, families with children with special needs need to come to terms with how they view their child regardless of societal views. They must also look to how their religious or
spiritual beliefs may impede or aid the process of healing, making meaning out of what has happened, coping, and acceptance.

**Religion and Spirituality**

Chan, Ng, Ho, and Chow (2006) found that examining spirituality to give meaning to life particularly during a time of suffering and grief is becoming a topic that is being discussed by those in clinic practice. These researchers also found that the frustration of not finding an answer to why this has happened to me and/or my family has been closely aligned to an increase in morbidity and mortality among bereaved spouses and family members (Chan et al., 2006). In times of suffering some people will turn to their religious beliefs for a source of strength and comfort; while other individuals may question their beliefs; and some people will both seek comfort and question their religion and/or spirituality simultaneously and intermittently.

Most people living in the United States are enormously influenced by spiritual beliefs (Hayes, 1984). According to the Pew Global Attitudes Project, 2002 religion is an enduring and pervasive aspect of life in America as Americans are the most religiously inclined of the developed nations of the world. Cited in Michie and Skinner (2010), Davis and Smith (2009) found that “ninety percent of Americans believe in God or a higher power and eighty percent self-identify as Christian with over half of the American population stating that they participate in some religious activity or religious group at least once or twice a year (Davis & Smith, 2009)” (Michie & Skinner, 2010, p. 108). Therefore, at least in this country, religion and/or spirituality should be examined as an influence on human
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health, behavior, as well as a possible coping mechanism/strategy for those dealing with issues of bereavement, loss, and suffering.

Numerous studies indicate a connection between religion and an individual’s well-being in response to dealing with stressful events. Religiosity and spirituality can be measured using a variety of indicators such as faith, religious practices, and affiliation with religious congregation (Skinner, Correa, Skinner, & Bailey, 2001). In a systematic review undertaken by Becker et al. (2007) to assess whether spiritual or religious beliefs affect the grief and/or bereavement process they first investigated the terms spirituality and religion and how they were being applied to the studies. According to Becker et al. (2007)

Only a fifth of the studies differentiated between religious and spiritual beliefs and addressed the issue of definition. The terms ‘religion’ and ‘spirituality’ even in the scientific literature are often used interchangeably. The word ‘religion’ derives from the Latin ‘religare’ or ‘religio’, which means ‘to bind back’ or ‘to bind together’ or ‘to be in relation with’. Religion therefore describes a condition of being related to someone or something transcendent that in monotheistic Jewish-Christian tradition is called God. Over time, the meaning of the original concept of ‘religio’ has narrowed. “Religion’ has become the outward expression of a particular spiritual understanding and/or framework for a system of beliefs, values, codes and rituals. Religiosity is the expression of faith or belief in a higher power through rituals or practices of a particular religion or denomination. Spirituality, however, is a more abstract and elusive
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term. Preliminary definitions indicate that spirituality is broader than
religion and relates to the universal quest to make sense out of existence, a
characteristic of human beings. (p. 214)

In the end the authors found that the data did not provide a definitive answer as to
whether or not religious or spiritual beliefs influence bereavement (Becker et al.,
2007).

For bereaved people who have had or wish to have a religious or spiritual
connection, the complex notion of God’s justice needs to be examined. On a large
scale, many are troubled by the unfair distribution of suffering in the world
(Kushner, 1981). On a personal level, each individual will need to come to a
sense of acceptance if he or she is going to continue to believe in a higher power.
While not setting out to explain nor defend God, Rabbi Kushner in his seminal
work, When Bad Things Happen to Good People, examines this most puzzling
question. Kushner struggles with the question of why God allows bad things
occur to those who are righteous. According to Kushner, a clergyman’s job should
be to comfort the selfish, dishonest people when tragedies occur by assuring them
of the forgiving love of God (Kushner, 1981). But if a person is benevolent with
others and follows the commandants and beliefs of his or her religion, how can a
person of faith comprehend a devastating medical event happening to their
innocent child?

Beder (2004-5) described the concept of the assumptive world where
assumptions or core beliefs provide a way to see the world which functions to
ground, secure, stabilize, and orient people. This sense of how the world works is
shattered in face of trauma as tragic losses invalidate the ‘assumptive world’ (Janoff-Bulman & Berg, 1998) on which we rely as our “taken-for-granted senses of security, predictability, trust, and optimism are profoundly and perhaps permanently undercut by traumatic experience” (Neimeyer et al., 2002, p. 240). The security once found in the beliefs is no longer present. The world can no longer be seen as a safe place with good and caring people who have at least some control over what happens to them and their loved ones (Beder, 2004-2005). For many, when something devastating happens to their child, the world no longer makes sense.

Those brought up with a belief in the Bible, Torah, or Quran have heard and read the stories of good behaviors being rewarded. But, as Rabbi Kushner (1981) wrote,

Imagine the mind and heart of a blind or crippled child who has been raised on pious stories with happy endings, stories of people who prayed and were miraculously cured. Imagine that child praying with all the sincerity and innocence he can muster, that God make him whole, like other children. And now imagine his grief, his anger turned outward at God and at those who told him those stories, or turned inward on himself, when he realizes that his handicap is going to be permanent. (pp. 126-7)

Many people feel a need to blame themselves or others in an attempt to make sense of what has happened. It sometimes seems as if it easier to blame oneself than to “blame” God. In my experience as a social worker in the stroke program, dealing with the parental sense of guilt can last a long time even after
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developments and other professionals declare that they had nothing to do with their child suffering a stroke. Time must be spent reassuring the family that there was nothing they did to cause the stroke nor was there anything they could have done to prevent the stroke. A member of Rabbi Kushner’s congregation confessed that she and her husband did not fast last Yom Kippur and wondered if this could have been the cause for their child’s death. Others have tried to rationalize that God gives people what they deserve for it is our misdeeds that cause our misfortunes. While this may be seen as a neat and simple solution to the problem of evil and misfortunes, it has serious limitations (Kushner, 1981). People may also try to “defend” God by suggesting that painful things that happen are ways of God helping us. By using words and ideas to convert misfortune into good does not address the suffering.

For those with spiritual or religious beliefs based in Christian and Jewish teachings, the question of why do the righteous suffer is the most perplexing one. People want to believe in a just and fair world with rewards and benefits for those who are “good” and punishments and unhappiness for those who are not. However, the world does not fit this easy model and so questions are raised about the role of goodness and kindness and even the existence of God or a higher power. In the past, research has demonstrated that the need for people to perceive the world as fair is so strong that victims of tragedy are sometimes blamed and derogated. In contrast sometimes people give extra meanings and importance to the lives of those who have suffered in order to believe that the world is just (Anderson, Kay, & Fitzsimons, 2010).
In both scientific and religious studies people are taught from early childhood that the world makes sense and everything happens for a reason. Those experiencing devastation from an earthquake or tsunami, may understand the scientific reason for the force of nature while still questioning how God could have let so many innocent people perish. Even harder to understand for families of pediatric stroke survivors is why it is their child and their family has been made to suffer this diagnosis. It is especially difficult for the families where the cause of the stroke goes undetermined. In reality there is chaos in the world and according to Rabbi Kushner, “chaos is evil; not wrong, not malevolent, but evil nonetheless, because by causing tragedies at random, it prevents people from believing in God’s goodness” (Kushner, 1981, p. 61) for if God is the cause we need to understand why God wants some to suffer. Some hate themselves for deserving such a fate or hate God for giving them a burden they did not deserve (Kushner, 1981).

In the Bible, the Book of Job highlights the issue of God’s justice. Many years ago in my role as a religious school teacher I heard a presentation by a well-known religious educator. He announced that it was possible to believe only two of the three following statements. The choices of statements are that 1. God is all-powerful; 2. God is just; and, 3: Job was a good man. If we believe that God causes everything to happen and people get what they deserve, then Job could not have been a good man. If God is fair and Job was good, then maybe God cannot control all that happens on Earth. The third combination which credits God as being able to command everything that happens and Job was a righteous person,
is the most disturbing for the majority of people. In reality bad things do happen to good people. According to Kushner while God would like people to get what they deserve, he does not always have the power to make it happen. When forced to choose between a God that is good and not all-powerful and a God who is all-powerful but who is not always good, the Book of Job chooses the goodness of God (Kushner, 1981).

Some people will express the idea of being at peace for the person who is “going home” to a better world, to a place residing with a higher power. Parents and others are told to rejoice because the child has been transported from a world full of sin and pain to a world where there is neither grief nor pain. Some are being told by a representative of their religion that they should not cry or feel sad at the sudden death of their child, but should be thankful that their innocent child will be in a happier place. The belief in a world after death that is only filled with happiness and joy may serve to help people endure the unfairness in this world without losing faith (Kushner, 1981).

As America is becoming increasingly diverse, in addition to patients coming to hospitals in the United States from all over the world to receive medical care, it is important to consider faiths other than those based on Christian and Jewish beliefs.

From the Muslim perspective, everything is in God’s hands. As explained during a presentation by representatives from the Muslim community for social workers at the Children’s Hospital of Philadelphia on November 14, 2011, when a person is sick, it is felt that he or she is closer to God and therefore the
hospitaled person prays for those in the community. When someone is ill, it is not something the person, their parents, or anyone else did wrong- all is determined by God. When illness happens it is for the purification of the person and/or the family. Death is considered as much a part of life as life is. If a child dies before the parent(s), the child will be waiting at the Gates of Paradise for his or her parents (CHOP presentation, 11/14/11).

God is the creator of life according to Islamic law (Sarhill, LeGrand, Islambouli, Davis, & Walsh, 2001) and, as such, Islam holds “life as sacred and belonging to God and that all creatures will die one day” (Sarhill et al., 2001, p. 251). For Muslims death is only a transition between two different lives for “the Quran emphasizes that death is only a move from this existence to a future life. The Quran always affirms the unlimited mercy and forgiveness of God, but links future life to performance in the present life (from birth to death)” (Sarhill et al., 2001, p. 252). In Islam, death is believed to be a passageway to eternal life. Paradise is guaranteed to a child in his or her next life for children as are seen as innocent and pure. This is a great comfort for the family (Sheikh, 1998).

Therefore, for those who are Muslim, there may be less of a struggle and feeling of suffering when compared with people who identify as Jewish or Christian. Although similar to the Muslim perspective that God is all powerful and nothing happens without his willing it, some Christian, Catholic, and Orthodox Jewish families may also feel comforted in the belief that God will take care of their child/family and/or everything is in God’s hands. Their suffering may be eased by these beliefs as well.
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For those who are Buddhist, there are specific teachings in regard to suffering and why things might happen in life. From a Buddhist viewpoint, individuals experiencing problems associated with a traumatic experience may describe the symptoms as a form of suffering. Sufferers from trauma and grief may exhibit limited behavioral responses and emotional numbing. Buddhist philosophy is concerned with basic human suffering and ways to alleviate such suffering (Turner, 2009). In addition, the idea proposed in the well-known Chinese saying, “In every 10 life events, eight or nine of them happen against our wishes” (Chan et al., 2006, p. 823) may help people manage disappointment and ease individual suffering. According to Moffitt (2008),

the path to happiness and a sense of well-being in this life lies not in avoiding suffering but in using the conscious, embodied, direct experience of it as a vehicle to gain deep insight into the true nature of life and your own existence. (p. xx)

Life is said to be challenging, often difficult, always uncertain and changing, and, mostly out of one’s control (Moffitt, 2008). Morris (2008) wrote in What Do Buddhists Believe? that suffering is caused because people do not fully understand what it means to be human in a world that is constantly changing. It is necessary for people to be comfortable in a world that never remains the same. Human beings are meant to be confronted by all experiences in life, no matter whether these experiences are good or bad. All kinds of experiences simply happen in life and one should not take good fortune for granted nor deny bad experiences (Chan et al, 2006).
The Four Noble Truths comprise the basic tenets of Buddhist beliefs. The first of these Noble Truths, the Truth of Suffering (*duhkha*), describes the belief that difficulty and disappointment are an inescapable aspect of the human experience. “No one is immune from illness, whatever the wonders of modern medicine. Suffering also includes emotional and psychological distress, which is no less real for being invisible” (Morris, 2008, p. 40). The Second Noble Truth, the Truth of Arising (*samudaya*), explains that suffering comes from wanting things to be different (Morris, 2008). The possibility of hope is a component of the Third Noble Truth, the Truth of Cessation (*nirodha*). Morris (2008) clarified that

if the root of suffering is attachment to false ideas, grasping onto things we can’t have, or failing to come to terms with the way things really are, then the solution is to resolve that ignorance. In order to be happy we need to understand that change is inherent in all things, abandon our fantasy of trying to control it or stop it happening, see it more clearly for what it really is- a natural process. (p. 42)

And the Fourth Noble Truth consists of eight factors called the Noble Eightfold Path or Eight Steps to Enlightenment (Morris, 2008, p. 43) that is a set of teachings that includes right view, resolve, speech, action, livelihood, effort, mindfulness, and concentration (Cadge, 2004) and is the basis for leading a righteous life.

Looking at potential benefits that spirituality may contribute to specific areas of one’s life, there have been many studies, over the past few decades, from
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a variety of sources supporting the use of a holistic approach. These studies have shown a positive correlation between spiritual, physical, and mental health. The use of spirituality by patients has been reported to decrease morbidity and mortality, improve outcome after surgery, and improve coping skills as well as overall well-being (Rubin, Dodd, Desai, Pollock, & Graham-Pole, 2009).

Research has also shown that religious beliefs and spirituality correlate with greater positive maternal socio-emotional outcomes (Ekas, Whitman, & Shivers, 2009). While definitions of spirituality often differ (Speraw, 2006) and religion and religiosity are somewhat nebulous terms, spirituality, religion, and religiosity have been shown to be positive factors for both physical and mental health (Rubin et al., 2009).¹

Many individuals reported relying on support from friends, gaining information, as well as prayer and religious tradition when faced with a difficult situation (Northington, 2000). Speraw (2006) noted that spiritual beliefs, along with expanded networks of support that included health care professionals and faith communities, were found to provide comfort for families impacted by major health related events.

Reframing the narrative in a religious and a more positive light does not negate the challenges of caring for a child with special needs for the struggles and

¹ Rubin, Dodd, Desai, Pollock, and Graham-Pole note that religion and religiosity are usually identified with specific values, beliefs and rituals within a religious framework while spirituality is often seen as a broader concept. Spirituality can include beliefs about the meaning of life, the will to live, and one’s relationship with others, a higher power, and the environment.
“positive blessings, never canceled one another out. Rather, they existed side by side” (Michie & Skinner, 2010, p. 107).

Religion plays a similar role in coping with other chronic medical conditions such as HIV. With the introduction of anti-retroviral therapies, HIV is now considered a chronic illness by the medical profession. A descriptive study by Richards, Wrubel, Grand, and Folkman (2003) explored the experiences of mothers of children with HIV. The researchers found that prayer was used frequently in the course of everyday activities. The benefits of prayer included a shift in attitude toward a more positive perspective as “positive states of mind grew out of prayer that nurtured gratitude, faith, trust, and wonder” (Richards et al., 2003, p. 201). Wilson and Miles (2001) found similar benefits of prayer. The researchers conducted a study looking at the effect of spirituality among African-American mothers of seriously ill children. This qualitative study found that prayer was central to the spiritual life of these women and in helping the mothers cope with their child’s illness.

In Mormon theology, serving others is seen as a means of fulfilling God’s teachings. Members of the Church of Jesus Christ of Latter-Day Saints (Mormon) believe that it is important to share their time and expertise for those within the church, those in the larger secular community, as well as society in general (Cnaan, Evans, & Curtis, 2012). Marks and Dollahite (2001) have studied the effect of religion on fathers who were/are members of the Church of Jesus Christ of Latter-Day Saints. The researchers defined responsible fathering as the father’s awareness to his child’s needs and to his own deeply held beliefs, in
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contrast to reacting to a role created by outside cultural or societal ideas. In the interviews, fathers expressed that while the experiences with religion were at times challenging, their faith was meaningful and helped sustain them in their efforts to be responsible fathers. Religion may be valuable in supporting and encouraging responsible fatherhood for a number of reasons. In many communities, religious institutions can reach a large number of people. According to Horn (2001) churches and synagogues have a higher degree of contact with men than any secular organizational network. Additionally, the length of quality and contact between the fathers and the religious institution has been shown to be advantageous. Religious communities’ contact with men over extended periods of time thereby increases the chance for positive influence. This is in contrast to many intervention programs that may be limited by time and/or funding sources. Lying outside of secular interventions, religious approaches can accentuate revered spiritual beliefs about being a husband and father that may be both significant and motivational (Marks & Dollahite, 2001).

The narratives of 35 Latter-Day Saint fathers of children with special needs explored the influence of their religious beliefs and practice on their experiences of fatherhood. When considering a divine plan for both life here on earth and an eternal life, the fathers were able to create “a coherent sense of meaning despite disability and death. The fathers’ beliefs and expectations inspired them to make and keep a commitment to a sacred responsibility of loving, serving, and caring for their children with special needs” (Dollahite, 2003, p. 237). In research with fathers whose children had been diagnosed with cancer,
several fathers described a personal spiritual search for meaning and comfort. Some fathers experienced an increased reliance on faith since their child’s diagnosis. This faith was used as a means to “bargain for a positive outcome, cope with their child’s condition, and find an outlet for their grief and fears” (Nicholas et al., 2009, p. 269). While most fathers reported a deeper sense of spirituality in attempting to come to terms with their child’s illness, other fathers described a decreasing level of trust in a divine power (Nicholas et al., 2009).

The more recent look at spirituality, among other factors, has created a shift in the medical community. Many medical professionals in the past would focus on the physical issues of their patients. Over the past few decades, those in the health care community have seen a shift from a purely biomedical model to a more inclusive model of care that “examines the effects of biological, psychological, environmental, and spiritual factors on overall health” (Engel, 1980, p. 35). Therefore, with research showing that more than 90% of Americans report having some degree of belief in God (Graham, Furr, Flowers, & Burke, 2001), individual religious beliefs and practices and spirituality may provide resilience for those in crisis and should be considered as a possible resource for families.

Religion has the capacity to provide various compensatory strategies. Belief in a religious deity that assumes control may prove especially attractive in restoring some sense of external control in an indiscriminate and uncertain world (Kay, Gaucher, McGregor, & Nash, 2010). Boss (2010) wrote that it is important for people to stay strong and hopeful when facing an ambiguous loss. Boss felt
that hope lies in the understanding that suffering is more than attack on oneself; becoming more spiritual can lead to that discovery. Parents facing the challenges of raising a child with a chronic illness or disability may “find that religious beliefs, practices, and communities can provide meaningful and helpful resources for them to help them become or remain committed to providing the increased care for the child” (Dollahite, 2003, p. 237). A recent article in a local newspaper in Philadelphia, Pennsylvania highlighted synagogues and churches in the area that offer various programs and inclusion opportunities for children with special needs. According to one parent interviewed, there is a “change in religious communities across the faith spectrum, where sanctuary doors- and Sunday schools, youth groups, and vacation Bible study camps- are slowly opening to kids with special needs” (Hockman, 2012). Although there is much work to be done to ensure that all feel valued and welcomed in every faith community, the increase in the number of children with special needs may make help increase awareness and acceptance for all families who wish to be part of a religious community.

For some families, religious beliefs and communities may play a beneficial role in coping with devastating realities. Medical providers and their teams may need to not only ask open-ended questions as to a patient’s religious or spiritual beliefs as it relates to their understanding of their illness (Richards et al., 2003) and religious attitudes toward treatments but also acknowledge that a patient, or the patient’s family, may be able to tap into their religion or spirituality to aid in coping with a devastating diagnosis. For, if religion/spirituality can be a
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mechanism for coping, finding meaning in spite of (or because of) a tragedy, and/or support for a family of a child with special needs, then this should to be explored with families. If research can provide the data to support positive experiences of families of children with special needs, then professionals may be more inclined to suggest religious communities/spirituality as a potential resource.

Neurotheology

Some researchers are even suggesting that there is a relationship between religious experiences and brain functioning. The theory of neurotheology, as postulated by d’Aquilli and Newberg, looks at this connection. Andrew Newberg, M.D. is the director of research at the Myrna Brind Center of Integrative Medicine at Thomas Jefferson University and Hospital in Philadelphia. According to his obituary, Eugene G. d'Aquili (1940-1998) was a research psychiatrist who specialized in using brain scans to study members of religious communities. He was connected with the University of Pennsylvania where he won the Priestly Prize for original scientific research. Neurotheology seeks to discover whether there is a biological factor “that is responsible for either enabling and/or generating the experience of that which is called ‘religious’” (Feit, 2004, p. 3).

According to their theory of neurotheology, d’Aquili and Newberg believe that there is an overload in the limbic structures when people are involved in religious rituals and meditation. Located within the limbic system are the hypothalamus and the amygdala that are important in emotional regulation and maintaining an internal equilibrium. “This overload of stimuli blocks perceptual input which in turn causes a deafferentation [an elimination or interruption of

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sensory nerve impulses by destroying or injuring the sensory nerve fibers (The American Heritage Stedman’s Medical Dictionary)] of the associative areas and eventually leads to an altered state of consciousness” (d’Aquili & Newberg, 1998, p. 87). The brain is responsible for gathering and processing various emotional, sensory, and cognitive data and the mind experiences the thoughts, emotions, and memories that come up from the brain processes. From a neurological point of view, the mind cannot subsist without the brain and the brain strives to create the mind. Therefore, the brain and the mind are intimately connected (d’Aquili, Newberg, & Rause, 2001).

From a neurological standpoint, the concept of God enters through the neural pathways of the brain, similar to the way ordinary experiences are processed. Additionally, within the theory of neurotheology a God can only exist within one’s mind. (d’Aquili, Newberg, & Rause, 2001). Religious rituals generate varying degrees of emotional intensity that can represent feelings of “tranquility, ecstasy and awe” (d’Aquili, Newberg, & Rause, 2001, p. 86) that are often experienced in a religious context as spiritual transcendence. These feelings are usually interpreted as a personal closeness to God. According to neurotheology, both the emotional discharges and the feelings of transcendence are neurobiological (d’Aquili, Newberg, & Rause, 2001).

The increase in the technological sophistication of brain imaging along with the improvement of the analyses of the imaging (Ladd, 2010) has allowed researchers to use brain scans to test the casual relationship between religious behavior and cognitive functioning (Schjoedt, 2009). The majority of the studies
have focused on religiously inspired meditation techniques (Cahn & Polich, 2006; Schjoedt, 2009). Rooted in Buddhism, meditation and mindfulness practices have been incorporated into the treatment for various mental health issues (Wada & Park, 2009). As suffering is considered part of the human experience, Buddhist philosophy seeks to lighten such suffering. From a Buddhist viewpoint, suffering is part of the human experience and individuals experiencing problems associated with a traumatic experience may describe the symptoms as a form of suffering. Sufferers from trauma and grief may exhibit limited behavioral responses and emotional numbing. As Buddhist philosophy is concerned with basic human suffering, various ways to alleviate such suffering are incorporated into Buddhist practices. According to traditional Buddhist belief, the purpose of mindfulness training is to alleviate human suffering (Turner, 2009).

Some researchers and clinicians believe that meditation is an effective practice regardless of whether a belief in spiritual or cultural origins (Baer, 2003; Ladd, 2010), and many Western practitioners and researchers are now investigating the value of mindfulness as a means to reduce difficult and uncomfortable feelings. In the practice of mindfulness, thoughts are feelings that are experienced as they occur without judging the sensations or reactions. Mindfulness meditation is believed to help one attain self-acceptance by commitment, willingness to experience unpleasant thoughts, awareness, and being in the present (Follett, Palm, & Pearson, 2006).

However, the theory of neurotheology continues to be extremely controversial. There are some who believe that while the theory is still in its
beginning stages, statements are being made as if they are unquestionably true (Feit, 2004). Others believe that meditation does not necessarily involve a higher power and therefore suggesting that religious practice and meditation fall in the same category is problematic (Shapiro, 1982). In addition, some question the assumption that various forms of praying and meditation techniques are fundamentally the same. Most of the studies have focused on monks and nuns from different cultures. It is unknown if those from different cultures participating in various forms of prayer and meditation constitute the same experiential category. It cannot be assumed that religious and mystical occurrences are unvarying and therefore categorized within the study of comparative religion (Schjoedt, 2009). The correlation between the subjective experiences of the participants and the underlying brain processes is also subject to debate. It is unknown if the areas of the brain, as postulated by Newberg and d”Aquili, are responsible for specific higher order cognitive functions (Schjoedt, 2009) or if isolated areas of the cortex can be activated (Spezio, 2001) by spiritual or religious occurrences.

Some of the challenges with understanding the neuroscience of religion are inherent to the problems seen with the experimental neurosciences that rely on imaging technology. These challenges include issues with the acquisition of data and data analysis and the understanding of brain anatomy and functioning. However, as developments in theories and methodology in the neurosciences continue to improve, it is likely that these challenges will be lessened or resolved (Schjoedt, 2009). Whether or not positive correlations to spirituality and/or
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religion can be shown through the use of brain imaging, research has shown that some people do use spiritual and/or religious beliefs as a means of coping with difficult life circumstances.

In the next chapter the different ways men versus women react will be explored for depression and sadness may look different in men than it does in women. In our society men have been socialized not to show how they are truly feeling. Men do not seek professional help in dealing with problems and may turn to unhealthy means to cope. Other options for assisting men to express and resolve feelings of sadness and depression will be discussed.
The “mantra” of men who grew up in certain generations was that “boys will be boys” when the youngster was behaving badly. If male children were not following role expectations, they would be called derogatory names such as “girlie.” These role expectations caused conflicts for men, who as adults, wished to be more nurturing. Men also present sadness and depression differently than women and often “act out” in trying to deal with emotions for they often do not even have the words to describe how they are feeling. This chapter will describe how society influences male sadness and depression and how it affects the male and those around him.

Learning to Conform

Infants learn what is expected from little boys versus little girls. As male infants grow into toddlers, children, teens, young adults, and finally adult men and fathers, they have been prescribed acceptable male roles by society. Conflict arises when boys and men wish to step out and change these societal pronouncements.

Child rearing. Hart (2004), an author and psychotherapist who self-identifies as spiritually based in the Jesuit tradition, describes a situation found in many American homes. The baby boy is crying when he feels pain or recognizes a need. This cry is no different from that of his sister’s. For a while the cry has gotten him a positive response in that someone has come to his aid and taken care of feeding, changing, putting him to sleep, or perhaps just soothing him.
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However, at some point in his young life, it is no longer acceptable for the boy child to cry, for it is not masculine. This is the beginning of a youngster’s gender education. A boy has to learn to hide what he is feeling; to pretend that the feelings of fear and sadness are no longer part of his being. He needs to hide traits that his male friends may consider unmanly, for a boy learns early that it is not permissible to show certain emotions (Hart, 2004). All the while it is permissible for his sister to cry and show emotions, and then be comforted.

In a study of schoolboys, Frosh, Phoenix, and Patterson (2002) found that the participants noted the importance of identifying with masculinity and thereby felt it necessary to avoid being perceived as feminine or homosexual. Unforgettable maxims for many young boys, and later men, include “big boys don’t cry” and “don’t be a sissy.” These clichés remind males to deny their emotions. It is important to understand the effects of these cultural expectations as developing boys socialize into young men who are not able to express emotions and acknowledge depression or sadness. There is a tendency for these boys, and later as they become men, to externalize pain (Banney & White, 2008; Cochran & Rabinowitz, 2003).

**Gender Roles**

Gender generally denotes the difference between male and female in social behaviors. Although it is commonly used to deliberately exclude factors of biology, it is really a blend of factors that include biology, culture, history, psychology and social features. While a sex difference is not only biological, it does rest on an assumed common understanding of the biological differences
between men and women (Banney & White, 2008). “Gender role theory sees
gender in terms of the cultural and historical ways in which biological sex
differences are played out at the individual and social level” (Banney & White,

Female gender role highlights a feminine show of feelings as well as a
belief in the inadequacies women feel based on their internal judgments. It is
therefore felt that women often “act in” whereas men are taught to “act out.” This
bipolarization of emotional-feminine and unemotional-masculine (Banney &
White, 2008) affects the ability of men to be aware of any feelings of emotional
difficulties, how to express those feelings, and how to seek help to deal with those
feelings. As men are socialized to avoid thinking about how they are feeling and
the causes of such feelings, many men fail to recognize that they are depressed
(Kilmartin, 2005) and could be helped through psychotherapy and/or medication.
Thus, expression of depression in men “is more likely to be expressed through
chronic anger, self-destructiveness, drug use, gambling, womanizing, and
workaholism” (Kilmartin, 2005, p. 96).

In cultures based upon Western Europe traditions, boys and men are
taught to smother any strong emotion, particularly if it is one of sadness.
According to Kilmartin (2005) experiences of loss and persistent feelings of
hopelessness, helplessness, and worthlessness are the hallmarks of depression.
Depression in men may occur because Western societies do not allow males an
adequate period to mourn (Cochran & Rabinowitz, 1996). In addition, because
men are not given culturally permitted means of honestly grieving, it is felt that
some men continue to remain vulnerable to depression (Cochran & Rabinowitz, 2003).

**Masculine gender role stress.** In every day events boys and men are told that to be masculine is the opposite of feminine. One of the worst insults is the comment that a boy runs, throws, looks, or acts like a girl. From a young age, boys learn to avoid any actions and activities that have been defined as feminine for displaying such behavior “can lead to social punishment from male peers, parents, and other adults, siblings, and even from female peers” (Kilmartin, 2005, p. 96). Various forms of American media reinforce images of attractive men as being independent, violent, and unemotional whereas men acting with stereotypical feminine traits are seen as weak, neurotic, and justified for punishment by others. Therefore, most boys and men are “programmed” that they must not respond to psychological stress by crying, worrying, or talking to others as women would do but to do the opposite by remaining stoic and banishing thoughts or emotions about the problem (Kilmartin, 2005).

Therefore, male gender-role strain and conflict can occur in trying to avoid all the behaviors associated with being female. Pleck (1982) found a correlation between the limited range of behaviors men are allowed by society and themselves and the subsequent sex-role strain. According to Pleck (1981), society created a psychology of masculinity that was grounded in myths and assumptions. This idea of masculine societal behavior became deeply embedded in the public social structure (Meth & Pasick, 1990). Therefore masculine gender role stress (MGRS) can occur when a man judges himself as failing at “being a man” based
on society’s definition of manhood (Wexler, 2009). Whether or not a male experiences masculine gender role stress is entirely dependent on how he assigns meaning to particular situations in his life; notably how the meaning of a situation relates to his identity or capability as a man (Eisler & Skidmore, 1987; Saurer & Eisler, 1990).

It must be noted that not all individual reactions to the cultural definitions of masculinity are the same. There are women who enjoy sports and there are many men who do not; there are men who express emotions and women who do not. While the “acting-out” depressive pattern is described as “masculine” (a psychological term) rather than “male” (a biological term) there is evidence that women may also exhibit this acting out style of (male) depression. However, most sufferers of masculine depression are men due to the strong pressure to conform to cultural gender roles (Kilmartin, 2005).

**Gender role conflict.** Similar to masculine gender role stress are gender role conflict (GRC) constructs. Wexler (2009) includes the following concepts:

1. Restrictive emotionality (RE) is defined as having restrictions and fears about expressing one’s feelings as well as restrictions in finding words to express basic emotions

2. Restrictive affectionate behavior between men (RABBM) represents restrictions in expressing one’s feelings and thoughts with other men and difficulty touching other men
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3. Success/ power/ competition (SPC) describes personal attitudes about success pursued through competition and power

4. Conflict between work and family relations (CBWFR) reflects experiencing restrictions in balancing work, school, and family relations resulting in health problems, overwork, stress, and a lack of leisure and relaxation. (pp. 5-6)

Levant coined the term “normative male alexithymia” to describe an extensive phenomenon in our society (Pollack & Levant, 1998). Wexler also uses the word alexithymia, which literally means ‘lacking the words for emotions,’ in relation to “problems identifying, describing, and making sense of one’s own feelings” (Wexler, 2009, p. 13). Examples of alexithymia include “problems in recognizing and identifying feelings at a subjective level” and “difficulties in describing ambivalence and conflicts of feelings, and tendencies to focus on external events rather than internal ones” (Gilbert, 2010, p. 33). Liotti and Prunetti (2010) found that alexithymia-type problems are common in a variety of mental health issues especially those related to traumatic events.

Effects on the Adult Male

The effect of the inability of men to have the language to describe feelings sadness, depression, and grief affects their lives and may even be life-threatening. Professionals and non-professionals alike must understand that men may be
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depressed and that depression exhibits itself differently in men than it does in women.

**Differential rates of suicide, depression, crime, and substance abuse in men versus women.** According to the American Psychiatric Association’s (2013) *Diagnostic and Statistical Manual of Mental Disorders, fifth edition (DSM-5)*

Although the most reproducible finding in the epidemiology of major depressive disorder has been a higher prevalence in females, there are no clear differences between genders in symptoms, course, treatment response, or functional consequences. In women, the risk for suicide attempts is higher, and the risk for suicide completion is lower. The disparity in the suicide rate by gender is not as great among those with depressive disorders as it is in the population as a whole. (p. 167)

It must be noted that this information is in the major depressive disorder section. Other research has documented that men commit 86% of the violent crimes and are at least twice as likely as women to abuse alcohol and other drugs (Kilmartin, 2005; Real, 1997; Rochlen, Whilde, & Hoyer, 2005). The differential rates of suicide, substance abuse, and incarceration question the postulate that men are less prone to depression. For “it is possible that there is a ‘masculine’ form of depression that is under-diagnosed and under-treated” (Kilmartin, 2005, p. 95).

Research in England has shown that although men are diagnosed with depression and receive treatment for their depression, the numbers of men who actually suffer from depression is considerably higher. This growing recognition
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has caused a policy change in the United Kingdom whereby health services are required to integrate services that recognize and treat men suffering with depression (Banney & White, 2008). Unfortunately, for many in the United States, access to mental health services is often difficult. There is both a shortage of providers and a lack, for most people, of independent financial resources to pay for treatment and the reluctance of some insurance companies to pay for such treatment.

**Depression, suicide, grief.** It is clear that overt depression affects men, women, and even children. It affects those from all economic classes, all educational backgrounds, and all religious and cultural groups for it does not discriminate. While affecting people from all paths of life, the current research has shown that there is probably an inherited biological condition that creates a vulnerability to depression (Real, 1997). Many other factors in a person’s life can, of course, contribute to covert and overt forms of depression, grief, and suicide attempts.

Real (1997) noted that “if overt depression in men tends to be overlooked, covert depression has been rendered all but invisible” (p. 41). Back in 1974, Opler observed that masked depression is one of the most frequently found disorders in modern society in America, yet it is perhaps the most neglected condition to be found in psychiatric literature. That neglect continues to this day. It is this hidden depression that is the cause of many of the difficulties in the lives of men. Experienced as both shame-filled and shameful, this depression is largely unacknowledged and unrecognized. This hidden and unspoken depression causes
many of the problems we consider typical for males, including physical illness, 
substance abuse, domestic violence, problems with intimacy, and sabotaging 
one’s career (Real, 1997).

While these different presenting symptoms, when compared with the 
symptoms of women, may be explained by different patterns of behavior, it is 
plausible that there might be a different form of depression. Some theorists 
advanced the concept of male depression or ‘male depressive syndrome’ (Rutz et 
al., 1995, 1997; van Pragg, 1996). It is felt that the symptoms of male depression 
are compatible with societal and cultural norms for men. Men may be “taught” 
that there are only certain acceptable ways to act when saddened and/or 
depressed. These gendered sanctioned responses to depression include sudden and 
periodic irritability, anger attacks and crises, hostile aggressive and abusive 
behavior and alexithymia (Bech et al., 2001; Moller-Leimkuhler, 2002; Real, 
1997). The Godland Scale of Male Depression (Zierau et al., 2002) was been 
developed with such symptoms in mind (Banney & White, 2008). These gendered 
sanctioned responses are usually opposite for girls and women. Females are 
taught to show their emotions and confide in others. In addition, girls and women 
are generally reared with the idea that aggression is an unacceptable form of 
response (Banney & White, 2008; Hart, 2004).

As men are culturally taught to not acknowledge loss, they may find a 
triggering event can cause a resurfacing of the initial loss experience. If not 
resolved, these accumulated experiences of loss may leave a man vulnerable to a 
full-blown depression (Cochran & Rabinowitz, 2003). Men have been
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programmed to grieve quickly and privately and without long or intense shows of emotions of sadness, grief, or asking for help in dealing with their grief or loss (Cochran & Rabinowitz, 2003; Meth & Pasick, 1990). Psychologists are now beginning to recognize the seriousness of male depression and feel that the often undiagnosed and untreated depression in men may be one reason for the high suicide rates of men (Cochran & Rabinowitz, 2003).

There must be a continued mission to alert the public that men, in fact, do suffer from depression and that hope and treatment are available. The national Real Men, Real Depression (RMRD) campaign was created to raise awareness of male depression and to address the reality that “men are less likely than women to recognize, acknowledge, and seek treatment for their depression” (NIMH, 2003e). Developed and released by the National Institutes of Mental Health (NIMH) in April 2003, the RMRD program reached 42 million people through public service television broadcasts and through their website (Mahalik & Rochlen, 2006; Rochlen, Whilde, & Hoyer, 2005). Similar to the Real Men, Real Depression campaign, the U. K. Royal College of Psychiatrists published in 2006 a leaflet entitled Men Behaving Sadly to make public the growing recognition of male depression (Banney & White, 2008). However, much more needs to be done to get the message out that men can, and do, suffer from depression and that it is not unmasculine to seek help; rather it is a judicious act to help both the male and those close to him.

Cultural Differences
In both the United Kingdom and the United States there are considerable cultural, ethnic, and religious differences that may need to be acknowledged, understood, and appreciated. Lifestyles and options may be dictated through identification and adherence to norms set by various groups. Lowenthal, Goldblatt, and Gordon (1995) noted when certain religious sanctions operate, such as those in Orthodox Jewish communities where suicide is not an option, and the use of alcohol is not allowed such as in certain Christian denominations, no differences in reported rates of depression were found (Moller-Leimkuhler, 2002). Other researchers note that in some cultural groups, male physical affection is normative behavior particularly when greeting or saying goodbye (Meth & Pasick, 1990). As a result of different masculine role socialization, patterns and the norms concerning emotional expression are other areas of variance. The diversity of these gender role norms creates confounding factors when trying to identify depressive symptoms in men (Cochran & Rabinowitz, 2003). It is important that the behavior of the individual man is seen through his cultural/ethnic normative lens.

Potential Sources of Support

**Help seeking.** Nearly all people have mixed feeling about seeking help. Men, as noted earlier, have a particularly difficult time due to the prescribed “rules” for male behavior that stress controlling one’s emotions and being self-sufficient (Kilmartin, 2005). Many studies over the past three decades have looked at the different frequency rates for men and women seeking help for medical, alcohol and drug abuse, and mental health issues. The studies show that
men seek professional help less frequently than women (Addis & Mahalik, 2003), no matter what the age (Husaini et al., 1994), nationality (D’Arey & Schmitz, 1979), or ethnic and/or racial group (Neighbors & Howard, 1987). The reluctance to seek help conforms to the restraining male norms of not recognizing or acknowledging anxiety, dilemmas, or difficulties (Good & Wood, 1995; Mahalik & Rochlen, 2006; Moller-Leimkuhler, 2002). Males are not supposed to need help, and even the perception of needing help will create a sense of a double offense to the male sense of self (Moller-Leimkuhler, 2002). When looking specifically at male depression, researchers Padesky and Hammen (1981) and Weissman and Klerman (1977) found that men are also reluctant to allow informal help from friends and are more likely to state that they would never seek psychotherapy for depression (Addis & Mahalik, 2003).

Men also refuse medication and may instead use alcohol as a way to deal with depression in a gender-role acceptable manner (Riska & Ettore, 1999). Some men become workaholics as this is also socially acceptable. In a last testament to their control of self, some men commit suicide. It is therefore imperative that society help men seek different means of dealing with depression.

Help seeking is often seen as a crucial step for dealing with numerous problems and a crucial link in the chain of effectual delivery of health care services (Addis and Mahalik, 2003). For most men the link remains broken. Looking at both surveys and studies of the utilization of physicians, gender differences in help seeking behavior was supported at a rate of male: female = 1:2.
(Moller-Leimkuhler, 2002). From their Swiss study of suicide preventions Angst and Ernst (1990) concluded that “women seek help—men die.”

**Social support.** Unfortunately, according to Hart (2004), men rarely have real friends. This lack of social support from other men or women increases the probability of symptoms of depression (Johnson et al., 2001). Viewed as a component of the coping process in living with a chronic strain, social support (Varni, Wilcox, & Hanson, 1988; Wallander & Varni, 1989) may provide a key facet in helping people deal with traumatic events. Perceived social support has become known as a major concept in a person’s cognitive appraisal of connections to others (Barrera, 1986).

Abramson, Metalsky, and Alloy (1989) describe a hopelessness theory of depression. It is hypothesized that “when negative life events occur, a lack of social support may lead to increased hopelessness and, thereby, to onset of a syndrome referred to as hopelessness depression” (Johnson et al., 2001, p. 1056). A longitudinal study examined whether hopelessness acts as a go-between in social support and depression. Measures of social support, hopelessness, and depression were administered to 103 HIV-infected men and then administered again six months later. The researchers found that low baseline social support showed increases in both hopelessness and depression and increases in hopelessness also predicted increases in depression (Johnson et al., 2001). For men, a close interpersonal relationship or marriage often provides some protection against depression (Ali & Toner, 1996; Wu & DeMaris, 1996).

**Impact of Male Depression on Others**
Effect on others. It is clear that male depression has an effect not only on the depressed man but on those who interact with him as well. Williamson (1987) found that depressed men have shown an increase in interpersonal conflict. These men also exhibit work-related problems and conflicts related to job functioning (Vredenburg, Krames, & Flett, 1986) along with self-esteem and self-respect problems (Ahnlund & Frodi, 1996). Black, Baumgard, and Bell (1995) found that depressed men also exhibited antisocial and narcissistic traits, which in turn, have an effect on society. Some men may turn to anger rather than a show of a more appropriate emotion because men have been socialized to express anger (Kilmartin, 2005). This anger can easily impact those who are in his presence that can be especially devastating for his wife/partner and children.

Compounding the effect on others is the stigma of male depression that affects both the man and his family members. Those close to him may feel it necessary to “protect the male ego” and therefore not challenge his reactions to situations and problems. This may cause an enormous amount of distress for the people who live with him; this may be even more problematic than the turmoil felt by the depressed male (Real, 1997). Clearly, eliminating the stigma of male depression would go a long way for both the male and his family. It would make the man more likely to acknowledge the feelings of sadness and/or depression and then do something constructive to help him deal with these emotions.

Impact on children with special health care needs and their families.
For children with a congenital or acquired limb abnormality “family support had a positive effect on child adaptation, as did parent, classmate, teacher, and friend
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social support” (Varni & Setoguchi, 1993, p. 13). It is therefore important to look at parental emotional factors, in addition to those of others who provide support, that contribute to the support of both the parents and the child with special needs. Psychological and marital adjustment of parents (typically mothers) of chronically ill and children with disabilities have been reported in the literature (Breslau, Staruch, Mortimer et al., 1982; Sabbeth & Leventhal, 1984; Wallander, Varni, Babani et al., 1989). However, no research could be found that “empirically investigated the predictive value of both maternal and paternal adjustment and marital accord on child psychological adaptation to a chronic physical disorder” (Varni & Setoguchi, 1993, p.13).

While both the mental state of the mother and the father would seem to have an effect on the child, Varni and Setoguchi (1993) found that maternal depression and anxiety did not predict the psychological adaptation of the child with a limb abnormality. The researchers looked at parental depression, anxiety, and marital discord to determine which factors correlated with and were predictive of depression, anxiety, and self-esteem in 54 children with deformities of a limb. Varni and Setoguchi (1993) concluded that higher paternal depression and higher anxiety predicted higher child depression and higher anxiety. In addition, higher paternal anxiety also predicted lower self-esteem in the child. Higher marital discord as well predicted higher depression and anxiety along with lower self-esteem (Varni & Setoguchi, 1993).

Research has also found that parents of children with chronic physical disorders are a group at-risk for psychological adjustment problems (Breslau,
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Staruch, Mortimer et al., 1982; Sabbeth & Leventhal, 1984; Wallander, Varni, Babani et al., 1989). One hypothesis is that the child’s adaptation to the disorder affects the adjustment of the parents (Varni & Setoguchi, 1993). Knowing that both parental and child adaptations to a chronic illness are extremely important, individually and collectively, it is vital that parents and children are afforded the opportunity for intervention if the situation warrants such involvement.

In the Chinese social context, epilepsy is stereotyped as “sudden craziness” which causes familial shame as a result (Mu, 2003; Mu, 2005). In a study of Chinese fathers of children suffering from epilepsy, Mu (2003) looked at the relationship among father’s uncertainty of the child’s prognosis, strategies for coping, and depression. This study was based on the resiliency model of family stress and adjustment and adaptation. Similar to pediatric stroke, a child diagnosed with epilepsy (or seizures) creates uncertainty as to the child’s survival as well as the lasting degree of impairments. This uncertainty weighs heavily on the family and can alter the family structure. Little research has been done to understand the fathers’ perceptions of the uncertainty of the child’s prognosis, his mental health, and the coping patterns of the family. Mu (2005) did find a positive association between paternal depression and the uncertainty of his child’s medical condition. “Maintaining family integrity, keeping an optimistic outlook, preserving social support and self-esteem, and understanding the medical condition were significant coping strategies for functional paternal adaptation” (Mu, 2005, p. 371). A half a world away, these are ideal key components in our
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Pediatric Stroke Program at CHOP not only for the fathers, but for the child and his or her entire network of family and friends as well.

**Conclusion**

In looking at the socialization of boys and men, there are two major related topics. These topics are masculine ideology and masculine gender-role conflict (Betz & Fitzgerald, 1993; Good, Borst, & Wallace, 1994), which are found in both research and theory. Masculine ideology focuses on beliefs of what it means to be male and seeks to measure an individual’s level of conviction and agreement with the cultural norms regarding masculinity and gender roles (Pleck, Sonenstein, & Ku, 1993; Thompson & Pleck, 1986). It is important to understand that these ideologies may vary among persons and groups and change over time, and that some ideologies are more powerful than others. At the same time, it is recognized that some ideologies are more dominant than others. For men not adhering to the cultural norms for males in the group, gender-role conflict may emerge (Addis & Mahalik, 2003).

Research has noted a concerning pattern of male depression, suicide and lack of help-seeking behavior. When compared to females, men are diagnosed with depression at lower rates (Cochran, 2001; Cochran & Rabinowitz, 2000) yet commit suicide 4-15 times more often (Cochran & Rabinowitz, 2000; Murphy, 1998; Vannatta, 1997). Even with the frightening rates of male suicide, men avoid acknowledging and asking for help with their depression (Kessler, Brown, & Boman, 1981; Moller-Leimkuhler, 2002; Padesky & Hammen, 1981; Rickwood & Braithwaite, 1994; Weissman & Klerman, 1977). Research found
that men who showed symptoms of depression reported more negative attitudes toward help-seeking (Good & Wood, 1995). Attitudes for males to seek help may also depend on how normative the problem is thought to be (Mahalik & Rochlen, 2006).

Men may also prefer to obtain help from sources that safeguard their identity (Nadler & Porat, 1978). There is research that has shown encouraging response for an internet support group aimed at Chinese American men (Chang, Yeh, & Krumboltz, 2001) and to online counseling especially for men who acknowledge difficulty with sharing emotions (Rochlen, Land, & Wong, 2004). Other men might prefer self-help materials such as books and computer programs or taking a workshop or classes (Robertson & Fitzgerald, 1992). Some men may utilize their existing support systems including their wife/partner, member of the family, close friend, or someone from their clergy. Although rarely studied, both men and women have been noted to prefer to get help from a close friend when faced with a psychological problem (Rule & Gandy, 1992). In addition, men may engage in a variety of different activities to deal with their depression.

Researchers Carpenter and Addis (2001) investigated responses to depression which included turning to friends or family members, contemplating the cause(s) of the problem, asking for help from a medical doctor, distracting oneself, and not sharing the situation with anyone else.

Contacting clergy, anonymous chat-rooms, workshops, self-help books or computer programs, and engaging a personal coach were the least likely responses reported by men dealing with depression (Mahalik & Rochlen, 2006). Overall,
men did feel that talking to members of their support system was valuable and therefore it may be advantageous for therapists to provide information and resources to those in men’s support systems. This information and resources would help in both education and outreach for men suffering with depressive symptoms.

A number of empirical studies have found cognitive-behavior therapy techniques helped in treating male depression, anxiety, and marital discord (Falloon, 1988). Parental distress and marital conflict have been shown to be risk factors for children’s development. Routine assessments of both mothers and fathers may help spot at-risk youngsters whose parents may be helped by appropriate treatment (Varni & Setoguchi, 1993).

There is little doubt that men who could benefit from therapy underutilize traditional helping services. Masculine ideologies, cultural norms, and gender roles play a part in discouraging men from seeking help when they experience a wide range of problems (Addis & Mahalik, 2003). Because of the cultural conditioning that discourages expression of depression, assessments, along with treatments, of depression in men are often difficult. Using assessments and treatments geared to males will increase the likelihood that more men will be identified and treated for depression (Cochran & Rabinowitz, 2003). Even when in treatment, it is important to understand that men may be tempted to stop therapy when symptoms decrease to a barely tolerable level. Stopping interventions prematurely will often cause depressive symptoms to increase. Professionals should recognize this possibility and discuss it with their patients.
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while offering support and strongly advising that they continue with therapy even though they might be feeling a little bit better (Kilmartin, 2005). Those in the professional community as well as the general community must acknowledge depression in men. Only by having men seek and gain appropriate help for their feelings of sadness and depression will the unhealthy male normative ways for dealing with such emotions be changed and the horrific rates of suicide be brought down. Furthermore, their wives, partners, friends, and other family members, including their children with and without special needs, will be forever grateful.

It is important to understand how individuals evaluate stressful events and the coping mechanisms they may choose to employ in order to deal with the stress they are experiencing. The next chapter will examine the *Stress, Appraisal, and Coping* theory of Lazarus and Folkman as a framework for examining the responses to situations that may be stressful. In addition, some theories related of grief and loss will be reviewed in relation to the experiences of fathers of pediatric stroke survivors. Fathers may need to change the way they viewed the world, for all those close to a child with special needs must now come to terms with a world that no longer seems fair and just. Issues of bereavement and the theories of ambiguous loss and chronic sorrow will be reviewed to assist in understanding the pain that fathers and others might experience at various times in the child’s lifetime.
Chapter V

Theoretical Frameworks

Several theories relevant to fathers studied in this research will be explored in this chapter. The major theory of *Stress, Appraisal, and Coping* will be presented first. Additional relevant theories such as chronic sorrow, ambiguous loss, boundary ambiguity, adaptation and resiliency, and posttraumatic growth will also be included in this chapter.

The *Stress, Appraisal, and Coping* theoretical framework of Lazarus and Folkman is a transactional theory that “integrates stress, appraisal, and coping theories as they relate to how individuals react to psychologically stressful situations and/or environments” (Matthieu & Ivanoff, 2006, p. 337). The anxiety and stress felt by fathers of pediatric stroke survivors along with perceived supports, resources, and coping strategies will be examined through the lens of this theoretical framework.

Many cognitive approaches (Folkman, 1984; Folkman, Lazarus, Gruen, & DeLongis, 1986) view stress as the consequence of the disparity between the individual’s perceived demands and the noted personal resources at his or her disposal (Eaton & Bradley, 2008). It is this mismatch between requirements and supply of known resources that creates anxiety especially when dealing with a new and alarming situation. Although disasters can happen to numerous people at any given time, such as a hurricane or tsunami, or a situation may affect only one person or relatively few people, the number of people affected does not crucially affect the severity of the crisis (Lazarus & Folkman, 1984). As pediatric stroke is
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a condition that most people have never heard of, it is likely that this initially adds to the stress felt by the families. For not having heard of the condition, they also do not know anyone who has done well after being given the same diagnosis. Families may also find that their child is being treated at a hospital far from home with no friends or family nearby.

Responses to stressful events, according to this transactional framework, are mediated by cognitions and perceptions, or appraisals (Lazarus, 1999). According to Lazarus and Folkman (1984), an appraisal is a reaction to a specific event or stress in which an individual’s cognitive belief of his or her ability to handle the event is determined. Appraisal refers to the process by which feelings and emotions are brought forth as a result of the individual’s subjective evaluation of the significant event or situation. This assessment determines an individual’s feeling of safety in relationship to his or her environment (Lazarus, 1999).

**Stress**

Stress has traditionally been viewed as a response to the situation. This response was shown in four main types of reactions. These types include “reports of disturbed affects, motor-behavioral reactions, changes in the adequacy of cognitive functioning, and physiological changes” (Lazarus, 1996, p. 29). Stress, particularly mental stress, is thought of as a transaction (Lazarus, 1999; Lazarus & Folkman, 1984) whereby a person decides if he or she has the personal resources to handle the event. The transactional, or interactional, response can have an impact on the individual’s mind and/or body (Matthieu & Ivanoff, 2006). As a concept, stress is strongly related to emotion and adaptation. Stress can be caused
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by both internal as well external forces (Lazarus, 1996), which can affect the individual, a group, or a large community.

While there are specific environmental demands and pressures which produce stress in sizable numbers of people, there are individual and group differences both in terms of the severity of the stress and the reaction to the situation (Lazarus & Folkman, 1984). Individuals and groups may be influenced by belief systems and previous experiences. Various ethnic, religious, and cultural groups may also interpret and react differently to stressful events.

**Primary Appraisal**

Primary appraisal is the individual’s evaluation of the event or situation in regard to possible harm to his or her well-being. Stress appraisal, where the individual can see only negative consequences, is one type of primary appraisal. The other two types are (1) irrelevant appraisals where the person has no real interest or concern with the matter, and (2) benign positive appraisals where the person believes that the situation is positive and there are no potentially negative effects to his or her well-being (Matthieu & Ivanoff, 2006).

**Stress appraisals.** There are three different types of stress appraisals. In harm/loss there has already been some damage to the person. This can be in the form of a debilitating injury or severe illness, belief of a lessening of self-esteem or decrease in the admiration felt within one’s social network, or loss of an important person in the individual’s life. Threat, the second type, is an anticipated harm or loss. A threat is usually a possibility that goes hand-in-hand when a harm/loss has occurred as the implications for the future are loaded with negative
implications. However, the fear of future harm/loss can, at times, allow for anticipatory coping (Lazarus & Folkman, 1984). Anticipatory coping involves groundwork for coping with the stressful consequences of a future event that is likely or certain to happen (Breznitz, 1983; Folkman & Lazarus, 1985).

Challenge, the third type of stress appraisal is akin to threat as it also calls for the enlistment of coping strategies. With challenge, unlike threat, there is an emphasis on the potential for growth intrinsically found in the encounter. Threat centers on potential harm and is exemplified by such emotions as fear, anger, and anxiety; in contrast, challenge is distinguished by positive emotions such as eagerness and excitement, and high spirits (Lazarus & Folkman, 1984).

“Challenge also can be defined as the potential for positive personal growth by applying coping skills to mitigate the stressful event or encounter” (Matthieu & Ivanoff, 2006, p. 342). It should be noted that threat and challenge are not automatically mutually exclusive for they are not opposite poles on a continuum; they often occur at the same and need to be considered as separate though related constructs (Lazarus & Folkman, 1984).

Secondary Appraisal

“Secondary appraisal is the individual’s evaluation of his or her ability to handle the events or situation” (Matthieu & Ivanoff, 2006, p. 342). The judgment of the individual concerns what might and can be done. The secondary appraisal may be influenced by the primary appraisal in terms of the context of the demands, limitations, and opportunities. Attributed to the specific situation or event, the secondary appraisal then produces an emotion or meaning (Lazarus,
While primary and secondary appraisals come from different sources within the same encounter or event, they cannot be considered separately for they are interdependent and most likely influence each other (Lazarus & Folkman, 1984). According to Lazarus and Folkman (1984), secondary appraisals of coping options and primary appraisals of what is at stake interact with each other in shaping the degree of stress and the strength and quality (or content) of the emotional reaction. This interplay can be quite complex. If the person is helpless to deal with a demand, stress will be relatively great because the harm/loss cannot be overcome or prevented. If the person has a high stake in the outcome, meaning that it touches a strong commitment, helplessness is potentially devastating. (p. 35)

Whereas the “cognitive appraisal processes mediate the connection between potential and actual (subjective) stressors, (the) coping processes mediate the association between actual stressors and strain” (Eaton & Bradley, 2008, p. 94). The coping process is strongly influenced by the way an individual appraises the event and how he or she emotionally reacts to the encounter. Coping options are evaluated to see if a particular strategy or a group of strategies can be used effectively given the nature of the external and/or internal demands (Lazarus & Folkman, 1984).

**Factors Which May Influence Appraisal**

Although appraisal may be a “conscious, rational, and deliberated process the individual may be unaware of any or all of the basic elements of an appraisal”
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(Lazarus & Folkman, 1984, p. 52). In addition, there are many factors that influence a person’s appraisal of the situation or event. Some of these influences are noted and discussed below.

**Commitments and beliefs.** Commitments and beliefs are two of the most important personal factors that affect an individual’s cognitive appraisals. Commitments affect appraisals by leading people into or away from situations that may harm or may benefit them. They demonstrate what is important to people and are usually the foundation for the choices that individuals make. People are motivated by the commitments they make to themselves and/or to others. While a deep commitment creates a great potential for both threat and challenge, it may also help sustain hope (Lazarus & Folkman, 1984).

Beliefs also influence appraisal in evaluating what is happening or may happen in the near future. As beliefs often operate on an implicit level, it may be hard to see their effect on the appraisal. However, when there a sudden loss of beliefs or a change to a different system of beliefs the impact of this change can be observed (Lazarus & Folkman, 1984).

**Sense of control.** According to Lazarus and Folkman (1984) beliefs about personal control are of special interest in stress theory. The theorists note that beliefs about personal control can be thought of in both general and in specific situations. The degree to which an individual believes significant results can be controlled is most likely to shape appraisal in situations that are ambiguous. For “the less ambiguity there is about a particular encounter, the more likely
situational appraisals of control will affect emotion and coping” (Lazarus & Folkman, 1984, p. 80).

There is an appraisal continuum in regard to locus of control. At one end are the situations over which the person believes he or she is in control with the other end those situations seen as totally outside the individual’s control (Parkes, 1984). Research suggests that appraising something as controllable can be stress-reducing; however, it may also heighten threat especially when it conflicts with other goals or commitments. Whatever the result, situational appraisals of control influence emotion and coping abilities (Lazarus & Folkman, 1984).

**Situational and environmental factors.** Completely novel situations will cause a threat appraisal if some aspect of the event has been previously associated with harm, whether this associated harm was based on previous experience or on general knowledge (Lazarus & Folkman, 1984). It must be remembered that situational factors are always interdependent with personal factors for the “four environmental factors- demands, constraints, opportunities, and culture, in combination with person variables, operate together as important potential influences on the appraisal of harm/loss, threat, and challenge, the coping process, and the emotions that result from them” (Lazarus, 1999, p. 70).

Cultural variables are considered environmental factors. While cultural values have the potential for influencing emotion, the cultural meaning must be internalized to become part of the person’s belief system (Lazarus, 1999). It is therefore important to investigate the individual’s ethnic, cultural, and religious traditions and beliefs the extent to which the person identifies with and accepts
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**Coping**

While the distinctive characteristics of the individual influence the significance of the situational appraisal, the individual’s psychological, intellectual, and social characteristics can also serve as resources for coping (Lazarus & Folkman, 1984). The individual’s appraised meaning of the event is also central to the process of coping itself (Folkman & Moskowitz, 2000).

Lazarus and Folkman (1984) defined coping as constantly changing cognitive and behavioral efforts to manage specific external and/or internal demands that are appraised as taxing or exceeding the resources of the person. This definition is process-rather than trait-oriented in that it is concerned with what the person actually thinks or does in a specific context, and with changes in these thoughts and actions across encounters or as an encounter unfolds. The definition also distinguishes between coping efforts and automatized adaptive behaviors, and it avoids the problem of confounding coping with outcomes by defining coping as all efforts to manage regardless of outcome. (p. 178)

The function of coping is to lessen the perceived discrepancy between situational demands and personal resources (Matthieu & Ivanoff, 2006). Deciding which behaviors to employ in a specific situation is part of the coping process (Lazarus & Folkman, 1984).
While coping strategies change over time, the belief that changes in coping occur in stages over time may not be accurate. There is evidence to suggest that there are major variations among people in both the ordering and length of time of coping even when faced with similar kinds of stressful events. In addition, what appeared to be self-generated stages may in fact be a result of a change in external demands (Lazarus & Folkman, 1984).

**Problem-focused coping and emotion-focused coping.** There are two main approaches to coping that are often noted; those being problem-focused and emotion-focused coping (Folkman, 1984; Folkman, Lazarus, Dunkel-Schetter, DeLongis, & Gruen, 1986; Tamres, Janicki, & Helgeson, 2002). Problem-focused coping makes use of active and deliberate efforts to deal with a stressful circumstance (Eaton & Bradley, 2008). Problem-focused coping is seen as behaviorally handling distressing situations by collecting information, making decision, using conflict resolution, and acquiring resources including knowledge, abilities and skills (Folkman & Moskowitz, 2000). This type of coping allows the individual to focus attention on situation-specific goals that allows for a sense of mastery and control in working toward attaining that specific goal. Problem-focused coping can be seen in trying to manage or change the environment that is causing the suffering whereas emotion-focused coping regulates the emotion response (Lazarus & Folkman, 1984). “Emotion-focused coping aims at reducing unpleasant emotions resulting from the stressor by, for example, accepting responsibility, seeking support from others, venting of emotions, and self-blame”
(Eaton & Bradley, 2008, p. 96). Both types of coping influence each other and can
smooth or hinder the process (Lazarus & Folkman, 1984).

**Coping as process.** In the late 1970s, coping theory and research changed
from viewing coping in a hierarchical way with an emphasis on trait and/or style
to treating coping as a process. In this new paradigm coping changes over time
and is dependent on the situational contexts (Lazarus, 1993a). The principle of
this process approach includes the notion that “coping thoughts and actions under
stress must be measured separately from their outcomes in order to examine
independently their adaptiveness or maladaptiveness. There may be no universally
good or bad coping processes, though some might more often be better or worse
than others” (Lazarus, 1993a, p. 235).

While researchers make no assumptions about what constitutes good or
bad coping, as coping is simply defined as an individual’s efforts to manage
demands regardless whether they are successful (Folkman, et al, 1986) there are
other factors that must be considered. Vulnerability is often thought of in terms of
coping in that a vulnerable person’s resources are scarce. The importance of the
individual’s commitments in any encounter is his or hers psychological
vulnerability (Lazarus & Folkman, 1984). Gender can also play a part in regard to
coping. There are theories that men and women have different coping styles
(Endler & Parker, 1994). As considered in a previous chapter, it has been noted
that men usually confront problems directly or deny their existence. Women are
more prone to have an emotional response and seek support from friends and
family (Greenglass, 2002).
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Proactive coping and anticipatory coping. Proactive coping involves efforts carried out before a potentially stressful event or situation. Temporally, it therefore comes prior to coping and anticipatory coping. The function of proactive coping is to prevent possible stress or to at least modify the degree of stress that may be associated with the event. Proactive coping involves the accumulation of resources and skills that may be useful in any stressful situation. The acquisition of resource and skills are not directly linked to any existing stressors but may helpful for a wide range of stressful situations that may occur in the future (Aspinwall & Taylor, 1997). On the other hand, as discussed earlier, anticipatory coping is seen in dealing with an event that is likely to occur (Breznitz, 1983; Folkman & Lazarus, 1985).

As most people in America live stressful lives, learning and accumulating skills may be beneficial for all. Lazarus pointed out that “to a considerable major extent major life events affect morale, social functioning, and health by disrupting and changing the daily grind of stress, adding new demands and frustrations- hence, new sources of daily hassles, many of them recurrent or chronic” (Lazarus, 1999, p. 146). Many people have learned and practiced various methods of stress relief in their everyday lives (i.e. yoga, exercise, meditation, belief in a higher power).

Reappraisal

Reappraisal occurs when an initial appraisal is altered; the reappraisal differs from an appraisal only in that it comes after an earlier appraisal. This appraisal is based on new information concerning the person and/or the
environment. Sometimes reappraisals, called defensive reappraisals, are the consequence of cognitive efforts to cope. Defensive reappraisals are often difficult to differentiate from reappraisals based on new information (Lazarus & Folkman, 1984). It is also important to recognize that the relationship among variables may influence coping and that “certain kinds of coping, such as positive reappraisal may be influenced by the outcome of an encounter rather than vice versa” (Folkman, Lazarus, Dunkel-Schetter, DeLongis, & Gruen, 1986, p. 1001).

Positive reappraisal is the reframing of a stressful situation, using cognitive strategies, to view the situation in a positive light (Folkman & Moskowitz, 2000).

Deeply held values are often activated by a stressful situation which then leads to a positive reappraisal of the situation. For example, caregivers noted how their activities showed their love and allowed their loved ones to live in dignity (Folkman, Chesney, & Christopher-Richards, 1994). Folkman and Moskowitz (2000) noted:

The potentially painful, exhausting, and stressful experience of being a caregiver was reappraised as very worthwhile. Awareness of the value of caregiving activities should have a motivational effect on subsequent caregiving. This kind of coping, in which people focus on the value of their efforts and appraise them positively, may thus be especially important in helping people sustain efforts, such as those associated with caregiving, over long periods of time. (p.650)

**Summary**
Hope lives here is the saying found on many signs for the Children’s Hospital of Philadelphia. Certainly being optimistic and hopeful are ways that many people initially react when a child is given a devastating diagnosis. For many people being hopeful and optimistic serve to facilitate coping. “Coping may not be capable of terminating the stress, but the person can often manage it, which includes tolerating or accepting stress and distress” (Lazarus, 1999, p. 147). Haan developed a tripartite hierarchy in the process of adaptation. Coping was seen as the healthiest way to adjust; defense as a neurotic process; and ego-failure as harshly regressed and possibly a psychotic way to adapt (Lazarus, 1993b).

While emotion-focused coping and problem-focused coping are each important in their own right and more importantly ideal when united, problem-focused therapy may be of particular importance when looking at helping men cope. Robert Naseef, Ph.D. (personal communication) has stated that men are more comfortable taking action; therefore problem-focused coping deserves special consideration. Folkman and Moskowitz (2000) wrote:

Problem-focused coping can be very meaningful, first, because it involves identifying situation-specific goals that engage the individual and focus his or her attention, and, second, because the enactment of problem-focused coping makes it possible for the individual to feel effective and experience situational mastery and control. (p. 650)

While parents do not wish their son or daughter to suffer a stroke, after some time has passed most families do recognize some positive results. This can be from meeting new people, helping others going through a similar crisis,
Creating an awareness of pediatric stroke for the general community, getting involved in various organizations, and other benefits. Folkman and Moskowitz (2000) noted that it is important to emphasize positive affects in models of stress as well as describe the coping processes used by individuals to generate or maintain positive affect when going through a personally stressful situation.

Folkman and Moskowitz (2000) go on to suggest that there is evidence showing that positive affect has important adaptational functions in the process of coping and it therefore becomes necessary to understand how it relates to chronic stress.

Folkman and Moskowitz (2000) argued that:

* positive affect can co-occur with distress during a given period.
* positive affect in the context of stress has important adaptational significance of its own, and
* coping processes that generate and sustain positive affect in the context of chronic stress involve meaning. (p. 648)

It may be important to look at how positive affect can help parents cope when raising children with special health care needs and/or disabilities.

Folkman and Lazarus’ Stress, Appraisal, and Coping theoretical framework remains a useful model in determining how individuals deal with the reality of stressful events. It is crucial to hear how each individual appraises the event in order to assist families in coping with what has occurred; coping is the way for individuals to manage psychological stress (Lazarus, 1999).
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In addition to the Stress, Appraisal, and Coping theory other important concepts were relevant to my understanding how fathers dealt with their child’s stroke. These theories will be discussed in the remaining sections of this chapter.

**Grief and Loss**

For many, spiritual beliefs may help individuals and groups cope with various instances of grief and loss. While many people associate grief with the death of a loved one, grief does not confine itself solely to reactions associated with death (Moulton, 1984); rather some form of grief follows any significant loss (Lewis, 1983). Therefore both the stroke survivor and his or her family will most likely experience a sense of grief surrounding what has happened and a sense of loss in terms of what their lives would probably have been like if the stroke had not occurred. Moulton (1984) proposed that, “the real and potential losses associated with chronic illness can be viewed as a continuum covering an indefinite period of time” (Moulton, 1984, p. 76).

A period of time is needed for the child and the family to make an assessment of the implications and for the full understanding and the realization that almost everything associated with the child and family has been changed to some degree (Lewis, 1983). Moos (1977) wrote,

> grieving the loss entails a progression from the initial reaction of numbness of disbelief to a growing awareness of pain, sorrow and often anger and preoccupation with the lost object, and gradually reorientation in which the loss is accepted and equilibrium restored. (p. 18)
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Many living in contemporary Western cultures have an essentialist understanding of grief that views grief as a natural response to loss (Neimeyer, 2002). From a Western perspective the grief remains within the person akin to the cultural emphasis on individualism (Foucault, 1970). In American culture there is a tendency to ‘psychologize’ grief (Neimeyer, Prigerson, & Davies, 2002). Frankl (1984) in Man’s Search for Meaning suggested an analogy for personal suffering likening the behavior to that of gas. He wrote that

if a certain quantity of gas is pumped into an empty chamber, it will fill the chamber completely and evenly, no matter how big the chamber. Thus suffering completely fills the human soul and conscious mind. Therefore the ‘size’ of human suffering is absolutely relative. (p. 55)

Human beings need to find a sense of meaning for their loss and grief. It is necessary for each individual “to construct a coherent account of their bereavement that preserves a sense of continuity with who they have been while also integrating the reality of a changed world into their conception of who they must now be” (Neimeyer et al., 2002, pp. 235-6). “Complicated grief can be viewed as the inability to reconstruct a meaningful personal reality” (Neimeyer et al., 2002, p. 235). For those facing the death of a loved one, there are cultural rituals, such as a Catholic funeral masses, sitting shiva for those of the Jewish faith, and even secular memorials which can provide a structure for dealing with the emotional chaos of the grief and loss. These rituals can serve to facilitate a shared meaning for the family, community, and, in some cases, even the nation
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(Neimeyer et al., 2002). However, no such rituals for loss of the lives they were living or had hoped to be enjoying exist for those who are still living.

All people coping with life-altering events experience change. Some people turn to negative sources such as alcohol, excessive working, overeating, or illegal drug use. It is important to find ways to help people cope with tragedies in a more positive manner and to give people a variety of resources and coping strategies. Some people may even realize various positive outgrowths of the tragedy whether a change in looking at what is important in life, a deeper sense of spirituality, or a way to make a difference in the lives of people they may never meet. In a view towards helping all parents reach positive coping strategies when faced with an unforeseen crisis, it is also important to look at the ways that the coping strategies of men may differ from those of women; for in Western society it is often difficult for men to feel comfortable expressing emotions of sadness and depression.

Stage Theory of Loss

Most people, regardless of their prior or current spiritual or religious beliefs, still need to face the emotional grief and sometimes physical loss for themselves and those around them. In dealing with a significant loss Kubler-Ross (1970) is well known for her time bound theory of grief. She identified five stages of emotional response to the death of a significant person: denial, anger, bargaining, depression and acceptance. In addition to Kubler-Ross’s theory, a number of other grief theories incorporate various stages in the grief process. This suggests that there is a sequential progression through the various stages of grief.
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where at the end of the process, the individual comes to a sense of acceptance or resolution. Therefore, failure to reach a state of acceptance or resolution may be considered abnormal (Lowes & Lyne, 2000). It is important to note that Kubler-Ross does acknowledge that individuals do go back and forth between stages. Some theorists argue that acceptance is central to healthy adjustment to the situation. Failure to accept the loss is viewed as maladaptive and requiring intervention (Kearney & Griffin, 2001).

**Chronic Sorrow**

Several researchers propose that it is inappropriate to use time bound theories of grief (Lowes & Lyne, 2000) when attempting to help ease the grief and sadness that may afflict parents who are facing the loss of the “perfect” child. Many studies support the paradigm shift toward the concept of chronic sorrow away from the time-oriented theories of grief (Cameron, Snowdon, & Orr, 1992). Teel (1999) postulated that the response to ongoing loss is differentiated from bereavement following death in that the relationship deprivation is not because of a physical death, but is due to the symbolic death of a loved one. Understanding response to loss that is not temporarily circumscribed, but ongoing and of extreme significance to the grieving person, requires a conceptual shift from the linear bereavement model of grief to a less restrictive, non-linear bereavement model of response to loss. (p. 1313)

When parents are faced with raising a child with a chronic illness and/or disability, the theory of chronic sorrow may be more appropriate. This theory
looks at normal reactions to complicated situations. Olshansky (1962) introduced the term ‘chronic sorrow’ to explain the parental response to the birth of a child who was diagnosed with a mental disability. These parents were facing times of sadness that reoccurred at different times throughout the lifespan of the child or the parent. Olshansky also noted that some parents of mentally challenged children might never completely abandon the grief of having a child with special needs. “Rather, he suggested, that the normal reaction to the birth of a child with a disability is chronic sorrow” (Seligman, 1991, p. 57). The majority of research on chronic sorrow has focused on parents coping with a child with a cognitive or physical disability. Chronic sorrow may also be experienced by parents of children with chronic illness who do not have a developmental delay (Gordon, 2009).

Thus, chronic sorrow is a way to explain the reaction to an ongoing living loss that is permanent, progressive, persistent, and cyclical. It is a way not to pathologize the feelings of parental grief and sadness. Olshansky stated that chronic sorrow is a normal psychological reaction rather than a neurotic response to a tragic fact (the birth of a disabled child) (Teel, 1999). Similar to Olshansky, Teel described chronic sorrow as a “recurring sadness, interwoven with periods of neutrality, satisfaction and happiness; a parental reaction to chronic illness which suggests functional adaptation to, but not acceptance of, the child’s condition” (Lowes & Lyne, 2000, p. 43). In addition to parents facing chronic sorrow over the condition of their son or daughter with a special health care needs and/or disability, chronic sorrow can also occur in the individual with a chronic illness...
and/or disability. Health care professionals need to have an understanding and acceptance of chronic sorrow in order to assist individuals and their caregivers in adjusting to life with chronic illness or disability (Northington, 2000). Copley and Bodensteiner (1987) elaborated on the theory of chronic sorrow. In working with parents of children with disabilities, Copley and Bodensteiner identified two phases of parental feelings of loss. The first phase includes the impact, denial and grief and is experienced as a cycle of highs and lows. In the second phase, parents begin to use appropriate coping strategies in resolving crises and adapting to their new life situation. While emotional turmoil continues, it is less intense in this second phase. Even though the sorrow may fade over time, the sorrow never ends.

Copley and Bodensteiner also acknowledged that because of the on-going nature of the loss, some parents of children with disabilities are never able to move on to phase two and remain in the phase one (Lowes & Lyne, 2000). As the person with the chronic illness or disability remains in the physical environment, family members are constantly reminded of the loss. Though there may be adaptations and adjustments and even some times of happiness, many continue to experience periodic and recurrent sadness. Therefore, where there is a “disruption in the relationship, consideration of bereavement theory does not necessarily contribute to an understanding of response to loss- loss that is ongoing” (Teel, 1999, p. 1312).

**Chronic illness/chronic sorrow.** According to research, the psychosocial impact of chronic health conditions is more similar than different across various diagnoses (Garstein, Short, Vannatta, & Noll, 1999). However, it is important to
remember that certain factors can both unite as well as divide different disability distinctions. In the Deaf culture, most people who are deaf are proud of being so and ask the world to recognize Deaf people with a capital “D” which is in contrast with other disabilities who prefer lower case letters such as in blind and intellectually disabled. Various medical and disability categories are also “fighting” for the same pot of money in terms of research and resources. A person’s ethnicity may also be a contributing factor as some groups are more ready to accept and embrace a person who is different.

As noted earlier, there is extremely limited information concerning pediatric stroke survivors. As no information could be located describing chronic sorrow in this population or their parents, the following is a summary of findings of chronic sorrow in parents of premature infants, children with sickle cell disease, and children with diabetes. Fraley (1986) studied the relationship between the stress of giving birth to a child prematurely and the experience of chronic sorrow. The data showed that many parents experienced chronic sorrow when the child needed surgery, had medical or behavioral problems, and/or was diagnosed with a chronic illness. These parents also described chronic sorrow when the child was in daycare as well as when another child developmentally surpassed their child (Fraley, 1986).

Sickle cell disease (SCD) affects approximately 1 in 375 African Americans in the United States (Northington, 2000) and is another condition present at birth with lifelong effects for both the child and his or her caregivers. Research suggests that caregivers experience three stages that do overlap. Initially
parents learn about the disease and how to incorporate it into their everyday lives. The next stage involves experiencing the sorrow while the final stage is doing what needs to be done and trying to move on. Caregivers begin the process of repatterning as they learn to live with the consequences and complications of SCD. Sickle cell disease is a potentially life-threatening condition that requires careful monitoring and supervision. This places heavy burdens and demands on the caregivers. This caregiver responsibility causes psychological stressors leading to a variety of emotions. Chronic sorrow is one of the emotions faced by parents of children with sickle cell disease (Northington, 2000). Some parents of children with sickle cell disease have shared with me that, like parents of children who are at risk for a another stroke, that they often cannot plan for a vacation as they do not know what that day will bring. Similarly, families need to be near a hospital that is familiar with the diagnosis and can effectively handle the condition and any complications including being ready to transport the child to a more appropriate facility. Diabetes in children is also a chronic, life-long condition in which most parents experience a deep emotional response. The research conducted by Lowes and Lyne (2000) has shown that a diagnosis of childhood diabetes may represent multiple losses to parents, including the loss of the healthy child they thought they had, loss of a certain lifestyle, loss of freedom, loss of former support systems, a loss of confidence in their ability to protect their child from danger and the potential loss of their child’s life. (p. 42)
Chronic sorrow for families of children with special needs and/or disabilities. For parents of children with chronic illness and/or disabilities the intensity of parental stress may vary over time and may significantly impact the functioning of the family unit. The stress is most acute during times of diagnosis, complications from the illness, and developmental transitions. During these times, parents often are reminded of the loss of the child they hoped to have been raising and the fear that the child may not be able to live the life they had anticipated for their son or daughter (Gordon, 2009). Parents may realize more acutely the disparity between their child and the “fantasized” child experiencing a more intense sense of loss during specific milestones in the life of the child (Teel, 1999). Teel delineates these developmental milestones:

1. Encountering the disability

2. Early childhood: “The chronicity or episodic nature of a child’s disabilities and what it means to the family is a major part of the early childhood years” (Seligman, 1991, p. 47). At a time when normally developing children are being potty trained and learning how to eat with finger foods and progressing to using utensils, a child with a disability and/or health concern may be heavier to pick up and diaper and/or may still need to be feed either with soft foods or through tubes inserted into his or her nose or stomach. This difference, when compared to “normal” children, becomes noticeable and impossible to ignore.

3. School entry: Parents realize that their child fails to fit into the mainstream and needs to deal with the shift in educational and vocational goals they may have to set for their child. Most families will be involved with special
education programs that entail laws and an educational language they will need to master.

4. Adolescence: This time may be a painful reminder that their child cannot begin to separate from his or her parents. The parents need to deal with the hormonal changes of adolescence even though their teens may not be able to comprehend what is happening to their bodies. Parents must also be hypervigilant as to the vulnerability of adolescent children fearing that others may take advantage of their children along with the increase in risk taking behaviors found in most teens. For those teens with “invisible” medical concerns or disabilities, they need to decide what and when to disclose to possible dating partners.

5. Beginning of adult life: Parents may be overwhelmed with the question of what will happen to their child. Many parents did not expect to be caring for child at this stage in their lives. Caring for an adult child may be physically and emotionally draining and it may be unrealistic to expect parents to be able to handle the caregiving responsibilities as well as they could when everyone was younger. There is also a lack of vocational opportunities, day programs, community living arrangements, etc. to help ease the everyday burdens. At age 21 the guaranteed educational programs (free and appropriate education) cease. At this point many parents and children lose the anchor of the educational system.

6. Maintaining adult life: Many parents need to consider who will be the caregivers for their child when they are deceased or no longer able to care for the adult child. While some adult siblings may want to assume partial or full
responsibility for their brother or sister, many cannot or choose not to do so. This may also create tension and stress due to altered expectations within the family.

While the degree of sadness varies according to the person, situation, and time, the sadness is not constant and unrelenting. However, the sorrow felt usually increases during these critical milestones in the child’s development (Teel, 1999).

**Ambiguous Loss**

It is important not only to understand the implications of chronic sorrow in the patient and family of the pediatric stroke survivor, but also that some patients and family members must deal with a loss that is ambiguous. Boss’ concept of ambiguous loss identifies another quality of loss when compared to normal grief. Boss (1999) stated that

in normal grieving, as Sigmund Freud wrote in *Mourning and Melancholia*, the goal of recovery is to relinquish one’s ties to the loved object (person) and eventually invest in a new relationship. This is the difficult work of mourning, but it is a process that is meant to end. From this perspective, people who are emotionally healthy are expected to resolve a loss and move on to new relationships- and to do so relatively quickly. (p. 9)

As with chronic sorrow, ambiguous loss theory can be helpful in understanding parental responses to learning that their child has a lifelong and pervasive disability (O’Brien, 2007).

Ambiguous loss is defined as a circumstance where a loved one is seen as physically present while psychologically absent or physically absent but kept
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psychologically present because the physical status is unclear. It is not known if
the loved one is dead or alive, dying, or in remission (Boss, 1999; O’Brien, 2007).
Both types of ambiguous loss lead to suffering that is very different from a clear-
cut, ordinary loss (Boss, 1999). Boss delineated the following attributes when
describing ambiguous loss: “ambiguous loss is unclear loss; ambiguous loss is
traumatic loss; ambiguous loss is a relational disorder; ambiguous loss is
externally caused (e.g., illness, war), not by individual pathology; and, ambiguous
loss is an uncanny loss- confusing and incomprehensible” (Boss, 2010, p. 138).
According to O’Brien (2007), Boss and her colleagues found several areas of
ambiguity that may contribute to family distress. These include:

(a) A lack of clarity in diagnosis
(b) Difficulty in predicting outcomes
(c) Day-to-day changes in functioning of the ill person that
affect family relationships
(d) The fact that the ill individual may give an outward
appearance of health thus raising expectation for his or her
behavior and functioning within the family
(e) Fear that important emotional relationships will be
affected by the illness. (p. 136)

Boss (1999, 2010) stated that ambiguous loss might traumatize and be traumatic
because the pain can be so incomprehensible and immobilizing that coping is
blocked. Denial of the loss may sometimes provide a temporary respite from the
reality of a potential loss. It may sometimes be beneficial when it allows the
family to maintain its optimism and hope. However, it may also render people powerless in dealing with the situation at hand (Boss, 1999). There is no resolution of grief when there is no verification of death or the possibility of closure. There are no rituals to support the beloved at this time of trauma and ambiguity (Boss, 1999; Boss, 2010). It is difficult for people to cope with uncertainty (Boss, 1999) and the feeling of loss of control over in a world that does not make sense. For ambiguous loss can make one feel incompetent by eroding one’s feeling of mastery and, at the same time, destroy one’s belief in a fair, orderly and manageable world (Boss, 1999). “Finding meaning, or being able to make sense out of what is happening is especially difficult with ambiguous loss. Viktor Frankl (1984) believed that there is no meaning without hope and no hope without meaning” (Boss, 2010, p. 141). In cases of ambiguous loss, people may move from hope to hopelessness and then back again to hope. This uncertainty is confusing and can cause tension, stress and torment that can cause personal and family problems. These conflicts occur, not because of any inherent deficit of the person experiencing the loss, but rather because the situation is out of their control or there are other constraints blocking the coping and grieving processes. People can feel helpless and are therefore more susceptible to anxiety and depression. Relationships with those who are present may suffer. The uncertainty prevents an adjustment in the relationship with the loved one who is causing the ambiguous loss. This uncertainty and confusion freezes the relationship as well as the grieving process (Boss, 1999).
Research has shown that this ambiguity can erode couple and family relationships (O’Brien, 2002). From a family stress perspective, stress is caused by change, whether ordinary or catastrophic, or even the threat of change within the usual family structure. “When the ambiguous loss is the result of a chronic illness or a disability, even strong families may need help in managing the stress” (Boss, 1999, p. 21). Boss noted that while persistent distress is not good for any individual or family, people do have the ability to learn how to manage the stress and ambiguity (Boss, 1999). Various cultural traditions may offer exemplary models of coping with ambiguous loss. Boss (1999) wrote,

I learned that these Anishinabe (Native American) women cope with the psychological absence of a demented parent by combining mastery of the situation with a spiritual acceptance of the illness. The Anishinabe women took charge, making sure that their parents saw the right doctors and took their medication, but at the same time, they accepted the challenge that nature had given them. They saw an elderly person’s illness as part of nature’s cycle from birth to death. The women were comfortable with not knowing what lay ahead for their sick loved ones or for themselves as caregivers. (p. 17)

Families should be made aware of any information. If the professional does not know what the outcome will be, families are entitled to hear that piece of information. The goal for families is to be able to adapt to the loss even though the ambiguity remains for the trauma and the ambiguity continues to exist (Boss, 1999). As the grief remains unresolved, making sense and meaning is even more
difficult than in an ordinary loss. Boss (1999) advised that family therapists and medical professionals must listen to what the individual’s loss means to them. Their stories “will vary with culture, gender, race, ethnicity, sexual orientation, and even age” (Boss, 1999, p. 132). It is also important to those within communities of faith to understand this complicated loss as these communities often function as the central support system for people who are grieving (Boss, 2010). Boss (2010) offered “guidelines (not prescriptions) for resiliency (not normalcy) in the face of complicated loss: (1) finding meaning, (2) tempering mastery, (3) reconstructing identity, (4) normalizing ambivalence, (5) revising attachment, and (6) discovering hope” (Boss, 2010, p. 141).

**Boundary Ambiguity**

Whereas ambiguous loss is a situation in which information is unclear or unavailable, boundary ambiguity may be a family’s response to the ambiguous loss. For example, the parent of a child with special needs may feel like a medical provider rather than a mother or father (Berge & Holm, 2007). Boundary ambiguity “has been defined as a state in which family members are uncertain in their perception about who is in or out of the family and who is performing what roles and tasks within the family system” (Boss & Greenberg, 1984, p. 536). For parents of children with chronic illness boundary ambiguity can lead to psychological distress (Berge & Holm, 2007). In Taiwan, researchers found a significant correlation between boundary ambiguity and depressive symptoms in mothers of children who have epilepsy (Mu, Kuo, & Chang, 2005; Mu, Wong, Chang, & Kwan, 2001).
Adaptation and Resiliency

Researchers examined the change over time of bereaved persons. Rather than recovery, they proposed that adaptation might be a more accurate description. Using a resiliency framework, this adaptation is shaped by both personal and environmental factors (Sandler, Wolchik, & Ayers, 2008). Using the resiliency model, Sandler et al. (2008) noted that it is important to identify risk and protective factors that predict differential functioning for those exposed to adversity. Risk and protective factors can be at the individual, family, community, or cultural level. As applied to the bereaved, positive and negative outcomes are best predicted not from any single factor but from the accumulation of multiple risk and protective factors that may proceed or follow the death. (p. 61)

For if a parent does not have an adequate support system or receive help coping with a child with special health care needs and/or disabilities, it is possible that the parental chronic sorrow may become pathological in that the grief may turn to severe depression (Gordon, 2009). Olshansky (1962) proposed that while parents never fully recover they are able to adjust and adapt to the circumstances now facing their child and the family, although these adaptations and adjustments do not represent acceptance (Kearney & Griffin, 2001).

The majority of research exploring families of children with disabilities emphasizes the negative emotions that parents experience. Raising a child with special needs can be viewed as looking at a series of transitions where each transition creates new individual and family needs. If these needs can be met,
transitions will be more positive both for the individual and the family (Burden & Thomas, 1986). Although the experience of the parents is one of ambiguity, sorrow, and sadness parents also identified feelings of hope, love, and joy when raising their son or daughter with special needs. Many parents find the challenging experience strengthening and were able construct meaning and fresh perspectives on life (Kearney & Griffin, 2001).

Posttraumatic growth

‘Vinegar into honey’ is a Tibetan alchemical metaphor, similar to the European metaphor of turning lead into gold. “The literal meaning is not the inner meaning. Spiritual alchemy is not the literal, chemical transformation of lead into gold. Its inner meaning is the quest to transform unhappiness into happiness and suffering into joy” (Leifer, 2008, p. 7). Some believe the suffering associated with a devastating loss may give a person the strength to endure the pain or the loss (Wada & Park, 2009). For many people it is necessary to make peace with the pain and find meaning in the loss; that some good can come from the tragedy. There are many examples of foundations and charities that champion to assist others who may be afflicted with a similar loss. The day after Alexandra “Alex” Scott’s fourth birthday she received a stem cell transplant and told her mother that when she got out of the hospital she wanted to have a lemonade stand to raise money so that doctors could help other children like they helped her (www.alexslemonade.org, retrieved 5/1/12). Although Alex lost her battle with cancer at the age of eight, Alex’s Lemonade Stand has raised millions of dollars for pediatric cancer and has given an adorable face to the disease. Similarly, a
major funding organization for breast cancer research and prevention came about through one person’s plight. Susan G. Komen was diagnosed with breast cancer at the age of 33. After she passed away at the age of 36 in 1980 her sister founded the Susan G. Komen Breast Cancer Foundation in her memory (www.komen.org, retrieved 5/1/12).

According to Park and Helgeson (2006), most people who experience a devastating traumatic event report a sense of personal growth after the harrowing experience. “Posttraumatic growth is usually characterized by finding a clearer meaning and purpose in life, a closer connection with others, and a greater sense of personal strength and self-reliance, as the result of confronting and dealing with a difficult life event” (Proffitt, Cann, Calhoun, & Tedeschi, 2007, pp. 220-221). Tedeschi and Calhoun’s (2004) model of posttraumatic growth describes the systematic study of growth that arises from a struggle with a trauma resulting from an extremely challenging life event. Calhoun and Tedeschi, renowned for their work in the area of posttraumatic growth, observe that personal experiences and responses to the psychological processes of growth are complex and that in the wake of traumatic events, suffering may often go hand in hand.

Examples of posttraumatic growth are frequently noted in philosophical teachings as well as in spiritual and religious traditions studies (Bray, 2010). “In fact, the experience of growth emerging from the struggle with major life crises has been a theme of world religions and literature since ancient times” (Proffitt, Cann, Calhoun, & Tedeschi, 2007, p. 220). Calhoun and Tedeschi (1999) report that in the area of spirituality, individuals can experience posttraumatic growth to
a significant degree and many people experienced a greater spiritual understanding as a result of the perceived growth (Tedeschi & Calhoun, 1996). Most people use prayer in their efforts to cope with and make meaning of traumatic experiences while resolving spiritual struggles (Ai, Tice, Peterson, & Huang, 2005; Schuster et al., 2001) and within the spiritual domains of the experience there are often influential degrees of individual growth as a result of the stressful events (Bray, 2010). When considering the existential struggle with death and morality, many experience a growth that, in turn, affects other domains of the individual’s life (Calhoun & Tedeschi, 2006).

There have been various studies that have shown a connection linking trauma-induced spiritual struggles and posttraumatic growth (Pargament, Desai, & McConnell, 2006). A number of recent studies found that religiosity/spirituality is an important predictor of posttraumatic growth. In these studies participation in religious activities and religious commitment are shown to positively correlate with posttraumatic growth (Shaw, Joseph, & Linley, 2005). Studies exploring prayer and posttraumatic growth have shown that those who pray more often report more posttraumatic growth (Harris et al., 2010). For some, posttraumatic growth can result as an attempt to make meaning of the experience with their beliefs in a divine being (Pargament et al., 2006; Park, 2005). Most religious strategies for coping are based on the beliefs that one has a secure relationship with a compassionate God and that God will help them endure life’s challenges. There is a belief that God is a partner in the struggle in contrast to a God who sits
in judgment. These beliefs of the layperson are associated with more positive and encouraging outcomes (Proffitt, Cann, Calhoun, & Tedeschi, 2007).

In a study exploring how clergypersons cope with and make meaning of their own difficult life and/or traumatic events, Proffitt et al. (2007) sampled 30 Jewish and Christian members of the clergy. It was theorized that the use of religiously based strategies for coping would facilitate posttraumatic growth and therefore a greater sense of well-being would be gained as a result of the clergyperson’s posttraumatic growth. The study found that the clergy’s use of religious beliefs, whether focused on God as a source of sustaining or maintaining hope or seeing the traumatic experience as a measure of a test from God, was positively correlated with higher degrees of posttraumatic growth. When exploring outcomes of clinicians working with trauma survivors, posttraumatic growth was often reported; not only for the trauma survivor but for the clinician as well. While it is clear that therapists working with survivors of trauma confront extraordinary challenges, Arnold, Calhoun, Tedeschi, and Cann (2005) found that all the clinicians in their sample spoke of personal positive growth. The investigators reported that clinicians sometimes “perceive important work-related benefits or rewards, including gains in relationship skills, increased appreciation for the resilience of the human spirit, the satisfaction of observing clients’ growth and being part of the healing process, personal growth, and spiritual well-being” (Arnold et al., 2005, pp. 242-243). These findings suggest that the positive benefits for the clinician working with trauma survivors are likely to be more powerful and extensive than the limited existing research suggests.
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Despite an abundance of qualitative accounts of prayer as it relates to posttraumatic growth, there has been little scholarship in this area (Tedeschi & Calhoun, 2004). One reason may be the difficulty of quantifying the varied cognitive behaviors people identify as prayer, religious beliefs and spirituality. Harris et al. (2010) sought to detail the meaning and purpose of prayer as it is related to posttraumatic growth for various experiences of trauma. Based on survivors from diverse Midwestern Christian churches, the “findings suggest that contemplative approaches to prayer coping, such as meditation, reflection, and self-disclosure to the Deity, can facilitate posttraumatic growth” (Harris et al., 2010, p. 35).

While people may not be able to alter their own tragedy and grief, many individuals do use their power and influence to help others who might have to face a similar loss. It is one way to resolve the ambiguous loss found in a world that is unjust. By attempting to make meaning from something that seemingly makes no sense, comfort is sometimes found by lowering the risks that others may feel when faced with a comparable tragedy (Boss, 1999).

A major component of the qualitative study of fathers of pediatric stroke survivors is to find out what coping strategies the 13 fathers found useful when dealing initially and over time in parenting a pediatric stroke survivor. In addition, I will be looking for what factors added to and lessened the stress felt by these fathers. The other relevant theories discussed in this chapter will also be integrated into the discussion. It is hoped that the information gleaned from these
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participants will go on to help all fathers, and perhaps mothers, who are raising children with chronic illnesses and serious medical conditions.
Chapter VI

Methodology

This qualitative study addressed the gap in hearing and listening to fathers of children with special health care needs and/or disabilities. While the study focused on the fathers of pediatric stroke survivors, it was anticipated that findings could be applicable to fathers who are raising children with medical, emotional, cognitive and/or physical challenges.

Certain concerns did exist in regard to the relationship between the fathers and the interviewer. One focused on a potential conflict of interest. Fathers whose wives/partners were participants in the monthly family support program were excluded, as there was a concern that fathers may have felt pressured to participate. Fathers were informed that whether or not they chose to participate in the study, the care their child and family received from the stroke program would not be affected in any way. Fathers were also told that every attempt would be made to keep all the information confidential as the study was focused on the aggregate of the information gleaned. The connection between the participating fathers and the interviewer, as explained in the next paragraph, may have had an effect on the outcome that may limit the fathers’ candidness and the transferability of the findings. However, as so little information is available about fathers and their experiences with their children with special needs, it was felt that the qualitative research will serve as a beginning stage to further research.

The interviewer is the social worker for the Pediatric Stroke Program at the Children’s Hospital of Philadelphia, and is acquainted with most of the
families in the stroke program through her role as the social worker for the
program. Charmaz (2006) raised concern about the relative difference in power
and status that may come into play. As a researcher, there was an apprehension
that a father may have wished to be seen in a socially desirable way and therefore
voice what he believes the social worker wishes to hear or is concerned that he is
portrayed in a most favorable way. The researcher stressed the need for fathers to
respond in truly authentic ways to gain accurate information. Likewise, fathers
were also made aware that no information gained in the interview, unless they
implied or stated a desire to hurt themselves or someone else, would be discussed
with anyone in any manner that could identify the participant or his child. The
respect for confidentiality was reviewed and reinforced.

I was cognizant of the notion that all research could be considered an
intervention as it can lead to people gaining different perspectives (Dickson-
Swift, James, & Liamputtong, 2008). Although the goal of the study was to
provide systemic information and strategies to be of assistance to fathers of
children with special health care needs and/or disabilities, reflecting and sharing
information with me could have impacted and changed fathers’ perceptions or
feelings.

**Study Design**

**Qualitative Methods**

A qualitative approach was chosen for a number of reasons. These
include: 1) there is little known about the topic of fathers of children with special
needs; 2) this topic may be sensitive and not easily amenable to quantification; 3)
it is important to capture the lived experiences; and 4) may be most helpful in blending advocacy with knowledge building (personal communication, Leslie Alexander, Ph.D., 2010). The flexibility of a qualitative design allows the researcher to follow the experiences of individuals leading to a formulation of emerging themes (Charmaz, 2006). The qualitative method allowed for understanding the meaning of the experience from the individual’s own frame of reference (Holosko, 2006). A qualitative approach was appropriate for exploratory research because the method provided the ability to gain study participants’ diverse experiences that are told in detailed responses to the interviewer’s queries (Padgett, 1998). The qualitative method of data gathering that was used was the individual interview.

**Grounded Theory**

Grounded theory does not purport to validate any specific hypothesis but uses observations to look for patterns and identify common themes and categories. “The openness of the grounded theory approach allows for greater latitude for the discovery of the unexpected” (Rubin & Babbie, 2008, p. 418). While similar experiences can generate very different outcomes, different experiences can generate similar results (Shapiro, 2008).

Charmaz (2006) describes the steps of the research process and provides a path to follow in pursuing a grounded theory study. The researcher can adapt the guidelines to meet the needs of a specific study. The flexibility inherent in the process allows the researcher to follow leads that come forward. New questions may arise and interview guides may need to be altered. Intensive interviews will
be conducted in an effort to gain in-depth information of each father’s experience (Charmaz, 2006).

**Institutional Review Board (IRB) Approval**

This study was being conducted as part of a doctoral program at the University of Pennsylvania’s School of Social Policy & Practice. However, as all the subjects were recruited through their connection with the Children’s Hospital of Philadelphia, it was determined by IRB staff at Penn and CHOP that approval should be given through the IRB at CHOP.

**Protection of Human Subjects**

Throughout the recruitment process, the interview, the data collection, and the analysis, care was taken to protect the fathers and their families. I spoke about and reinforced that this study would not impact the care their child received or access to any services or resources provided by the stroke program. I also assured the participants that their responses were not judged in any way nor did individual interviews have any impact on the care and services the child and the family received or will receive. All fathers had verbally agreed to participate. Before the interview took place, I discussed the voluntary nature of their participation and went over, in detail, the consent form and process. All study documentation including the completed pre-interview questionnaires, the consent forms, and the printed copy of the dictation were stored in a locked cabinet within my locked office at the hospital. As part of the protocol in the CHOP IRB, once I checked the digital recording against the transcription, the digital recording was destroyed. A transcription service was not used for two reasons. First was the confidentiality
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concern; second, I felt it was important for me to actually hear the voices of the fathers as I was transcribing each interview.

Throughout the recruitment process and the interview, care was taken to continually assess and reassess the emotional state of the fathers. One particular father cried a number of times throughout the interview. At each emotional point, I asked the father if we should continue with the interview. I let him know that it would be fine if we stopped the interview. Each time he expressed that he wanted to continue and felt better as he got to “tell his story.” While I spent some time with each father after the interview to check their emotional state, much more time was spent with this father and, to a lesser extent, with two other fathers who seemed emotionally affected during the interview. Both of these fathers were given the option to stop the interview process and both declined to do so. While there was a plan to refer fathers to a local resource if distress was present at the conclusion of the interview process, it was not necessary for me to initiate this plan with any father.

Inclusion and Exclusion Criteria

The following criteria were used to guide the recruitment process. The goal was to produce a sample that was relatively homogeneous with regard to their situation but sociodemographically diverse.

Inclusion criteria:

* Biological father or acting in role of father

* Participant living with child and mother in same residence
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* Child has been left with mild to moderate deficits due to stroke or family has been informed that the potential for deficits exist.
* English speaking
* Child currently aged 9 months to 18 years of age

Exclusion criteria:

* Father has shown overwhelming emotional reaction (as determined by the social worker with possible input from stroke team members) to child’s deficits so that participation in study may cause an unacceptable risk
* Father not involved in care of child
* Child left with no or minimal deficits

Recruitment and Sampling

All fathers were recruited from the group of fathers whose children are part of the Pediatric Stroke Program at CHOP. Different forms of recruitment were employed. When the child was seen in clinic and the father was not present, a recruitment flyer was given to the mother. It was felt that there could be a conflict if the flyer was given to a father who was attending the visit and the flyer was presented in front of the child. The recruitment flyer stated the basic reason for the study and gave the inclusion and exclusion criteria. It should be noted that the flyer was given only to families of fathers who met both the inclusion and exclusion criteria. Most participants responded to this recruitment by emailing or calling the contact person listed on the flyer. A flyer was also placed on the bulletin board in the neurology waiting room. No father stated that he responded
directly because of this method. Some targeted fathers received the recruitment flyer via email where an email script with IRB approval was employed (see Appendix A). One father was recruited when the educational coordinator with the stroke program met with the parents at the child’s school and handed him the flyer. Another father was called after the neuropsychologist with the program suggested that he may a good participant for the study. This father was called directly as the family does not have an email account. The IRB approved telephone script was read to this father. When a father indicated he was interested in participating he was given more detailed information and I completed a screening form. A date, time, and place for meeting was then set.

Purposive sampling was used during recruitment to obtain a diverse sample of the fathers in our program. Attribute variables included race, SES, gender of child, degree of disability child sustained and the continued impact on the child, religious affiliation, and length of time since (first) stroke.

It was relatively easy to recruit fathers. On two occasions meetings had been set up but did not take place. One involved a stepfather who stated that he was quite shy and, on second thought, decided it would be difficult to complete the interview. I got the impression that it was not related to feeling discomfort of the topic; he was not used to speaking. The other would-be participant was a physician. When he had to reschedule two meetings, once because he needed to see an additional session of scheduled patients and once because of an emergency in the hospital, I decided not to pursue this potential interviewee. Two additional Caucasian fathers had wished to participate but I already had enough Caucasian
fathers by the time they responded and made sure to thank them for their interest. Once all the fathers who were selected, recruitment and enrollment procedures were stopped.

All fathers were given the option of where to meet. The only stipulation was that the setting would be quiet and private. Nine fathers chose to be interviewed at home; two at their work offices; one at bookstore with a private seating area; and one in a private room at a CHOP satellite office. All fathers were given $50 in cash for any expenses incurred. Although some fathers did not wish to accept the payment I explained that it was necessary as part of the study and they were free to use or donate the money in any way they chose. One father asked that the cash be donated to the stroke program. The money was given to the stroke fund through the fundraising department at CHOP. The shortest interview lasted 45 minutes; the longest was 2 ½ hours. The average interview lasted between 60 and 90 minutes.

Description of Participants and Children

The demographics of the fathers in this study were representative of a cross section of the fathers in the Pediatric Stroke Program. The only difference was, perhaps, a higher degree of educational attainment. Table 1 provides a description of salient characteristics of the participants. The fathers ranged in age from 31 to 50 years of age. In terms of employment, one father was a stay-at-home dad with the day-to-day responsibility for his son, the stroke survivor, and his daughter. All the other fathers worked outside the home and were employed at a variety of jobs. The number of hours worked varied greatly due to the
Hearing His Story

employment situation. For example, a father who was a football coach worked 80 hours per week during football season. Most fathers stated that they averaged 40+ hours per week. Fathers were also asked whether they felt that their child’s stroke created a financial burden. Answers varied from not feeling that their child’s medical condition created a financial burden to feeling that it did cause a financial strain for himself or his family. Regarding the highest level of education completed by the fathers, there was a range from high school graduate to one father with his Ph.D. Another father who is counted as completing the master’s level of education is currently in a doctoral program.
Table 1

Description of Participants (N=13)

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>Frequency or other designation</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Age</strong></td>
<td></td>
</tr>
<tr>
<td>31-35</td>
<td>4</td>
</tr>
<tr>
<td>36-40</td>
<td>2</td>
</tr>
<tr>
<td>41-45</td>
<td>3</td>
</tr>
<tr>
<td>46-50</td>
<td>4</td>
</tr>
<tr>
<td><strong>Highest level of education</strong></td>
<td></td>
</tr>
<tr>
<td>High school graduate</td>
<td>7</td>
</tr>
<tr>
<td>Some college</td>
<td>1</td>
</tr>
<tr>
<td>College graduate</td>
<td>2</td>
</tr>
<tr>
<td>Master’s degree or more</td>
<td>2</td>
</tr>
<tr>
<td>Doctoral degree</td>
<td>1</td>
</tr>
<tr>
<td><strong>Caregiver status</strong></td>
<td></td>
</tr>
<tr>
<td>Primary</td>
<td>1</td>
</tr>
<tr>
<td>Secondary</td>
<td>12</td>
</tr>
<tr>
<td><strong>Employment</strong></td>
<td></td>
</tr>
<tr>
<td>Self-employed business</td>
<td>2</td>
</tr>
<tr>
<td>Human service worker</td>
<td>3</td>
</tr>
<tr>
<td>Skilled worker</td>
<td>2</td>
</tr>
<tr>
<td>Professional</td>
<td>4</td>
</tr>
<tr>
<td>Other</td>
<td>1</td>
</tr>
<tr>
<td><strong>Reported financial burden</strong></td>
<td></td>
</tr>
<tr>
<td>None or minimal</td>
<td>6</td>
</tr>
<tr>
<td>Somewhat or modest</td>
<td>4</td>
</tr>
<tr>
<td>A great deal</td>
<td>3</td>
</tr>
</tbody>
</table>

Note: Most stroke survivors living in Pennsylvania qualify for Medical Assistance that covers most medical expenses including co-pays for therapies, doctors’ appointments, and physical equipment such as braces. The regulations are different in New Jersey and most stroke survivors do not qualify if a parent is employed.
Fathers were married/partnered from 6 to 20 years with the mean computed at a little over 12 years. Religious affiliation totals were as follows: 1 Baptist, 1 Muslim, 1 Quaker, 3 Roman Catholic, 1 Jewish (Orthodox), and 6 of various other Christian denominations. All fathers had 2-3 children. Four fathers were African-American; all the others were Caucasian. Only two of the fathers reported that they had sought counseling to cope with their child’s stroke diagnosis; one had seen the counselor previously for unrelated issues.

Table 2 describes salient characteristics of the stroke survivor children of the fathers who were interviewed.
### Table 2

Description of stroke survivors N=14 (one father has two children in the Stroke Program)

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>Frequency or other designation</th>
</tr>
</thead>
<tbody>
<tr>
<td>Gender</td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>8</td>
</tr>
<tr>
<td>Female</td>
<td>6</td>
</tr>
<tr>
<td>Ages of Children</td>
<td></td>
</tr>
<tr>
<td>3-5</td>
<td>6</td>
</tr>
<tr>
<td>6-8</td>
<td>6</td>
</tr>
<tr>
<td>9-11</td>
<td>1</td>
</tr>
<tr>
<td>12-14</td>
<td>0</td>
</tr>
<tr>
<td>15-17</td>
<td>1</td>
</tr>
<tr>
<td>Added Diagnosis of Epilepsy/Seizures as a result of stroke</td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>8</td>
</tr>
<tr>
<td>No</td>
<td>6</td>
</tr>
<tr>
<td>Time since first stroke</td>
<td></td>
</tr>
<tr>
<td>9 months-1 year</td>
<td>1</td>
</tr>
<tr>
<td>2 -3 years</td>
<td>6</td>
</tr>
<tr>
<td>4+ years</td>
<td>7</td>
</tr>
</tbody>
</table>

Note: The Stroke Program began about 8 years ago. For the most part, children who suffered a stroke before the beginning of the program were seen at that time by a general neurologist and have maintained care with that physician. This may account for the high number of younger children.

At the time of the study, all children, except for one, were receiving one or more therapies as a result of their stroke either as an outpatient or as part of a school program. One child was in Boston for specialized proton beam therapy. Four of the stroke survivors have at least one other significant medical diagnosis. There is a wide variety in terms of educational placement. Some stroke survivors are in specialized approved private schools, as their needs cannot be met within
the regular public school system. Some children are in special education
preschools. The overwhelming majority of the other stroke survivors receive
accommodations in a public school setting. One child attends a Jewish day school.

Research Design and Setting

Procedure. The format used was semi-structured, in-depth interviews.
The questions were designed to be reflective and open-ended. Probes and
occasionally field notes were used. According to Leslie Alexander, Ph.D. (2010)
field notes are use when the interviewer wants to explore further a comment given
by the participant. A note is made by the interviewer to follow-up with the
participant at a later point in the interview. All participants were interviewed
following the basic format of the interview guide. All interviews were audio
recorded. Interviews took place between July, 2012 and January, 2013. The
sample size was limited to 15 fathers or when saturation was achieved. Thirteen
interviews were included in the final analysis after it was realized that one
participant’s child did not meet the inclusion criteria and one father was
interviewed as a pilot interview and therefore was not eligible according to
CHOP’s IRB.

Appendix A contains the verbal HIPAA consent needed in order to
continue with the description of the study. Appendix B is the written consent
form, which was reviewed by the researcher and the father and then signed by the
father before the interview began. Fathers were asked to complete the
questionnaire (Appendix C), which allowed the researcher to obtain information
Hearing His Story

on such variables such as age, level of education, financial impact, and paternal participation in psychotherapy and/or pediatric stroke based activities.

Appendix D identifies items found within each child’s hospital electronic medical record. This information was obtained to confirm the accuracy of the information received from the father, to add information if not known by the father (such as if he could not remember the month of the child’s first stroke), and to be able to seek further medical information, if needed. The description of the items collected can be found in Appendix D. Additional data obtained in the electronic medical recorded included recommendation for and/or participation in specialized therapies, any co-morbid condition, type of school placement, and ethnicity.

The interview guide (see Appendix E) was designed to gain information about the impact of the child’s stroke on the life of the father. In order to obtain information about the changes that the father may have experienced, the questions in the interview guide included such queries as the father’s reaction to the diagnosis, coping strategies used both initially and over time, changes in significant relationships, supports that he found useful, changes, if any, in religious or spiritual beliefs, concerns for the future, changes in expectations for his child, and advice to others.

In summary, the telephone script, description of data obtained from child’s hospital medical record, pre-interview questionnaire, the interview guide, and the consent form can be found in the following appendixes:
Analysis of Data

With the permission of the fathers prior to the interview, hand written notes were taken during the interview process. These notes, taken by the interviewer, were used for noting probes and markers as the fathers spoke. In addition, if there was an emotional reaction such as tearing up, crying, smiling, laughing to a specific question, these were noted as well. The researcher also noted some thoughts after the interview was over and she had left. Each interview file consisted of the pre-interview questionnaire completed by the father immediately before the interview, my notes, the transcribed interview, and the information obtained in the child’s electronic medical record. No identifying information has been retained or can be associated with the actual data.

Rigor and Trustworthiness

After the first three interviews were transcribed, the coding process began. An initial coding was followed by a second round of coding which helped to synthesize and organize the data into themes. As a means of confirming the accuracy of the coding, another student coded two of these first three interviews.
Hearing His Story

This student is a doctoral candidate in psychology. During her undergraduate program in psychology at the University of Pennsylvania, she held a part time position that involved coding qualitative interviews. Together we examined our individual coding, discussed the minor differences that were found, and then made very slight adjustments to the final coding.

With the coding of the next set of interviews, I found it more helpful to organize first by the number of the question in the interview guide. For example, all responses to changes in the relationship with siblings were compiled into one document. Those individual responses were then coded using the categories of open, axial, and selective coding (Corbin & Strauss, 1990). Responses that did not fit into the specific topic but seemed to offer useful information were then moved to a more appropriate spot under a different question or put into an additional category. A prime example of an additional category was the descriptions of the appreciation of all the work and dedication of the wife/partner. This was not a question that was asked yet so many fathers made statements of gratitude that it needed to be included in the findings. Memo writing was also used throughout the process as memos provide an ongoing written record of the process (Birks, Chapman, & Francis, 2008). Included in the memos were items that could not be captured on the digital recordings such as emotional reaction to specific questions.

Originally I had planned to have the fathers read the transcription of their individual interview as a means of member-checking. Fathers would have been asked to make sure I captured an accurate dictation and add any further thoughts or clarifications. However, there were two reasons that this did not occur. The
first was that it would have been difficult for the fathers to receive a copy of the transcription and maintain confidentiality. Initially I had planned to send an electronic file to the participant. A member of the CHOP’s IRB explained the process of sending a secure document to me. I felt that the process was just too cumbersome, time consuming, and impractical. I also toyed with the idea of sending a hard copy of the dictation via regular or certified mail. However, I could not be assured that someone other than the father would read the transcript. Secondly, I was concerned that the father may have a negative emotional reaction to this step in the process and I would not be there to assess his emotional/behavioral state.

Reflexivity Statement

My initial interest in this topic was inspired by a comment made by a father about his feelings of helplessness related to not being able to protect his child from suffering a stroke. He shared that he was used to taking care of his family, yet his best efforts were unable to prevent the stroke from occurring. He wanted to be an involved father and felt the need to “do something.” I was overcome by his heartfelt comments. I realized that often times I, and others, excluded fathers from total participation in the care of their own children. On occasion I have witnessed a physician, when entering a child’s hospital room, ask the father where the mother is in order to speak with her in addition to the dad. I have never heard anyone ask a mother where the father was in order to discuss everyday care with the parents. I now make a concerted effort to respond to each parent equally.
Hearing His Story

In my experience growing up and in the period of time I raised my own children, the mother was responsible for the care of the sons and daughters even if she worked outside the home. Fathers, in my biased view, were seen as the primary breadwinner in most middle class families. They may have attended their child’s Little League games or a school play, but the everyday care for the children and the home fell to the often-exhausted mother. My experience working with fathers revealed a new generation that wanted to be, perhaps, an equal partner in parenting their children.

Over the five years that I have been a social worker, all of which have been in my current position, many of the mothers would share their emotions, feelings, and concerns with me, other members of the stroke team, and at family support group meetings. Very few fathers acknowledged grieving the loss of the child without medical issues/disabilities or the added stress in caring for a child with special needs. I wanted to find out how they felt their child’s stroke affected their lives and gain insight into how I could help them (and other fathers) cope with the (new) identity of a father of a pediatric stroke survivor.

I felt very honored and privileged that the participating fathers were so willing to share their experiences with me and I was surprised by their openness and eagerness to do so. Many fathers faced and will continue to face life-altering challenges. When meeting with young mothers I am saddened when they are able to rattle off so easily a list of all the medications their children must take. I often am struck by the poignancy of how unfair life can be- why some families have to cope with conditions such as pediatric stroke. These mothers and their families
should be concerned with what to have for dinner or where to go on vacation. I was likewise saddened when thinking about what the fathers revealed. After many of the interviews I needed to drive a short distance and park so I could “decompress” before continuing home. I often relied on social work colleagues at work and members of the DSW cohort to help me deal with these feelings. Sometimes I just sat quietly alone. Yet, many of the fathers had made peace with what had happened and reveled in their reordered priorities.

In terms of the theoretical framework of Folkman and Lazarus, I noticed that I use the concepts of Stress, Appraisal, and Coping on a daily basis. I often think of this framework to help me cope with various aspects of my life. (I’m stressed, but even if I don’t finish the program, my family and friends will still love me.) However, personally I cannot imagine any way I could cope with hearing that one of my children or grandchildren was given a devastating diagnosis. I realize that people have to deal with life as it hits them for they do not have any other choice.

I also wanted to learn from these fathers how their religious or spiritual understanding might have played a role in making sense of what happened to their child. Personally I have always questioned how, if there was a God, could such things happen to innocent children? On a trip to Israel I remember inserting a message at the Western Wall in Jerusalem to plea with God to “cure” a very special child. (Placing a slip of paper in the Western Wall with a prayer/request is a common practice among Jews who visit Jerusalem.) This dissertation is dedicated to that special child. I had the honor to know Candace Garner who, for
two years, was a student in a class I taught before I entered into the MSW program. Candace had suffered a stroke that left her with a vision problem along with physical impairments and speech issues. The vision loss qualified her for my class of children with visual impairments. Soon after returning from Israel, I enrolled in a semester long class looking at “God’s justice.” Led by a noted rabbi, he basically said that we do not know God’s plan but that perhaps, one day (in heaven) we will. I never felt completely comfortable with this explanation. Very sadly, shortly before her nineteenth birthday, ten years after suffering her first stroke, Candace lost her life as a result of the damage caused by the strokes.
Chapter VII
Findings

Various themes emerged from the interviews with the 13 fathers of children involved with the Pediatric Stroke Program at the Children’s Hospital of Philadelphia. Some themes surfaced as a direct result of an individual question asked; others appeared throughout the interview. Prominent themes will be presented in separate sections throughout this chapter; although at various times the information will overlap. The first three major themes of this chapter include: (1) initial emotional reactions to the diagnosis, (2) the negative and positive effects on the life of the father and the lives of his family, and (3) the various coping strategies used by the participants. A fourth theme and specific area of interest is the impact of the father’s religious or spiritual beliefs and any change that occurred as a result of their child suffering a stroke. This will be covered in a separate section. A fifth section, titled “Moving Forward,” will cover the father’s self-identified concerns and challenges, what advice they would like to share with others, and noted instances of family and/or personal growth. All fathers have been given Anglicized/common pseudonyms.

Part 1: Reactions To The Diagnosis

All but three of the fathers were expecting normal healthy children. One of these children with other medical issues came into his present family through kinship care adoption; the other two families knew that their children had suffered a stroke in utero. The other 10 fathers reported being excited, thrilled, and it being the best feeling in the world with the thought of the birth of their new son or...
daughter. James and his wife were one of the couples who knew that their son had suffered a stroke in utero. The physicians informed them that the baby’s ability to survive at birth was in question. The parents had developed a plan before his birth in regard to what extent they were willing to accept medical interventions. James indicated:

I was sad. It was more of holding it together to find out what the situation was. We didn’t know. We knew there was hydrocephalus. They figured it out that it had something to do with the stroke. And at that point it was month to month until he was delivered. We had prepared for the fact that if he did not breathe on his own that we were going to try and keep him breathing long enough that everybody could spend a moment with him. We didn’t want any kind of ventilation system started because if it wasn’t meant to be, it wasn’t meant to be. We didn’t want to subject him to a life that was a burden to him, to live that way. So we actually had a priest there. He was born at approximately 5 o’clock in the morning at the university hospital and he was on oxygen, but that was standard.

Another family that was expecting twin boys after many years of trying to have a pregnancy result in a healthy baby had been informed that it was doubtful that one of the twins would survive. This father shared his feelings about this son:

I felt a blessing and a gift. That’s why I named him ________. I knew he was going to be something special in our life. I just prayed on her stomach as she was having him because they said he wasn’t going to make it out of the womb. So I just prepared myself. And our family prepared themselves
Hearing His Story

too. We just prayed; our pastor prayed; everybody prayed that he’d be around for a long time. (Matthew)

Other fathers, who did not know that their child was medically fragile, had very different situations and reactions. Most did not have time to adjust as they were expecting typical children or the stroke happened suddenly to an older child.

Below are the most common reactions of these fathers.

**Shock and Disbelief**

When given the diagnosis of pediatric stroke, most fathers reported being in a state of shock and disbelief. Part of this reaction may derive from the fact that many have not heard of children having a stroke. Nicholas, when asked, reported that he was in shock for “I didn’t know babies could have strokes. Nothing I ever thought about; nothing that happened on either side of the family. It was unbelievable. I couldn’t believe what I was hearing.” Another contributing factor may be receiving this diagnosis for their child in the context of the intensive care unit, which is an unexpected place for families to find themselves.

The response of another dad whose child was transported to CHOP after being at two other hospitals and who was in extremely critical condition was also one of shock and disbelief. Edward responded, “You just looked at her, waiting for her to wake up. You’re almost waiting to be home that night. No comprehension of how bad, or how long, or how much would be involved.” Kenneth, the father of a child who had his first of eight strokes at age four, revealed, “I was just shocked.”
Hearing His Story

Ryan and Anthony echoed similar comments. Ryan described the reaction to the diagnosis as “one of disbelief given the fact that she was full term and had been healthy. The day she had the stroke (at two weeks old), that was tough; that and seeing her in the intensive care unit” whereas Anthony questioned why this had happened to his son. He stated that he was in shock and that “It didn’t make sense to me. Why him? If someone needed to have this, why not me? Why an innocent, completely happy two year old would have to go through this were all my initial feelings.”

The father of another child who suffered a stroke right after delivery, while in shock that this had happened to his daughter, felt he was in a unique situation that was helpful in dealing with the initial diagnosis. Paul was able to appraise the situation using his prior knowledge of how to access special education services and knew the individuals who had the power to assure that therapies commenced quickly. He offered:

Well, thankfully the field I’m in—I was a special ed teacher, a supervisor of special ed and now director of special education so I’m immersed in all that and I know all the supports. Quite honestly, the discussion I had with the doctor at the time and she explained to me that there might be weaknesses, she could have learning disabilities and other stuff, and the only thing I said to her- I don’t care about all that stuff- is she going to be alive? She assured me she was going to live and I said I could deal with everything else.

Uncertainty

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Hearing His Story

Most fathers shared that initially there was the almost paralyzing fear of the unknown. They could not comprehend how bad the situation was or could be, how long their child would be in this situation, or what the future would entail. As Edward asked, “Is she going to make it out? Is she going to survive this? You’re just in terrain that you have no clue where it’s leading.”

Some fathers were uncertain of the diagnosis for a period of time. Simon, for example, shared his feelings about waiting for the diagnosis and not knowing what challenges his son would face. He indicated:

The diagnosis was, we weren’t sure at first. We were back and forth what it is exactly. Meaning is it going to be something recurrent, chronic that’s going to keep coming back or a one-time deal? It took a while for that so it settled very slowly. So I guess, originally crushing because we feared the worst. I happen to be someone who many times imagines the worst. And then the final diagnosis was relieving in a way. I guess not knowing what the repercussions would be socially and the challenges that he was going to have.

**Panic and Anxiety**

Many fathers reported being extremely anxious when first being told the diagnosis. For fathers who were not physically nearby at the time of the stroke, there was an added sense of panic. George was in the Midwest with his mother for a bowling tournament. He needed to figure out a way to return quickly when his partner relayed the news that his son needed to be rushed to the hospital.
Hearing His Story

She (partner) called and said I had to rush ________ to the hospital. My first thought was that his asthma was acting up. No, he’s having a stroke or something. What? I just dropped the phone. I ran to my mom’s room, which was right across the hallway, trying to find any way I could to get back. Please just make sure he’s okay until I get back. I just started praying. When I got there I knew something was really, really wrong with him. It really took me down. I thought I was going to lose my son.

Heartbroken and Sad

A number of fathers reported how difficult it was to accept the diagnosis. Kenneth acknowledged that, “It was very hard, very hard to accept. I couldn’t put anything into words.” James, the father of the child who was diagnosed while still in utero was saddened by the loss of the child he had been hoping to raise, shared:

I was saddened with the fact that there were issues, probably feeling sorry for myself as much as for him. He was legally blind. He wouldn’t be able to drive a car or all of those things you want to teach your children. The milestones you look forward to...

The father of a three year old boy who was found to have an arteriovenous malformation (AVM), a tangle mass of arteries and veins which affects the circulatory system, expressed the following, when his wife was about to give birth to their third son:

I really didn’t know. I was really scared for him, not necessarily for me. I remember repeatedly telling my dad that if I could take his place, I would. If I could just fix him, I would. I really at that point started to go into a
dark place of worrisome, and scared, and almost like paranoid of how we were going to do all we planned. I was a dreamer, dreamed about traveling the world and surfing with my kids and doing all these amazing things. Now, how am I going to do that? We didn’t know if he would recover. If he wouldn’t recover … I kind of shut my brain off at this point and worked myself up into a meltdown basically. The whole time we never left the hospital, we never left his side. (Anthony)

Helplessness

Many fathers saw the fact that they could do nothing to help their child during the initial period as extremely problematic. They had previously been able to provide for their families and protect them from harm. Now there was nothing they could do. Some described waiting to see if their child would live or die as a period of indescribable angst. Paul said, “It was the most helpless feeling.” Others simply prayed.

Questioning God

As mentioned in previous chapters, most Americans have some religious or spiritual beliefs. In trying times it is often difficult for families to reconcile their belief in a divine power with the reality of what has happened to their son or daughter. Anthony reflected this sentiment stating, “A lot of people told me to turn to religion, which I couldn’t do. The way I was thinking at the time was how could God let something like this happen? How could any power let something like this happen?”
Hearing His Story

While Anthony questioned God, other fathers shared the belief that God would take care of their child and their family. This appeared to be a great source of strength as well as comfort in dealing with the diagnosis. Ryan affirmed his beliefs:

I didn’t think about it. I didn’t think that this was this great test or anything I had to overcome. I did accept quickly and I didn’t accept that she would be damaged. I mean, the physician said that she would have difficulties, but I didn’t see it. I knew I believe in a higher power. We would cope.

No matter the initial reactions to the diagnosis, most fathers felt that the child’s stroke impacted the life of the son or daughter, their life, and the lives of members of both the nuclear and extended family. As you will learn, the fathers in this study were able to identify negative as well as positive outcomes of their child’s stroke. While no parent would choose to have his or her child suffer a devastating medical condition, many fathers describe closer relationships with their families as well as a new and deep appreciation of everyday life that they had previously taken for granted.

**Part 2: Effect on the Life of the Father and on the Lives of His Family**

When fathers were asked how they thought their child’s stroke would affect their lives, many stated that they could not or did not even think that far into the future. They could only focus on the immediate “here and now.” For many it seemed like a question that made no sense. Below are examples of fathers expressing the feeling that initially they were not able to think about the long-term
Hearing His Story

impact of their child’s stroke on them, the child, or on members of the family. For example, George stated, “I really didn’t think about it. I was just hoping that he was strong enough to hold on. He’s a child. My father had a stroke and he passed away from it.” Kenneth shared,” At first I didn’t think I could do it. But, what am I going to do?” Some fathers, either initially or after a short while, realized that their lives and those of their wife/partner, other children, and their child who had suffered the stroke might be forever altered. While initially Kenneth stated that he did not think he could parent a stroke survivor, he later felt:

As time went on, I was coping with it a lot better than my wife. She was breaking down. I had to keep it together for the whole family because I didn’t want any of us to go into a nervous breakdown over this. So I tried to be strong, tried to look at the positive things. At first there was none.

William, whose child was left with significant deficits stated:

We knew it was going to be a big deal, a great deal to deal with. We knew it was going to be a burden. We wanted what’s best for her. As far as it impacting us, our lives just changed in a complete direction. I mean, drastically.

The father whose career focused on children with special needs was able to use his knowledge and resources to lessen the emotional impact of his daughter’s stroke and immediately connect with people who could help his child. Paul indicated:

If I didn’t have the background that I have, it would have just totally overwhelmed me. You don’t know where to go for supports. We had
supports in place before we left the hospital because I knew the people to call. That’s a huge plus I think my background. It’s your kid; I think you have to overcome no matter what.

Parenting a Stroke Survivor

One aspect of the potential impact on the father is figuring out if and how his parenting will need to change. Many fathers, like Kenneth and William, identified the everyday responsibilities now assumed by their partner/wife. The expression and details of the gratitude and admiration fathers felt for their wives will be discussed in a different section. Many fathers stated that they did not know how they would parent a child with a stroke. They simply knew that they would find a way to be a father to their child. Peter, the father who adopted his son through kinship care replied, “I didn’t even know I could parent a child with a stroke, I just figured the more love I had it would help me.” Matthew, who described himself as being very religious, stated, “I didn’t think it was a burden. Through the glory of God we made it.” Similar to Kenneth’s reaction, George offered, “I really didn’t know” and Edward remarked, “You can’t run away from it. Was I prepared? I don’t think so; I don’t think anybody can actually be prepared for his or her own child to go through.”

Emotional challenges of parenting a child with a disability. Fathers commented on the challenges and joys they could now identify in regard to fathering a child with special needs or medical concerns. Anthony shared his concern for the effect on the child with the stroke and for his family stating:
I did not know. That was probably one of the hardest things for me adjusting how I was parenting and adjusting how I was going to deal with certain situations such as sports and automatically looked to them being teenagers and how it would affect that and knowing that my wife was about to have our third son how it would affect that. Having three boys growing up and one stroke patient was a big concern.

Simon also felt the emotional difficulties of becoming a parent of a stroke survivor. He revealed, “I’m a type for whom it was very difficult. It’s funny because right now I’m reading right now about self-efficacy. I’m reading about myself.”

A few of the fathers commented on having the realization that no matter how much they loved and cared for their child they could not have prevented the stroke from occurring. Anthony, who could see positive changes in himself and his family eventually, in due course was able to come to the difficult understanding that something bad could happen to his child and he was helpless to prevent it:

I think it’s definitely changed, probably mostly for the better. I’ve learned a lot. I’ve become more caring and patient and have enjoyed simple things a lot more. My biggest fear, my biggest problem with the changes is realizing that I can’t protect my kids from everything. That was the hardest part for me to deal with because I always thought [because] I am their father I can protect them from anything.
**Becoming your child’s advocate.** Parental advocacy is often found in the hospital, in social situations, and most often at school. In my former profession as a teacher of children with special needs, the father was often the best advocate for his child. In some circumstances the professionals showed a more conciliatory response to fathers when compared to the mothers. Ryan shared that becoming his daughter’s advocate helped him in the coping process. He describes in detail a situation that occurred when his daughter was getting ready to enter kindergarten. There was a meeting where the school district was recommending the following:

And so, in the placement where they were saying that there’s this placement she can go to at __________ Elementary School, she’d do partial time in a special needs class and the partial time in the regular kindergarten class. I really was advocating and promoting to have her just be in the kindergarten class because I felt that she can just be and that she may just need a little bit of time to make the adjustment. It’s benefitted but the funny thing is, the first day, the orientation, the day before the first day of class, my daughter and I visited her first class. The teacher had a chair that had her name on it. And she was the only student that had a chair with her name on it. And it was on the rug where they convene when class begins. I asked the teacher,” What’s going on with the chair?” And she said, “Based on her scores, we thought that we did this until she gets acclimated.” I said, “Why would you start out othering her? Why not see how she works with the classroom team and if she can’t then we’ll have a discussion to see if that’s what’s needed with the chair?” So it was great
that she understood exactly what I said because I put it into those terms that I didn’t want my child being othered during that first day of class. Allow us/her to get acclimated; allow us to monitor her in that situation. And if the need arises then we can make the adjustment.

In this example, Ryan became an important advocate for his daughter. Usually the mother becomes the primary advocate for the child. Many fathers commented that they appreciated all the efforts of their wife/partner on behalf of the stroke survivor.

**Issues concerning time.** A number of fathers commented on the time spent on their child’s care. Families sometimes need to spend hours a week both at therapies and practicing therapeutic techniques at home, going to doctors’ appointments, as well as being conscious of medication schedules. Matthew commented that, “it changed tremendously because when you have less sicknesses going on in your family you have more time. It changed a lot but not to the point it was overwhelming.” William shared, “I guess she just basically has more of our time. We spend time with her every day doing her therapies and stuff like that. She just demands more of our time, but that’s not a bad thing.” Another father was concerned with his son’s medications. Kenneth said, “the medications- I usually have to be on top of those- making sure he gets them on time.

**Living with the fear.** Living with the concern that their child could have another stroke or seizure has affected some of the fathers. Some parents place a monitor in the child’s bedroom and are always conscious of how their child is when their son or daughter is not in their sight. Examples of three of the fathers
highlight the angst felt by other fathers, especially in the first few years after the child’s stroke. Edward recalled, “We had lights on and we kept checking. The nightmare of what if she stops breathing again. The whole thing with the seizures that could come back if she has a fever. So any time she had a fever it was panic.” Paul commented that, “We see tremendous improvement but my biggest fear is if it’s cold and she shutters, we freak out. Because OMG what if she’s having a seizure. She’s 4 years old and we still have a monitor in her room. I don’t know if I’m ever going to take the monitor out of her room.” Because Simon’s son was left with psychological/psychiatric issues, Simon is concerned with his son’s behavior and how it is affecting his wife and other children. Simon shared, “When I go to work, I have my cell phone with me. Anytime I get a call from my wife I’m thinking oh God. I’m always going to be on pins and needles.”

Anthony described both his fear and his joy in spending time with his family:

Life has changed a lot. I’m scared a lot; I’m scared to leave; I’m scared to go on trips; I’m scared to not be around, but a lot of it is positive. A lot of times rather that going out with friends, I’ll choose to go home and spend time with my family. I’ll choose to laugh more and enjoy simple things more like playing in the backyard or going to the beach. It’s just as fun as some exotic trip to an island because it’s being with the people you want to be with. But there are a lot of scary moments still. Went through a lot of sleep issues; a lot of posttraumatic stress anytime he was red in the face.
Anytime he would wake up at night; flashbacks of what happened and fear that it was happening again.

One father feared losing his job, which would mean losing his medical insurance. Edward said, “Everybody has a fear of losing his or her job. I don’t have the financial issue but I have the worry of losing medical insurance for her.”

No impact

While most fathers indicated that their child’s stroke did affect their lives, two fathers said that their child’s stroke had no real negative impact on their lives. The father of the first child may not realize or may be in denial as to how serious his son’s condition actually will become as the child grows older. George stated, “Actually my life has never changed. It’s like he basically never had it. He’s just running around. In the back of my mind, I know he has it; we still do the same things; he does nothing different.” Kenneth, too, reported that his life has not been impacted stating, “It hasn’t really changed. We’ll spend a lot more time together, which is good for me” (Kenneth). Obviously his life has changed for he is spending more time with his child, is concerned with making sure his son gets his medications on time, and needs to take time off of work to drive his son and wife, who does not drive long distances, to many doctor and therapy appointments each year.

Relationships

All the fathers identified changes in their relationships within the family. Most stated that they became closer to their immediate family members.

Relationship with the wife/partner. Most fathers shared that their child’s stroke resulted in a closer relationship with the mother of their child. As Anthony
said, “Initially my wife and I just leaned on each other and became really
dependent on each other and talked about how we would cope with it.” Other
fathers shared similar feelings of closeness with their wife/partner. Paul reported,
“It brought us closer together. It was kind of she and I against the world with
________” (daughter). Another father, Nicholas, commented on the impact of his
son’s stroke and his relationship with his wife saying, “It’s made it stronger.
Much stronger.” Similarly to Nicholas’ response, William shared, “It got better.
Our relationship- it was always good, never negative. We’ve been together a long
time- 18 years.”

One father shared how differing views affected their marital relationship.
As Lazarus (1999) points out, “coping with an ongoing source of stress can
increase tension or conflict between partners” (p. 147).

The relationship with my wife, after his initial stroke, was really good. It
brought us closer. As time went on and he was recovering better,
becoming more quote unquote normal, it pulled us apart because she’s a
free spirit and I’m very serious. And I felt like everybody was forgetting
about what he had and just going back to normal. She felt that going back
to normal was the best thing, the best type of rehab. We disagreed on a lot
of things, how to do them, how serious to take follow up appointments,
and talking with other neurosurgeons. It drove a wedge in us. We stopped
talking, clearly to each other. It made for some bad times. Luckily for both
of us we caught it before it got bad. We went to therapy together to get to
the root of the problem. The end result is we don’t have to agree on
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everything but we have to respect each other and communicate with one another. Taking down my guard as a man, father, and husband; be able to cry to her, tell her my fears and issues was the hardest thing for me to do but the best thing I could do. (Anthony)

This father has reprioritized what values are important in his life and now enjoys spending more time with his family and helping his one son with therapeutic exercises.

Many fathers described all the activities that their wife/partner needed to do to provide the best care for their child. The mother was the parent who usually brought the child to medical and therapy appointments. Some mothers needed to stop working outside the home, as their child’s needs were so involved that one parent needed to become a full-time caregiver. Paul shared, “She couldn’t even work part time because we’d have to worry when the schedule’s going to be made. Her full time job is basically taking her to therapy 3-4 times a week and doctors’ appointments or what have you. She gets a little stir crazy sometimes.”

This father commented that he goes home so his wife can teach aerobics some nights, an activity his wife enjoys. He helps his daughter stretch her limbs, which while painful for her is necessary.

Matthew, the husband of another woman who was not able to return to work due to their son’s medical complications remarked, “My wife is doing a wonderful job at home, raising them, and watching the staff that’s with them, making sure the medications is there, their appointments are ready. She’s a wonderful woman.” Jerry, the father of a teen diagnosed with neurofibromatosis
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(a genetically-inherited disorder which causes tumors to grow on nerves) and stroke, is also grateful to his wife for insisting that his daughter receives proper medical care. He stated, “Lots of things would have never gotten done if [my wife] hadn’t pushed, pushed, pushed.”

For some parents it is hard to leave their child even years after the stroke. This can create added tension and stress on the relationship. As Jerry described:

I surprised her by taking her away for our 15th wedding anniversary. She was really mad. She did it but she was mad. I had it set up but we can’t leave (daughter). We can’t do some of the things you could do. It’s hard. It’s hard. We don’t really trust my parents to watch the kids and do that. And that’s a hard relationship to try to tiptoe through that whole mess all the time.

**Relationship with the stroke survivor.** Fathers reported that their relationship with their son or daughter grew stronger after the stroke and expressed appreciation of the hard work that their child needed to do to regain skills. Fathers revealed that they have become more sensitive and sympathetic toward their child. As Edward explained:

Probably more sensitive to her needs. I feel there are times where the two of them are doing something, and I’m disciplining ______ (brother) for her. I’m not sure if it’s because he’s older and he can understand more or because I’ve seen what she’s been through and I might be a little more sympathetic to it.
**Relationship with the siblings of the stroke survivor.** Fathers commented on how their relationship with their other children was impacted by the stroke. One concern was that their other children were missing out on opportunities because they could no longer do certain activities as a family. Fathers were also concerned about the daily effect on the lives of the siblings.

Simon commented, “I just can’t cruise along. I can’t just go through the motions. Now it’s looking toward ______ (stroke survivor) and trying to make sure __________ (sibling) doesn’t get traumatized, that he should be affected by __________(stroke survivor)’s behavior. And he is affected. We can see it.”

For some siblings it was a gradual acceptance of what happened to their sibling and how it affected them. The stroke survivor is often in the hospital for long periods of time. Then there may be months of outpatient therapy.

With ______ (son), definitely. He’s just starting to come around now. He had a real hard time adjusting. When it first happened and she came home, he didn’t want anything to do with her. Maybe it was because he was staying at his grandmother’s house for 2 months and then he was walking around here “I hate______ (sister).” He came around. It took about a year but there was a big strain there. (Edward)

Another father, William, expressed a similar feeling sharing, “I think with the older daughter we had a little withdrawal from her because ______ (stroke survivor) was getting so much of our attention. I definitely see that in her attitude.”
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The father of two children in our program expressed that he is concerned for his other child who is talented in many ways. Matthew said:

________ thinks he’s missing out of something; I just got to take
________ out by himself. I just got to take care of everybody. It’s hard on one paycheck. Working over 70 hours a week, doing Army Reserve for 21 years, I need a break. But thanks to the glory of God I have my sanity; we have our sanity.

Another father, Jerry, spoke about his younger daughter in this way:

I try to do stuff with her. She jokes she’s the other child. She does a great job. ________ (daughter) is so smart, mature for 12. It’s unbelievable. She knows nothing but what ________ (stroke survivor)… She’s been dragged to a hospital, like today, her entire life. And takes care of ________ (stroke survivor); sleeps in her room and helps her with everything all the time. She’s 12 but she’s passing ________ (stroke survivor) mentally and all those kind of things you know, much more caring for others.

Time, energy, and financial resources became limited for most families. It often becomes a very delicate balancing act in trying to meet each child’s needs.

As noted above, most fathers expressed the desire to make sure their other child or children did not resent the child who suffered a stroke. Anthony explained, “But we really have to focus and drill into them that they are the same and we’re proud of them for all for things that they do and ways that they act.”
**Relationships with friends.** In this study two fathers reported that they did not have friends outside their family. Nicholas stated he had “no friends and that his family was his friends” and Matthew shared, “I don’t have no friends. My wife is my friend.” None of the fathers identified more than a few friends. This number may be much different for women. Some fathers reported that their relationships with their friends did not change after the stroke. They attributed this to the fact that they did not share information about the stroke with their companions. A sample comment shared by Simon was, “They’re not involved in my daily life so I don’t think it’s been affected at all.”

Jerry was in an unusual position in regard to his friends. He was grateful that some of his friends helped with the organization (camp) that he created for others to learn about his daughter’s condition. “There are lots of things I don’t do that I might do. They’re [friends/associates are] pretty understanding because they all help with the camp. They all know _______ (stroke survivor) and stuff. Sometimes I wish they didn’t know as much as they know, I guess.” Many of the fathers did not share information about their child with people they identified as friends. It is unclear whether they would or did share information about their children who did not suffer a stroke.

Two fathers expressed that they, “found out who their true friends were.” Anthony described the situation:

With my friends there have definitely been some friends who I don’t associate with anymore. Some of them don’t have families so they don’t even understand what it’s like to have a kid let alone have something this
serious happen. Some friends have become closer because they’re family. During these times, the majority of the people who were there for me were my friends because I have four best friends that are like brothers. They were the ones who actually drove me to the hospital when _______ (son) was being flown down. They would bring me clothes, food. So some relationships have definitely grown more because you don’t forget that type of stuff. Drop anything, their jobs, their wives, their kids because you need them. I think it scared a lot of my friends with kids. It hit pretty close to home. So there’s a mutual respect there- stand by your friend’s side while they’re going through a tough time. Be there for them and also being thankful that it’s not you. It is nice to have people to lean on. Sometimes it just takes letting down your guard and being able to open up to talk to somebody. I think it is what saved me.

The second father, Edward, commented:

I had a couple friends who I didn’t think were that close made me realize that they were better friends than I thought. I had really good friends I expected would be there and they weren’t. So I realized my not so good friends were my close friends and some of my close friends weren’t so close.

The father who belongs to a church whose members do not believe in medical care experienced added stress when it came to his friends. These church members had been his friends, his co-workers, and his community. William shared:
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It came to be that you really find out who your friends are. They don’t seem like they do too much with us anymore. We see them but not nearly as much. When we try to get together with them, it has to be on their schedule, the kids’ schedule. Of course, I’m always going to put _______ (daughter) first. So in that regard our friends kind of broke away.

**Relationships at work.** The father involved with his church (noted above) felt a strong need to change his work environment. Most of the men who are part of the church work together in construction. Due to the reaction of his fellow congregants he needed to go out on his own. Some fathers felt that they did not have close relationships at work; others were not comfortable sharing their feelings or details of their child’s condition with people at work. Matthew commented, “I don’t have any work relationships. If I need to take off to take the kids, that’s it.”

Fathers expressed a feeling of gratitude for the way some of their co-workers responded to the stroke. Some bosses simply told the fathers not to worry about work; one father revealed that his co-workers brought something special in for his son.

Paul, who worked in special education, stated:

Everybody from work was calling to see how things were going. Where was the baby, so I just let everybody know that we’re down here at CHOP and will be here till who knows when. I’ll just take off sick, vacation, whatever I need to do. We’ll deal with it. Everyone was so supportive. My supervisor, the superintendent, called and said, “Don’t worry about it,
whatever we need.” All my secretaries were so supportive and things like that. And then when I got back it’s just that educational process. What is it? OMG I didn’t know kids could have strokes.

Anthony, who owns his own company, said:

Relationships at work were kind of awkward at first because not too many people knew what to do or say. When it first happened I was emotionally drained. Stopped worrying about all the little things here at work that would usually get me fired up. It didn’t really matter; nothing mattered any more.

Another two fathers were also gladdened by the response they received from people who worked at the same place. Edward expressed:

Work was a big surprise there. When _______ (my daughter) got sick I always had a boss who said, “family first, family first.” But until you go through that you never put that in perspective either. When she got sick they actually gave me, told me just do what you need to do. And I was off for about 2 months. I didn’t have to take family leave, vacation, nothing. I was receiving full paychecks. That definitely was big.

George, who works at a restaurant, was also pleased by the response from co-workers. He reported:

When I got back to my job I was so shocked. Everybody asked me how he was doing. They put together and got my son a poster. Everybody knows he likes wrestling so that made me even happier. It made him happy. We still have the poster.
Impact on other areas of their life. The father who is a supervisor for special education in his district revealed how his experience with his child’s stroke impacts his work with parents, specifically with his ability to relate and communicate with families Paul stated, “Now when a parent gets upset and starts to yell and scream and says something like you don’t understand…I’m really quick to say, ‘oh, I do understand’.”

Fathers shared how hectic and stressful their lives had become. Simon indicated, “Less sleep. Again, stress. Stress will carry through 24/7.” Nicholas commented, “Constant monitoring of him every night with the video equipment. Cause if he has another seizure you have 5 minutes, and 5 minutes, and then Diastat (emergency medication to stop seizures), dial 911.

One child needs nurses to assist in his care. Matthew discussed the impact of the nurses being present, as well as on the hectic lifestyle. “We had to have a nurse in the house 16 hours a day. No privacy. I’ve got to come home to the madness; I have to straighten up, clean up; take the trash out; talk to the boy; talk to the girl. Give everybody their own time.”

Fathers commented on the exhaustion they felt. James shared, “Sometimes we are really tired; sometimes we’re just exhausted.” Simon, an Orthodox Jew, described his morning routine:

I go pray in the morning at 6:30. Come back at 7:30. He’s still running around. He’s supposed to go to his bus at 8:00. He’s running around screaming, acting out. And sure enough ________’s (my wife) in the kitchen or going down the steps and I’m totally exhausted already.
One participant is in the process of writing his dissertation to complete requirements for his doctorate (in urban planning). Ryan explained:

I’ve done a lot of things that need to be done for me because I think you still have to have yourself and you have do the things that make you happy so you can be there emotionally and in so many different ways with your child regardless of what condition that they may have.

Perhaps for this father, continuing his graduate school program was one way of coping with his daughter’s stroke shortly after her birth. The next section will outline some of the coping strategies and defense mechanisms the fathers identified as being a part of their journey processing life after the stroke.

**Part 3: Coping**

One of the major goals of this study was to learn how these fathers coped with the sudden and devastating diagnosis of pediatric stroke. The hope is that the experience and insight of what these 13 fathers found helpful will be a source of support for other fathers facing distressing news of stroke or another overwhelming diagnosis.

**Initial Coping**

As previously mentioned, most fathers acknowledged that they initially had great difficulty when confronted with the diagnosis of pediatric stroke. Additionally William, the father associated with the church whose beliefs are against any form of medical care, felt responsible for his daughter’s stroke shared:
Not good because of the severity of it. I didn’t know which way was up because of how bad it was. The doctor told me what they came up with. It was do or die at that point. They couldn’t guarantee me that she would live through it. So it was very hard to deal with that, as I had brought it on myself.

After the initial period, fathers described thoughts and actions that helped them begin to cope with the situation. Some described personal thoughts and affirmations that were helpful. Others revealed that it was doing something positive or thoughtful they found to be helpful. Some relied on the support of others to help them move forward step by step.

**Taking One Day at a Time**

After the initial shock wore off and they were assured that their child would live, many fathers expressed the idea that they would just have to take one day at a time. At this point there were still many questions regarding their child’s health status and how it might impact the child and the family’s future. While the shock and constant unanswered questions and concerns lingered, fathers dealt with the situation by taking time in small measures and not looking too much into the future. Simon revealed, “Probably cried for about four days straight. After that you just kind of have to pull yourself together and just deal with it one day at a time.” Jerry, the father of a daughter with neurofibromatosis added, “I think just taking it day by day.”

Taking it day by day is a helpful coping mechanism many fathers live by until they are more confident about their child’s recovery and they have built up
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their confidence that they can be a capable father to their child. Some fathers will continue to live day by day especially if their child is at risk for another stroke.

**Getting More Information**

Many families sought to gain more information on their child’s condition and prognosis. As mentioned earlier, there is very little information for a public audience (not in a research/purely medical context) about pediatric stroke. Even so, it was important for most fathers to get all the information that was available. George shared, “My mother and I started reading up on it.” Peter stated, “All the information I got once the diagnosis was told to us was very helpful. I was trying to become a little more knowledgeable about his current situation, his current status.” Jerry similarly offered that it was important for him to try to learn as much as he could. Additionally, Anthony indicated, “Reading and trying to become more familiar with different ways to help him, help him grow, help him cope himself, and I guess it’s a way for me to cope.

**Realizing They are Not Alone**

When the initial shock wears off and the child is out of life-threatening danger, families are told of the active parent support group that is part of the program. Edward affirmed:

As it became more of a reality, you start doing research and realize that you’re not the only one out there who has been through it. Talking to caseworkers and other people at the hospital you realize that you’re not in it by yourself, which helps along the way.

**Appreciation of the Small Things**

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Fathers shared that they now have a deeper appreciation for the little, everyday things that they previously had taken for granted. James, the father of a child with multiple disabilities was thrilled, when:

At 6 and ¾ he just went potty and we said, “Hurrah, that’s such a wonderful thing. For me I don’t look back and say he should have done that 4 years ago, as much as I’m just so happy that he’s making forward progress. It’s just the little things that mean so much when he does them.

Kenneth commented, “I realize you can’t take life for granted. I spend every moment I can with him. I know there are kids out there who can do more things than he can, but he has fun every day.”

**Changing Priorities**

Before their child’s stroke, some fathers were more involved with their work life and activities with their friends. The intensity of surviving a serious threat to their child’s life changed how many fathers choose to spend their time and energy. Anthony stated that his priority was “Spending time with him and my other boys. Cherishing every hour, every minute, every second of the day we got to spend together and not really focusing on the future.”

**Others Have it Much Worse**

At the hospital rarely a week passes that a parent does not comment on how happy or blessed he or she feels when they look at the difficult conditions other children and families face. Once their child is beginning the recovery phase and family members observe some regaining of lost skills, parents are extremely thankful that their child’s condition is “not that bad.” They will notice how their
child is faring in comparison to the child in the next bed or the next room.

Walking the halls at CHOP, whether in the main hospital, the rehabilitation center, or the outpatient building, they see many children who are clearly extremely disabled due to their medical condition. Even outside the walls of the hospital, Edward, who was staying with his wife at the Ronald McDonald House, shared the following:

We were in the lunchroom/dining area at Ronald McDonald and we’re talking to some lady. I guess she saw we were new there and she started giving us her cabinet and all the food she had in the cabinet. She said,” oh we’re going home” and we said, “Congratulations.” She said, “No you don’t understand. My daughter has 8 weeks to live” or something like that. It was such a sad story. She had an inoperable brain tumor at the base of her brain.

Jerry, whose daughter suffers from neurofibromatosis in addition to a stroke, shared an awareness and broader worldview when looking at his situation in comparison to those living in a war zone. He spoke about watching the violent news on television and expressed that his situation could be much worse.

I was walking the dog this morning with __________ (my wife). It’s a beautiful day. In Syria they’re being bombed. They’re fighting against a ruthless dictator. There’s so much bad out there. I always pray and say to myself that I’ve got it way better than I should have. I just think there’s got to be a higher being and you’re being tested. And you just think, it is bad but compared to all the things out there, it could be a lot worse. You
try to get the positives of all the things ________’s (his daughter) got to do. A lot of other kids will never get to do. I think she enjoys being ________ (his daughter). She’s famous. She enjoys it.

**Network of Support**

Fathers were quick to give credit for the support they received from others. Some of these supports came from people and organizations with which they had a relationship prior to their child’s stroke; other supports were part of the new world and network their family was entering. As Simon expressed:

Something we learned: There’s no point in trying to be proud. Save your pride. You’re put in a situation where you do need help. There’s no shame in reaching out for it. You were put in a situation, you deal with it best but you don’t have to deal with it all alone. It doesn’t have to be just you. You can get help.

**Family and friends.** Every father mentioned that his family was fundamental in coping and adjusting to the impact of their child’s stroke. Two fathers mentioned that during the initial period, they needed to be just with their wife and appreciated the privacy their families and friends gave them. Others were grateful that their families were involved each step of the way. Paul, the father of a daughter who suffered a neonatal stroke, shared his feelings.

My brother came down with me knowing that my wife was going to have to stay. So he followed the ambulance down from the hospital to CHOP. He stayed with me for a couple of days. Then my wife came down. At that point we kind of circled ourselves. It was like okay we’re in this together.
Even though my parents, her parents, my brother, everybody was coming around, I kind of didn’t want to deal with anybody at that point. We have to deal with it; it is our family.

Other fathers expressed sentiments similar George who stated, “Our families have been the biggest supporters through all this.”

Fathers expressed appreciation for on-going support provided by their family and friends. Anthony shared his acknowledgement and gratitude for this kind of support stating:

Amazing how your friends and family pull together and help you. From a coping aspect, I had a lot of great friends there for me. My family and my in-laws were amazing with helping us even if it was watching our other boys while ______ (my wife) and I did therapy with _____(our son) or just giving us a break so ______ (my wife) and I could have a night out and remove some of the stress.

Many fathers commented on the support they received in completing everyday tasks that still needed to be done. Many had a network of family and friends that took over responsibility for other children in the family. This was particularly important as parents wanted to maintain as much of the routine life for the stroke survivor’s siblings as possible. Some brothers and sisters stayed with family and friends while the parents were living at the hospital. Others made sure that the siblings still participated in their various activities.

Fathers noted the emotional support they received. As Anthony described:
There were a lot of people giving their insight and it was almost a catch-22 because it’s hard to accept insight when you’re in this position and listening to someone telling you how you should be reacting or feeling when they have no idea what you’re going through. So there was a lot of anger and who do you think you are telling me how I should be dealing with it. Sometimes the best help was somebody who just wanted to listen and not give me his or her input. Maybe I just need to talk; maybe I just need to cry.

While most of the comments concerning friends and family were positive, there were some negative reactions. One father shared his feeling on when people made comments that were not helpful regarding the stroke. Simon shared, “What was bothersome was when people really said stupid comments for the wanting to say something. I don’t blame people because you want to acknowledge someone’s crisis they’re going through.”

**Specific organizations.** Fathers acknowledged at least one organization or group they found useful. As part of the new identity of a parent of a stroke survivor these groups helped them adjust to their new lives. Ronald McDonald Houses provide a place for families to stay that is close to CHOP. Edward commented, “Ronald McDonald House was a tremendous help. If not for being there, we’d be hours away from her so that would have been a real tough deal.”

Certain organizations are based in specific communities. The Orthodox Jewish father mentioned Chai Lifeline, which provides many programs and resources programs for seriously ill children and their families in the Jewish
community. BIMA, a group in the Orthodox community that focuses on issues related to brain injuries, was also mentioned.

The father of the child with neurofibromatosis mentioned Camp Sunshine, a camp that the child and the family attend for families whose children have that specific condition. Other fathers spoke about early intervention, which provides various therapies for children birth through age 5, and BrainSTEPS, an advocacy program available to school age children in Pennsylvania which helps facilitate communication between school professionals and families to ensure students get the support and accommodations they require.

Most fathers spoke about the hospital staff at CHOP and/or specifically the members of the stroke program. All the fathers who spoke about it appreciated the honesty expressed by the physician and neurosurgeons. Comments included: “We had great help from CHOP. Everybody there was great” (Kenneth). “CHOP’s stroke program has been helpful” (William). “I didn’t want to hear she’s going to be fine, don’t worry about it. I didn’t want it sugar coated. I wanted the facts. I wanted honesty” (Paul); and, “I would certainly rather tell me the worst-case than be surprised by the worst-case scenario” (Edward).

Anthony expressed how beneficial other fathers were to him during his child’s stay in the hospital:

While at CHOP I did find a lot of comfort with other dads. You see fathers walking up and down the halls all day. Go outside get fresh air, a cup of coffee. There would be fathers with worse scenarios, not severe scenarios, but you’re all dads and you’re all there together. Kind of just chit chat.
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We’re talking about real situations and your fears. It kind of felt good to talk.

**Counseling/speaking with others.** Fathers seemed divided on their willingness and level of comfort in sharing their feelings with others. Anthony, who had seen a counselor previously, shared that he returned to the same therapist after his son’s stroke:

I had a counselor who’s been a life-long counselor for learning disabilities or adolescents, even relationship counseling for my wife and I before any of this happened. So he had a lot of history with me and was really a positive influence in helping me.

However, others fathers did not see themselves going to a therapist for help. Matthew, even when not asked about seeing a therapist declared, “I’m not going to go see a therapist. I’m not going to do any of those things. There’s no way. I don’t see myself doing that.” Kenneth indicated, “Maybe I’ll explode at some point but I feel I can handle whatever the situation is.”

Some fathers were willing to share with others, while others were not. Matthew revealed:

I let it out. I talk to people. I take an extra hour coming home to talk to somebody that I know so I can calm myself down. I’m not one who really shows that much emotion so most of it stays bottled up or keep it inside.

For other fathers it was difficult to share. As Ryan said, “It’s tough to talk about it with others.”

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When children are seen in the outpatient clinic it is inevitable that as the child does better, the parents reflect this improvement and feel better themselves. Even when the child is still in the hospital, every sign of improvement in their son or daughter’s condition helps the parent begin to cope with the diagnosis. Fathers are comforted as their son or daughter regains skills. Kenneth stated, “Once we came home I coped with it by working with him and helping him get stronger.” Paul indicated, “Her therapy helps; she’s getting a little bit stronger, but she’s still young. But seeing her progress, I think that’s helped along the way.” Additionally, George said, “Over time he started getting better. It’s treatable. We’ll just try to get him the right treatment. Right now I’m happier than ever because I see him running around.”

Accepting the Situation

At some point it is necessary for the family to accept the situation and adjust to the circumstances and reality they face. In order to move on, many fathers expressed the realization that their former life will not return and things have changed. Therefore, they needed to accept their new reality and treat it as their “new normal” life for themselves and their family. This acceptance may be a significant step in coping with the idea that their child is now identified forever as a stroke survivor. A number of fathers touched on the experience of having to accept the diagnosis and adjust to a new version of their life. James spoke of “understanding that one can’t change what has happened.” Edward affirmed, “One way I always tell myself is that you can’t change the situation. It’s what you do with it. I can’t go back. There’s nothing I can do to change it. The only thing
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we can do is make the best out of the situation we possibly can—which I think we try to do every day.” Jerry shared, “It’s the new normal. So I don’t really remember; I don’t do a lot of what life would have been like.” Ryan said, “I probably focus more on how do we make the new normal work for us. I know what was lost; I have to live with it every day. So camping out there doesn’t really help me or her a lot.” Anthony theorized, “Somewhere along the way, unless you have something severe, we all need to eventually find a new normal. Part of the new normal is disappointments, sadness… you’ll be depressed some days; you’ll be excited others- that’s a part of the new normal.” And Paul shared, “This is what our family is now and this is what we’ll have to do.”

Part 4: The Impact of Religion/Spirituality

One major focus of the research was to investigate the role, if any, that religion/spirituality played in the lives of the fathers who participated in the study. Whenever a tragedy occurs, people often question their belief in a divine power. While two fathers did initially question God, most of the comments of the participants reflect a deeper sense of spirituality/religion or no change from prior beliefs and activities.

A Sense of Struggle

It was difficult for fathers to reconcile, especially initially, their child’s stroke with their spiritual and religious beliefs. They questioned how God could let their son or daughter suffer such a devastating condition. As two fathers said:
Both my wife and myself are Roman Catholic and I struggled with the church from the time I was younger. I went to a Catholic college. So everything was good. We were going to church before we had her. We would go to church with her. It’s not that I question, but I still have an issue about why it happened to her. When you look at this cute little girl who did nothing and this happened to her. Things happen for a reason and God doesn’t give you what you can’t handle. This doesn’t help everybody.

(Paul)

I’m a born and raised Quaker, which is a pretty unique religion.

Throughout my teenage years I was always into spirituality, read some books, some Chinese proverb books and definitely can’t say I’m not antireligious, anti-God. I believe there’s a God. I believe there’s a higher power. Had a real hard time believing that that higher power or God was a good person after ______ (his son’s) incident. I went out with a lot of friends who were telling me just give yourself to God, or do this or do that. Wait a minute, why? You want me to give myself to God when he’s hurting my son? There was a long struggle I had with that. Over time and a little bit of more reading, some of the Bible, some just spirituality books, a lot honestly was Dali Lama, lot of Buddhism stuff I was reading, I came to the conclusion that I don’t hate God and I don’t understand why he let happen what he did and if he has all controlling, but I came to peace more so with it was uncontrollable at there might be a reason behind it and I
might never know it. I never prayed pretty much my entire life. I do pray now. I’m not exactly sure whom I’m praying to but I do pray. (Anthony)

Changes in Spiritual or Religious Beliefs

Not one of the fathers stated that he became less religious/spiritual after his child’s stroke. While two participants questioned how God could let this happen to their son or daughter, none of the fathers reported that they rejected their religious beliefs. Some fathers felt an increase in their level of religious and/or spiritual beliefs. Many fathers felt that the act of praying helped them cope.

Prayer. Many fathers noted that they prayed the same amount or more frequently after their child’s stroke compared to before the stroke. For some, everyday prayers are part of their religious practices. George, who is Muslim, said there was no difference in his routine. This father said, “It’s the same. We get up and pray every day.” Peter said, “With our Christian background, we just prayed.” Matthew shared, “I just keep praying and it keeps getting better and better.” Kenneth revealed, “We say prayers every night.” Jerry shared:

I believe in God. I pray. I’d say I pray a lot more for______ (stroke survivor). Someone gave us a prayer one time which I say every night when I go to bed and about every night with her and _______ (her sibling). I feel like as the years have gone by, more inner prayers and stuff.

Matthew spoke of the nurses that help care for his child at home. According to this father, “You’ve got to have praying people that can get the prayer up to be around you. That’s why we got a good staff of nurses now that know the Lord.”
\textbf{More religious.} Some fathers reported they feel more religious after their child’s stroke than before. Nicholas revealed he thinks about God more frequently. He stated, “I don’t do anything differently but I’d say probably think about it more. Think about God on a daily basis now instead of occasionally.” Another father, Edward, said, “I would say, more religious than I was.”

As for the father whose religion does not believe in medical care, he and his family still belong to the same church, but their involvement with that church has changed. This father feels that his child’s stroke could have been prevented if they had sought medical care more promptly. The family went against church doctrine and now makes sure that the stroke survivor and their two other children receive medical care. The stroke survivor also receives various therapies each week.

I would consider ourselves more religious as we never sought medical attention for anything at any time. Has it changed? Yes, definitely. Now we still have a religion but we crossed that fine line. Yes, we do. But we don’t go as often as we used to. We used to go three times a week. Now we’re down to one. Because other than church we go for “the man upstairs” not for any of the friends anymore because we don’t seem to do much with them anymore. (William)

\textbf{Finding the positive.} The following examples of responses from a few fathers typify the responses of the participants. Anthony shared, “I think having an understanding of religion puts you in a position to have a greater appreciation for spirituality. I’m more spiritual now than a religious person.” James said, “I’m
not terribly religious. I believe that there’s a good chance that there’s a God, but at the same time I don’t want to be a sucker and be sold that bill of goods on pagan beliefs. It does help to believe in something emotionally to get through the tough times.”

**Part 5: Moving Forward**

Families need to make adjustments to their lives when the medical crisis has resolved, although there is no guarantee that another medical crisis will not occur. At the end of the first medical crisis and any subsequent crisis, the child may no longer be able to continue on the path that he or she was expected to take. There have often been changes in the family unit. As noted previously, many fathers felt that their relationships became deeper and their priorities had changed. Fathers were also queried for advice they would give to other fathers facing a similar situation, those in the medical community, and the general community at large.

**Expectations**

Fathers were asked if their expectations for their child changed after the stroke. Most participants were hopeful that the stroke would not affect their son or daughter in the future. Edward saw an amazing spirit in his young daughter that increased his expectations. He said, “I would say if anything it probably raised the bar because you see what she went through. Kind of showed her courage so I probably expect more than I would have.” George shared:
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It’s the same thing. I still want my son to make it. I want him to go to college. He loves playing basketball. We go to the Y. I just want him to be the ________ (child) that he was which was straight A’s, honor roll student, a loving son, my little man.

Some fathers took a more “wait and see” approach. Ryan stated, “As far as expectations go, at this point we have not lessened them. She’ll have her own expectations and if she can’t make those expectations we’ll deal with it.” James said, “I guess I’ll take what he gives me.” Anthony commented:

Having three boys, I was a big athlete, a big extreme athlete, an adventure sports guy. I wanted to raise my kids, not forcing them to do anything. Like, if they don’t want to play sports, don’t play sports. If you want to play sports, I’ll sign you up and coach you for everything. I did plan on traveling and doing surfing all over the world with them. So my expectations have changed. We don’t still have a clear understanding of what he can and cannot do. I look at him in the backyard and I feel he can do anything but I don’t want to put him in harm’s way signing him up to play soccer or do karate or any of these things his brothers might do. But at the same time, I don’t want to put him in a bubble and try to protect him from the world and still have it not work out. So, our expectations we take one scenario at a time and we don’t really set long-term goals.

The fathers of children who were left with significant deficits revealed that their expectations did change after the stroke. For the father of the young teen suffering from neurofibromatosis, his expectations have been altered as well.
Jerry revealed, “Every time you think it can’t get worse, it does. My expectations have gotten less. Each time, it’s just gotten less.”

**Concerns**

Many fathers expressed clear concerns; some were visibly shaken when asked about this and formulating an answer. Some of the concerns centered on the fear that their child could have another stroke. Although additional strokes and/or seizures are unlikely, parents are still on high alert for any change in their child that might have medical implications. For many of the fathers the fear is relentless. As Edward expressed:

> Your concerns change. When she gets a basic sickness and we’re rushing her to the hospital and you have to wait. You don’t understand- she’s going to have another stroke. This has to be done this second. We call on the way. Lay her flat; put her on oxygen.

Kenneth shared, “I’m always going to have concerns, every day, 24/7,” and Nicholas said, “I always have concerns about what happened and could it happen again.”

One father was concerned that his daughter would not be successful in finding someone to share a meaningful relationship with when she grows older. He verbalized that when he was dating he could not see himself having an emotional relationship with a woman who had a disability. Other fathers also expressed concerns about what their child’s life would be like in the future. William stated, “I guess my concern for her is that she is going to have a full life because she’s definitely behind kids her own age.” Anthony shared, “I’ve got tons
of concerns for ______ (my son). That’s a scary one to get into. Sometimes it’s better not to focus on them because that brings out negative feelings so, I guess the overall major concern is will he be able to be normal?”

Challenges

Fathers identified a variety of challenges. For some the challenges were emotional. Paul revealed, “I never got an answer (to why my child had a stroke). The father’s supposed to take care of the family. And having to just be helpless, beyond the fact of not knowing why, the helplessness for me is probably the bigger piece to handle.” Additionally, Kenneth identified, “My greatest challenges have been staying strong, staying a believer.” William expressed his concern saying:

I feel that she’s not going to get a nice childhood or a good childhood or something to look back on. I want her to forget what happened. Not that she knows. She knows she goes for therapy every day. Eventually she’s going to ask me why. Why do I go and not _____ (her sister)?

For other fathers getting the help the child needs is a huge challenge. Many children need ongoing therapy. Stroke survivors often have very specific therapeutic needs that cannot be met by all occupational, physical, speech, and psychological therapists. In addition time needs to be set aside to take the child to their therapies and also do the exercises at home. There are financial costs in transportation, time missed from work, and, at times, co-pays. Some comments on these challenges the fathers shared. Kenneth saw the challenge as, “Getting him to appointments, making sure he has his medications. Make sure he’s safe.” James
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said, “Helping him get the help, the therapy he needed.” Matthew’s challenges were expressed in terms of the nurses. He stated, “The biggest challenge is the nurses. I want you to love my son like he’s yours when you’re here. Some of them just come for the check. It’s not right. I want you to come and do your job.” Ryan felt that he needed, “A level of financial wealth in order to do more things.”

Areas of Reward/Personal or Family Growth

In addition to feeling closer to some members of their family and some friends, feeling better about their restructured sense of priorities, and, for some, a deeper sense of religion and spirituality, many fathers identified specific areas of personal or family growth. One father, whose daughter also suffered from neurofibromatosis, started his own organization.

Closer as a family. Many of the identified areas of growth or reward focused on the family. William noted, “I would say because we give her so much attention and we go beyond to make sure. We overcompensate for her disability. I would say it brought us closer together.” Similarly Nicholas stated, “I’ve seen my family being closer, more caring about each other on a daily basis.” Ryan identified a close relationship with his mother, noting, “The time and attention that my mother probably gives to my children as a grandmother. I’m wondering that would be the case if she weren’t diagnosed.”

Reaching out to others. The father who is a sports coach at a university began a foundation to raise money and awareness. This group brings together players and athletes who learn his daughter’s story during their time at sports camp. Jerry stated:
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I think how many people ________ (my daughter) has touched. I think our players and high school players at this camp. I know when I was 16 or 17 I never would have thought about somebody else as far as that. And when ________ (my daughter) gets up she talks to 2100 campers. (Because of her) kids will send us additional money or do a fundraiser or do all these little things.

Advice from the Participants

As part of the interview, fathers were asked to give their advice to those in the professional (medical) community, for fathers facing similar situations, and to the community at large. The researcher felt this was an important component of the study as no literature could be found in her search for information from those living with the situation.

Professional community. Fathers were asked for special advice to those who interact with the child and the family in a medical setting. It was explained that the professional community includes the physicians, nurses, therapists, social workers, environmental workers, security, chaplains- anyone who works in a hospital setting. In addition to the desire for honesty and compassion mentioned in the coping section, many of the recommendations revolved around the relationships of the family and the professional.

Several fathers mentioned the importance of a caring relationship. This was a critical factor for many of the fathers. They needed professionals not only to excel at what they did professionally (e.g., knowledgeable and skilled neurosurgeon) but also to be caring and compassionate toward their child and
their family. Peter advised, “Just be there for families when they really need you. Be there in a caring way. When you have doctors or social workers you feel care, I think it helps you with the adversity.” Jerry warned, “Be careful of statistics. We’re not a statistic; she’s a person. When she got the spinal tumor it sounded like a death sentence. And it’s been 4 years.” Kenneth replied to me:

You’re a perfect example. You’ve taken every opportunity to reach out to me and have been caring and nice but not overly where it takes me back. I’m shy when it comes to talking about things so I think a really good piece of advice for anybody that would work with these types of patient is be understanding, kind and friendly but not pushy. Towards fathers just from my experiences, we’re scared. Men when they’re scared shut down. At least the men I know. But you want somebody to talk to; you want somebody who can lead you in the right direction. Might not have the answer but lead you in the right direction or be able to provide you information or provide with other fathers or lead you to the right place.

Other fathers similarly stated the importance of getting information and an opportunity to learn about their child’s condition, access to resources and connecting with other fathers. Edward offered, “Provide as much information; the opportunity for peer learning is useful.” and Simon similarly suggested, “Providing the information, knowledge, space, and time to come together.”

**Advice to fathers facing a similar situation.** Almost all of the fathers spoke about the importance of being there for their families. All of these participants expressed the sentiment that they have an important role and duty as
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fathers. They emphasized the importance of helping the stroke survivor recover and doing their best to fulfill their crucial, stable, and vital role in maintaining the family structure. Kenneth stated, “Don’t give up, stick with your kid, stick with your family, and there’s so much to gain and don’t be selfish and run away from it.” Jerry shared:

You’ve got to endure for the sake of your child, for the family. You got to hang in there. Endure and not give up on your marriage in the midst of taking care of your child, because I think that happens easily where the child sucks everything out of the marriage. You can’t let that happen.

Matthew commented, “It’s what I like to think of as the survival mentality. Your family needs you. Your children and your spouse and you really don’t have a choice.” Matthew, who has deep religious convictions, continued, “Find the Lord. Have a spiritual relationship with the Lord and have him be a foundation in your structure and don’t forget him and he’s going to always be there for you. And have some praying people around you.”

Fathers mentioned that gaining more information helped them in coping with the diagnosis. Many fathers also recommended that fathers facing similar situations needed to gain an understanding of what happened and what they needed to do to best support and help their child. Ryan advised:

Once you give a couple days however the case may be, things to sink in that your child had a stroke, then I think you’ve got to get them educated. The father needs to know everything. Most fathers believe that I’m the father; I’m supposed help the family; I’m supposed to fix everything. And
I think the more education you get, the more you understand that you can’t fix it, but you can help by doing this, this, and this. That helped me knowing I can set up the therapies. I’m going to make sure this is set up. We’re going to have to get certain things done in the house. I’m going to be the one if we have to do tube feeding. I think it helped me become a little more involved.

Acceptance and reaching out to allow others to help were mentioned both as coping strategies and as recommendations to other fathers. Anthony put it this way:

Put down your wall; accept that something’s happening; that there’s nobody to blame; it’s not worth blaming; it’s not worth being angry over. If you want to show how tough you are and how strong you are, focus on what you have in front of you. Become somehow better at whatever it is that you do and find strength within your love ones and your care group. Communicate with those people because if you don’t communicate you’re definitely can eat yourself from the inside out. Without communication I found myself become an insomniac, drinking too much, heartbroken because I wanted to talk to somebody but didn’t know how. I wanted somebody there for me but I wouldn’t ask for it. Once I could let down that guard things got easier, brought me to a better place. There’s still pains, still scared, still fearful, still get frustrated, still cry but I’m a better person when I’m doing and better when I’m talking to somebody and better when I’m letting my fears out.
The parents who met a mother staying at the Ronald McDonald House whose child was dying were struck when the woman gave them her food. Their experience and interaction with her also helped them with acceptance and gaining some insight into moving forward. Edward revealed:

_________ (my wife) and I couldn’t understand how this lady could talk about this and just not be in tears. I guess she had been going through it for so long that it was just part of her life. Then finally toward the end of us dealing with _______ (my daughter) it made us realize the transition this lady went through at that moment of your life you’re no longer crying 24 hours a day. This is your life. Accept or die is what it comes down to. She actually grasped what was happening instead of just letting her life come to an end. That was a big changing point in my life once I realized how she got to that point in her life.

The two quotes listed below on advice to the general community highlight the feelings of the fathers in the study. Simon shared, “I wish everybody were a little bit more compassionate. I wish everybody were a little bit more caring because life can change like so quickly. Children are precious and times that we spend with them; you can’t go back in time.” And James stated, “My advice is don’t take life for granted.”

**Summary**

Each of the fathers traveled his own path when his child had a stroke and continues on the road of moving forward as the stroke survivor grows and moves toward adulthood. This is a journey for the whole family: the stroke survivor, the
father, his partner/wife, and other children in the family. Although each journey is unique, there were many overlapping themes and shared experiences revealed in the fathers’ stories throughout the interviews. Many of the fathers expressed similar reactions to the devastating diagnosis and the impact of that diagnosis on their lives and the lives of those close to them. There were also some noted differences reported by the participants particularly with regard to concerns and expectations as well as difficulty in handling the projected future. Some of these differences might be explained by the realities. For example, one child has a brain abnormality for which nothing can be done. The father is aware that the child will continue to deteriorate and will have additional strokes and stroke-like events. Other children have additional medical issues that will affect their lives.

All the fathers were able to identify strategies they found effective in helping them cope. Participants were able to find reward and joy even though their lives may be changed forever along with the dreams they had for their child. Lastly, having gone through this experience firsthand, knowing the challenges and concerns they have gone through, the fathers were able to offer advice to professionals, the community, and most importantly other fathers facing a similar situation.

The next and final chapter will discuss these findings in conjunction with previous research literature and the theoretical framework of Folkman and Lazarus. The fathers’ responses to the traumatic event, the shifting priorities after such an event, the importance of their old and new support networks, and the positive ways in which they found meaning in their new and unexpected lives will
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be discussed. Unlike the common perception of males not wanting to talk about
difficulties in their lives, these fathers were able to use their voices and in doing
so will help others do the same. It is recognized that the participants were perhaps
a unique group of men. Clinical implications, additional limitations, as well as
ideas for future research, will also be presented.
Chapter VIII
Discussion, Implications, and Conclusions

Introduction

The described study here explored how fathers described the impact of their child’s stroke on their lives, both initially and as time passed. While the experiences of each father varied to a certain extent, many articulated similar feelings toward their experiences of becoming a father of a pediatric stroke survivor. Shapiro (2008) noted that while similar experiences can generate very different outcomes, different experiences might generate similar results. In this chapter significant findings from this study will be compared with previous relevant research and then discussed in terms of fathers of children with special needs. The Stress, Appraisal, and Coping theory of Folkman and Lazarus will be reviewed as it pertains to the appropriateness for this population. The concepts of chronic sorrow, ambiguous loss, and posttraumatic growth were shown to be important in understanding both the anguish and then the acceptance in coming to terms with the impact of the child’s stroke and will be highlighted in this section. Lastly, clinical implications for social workers, limitations of the study, and ideas for future research will be explored.

Significant Findings

Stress, depression, and a sense of loss. Most fathers experienced two phases of loss. The first included the initial reaction to the diagnosis and the roller coaster of highs and lows concerning potential recovery and hope that their child would not suffer another stroke. During the second phase fathers began to use
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coping strategies to help them come to terms with the situation they cannot change. This finding corresponds to the work of Copley and Bodensteiner (1987) that describes a two-step process of coping. For many of the fathers the sorrow will endure, although the depth of that sorrow will lessen. Over time these fathers have or will realize that many things associated with the stroke survivor and the family has been altered, at least to some degree.

In the beginning, the fathers experienced many emotions including stress, depression, sadness, and worry. For many of the fathers there were feelings of stress and depression in reaction to their child’s suffering a stroke. Fathers used the words “stress and depression.” However, it was not determined that any participant would identify these feelings as clinical depression, as defined by professionals. Much of the stress could be viewed as a result of multiple levels of uncertainty. In a considerable percentage of pediatric stroke survivors no direct cause can be found for the stroke. Not knowing caused considerable anguish for the fathers. Many of the fathers were also left with the questions of why this happened to their child from an existentialist viewpoint. While no research could be found on the impact of not knowing why something happened to a son or daughter, there was a study that looked at family members whose older loved ones suffered a decline. Looking at bereaved spouses and family members, Chan, Ng, Ho, and Chow (2006) found an increase in morbidity and mortality due to the frustration of not knowing why something happened to their loved one.

In the current study some of the fathers expressed feelings of sadness and regret knowing that they would not be able to have the joy of teaching their
children specific skills and/or sharing with them certain experiences that fathers of children without special needs get to do. Fathers also reported feeling depressed (again, perhaps not clinically) not only over what had happened and the concerns for the future, but simply trying to keep up with the present. Some fathers experienced pressure to work outside the home in order to earn money and keep insurance for their child, while still meeting the emotional and physical needs of all the children and their wife/partner. In looking at previous research, Dowling (2007) found many parents attributed their depressive emotions to work overload which left scarce time to take care of themselves.

The fathers in the study expressed feelings of frustration and sadness that their child’s stroke prevented the family from engaging in activities because the stroke survivor was unable to participate in the experience. The impact was particularly traumatic for the fathers as they were concerned with the siblings who were likewise forced to have limited opportunities. Fathers were concerned that siblings could not have equal access to parental time and resources as so much time, energy, and available finances were needed to assist the stroke survivor.

Many of the fathers were also extremely concerned about the future of their child. For some, the dreams they previously had would need to be revised. Fathers were apprehensive that their child would not be able to live independently, find a loving partner, and/or to be gainfully employed. These uncertainties were a source of ongoing stress for the fathers.

The negativity of having a son or daughter diagnosed with a stroke did have some positive implications. Many fathers increased the amount and quality
of time they spent with their family. Fathers were able to verbalize that their children and wives/partners were now their undoubted priority. The child’s stroke forced them to review what was truly important in their lives. The fathers described a closer bond with their wife/partner and immediate family members. They looked upon their son or daughter who survived a stroke with admiration for all the achievements he or she was able to achieve through the hard work completed as part of the therapeutic activities.

**Friendship.** While all fathers felt that their families were the fundamental component of their support system, very few mentioned friends as a part of their support system. One father was close to a group of friends whom he stated he could count on with all types of support; another father stated that he found out who is true friends really were in that some people whom he previously thought were close friends, were not and some friends that were previously not particularly close, became true friends.

In all the families except for one where the father stayed at home, the mother was the parent more responsible for the day-to-day care of the child. This allowed for the fathers to “escape” the daily primary care of their children. However, this also enabled for fathers to spend time escaping into negative activities such as workaholism (Simon and Anthony) and alcoholism (Anthony). The initial reactions of the fathers to the diagnosis were similar to those reported in the initial grief process. Although no previous research could be found which looked at fathers’ reactions to the loss of the child they were expecting to parent Cameron, Snowdon, and Orr (1992) found that mothers experienced a sense of
Hearing His Story

loss of the “normal” child that was similar to experiencing the death of a child. In addition, these researchers reported that some mothers felt that they needed to distance themselves from their child in order to grieve for the loss of the child they were expecting to parent. For many mothers this was difficult, as they needed to care for the day-to-day needs of their children.

**Spirituality.** While two fathers questioned why God had allowed their child to have a stroke, many looked to their faith to help them cope. For families involved with communities of faith, the members of their religious community provided many of the tangible supports such as delivering meals and taking care of household responsibilities when the family was in the hospital with their child. Many in the religious communities sent prayers and wishes for the child and the family. Some leaders of their congregations made visits to the hospital to see the child and the family.

Some fathers in the study had a deep and unquestioning faith in God. For them, God was in control and had a reason for what happened to their son or daughter although the fathers, at this time, could not understand what that reason might be. A few fathers also felt that everything would be all right because God would see to it that they and their family would be fine. For others, there was a period where they needed to work out in their own minds and hearts the question of how, if God is all-powerful, could He/She allow this to happen to an innocent child.

**Coping.** Fathers in the current study did report a change in their feelings and ability to cope as time went on. Initially most fathers could not even think of
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dealing with the future, as they needed to be focused only on the here and now—whether their child would live or die. For these fathers in the study there was a progression from shock and disbelief, towards sorrow and uncertainty, and then a gradual acceptance/adaptation of the “new normal.” As time went on most fathers were able to look at the present needs of their child and their family. Out of this journey to acceptance and as part of the “new normal” life for the father and the family came a sense of strength which rose from the suffering. Mothers, fathers, and children all needed to make meaning from what has happened to them in order to move on in their journey. The rules of the assumptive world that once made sense, no longer hold true. For many fathers the rules have been changed without new rules being announced. It was crucial for some of the fathers to derive meaning from the loss and suffering. Fathers also reported developing a greater sense of compassion, charity and sympathy for others with some fathers quietly disclosing to the researcher that they would like to reach out to others who are now parenting a pediatric stroke survivor.

Many of the coping strategies used by the fathers, including religious/spiritual beliefs, support networks, therapy, making meaning, finding gratitude, and active participation in their child’s life, will be discussed in more detail in the implications for clinical social workers section.

**Theoretical Framework**

The theoretical framework *Stress, Appraisal, and Coping* developed by Folkman and Lazarus was employed in this study. For almost all the fathers in the study, their initial reactions to their child’s stroke diagnosis did not allow for the
time or the ability to consider whether or not they had the personal resources to deal with situation. They were only concerned whether the child would live through the immediate life-threatening crisis and what that might mean for the child and his family. An interesting note was the father who was involved in the special education process. As soon as the physicians assured him that his daughter would live, he was quick to realize that he had the personal resources to know what needed to be done to insure his daughter had appropriate therapies and had the personal connections to do so.

Other evidence of the fathers’ reactions was also noted in connection with this theoretical framework. Most families experienced threat in terms of concern for their child suffering another stroke. However, the fear of future harm/loss can, at times, allow for anticipatory coping (Lazarus & Folkman, 1984). Anticipatory coping was evident in a number of responses from the fathers. Some of them used their belief in spirituality and/or religion. Others used their understanding that given the situation they could only deal with the future one day at a time, needed to rely on support from friends and family, gather information, and so on. These coping strategies were evident as fathers reappraised the situation. All fathers expressed that they were committed to the pediatric stroke survivor, their other children, and their wife/partner. It has been noted that commitments and beliefs are two of the most powerful factors in an individual’s cognitive appraisals (Lazarus and Folkman, 1984). The third type of stress appraisal is challenge that also calls for the use of coping strategies. All of the fathers were able to identify ways in which they met the challenge of dealing with this situation, which led to
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personal and family growth including a changing of priorities, various forms of appreciation, strengthening of family bonds, and creating foundations to help their child and others.

The theoretical framework chosen for this study was useful in understanding how fathers dealt with their ability to handle the stress and impact of their child’s stroke. Instances of reflection and reappraisal of the situation and using the negative event to turn aspects of it into positive actions were particularly poignant. While the theoretical framework of *Stress, Appraisal, and Coping* (Lazarus and Folkman, 1984) was extremely beneficial for this study, incorporating trauma theories may also be important in the future to gain a better understanding of what it might mean to fathers facing a similar event. Theories of ambiguous loss, chronic sorrow, and posttraumatic growth figured heavily in interpreting the experiences of the participating fathers.

**Ambiguous Loss, Chronic Sorrow, and Posttraumatic Growth**

Stress, according to the family stress perspective, is caused by change or the threat of change in the family functioning or structure. When there is a difference in the function of one member of the family, a ripple effect may be created that challenges the past integrity of the family unit. This may be especially true when something devastating happens to a child who was previously healthy. Changes within the family may continue well into the future as the impact of a stroke may linger and affect the child and his or her family for “the real and potential losses associated with chronic illness can be viewed as a continuum covering an indefinite period of time” (Moulton, 1984, p. 76). According to the
fathers who participated in the study, there are and will be many losses as well as some positive gains as a result of the child’s stroke on them and those in their family.

Ambiguous loss theory may be useful in understanding how the fathers responded to learning that their son or daughter might have a lifelong and pervasive disability (O’Brien, 2007). While the stroke survivor was physically alive and fathers were so very thankful, the dads also realized that, in most cases, the child might no longer function as they had previously. Boss (1999) wrote that “when the ambiguous loss is caused by a chronic illness or disability, even strong families may need help in managing the stress” (p. 21) and that the sense of loss could both traumatize and be traumatic. During this time there are no established rituals to help comfort those faced with the trauma and ambiguity (Boss, 1999; Boss, 2010).

While caregiving usually looks at the individual taking care of his or her partner or parent, the parents of stroke survivors must also do many caregiving activities for their child, especially in the beginning of recuperation. An adult child taking care of an aging parent is not unusual; a parent taking care of their son or daughter over a certain age is something both our mothers and fathers need to face. I have found that some parents find comfort in being able to care for their older child, teen, or young adult. They feel that they are helping their child to gain back skills that were lost and thereby contributing to the child’s recovery. As they see their child progress, they gain a sense of pride in the devotion they have provided. There is even a sense of hope and optimism as the child regains skills.
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However, since most pediatric stroke survivors are left with some level of cognitive, physical, or behavioral impairment, the concept of chronic sorrow may describe some of the experiences fathers have faced or will be facing in the future. The theory of chronic sorrow is beneficial in understanding that it is important not to pathologize the fathers’ reaction to the new life they might now have to live as a result of their child’s stroke. Fathers may have to face daily a sense of sadness, as the child who is before them is not the one they dreamed of parenting. The son or daughter may no longer be able to compete with and/or reach the achievements of the sons and daughters of their friends and family members. Participating fathers felt a sense of sadness at the loss of things they had wanted to do with their children and concerns for what the future would eventually be like for their child who did not make a full recovery. According to Teel, chronic sorrow is a “recurring sadness, interwoven with periods of neutrality, satisfaction and happiness; a parental reaction to chronic illness which suggests functional adaptation to, but not acceptance of, the child’s condition” (Lowes & Lyne, 2000, p. 43).

Some fathers exhibited concrete examples of posttraumatic growth. One father established an organization; some are more involved in the lives of the stroke survivor; other fathers are becoming more involved in the pediatric stroke community. Reaching out to others and showing compassion for those in similar circumstances may also be beneficial for the father as “there is now evidence that developing compassion for others is conducive to well-being” (Fredrickson et al., 2008; Lutz et al., 2008).
Hearing His Story

The Strengths of Fathers

There is much to learn from these fathers of pediatric stroke survivors who have shared their stories so valiantly. Clinicians must realize that some men do want to talk to express their emotions, fears, and joys. Two fathers spoke to this exact point.

The more I talk about it…it’s more cathartic. It always helps me to feel a little bit better to talk through what I went through. (Simon)

I wanted to talk. It’s therapeutic. Thank you for letting me do this interview. This is the first time I’m doing anything like this. (Kenneth)

In addition, the fathers in this study were able to identify various coping strategies that they employed. These strategies may not only be useful for fathers of pediatric stroke survivors but should be considered for fathers of children with other disabilities and/or special health care needs. In reality, these strategies may be beneficial for all fathers wishing to establish closer relationships and a healthier and more fulfilling outlook toward fatherhood.

Role of fathers. According to previous research, men in this country have been taught not to show emotions, especially feelings of sadness and depression. This programming begins at a very young age. If men must grieve they learn to grieve quickly, privately, and without long or deep expression of emotions (Cochran & Rabinowitz, 2003; Meth & Pasick, 1990). As men are socialized in this manner they may not realize that they are depressed. This depression may be expressed through on-going anger and self-destructive behaviors (Kilmartin, 2005). Psychologists are now starting to realize that these unresolved feelings of
Hearing His Story

sadness and depression may lead to serious consequences such as the high male suicide rates (Cochran & Rabinowitz, 2003) as well as many of the problems we consider typical for males, such as physical illness, substance abuse, domestic violence, problems with intimacy, and sabotaging one’s career (Real, 1997). It is therefore imperative to appreciate the seriousness and extensive consequences of male sadness and depression and take actions to combat these negative results.

While not resolved by any means, in recent times there have been some changes for men in regard to the male stereotypes of previous generations. Fathers of typically developing children are expected to be more involved, when compared to fathers in the past, in the lives of their children (Cornille, Barlow, & Cleveland, 2006) and men wanted to become part of the daily experiences of their children and part of the making of decisions that might affect the lives of their children (Carpenter & Towers, 2008). Fathers interviewed for this study also felt that it was important for them to be engaged with their children because their involvement was crucial to their sons and daughters (McNeill, 2007). May (1992) noted that the father’s involvement is likely to create positive results for all members of the family.

There has also been a shift for some fathers of children with special health care needs and/or disabilities. Some fathers of children born with a disability discover aspects of their personality that were not previously brought to light (Carpenter & Towers, 2008). McNeill (2007) found that fathers of children with a chronic health condition often rose above the traditional stereotype and became more involved with parenting their child. This is crucial as the amount of time and
Hearing His Story

dedication needed to support these children may be immense. The day-to-day
tasks of caring for children with special needs have traditionally rested heavily on
the shoulders of the mother. Fathers in this study voiced a desire to share
parenting responsibilities with their wife/partner. They reported being involved
with their child’s therapies and administration of medications, and enjoyed
spending time with their son or daughter.

Implications for Social Workers

While most studies focus on the negative impact of parenting a child with
special health care needs and/or disabilities (Hastings, Allen, McDermott, and
Still, 2002) there is a growing body of research espousing positive effects of being
a family with a special needs child (Seligman & Csikszentmihalyi, 2000). In a
qualitative study by King, Zwaigenbuam, Bates, Baxter, and Rosenbaum (2011)
parents not only expressed benefits that they perceived as the parent but also
identified family and societal benefits as well. These researchers suggest that
practitioners share with new families that, in addition to challenges, there are
positive aspects to raising a child with a disability. Social workers can provide an
important bridge with assisting those coping from a sense of despair to one of
celebration. While many fathers express beliefs in integral family and personal
values and may now be more willing than in previous times to seek help with
dealing with negative emotions, there remains a shortage of mental health
providers. Also problematic is the fact that most insurance companies do not
cover the cost of such services. There is still reluctance from some men, including
many in the study, to seek traditional therapy as a way of dealing with unresolved
feelings surrounding their child suffering a stroke, in addition to general life circumstances. While individual and/or group therapy may be seen as the most beneficial way to assist these fathers, all options must be explored.

**Therapy.** When men do seek therapy it is vital that those in the professional community understand what angst the client may have felt in simply admitting his need and willingness to begin therapy. Clinicians need to be aware that the behaviors of men who are dealing with sadness and depression often look different than they do in women. Men may also respond to treatment suggestions differently than women and therefore therapeutic recommendations may need to be tailored to meet male ways of coping. For example, even though emotion-focused coping and problem-focused coping are both valuable, problem-focused therapy may be more useful for men. In the present research study, some fathers noted that they coped by helping their child with the child’s therapy, arranging for doctors’ appointments, and being more involved in their child’s life and the lives of all their family members.

**Religion/Spirituality.** The use of religion and/or spirituality may provide comfort for individuals facing a crisis and should be explored with individual clients to determine whether the clients are interested in the use of religion and/or spirituality as a possible resource.

Many people living in the United States, including one father in the study, are also looking toward traditional Eastern religions, whether or not that religion is the religion of their youth. Some concepts and practices found in these religions may be of use to fathers, and families, of children with special needs and/or
disabilities. Mindfulness is now a popular technique especially for those wishing to become more focused and reduce the level of stress found in the lives of typical Americans. Based on traditional Buddhist beliefs, the purpose of mindfulness training is to alleviate human suffering (Turner, 2009). At a conference of religious leaders, Rabbi Kushner was speaking with a Hindu representative. The representative told him “his religion taught him to deal with pain and suffering not by denying it or ignoring it but by rising above it” (Kushner, 1986, 87). For some fathers facing parenting a child with special needs, religion and spirituality may provide support and a sense of community that is needed to counteract feelings of isolation, which is so often felt by families of children with special needs or disabilities.

Support systems. All the fathers in the current study stated that their families and, for some, their friends, provided invaluable support in helping them deal with the diagnosis and the resulting aftermath. Many fathers accessed new support systems that focus on children with special medical issues. Appropriate support systems and networks may be crucial in aiding a father going through their child’s critical diagnosis. Even after the life-threatening crisis had subsided, support systems have been shown to be a valuable resource.

Men should be encouraged to set up or join existing support groups, although for some men it will still be difficult to speak to others about their emotions. One participant father expressed his idea for such a group of parents who are all experiencing the challenges of raising a child with special needs.
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A few years ago at one of our Pediatric Stroke Conferences, which is organized every other year and held on a Sunday in November, a specific breakout session for fathers was held. Due to the emotional involvement of the fathers, this group needed to extend the time allotted. This speaks to the fact that given the correct environment, fathers want and need to speak to others facing similar situations in order to gain and give support. It should also be noted that these fathers were willing, even eager, to speak to me and participate in this study. Fathers want to learn from other dads and help other fathers who are traveling down the same path. Perhaps special support groups for fathers of medically compromised children ought to be considered as a vehicle for fathers coping with parenting such children.

Making meaning. The trauma has associated with their child’s stroke may have undercut what they previously held as true. Fathers now need to try to make sense of what happened to their child in order to come to peace with the world.

Some fathers were able to make meaning by telling their narrative of the ordeal and thereby helping others facing similar situations. A few fathers expressed gratitude for allowing them to be part of this study and share their story. Others experienced posttraumatic growth. Some fathers still struggled to find meaning in what happened and preferred to put the dilemma aside for the time being and concentrate on supporting their children and family. Care should be taken by others not to impose their value system on the father but rather simply listen and hear how he is trying to make meaning out of the situation. Statements
such as “God only gives you what you can handle” or “God has a plan” do not help most fathers cope with the loss of the child they had or were planning to raise.

**Finding gratitude.** Some fathers were grateful for the deep bonds they felt with their families and the experience of joint parenting with a wife or partner. Still others enjoyed a new sense of what was really important in their lives. In addition to the strengthening of the family unit, many fathers expressed a deep sense of gratitude towards their wives. Interestingly these responses were not a result of any question; these were simply a statement of the gratitude they felt for their partners in helping to take care of the child.

**Conclusion**

By far the hardest thing I ever had to do; the scariest thing I ever had to do. Without great friends and family and the resources that we have, it would be a lot tougher. I’m a happier person; I’m a stronger person; I’m thankful for my friends and my family. I try to enjoy every moment I get with them. (Anthony)

There has been very limited research that specifically focuses on reactions and coping of fathers of children with special health care needs and/or disabilities. The majority of literature looking at families of children with special needs emphasizes negative emotions and undesirable life factors in trying to parent the children while at the same time taking care of themselves and others in the family unit. Burden and Thomas (1986) wrote that raising a child with special needs should be seen as a series of transitions with each transition creating new
individual and family needs. When these needs are met, life is more positive for everyone.

Many researchers and theorists in the field suggest that while parents may never completely come to terms with having a child with special needs, they are able to adjust and adapt to the situation (Olshansky, 1962) over time. Although both mothers and fathers may have feelings of ambiguity, sorrow, sadness, and depression they also experience love, hope, and joy in raising a son or daughter with health care needs and/or disabilities. As one father stated, he coped with the diagnosis of pediatric stroke by just basically never losing hope.

According to Kearney and Griffin (2001) many parents found that the challenges of raising their son or daughter were strengthening and enabled them to construct meaning and fresh perspectives on life. By altering their ideas of having a child with special needs, parents may find new coping strategies and a heighten feeling of well-being and happiness. Taylor (2012) advised, happiness is so often related to whether we feel a loving sense of connection with other people and our environment. If we can find ways to develop this profound quality, then we become reconnecte with our ability to love and find that we are loved in return. As we search for a lasting happiness, we discover a wisdom that is compassionate and a compassion that is wise. (p. 2)

All the fathers in the study were able to obtain a sense of happiness, fulfillment, and appreciation for the life they now identified as the “new normal.” By and
large the fathers developed an altered view of their previous vision for happiness. Many of them would now relate to the following quote:

Happiness is a butterfly- the more you chase it, the more it flies away from you and hides. But stop chasing it, put away your net and busy yourself with other, more productive things than the pursuit of happiness, and it will sneak up on you from behind and perch on your shoulder (Kushner, 1986, p. 18).

It must be remembered that many of these fathers will face all the normal experiences of joys and sorrows of raising a child. It is imperative that they are cognizant that even a child with intensive health care needs and multiple disabilities has many challenges that impact both the child and his or her family.

**Limitations**

This was a qualitative study with a small sample and therefore the ability to generalize from such a study is limited. Participants were fathers to children who are part of a specific program. This program is the first such program in the country. While other hospitals are beginning to start programs for pediatric stroke survivors, about 4-5 so far in this county, none of the programs have the number of disciplines and the interdisciplinary and transdisciplinary approach that are integral to the CHOP program. The experiences of fathers whose children are not seen in a formal program or seen in a limited program may be different from those of the fathers in this study. In addition, all participants were in a heterosexual relationship with their wife or partner who was the mother of the
stroke survivor. Fathers who chose to be interviewed may have responded differently than those who did not wish to participate.

**Future Research**

Although there has been an increase in research over the past 20 years that focuses on fathers, there continues to be limited literature on the various aspects of the father as parent, especially where the research includes fathers as participants (Shapiro & Krysik, 2010). This dearth of information on the experiences of fathers persists particularly with minority fathers and fathers of children with chronic health care issues and/or disabilities. This is especially unfortunate due to the increase in parental stress and burden often associated with parents raising children with special needs (Drew et al., 2009).

Harnessing and utilizing the skills and commitment of fathers has the potential to enhance the lives of the parents as well as the children. The fathers in the present study expressed a desire to be involved. As men may react differently to negative situations it is important to investigate additional ways to meet the needs of these fathers. The usual expressions of sadness and depression may not be seen in men who may act out in a more male “sanctioned” manner. It is vital to research how fathers of children diagnosed with a devastating illness or condition come to terms with their “new normal” life.

While traditional therapy is certainly one option, research needs to focus on other choices and opportunities. As men may be more adept and comfortable taking actions to cope with a specific situation, research in this area may yield fruitful results. In addition in-depth research of single parents needs to be
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undertaken; the vast majority of these parents are raising these children without the assistance of another adult. Similarly single parents, gay and lesbian couples may have different and unique challenges in parenting children with special needs.

There is a continuing need for hearing the voices of fathers of children with various health care needs and/or disabilities. Focus should be on learning from their experiences with an emphasis on finding various methods to best meet the emotional, physical, and spiritual needs of these fathers.

Fathers of children with special health care needs and/or disabilities should be revisited periodically. Both the father and the child may be faced with new challenges as time passes. Time will also give perspective as to what coping strategies were effective in the long-term.
Appendix A: Telephone Script

Verbal Informed Consent Form and HIPAA Authorization for Screening

Study Title: Hearing His Story: A qualitative study of fathers of pediatric stroke survivors

Version Date: May 22, 2012

Consent Name: Telephone Eligibility Screening

Principal Investigator: Lauren Krivitzky  Telephone: (215) 590-7063

You may be eligible to take part in a research study called Hearing his story: A qualitative study of fathers of pediatric stroke survivors. In order to determine if you are eligible to participate in this study, we would like you to participate in a screening interview.

Before we do that, we will give you important information about the study and the screening interview. This includes information about the purpose of the research and screening, and the risks and possible benefits of participating in the screening.

If there is anything you do not understand, please ask questions. You do not have to take part in the screening interview if you do not want to. If you take part, you can leave the study at any time.

Why are you being asked to take part in this screening?
You are being asked to take part in the screening interview because you are the father of a child who is a part of the Pediatric Stroke Program at the Children’s Hospital of Philadelphia (CHOP) and our records show that you might be eligible to participate.

What is the purpose of this research study?
The main part of the research study is being done to learn more about the experiences of fathers of children who have suffered a stroke. Participation in the study participation involves one interview that will last approximately an hour to an hour and a half. We would also collect some information from your child’s medical record.


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**What is the purpose of the screening?**
The purpose of the screening part of the study is to identify individuals who are interested and eligible for the main study.

There will be a second consent form that describes the main study. You will have a chance to review that consent form before making a final decision about taking part in the main study.

**What is involved in the screening?**
If you agree to take part in the screening interview, we will ask you a few questions about you (e.g. language spoken, age), your relationship to your child, your involvement in your child’s care, and your child’s health history to see if you are eligible for the main study. This will take about 10 minutes.

**What are the risks of the screening?**
You may feel uncomfortable or nervous about answering some of the questions during the phone interview. You do not have to answer any questions that make you too uncomfortable and you can stop the interview at any time.

As with any study involving collection of data, it is possible that someone who is not involved with the study may find out who you or your child are or get access to your or your child’s confidential information. Every precaution will be taken to secure your personal information to ensure confidentiality.

**Are there any benefits to taking part in this screening?**
There will be no direct benefit from taking part in the screening interview. The screening interview will help us determine if you can take part in the main study.

**Do you need to give your consent in order to participate?**
If you decide to take part in the screening interview, you must tell us that you agree. You do not have to participate in the main study, even if you agree to participate in the screening interview.

**What happens if you decide not to take part in the screening?**
Participation in the screening is voluntary. You do not have to take part in order for your child to receive care at CHOP.

If you decide not to take part or if you change your mind later there will be no penalties or loss of any benefits to which you or your child are otherwise entitled.

**Can you stop your participation in the screening early?**
You can stop the screening interview at any time.
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**What about privacy, authorization for use of Personal Health Information (PHI) and confidentiality?**

As part of the screening, health information about your child will be collected. This will include information from the questions we ask you. We will do our best to keep your and your child’s personal information private and confidential. However, we cannot guarantee absolute confidentiality. Your and your child’s personal information may be disclosed if required by law.

Several people and organizations may review or receive your or your child’s identifiable information. They will need this information to conduct the research. These groups include:

- Members of the research team at CHOP;
- CHOP staff who are directly or indirectly involved in your child’s care;
- People who oversee or evaluate research and care activities at CHOP;
- People from agencies and organizations that perform independent accreditation and/or oversight of research; such as the Department of Health and Human Services, Office for Human Research Protections.

By law, CHOP is required to protect your child’s health information. The research staff will only allow access to your child’s health information to the groups listed above. By verbally agreeing, you are authorizing CHOP to use and/or release your child’s health information for this research. Some of the organizations listed above may not be required to protect your child’s information under Federal privacy laws. If permitted by law, they may be allowed to share it with others without your permission.

If, after the screening interview, you are not eligible to take part in the research study, or if you are eligible, but decide that you don’t want to participate in the study, the information we collected during the interview will be destroyed.

If the screening interview shows that you are eligible and you consent to take part in the main study, the information collected will be retained at least until the completion of the study. There is no set time for destroying the information that will be collected for the main study.

**What are the financial considerations?**

Participating in the screening will not result in any additional costs. You will not receive any payments for participating in the screening part of the study.

**Who is funding this research study?**

The main study is funded by The Children’s Hospital of Philadelphia.
All funding information will be reviewed at a later date if you decide to participate in the main study.

**What if you have questions about the study?**
If you have questions about the study, call the study doctor, Dr. Lauren Krivitzky at (215) 590-7063 or Lois Robbins, at 267-426-0218.

The Institutional Review Board (IRB) at The Children’s Hospital of Philadelphia has reviewed and approved this study. The IRB looks at research studies like these and makes sure research subjects’ rights and welfare are protected. If you have questions about your or your child’s rights or if you have a complaint, you can call the IRB Office at 215-590-2830.
Hearing His Story

**Documentation of Verbal Consent to Take Part in this Research Study and Authorization to Use and Disclose Health Information for the Research**

Name of Father

Name of Child

The research study and consent form was explained to:

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<th>Person Providing Consent/Parental Permission</th>
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<td>□ Parent □ Legal Guardian</td>
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The person who provided consent and parental permission confirmed that all of his questions were answered, he agreed to his participate in the screening interview and he agreed to collection of information about his child.

He confirmed that he is legally authorized to consent to his child’s participation.

He agreed to let CHOP use and share his child’s health information for the screening.

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<th>Person Obtaining Consent/Parental Permission</th>
<th>Signature of Person Obtaining Consent/Parental Permission</th>
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Appendix B: Informed Consent (Written)

Informed Consent Form and HIPAA Authorization

Study Title: Hearing his story: A qualitative study of fathers of pediatric stroke survivors

Version Date: May 30, 2012

Principal Investigator:
Name: Lauren Krivitzky, PhD
Telephone: (215) 590-7063

You may be eligible to take part in a research study. This form gives you important information about the study. It describes the purpose of this research study, and the risks and possible benefits of participating.

If there is anything in this form you do not understand, please ask questions. Please take your time. You do not have to take part in this study if you do not want to. If you take part, you can leave the study at any time.

In the sections that follow, the word “we” means the staff involved with the study.

Why are you being asked to take part in this study?
You are being asked to participate in this study because you are the father of a child who is a part of the Pediatric Stroke Program at the Children’s Hospital of Philadelphia (CHOP).

What is the purpose of this research study?
The purpose of the study is to learn more about the experiences of fathers of children who have suffered a stroke. The results of the study will be used to inform professionals in the field as to how to best help fathers of children with special needs.

How many people will take part?
About fifteen fathers will take part in this study.

What is involved in the study?
Fathers will be interviewed individually in order to gain an understanding of what might have helped or hindered in the coping with their child having a stroke. Findings will be based, not on individual responses, but rather on similar experiences of many fathers.
How long will you be in this study?
Your participation will be limited to one interview lasting approximately an hour to an hour and a half.

What are the study procedures?
The study involves the following tests and procedures:

Questionnaire: We will ask you to complete a short questionnaire to provide some basic information (e.g. age, race/ethnicity, education, occupation), information about any previous therapy or counseling you’ve had to cope with your child’s condition, information about participation in support groups or stroke awareness groups and other information about your family. We will also ask some questions about your child, your child’s medical history related to his/her stroke and your child’s school placement.

Interview: We will be asking you about your feelings about being a father and how that may have changed after your child’s stroke. Questions concerning relationships with others will be included. In addition, you will be asked about any supports you found to be helpful. The interview will take place at a place of your choosing. It may be at CHOP, your home, your office, or a quiet public place. The interview will be audio-taped.

Medical record review: We will collect some information from your child’s medical records at CHOP to make sense of the information from the interview. We will collect some demographic information like your child’s age in addition to information related to your child’s stroke.

What are the risks of this study?
Taking part in a research study involves inconveniences and risks. If you have any questions about any of the possible risks listed below, you should talk to the study investigator or your regular doctor.

Risks Associated with the Interview and Questionnaire:
You may become upset or uncomfortable when discussing or thinking about issues revolving around your child’s stroke. If at any time during or after participation in this study, you become upset or uncomfortable, please let us know. We will provide you with the names and numbers of some individuals or agencies that can provide further assistance, although we cannot be responsible for the cost of any follow up care. You do not have to answer any questions during the interview or in the questionnaire that make you too uncomfortable.

Risks Associated with Data Collection:
As with any study that involves collecting data, there is the possibility that confidentiality will be breached. Every precaution will be taken to secure participants' personal information to ensure confidentiality.

At the time of participation, each participant will be assigned a study identification number. This number will be used on data collection forms, audiotapes, and in the study database instead of names and other private information. A separate list will be maintained that links each participant's name to the study identification number for future reference and communication.

Are there any benefits to taking part in this study?
There will be no direct benefit to you or your child from taking part in this study. However, it is possible that having a chance to share your experience will be an interesting and possibly even a rewarding experience for you.

The knowledge gained from this study may help fathers of children with special health care needs and/or disabilities in the future.

Do you need to give your consent in order to participate?
If you decide to participate in this study, you must sign this form. A copy will be given to you to keep as a record. Please consider the study time commitments and responsibilities as a research subject when making your decision about participating in this study.

What happens if you decide not to take part in this study?
Participation in this study is voluntary. You do not have to take part in order for your child to receive care at CHOP.

If you decide not to take part or if you change your mind later there will be no penalties or loss of any benefits to which you and your child are otherwise entitled.

Can you stop your participation in the study early?
You can stop being in the study at any time. You do not have to give a reason.

Can the study doctor take you out of the study early?
The study doctor may take you off of the study if:

- The study is stopped.
- You cannot meet all the requirements of the study.
What about privacy, authorization for use of Personal Health Information (PHI) and confidentiality?
As part of this research, health information about you and your child will be collected. This will include information from the study procedures described above (e.g. interview, audiotape, transcriptions of the audio-taped interview, questionnaire) and information from your child’s medical record as stated above. We will do our best to keep your and your child’s personal information private and confidential. However, we cannot guarantee absolute confidentiality. Your and your child’s personal information may be disclosed if required by law.

The results of this study may be shown at meetings and published in journals to inform other social workers and health professionals. We will keep your and your child’s identity private in any publication or presentation.

Several people and organizations may review or receive your and your child’s identifiable information. They will need this information to conduct the research, to assure the quality of the data, or to analyze the data. These groups include:

- Members of the research team at CHOP;
- CHOP staff who are directly or indirectly involved in your care;
- People who oversee or evaluate research and care activities at CHOP;
- People from agencies and organizations that perform independent accreditation and/or oversight of research; such as the Department of Health and Human Services, Office for Human Research Protections;
- A professional transcription company that may assist with the researchers with transcribing the interviews (i.e. making written copies of the audio-recorded interviews).

By law, CHOP is required to protect your and your child’s health information. The research staff will only allow access to your and your child’s health information to the groups listed above. By signing this document, you are authorizing CHOP to use and/or release your and your child’s health information for this research. Some of the organizations listed above may not be required to protect your and your child’s information under Federal privacy laws. If permitted by law, they may be allowed to share it with others without your permission.

There is no set time for destroying the information that will be collected for this study. Your permission to use and share the information and data from this study will continue until the research study ends and will not expire. Researchers
continue to analyze data for many years and it is not possible to know when they will be completely done.

**Can you change your mind about the use of personal information?**

You may change your mind and withdraw your permission to use and disclose your and your child’s health information at any time. To take back your permission, you must tell the investigator in writing.

Dr. Lauren Krivitzky  
The Children’s Hospital of Philadelphia  
34th Street and Civic Center Blvd.  
Children’s Seashore House, Room 021  
Philadelphia, PA 19104

In the letter, state that you changed your mind and do not want any more of your and your child’s health information collected. The personal information that has been collected already will be used if necessary for the research. No new information will be collected. If you withdraw your permission to use your and your child’s personal health information, you and your child will be withdrawn from the study.

**Financial Information**

While you are in this study, the cost of your and your child’s usual medical care – procedures, medications and doctor visits – will continue to be billed to you or your insurance.

**Will there be any additional costs?**

There is no cost to participate in this study.

**Will you be paid for taking part in this study?**

- You will be paid $50 for your time and effort for participating in the study. If you participate in the interview, but do not complete the full interview, you will be given $25.

**Who is funding this research study?**

The Division of Neurology at The Children’s Hospital of Philadelphia is funding this research.

**What if you have questions about the study?**

If you have questions about the study, call the study doctor, Dr. Lauren Krivitzky at (215) 590-7063. You may also talk to your own doctor if you have questions or concerns.
The Institutional Review Board (IRB) at The Children’s Hospital of Philadelphia has reviewed and approved this study. The IRB looks at research studies like these and makes sure research subjects’ rights and welfare are protected. If you have questions about your rights or if you have a complaint, you can call the IRB Office at 215-590-2830.
Consent to Take Part in this Research Study and Authorization to Use and Disclose Health Information for the Research

The research study and consent form have been explained to you by:

_________________________________________  ________________________________
Person Obtaining Consent  Signature of Person Obtaining Consent

_________________________________________
Date:

By signing this form, you are indicating that you have had your questions answered, you agree to take part in this research study and you are legally authorized to consent to your child’s participation. You are also agreeing to let CHOP use and share your information and your child’s health information as explained above. If you don’t agree to the collection, use and sharing of your information and your child’s health information, you cannot participate in this study.

Consent and Authorization of Father:

_________________________________________
Name of Father

_________________________________________  ________________________________
Signature of Father  Date

Parental Permission and Authorization for Child:

_________________________________________
Name of Child

_________________________________________  ________________________________
Name of Authorized Representative (Father)  Relation to subject:

☐ Parent  ☐ Legal Guardian
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__________________________________________  ______________________________
Signature of Authorized Representative  Date

(Father)
Appendix C: Preinterview Questionnaire

Data to be completed by father (before interview)

1. Name:

2. What is your age (as of last birthday)?

3. Highest Education Completed:

4. Occupation:
   a. Are you currently employed?
   b. If so, how many hours a week do you work?
   c. If not currently working, do you feel the reason is in part or in total related to your child’s medical diagnosis and/or current needs?

5. Do you feel your child’s medical needs have created a financial burden for you or your family?

6. Ethnicity/race/culture (optional):

7. Therapy/ Counseling:
   a. Many parents have found outside therapy helpful to cope with the stress of parenting a child with medical issues. Are you currently seeing a counselor or therapist related to your child’s medical condition?
   b. In the past have you seen a counselor or therapist related to your child’s medical condition?

8. Number of years married/partnered to the child’s mother:

9. Participation/involvement with pediatric stroke awareness and/or family support programs:
Have you ever participated in the following activities?

a. A support group? If so, which one(s)?

b. CHASA picnic

c. Pediatric Stroke Conference

d. Other? Please name:

10. Please list other children in your family by age and gender:

Please answer the following questions about your child:

1. Present age and date of stroke (approximate if exact date is not known):

2. Impairments due to stroke: (e.g. physical impairments, problems with learning)

3. Therapies received or recommended: (e.g. physical therapy, feeding, speech and language, occupational therapy, Botox)

4. Co-morbid Conditions: (e.g. cardiac; oncologic; sickle cell disease)

5. School placement: (what kind of class or classes)
Appendix D: Information obtained from child’s hospital electronic medical record.

Child’s name (after child/father pair had been identified, the pair was given a number code that was used in place of names throughout the study)

CHOP Medical Record Number: the following information is available to researcher through hospital’s computer system

Present age; date of stroke (if known); time out from stroke (date of stroke subtracted from present date)

Impairments due to stroke: (e.g. physical impairments, executive functioning)

Therapies received or recommended: (e.g. physical therapy, feeding, speech and language, occupational therapy, Botox)

Co-morbid Conditions: (e.g. cardiac; oncologic; sickle cell disease)

School placement if appropriate: (type of placement; percent of time in special education)

Race

Religious affiliation
Appendix E: Interview Guide

Thank you for agreeing to participate today. At the end of this session, you will be given $50 in cash as a thank you for assisting with this research. I will ask you to sign an invoice acknowledging your acceptance of the cash. During the interview, please let me know if the questions are too emotionally difficult for you to continue. We will also spend some time after the interview talking about how you felt during the interview and how you are feeling now. As discussed earlier, no identifying information of you, your child, or your family will be in the final report. The digital recorder and my handwritten notes will allow me to review our interview. If you wish to tell me something “off the record” please let me know. There is no right or wrong answer. We are hoping what you will be sharing will help fathers who are facing similar situations. Are you ready to begin? Shall we just jump into it?

(Note: Not every question will necessarily be used. If a father’s answer gives enough information to a question not yet asked, the interviewer will not ask that question. In addition, the order of the questions may vary as to provide a smoother flow to the interview.)

1. What was it like for you to become a father to (insert child’s name)?
2. What was your first reaction when you heard the diagnosis?
3. When you first heard of the diagnosis, how did you think your child’s stroke would affect your life?
4. How did you think you would be able to parent a child diagnosed with a stroke?

5. How did you cope with the diagnosis initially?

6. How did you cope with the diagnosis over time?

7. Did you have any particular people or other supports which helped you during the initial time?

8. Did anyone say or do anything that was particular helpful or harmful during the time following the diagnosis? How was that helpful/hurtful?

9. How has your life changed since your child had his (her) stroke?

10. Has your role of the father changed? Is so, how?

11. How have your relationships changed?
   
   With you wife/ partner?
   With (insert child’s name)?
   With your other children or family members?
   With your friends?
   At work?

12. How have other areas of your life been impacted?

13. What are some ways in which you deal with (cope with) these changes?

14. What supports and/ or resources have been a help to you?

15. Did you consider yourself a religious or spiritual person before (insert child’s name) stroke diagnosis? If so, please explain. What is your religious or spiritual life like for you now? Do you do anything differently?

16. Have your expectations for (insert child’s name) changed after the stroke? If so, how? Can you give me particular examples?

17. Have your concerns for (insert child’s name) changed after the stroke? If so, how? Can you give me particular examples?

18. What have been your greatest challenges?

19. Have you seen any rewards or areas of personal or family growth?
20. What advice would you give those in professional community?

21. What advice would you give to fathers going through this situation?

22. What advice would you give those in the general community?

23. Is there anything else you would like to share?
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