ABSTRACT

Walking a fine line: How coping styles impact polio survivors asking for and receiving assistance from their family and friends.

By
Hallie Baker

After appearing to have been cured, polio is now making a new impact on the lives of its survivors. This new impact has been named Post Polio Syndrome and is causing new symptoms of fatigue and increasing disability in survivors of polio anywhere from 20 to 40 years after the initial infection. As a result, these survivors are now facing new challenges which impact not only them, but their family members as well. This study seeks to look at how the individuals with Post Polio Syndrome cope with both their past polio infection and the current experience with Post Polio Syndrome. Specifically the social network of helpers is examined in the context of the coping strategies utilized by polio survivors in the past.
Walking a fine line: How coping styles impact polio survivors asking for and receiving assistance from their family and friends.

A Thesis

Submitted to the

Faculty of Miami University

in partial fulfillment of

the requirements for the degree of

Master of Science

Department of Family Studies and Social Work

by

Hallie Elizabeth Baker

Miami University

Oxford, Ohio

2005

Advisor____________________________________

Dr. Gary Peterson

Reader____________________________________

Dr. Cheryl Burgan Evans

Reader____________________________________

Dr. Jennifer Kinney
# TABLE OF CONTENTS

Dedication

Acknowledgements

List of Figures

List of Tables

Chapter 1: Introduction

- Statement of Purpose 1
- Conceptual Framework 2

Chapter 2: Literature Review

- Polio 7
- Post Polio Syndrome 16
- Conclusion of Literature Review 24

Chapter 3: Methodology

- Sample 26
- Sample Demographics 27
- Instrumentation 28
- Research Procedure 31
- Analytic Plan 32

Chapter 4: Findings

- Phase Two: Variable construction 34
- Coping styles utilized 34
- ADL and IADL tasks 36
- Social networks of helpers 38
- Phase Three: Hypothesis Analysis 41
- Qualitative analysis what family and friends should know 45
- Summary 45

Chapter 5: Discussion and Conclusions

- Coping styles/strategies 48
- Social network 50
- Voices of the Participants 52
- Limits of the Sample 54
- Conclusion 54

Appendices

A. Email to Listserv owner for permission to recruit on their listserv 56
   Listserv owner’s response 58
B. Recruitment Emails 59
Dedication

This thesis is dedicated to my parents, Charles and Sarah Baker, without whom I would have never gotten this far. I’d also like to mention my Aunt Millie and Aunt Chirpy who along with my mother showed me just how unique polio survivors are. Without these ladies this thesis would never have been thought of.
Acknowledgement

A note of thanks must be given first to my thesis committee Dr. Gary Peterson, Dr. Jennifer Kinney, and Dr. Chryel Evans. Also of great assistance was Dr. Jhan Berry and Dr. Charles Hennon, who helped guide me through the Human Subjects process.
List of Figures

Figure 1: Family Adjustment and Adaptation Response Model .........................6
Figure 2: Percent of helping network used ......................................................41
Figure 3: Family Adjustment and Adaptation Response Model to PPS .................47
List of Tables

Table 1: Age Statistics of the sample .................................................................28
Table 2: Statements based on coping styles .........................................................30
Table 3: Coping style used .............................................................................35
Table 4: Frequency of coping style statements ....................................................36
Table 5: ADLs and IADLS help frequencies .........................................................37
Table 6: Available Help Network Sizes ...............................................................39
Table 7 Received Help Network Size .................................................................40
Table 8 Percent of Help Used Statistics ............................................................41
Table 9 ANOVA analysis of coping styles and help network sizes ......................42
Table 10 one-way ANOVAs of coping statements relationship to help networks ....42
Table 11 One-Way ANOVA of Social Help Networks as related to
Gender of Participants ..............................................................................44
Chapter 1

Introduction

In the 1980’s Polio came back to haunt its survivors. Starting with fatigue and general weakness, the virus that medical science thought was eradicated started once again to affect it’s survivors. Families are now watching loved ones go from vital, independent people to being disabled and dependent as a result of Post-Polio Syndrome or PPS. The psychological and structural issues that result can affect both the individual and his/her family deeply. One patient cited in an article on the psychological issues of Post-Polio Syndrome stated, “I thought I had all this behind me; I don’t know if I can go through it again” (Backman, 1987, p.24).

Poliomyelitis, known as Polio or infantile paralysis, had previously caused epidemics in the 1930’s, 40’s, and 50’s. During the 1940’s, for example, the number of cases reported in the United States ranged from 4,167 in 1942 to 42,033 in 1949, with the largest number of cases (over 58,000) ever reported in 1952 (Bridges, 2003). The great New York epidemic of 1916 alone killed 6,000 and left 27,000 disabled (Bridges, 2003). The World Health Organization estimates that today there are up to 20 million polio survivors in the world and the Center for Disease Control estimated that at least 1 million polio survivors are living in the United States. Approximately 450,000 of those survivors are living with the effects of polio to this day (Bridges, 2003).

Poliomyelitis was a viral infection that affected the nervous system, causing partial or complete paralysis as the virus attacked the nerves inside the spine. It could also affect the brainstem, causing paralysis of the respiratory system (March of Dimes, 2002). Polio primarily affected children and young adults, killing thousands a year prior to the vaccine being perfected (March of Dimes, 2000). For parents, the introduction of the vaccine ended summers of fear and allowed children to go swimming and engaging in other activities that the fear of Polio prevented. Often the fear of Polio is compared to fear of HIV/AIDS in the early 1980’s. The fear of Polio and efforts to cure it led to the formation of the foundation known as the March of Dimes, which continues to be an advocate for polio survivors to this day.

On April 12, 1955 the medical community celebrated the breakthrough by Dr. Jonas E. Salk, who had found an injectable vaccine for the polio virus (Dalakas & Bartfeld, 1995). In 1961, Dr. Albert B. Sabin introduced an oral vaccine that is still given to children today (Dalakas
& Bartfeld, 1995). With the arrival of these vaccines, polio was virtually wiped out in the United States and most Western countries. As a result, much of the global focus on polio was gradually erased from our national and international consciousness, certainly in terms of mainstream media.

Prior to the official identification of Post Polio Syndrome, survivors of polio began to face new health issues including fatigue and muscle deterioration. With the identification of Post-Polio Syndrome in the mid 1980’s by Dr. Lauro S. Halstead, M.D., survivors found themselves facing new obstacles and issues. One big obstacle for most families and individuals with Post-Polio Syndrome is a lack of information. From both within and outside the medical community, individuals with Post-Polio Syndrome face a lack of understanding and knowledge, not only about the disease process of Post-Polio Syndrome, but of Polio itself. This had led to misdiagnosis or some physicians even attributing the symptoms to psychological issues (Gordon, Feldman, Griffing, & Bowman, 2002). Other consequences have been individuals who feel frustrated at a lack of resources for their condition.

The fact remains that Post-Polio Syndrome affects up to 50% of polio survivors (Acello, 2003). While the medical community begins to identify and find ways to treat Post-Polio Syndrome, it is up to the individuals and their families to make needed adjustments to cope with the losses associated with the return of this forgotten foe. Although the attention of other helping professions is needed, evidence of growing concern over Post-Polio Syndrome can be found in an article that cites the high-risk nature of this population due to misunderstandings about PPS and failures to serve those who have the syndrome (Foster, & Berkman, 1993). Hence, it is important for professionals who deal with individuals and their families to do so by understanding the impact of Post-Polio Syndrome in all aspects of their clients’/subjects’ lives.

**Statement of Purpose**

After a review of the literature, it is apparent that there is a lack of information on how the family is impacted by Post Polio Syndrome. The only in depth mention of how the family influences the individual with Post Polio syndrome was noted by Dr. Bruno in his 2002 book *The Polio Paradox* in which he suggests a golden rule for family members “know everything about PPS, say nothing, and help only when asked” (Bruno, 2002, p.238).

Given the current state of deficient knowledge about PPS, the purpose of this investigation was to begin to fill in the current gaps of knowledge in our understanding of PPS.
Specifically this study asked four questions. First, what coping styles are embraced by individuals with PPS? Second, who is asked for help or provides assistance to individuals with Post Polio Syndrome? How do the coping styles used by individuals with polio and PPS impact those who help them? Finally what do individuals with PPS want their families and friends to know about Post Polio Syndrome?

Based on the literature available it was hypothesized that individuals with Post Polio Syndrome will show one of three coping styles (passer, minimizer, or identifier) as theorized by Maynard and Roller in a 1991 article. However the delineation between these three styles may not be as clear as one thinks, because even Maynard and Roller admit to the existence of significant conceptual overlap among the styles. Consequently, this typology was examined with this conceptual qualification in mind.

Another focus of this study was to examine the social network of each person within the sample of individuals with Post Polio Syndrome. The purpose of this examination was to determine the proportion of available or potential helpers compared to those who actually were asked to help or who’s assistance the individual with PPS actually accepts. Current literature indicates that due to the conditioning they received after polio, individuals with Post Polio Syndrome often strive to hide their condition as much as possible; thus a small percent of their social network of available helpers will be utilized, instead of a more diverse group. Consequently, it was hypothesized that individuals with Post Polio Syndrome would approach more intimate family members for assistance versus casual friends and acquaintances. Another factor that influences who the individual with PPS asks for or accepts help from is the coping style they are accustomed to using. Based on the previously described individual coping styles, it was expected that patterns or categories would emerge in the percentages of available helpers in the social network. Further, again based on individual coping styles, patterns were predicted to emerge as to whom (e.g., from other family members) PPS patients actually were most likely to rely upon for help.

Finally, it is important to give voice to the individuals going through this process. As a result of this imperative, the participants in this study were asked what they want others to know about Post Polio Syndrome. By asking the participants to answer such an open-ended question allowed them to speak to us and to provide their unique insights into individual experiences and
the meanings assigned to it. The ultimate goal of this research was to add to the information about Post Polio syndrome, specifically in the area of how it impacts the family.

**Conceptual Framework**

The dynamics at work within a family that is dealing with Post Polio Syndrome can be understood using Family Stress Theory, particularly the concepts such as family resiliency, resources and deficits. From the resilience of children when they dealt with polio originally, to the stress placed on families arising from new health problems triggered by Post Polio Syndrome, it is how the family unit responds to stressors that can be negative or positive (Patterson, 2002).

The model put forth by Patterson in 2002 to integrate family stress and resilience includes a model of a family’s adjustment and adaptation response. (See figure 1) There are two distinct stages for dealing with increased stress or demands on a family, the adjustment phase and the adaptation phase (Patterson, 2002). When something comes into the family’s life that exceeds their capabilities (i.e., their resources and coping behaviors), the family gets out of balance and enters the adjustment phase (Patterson, 2002). During the adjustment phase, the demands, stressors and strains create an imbalance and, if this imbalance persists, a family will enter a crisis (Patterson, 2002). It is during this time of crisis that a family will change their structure, interaction patterns or even both in order to resolve the crisis or imbalance (Patterson, 2002). Once a balance is restored, the family enters the adaptation phase where it permanently incorporates the various changes into its structure, resources, and coping behaviors (Patterson, 2002). See Figure 1.

For the present research, a snapshot of the family was taken when the family has entered or was already in the adaptation phase. The initial impact of Post Polio Syndrome and the increasing fatigue or disability of the individual with PPS within the family had triggered a crisis and now the family has begun to regain its balance. Part of the crisis includes the individual actually acknowledging the fact that he/she was experiencing new issues and was coming to accept the diagnosis of Post Polio Syndrome. Thus by taking a sample of individuals who have already come to accept the title of person with Post Polio Syndrome, the context of this study was within the adaptation phase.

The demands on the family included the change in abilities experienced by the individual with Post Polio Syndrome. These demands have accumulated progressively as supportive
individuals stepped up to take on the tasks and duties that the individual with PPS had been forced to relinquish. Other demands included providing assistance to the individual with Post Polio Syndrome for tasks that can vary from helping with housework to assisting with care issues. This accumulation and reallocation of role behavior within the family system can lead to strains as individuals take on new roles, such as when a child must become a caregiver for his/her parent in response to PPS. As adjustment progresses, these roles and tasks become divided up as the family balances the demands with the resources that are available.

The resources that the family and individual can use to help them adapt to Post Polio Syndrome include their social networks and past coping styles. By tapping into their social network of potential helpers, both the individual with Post Polio Syndrome and his/her family can expand the capabilities and resources they have on hand to deal with the disease process. The family reestablishes an equilibrium by seeking and using others to assist with either everyday or unusually demanding tasks.

Another important resource to keep in mind is that many of the individuals with Post Polio Syndrome have already demonstrated past resilience through the use of coping behaviors that helped them become polio survivors. An important qualification, however, is the existence of some evidence that prior coping experience may be either a resource or a strain, depending on the individual. Thus, how survivors use those skills to adapt to this new challenge is important as well. For example, if a person classified as a minimizer attempts to solely use their capabilities as a means of hiding their disability, they may fail if a real need exists to rely on others for more of their housework (Maynard & Roller, 1991). Hence the individual and his/her family will need to either accept the change and adapt to it or refuse to accept the change and remain in a state of crisis or unbalance (Patterson, 2002). So it is important to acknowledge that the coping style can be as much of a capability/resource as a demand. Overall, a general focus of this study was to begin to describe the adaptations that persons with PPS must face in asking for and actually receiving help in response to issues they face by renewed challenges from an old foe.
Figure 1. Family Adjustment and Adaptation Response Model

Adjustment Phase

Meanings

Capabilities: Resources, Coping behaviors

Demands: Stressors, Strains

Family Adjustment

** situational family identity & world view

Adaptation Phase

Meanings

Capabilities: Resources, Coping behaviors

Demands: Stressors, Strains

Family Adaptation

Chapter 2

For polio survivors both their families and society have pushed them to recover as much of their previous functioning as possible and to hide any lingering disability from their bout with this virus. These same individuals are now facing new symptoms and increasing disability as this old foe comes back to impact their everyday lives. Within the context of families, this new development on an often forgotten or taboo topic can cause changes in the structure and function of entire family systems as individuals cope with the disability of a loved one. Hence, families are responding to a new stressor, the new or increased disability of one of its members, within the context of how society has dealt with polio in the past. This study examines, in part, how the coping styles of polio survivors in the past impact how individuals deal with the new challenges of Post Polio syndrome and from whom each of them ask for and accept help from.

The examination of how individuals with Post Polio Syndrome cope with the resulting disability and health issues requires that three different subcategories of literature be consulted. The first subcategory of literature is concerned with the history of and physical impact of polio in its acute stage. A second category deals with the period of history for polio survivors during which a vaccine was discovered and implemented. Finally, the third subcategory of literature focuses on Post Polio Syndrome proper. Consequently, this review of literature is divided into two major sections, the first of which provides both a history of Polio in its acute phase and its impact on society and its survivors. A second section, in turn, is concerned with the emergence and current knowledge that exists about Post Polio Syndrome.

Polio (Poliomyelitis)

The polio virus, or poliomyelitis, has a long history dating back to at least 1350 BC (Bridges, 2003), though little documentation on the virus exists until the 20th century (Bridges, 2003). Polio reached epidemic proportions throughout the early 20th century, particularly during the summer months. The first vaccine for the polio virus was an injectable vaccine announced on April 12, 1955 by Dr. Jonas E. Salk, whereas an oral vaccine was developed in 1961 by Dr. Albert B. Sabin (Dalakas & Bartfeld, 1995).

Prior to the development of a vaccine, polio had a major impact on society in a variety of ways. Polio, which was also called the “summer grippe,” had two forms, paralytic and non-paralytic. Infants and children were the ones most often infected by the polio virus, but young
adults and the elderly were infected at times as well (March of Dimes, 2002). Polio and the fear it inspired has been compared to the AIDS epidemic, especially during the 1980’s. Newspapers in the early 20th century documented the mass hysteria and anxiety caused whenever polio was diagnosed in a community (Mulder, 1995). Polio was referred to as “the sword of Damocles that hung over every child and young adult (Mulder, 1995 p.6). An example of this panic from the perspective of one town was the statement that, because of polio, “the whole town must be closed as far as children are concerned, they must be kept strictly in their own yards” (Mulder, 1995, p.6). Towns were sprayed with DDT and parents were encouraged to spray their houses with DDT (Mulder, 1995). A nationwide panic was evident and, at times, even medical personnel were included in the panic when polio made its annual appearance in late summer and early fall.

It is important to note that medical personnel could be impacted by the virus as well as the general public. As was demonstrated in the polio epidemic of 1934 in Los Angeles, 198 hospital employees, 18% of whom were nurses, were among the stricken (Mulder, 1995). Hence, medical personnel often reacted to news of a polio outbreak with fear or “altered medical perception” or allowing his/her own fear of infection impact how care was delivered (Mulder, 1995, p.6).

Poliomyelitis was spread by person-to-person contact or by contact with infected secretions (March of Dimes, 2002). It is important to note that, once infected, no cure for polio or drug existed that could treat all the symptoms (March of Dimes, 2002). The early signs of infection included non-specific symptoms such as fever, headache, sore throat, nausea, vomiting, neck stiffness, lack of appetite and abdominal pain (Dalakas & Bartfeld, 1995). Of the individuals infected by poliomyelitis, 90% of the cases were mild and the patient would make a full recovery. For the remaining 10%, however, more severe symptoms developed (Dalakas & Bartfeld, 1995) and it is members of this group who are often thought of as polio survivors. Symptoms of the severe group included high fever, signs of meningitis, and severe back and neck pain (Dalakas & Bartfeld, 1995). One percent of the severe group experienced the virus attacking the nerves inside the spine, which caused partial or complete paralysis (March of Dimes, 2002). For some, the virus stayed within the spine but, for others, the virus actually reached the brainstem, causing paralysis in the muscles needed for breathing, swallowing, and other vital functions (March of Dimes, 2002). The mortality rate for polio emerged within the
1% of those experiencing paralytic polio; approximately 5% of this group died (Dalakas & Bartfeld, 1995).

A notable study by Bruno (1993) questions the commonly accepted rates described above, arguing that greater numbers of polio survivors had the paralytic form than is initially apparent. Specifically, Bruno (1993) reported that 39% of those diagnosed with non-paralytic polio actually did have muscle weakness in one or more muscles (Bruno, 1999e). Moreover, Dr. Bruno argues that pressure existed during the height of polio epidemics to diagnose patients with mild paralysis or muscle weakness as being non-paralytic because of the large numbers of patients with severe forms of paralytic polio (Bruno, 1999e). This misdiagnosis or ignoring of more minor paralysis will cause problems later when polio survivors begin to develop Post Polio syndrome. This pattern of misdiagnosis underscores the importance of understanding just what the polio virus does to cause paralysis or muscle weakness.

Poliomyelitis attacks the neurons, often damaging or killing the impacted nerves, primarily anterior horn cells or the motor neurons of the spinal column (Dalakas & Bargfeld, 1995). The non-affected neurons would then take over for the affected neurons. Thus a neuron once responsible for 200 muscle fibers would then become responsible for 800 to 1,000 muscle fibers (Dalakas & Bargfeld, 1995). Because this compensating function could improve after a paralysis of weeks or months, improvement could continue for up to 2 years after the acute infection (Dalakas & Bargfeld, 1995).

The course of the polio infection began with the more minor symptoms of fever, headache, and gastrointestinal symptoms. After a few days, the initial symptoms would subside never to return, but for some patients, the initial symptoms initially subsided, only to recur after several days (Mulder, 1995). The paralysis form of polio began with patients complaining of a stiff neck and headache, along with other neurological symptoms. In the case of children, apprehension and irritability also were frequent occurrences during these times (Mulder, 1995). Between two to five days after the onset of initial symptoms, the paralysis would set in, often coincident with a fever that would end before the paralysis was complete (Mulder, 1995). Paralysis patients often complained of severe muscle pain and spasms. Those who experienced weakness in the respiratory or throat areas often experienced symptoms of increased anxiety and drowsiness, which frequently were misdiagnosed early on in an epidemic (Mulder, 1995).
Treatments for those with polio included medications and support, especially for those with respiratory paralysis. One infamous treatment was the “iron lung,” which was a precursor of ventilators and more current medical technology (Mulder, 1995). For the survivors, however, the iron lung was the treatment and rehabilitation experience following the acute period of their infection that had the greatest impact. In order to better understand the recovery and rehabilitation processes experienced by polio survivors, therefore, it is best to divide the recovery into separate phases.

In their 2003 article, Dr. Harry K. McNaughton and Dr. Kathryn M. McPherson discuss the 5 clinical phases of Polio. Phase one lasts one month and includes the denervation of muscles secondary to the polio virus, which also involves destroying motor neurons in the spinal cord and brain stem (McNaughton & McPherson, 2003). Phase 2 lasts from 2 to 12 months and includes the recovery of motor neurons and reinnervation (McNaughton & McPherson, 2003). This involves the recovery of those nerves not completely destroyed, while as mentioned before, other neurons take over or add extra functions (McNaughton & McPherson, 2003). Phase 3 lasts two to eight years after the infection, during which continued clinical recovery occurs (McNaughton & McPherson, 2003). During this phase, the strength of patients tends to improve and become more functional and independent by using other muscles to substitute for those affected by polio and by learning adaptive strategies (McNaughton & McPherson, 2003). Phase 4 is a period of functional stability lasting eight to forty years after the initial infection (McNaughton & McPherson, 2003). During this time the muscle fibers are divided into three populations (McNaughton & McPherson, 2003): those that 1) were either not affected by polio and are, therefore normal; 2) were affected but are stable; and finally 3) were affected but unstable, meaning that they cannot provide consistent function (McNaughton & McPherson, 2003). The final or fifth phase, which not all polio survivors experience, involves late deterioration in function currently known as Post Polio Syndrome (McNaughton & McPherson, 2003).

Expressing an important qualification, McNaughton & McPherson (2003) indicate that they are not sure how many polio victims go through these phases. For polio survivors, however, the critical times of phase 2 and 3 have been shown to demonstrate as great, if not a larger impact, than the initial infection.

Besides the physical symptomology of polio, the majority of polio survivors, who were infected between the ages of 6 months to 10 years of age, probably were affected as much
psychologically as physically. The literature on the psychological influence of polio reflects changes in conceptions of child development. Morton Seidenfeld (1948) discusses some of the psychological impact of poliomyelitis in children, which consist of direct and indirect effects on the child. Direct effects include psychological reactions to the pain that results both from symptoms of the virus as well as from the medical procedures and treatments involved (Seidenfeld, 1948). Indirect effects include the fears and uncertainty of parents and siblings, which may lead to different behavioral responses aimed at the infected child, particularly when compared to patterns of family responses before the onset of the disease. The community’s attitudes toward the disabled child indirectly impact the child through “lack of provisions for schooling,” and inadequate facilities and/or transportation for the child to attend various events, (Seidenfeld, 1948). Seidenfeld’s article reflects extensive use of Freudian (psychoanalytic) concepts through repeated references to such ideas as ego-security and other closely related Freudian terms.

Demonstrating a somewhat different theme at the Ontario March of Dimes Conference on Post-Polio Sequelae in 1995 was the work presented by Nancy Frick on how the childhood physical and emotional trauma of polio survivors influenced their later reactions to stress. Frick breaks down the psychological experience of polio into five main areas consisting of 1) the initial terror of polio, 2) the hospital experience of being away from home, 3) the hospital experience in the form of medical abuse, 4) returning home again, and 5) getting normal (Frick, 1995). Specifically, for individuals infected by the polio virus, there is initial trauma simply from the fear of determining exactly what disease they now faced (Frick, 1995). Frick compares polio survivors to the AIDS patients of the 1980’s in the sense that everyone was terrified of polio survivors and their families for years after the initial infection (Frick, 1995). Such fearful reactions of others often led to isolation within their communities because no one wanted to be around polio survivors or their families (Frick, 1995). Second, for those survivors who were old enough to understand that they had polio, they also knew that subsequent disability was likely and that death also was possible (Frick, 1995). Often the survivors of polio knew someone who had been disabled or died from polio, either during the time or before the onset of their own infection (Frick, 1995). Consequently, it is clear that survivors often had an initial emotional trauma during the acute stage of polio, caused simply by the onset and meaning of becoming infected.
The next traumatic experience for polio survivors was being in the hospital away from home. Frick (1995) writes: “There was the confusion and terror connected with polio survivors’ being wrenched from their homes, dropped in a hospital and being left there for months or even years, while they received treatments that no one explained to them. Polio survivors went to the hospital, usually when they were very young, and lost their emotional support system.” (Frick, 1995, p.3). Polio survivors have written about this trauma, often citing their inability to take care of themselves (i.e. in reference to such things as taking a bath or going to the toilet, and not having a family member present to help) (Frick, 1995). Such experiences often fostered feelings of abandonment by one’s family and isolation within the hospital when medical professionals failed to inform the patient what was happening and offer emotional support. Frick and Bruno (1991, p.1188) cite a chart written by polio ward mates at Baltimore’s city hospital which listed unwritten rules for polio patients that included: “Listen to the Doctors, obey the nurses, do not fight, do not be bad, be good in school, do your homework, do not talk at dinner or in school, and little folks should be seen and not heard”. Normal behaviors for children such as crying or asking questions were subject to punishment (Frick, 1995). One must keep in mind that these rules were written down by and obeyed primarily by children below the age of 10. Consequently, Frick often poses the question of how did this experience in the hospital impact the survivors psychologically in her ongoing research.

Along with the isolation and fear experienced from being in a hospital, Frick also identifies the medical abuse that some patients were subjected to in hospitals. Therapies were painful and frightening, including being burned by hot packs, being splinted, having no one willing to remove splints when they began cutting into the skin, being braced, and even having physical therapy in pools when patients couldn’t swim (Frick, 1995). Moreover, children with polio rarely had their questions answered and sometimes faced angry staff who answered inquiries with unresponsive questions like “You want to get out of here, don’t you?” (Frick, 1995, p.4). Such unresponsive questions gave the children the idea that, if they failed to do what they were told, then they would remain in the hospital forever (Frick, 1995). This abuse led to substantial mistrust of medical staff by some polio survivors (Frick, 1995).

It is important to note that research since the 1950s and 1960s has demonstrated that failing to explain treatments or provide information to children about their illness makes the young think that they are actually sicker than they really are and leads to anxiety and fear of
death. Along with the emotional and physical pain of undergoing treatment, cases of actual abuse by medical staff were evident. These atrocities included being locked in closets or placed in straight jackets to teach the polio survivor to behave in a more acceptable manner (Frick, 1995). Moreover, some cases of sexual abuse became evident on occasion (Frick, 1995).

An important thing to remember is that, due to their disabilities, polio survivors were completely dependent on the staff, despite any emotional, physical or sexual abuse that might occur (Frick, 1995). Secondly, families often could not visit their children in the hospital as regularly as they would have liked, a circumstance that placed the young at-risk for abuse. Reduced family interaction also led to feelings of abandonment on the part of children and reinforced the condition of total dependence on medical staff who often “behaved in ways that made them constantly feel, as one polio survivor described it, ‘As if I was in mortal danger.’” (Frick, 1995). Frick proposes, in turn, that polio survivors often responded by suppressing their fears and by striving to “be good” (Frick, 1995).

When young children form such strong and basic fears so early in development, however, these emotions often remain with them forever and may become applied to every other relationship in the future. Many polio survivors learned to deal with feelings of abandonment, loss of control, fear and pain by putting up a mask of happiness and contentment (Frick, 1995). To do otherwise was too dangerous because they would have had to examine their real feelings and not comply with the external pressures and expectations they were experiencing (Frick, 1995). Frick argues that polio survivors subsequently “learned to deny their personal needs, feelings, pain and, worst of all, deny their own identity.” ( p.5).

Unfortunately for polio survivors, the trauma might not be over once they leave the hospital but may continue and cause further trauma with the victim’s return to the community. Specifically, responses of others, such as fear of anyone with polio, often became evident with a child’s return from the hospital (Frick, 1995). This resulting isolation often included not being able to play with other children because their parents feared that the polio survivor might still be contagious long after recovery (Frick, 1995). For those who could play with other children, they often could not keep up with their peers because of residual weaknesses from the disability (Frick, 1995). Polio survivors often were ostracized or teased because of their disability or for any other way they were different (Frick, 1995). This not only contributed to polio survivors’ feelings of being isolated but also to feelings of being unwanted, unworthy, and guilty (Frick,
In addition, the survivors found themselves believing that they must have done something terrible or else they would not have ever gotten polio (Frick, 1995). As a result, polio survivors often thought little of themselves and faced further indignities by being stared at, asked impolite questions, and reduced to little more than curiosities (Frick, 1995).

In response to all these traumas and the reactions of society, polio survivors often strove to appear as normal as possible (Frick, 1995). Many polio survivors took the mantra to heart and strove to ‘get normal’ (Frick, 1995). This was often reinforced by parents, once the child recovered, who expected/encouraged her/him to equal or exceed his/her previous physical performance (Frick, 1995). Survivors often were pressured to outperform others academically in order to please others in the context of social demands to be normal or better and thus hide the stigmatized disability (Frick, 1995). Ironically, other parents felt shame due to their child’s disability and tried to hide this condition or their child, all of which are unfortunate practices that may lead to additional fears of rejection due to their disability (Frick, 1995). As a consequence, polio survivors often learned from early experiences at home and in the hospital to become Type A overachievers who are especially sensitive to criticism and failure (Frick, 1995). Polio survivors frequently became successful at many things they did either academically, professionally or personally (Frick, 1995). Polio survivors also discarded any adaptive and assistive devices they could in order to disappear into society and become normal to the point where they could hide and ultimately try to forget their disability (Frick, 1995).

A similar idea is discussed by Bruno (1995a) as “the paradigm of normalcy” through which he proposes that polio survivors were taught that, for them to be accepted back into society, they must become “normal” again (Bruno, 1995a). For polio survivors, this meant that they must work harder in physical therapy to rid themselves of assistive aides, especially since the world to which they returned was a totally inaccessible world (Bruno, 1995a). Bruno (1995a) states that polio survivors went to college when those who escaped this dreaded disease simply finished high school. According to Bruno (1995a), a profile of a polio survivor includes the fact that most worked overtime and took fewer sick days than their non-disabled co-workers; “they are hard-driving overachieving perfectionists who become the leaders of their communities, their professions, the chief executives of the largest corporations.” (Bruno, 1995a. p.3).

Contrasting with Frick and Bruno’s claims that polio survivors are over-achievers, a study conducted by Farbu, Elisabeth & Gilhus (2002) in Norway reported no difference in
education, occupation, and perception of health between polio survivors and their siblings.
Consequently, one must ask if overachievement is unique to the culture and society of the United States and how the disabled are viewed within this context versus other socio-cultural settings. Unfortunately, no further literature is available to address this issue at this time.

An important study by Maynard and Roller (1991) made use of a study conducted in 1963 to describe and discuss three typical coping styles of polio survivors: passers, minimizers, and identifiers (Maynard & Roller, 1991). Passers are survivors whose disability or weakness was so mild as to be easily hidden from the casual observer (Maynard & Roller, 1991). Passers strove to hide their disability from those who were not intimate family members or friends (Maynard & Roller, 1991). This group invested a large amount of time, energy and vigilance in disguising themselves as non-disabled, often not wanting to talk about their polio experience and their disabilities (Maynard & Roller, 1991). These survivors are very sensitive to the social stigma often attached to the disabled and, as a whole, do not view themselves as disabled (Maynard & Roller, 1991).

The next group of survivors are the minimizers who had/have a disability that is readily recognized by others (Maynard & Roller, 1991). Frequently, this recognition is due to the use of adaptive equipment or the need to do things in a different way to compensate for weakness or paralysis (Maynard & Roller, 1991). Minimizers tend to cope by focusing on other positives and work to get others to look beyond their disability by being high achievers who often push themselves to the limit (Maynard & Roller, 1991). This group de-emphasizes the pain, deformity and functional short-comings, thereby tuning out their bodies or “devaluing physique” (Maynard & Roller, 1991).

Finally, identifiers are those who, due to being severely disabled by acute polio, “fully identify with their disability in order to make major lifestyle adaptations to successfully cope” (Maynard & Roller, 1991, p.71,). This group consists of the survivors who have used wheelchairs, other mobility equipment, or respiratory equipment since their acute polio stage (Maynard & Roller, 1991). This group also tends to be high achievers, but instead of ignoring their disability like the other two groups, these individuals are advocates for the disabled (Maynard & Roller, 1991).

The acquisition of knowledge about the past experiences of polio survivors can provide insight into understanding each individuals’ reactions to Post Polio Syndrome. Many of the
coping strategies and past experiences may even complicate how they deal with this new development. As noted by Foster and Berkman (1993), some polio survivors have been found to “suspect that they are being misinformed, misdiagnosed, and treated inappropriately and feel they are being ignored or devalued by health care providers and the larger community” (p.140) due to the methods employed in the past to rehabilitate polio survivors. Consequently, it is important to understand the past as one examines how polio survivors deal with Post Polio Syndrome in order to make sense of some of the emotional reactions the individuals have in the present (Foster & Berkman, 1993).

Post Polio Syndrome (or Sequelae)

Post Polio Syndrome is not a new topic because, as early as 1875, weakness in later life among polio survivors was described in French medical literature. Moreover, during the subsequent 100 years, about 35 additional reports of post polio weakness appear in the published literature (Halstead, 1998). Raymond and Charcot, for example, in their article written in 1875, described new weakness and atrophy in the arms and legs of a 19 year old that they classified as an “overuse” phenomena (Dalakas, 1995b). This overuse hypothesis has since become a theory that is often discussed as a main cause of Post Polio Syndrome (Dalakas, 1995b), though substantial work on the late effects of polio did not become prevalent until the 1980’s.

In the early 1980’s more and more survivors of the polio epidemics from the first half of the 20\textsuperscript{th} century began to develop new symptoms. Reports of these re-emergent symptoms led to the first studies aimed at identifying whether these symptoms were unique or had other causes (Dalakas, 1995b). In 1984, the first international conference on PPS was held (Halstead, 1998) and, in 1994, the New York Academy of Sciences and the National Institute of Health cosponsored a meeting that led to a 1995 special issue of the *Annals of the New York Academy of Sciences* on Post Polio Syndrome (Dalakas, 1995b). Moreover, in 1994 and 1995, the National Health Interview Survey administered by the Centers for Disease Control did a sub-survey of polio survivors.

The term Post Polio Syndrome was termed and defined by two primary pioneers, Dr. Lauro Halstead and Dr. Marinos Dalakas, in the early 1980’s. Post Polio Syndrome is a progressive neurological/musculoskeletal disorder that occurs 10 to 40 years after an individual has recovered from polio (Acello, 2003). Specific symptoms of Post Polio Syndrome that researchers originally identified included fatigue and decreased endurance in muscles, increase in
skeletal deformities, pain in joints that were deformed or weakened by the earlier acute polio episode, new muscle weakness or atrophy, and possible respiratory weakness (Dalakas, 1995b). Subsequently, cold intolerance, fatigue, and other symptoms were discovered as additional symptoms. The process of diagnosing Post Polio Syndrome is more a process of exclusion rather than a direct diagnosis (Dalakas, 1995b).

The exact cause of Post Polio syndrome is not known at this time, though several theories have been proposed as possibilities. Some experts offered the opinion that normal aging was playing a role and causing notable declines in functioning (Dalakas, Bartfeld, & Kurland, 1995). Bruno and others (1987), including Dalakas et al. (1995), also believe that overuse theory, first proposed in an 1875 article, has some merit. The overuse theory proposes that polio survivors wear out either the neurons that were originally damaged or those that had covered for the destroyed neurons during the initial episode of infection (Richardson, 1995). Dr. Richard Bruno, Director of the Post-Polio Institute and The International Centre for Post-Polio Education and Research, has written extensively about how polio survivors were driven by their experience with polio to overachieve. A possible result, in turn, is that their bodies may simply be wearing down more rapidly than would be the case under normal conditions of use (Bruno & Frick, 1987). This lack of a direct answer to an individual’s question concerning why this is happening again can lead to frustration and feelings of being conspired against by the medical profession (Foster & Berkman, 1993). An important thing to remember, therefore, is that a significant lack of knowledge exists concerning why these new symptoms are occurring (Foster & Berkman, 1993).

Regardless what the exact cause may be, the most common treatment for Post Polio Syndrome includes the management of pain and the application of exercise to maintain function, not to build strength. Changes in lifestyle are recommended, such as using adaptive equipment, to accommodate the new weakness and fatigue that develops (Halstead, 1988). The current mantra that the medical community is prescribing for polio survivors is conservation to preserve function (Bruno, 2002). The down-side of this treatment option, combined with the past histories of coping with polio, may be that patients with Post Polio Syndrome will experience adverse psychological consequences as they cope with this new health problem.

Halstead, in her 1998 article, proposes that polio survivors have already overcome the severe challenges of disability, stating that “Post polio survivors tell a story of struggle and triumph: the sudden, random onset of paralysis, the gradual restoration of strength seemingly as a
result of individual willpower and, finally, for many, resumption of an active, productive life, which leads them to believe they have put polio behind them” (p.46). Now after 30 years of struggle to lead active lives, polio survivors again may be dealing with symptoms that are very much like those that they had overcome in the past and supposedly left behind (Frick & Bruno, 1986). Frick and Bruno also argue that the return of these symptoms can be psychologically devastating because it combines the effects of reoccurring symptoms that were unexpected with the lack of knowledge and understanding on the part of the medical community. A subsequent realization is the loss of “hard won physical abilities whose recovery was thought to be permanent” (Frick & Bruno, 1986. p.109). By examining these three issues separately one can better understand the psychological impact of Post Polio Syndrome on its victims.

As mentioned before, the exact cause of Post Polio Syndrome is not known, which means that uncertainty about the unknown can have a psychological impact on patients. Foster and Berkman have commented on how “the nonspecific and open-ended nature of the post polio syndrome creates unique difficulties in the patient, provider, family and work relationships” (Foster & Berkman 1993, p.144). Dealing with post polio syndrome is very much a patient empowerment issue in which those who are more knowledgeable about their illness and have access to knowledgeable physicians will adapt much better than those who lack knowledge and quality services (Foster & Berkman 1993). A key to successful coping, therefore, is to diminish some of the unknowns that are evident for polio survivors.

The psychological impact of misunderstandings and issues with the medical community comes from previous experiences discussed earlier and the initial reactions of the medical community to the re-emergence of post polio symptoms. When the first polio survivors started noticing the presence of new symptoms in the 1980s, the medical community seemed disinterested at best. Even the father of Post Polio Syndrome, Dr. Marinos Dalakas, admits that, when he was first approached by his fellow physician Dr. Marilyn Fletcher, who happened to be a polio survivor, he did not think initially to examine this phenomenon. Instead, it took a later meeting to initiate respondents who subsequently requested that research be conducted on the issue (Dalakas, 1995b). For most physicians, little continuing knowledge existed about a disease that was supposed to be eradicated during the 1950’s in the United States (Backman, 1987). Frequently, during the 1980’s and 1990’s, polio survivors had their symptoms dismissed, misdiagnosed, or even were told that their re-occurring problems were psychological and
unrelated to polio. Such responses led Post Polio victims to experience astonishment, frustration and a loss of faith in health care professionals (Saxon, 2001).

The stage was set, therefore, for further distrust of authority beyond what polio survivors experienced during their acute phase of polio and rehabilitation in the past. Doctors and the medical community were perceived as not being completely truthful and open about Post Polio Syndrome (Backman, 1987). Such problematic conflicts of interest with the medical community during initial contacts structures how individuals interact with the medical community in subsequent contacts.

Considering the psychological impact of the renewed loss of physical capabilities, several authors have drawn upon existing general literatures concerned with the reaction of patients to new disabilities other than Post Polio Syndrome. They have attempted to apply this general literature on a variety disabilities to what polio survivors are experiencing as a result of newer-emergent problems with Post Polio Syndrome. A recent study by Hollingsworth, Didelot, and Levington (2002), for example, makes use of the adjustment to disability scale developed for spinal cord injury patients and applies it to post polio patients. This literature proposes a set of five stages for conceptualizing adjustment to this disability: initial impact, defense mobilization, initial realization, retaliation and reintegration (Hollingsworth, Didelot, & Levington, 2002). Stage one or the initial impact occurs immediately after the disability occurs and is characterized by shock and anxiety (Hollingsworth, Didelot, & Levington, 2002). During the first stage, the defense mechanism of depersonalization is used, with some victims becoming emotionally detached (Hollingsworth, Didelot, & Levington, 2002). Stage two, or defense mobilization, includes denial and the expectation that one will recover, thus avoiding the negative emotions associated with becoming disabled (Hollingsworth, Didelot, & Levington, 2002). Avoidance is used in this stage as patients attempt to appear unaffected by the impairment, often are cheerful or carefree, with any reminders of the disability causing them to become angry or experience despair and negativity (Hollingsworth, Didelot, & Levington, 2002). Common behaviors include seeking more medical information and consulting with experts, bargaining with God, setting unrealistic goals, having unrealistic expectations for a cure, resisting help from others, refusing rehabilitation efforts, and attempting to continue performing activities as they have in the past (Hollingsworth, Didelot, & Levington, 2002).
During stage 3, or initial realization, the individual typically comes to the conclusion that the disability is permanent, an awareness that may lead to depression and feelings of mourning the loss of what they were and a future that will not be (Hollingsworth, Didelot, & Levington, 2002). Another consequence concerns the self-perception of their own body, particularly in the sense that it may now seem foreign to them (Hollingsworth, Didelot, & Levington, 2002). Later in this stage, anger is directed toward self-blame, self-recrimination, guilt and shame, with isolation from others becoming a common pattern (Hollingsworth, Didelot, & Levington, 2002).

Stage 4, or retaliation, occurs when an individual’s anger turns from being focused inwards to being directed outwards and is aimed at others while the person rebels and retaliates against her/his fate (Hollingsworth, Didelot, & Levington, 2002). The individual becomes mentally focused on blaming others and retaliates against reminders of his/her circumstance. Another focus is on anyone who is perceived as being responsible for the return of disability, i.e. the doctors who want to prescribe braces or other adaptive equipment (Hollingsworth, Didelot, & Levington, 2002). The final stage of reintegration occurs, in turn, when the individual reorganizes his/her concept of self and accepts the disability (Hollingsworth, Didelot, & Levington, 2002). This includes acknowledgement of, acceptance of, and adjustment to the disability and all of the implications the impairment will have for the person’s life (Hollingsworth, Didelot, & Levington, 2002). New meanings are constructed and integrated into the self during this period (Hollingsworth, Didelot, & Levington, 2002). The literature also suggests that this is not a linear form of adjustment so an individual may vary between the stages.

Another set of stages or phases for conceptualizing how Post Polio victims are adapting to or dealing with this syndrome has been proposed by Anna-Lisa Thoren-Jonsson of Sweden. Specifically, her conception of stages consists of an inattentive phase, overloading phase, emotional crisis phase, withdrawal phase, gradual change phase, and flexible phase (Thoren-Jonsson, 2001). According to this perspective, during the first of these phases, the inattentive phase, individuals experience a stable polio stage in which they experience recovery and have adapted their lives to cope with the losses that polio initially caused (Thoren-Jonsson, 2001). Their current goal often is to live like other people and, as a result, polio survivors often are inattentive to changes in their own bodies, a characteristic that is probably due either to unconscious adaptations or because their tolerance for pain is high (Thoren-Jonsson, 2001).
The next phase, referred to as overloading, is evident when individuals tend to focus on maintaining their daily lives, while not paying attention to signals of their bodies (Thoren-Jonsson, 2001). The strategy here is to stretch the limits of their physical capabilities and use their current coping strategies for avoidance and for wishful thinking. Frequently, this is the phase to which individuals commonly return as each new loss of capacity occurs (Thoren-Jonsson, 2001). A third phase, characterized by emotional crisis, has been described by polio survivors as a time of darkness characterized by mental and physical fatigue along with a lack of initiative and cognitive dysfunction (Thoren-Jonsson, 2001). During the withdrawal phase, a fourth period, the individual needs to reduce his/her activities, both within the leisure and social dimensions of life (Thoren-Jonsson, 2001). Coping strategies used in this phase are to give up occupations and to practice avoidance as a means of preventing others from seeing their increased disability (Thoren-Jonsson, 2001). Subsequently, during the fifth stage, the gradual change phase, individuals begin to alter their lifestyles and compensate for new weaknesses/disabilities with assistive devices to cope more effectively (Thoren-Jonsson, 2001).

The final period, or the flexible phase, occurs when the individual begins to use a multiplicity of strategies for coping (Thoren-Jonsson, 2001). Post-Polio Syndrome patients begin to use a variety of strategies and options in order to facilitate their participation in daily occupations and social life (Thoren-Jonsson, 2001). Of particular importance is the fact that renewed coping requires time, energy, and the ability to make cognitive maps, orchestrate occupations, and set priorities. During this phase, individuals acquire knowledge about where to find information, develop a readiness to ask for assistance, learn to compensate with assistive devices, and no longer feel shame about being disabled (Thoren-Jonsson, 2001).

Frick and Bruno (1986) argue, in turn, that the past experiences of polio survivors, how they view that their society treats survivors of polio, and their resulting behaviors will influence the psychological issues faced by those with Post Polio Syndrome. Such psychological issues include periods of mourning, changes of values, and asset evaluations. The period of morning occurs as the loss of physical prowess diminishes, new assistance devices become necessary, and recognition of realistic requirements for change in one’s lifestyle is needed (Frick & Bruno, 1986). Generally, the literature acknowledges the need for a period of morning by individuals experiencing Post Polio Syndrome, primarily because losses need to be acknowledged so that active coping can be initiated. For some polio survivors, the need to rely on braces, wheelchairs
and other equipment again can be seen as a sign of failure (Foster & Berkman, 1993). A common feeling is one of loss of the control from previous circumstances and feelings of being emotionally threatened because they can no longer hide their disabilities (Gordon & Feldman, 2002). Hence psychological issues come to the forefront about how to deal with something seen as a personal defeat or a negative circumstance in reference to one’s values.

Necessary changes in values for coping with Post Polio Syndrome include enlarging one’s scope of values from that of the body being the primary source of personal worth to a broader set of evaluative factors (Frick & Bruno, 1986). For polio survivors, substantial pressure existed to appear normal (i.e., not appearing physically different from their peers), particularly when they wanted to be accepted back into society (Bruno, 1995a). Moreover, parents often pushed polio survivors to equal or exceed their previous physical performance in efforts to forget that they had been stricken with polio (Frick, 1995). Hence the message sent to polio survivors was that acceptance resulted if they appeared as normal as possible. Maynard notes that individuals with Post-Polio syndrome who adopted the pattern of trying to “pass” as normal, often work very hard to hide their weakness or disability under a non-disabled disguise (Maynard & Roller, 1991). Thus, Polio survivors often cope by seeking to present a physically normal appearance and by learning to value other abilities.

The support of family members for post polio patients appears to have profound affects on the patient’s treatment and quality of life (Bruno, 2002). However, the expressed fears of polio survivors, many of which are based in past insecurities acquired during their original experiences with polio are barriers to asking for and accepting help with which family members must deal (Bruno, 2002). In many cases, polio survivors do not wish to be burdens for family members and prefer to not ask them for help (Bruno, 2002). In fact, some are afraid to ask for help due to fear of losing their family’s acceptance when assistance is requested. The survivors of polio want their family’s acceptance and respect because they often had problems relating to this challenge during their initial bout with polio (Creange & Bruno, 1997).

Bruno and Frick (1991) argue, based on their work with polio survivors, that, for some of these individuals, the way their families treated them during their original polio experiences often made a distinct impression on them. Survivors often harbor fears of abandonment based on the family ethos of shame for having a disabled child (Bruno & Frick, 1991). Specifically, this family norm has been internalized from the larger society’s expectations of what a ‘good’ family
should consist of (Bruno & Frick, 1991). The survivors have affirmed this early conditioning to appear normal within their current families. This desire to appear normal, in turn, has been motivated by fears of rejection should they appear less than what they always have been (Bruno & Frick, 1991). In fact, in their research and clinical work with patients, Creange and Bruno (1997) found that the fear of appearing weak or disabled appears to be connected with resistance to changes found in patient. This resistance to change leads to a lack of cooperation with medical professionals and others who are attempting to assist the individual with PPS (Creange & Bruno, 1997). Consequently, only a minority of individuals with Post Polio Syndrome have actually made changes to their home, asked for assistance, or acquired special equipment as recommended by experts (Creange & Bruno, 1997). The majority of persons with Post Polio Syndrome are not taking advantage of the most effective ways to deal with and maintain effective functionality (Creange & Bruno, 1997).

Ironically, family members often want to help out more and are very interested in learning more about polio and the Post Polio Syndrome so they can help their loved one as much as possible (Bruno, 2002). Overall, Bruno’s research in 1994 (cited in 2002 book) indicates that Post Polio patients are more likely to complete the treatment offered in his center if they have strong family support. Further, polio survivors depend on their families and intimate friends for assistance with tasks they can no longer do (Bruno, 2002).

Conversely, a particular complication is that, if a family begins to become too helpful, polio survivors tend to be less likely to accept this assistance (Bruno, 2002). If individuals with PPS rely too heavily on their families for help, a common fear they experience is the potential for rejection by those closest to the polio survivor (Westbrook, 1991a). Further, Westbrook found that lifestyle changes, which were the most obvious to family members, such as asking the family for help, buying special equipment, and making home modifications, were adopted by the fewest polio survivors (Westbrook, 1996). This lack of change comes despite the fact that, on the same survey, polio survivors rated making those changes as the most effective in helping to manage PPS (Westbrook, 1996). In his 1997 study, Bruno found that patients who used crutches or a wheelchair, also felt less adequate as family members.

These feelings of inadequacy are important for professionals to keep in mind as they deal with individuals with Post Polio Syndrome. Bruno argues that family members are essential for the individual to make the lifestyle changes needed, yet the family also needs to understand a
“survivor’s need” to feel valuable, despite their reduced physical activity and appearing ‘more disabled’ as the result of using necessary assistive devices (2002 p.235). Bruno further proposes a golden rule for PPS family members as follows: “know everything about PPS, say nothing, and help only when asked” (Bruno, 2002, p.238). The family is often cautioned at the Post-Polio Institute that being overly involved and forceful about assisting the individual with PPS can often lead to anger and frustration from the individual who the family is trying to help (Bruno, 2002). The family must keep in mind that the polio survivors does not want to feel like a burden to their families, thus each family must strive to assist as much as possible, without alienating the person they are trying to help. This suggests that providing assistance to Post-Polio patients is a delicate line for the family members to walk.

**Conclusion:**

Unfortunately, few resources currently exist for the families of individuals with PPS to tap into and help them walk this fine line. This dilemma was what this paper strived to begin addressing. As the child of a polio survivor, this author has had many questions come to mind about the process of the disease of Post-Polio Syndrome. As the symptoms of muscle weakness, pain, and other symptoms related to Post-Polio Syndrome contribute to changes in the abilities of loved ones, families are often left trying to fill in and help out, despite the fact that little evidence exists upon which solid advice can be offered on how to best proceed. This is further complicated by the distinct psychological and emotional history that polio survivors bring with them to their present day relationships.

Such a history includes how polio survivors initially coped with the disease and the resulting physical consequences that developed in the past. These individuals have used specific methods of coping with their previous illness and its consequences, some of which may now be causing conflict with the treatment and management of Post-Polio Syndrome. The learned drive of many polio survivors to appear normal, however, makes it difficult for them to request help, even from family members and intimate friends.

Given these circumstances, this thesis sought to take a snapshot that illustrates how the coping styles of the past might influence the present. Did the individuals with Post Polio Syndrome rely on the three coping styles identified by Maynard and Roller in 1991? By carefully analyzing the responses of polio survivors with Post Polio Syndrome, this paper attempted to categorize respondents as utilizing one of the three styles (passers, minimizers, or identifiers). If
assumed to reflect reality, what impact these coping styles have on whom the individual with
PPS asks for and accepts help from in their social network? The three coping styles identified by
Maynard and Roller (1991) were examined as to how each influenced the extent to which polio
survivors request and rely on assistance from their family members. Consequently, this study
hypothesized that, based on individual coping styles, a pattern would emerge as to whom (e.g.,
from other family members) individuals with PPS were most likely to rely upon for help. Also of
interest was the current effort to determine the extent to which individuals with Post Polio
Syndrome actually utilize their social network of potential helpers and what connection this
might have to coping style. Finally, each participant was asked to give voice to what he/she
would like his/her family to know about Post Polio Syndrome.
Chapter 3

Methodology

This chapter describes the methodology used in this research. First, the sampling strategy is discussed, followed by a section that describes the instruments used in data collection. Subsequently, procedures for data collection are explained and explored, followed by a final section that describes the data analysis plan.

Sample

Due to the disability of the target population to be sampled, data were collected via a web based listserv for persons with Post Polio Syndrome (PPS). One source of information and support for persons with PPS is the internet (Bridges, 2003). An exploration of this resource revealed several active listservs along with web pages devoted to the topic. These resources revealed various methods used by polio survivors to maintain contact with each other, including direct support group meetings, listservs, and other methods such as newsletters and non-electronic communication. Compared to drawing a sample from more conventional support groups or other non-electronic means, a web based survey was determined be the most efficient and cost effective option for reaching a sufficiently large group from which to draw the sample.

The sample was recruited from the 384 members of the listserv Post Polio Syndrome on Yahoo!’s group listing. The group’s home page describes the listserv as:

“Open to all those affected physically or emotionally by PPS as well as all those with an interest in PPS whatever that interest may be. Support each other, chat, provide new medical info, etc. Just getting started here? All ages welcome. If you want to know more about this condition; or if you are a polio survivor with or without PPS; or if you have someone in your life that deals with this.” (http://groups.yahoo.com/group/Post_Polio_Syndrome/?yguid=155500597, 2005).

This group was selected because the list has an average of 100 or more postings per month, has a sizeable membership, and, of the listservs reviewed, appeared to be the most open and active. The group/listserv is based in the United States and all of its members use English to communicate with each other. Moreover, each participant appears to be capable of using a computer, accessing the internet, and typing.
Sample Demographics

A total of thirty-three individuals responded to the initial email recruitment and 24 of those individuals completed the survey. The basic demographic data gathered included age, gender, marital status, and education. Demographic information specific to polio survivors consisted of age at initial polio infection, age of diagnosis of Post Polio Syndrome, and level of original disability.

First to be described are the age of the sample at the time of the research, the age the participants initially had polio, and the age of their official diagnosis of having Post Polio Syndrome. The age range of the sample was 35 years, with the youngest participant being 39 years of age and the oldest reporting an age of 74. The mean age of the group was 55.38 with a median age of 54 and a standard deviation 7.67. The range of age for the initial polio infection was 14.5 years, with the extremes for this sample varying from an age of six months to 15 years of age. The mean age for polio infection was 3.3 years of age, with a median being 2.00 and a standard deviation of 3.64. Due to the existence of outliers consisting of one case of polio at the age of 15 and another at the age of 13, a strong positive skewness (2.340) existed in the sample for age. In point of fact, 91.7% (n=22) of the sample falls between the age of six months to 5 years of age. (see table 1)

Concerning the age of diagnosis of Post Polio Syndrome, of the 24 participants, only 16 had the official diagnosis of Post Polio Syndrome. Identifying that someone has Post Polio Syndrome involves a complicated diagnostic process through which other possibilities are eliminated, a fact that makes it understandable why the remaining eight participants did not have an official/ diagnosis of Post Polio Syndrome (Bruno, 2002). Several participants, in fact, also blamed a lack of knowledge about Post Polio Syndrome within the medical community as a source of frustration. Of the sixteen who have an official diagnosis of Post Polio Syndrome, the range is 32 years, with the youngest diagnosis coming at the age of 28 and the oldest diagnosis occurring at the age of 60. A mean age of 46.06 and a median age of 48 indicate a negative skew to the data. (See Table 1 below). The standard deviation was 9.55.
Table 1: Age Statistics of the sample

<table>
<thead>
<tr>
<th></th>
<th>N</th>
<th>Mean</th>
<th>Median</th>
<th>Minimum</th>
<th>Maximum</th>
<th>Std. Deviation</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age</td>
<td>24</td>
<td>55.38</td>
<td>54.00</td>
<td>39</td>
<td>74</td>
<td>7.666</td>
</tr>
<tr>
<td>Age of Initial Polio</td>
<td>24</td>
<td>3.3092</td>
<td>2.0000</td>
<td>.50</td>
<td>15.00</td>
<td>3.63891</td>
</tr>
<tr>
<td>Age of Diagnosis of PPS</td>
<td>16</td>
<td>46.06</td>
<td>48.00</td>
<td>28</td>
<td>60</td>
<td>9.553</td>
</tr>
</tbody>
</table>

A second aspect is the additional basic demographics of the sample. Of the 24 participants (19 were female or 79.2% and 5 were male or 20.8%). As to marital status, the largest subgroup was married (66.7%, n=16), with divorced (25%, n=6), and widowed (8.3%, n=2) following successively in numbers. The majority of the subjects have post high school educations, with 37.5% (n=9) reporting some college, 16.7% (n=4) reporting a college degree, one reporting a masters degree, two having PhD’s and two additional subjects having some graduate work. One individual reported having a junior college degree, while 8.3% (n=2) reported some high school and 12.5% (n=3) the completion of high school as their level of educational attainment. The subjects were not requested to report their race/ethnicity as part of this survey.

The final demographic specific to this group was the level of disability the participants reported after their initial recovery from polio. A majority or 75% reported mild to moderate disability (n=9 for each category), whereas, only two reported severe disabilities and only four reported no noticeable disability. Overall, this sample is a well-educated sample, primarily consisting of females who are or had been married at one time. Further, the majority reported a diagnosis of Post Polio Syndrome and has experienced some disability after their initial polio.

Instrumentation

The web-based survey consisted of items that assess demographics, the social network of potential helpers and actual helpers, basic information about the participants’ polio and post polio experience, the coping style they used when they had polio, and, for both ADLs and IADLs, what help they require as well as who provides this help (see Appendix E). The
demographic data included age, gender, and education level. Additional items recorded when the individual had polio and when he/she was diagnosed with Post Polio Syndrome. The web-based survey was designed to require the least amount of typing by the individual in response to concerns that individuals may have weaknesses in their hands or fatigue.

Coping style assessment is based on the three coping styles as identified by Maynard and Roller in their 1991 article. Maynard and Roller provide text descriptions of three orientations they name passers, minimizers and identifiers:

Polio minimally affected my life originally. The physical weakness it left me with was mild so I could easily hide it. I do not even consider myself disabled. In fact, only my immediate family and intimate friends know that I had polio. I really do not like to talk about my experience with Polio. - identifies the Passers

Polio left me with a physical weakness that I cannot hide from people. Therefore, I work hard to push myself in other areas, so my weakness is not very important. I push myself to achieve whatever I set my mind to despite any physical limitations I have. Often I ignore pain and fatigue in order to complete a task. - identifies the Minimizers

Polio left me disabled. I have to use a wheelchair, braces, or canes to help me get around. I have strived to achieve my goals and consider myself an advocate for those like myself. I am proud of what I am and what I have achieved. - represents the Identifiers.

Based on these descriptions provided in Maynard and Roller’s 1991 article, a set of descriptors was developed for this study. Participants were asked to identify which of the statements that best fits how they coped. Specifically the question will read: “Thinking back to when you were at your physical best and up to the time before the new symptoms of Post Polio Syndrome appeared, which of the following do you most closely identify with? (Please choose as many as you need to)” (see Table 1 for breakdown of statements by coping style)
### Table 2: statements based on coping styles

<table>
<thead>
<tr>
<th>Passers</th>
<th>Minimizers</th>
<th>Identifiers</th>
</tr>
</thead>
<tbody>
<tr>
<td>Polio minimally affected my life originally.</td>
<td>Polio left me with a physical weakness that I cannot hide from people.</td>
<td>Polio left me disabled.</td>
</tr>
<tr>
<td>The physical weakness it left me with was mild so I could easily hide it.</td>
<td>I work hard to push myself in other areas, so my weakness is not very important.</td>
<td>I have to use a wheelchair, braces, or canes to help me get around.</td>
</tr>
<tr>
<td>I do not even consider myself disabled.</td>
<td>I push myself to achieve whatever I set my mind to despite any physical limitations I have.</td>
<td>I have striven to achieve my goals and consider myself an advocate for those like myself.</td>
</tr>
<tr>
<td>Only my immediate family and intimate friends know that I had polio.</td>
<td>Often I ignore pain and fatigue in order to complete a task.</td>
<td>I am proud of what I am and what I have achieved.</td>
</tr>
<tr>
<td></td>
<td>I really do not like to talk about my experience with Polio.</td>
<td></td>
</tr>
</tbody>
</table>

In addition, these styles of coping are linked by Maynard and Roller to the level of physical disability that polio had caused originally for the survivor. In order to capture this aspect of the coping types, each participant was asked to identify the level of disability he/she experienced when he/she was at his/her physical best after polio. Individuals who answer no disability or no noticeable disability would qualify under the passer characteristics. Individuals who answer mild or moderate disability would fall under the minimizer category. Finally, individuals who answer severe disability would be counted as identifiers.

Other components of this assessment were survey items or modifications of survey items from the *National Health Interview Survey of Disability, Phase II, 1994-1995*. Specifically, the Centers for Disease Control conducted the National Health Interview Survey on Disability in 1994 and 1995 which included a subset of questions on Polio (National Center for Health Statistics, 2000). A total of 202,560 individuals were surveyed, with interviewers assessing the Activities of Daily Living (ADLs), Instrumental Activities of Daily Living (IADLs), and the individual’s perceptions of their abilities when they were at their best and at the present time (National Center for Health Statistics, 1994c). The tasks identified include bathing or showering; dressing; eating; getting in and out of chairs; walking; other transportation; light housework; heavy housework; preparing own meals; and shopping (National Center for Health Statistics,
These standardized categories of ADLs and IADLs were reviewed and validated in the Sirken’s “Integrating measurements of disability in Federal surveys: Seminar proceedings” which appeared in 2002 volume of *Vital Health Stat*. For each task the subjects were asked to identify if they need assistance by answering “yes”, “no”, or “I don’t do this.” This set of items is consistent with the questions asked in the National Health Interview Survey on Disability’s polio questionnaire (National Center for Health Statistics, 1994c). If they answer “yes”, the participant was asked to identify who assists them.

The size of the social network of potential helpers was identified through a series of questions that ask participants’ marital status, if they have children and how many, as well as the number of other family members and friends who are available to assist them. To determine who actually helps, in addition to indicating need for and who is available for assistance, participants provided information on all those who actually helps with specific ADL and IADL tasks, and how that person was related to the participant. The final question asked if the participants have anything that they would like their family and friends to know or understand about PPS?

**Research Procedures**

The primary investigator emailed the Post Polio Syndrome listserv owner, or the individual who is in charge of and who monitors what is allowed on the listserv. The purpose of this e-mail was to request permission to post a message for volunteers to participate in this study (see appendix A for email to listserv owner). Once the listserv owner granted permission (see appendix A for listserv owner’s response) and the study proposal reviewed and approved by the Miami University Institutional Review Board for Human Subjects Research (IRB), an email was sent to members of the listserv asking for volunteer participants (See appendix B for email to listserv). To assure confidentiality, volunteers were asked to respond directly to the primary investigator instead of the listserv.

Upon receipt of email responses from potential participants, the primary investigator emailed additional information about the study to the individuals. This communication included information about the subject’s rights and the measures taken to ensure confidentiality (see appendix C). Each participant was asked to respond with an email stating they understand their rights, give consent for their information to be used in the study, and grant permission to use their data for professional presentations and publications. Only then was each individual given an identification number and the web address for the survey (see Appendix D). At the web site, the
welcome page again stated the individual’s rights and the confidentiality of the study before the participant responds to the survey.

The survey was a form on the web that emailed the responses to the researcher as each participant submitted their answers. A database was constructed from the participants’ responses to the returned surveys using the identification numbers to distinguish between the participants. After the data was received, each participant then proceeded to a web page which thanked them for their participation, reviewed where they could go for more information, and provided them with a list of places where more information about Post Polio Syndrome could be found.

**Analytic Plan**

Data analysis for this research was conducted in three phases using the Statistical Package for the Social Sciences, Version 13 (Apache Software Foundation, 2004). In phase one, basic descriptive statistics, and demographic statistics were computed. This includes age, gender, education level, marital status, age of original polio, and age of diagnosis with Post Polio Syndrome. This permitted the identification of outlying values, measures of central tendency, and any possible errors in data coding and/or entry for all variables. A primary purpose of these initial analyses, of course, was to provide a description of the sample.

Phase two consisted of the construction of all of the composite variables. This includes coping styles, social network, and ADL/IADL assistance. The basis for the analysis of coping styles were the 13 statements that the participants were asked to check if they apply and the question about their level of disability following their initial experience with polio. As previously indicated, each level was identified with a particular coping style.

The statements were counted by coping style. An average was taken for each of the four categories to compute their scores on each coping style. The investigator acknowledges that an individual may fall between two categories, i.e. passer and minimizer or minimizer and identifier. Since a significant number of respondents show similar mixed results, two new categories were created to better fit their responses. For further analysis of the frequency of the statements Table 4 (see pg 36 in next chapter) was created with the frequency of the statements to review for other patterns.

The composition of the social network of potential helpers was computed by adding up the total number of individuals identified by the participant as being available to help based on filial relationships. Subsequently, each participant was asked to identify who helps with both
ADLs and IADLs, taking into account that more than one individual may assist them with each task. Thus the participant was asked to list as many individuals who assist them based on their relationship per task. The number of actual helpers were then added up to gain totals within each category (i.e. spouse, child, friend) across all of the participants. The availability of data on both potential and actual helpers allowed computation of proportion of helpers in addition to the absolute number of helpers in subsequent analyses.

Upon the construction of the composite variables, the major analyses were conducted in phase three. In order to determine who is asked for help, a series of frequency tables were constructed. The first table presented the potential pool of helpers as a function of kinship type (i.e. spouse, children, other relatives, friends). Next, a series of tables were constructed that presented actual helpers used as a percent of potential helpers, as a function of kinship type for ADLs and IADLs. To examine helpers as a function of coping style, similar tables were generated for the separate coping styles. To determine whether there were significant differences in who helps as a function of coping style, one-way ANOVA’s were conducted using a p<.05 as the criterion for statistical significance. The resulting tables are displayed in the next chapter.

Finally, a qualitative analysis was conducted to analyze the responses to the question asking what the individual with PPS wanted his/her family to know about the syndrome. In order to analyze the responses, the researcher read the responses over one time. Subsequently, a general set of categories was created, with the purpose being to match each statement with a category that characterized what the participants were expressing. Once categories were identified, the categories were defined on a page of paper. Each statement was read again and a tick made next to the category or categories which were mentioned in the statement. (See Appendix G for all of the responses to the open ended question.) The results were then analyzed and a description was created to describe the common themes concerning what the participants wanted their family and friends to know.
Chapter 4

Findings

This chapter presents the results of the analyses based on the data gathered with the survey instrument used for this project. These analyses involved both the production of descriptive statistics and completion of analyses that addressed specific issues within a sample of PPS participants. Using the analysis plan described in the previous chapter, three phases of data examination and analysis were pursued in this study. Phase one, concerned with sample demographics, was completed and reported in the previous chapter. Phase two involved the creation of variables that were constructed based on data returned in the project survey. Finally, phase three focused on data analyses of primary concern that addressed the key issues addressed by this study. Consistent with the current plan of analysis, the variables coping styles and social network were constructed, followed by the report of the primary data analyses for this study.

Phase Two: Variable construction

Coping styles utilized

Each participant was presented with a set of thirteen statements, each of which represented a specific coping style. Subsequently, the statements selected by each participant were noted and the number of statements per coping style was computed by counting the total number selected. In addition, consistent with the procedures described by Maynard and Roller (1991), each individual was asked to identify his/her level of disability after polio, which was then matched with one of the three coping style strategies. As discussed in chapter 3, Maynard and Roller included the original level of disability in their description of various coping styles. In order to represent this aspect of the variable, each participant was asked to answer what level of disability he/she had after the initial polio. In the analysis phase the answer to that question was translated into which coping style it matched as stated above. From there it was simply counted as equal to one of the coping statements checked by the participants. It was added into the final coping style score from there.

The score each participant had in each of the original three coping typologies were examined and several participants were found to have equal scores in two categories. As a result the researcher created two additional categories beyond the original categories of passer,
The two new categories (i.e., passer/minimizer and minimizer/identifier) were “hybrids” that fell between the original categories and formed a larger set of categories consisting of passer, passer/minimizer, minimizer, minimizer/identifier, and identifier. Of the total sample of 24 participants, 45.8% of the sample (n=11) were classified in the minimizer category, 25% (n=6) of the sample represented the minimizer/identifier category, 16.7% (n=4) of the sample were classified in the passer/minimizer category, and 12.5% (n=3) of the sample fell into the passer category. None of the participants fell into the identifier category (See Table 3 for frequencies). The frequencies in Table 3 support Maynard and Roller’s (1991) finding that minimizer statements were the most frequently selected responses, with minimizer/identifier being the second most frequent responses.

**Table 3 Coping style used**

<table>
<thead>
<tr>
<th></th>
<th>Frequency</th>
<th>Percent</th>
<th>Cumulative Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Passer</td>
<td>3</td>
<td>12.5</td>
<td>12.5</td>
</tr>
<tr>
<td>Passer/Minimizer</td>
<td>4</td>
<td>16.7</td>
<td>29.2</td>
</tr>
<tr>
<td>Minimizer</td>
<td>11</td>
<td>45.8</td>
<td>75.0</td>
</tr>
<tr>
<td>Minimizer/Identifier</td>
<td>6</td>
<td>25.0</td>
<td>100.0</td>
</tr>
<tr>
<td>Identifier</td>
<td>0</td>
<td>0</td>
<td>100.0</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td>24</td>
<td>100.0</td>
<td></td>
</tr>
</tbody>
</table>

As discussed in Chapter 3, the statements of coping styles were based on Maynard and Roller’s 1991 work. In order to check how accurately the statements fit into the typologies, an examination of the frequency of selection for each statement was completed. Table 4 was created to check for any anomalies or outliers among the statements. Table 4 reflects how often a specific kind of statement within each coping style was selected by the participants and the percent of the sample that agreed or identified with a specific statement.

As shown in Table 4, the minimizer statements numbered 1 through 4 were selected by the participants in frequencies that varied from 15-21, a pattern of selection that supported previous findings that minimizers were the largest group in the sample. Table 4 also shows that passer statements were selected with the next highest rate and that identifier statements were selected at the lowest rate, except for the Identifier 4 statement. Considering individual statements, the Minimizer 4 and Identifier 4 statements were the most frequently selected statements. In particular, the statement identified as Minimizer 4 which reads, “Often I ignore pain and fatigue in order to complete a task”, was selected by 87.5% (n=21) of the sample. In
addition, the statement identified as Identifier 4 in the study was selected by 79% (n=19) of the sample as applying to themselves (see Table 4).

Table 4 Frequency and Percentage of Participants Who Endorsed Each Coping Style Statement

<table>
<thead>
<tr>
<th>Statement identification</th>
<th>Coping statement</th>
<th>f</th>
<th>Percent of sample</th>
</tr>
</thead>
<tbody>
<tr>
<td>Passer 1</td>
<td>Polio minimally affected my life originally.</td>
<td>11</td>
<td>46</td>
</tr>
<tr>
<td>Passer 2</td>
<td>The physical weakness it left me with was mild so I could easily hide it.</td>
<td>6</td>
<td>25</td>
</tr>
<tr>
<td>Passer 3</td>
<td>I do not even consider myself disabled.</td>
<td>13</td>
<td>54</td>
</tr>
<tr>
<td>Passer 4</td>
<td>Only my immediate family and intimate friends know that I had polio.</td>
<td>7</td>
<td>29</td>
</tr>
<tr>
<td>Minimizer 1</td>
<td>Polio left me with a physical weakness that I cannot hide from people.</td>
<td>15</td>
<td>62.5</td>
</tr>
<tr>
<td>Minimizer 2</td>
<td>I work hard to push myself in other areas, so my weakness is not very important.</td>
<td>16</td>
<td>66.7</td>
</tr>
<tr>
<td>Minimizer 3</td>
<td>I push myself to achieve whatever I set my mind to despite any physical limitations I have.</td>
<td>17</td>
<td>70.8</td>
</tr>
<tr>
<td>Minimizer 4</td>
<td>Often I ignore pain and fatigue in order to complete a task.</td>
<td>21</td>
<td>87.5</td>
</tr>
<tr>
<td>Minimizer 5</td>
<td>I really do not like to talk about my experience with Polio.</td>
<td>5</td>
<td>20.8</td>
</tr>
<tr>
<td>Identifier 1</td>
<td>Polio left me disabled.</td>
<td>5</td>
<td>20.8</td>
</tr>
<tr>
<td>Identifier 2</td>
<td>I have to use a wheelchair, braces, or canes to help me get around.</td>
<td>6</td>
<td>25</td>
</tr>
<tr>
<td>Identifier 3</td>
<td>I have strived to achieve my goals and consider myself an advocate for those like myself.</td>
<td>8</td>
<td>33.3</td>
</tr>
<tr>
<td>Identifier 4</td>
<td>I am proud of what I am and what I have achieved.</td>
<td>19</td>
<td>79</td>
</tr>
</tbody>
</table>

Further analysis of the coping style variable are presented in phase three.

**ADL and IADL tasks**

Each participant was asked to identify the specific daily activities with which he/she needed assistance. These activities were conceptualized into two groups of daily endeavors, Activities of Daily Living (ADLs) and Instrumental Activities of Daily Living (IADLs). ADLs consisted of bathing, dressing, eating, transfers and walking, whereas IADLs consisted of transportation, light housework, heavy housework, meal preparation, and shopping. Each participant was asked to indicate if he/she didn’t need help with a task, needed assistance with the task, or did not do the task. Subsequently, the total number of these tasks with which the individual required assistance was calculated. The respective mean and median number of ADLs with which participants needed assistance was 0.42 and 0. Correspondingly, the mean and
median number of IADLs tasks with which the participants required assistance was 2.38 and 3.0, respectively.

As shown in the last column of Table 5 for the twenty-four participants, only eight individuals, or 33%, need assistance with ADL tasks. Moreover, as revealed in Table 5, the participants primarily needed assistance with the ADL tasks of walking and transfers. Walking was the ADL task that the most participants either needed help with (n=8) or did not do (n=2). (See Table 5) Next came transfers, or the task of getting out of a bed or chair, with two requiring assistance with this activity. One individual, in turn, reported that both bathing and dressing was a task with which he/she needed help. None of the respondents reported the need for assistance with eating.

Table 5 ADLs and IADLS help frequencies

<table>
<thead>
<tr>
<th>ADLs</th>
<th>Need assistance?</th>
<th>Bathing assistance</th>
<th>Dressing assistance</th>
<th>Eating assistance</th>
<th>Transfer assistance</th>
<th>Walking assistance</th>
<th>With one or more?</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Yes</td>
<td>1</td>
<td>1</td>
<td>0</td>
<td>2</td>
<td>8</td>
<td>8</td>
</tr>
<tr>
<td></td>
<td>No</td>
<td>23</td>
<td>32</td>
<td>24</td>
<td>22</td>
<td>14</td>
<td>15</td>
</tr>
<tr>
<td></td>
<td>I don’t do this</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>1</td>
<td>1</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>IADLs</th>
<th>Need assistance?</th>
<th>Transportation assistance</th>
<th>Light housework assistance</th>
<th>Heavy Housework assistance</th>
<th>Preparing meals</th>
<th>Shopping</th>
<th>With one or more?</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Yes</td>
<td>8</td>
<td>9</td>
<td>17</td>
<td>7</td>
<td>17</td>
<td>20</td>
</tr>
<tr>
<td></td>
<td>No</td>
<td>14</td>
<td>14</td>
<td>5</td>
<td>14</td>
<td>7</td>
<td>2</td>
</tr>
<tr>
<td></td>
<td>I don’t do this</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>0</td>
<td>2</td>
</tr>
</tbody>
</table>

Concerning the IADL tasks shown in Table 5, 20 of the 24 participants reported that they needed at least some assistance with IADLs. By comparing the number of those who answered “yes” to needing assistance with the various tasks in Table 5, one finds that 17 or 70.8% of these respondents identified heavy housework and shopping as activities that required assistance. Light housework was the next most commonly reported task requiring assistance, with 9 reporting they needed help and one participant indicating that he/she did not do the task. Eight participants indicated a need for help with transportation and 7 individuals reported the need for help with meal preparation (one participant reported that he does not do this task).
Table 5 provides the opportunity to compare the number of IADL tasks the participants needed assistance to the number of ADL tasks that the participants reported needing assistance to complete. Table 5 shows that only a maximum of eight participants reported needing assistance with one or more ADL tasks in comparison to the fact that as many as twenty participants reported needing assistance with one or more IADL tasks. This result demonstrates that the participants required assistance with IADLs at virtually twice the level needed for ADLs.

**Social Network of Helpers**

The social network of helpers for each participant was determined by asking each respondent to identify: (1) who they perceived as being able and willing to provide assistance should they need it, and (2) who actually assisted them. Moreover, the participants were asked to specify the nature of their relationship with each of their identified helpers. Thus the responses were split into the categories (1) Available Help network and (2) Received Help network. After examining the data for patterns, a set of categories was created for analysis in phase three of the analysis plan. The main two categories were Family Help and Friend Help. The Family Help category included the subcategories Spouse Help, Child Help, Parent Help, Sibling Help and Other Family Help (Other Family Help included in-laws, stepchildren and cousins.). Additional categories identified were Hired Help and Service Dog Help. Each of these subcategories was then further subdivided into Available Help and Received Help.

An examination of the Available Help network shows that a majority (87.5% or n=21) of the sample identified an available network of helpers consisting of under 6 members. The mean number of Available Help is 3.79, with a median of 3.00, an indication that the distribution is positively skewed. Such a skewed pattern is further indicated by the three outliers or participants who identified help networks of 8, 12 and 14 persons. (See Table 6)

Table 6 gives a summary of the available help network size and the categories mentioned above. The last row in Table 6 indicates that a total of 21 out of 24 participants cited at least one family member as an available helper, whereas only 11 cite friends as potential helpers. Another evident pattern in Table 6 is that family members consisting of spouses and children were most commonly identified as available helpers. Spouses were identified as an available helper by 13 of 24. Further, twelve participants designate children as potential helpers in addition to or instead of spouses. Three individuals identified siblings as potential helpers and 4 designated other family members as potential helpers. Somewhat unexpected categories were the 4 individuals who
employed hired help while another individual indicated that they had a service dog. Parents were identified by only 1 participant as potential helpers.

**Table 6 Available Help Network Sizes**

<table>
<thead>
<tr>
<th>Available Members</th>
<th>Family</th>
<th>Friend</th>
<th>Spouse</th>
<th>Child</th>
<th>Parent</th>
<th>Sibling</th>
<th>Other Family</th>
<th>Hired Help</th>
<th>Service Dog</th>
<th>Total Available Help</th>
</tr>
</thead>
<tbody>
<tr>
<td>0</td>
<td>3</td>
<td>13</td>
<td>11</td>
<td>12</td>
<td>23</td>
<td>21</td>
<td>20</td>
<td>20</td>
<td>23</td>
<td>2</td>
</tr>
<tr>
<td>1</td>
<td>7</td>
<td>5</td>
<td>13</td>
<td>3</td>
<td>1</td>
<td>1</td>
<td>4</td>
<td>1</td>
<td>1</td>
<td>7</td>
</tr>
<tr>
<td>2</td>
<td>4</td>
<td>3</td>
<td>6</td>
<td>1</td>
<td>2</td>
<td>2</td>
<td>1</td>
<td>1</td>
<td>1</td>
<td>3</td>
</tr>
<tr>
<td>3</td>
<td>4</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>3</td>
<td></td>
</tr>
<tr>
<td>4</td>
<td>2</td>
<td>1</td>
<td>3</td>
<td></td>
<td></td>
<td></td>
<td>1</td>
<td></td>
<td>3</td>
<td></td>
</tr>
<tr>
<td>5</td>
<td>1</td>
<td>1</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>3</td>
<td></td>
</tr>
<tr>
<td>6</td>
<td>2</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>2</td>
<td></td>
</tr>
<tr>
<td>7</td>
<td>1</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>1</td>
<td></td>
</tr>
<tr>
<td>8</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>1</td>
<td></td>
</tr>
<tr>
<td>9</td>
<td>1</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>1</td>
<td></td>
</tr>
<tr>
<td>12</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>1</td>
<td></td>
</tr>
<tr>
<td>14</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>1</td>
<td></td>
</tr>
<tr>
<td><strong>Total who identified one or more</strong></td>
<td><strong>21</strong></td>
<td><strong>11</strong></td>
<td><strong>13</strong></td>
<td><strong>12</strong></td>
<td><strong>1</strong></td>
<td><strong>3</strong></td>
<td><strong>4</strong></td>
<td><strong>4</strong></td>
<td><strong>1</strong></td>
<td><strong>22</strong></td>
</tr>
</tbody>
</table>

The next category, Received Help, was created when the participants identified who actually helped them with various Activities of Daily Living (ADL) and Instrumental Activities of Daily Living (IADLs). Specifically, this category of Received Help refers to those individuals who actually assisted the PPS respondents with the activities in question. The mean for received help among these participants was 1.71, with the highest total of received help for one participant totaling 6 individuals. Here again, family members are the category most relied upon for received help. The mean number of family members from whom the participants received help was 1.33, with the corresponding median being 1.00. All the other categories have means less than .60 and medians of 0.

Table 7 shows the received help in a similar fashion to how Table 6 shows available help. In Table 7, children and spouses are the largest subcategories among those who actually provided help to the respondents. Of the 24 respondents, only 10 received help from his/her spouse. Given that 16 of the 24 participants were married and, if the 10 who received help from spouses are divided by the 16 who are married, this indicates that only 62.5% of those who are
married received help from his/her spouse. Nine participants received help from their children, whereas 1 participant received help from parents. These patterns demonstrate that intergenerational support is selectively utilized by the participants. Two received help from siblings and none received help from other family members. (See Table 7).

Table 7 Received Help Network Size (marked as having helped with an ADL or IADL)

<table>
<thead>
<tr>
<th>Number of Network Members Utilized</th>
<th>Family</th>
<th>Friend</th>
<th>Spouse</th>
<th>Child</th>
<th>Parent</th>
<th>Sibling</th>
<th>Other Family</th>
<th>Hired Help</th>
<th>Service Dog</th>
<th>Total Available Help</th>
</tr>
</thead>
<tbody>
<tr>
<td>0</td>
<td>7</td>
<td>17</td>
<td>14</td>
<td>15</td>
<td>23</td>
<td>22</td>
<td>24</td>
<td>20</td>
<td>23</td>
<td>4</td>
</tr>
<tr>
<td>1</td>
<td>8</td>
<td>7</td>
<td>10</td>
<td>4</td>
<td>2</td>
<td>4</td>
<td>1</td>
<td>1</td>
<td>1</td>
<td>9</td>
</tr>
<tr>
<td>2</td>
<td>6</td>
<td></td>
<td>5</td>
<td>1</td>
<td></td>
<td></td>
<td></td>
<td>5</td>
<td></td>
<td>4</td>
</tr>
<tr>
<td>3</td>
<td>2</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>4</td>
</tr>
<tr>
<td>4</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>1</td>
</tr>
<tr>
<td>6</td>
<td>1</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>1</td>
</tr>
<tr>
<td>Total participants who utilize this help</td>
<td>17</td>
<td>7</td>
<td>10</td>
<td>9</td>
<td>1</td>
<td>2</td>
<td>0</td>
<td>4</td>
<td>1</td>
<td>20</td>
</tr>
</tbody>
</table>

Other categories of those who received help demonstrate lower frequencies occurred, with only 29.2% (n=7) of the sample receiving help with ADLs or IADLs from friends (See Table 7). The results in Table 7 also suggest that the 4 respondents who hired help to assist with their activities and 1 individual who had a service dog reported actually using this help. Such patterns indicate that some individuals may not utilize their whole social network that is available.

The next step was to calculate the percent of help used by the Received Help Groups relative to the Available Help Groups to provide greater insight into the extent to which the participants actually utilize their social networks. The Percent of Help actually used is calculated by dividing the Received Help in each category of helper by the Available Help in the same category. All of these calculations are reported in Appendix H and indicate that 6 participants utilized none of their available help and 9 reported utilizing 100% of their available help network.

Specific statistics about the percent of help used is shown in Table 8. For the sample of 24 respondents, the mean percent for the size of the social network utilized was 53.8%, with a corresponding median of 55%. Figure 2, a histogram, shows the spread of the total network.
response percentages and demonstrates a bimodal distribution pattern, with only 24% (n=6) of the individuals’ responses falling between 1 and 99 percent of the network used.

Table 8 Percent of Help Used Statistics

<table>
<thead>
<tr>
<th></th>
<th>Family</th>
<th>Friend</th>
<th>Spouse</th>
<th>Child</th>
<th>Parent</th>
<th>Sibling</th>
<th>Other Family</th>
<th>Hired help</th>
<th>Service Dog</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mean</td>
<td>55.54</td>
<td>18.75</td>
<td>50.00</td>
<td>30.21</td>
<td>4.17</td>
<td>6.25</td>
<td>4.17</td>
<td>12.50</td>
<td>4.17</td>
<td>53.83</td>
</tr>
<tr>
<td>Median</td>
<td>50.00</td>
<td>0</td>
<td>50.00</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>55.00</td>
</tr>
</tbody>
</table>

Figure 2: Percent of Helping Network Used

Further examination of Table 8 shows that when the responses for percent of help used for assistance are examined, it appears that these percentages (55.54% and a median of 50%) confirm the common expectation that family members are the primary source relied upon. However, when examining the percent of friends utilized, one finds that 18.75% is the mean and 0% is the median, indicating that 19 of 24 or 79.2% do not utilize their friends for assistance. At least for this sample, therefore, family members were used more extensively than other social network members for assistance with ADLs and IADLs.
Phase three: Hypothesis Analysis

A one-way analysis of variance (ANOVA was conducted on each category of assistance to test the hypothesis that coping style would be related to the size of available help, received help and percent of help actually utilized. Coping style was expected to have a significant effect on the size of the available help network, the received help and percent of the network actually used. Contrary to expectation, however, these analyses demonstrated that no relationships existed between the individual coping style used and the size of the available helping network, the received help or the percent of help actually utilized (p<.05) (see Table 9). Additional one-way ANOVA analyses were conducted using the individual coping style statements, as shown in Table 9, as the independent variables and the help network categories available, received and percent used as the dependent variables. After examining the responses of the participants several statements were found to be mutually exclusive. These statements have been categorized by their exclusivity resulting in a set of four categories of coping statements. Once again, none of these tests demonstrated significant effects.

Table 9 ANOVA analysis of coping styles and help network sizes

<table>
<thead>
<tr>
<th></th>
<th>Sum of Squares</th>
<th>df</th>
<th>Mean Square</th>
<th>F</th>
<th>Sig.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Available help total</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Between Groups</td>
<td>28.905</td>
<td>3</td>
<td>9.635</td>
<td>.733</td>
<td>.545</td>
</tr>
<tr>
<td>Within Groups</td>
<td>263.053</td>
<td>20</td>
<td>13.153</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Total</td>
<td>291.958</td>
<td>23</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Received total help</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Between Groups</td>
<td>5.383</td>
<td>3</td>
<td>1.794</td>
<td>.863</td>
<td>.476</td>
</tr>
<tr>
<td>Within Groups</td>
<td>41.576</td>
<td>20</td>
<td>2.079</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Total</td>
<td>46.958</td>
<td>23</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Percent total help</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Between Groups</td>
<td>1281.447</td>
<td>3</td>
<td>427.149</td>
<td>.205</td>
<td>.892</td>
</tr>
<tr>
<td>Within Groups</td>
<td>41617.886</td>
<td>20</td>
<td>2080.894</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Total</td>
<td>42899.333</td>
<td>23</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Table 10 one-way ANOVAs of coping statements relationship to help networks

**Coping Statements group 1**
Passer 1: Polio minimally affected my life originally.
Minimizer 1: Polio left me with a physical weakness that I cannot hide from people
Identifier 1: Polio left me disabled.

<table>
<thead>
<tr>
<th></th>
<th>Sum of Squares</th>
<th>df</th>
<th>Mean Square</th>
<th>F</th>
<th>Sig.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Available help total</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Between Groups</td>
<td>34.778</td>
<td>2</td>
<td>17.389</td>
<td>1.077</td>
<td>.366</td>
</tr>
<tr>
<td>Within Groups</td>
<td>242.167</td>
<td>15</td>
<td>16.144</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Total</td>
<td>276.944</td>
<td>17</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Received total help</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Between Groups</td>
<td>2.056</td>
<td>2</td>
<td>1.028</td>
<td>.403</td>
<td>.675</td>
</tr>
<tr>
<td>Within Groups</td>
<td>38.222</td>
<td>15</td>
<td>2.548</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Total</td>
<td>40.278</td>
<td>17</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Percent total help</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Between Groups</td>
<td>5274.944</td>
<td>2</td>
<td>2637.472</td>
<td>1.382</td>
<td>.281</td>
</tr>
<tr>
<td>Within Groups</td>
<td>28631.556</td>
<td>15</td>
<td>1908.770</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Total</td>
<td>33906.500</td>
<td>17</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

**Coping Statements group 2**
Passer 2: The physical weakness it left me with was mild so I could easily hide it.
Minimizer 2: I work hard to push myself in other areas, so my weakness is not very important.
Identifier 2: I have to use a wheelchair, braces, or canes to help me get around.

<table>
<thead>
<tr>
<th></th>
<th>Sum of Squares</th>
<th>df</th>
<th>Mean Square</th>
<th>F</th>
<th>Sig.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Available help total</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Between Groups</td>
<td>12.419</td>
<td>2</td>
<td>6.210</td>
<td>.413</td>
<td>.668</td>
</tr>
<tr>
<td>Within Groups</td>
<td>270.533</td>
<td>18</td>
<td>15.030</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Total</td>
<td>282.952</td>
<td>20</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Received total help</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Between Groups</td>
<td>1.219</td>
<td>2</td>
<td>.610</td>
<td>.263</td>
<td>.772</td>
</tr>
<tr>
<td>Within Groups</td>
<td>41.733</td>
<td>18</td>
<td>2.319</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Total</td>
<td>42.952</td>
<td>20</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Percent total help</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Between Groups</td>
<td>1356.310</td>
<td>2</td>
<td>678.155</td>
<td>.337</td>
<td>.718</td>
</tr>
<tr>
<td>Within Groups</td>
<td>36218.833</td>
<td>18</td>
<td>2012.157</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Total</td>
<td>37575.143</td>
<td>20</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Coping statements group 3
Passer 3: I do not even consider myself disabled.
Minimizer 3: I push myself to achieve whatever I set my mind to despite any physical limitations I have.
Identifier 3: I have strived to achieve my goals and consider myself an advocate for those like myself.

<table>
<thead>
<tr>
<th></th>
<th>Sum of Squares</th>
<th>df</th>
<th>Mean Square</th>
<th>F</th>
<th>Sig.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Available help total</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Between Groups</td>
<td>4.387</td>
<td>2</td>
<td>2.193</td>
<td>.203</td>
<td>.819</td>
</tr>
<tr>
<td>Within Groups</td>
<td>151.143</td>
<td>14</td>
<td>10.796</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Total</td>
<td>155.529</td>
<td>16</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Received total help</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Between Groups</td>
<td>1.165</td>
<td>2</td>
<td>.583</td>
<td>.209</td>
<td>.814</td>
</tr>
<tr>
<td>Within Groups</td>
<td>38.952</td>
<td>14</td>
<td>2.782</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Total</td>
<td>40.118</td>
<td>16</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Percent total help</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Between Groups</td>
<td>1190.476</td>
<td>2</td>
<td>595.238</td>
<td>.283</td>
<td>.758</td>
</tr>
<tr>
<td>Within Groups</td>
<td>29487.524</td>
<td>14</td>
<td>2106.252</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Total</td>
<td>30678.000</td>
<td>16</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Coping statements group 4
Passer 4: Only my immediate family and intimate friends know that I had polio.
Minimizer 5: I really do not like to talk about my experience with Polio.
Identifier 4: I am proud of what I am and what I have achieved.

<table>
<thead>
<tr>
<th></th>
<th>Sum of Squares</th>
<th>df</th>
<th>Mean Square</th>
<th>F</th>
<th>Sig.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Available help total</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Between Groups</td>
<td>.373</td>
<td>2</td>
<td>.186</td>
<td>.010</td>
<td>.990</td>
</tr>
<tr>
<td>Within Groups</td>
<td>284.048</td>
<td>16</td>
<td>17.753</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Total</td>
<td>284.421</td>
<td>18</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Received total help</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Between Groups</td>
<td>.143</td>
<td>2</td>
<td>.071</td>
<td>.028</td>
<td>.972</td>
</tr>
<tr>
<td>Within Groups</td>
<td>40.594</td>
<td>16</td>
<td>2.537</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Total</td>
<td>40.737</td>
<td>18</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Percent total help</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Between Groups</td>
<td>1361.63</td>
<td>2</td>
<td>680.818</td>
<td>.284</td>
<td>.756</td>
</tr>
<tr>
<td>Within Groups</td>
<td>38346.0</td>
<td>16</td>
<td>2396.628</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Total</td>
<td>39707.6</td>
<td>18</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

One final one-way ANOVA analysis was run with gender of the participant as the independent variable and the available, received, and percent total help networks as the dependent variables. (see Table 11) A significant effect (p<.05) resulted for gender and percent of the network utilized. Specifically, this gender effect indicated that men utilized a smaller
number of helpers for assistance than women. Overall, the hypothesis that the particular coping style used by the participants would predict the size of their social networks was not supported.

Table 11 One-Way ANOVA of Social Help Networks as related to Gender of Participants

<table>
<thead>
<tr>
<th></th>
<th>Sum of Squares</th>
<th>df</th>
<th>Mean Square</th>
<th>F</th>
<th>Sig.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Available help total</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Between Groups</td>
<td>16.000</td>
<td>1</td>
<td>16.000</td>
<td>1.276</td>
<td>.271</td>
</tr>
<tr>
<td>Within Groups</td>
<td>275.958</td>
<td>22</td>
<td>12.544</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Total</td>
<td>291.958</td>
<td>23</td>
<td>12.544</td>
<td>1.276</td>
<td>.271</td>
</tr>
<tr>
<td>Received total help</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Between Groups</td>
<td>5.211</td>
<td>1</td>
<td>5.211</td>
<td>2.746</td>
<td>.112</td>
</tr>
<tr>
<td>Within Groups</td>
<td>41.747</td>
<td>22</td>
<td>1.898</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Total</td>
<td>46.958</td>
<td>23</td>
<td>1.898</td>
<td>2.746</td>
<td>.112</td>
</tr>
<tr>
<td>Percent total help</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Between Groups</td>
<td>7663.333</td>
<td>1</td>
<td>7663.333</td>
<td>4.785</td>
<td>.040</td>
</tr>
<tr>
<td>Within Groups</td>
<td>35236.000</td>
<td>22</td>
<td>1601.636</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Total</td>
<td>42899.333</td>
<td>23</td>
<td>1601.636</td>
<td>4.785</td>
<td>.040</td>
</tr>
</tbody>
</table>

Qualitative analysis what family and friends should know:

Another aspect of this survey was to ask each participant what he/she would like their family and friends to know about Post Polio Syndrome. All of the participant responded in some way to this question ranging from brief one sentence answers to longer, more complicated answers. An overriding theme of these responses was frustration. Specifically, 7 respondents reported experiencing frustration associated with their decreasing physical abilities. An additional group of 7 participants reported frustration with individuals outside their families who do not understand the symptoms of Post Polio Syndrome. Frustration experienced with the medical community also was cited by 4 respondents, particularly with doctors who were not familiar either with the original polio condition or Post Polio Syndrome. One respondent also noted the tendency of health care providers not to acknowledge PPS as a valid diagnosis or condition. Overall, therefore, a theme of frustration for a variety of reasons is a common experience among this sample of PPS respondents. In contrast to a theme of frustration, four respondents reported positive feelings about how their family had responded to their diagnosis. For four of the respondents there is an acknowledgement that PPS is a long gradual progression of continual loss. One participant specifically stated:

“That this is a second “attack,” we have to learn to live with it and adjust and move on. It is pointless to try to “fight it”. Please understand I have been “fighting” it for the last 55 years, I’m tired of the battle and want to enjoy what I have left of my life.”

Ten participants acknowledge that they have to limit what they attempt to do in their daily lives, such as reducing IADLs or cutting back on work to maintain a high quality of life.
One respondent, in particular, felt frustrated that others attempt to tell her what her quality of life should be like now. Overall, some of the participants indicated a desire to make the best of Post Polio Syndrome in their own way. The important themes of frustration and the need for control emerged when the respondents were asked what they wanted family and friends to know about Post Polio Syndrome.

**Summary**

The data provided by the twenty-four participants provides insight into the coping strategies they use and their social networks. The conclusions that may be drawn from this data will be described in the next chapter.
Chapter 5

Discussion and Conclusions

The purpose of this research was to explore the impact of Post Polio Syndrome on the family. Although the literature provides substantial information on the medical aspects of Post Polio Syndrome, significant research has not been conducted on the family dimensions of this issue. In partial response to this deficiency, this chapter will analyze and interpret the current findings in terms of the limited literature on Post Polio Syndrome, the extant scholarship on Polio itself, and assess the potential directions for future research on these topics.

As discussed previously, it is the whole family that must react when a change causes an imbalance within the family system (Backman, 1987). From the perspective of stress theory, the increased weakness of one family member due to Post Polio Syndrome will initiate a period of crisis within the family system (Patterson, 2002). Such a crisis in the family system can cause a redefinition of the roles within the family as adaptation occurs to the new health status of one of its members.

As shown in Figure 3, an adaptation of Patterson’s model see Figure 1 (2002), the new disabilities and fatigue caused by Post Polio Syndrome causes an imbalance in the family as the resources such as caregivers and other helpers are overwhelmed or unavailable. In addition, there is a lapse as some roles the individual with PPS can no longer fulfill. This leads to a time of crisis which eventually leads to adaptation as new caregivers/Helpers are identified and assistance accepted from them. Further the family adapts with members assuming new roles as needed.
Figure 3 Family Adjustment and Adaptation Response Model to PPS

Adjustment Phase

Meaning given to polio **

Capabilities: Number of those available to help
Past Coping experience

Demands: new disabilities, fatigue
other symptoms of PPS

Family Adjustment

Crisis: family member needs more help than is available or can’t continue certain roles

Adaptation Phase

Meaning given to PPS

Demands: Continued increase in disability & fatigue
related to PPS
New roles needed

Capabilities: New helpers available & accepted
Coping styles adapted
Family members assume new roles

Family Adaptation
The research conducted in this study provides a snapshot of the family, once the crisis has been resolved and as others step up to assume new tasks or care-giving roles. Specifically, this study examined who would assist with the tasks that individuals suffering from Post Polio Syndrome can no longer do by themselves. Thus, in the process of regaining a balance or establishing an equilibrium within the family, some members have changed their roles (Patterson, 2002). This was accomplished, most likely, in a manner that was similar to the coping strategies used by these individuals in the past when they faced the original polio infection (Maynard & Roller, 1991). Providing interpretations of the present results suggest that the importance of first examining how coping styles might impact the individuals with Post Polio Syndrome. Although the family, as a whole, cannot be examined, it is possible and important to analyze each PPS participant’s social network of helpers (i.e., both those who were available and those from whom help was actually received) in terms of how each participant accessed his/her resources to adapt to their new disabilities.

**Coping style or strategies**

The coping styles or strategies used in this study came from Maynard and Roller’s 1991 article, with particular attention to three coping styles/strategies they designated as passer, minimizer and identifier (Maynard & Roller, 1991). As discussed in chapter 2, these distinctive styles of dealing with the original experience with polio were theorized to impact the individual polio survivor once he/she was diagnosed with Post Polio Syndrome. Briefly, the theory was that the passers, due to their lifelong habit of hiding their disability, would not acknowledge or ask for help easily because, in doing so, he/she would have to acknowledge the previous incident of polio. Minimizers also would experience difficulty asking for and accepting help. This difficulty was experienced due to the lifelong habit of Minimizers to ignore their disability and pain. As a result, minimizers resisted acknowledging the changes caused by PPS until the disease becomes quite advanced. Finally, identifiers tended to have difficulty surrendering control of their lives as PPS came to disrupt their lives (Maynard & Roller, 1991).

Passer and minimizer characteristics were found to be dominant in this study, whereas no identifiers were found, though a more important concept came to the fore. Specifically, instead of viewing survivors as distinctly falling in one of these three categories, a more complicated continuum of coping styles emerged. Individuals rarely were classified into just a single category but, in fact many fell into categories somewhere between the initially designated ones. These
new categories were identified as passer/minimizer and minimizer/identifier for those individuals who appeared to be equally split between the original categories. Consequently, coping styles were found to be better conceptualized on a continuum with passers on one end, minimizers in the center, and identifiers at the far end. In fact two statements, one from the minimizer category and one from the identifier category, according to Maynard and Roller (1991), appeared to be universal or accepted across all the types or styles of coping.

The first universal statement, which stated “Often I ignore pain and fatigue in order to complete a task,” was accepted by twenty one of the participants, though Maynard and Roller believed it to be a characteristic of minimizers (1991). In reference to other work, however, this statement is consistent with Bruno (1995a) and Frick’s (1995) idea that polio survivors were socialized into being over achievers in order to appear normal. Accordingly, one participant stated that: “After being told from a baby on from therapist and doctors etc. to push yourself,” she then went on to describe her frustration over her decreased abilities. Hence it is hardly surprising that the participants as a whole tended to embrace this statement.

The second almost universal statement embraced by the participants was that “I am proud of what I am and what I have achieved.” Maynard and Roller (1991) identify this as a statement typical of identifiers, whereas, it appeared in this study to be very common because 19 participants declared their agreement with it. Such findings suggest that the study participants have come to accept both their status as individuals with Post Polio Syndrome and their current health status. In fact, several respondents, during the open ended component of the survey, described their past accomplishments with pride and how they just want to make the best of their lives from now on (See Appendix G for these responses). This acceptance suggests that, from a family stress point of view, the family has passed the point of crisis and is now in a period of balance once again (Patterson, 2002).

This study further proposed that the coping styles used by these respondents would impact the size of the helping network and who was asked (Maynard & Roller, 1991). Although tests of this hypothesis were not confirmed, more questions were revealed about who is perceived as being available to help and whose help is actually accepted by PPS participants. Additional investigations are needed that address how coping strategies may provide barriers to the acceptance of help by the individuals with Post Polio Syndrome. Given the absence of significant effects for coping styles, the subsequent focus of this study shifted in the direction of
defining the typical network of helpers and how this information might be of use in the future to
deal with families who have a member with PPS.

**Social network of helpers**

For each participant who suffered from Post Polio Syndrome, a snapshot was captured of
their social network of potential and actual helpers. This information may provide professionals,
who work with such populations, important clues about who individuals suffering from PPS can
rely upon and perhaps from whom they are able to accept assistance. The subcategories of each
PPS individual’s social network were (1) the perceived available (potential) helpers and (2) those
from whom help was actually received or accepted. Such distinctions between potential and
actual or “received” helpers provided a more definitive picture of whom the individuals with
Post Polio Syndrome may rely upon and to whom they can actually turn to for help.

The overall network of available helpers for the participants in the study was relatively
small, with the majority of participants (n=21) having an available helping network totaling only
six or fewer individuals. Moreover, the number of family helpers were equal to or lower than six
for twenty-three of the twenty-four participants in the study. Even more restrictive, however,
were the findings for friends as helpers, with the present results indicating that 23 of the 24
respondents had only 5 or fewer friends they counted on as being available to help them. Other
moderate surprises included the finding that four individuals had hired helpers to assist them
with their disabilities, whereas one individual had acquired a trained service dog to use for this
purpose. Although the participants identified an almost equal number of family or friends as
being available to help, the difference between these potential sources of support became evident
when those who actually received help from their network were compared to those who were
simply available (i.e., potentially available) to help. The specific difference was 63% of the
participants accepted help from friends versus the 80.8% who accepted help from their families.
In most cases, it appears that those who suffer from PPS are more inclined to actually accept
assistance from family members than from friends.

When it comes to actually accepting or receiving help, only seven individuals relied upon
friends, while seventeen individuals turned to family members for assistance. This difference in
who is actually relied upon by individuals with Post Polio Syndrome is important for
professionals who need to be aware that PPS sufferers may be more comfortable or willing to
accept help from a family member more readily than from friends. In their 1996 Australian
study, for example, Westbrook and McLlwain, note that very few of their participants actually asked their family members for help only 39% of the time while asking friends only 19% of the time. Consistent with the conclusions of Bruno and Frick (1991), these investigators conclude that some of the survivors need help coming to terms with how they were driven in the past to appear normal and hide their disability (Westbrook and McLlwain, 1996). In fact, Westbrook and McLlwain (1996) propose that polio survivors need to pursue counseling in order to be able to overcome the past and the social taboo about discussing their disabilities (1996). Once this is done, Westbrook and McLlwain (1996) contend that polio survivors will be able to expand their social support network to the level they actually require, rather than simply displaying self-sufficiency based in falsehood. Thus, hints exist in the literature about patterned differences between accepting help from family versus friends. Additional research is needed, however, to identify exactly what causal factors contribute to this difference in the helping networks of PPS victims.

Moreover, the fact that spouses and children are relied upon the most for help, assists us to understand that family members and friends may require extra services to support their new roles as caregivers. Dr. Richard Bruno, in his recent book The Polio Paradox, notes that family members who participated in his treatment program are often hungry for information and ways to support their loved ones (2002). The assistance that families commonly request often centers on how to approach their loved ones with PPS and get them to allow family members to help (Bruno, 2002). Thus, practitioners require sensitivity to the common reality that family members are usually willing to offer or provide assistance, but that individuals with Post Polio Syndrome often resist accepting the help that is available (Bruno, 2002).

This conflict over receptivity to available help also can lead to a time of family crisis because PPS victims resist tapping into available resources as the family strives to correct imbalances caused by PPS (Patterson, 2002). As a result, the resources available to a family require additional examination by professionals who work with families as the first source of support for PPS victims. Consequently, a substantial need exists for greater support services for family members as the progressive nature of PPS continues to add additional responsibilities to the tasks of these caregivers.

Future research on the social networks of polio survivors with Post Polio Syndrome also should be compared to other health circumstances such as individuals with MS or other similar
disabilities. The results of this study suggest that (1) the network of available and actual helpers for PPS sufferers might be smaller than is the case for other health conditions and (2) this may be an important finding that requires additional research in the future. Westbrook and McLlwain (1996) propose, for example, that individuals with PPS often become depressed or anxious when they first experience the symptoms of Post Polio Syndrome. This depressive state, in turn, may lead these individuals to withdraw from friends and family. Could these problems stem from the fact that polio survivors have striven so hard in the past to hide their disabilities and the actual experience with polio? Moreover, could these initial psychological states function to limit the available support network they can tap into, once he/she must deal with the consequences of Post Polio Syndrome? (Bruno & Frick, 2001). Unfortunately, there appears to be a lack of research literature that attempts to answer these questions.

Another area for future research would be to focus on the additional stress family members experience as a result of a loved one’s diagnosis of or experience with Post Polio Syndrome. The literature has focused primarily on individuals with Post Polio Syndrome, leaving a substantial gap when it comes to the direct impact of PPS on the larger family system and its members. Important questions remain about the stress experienced by the larger family from the effects of PPS or how family members assign meaning to Post Polio Syndrome, both for its implication within and beyond family boundaries.

Voices of the participants

The final aspect of this study requiring attention are the responses to the question “What would you like your family and others to understand about PPS?” By asking this question the researcher strove to discover what the participants felt about their families and others within the context of understanding Post Polio Syndrome. Although each individual provided a unique answer to these questions, there were common themes that require understanding by professionals dealing with individuals with Post Polio Syndrome.

An important recognition is that this population, while coping with their syndrome and disabilities, often expressed feelings of frustration about how the changes they have experienced are not necessarily visible to the casual observer. Moreover, they are dealing with new losses caused by an ‘old foe’ or as one individual says: “That this is a second “attack”, we have to learn to live with it and adjust and move on. It is pointless to try to “fight it”. Please understand I have been “fighting” it for the last 55 years, and I’m tired of the battle and want to enjoy what I have
left of my life.” Each individual is dealing with this new, unforeseen consequence of polio in his or her own way, and often resenting others who tell them how they should be feeling or what they should be doing.

For individuals with PPS, during their time of crisis, the family often strives to redefine the meanings that members use to define the family’s identity and world view (Patterson, 2002). Consequently, efforts by others to impose outside meanings or values is stressful and can cause conflict within the family (Patterson, 2002). Each family and its members are unique in term of how definitions and responses are made to the challenges of PPS due, in part, to the varied resources and capabilities that are available to each family and individual (Patterson, 2002). Some families can afford to hire professional help, whereas others must rely solely on family members to provide assistance with IADLs. Hence, for the families and individuals facing such a stressor, the advent and progression of PPS is a time of redefining both themselves and how they view the world. Consequently, having someone who is outside family boundaries attempt to tell them how they should feel or act can be a very frustrating experience.

In contrast to frequent expressions of frustration, the participants also made a significant number of positive assessments concerning the assistance that was provided by their families. The participants further noted that, although their families wanted them to slow down and were willing to help, the respondents often found it difficult to ask for help, a theme also addressed in the work of Bruno (2002). The resistance of PPS sufferers to accepting help from family members that is offered can contribute to conflict within these families, or a consequence of the fine line that families must walk (2002) when dealing with this crisis. Moreover, PPS respondents also indicate that they become increasingly aware how their new physical disabilities have impact on their families. For example, this is certainly true as the participant’s children see their once capable parents go from being active and non-disabled individuals to being increasingly disabled.

Another important thing to remember is that each experience is individual or subjective in nature and, while conclusions can be made about group perceptions, there must be continued awareness of the wide of diversity in perceptions, even within small groups like the present sample of 24 PPS participants. Again, practitioners should remember to consider how much variability exists across families in the capabilities and resources available for adjustment and to restore a sense of equilibrium in the family system (Patterson, 2002). One obvious example, of
course, is the available help network that the polio survivors have reported in this study. For example, one individual was able to obtain a service dog while four others utilized hired help to complete IADL tasks involving both light and heavy housework. Thus, just how each family or family member will adjust and find ways to establish a sense of balance following a crisis will vary considerably from family to family and from member to member (Patterson, 2002).

**Limits of the sample**

The primary limitations of this sample are its size and demographics, a concern that is based on the fact that only 24 individuals responded to the survey and may provide an unrepresentative picture of this population. Moreover, the present sampling outcome was limited or biased by the specific strategy used to draw this convenience sample. Specifically, the sample was drawn from a listserv, a procedure that limits participants to individuals who can visit this listserv by having access to a computer and knowledge of e-mail. This means that potential participants of the lower socioeconomic standing, who have less access to computer technology and less computer training, are less likely to be sampled through the strategy used for this study. Moreover, the participants’ ethnicity/race was not determined by the survey, so generalizing these results to various ethnic/racial groups was not possible.

**Conclusion**

In general, this study has probably raised more questions than answers. One way that future research can build upon the present results is to examine how the coping strategies used by polio survivors create barriers to accessing their support networks? (Westbrook & McLlwain, 1996) Moreover, do past coping experiences (i.e., the strategies used to cope with the initial experience with Polio) provide a strength or resource for the family when Post Polio Syndrome disrupts the balance of the family?

The past coping experience with Polio can be seen either as a resource that individuals bring to the family as it deals with Post Polio Syndrome or as an additional stressor or strain on the family system (Patterson, 2002). Berkman and Foster propose, for example, that social workers can use the fact that individuals have overcome the original polio as a strength from which the client with PPS can then build upon as they deal with this new challenge (1993). Thus the fact that individuals have overcome disability in the past is a source of potential strength upon which individuals and their families can draw.
In contrast, Westbrook and McLlwain (1996) and Bruno and Frick (1991) argue that the coping strategies and personality traits that polio survivors utilized in the past can be detrimental to coping with PPS. For these authors, the past coping strategies and personality traits may lead to denial and difficulty in acknowledging the impact of PPS and in accepting or even asking for help (Westbrook & McLlwain 1996). Thus it depends on how the family uses the past coping styles, it may be either a strength or a weakness.

In addition to the importance of past coping strategies, another focus of future work should be to monitor the stresses placed upon their families. Future research should seek to identify patterns relating to who individuals with Post Polio Syndrome turned to for help and how the family is influenced by this new challenge. The strategies used in the past may provide barriers to asking for and accepting help, and, in the end, it simply comes down to who actually is called upon to provide the help that is needed. Individuals who provide assistance to individuals with Post Polio Syndrome need to be identified and supported so that they can provide the continuing assistance required by those with PPS.

Finally, how the social network of helpers is utilized could be examined in greater detail. Specifically, exactly how families draw upon resources to meet the needs of individuals with Post Polio Syndrome (Patterson, 2002) is an issue that requires greater attention. By drawing on a network of available helpers, families can spread and share the burden of care-giving and are more likely to re-establish an equilibrium as an effectively functioning unit during a time of crisis (Patterson, 2002).

Although the participants of this study expressed frustrations and hopes, future work should also assess the family members of PPS sufferers and acquire knowledge about their frustrations and hopes. Moreover, just because family members are willing and able to assist, it does not mean that the individual with Post Polio Syndrome is able or willing to accept this help. As the daughter of a person with Post Polio Syndrome it does appear at times that I am walking a fine line between being helpful without being seen as ‘pushy’. This frustration is one that needs further examination as families continue to walk the fine line between being seen as helpful or intrusive.
Appendix A

Email to Listserv Owner for permission to recruit on Listserv & Listserv owner reply.
Hello, my name is Hallie Baker and I’m writing to you today for permission and some help. I am currently working on my masters in Family Studies at Miami University in Oxford, Ohio. After discussing my interests I have decided to focus on the impact of Polio and Post Polio Syndrome on the individual and his/her family. The title of my thesis is: “Walking a fine line: How coping styles impact polio survivors asking for and receiving assistance from their family and friends”. This brings me to why I’m writing you today.

Due to the limitations and distance between polio survivors, I would like to use listservs such as yours as a way to contact a variety of individuals who would be willing to complete a survey for my study. Thus, I would like your permission to submit an email to your listserv asking volunteers for the survey and requesting that they contact me off list for more information.

I would like to assure you that I would hold all information in the strictest of confidence and I would only use the information with the individual’s permission. The survey will be available online to the participants, but their information will not be accessible by the public. Besides the initial email asking for participants, I would not post any further messages to the listserv.

Thank you for your time. If you have any further questions, I would be happy to answer them. You may email me back or call me at 513-529-3635 or contact my thesis advisor Dr. Gary Petterson at 513-529-2323 or Dr. Charles Hennon at 513-529-2323.

Sincerely,
Hallie Baker
Hello Hallie,

I have no issues at all with you contacting the list and am honored that we will be a part of your thesis. They are quiet a nice group of people and like to be well informed. You will find most will be willing to help you, at least I hope! Also, if you are not getting any responses privately, let me know and I’ll announce to the list for you to do or ask what you would like publicly.

If I can be of any further help, feel free to let me know.

Good luck to you!
Katlee
Moderator and List Owner
Post_Polio_Syndrome@yahoogroups.com
Appendix B

Recruitment Email
My name is Hallie Baker. I am a part time graduate student at Miami University, Ohio. I am pursuing a master’s degree in Family and Child Studies. I will be completing a thesis project as part of my graduation requirement. I am currently recruiting participants to take part in a survey about Post Polio Syndrome and its impact on the individual and his/her family.

I have selected as a thesis topic that focuses on Polio, Post Polio Syndrome and it’s impact on family relationships. I am interested in learning about how one coped with polio originally and the impact that has on the survivor requesting and accepting help from their family members in order to deal with Post Polio Syndrome. I want to help family members understand the best ways to help their loved one with Post Polio Syndrome. Those who participate in this study will play a role in helping to provide insight into the best ways for family members to help their loved ones.

You will be assigned an identification number and will be asked to complete an online survey that will take less than 1 hour to complete. Once completed the participant submits the survey. The data will then be sent to myself directly to be entered into a password protected database. Participants emails and names will be kept in a password protected computer file, with only the identification number to be placed on the survey. This survey is completely voluntary and participants may choose not to answer part or all of the survey if they wish.

Persons interested may contact me for more information bakerhe@muohio.edu. Please do not reply to this email on the listserv.

Sincerely,
Hallie Baker
Appendix C

Informed Consent
Will be emailed to each interested participant.
Dear Potential Participant,

My name is Hallie Baker. I am a part time graduate student at Miami University, Ohio. I am pursuing a master’s degree in Family and Child Studies. I will be completing a thesis project as part of my graduation requirement.

I have selected as a thesis topic that focuses on Polio, Post Polio Syndrome and it’s impact on family relationships. I am interested in learning about how one coped with polio originally and the impact that has on the survivor requesting and accepting help from their family members in order to deal with Post Polio Syndrome. I want to help family members understand the best ways to help their loved one with Post Polio Syndrome. Those who participate in this study will play a role in helping to provide insight into the best ways for family members to help their loved ones.

If you agree to participate in this study please read the information and reply to this email stating that you understand the study and agree to participate in it. (This information will also be posted before you enter the survey.) Once your email is received you will be sent an identification number and a web address. Please complete the survey by March 15, 2005.

In order for me to gain this knowledge;
1. You will be asked to complete the enclosed survey that I have sent to you.
2. The survey will ask you to reflect upon how you have coped with polio and it’s impact on your life as well as your relationship with your family and friends.
3. You will receive a web address for an online survey for you to complete. Please only enter the identification number on the form.
4. Your returned survey will be entered into a database for analysis. I, Hallie Baker, will be the only person who will know your identity and all identifying information will be kept confidential and in a password protected file separate from your answers. All surveys and identifying information such as name or email address will be destroyed by May 30, 2005.
5. Your participation in this study is completely voluntary. You can withdraw at any time or refuse to submit the survey. You can refuse to answer any question.

Please note that the survey must be completed in one sitting.

For questions about the study, contact:
Hallie Baker (513) 529-3635 or (513) 523-2654, or email at bakerhe@muohio.edu
Dr. Gary Peterson – (513) 529-2323, or email at petersgw@muohio.edu
Dr. Charles Hennon at 513-529-2323 or email at: hennoncb@muohio.edu
For questions concerning your rights as a subject, feel free to contact:
Office for the Advancement of Research and Scholarship– (513) 529-3734 or HumanSubjects@MUOhio.edu

Please email back the following statements with your name and the date you agree.
I give my permission to participate in this study.
I give my permission for my data to be used if the research is published.
Appendix D

Confirmation email.
Participant,

Thank you for agreeing to participate in this study. Your identification number is: __________.
The web address for the survey is: http://www.users.muohio.edu/bakerhe/

Please enter your identification number when you fill out the survey. All information will be sent directly to me and placed in a password protected computer file for confidentiality.

Thank you again,

Hallie Baker
Appendix E

Web Survey Pages
Dear Participant,

My name is Hallie Baker. I am a part time graduate student at Miami University, Ohio. I am pursuing a master’s degree in Family and Child Studies. I will be completing a thesis project as part of my graduation requirement.

I have selected as a thesis topic that focuses on Polio, Post Polio Syndrome and it’s impact on family relationships. I am interested in learning about how one coped with polio originally and the impact that has on the survivor requesting and accepting help from their family members in order to deal with Post Polio Syndrome. I want to help family members understand the best ways to help their loved one with Post Polio Syndrome. Those who participate in this study will play a role in helping to provide insight into the best ways for family members to help their loved ones.

In order for me to gain this knowledge;
1. You will be asked to complete the online survey.
2. The survey will ask you to reflect upon how you have coped with polio and it’s impact on your life as well as your relationship with your family and friends.
3. Your returned survey will be entered into a database for analysis. I, Hallie Baker, will be the only person who will know your identity and all identifying information will be kept confidential and in a password protected file separate from your answers. All identifying information will be destroyed upon the completion of this study which is expected to be before May 30, 2005.
4. Your participation in this study is completely voluntary. You can withdraw at any time or refuse to submit the survey. You can refuse to answer any question.

For questions about the study, contact:
Hallie Baker (513) 529-3635 or (513) 523-2654, or email at bakerhe@muohio.edu
Dr. Gary Peterson – (513) 529-2323, or email at petersgw@muohio.edu
Dr. Charles Hennon at 513-529-2323 or email at: hennoncb@muohio.edu

For questions concerning your rights as a subject, feel free to contact:
Office for the Advancement of Research and Scholarship– (513) 529-3734 or HumanSubjects@MUOhio.edu

If you agree to participate in this study please read this information, before hitting the next page button below. Please complete the survey by March 15, 2005.

Please note that this survey must be completed in one sitting. Thank you.

By clicking on the next page button, I give my permission to participate in this study.
By clicking on the next page button, I give my permission for my data to be used if the research is published.

Next Page - on to the survey
Post Polio Syndrome Survey:

Id Number: __________

A. Basic Demographic information:

Gender: □ Male □ Female

What year were you born in? __________

What is your marital status? ▼ (married, never married, divorced, widowed)

Educational Level: (please check highest achieved) ▼ (Some high school, High school, some college, college degree, master’s degree, some graduate work, PhD, other)

□ Other, please describe: __________

B General Questions:

1. How old were you when you had polio? __________

2. During the period of your physical best AFTER THE ONSET OF POLIO, which phrase best describes the extent of your disability? Would you say.... ▼ (No disability, no noticeable disability, mild disability, moderate disability, severe disability, do not know)

3. When you were at your physical best did you use any assistive devices? ▼ (Yes, No, Do not know)

□ If so what? __________

4. When were you diagnosed with Post Polio Syndrome? __________

Thinking back to when you were at your physical best and up to the time before the new symptoms of Post Polio Syndrome appeared, which of the following do you most closely identify with? (please choose as many as you need to)

□ Polio minimally affected my life originally.

□ Polio left me with a physical weakness that I cannot hide from people.

□ Polio left me disabled.
The physical weakness it left me with was mild so I could easily hide it.
I work hard to push myself in other areas, so my weakness is not very important.
I do not even consider myself disabled.
I have to use a wheelchair, braces, or canes to help me get around.
I push myself to achieve whatever I set my mind to despite any physical limitations I have.
Often I ignore pain and fatigue in order to complete a task.
I have strived to achieve my goals and consider myself an advocate for those like myself.
Only my immediate family and intimate friends know that I had polio.
I really do not like to talk about my experience with Polio.
I am proud of what I am and what I have achieved.

D. Daily life with Post Polio Syndrome:

Often times people with PPS need/appreciate assistance in completing daily tasks. Please list below who are willing to assist you with daily tasks. Only use an initial or first name to identify an individual. There is a list for family and one for friends:

<table>
<thead>
<tr>
<th>Family</th>
<th>Initial/First Name</th>
<th>This person is my (relationship)</th>
</tr>
</thead>
</table>

<table>
<thead>
<tr>
<th>Friends</th>
<th>Initial/First Name</th>
<th>Gender</th>
</tr>
</thead>
</table>
For each activity below, please indicate whether you require assistance to do the activity. Next, using the initials/name you provided above, please indicate all of the family & friends who assist you with the activity.

1. **Bathing or showering**
   - Need assistance? (yes, no, I don’t do this)
   - Who assists you?

2. **Dressing**
   - Need assistance? (yes, no, I don’t do this)
   - Who assists you?

3. **Eating**
   - Need assistance? (yes, no, I don’t do this)
   - Who assists you?

4. **Getting in and out of bed or chairs**
   - Need assistance? (yes, no, I don’t do this)
   - Who assists you?

5. **Walking**
   - Need assistance? (yes, no, I don’t do this)
   - Who assists you?

6. **Other transportation**
   (driving, using a wheelchair, etc.)
   - Need assistance? (yes, no, I don’t do this)
   - Who assists you?

7. **Doing light housework?**
   (doing dishes, straightening up, or light cleaning)
   - Need assistance? (yes, no, I don’t do this)
   - Who assists you?

8. **Doing heavy housework?**
   (like scrubbing floors, or washing windows)
   - Need assistance? (yes, no, I don’t do this)
   - Who assists you?

9. **Preparing your own meals?**
   - Need assistance? (yes, no, I don’t do this)
   - Who assists you?

10. **Shopping?**
   - Need assistance? (yes, no, I don’t do this)
   - Who assists you?

**E. Other comments?**
What would you like your family and others to understand about PPS?

Submit
Thank you for your participation in this study.

Please remember that at any time before May 30, 2005 you may withdraw or ask that I remove your data from the data set. After May 30, 2005 all identifying information will be destroyed, so I will not be able to delineate between your information and those of other participants.

For questions about the study, contact:
Hallie Baker (513) 529-3635 or (513) 523-2654, or email at bakerhe@muohio.edu
Dr. Gary Peterson – (513) 529-2323, or email at petersgw@muohio.edu
Dr. Charles Hennon at 513-529-2323 or email at: hennoncb@muohio.edu

For questions concerning your rights as a subject, feel free to contact:
Office for the Advancement of Research and Scholarship– (513) 529-3734 or HumanSubjects@MUOhio.edu

For more information about Post Polio Syndrome or for places you can go for assistance, please see the following.

International Polio Network
http://www.post-polio.org/ipn
This site is a “resource of post-polio information for polio survivors, their families, and the health care community that actively promotes networking among the post-polio community.”

March of Dimes
http://www.modimes.org
The March of Dimes continues to be active in the fight against polio. In 2000 it co-sponsored an international conference on the causes of post-polio syndrome and the best practices for treatment and management. It has information and fact sheets on polio and post-polio syndrome.

Post-Polio Syndrome Central
http://www.skally.net/ppsc/
Maintained by volunteers this site offers a number of links to PPS e-mail support groups, listservs, and news groups. They offer advice as non-PPS professionals and is easy to understand.

The International Post-Polio Centre for Education & Research
http://www.postpolioinfo.com/postpolio/
Located at the Englewood (NJ) Hospital and Medical Center, USA, this site offers both information and options for treatment. Run by Dr. Richard Bruno, the author of *The Polio Paradox*, it offers information for both the individual and professionals working with polio survivors.

Appendix F

Email to list as a whole at end of project
Thank you for your support of my project. I have completed gathering my data and will begin analyzing it. It will be available in online through the Miami University Libraries web site once it is completed.

I want to share with the group some of the resources I have found during this study that might be of use to the members.

Thank you again,
Hallie Baker

For more information about Post Polio Syndrome or for places you can go for assistance, please see the following.

International Polio Network
http://www.post-polio.org/ipn
This site is a “resource of post-polio information for polio survivors, their families, and the health care community that actively promotes networking among the post-polio community.”

March of Dimes
http://www.modimes.org
The March of Dimes continues to be active in the fight against polio. In 2000 it co-sponsored an international conference on the causes of post-polio syndrome and the best practices for treatment and management. It has information and fact sheets on polio and post-polio syndrome.

Post-Polio Syndrome Central
http://www.skally.net/ppsc/
Maintained by volunteers this site offers a number of links to PPS e-mail support groups, listservs, and news groups. They offer advice as non-PPS professionals and is easy to understand.

The International Post-Polio Centre for Education & Research
http://www.postpolioinfo.com/postpolio/
Located at the Englewood (NJ) Hospital and Medical Center, USA, this site offers both information and options for treatment. Run by Dr. Richard Bruno, the author of *The Polio Paradox*, it offers information for both the individual and professionals working with polio survivors.
Appendix G

Answers to open ended question: “What would you like your family and others to understand about PPS?”
What families should know:

Participant Response (exactly as sent by the participant)

Female, 54

“Just to know that I am not “lazy”. Since I have always walked (but with a drop foot), they don’t realize that polio now affects my whole body and that I can’t keep up with them in their activities, i.e. walking, shopping, bowling, etc. They can’t “see” the disabling effects of PPS, therefore it doesn’t exist. This mainly applies to my younger siblings who never had any experience or knowledge of polio. It used to take me 1.5 hours to clean my house - now it takes days.”

Female, 55

“Actually, they are very understanding; they recognize my new weakness and PAIN -- basically they treat me no different than in my pre-PPS life. They do recognize that I should limit many daily activities and don’t hesitate to help...however, I have a hard time limiting. The pain is what STOPS me cold! , , I think my daughter has most difficulty accepting my changes. She wants Mom “to be like before”...she’s helpful; however, I can see the pain in her eyes. I know it must be very difficult for her to see me as “disabled” since I was the typical ‘Polio Supermom’. (I bet you hear that through your research too! : )”

Male, 54

“As it gets harder to do things without assistance, I find myself angry and upset which causes more problems with the PPS which causes more..... , I find that more and more I depend on others for assistance.. , The more you fight it the harder it gets, the more you accept the limits the easier it is.”

Female, 66

“That as we get older, it is almost like going back to the original polio, and paralysis. It is definitely not that bad because I was paralyzed from the neck down, but physically I have to be more reliant on others, to “lift” the the groceries onto the counter, etc., where I have done this for the last 40 years, am walking much slower now, etc. I held a job for many years in the adult probation in Ontario and worked for child abuse in the State of Florida and also managed a strip mall, and while I did my job well, I did notice that I could not walk the strip mall as when I first started there, and it has been going “downhill” for the past 10-15 years. I am struggling to do whatever I can like sewing and keeping busy, I have refused to get a wheelchair in the past two years but I might have to give into that this year. Presently I do volunteer work (answer the phones) at my church, it is not hard work but it is important to try and stay on top of everything mentally and emotionally. The physical “part” of me just sucks, there is way too much to do with family, grandchildren, etc, to be hindered by this physical inability. I have one question, there never was anyone in my family who was overweight not even me until after polio. It was not really excessive overweight, but now that I am not active, I have put on way too much weight, but my children are way too overweight also, they are active, hold good jobs, etc., and I just can’t help to think that this all ties in with polio somehow. They are the only ones in the whole family including cousins, etc. etc., who are overweight. Thank you.”
Female, 52  “That it is very depressing, awfully painful, hard to ask people to help you, You spend the majority of your life trying to hide a disability & now you can’t it’s too obvious. If we need to cry let us if we need help help us, try not to take our dignity away from us that is all we have”

Male, 56  “My wife does not understand how PPS is affecting me. It is the exact opposite of polio. With the polio, I dealt with my handicap by pushing myself to overcome obstacles. With PPS, what worked with polio only makes things worse. My wife does not understand that I now need to conserve my abilities. Also, she does not understand how profoundly terrifying it is each time I find another barrier that I used to be able to handle that has become insurmountable.”

Female, 50  “The fatigue from PPS for me is horrible. Although I don’t like having to use a power wheelchair, it’s the constant fatigue that is my worst complaint. I hate it that I can only leave the house 1-2 days a week, on a good week, and then only be gone for 2-3 hours by myself. If I have a driver, I can sometimes stay out longer. However, there have been weeks in a row, where I haven’t left the house at all., , People say, oh, I understand, I know tired. But they don’t. They have no idea. , , PPS makes me feel so isolated. I have even had to stop going to church, because of the fatigue. It has been disappointing that no one from my church has tried to maintain contact with me. However, they don’t understand the fatigue either.”

Female, 51  “That this is a second “attack”, we have to learn to live with it and adjust and move on. It is pointless to try to “fight it”. Please understand I have been “fighting” it for the last 50 years, I’m tired of the battle and want to enjoy what I have left of my life.”

Female, 63  “Its gradual progression, which means that some things I can do now might be difficult next year.”

Male, 56  “When you’ve been fatigued for years, if not all your life, and other people haven’t, there’s no point of reference for when you’re REALLY “too tired” to do anything, vs. simply “not in the mood”. You don’t have the point of reference, and neither does your spouse.”

Female, 39  “That it is progressive and I will need alot more care later in life.”

Female, 52  “That it is like a double whammy because having gone from disabled to normal to disabled again is very hard to deal with. I also get a lot of guilt about being so tired all the time and hate ‘putting on to’ people so have a tendency not to ask for help when I really need it. I need help in being able to say ‘Please help me’ without feeling such a fool when I do. Also the sheer helplessness I feel in the face of medical skepticism ruins my confidence and makes me feel like a hypochondriac and so I tend to ask for help less as a result of this.”
Female, 51 “Whether you believe in PPS or not, I still have it and must deal with it.”

Female, 51 (B) “Most of us have worked very hard all our lives to become independent. I was able to be that way all my life. Polio people have been pushed all their lives to be independent with PPS we are being told the opposite in some ways. some of us like myself who were very independent with mild cases of polio and now being hit very hard with PPS are having hard time adjusting to needing help and having to ask for it. After being told from a baby on from therapist and doctors ect. to push yourself and now having that body refusing to even pick up a 2 pound milk jug when for years you helped to take care of other people and children ect. Just to be patient its hard to make adjustments of 50 years of one way of doing things. of course when your body refuses it does help.”

Male, 58 “That I am the same person I always was, just with increasing physical weakness.”

Male, 58 (B) The things I used to be able to do are now limited as time continues. There is no way to convey the constant ache and discomfort in the legs. I have problems trying to respond to questions as to the AFO braces I now use as mobility aids. I get a mental block when trying to respond and mumble and stutter through a response. I am not trying to be rude to honest questions, but it seems that way.”

Female, 61 “I can’t do the things I used to do.”

Female, 54 “That we are still able to function. We can do anything that we set our minds to just like anyone else we just need to do it in our own way.”

Female, 58 “Fatigue, muscle weakness and not to say “we are all getting older” Also Doctors to at least try and understand PPS.”

Female, 43 “That we are weaker and in more pain than we look. That we are not being lazy, but we are afraid to do too much and loose what little mobility we have left.”

Female, 70 “While I have thus far maintained my independence as listed above, almost all of the items you have listed that I can do are getting more and more difficult. I feel I am living on the margin, and will not be able to take full care of myself for too much longer. I have accomplished a great deal in my life, partly by trying to keep people’s focus on my abilities rather than my disability. I am socially adept, so have been able to live reasonably successfully. But PPS had made this Increasingly difficult, put me into a social bind, and created an increasingly higher level of anxiety for me. My grown children (boys) understand my problems better than my friends do, but even they still have an expectation that I will just keep going and going. They are scattered across the country and not in positions to assist me, nor do I want them to try. Because I raised them as a single mother from the time they were in junior high (while working full-time), then helped one who is also disabled to raise his own four young kids, I was unable to save an adequate amount to cover my needs in retirement four years ago (at age 66). So I
am now struggling on social security and a short-term pension that pays just enough to make me ineligible for Medicaid or most other financial assistance.,

Despite what sounds like a sad story, I am not particularly depressed. I am very proud of having achieved a great deal, such as building a primary care clinic and ambulance service in a rural area with no other medical help available to residents there. I have raised three fine children, had a hand in raising four more, and driven my motor home (which I live in) around the country for several years. I've made wonderful friends and feel I've left the world a little bit better for my efforts.,

When I was fifteen years old, a new polio victim, I was told I would probably never walk again. Because I was in denial, lucky, and worked hard, I did walk again -- and continued to do so for about 45 more years. Back when I got sick, however, there were many who thought it was too bad that I didn’t die when I come down with polio, since there was no way I could live with any acceptable quality of life. I suppose that the main thing I’d like people to know is that “Quality of Life” is a very personal matter, and that no one should presume to judge that for another person. My quality of life has been immeasurable.”

Female, 52  “That when I say I feel like crap, I really mean it no matter how I look. Most people look at you and think you look ok so you must be faking.”

Female, 74  “My family understand what has happened to me, however Drs, are not understanding at all, there are none I can use with my HMO in my area. I have big troubles with meds prescribed and if Drs were aware of what PPS people can tolerate would be a big help to me. this is going on to this day!”

Female, 51  “How it might affect my ability to do things in the future.”
Appendix H

Frequency tables of the data
### Gender

<table>
<thead>
<tr>
<th></th>
<th>Frequency</th>
<th>Percent</th>
<th>Valid Percent</th>
<th>Cumulative Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Valid Female</td>
<td>19</td>
<td>79.2</td>
<td>79.2</td>
<td>79.2</td>
</tr>
<tr>
<td>Male</td>
<td>5</td>
<td>20.8</td>
<td>20.8</td>
<td>100.0</td>
</tr>
<tr>
<td>Total</td>
<td>24</td>
<td>100.0</td>
<td>100.0</td>
<td>100.0</td>
</tr>
</tbody>
</table>

### Marital Status

<table>
<thead>
<tr>
<th></th>
<th>Frequency</th>
<th>Percent</th>
<th>Valid Percent</th>
<th>Cumulative Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Valid Married</td>
<td>16</td>
<td>66.7</td>
<td>66.7</td>
<td>66.7</td>
</tr>
<tr>
<td>Divorced</td>
<td>6</td>
<td>25.0</td>
<td>25.0</td>
<td>91.7</td>
</tr>
<tr>
<td>Widowed</td>
<td>2</td>
<td>8.3</td>
<td>8.3</td>
<td>100.0</td>
</tr>
<tr>
<td>Total</td>
<td>24</td>
<td>100.0</td>
<td>100.0</td>
<td></td>
</tr>
</tbody>
</table>

### Educational level

<table>
<thead>
<tr>
<th></th>
<th>Frequency</th>
<th>Percent</th>
<th>Valid Percent</th>
<th>Cumulative Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Valid Some High School</td>
<td>2</td>
<td>8.3</td>
<td>8.3</td>
<td>8.3</td>
</tr>
<tr>
<td>High School</td>
<td>3</td>
<td>12.5</td>
<td>12.5</td>
<td>20.8</td>
</tr>
<tr>
<td>Some College</td>
<td>9</td>
<td>37.5</td>
<td>37.5</td>
<td>58.3</td>
</tr>
<tr>
<td>College Degree</td>
<td>4</td>
<td>16.7</td>
<td>16.7</td>
<td>75.0</td>
</tr>
<tr>
<td>Master’s Degree</td>
<td>1</td>
<td>4.2</td>
<td>4.2</td>
<td>79.2</td>
</tr>
<tr>
<td>Some Graduate Work</td>
<td>2</td>
<td>8.3</td>
<td>8.3</td>
<td>87.5</td>
</tr>
<tr>
<td>PhD</td>
<td>2</td>
<td>8.3</td>
<td>8.3</td>
<td>95.8</td>
</tr>
<tr>
<td>Other</td>
<td>1</td>
<td>4.2</td>
<td>4.2</td>
<td>100.0</td>
</tr>
<tr>
<td>Total</td>
<td>24</td>
<td>100.0</td>
<td>100.0</td>
<td></td>
</tr>
</tbody>
</table>

### Level of original disability

<table>
<thead>
<tr>
<th></th>
<th>Frequency</th>
<th>Percent</th>
<th>Valid Percent</th>
<th>Cumulative Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Valid No Noticeable Disability</td>
<td>4</td>
<td>16.7</td>
<td>16.7</td>
<td>16.7</td>
</tr>
<tr>
<td>Mild Disability</td>
<td>9</td>
<td>37.5</td>
<td>37.5</td>
<td>54.2</td>
</tr>
<tr>
<td>Moderate Disability</td>
<td>9</td>
<td>37.5</td>
<td>37.5</td>
<td>91.7</td>
</tr>
<tr>
<td>Severe Disability</td>
<td>2</td>
<td>8.3</td>
<td>8.3</td>
<td>100.0</td>
</tr>
<tr>
<td>Total</td>
<td>24</td>
<td>100.0</td>
<td>100.0</td>
<td></td>
</tr>
</tbody>
</table>
## Percent total help

<table>
<thead>
<tr>
<th>Frequency</th>
<th>Percent</th>
<th>Valid Percent</th>
<th>Cumulative Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Valid 0</td>
<td>6</td>
<td>25.0</td>
<td>25.0</td>
</tr>
<tr>
<td>7</td>
<td>1</td>
<td>4.2</td>
<td>4.2</td>
</tr>
<tr>
<td>17</td>
<td>1</td>
<td>4.2</td>
<td>4.2</td>
</tr>
<tr>
<td>20</td>
<td>1</td>
<td>4.2</td>
<td>4.2</td>
</tr>
<tr>
<td>33</td>
<td>1</td>
<td>4.2</td>
<td>4.2</td>
</tr>
<tr>
<td>50</td>
<td>2</td>
<td>8.3</td>
<td>8.3</td>
</tr>
<tr>
<td>60</td>
<td>1</td>
<td>4.2</td>
<td>4.2</td>
</tr>
<tr>
<td>75</td>
<td>1</td>
<td>4.2</td>
<td>4.2</td>
</tr>
<tr>
<td>80</td>
<td>1</td>
<td>4.2</td>
<td>4.2</td>
</tr>
<tr>
<td>100</td>
<td>9</td>
<td>37.5</td>
<td>37.5</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>24</strong></td>
<td><strong>100.0</strong></td>
<td><strong>100.0</strong></td>
</tr>
</tbody>
</table>

## Percent family help

<table>
<thead>
<tr>
<th>Frequency</th>
<th>Percent</th>
<th>Valid Percent</th>
<th>Cumulative Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Valid 0</td>
<td>6</td>
<td>25.0</td>
<td>25.0</td>
</tr>
<tr>
<td>11</td>
<td>1</td>
<td>4.2</td>
<td>4.2</td>
</tr>
<tr>
<td>33</td>
<td>2</td>
<td>8.3</td>
<td>8.3</td>
</tr>
<tr>
<td>40</td>
<td>1</td>
<td>4.2</td>
<td>4.2</td>
</tr>
<tr>
<td>50</td>
<td>3</td>
<td>12.5</td>
<td>12.5</td>
</tr>
<tr>
<td>66</td>
<td>1</td>
<td>4.2</td>
<td>4.2</td>
</tr>
<tr>
<td>100</td>
<td>10</td>
<td>41.7</td>
<td>41.7</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>24</strong></td>
<td><strong>100.0</strong></td>
<td><strong>100.0</strong></td>
</tr>
</tbody>
</table>

## Percent friend help

<table>
<thead>
<tr>
<th>Frequency</th>
<th>Percent</th>
<th>Valid Percent</th>
<th>Cumulative Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Valid 0</td>
<td>19</td>
<td>79.2</td>
<td>79.2</td>
</tr>
<tr>
<td>50</td>
<td>1</td>
<td>4.2</td>
<td>4.2</td>
</tr>
<tr>
<td>100</td>
<td>4</td>
<td>16.7</td>
<td>16.7</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>24</strong></td>
<td><strong>100.0</strong></td>
<td><strong>100.0</strong></td>
</tr>
</tbody>
</table>

## Percent spouse help

<table>
<thead>
<tr>
<th>Frequency</th>
<th>Percent</th>
<th>Valid Percent</th>
<th>Cumulative Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Valid 0</td>
<td>12</td>
<td>50.0</td>
<td>50.0</td>
</tr>
<tr>
<td>100</td>
<td>12</td>
<td>50.0</td>
<td>100.0</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>24</strong></td>
<td><strong>100.0</strong></td>
<td><strong>100.0</strong></td>
</tr>
</tbody>
</table>
### Percent child help

<table>
<thead>
<tr>
<th>Frequency</th>
<th>Percent</th>
<th>Valid Percent</th>
<th>Cumulative Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>0</td>
<td>15</td>
<td>62.5</td>
<td>62.5</td>
</tr>
<tr>
<td>25</td>
<td>1</td>
<td>4.2</td>
<td>66.7</td>
</tr>
<tr>
<td>50</td>
<td>2</td>
<td>8.3</td>
<td>75.0</td>
</tr>
<tr>
<td>100</td>
<td>6</td>
<td>25.0</td>
<td>100.0</td>
</tr>
<tr>
<td>Total</td>
<td>24</td>
<td>100.0</td>
<td>100.0</td>
</tr>
</tbody>
</table>

### Percent Parent help

<table>
<thead>
<tr>
<th>Frequency</th>
<th>Percent</th>
<th>Valid Percent</th>
<th>Cumulative Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>0</td>
<td>23</td>
<td>95.8</td>
<td>95.8</td>
</tr>
<tr>
<td>100</td>
<td>1</td>
<td>4.2</td>
<td>100.0</td>
</tr>
<tr>
<td>Total</td>
<td>24</td>
<td>100.0</td>
<td>100.0</td>
</tr>
</tbody>
</table>

### Percent Sibling Help

<table>
<thead>
<tr>
<th>Frequency</th>
<th>Percent</th>
<th>Valid Percent</th>
<th>Cumulative Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>0</td>
<td>22</td>
<td>91.7</td>
<td>91.7</td>
</tr>
<tr>
<td>50</td>
<td>1</td>
<td>4.2</td>
<td>95.8</td>
</tr>
<tr>
<td>100</td>
<td>1</td>
<td>4.2</td>
<td>100.0</td>
</tr>
<tr>
<td>Total</td>
<td>24</td>
<td>100.0</td>
<td>100.0</td>
</tr>
</tbody>
</table>

### Percent Other Family help

<table>
<thead>
<tr>
<th>Frequency</th>
<th>Percent</th>
<th>Valid Percent</th>
<th>Cumulative Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>0</td>
<td>23</td>
<td>95.8</td>
<td>95.8</td>
</tr>
<tr>
<td>100</td>
<td>1</td>
<td>4.2</td>
<td>100.0</td>
</tr>
<tr>
<td>Total</td>
<td>24</td>
<td>100.0</td>
<td>100.0</td>
</tr>
</tbody>
</table>

### Percent hired help

<table>
<thead>
<tr>
<th>Frequency</th>
<th>Percent</th>
<th>Valid Percent</th>
<th>Cumulative Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>0</td>
<td>21</td>
<td>87.5</td>
<td>87.5</td>
</tr>
<tr>
<td>100</td>
<td>3</td>
<td>12.5</td>
<td>100.0</td>
</tr>
<tr>
<td>Total</td>
<td>24</td>
<td>100.0</td>
<td>100.0</td>
</tr>
</tbody>
</table>
Percent Service dog Help

<table>
<thead>
<tr>
<th></th>
<th>Frequency</th>
<th>Percent</th>
<th>Valid Percent</th>
<th>Cumulative Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Valid</td>
<td>0</td>
<td>23</td>
<td>95.8</td>
<td>95.8</td>
</tr>
<tr>
<td></td>
<td>100</td>
<td>1</td>
<td>4.2</td>
<td>100.0</td>
</tr>
<tr>
<td>Total</td>
<td>24</td>
<td>24</td>
<td>100.0</td>
<td>100.0</td>
</tr>
</tbody>
</table>
References:

Bruno, R.L. 1997a. After the fall: Do illness, injuries and surgeries trigger PPS? New Mobility, 8. p.54
Bruno, R.L. 1999e. The Stealth Polio Epidemic of 1947. New Mobility, 10(June)
Bruno, R.L. 1999f. The Ten Commandments of PPS. *New Mobility*, 10(6).


National Center for Health Statistics. 1994b *Disability Follow Back Survey (Phase II): Adult Questionnaire*. National Center for Health Statistics, Hyattsville, Maryland
National Center for Health Statistics. 1994c *Disability Follow Back Survey (Phase II): Polio Survivor Questionnaire*. National Center for Health Statistics, Hyattsville, Maryland


