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## Ghosts of the past : polio survivors confront post polio syndrome

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### **Abstract**

This qualitative study explores the experience, attitudes, and coping skills of polio survivors confronting post polio syndrome (PPS), the re-emergence of polio-related symptoms in older age. It asks the question, ““What are the experiences and attitudes among individuals experiencing PPS towards declining physical functioning and secondary disability, and what are the resiliencies and coping strategies they are drawing upon in confronting symptoms?” This study seeks to provide social workers with a more richly described narrative of the resiliencies, approaches to coping, and challenges confronted by those with PPS than has been provided by past literature. Furthermore, it seeks to provide insight around the experience of secondary disability and recurrence of illness in general, the needs of these individuals, and their experiences with systems of healthcare.

Data for this research was gathered from individual interviews with five male and eleven female polio survivors (n=16) between the ages of 56 and 78, medically diagnosed and/or self-identifying as experiencing symptoms of PPS. They were questioned about their experience of polio and PPS, the coping strategies they are drawing upon, issues of identity construction, and positive and negative residuals to having polio and PPS. Findings suggest that those confronting PPS often experience similar emotional reactions and challenges, and cope with a rich variety of strategies, some of which are newly formed, some of which they have used throughout their lives. Furthermore, findings illustrate that polio survivors confronting PPS construct meaningful narratives from these experiences and find important residual benefits to them.

**GHOSTS OF POLIO PAST: POLIO SURVIVORS CONFRONT  
POST POLIO SYNDROME**

A project based upon an independent investigation,  
submitted in partial fulfillment of the requirements  
for the degree of Master of Social Work.

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2011

## **Acknowledgments**

This thesis is dedicated to my mother, a polio survivor who inspired this study, and the sixteen polio survivors who generously shared with me their stories of resilience, struggle, and hope so that this study could be realized.

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## **Chapter I**

### **Introduction**

The purpose of this study is to describe the attitudes, experiences, and coping skills of polio survivors now experiencing post polio syndrome (PPS), a cluster of often debilitating physical symptoms which survivors of the polio epidemics of the 1930s, 1940s and early 1950s are increasingly confronting as they age. It asks the question, “What are the experiences and attitudes among individuals experiencing PPS towards declining physical functioning and secondary disability, and what are the resiliencies and coping strategies they are drawing upon in confronting symptoms?” Health professionals have discovered that those with PPS are often slow to seek treatment. When they do, they often don’t follow the treatment regimens recommended by treatment teams, such as engaging in less physical activity, slowing down, increasing time spent resting, and reducing stress (Bruno & Frick, 1991). The literature has presented multiple possible reasons for this: distrust of doctors by PPS patients, grounded in their early childhood experience of polio treatment which was often painful and traumatic; a stubborn, “type A” personality; denial of disability due to internalized social stigma; and a mentality of “use it or lose it” from childhood (Shell, 2005). These finding suggests that there is a disconnect between approaches to treatment currently being offered, and the experiences, attitudes, and needs of PPS patients.

This study seeks to bridge this disconnect by offering health professionals, particularly social workers, a better understanding of these experiences, attitudes, and needs using the voices of individuals experiencing PPS, gathered from sixteen in-person interviews. Research up to this

point has done little to explore patients' attitudes towards PPS using their own narratives and a qualitative research approach. In doing so, this study seeks to provide social workers and other treatment providers with a more richly described narrative of the resiliencies, approaches to coping, challenges, and residual benefits experienced by those with PPS, so that both medical and psychological treatment may be better tailored to their needs and experiences, and thus be made more palatable and accessible to them. This is particularly important now, as the number of those confronting PPS is already large, and expected to continue to rise as polio survivors age (Hollingsworth, Didelot, & Levington, 2002).

In the medical literature up, recommendations for treatment have been based largely on an understanding of the physical symptoms of PPS and resulting psychological responses using a deficit model: that is, physical and psychological experiences are negative ones, and treatment is therefore focused on helping individuals accept secondary disability, replace destructive coping responses with beneficial ones, and make the lifestyle changes that a decrease in physical functioning calls for. This study yields a broader understanding of the PPS experience, one that assumes that secondary disability does not necessarily have to be constructed only as an experience of loss, anxiety, and trauma. By providing participants with a space to describe their experience of PPS, I wish to capture the resiliencies and coping strategies they bring to the experience of declining physical functioning, as well as how the experience may be a richer and more varied one than what previous literature has assumed. This study is also meant to provide a space for those confronting PPS to freely express their experiences, thoughts, and feelings and, in doing so, validate the voices of a group whose needs and wishes are often overlooked both by treatment professionals and by the wider society. Finally, this study seeks to provide insight for social workers that goes beyond the post polio population to others experiencing the recurrence

of an illness believed to be cured. Indeed, as the population in the United States ages and as Americans live longer, an increasing number of people will experience secondary disability or the return of illnesses that were cured earlier in life, such as cancer. It is vital that social workers are prepared to work with these populations.

Indeed, social workers, due to their prevalence in locations where those with PPS seek treatment, particularly in hospitals and in the psychotherapeutic community, have a significant opportunity to enact change in the manner that treatment is provided to this population and others confronting similar issues. Furthermore, social workers' sensitivity to the reflexivity between the person and their environment can provide a unique lens to the understanding of the experience of PPS, one different from the medical model usually employed in the treatment of both physical and emotional symptoms. Finally, the awareness of the social work profession to issues of race, ethnicity, gender, and socio-economic position is a key strength they bring to working with the highly diverse PPS population. The intended audiences of my study are polio survivors, those in the medical community providing treatment for the physical symptoms of PPS, and the social work community and others addressing the socio-emotional component that can accompany this illness and others like it.

### **History of Post Polio Syndrome**

An understanding of the social construction of polio in the mid-twentieth century is important for understanding polio survivors' experience of post polio today. In the mid-1950s, with the discovery of the Salk and Sabin vaccines, America declared victory over polio, one of the most dreaded diseases of the 20<sup>th</sup> century (Shell, 2005). Just as America had "conquered" polio, survivors of these epidemics, mostly children and adolescents who had lost physical functioning as a result of contracting polio, were expected to do similarly. Pushed by their



families, doctors, themselves, and American society, they were encouraged to return to “normalcy” as much and as quickly as possible: that is, to recover physical functioning so that they could participate in society as a non-disabled person. Furthermore, polio survivors were encouraged to deny the experience of emotional distress from experiencing a life threatening illness, losing mobility, and being different from other children (Shell, 2005 & Wilson, 2005). Polio survivors were exceptionally adept at meeting these expectations and mainstreaming into the larger society. In fact, a 1990 study showed that, as a group, they exceeded the accomplishments of their disabled and non-polio cohorts in terms of educational attainment and having families of their own. They also had a higher level of employment than others with disabilities (Bruno & Frick, 1991).

Until the 1980s and 1990s, many of those who survived polio, now aging baby-boomers, believed that their struggle with polio had ended long ago. However, a growing number of polio survivors, many of whom had lived lives of full or near-to-full mobility, began unexpectedly facing declining physical functioning at this time (Shell, 2005). First described in 1879 but largely forgotten in the medical community until the 1980s (Shell, 2005), these polio survivors were encountering the “late effects” of polio, also called post polio syndrome. The symptoms of PPS were first collectively defined in Halstead and Rossi’s 1985 paper, *New problems in old polio patients: Results of a survey of 539 polio survivors*. By the time this paper was published, some polio survivors had been experiencing PPS symptoms for over a decade, but they, along with their physicians, were unaware that these symptoms were connected to the polio they had encountered as children and as adolescents (Halstead & Rossi, 1985). By the late 1990s, it was estimated that there were approximately 600,000 survivors of polio in the United States, of whom 20 to 40 percent were experiencing PPS (Sass, 1996).

## **Symptoms of Post Polio Syndrome**

PPS is a gradual disease, usually first experienced in middle to older age, during which polio survivors experience the return of many of the original symptoms of polio, including muscle weakness and atrophy, a decline in motor functioning, fatigue in joints and muscles, difficulty breathing, decrease in stamina, lower back pain, and intolerance to cold (Hollingsworth et al., 2002). Progressive wasting and weakness may occur in areas of the body, particularly limbs, originally affected by polio. Due to skeletal deformation and muscle weakness caused by polio, there are often orthopedic complications in other areas of the body, the result of a lifetime of abnormal stress and compensatory use (Howard, 2005). Although there are no longitudinal studies which show that PPS is not progressive, Howard (2005) states that “experience suggests that postpolio (sic) functional deterioration does not necessarily progress once it has occurred. Fatigue and reduced mobility may often progress only slowly or stabilize” (Howard, 2005, p. 1318).

The cause of PPS is unknown but it is predicted that, with increasing age, most polio survivors will experience PPS symptoms (Wilson, 2005). One study found that the risk of contracting PPS symptoms increased with the level of permanent physical impairment caused by the initial bout with polio, the number of years following the initial bout, and being female. It found no correlation between contracting PPS and age of the first polio onset, initial severity, or the level of physical activity after recovery (Ramlow et. al., 1992). However, other studies have found that patients engaged in intense physical activity are more likely to develop PPS symptoms (Sass, 1996).

## **Current Treatment of Post Polio Syndrome**

There has been much debate within the medical community regarding how to treat the physical effects of PPS effectively. There is no cure. Rather, the purpose of treatment is to manage and minimize symptoms as much as possible. Randomized clinical trials have suggested that muscular training, such as graded exercise and non-swimming exercise in warm water, can be helpful for improving fatigue and mobility and decreasing weakness and pain. However, it is advised that exercise be limited so that already damaged muscles do not become more traumatized (Howard, 2005). Increasing the amount of rest and decreasing the amount of physical activity is often a component of treatment plans (Bruno & Frick, 1991). Research has also considered the potential psychological consequences of being confronted with the reemergence of an illness assumed to have concluded long ago, and the secondary disability and changes in lifestyle PPS often necessitates. This research is described in detail in the following chapter.

## **Study Structure**

The purpose of this study is to give voice to the experiences, attitudes and coping strategies of polio survivors confronting post-polio syndrome using their own narratives. In doing so, this study seeks to offer treatment providers, particularly social workers, with a richer and more holistic understanding to draw upon in their work with this population than has been previously put forth by the literature. It is hoped that this understanding will help treatment providers offer services to those confronting PPS that is more attuned to their needs, wishes, and strengths. I locate this study within the existing literature in Chapter II by providing a socio-historical understanding of polio, describing the theoretical approaches that have been used by medical professionals to understand the psychological experience of PPS, and presenting

findings from the empirical research on the psychological effects of PPS. Chapter III describes the methodology used to complete this study, followed by Chapter IV which presents findings. A discussion of these findings and suggestions for further research follows in Chapter V.

## **Chapter II**

### **Literature Review**

The increasing prevalence of PPS, along with the fiftieth anniversary of the Salk vaccine in 2005, has sparked renewed interest among historians, scientists, physicians, mental health professionals, and others in the medical field, in the social history of polio, the experiences of polio survivors and their families, and the late effects of polio. The following literature review examines, first, the social context of polio in the mid twentieth century. Polio's construction in American culture, particularly during the outbreaks of the 1940s and early 1950s, shaped the identities and coping strategies of polio survivors, and has influenced how polio survivors understand and confront PPS today. The theoretical frameworks that have been used in the medical and mental health fields to conceptualize the polio survivor's experience of PPS are reviewed next. This literature suggests ways that treatment providers can use these frameworks to support the individual around the experience of second disability. Third is an examination of the empirical research on the psychological effects of PPS, efforts at treatment, and treatment compliance rates. Finally, the strengths and limitations of the existing literature in understanding the experience, attitudes, resiliencies, and coping strategies of individuals experiencing PPS are reviewed.

#### **Socio-Historical Literature**

Several social histories of polio were published at the beginning of the twenty-first century, no doubt reflecting the revived interest in polio engendered by the fiftieth anniversary of the Salk vaccine in 2005. These texts can be divided into two categories. The first trace the history of polio in the United States, and tend to follow a common narrative structure of initial

helplessness toward, then struggle against, and ultimate conquest of the disease, with Salk as the central hero. Although written at the turn of the turn of the twenty-first century, the tone of these narratives largely echoes those of the mid twentieth: science and technology are the victors against polio, and polio is “defeated” by the tireless efforts of a few heroic scientists. The lens of conquest is evident in the titles of these texts. *A paralyzing fear: The triumph over polio in America* (Seavey, Wagner & Smith, 1998), released to accompany a PBS television special of the same name, traces the epidemics of the mid twentieth century, the experiences of those who lived through them and survived, and concludes with the discovery of the polio vaccine. Similarly, *Splendid solution: Jonas Salk and the conquest of polio* (Kluger, 2004) also has a narrative structure that highlights the struggles against the disease in the late 1940s and early 1950s, and ends triumphantly with its eradication. The struggles, setbacks and triumphs of Salk are chronicled, and the narrative is complemented by images of crippled young children and Salk working steadily in his lab. These narratives are not only ones of triumph and unwavering optimism in the capacities of science and technology, but also of patriotism. Although polio was, and continues to be, a disease found throughout the world, the conquest of polio is constructed as a uniquely American narrative, embodying American ideals and the result of American ingeniousness and unwavering determination. This is perhaps best exemplified in the title of *Polio: An American story* (Oshinsky, 2005), which chronicles the mid-century epidemics, and takes as its focus the contentious relationship and rivalry of Salk and Sabin, who would develop the oral vaccine for polio which was used in the US on a large scale beginning in 1960. These narratives dedicate few, if any, pages to examining the often challenging experiences of reintegration of polio survivors after they returned home from the hospital. Similarly, the new challenges to polio survivors brought on by the advent of PPS are mentioned only as footnotes.

In these narratives, polio is conceptualized as a disease whose history concluded with the advent of the Salk vaccine.

The second category of texts examines the mid century social construction of polio in the United States. These texts, such as *Living with polio: The epidemic and its survivors* (Wilson, 2005), *Polio and its aftermath: The paralysis of culture* (Shell, 2005), and *A summer plague: Polio and its survivors* (Gould, 1995) argue that mid century American cultural values such as the protestant work ethic, conformity, normalcy, and repression of emotional distress, shaped the medical treatment and rehabilitation polio survivors received, the manner in which they were encouraged to move forward with their lives afterwards, and their current responses to PPS. Wilson, for instance, writes that children who survived polio and began the process of rehabilitation were “generally encouraged to be compliant, work hard at the tasks set before them...Being a good patient meant repressing as well as one could feelings of confusion, fear, anger, rage, hopelessness, and despair” (Wilson, 2005, 67). The American protestant work ethic, in which one works patiently and diligently toward a long-term goal, he argues, underlied the philosophy of polio rehabilitation. This philosophy also held that rehabilitation was to be undertaken by a team of specialists who would work together to rehabilitate polio survivors to physical and psychological “normalcy” (Wilson, 2005). Parents were encouraged by medical professionals to treat children who had survived polio as any other child in their family, and to have similar expectations for them (Shell, 2005). The polio survivor was expected to conform as well as he or she could to being “not disabled”, and to repress any distressing feelings that physical difference could produce. In American society of the 1940s and 1950s, in which few accommodations for the disabled were made, this philosophy was crucial for preparing children for partaking in mainstream life (Wilson, 2005, Shell, 2005 and Gould, 1995). Thus, polio

survivors, these authors argue, grew up with the belief that through hard work, perseverance, compensation, and denial, most could pass as “normal” to “near-normal” and, in doing so, successfully partake in American society. Just as American society was victorious over polio, so too could the polio survivor conquer the physical limitations the disease had imposed on the body (Shell, 2005). *Bracing Accounts: The Literature and Culture of Polio in Postwar America* (Foertsch, 2009) lends further support to this idea by deconstructing textual accounts, particularly autobiographies of polio survivors, to illustrate the identity of victor that many polio survivors were encouraged to take on by their families and the larger society, and which some ultimately internalized (Foertsch, 2009).

The authors of these social histories correlate the social construction of polio and the expectations for polio survivors in the 1940s and 1950s with the psychological effects of depression, anxiety, anger, and identity fragmentation that some with PPS experience today. The authors suggest that PPS is particularly emotionally devastating because it not only causes an individual to relive symptoms of a disease they felt they had conquered a half century before, but it also forces the individual to renegotiate their identity around the disease. This often means coming to terms with being physically disabled, internalized long ago as a negative identity. Indeed, although they had physical limitations, many polio survivors have not self-identified as disabled up to the time they are diagnosed with PPS. Furthermore, PPS can bring forth painful memories and emotions which were not dealt with during the first experience with the disease, due to social pressure to get on with life and keep a positive attitude (Wilson, 2005, Shell, 2005 and Gould, 1995). Finally, the coping mechanisms that polio survivors have used successfully in their lives, according to these authors, are often not appropriate for coping with PPS. For instance, after being told for years to “use it or lose it”, that is, to push through physical pain and



continue to use parts of the body damaged by polio as much as possible, medical professionals are now warning polio survivors with PPS to “use it and lose it” (Wilson, 2005). Polio survivors, used to pushing their bodies to overcome their physical limitations, are now advised to rest and to give up physically demanding activities. For some, the authors argue, this represents surrender, which during their initial experience of polio was internalized as an unacceptable way of dealing with physical limitations. Thus, for many polio survivors confronting PPS, modern treatment recommendations collide with long-held attitudes and beliefs (Wilson, 2005, Shell, 2005 and Gould, 1995).

### **Theoretical Literature**

Since PPS was first named in Halstead and Rossi (1985), theoretical research conceptualizing the experience of PPS and suggesting clinical approaches for the treatment of psychological symptoms has relied on two models of understanding. First, this literature has advocated the use of a stage model of disability acceptance. This model suggests that those with PPS must work through various stages of profound loss and grieving before finally accepting a decline in physical functioning. Interventions are based on the stage of disability acceptance that individual occupies. Second, studies have argued for a strength-based approach to understanding the experience of PPS, locating it within the biography of the individual and modeling interventions based on the unique resiliencies, skills, and resources such an approach reveals.

Research advocating the use of the stage model approach to understanding PPS suggests psychotherapeutic treatment should focus on helping people move through stages toward acceptance of second disability. Frick (1985) argues that coming to terms with the decline in physical functioning which accompanies PPS is a process of acceptance in the face of negative societal attitudes toward the disabled, which individuals experiencing PPS cannot help but

internalize, leading them to “devalue themselves as the rest of society does” (Frick, 1985, p. 852). Frick models this process of adjustment on past studies of adjustment to disability, modifying them “to apply to the post-polio experience” (Frick, 1985, p. 852). These stages are: 1) a period of mourning for the loss of physical ability; 2) devaluing the physique, so that physical achievement and appearance become unimportant, allowing for the individual to be better prepared psychologically to deal with using new or additional assistive devices; 3) enlarging the scope of values so that one’s body is not decisive in determining one’s worth; and finally, 4) upholding asset evaluation, which entails “emphasizing and learning to value what persons can do within the limitations of their disability instead of judging themselves by so called ‘normal’ standards inappropriate for them” (Frick, 1985, p. 853). Frick argues that peer support groups are helpful in facilitating the individual’s movement through these stages, because such groups decrease feelings of isolation, provide access to community resources and the coping strategies of others, and can be protective against the effects of stress (Frick, 1985).

Hollingsworth, Didelot, & Levington (2002), too, argue that the experience of PPS can be understood through a stage model perspective. Like Frick (1985), this experience is conceptualized as a largely negative one. Indeed, the authors cite past quantitative studies (for example, Bruno & Frick, 1991) that have found that PPS is often accompanied by psychological symptoms such as depression, anxiety, loss of control, compulsions, and phobic reactions to change (Hollingsworth et al., 2002). The authors state that the majority of the disability literature supports the tenet that there are five stages to the adjustment of a disability experienced after birth, each characterized by its own reactions, emotions, and coping mechanisms: 1) initial impact; 2) defense mobilization; 3) initial realization; 4) retaliation; and 5) integration. The authors argue that supporting those with PPS through these stages with a multidisciplinary team

of nurses, psychologists, physicians, social workers, occupational therapists, nutritionists and spiritual guides, is at the core of treatment for the psychological effects of PPS. A guide is included with the paper for patient self-assessment to help the individual and treatment team determine what emotional stage of PPS the patient is experiencing (Hollingsworth et al., 2002).

Wiley (2003), on the other hand, suggests that the experience of individuals with PPS can be best understood through a qualitative approach using the voices of the patients themselves. She writes, “The rewards of qualitative research are in revealing the life history or narrative of an individual, experiences that cannot be documented quantitatively. Innermost thoughts, modes of thinking, personal ways of coping, person-environment interactions, and degrees of resiliency are just some of the attributes of persons that are revealed” (Wiley, 2003, pp. 39-40). Suggesting a narrative and strength-based approach to treatment, Wiley argues that interventions should be developed around the experiences and resiliencies that these interviews reveal. Wiley suggests that the act of engaging in the story-telling process used in qualitative research can act as a meaningful intervention for those experiencing PPS symptoms. It can aid in facilitating adaptation and feelings of empowerment by allowing the individual to feel a sense of control and agency in telling his or her story, allow for the communication of what is important to the individual who is dealing with aging with a disability so that interventions can be developed which match his or her needs, and can provide meaningful interaction which helps an individual determine what their anticipated needs will be and benefits achieved through managing the disability (Wiley, 2003). The emphasis on quantitative data collecting in past research to understand the emotional component of PPS, she argues, may inadvertently overlook important information that can be used in approaches to treatment (Wiley, 2003).

## **Empirical Literature**

Since the designation of PPS, research has focused on describing its physical, emotional, and quality of life repercussions, as well as efforts at treatment. Although the late effects of polio were first discussed in the medical literature in the 19<sup>th</sup> century, quantitative studies exploring the psychological effects that can accompany PPS symptoms, as well as treatment approaches, are not extensive. The most complete of these is Bruno and Frick (1991), which presents a model of PPS treatment provided at the Post-Polio Rehabilitation and Research Service in New Jersey, and a quantitative, cross sectional study of compliance rates to the treatment (Bruno & Frick, 1991). The program is focused on treating both the physical and psychological impacts of PPS using a multi-disciplinary approach consisting of a physician, psychologist, occupational therapist, and physical therapist. Patients are asked to list treatment goals and to make a daily log of “perceived exertion, fatigue, muscle weakness, pain, emotional stress, thoughts, and emotion...to document physical and emotional symptoms and demonstrate their relationship to thoughts, affect, and compulsive, Type A behavior” (Bruno & Frick, 1991, p. 1191). Log data and evaluation results are used to formulate a behavioral plan “designed to decrease behaviors that cause physical symptoms, initiate selfcare activities, and incorporate stress and time management, energy conservation, work simplification, and a program of relaxation, stretching, and non-fatiguing progressive resistance exercises into patients’ daily routine” (Bruno & Frick, 1991, p. 1191).

Of the 55 patients treated by the Post-Polio Rehabilitation and Research Service over one year, 47% were fully compliant to treatment, 34% were partially compliant, and 19% were discharged for non-compliance. Twenty-eight percent who received an initial evaluation declined any further treatment. Even those who were fully or partially compliant over the course

of treatment had “a tendency to resume compulsive, Type A behavior” (a term which the authors ultimately leave undefined) and detrimental physical activity on follow up (Bruno & Frick, 1991, p. 1192). Depression, which the authors attribute to Type A characteristics, also played a role in compliance. Thirty-one percent of patients at intake met the DSM-III-R criteria for Major Depressive Episode (MDE), far higher than that of 3% to 7% found in the general population. Not surprisingly, MDE was found to be significantly correlated with treatment non-compliance, diagnosed in 63% of patients who declined further treatment after the initial evaluation, and in 50% who were discharged for noncompliance during treatment. On the other hand, only 11% of patients who were fully compliant and 29% who were partially compliant with therapy were diagnosed with MDE (Bruno & Frick, 1991). The authors conclude that non-compliance with treatment is a result of fears of relinquishing Type A behaviors that polio survivors have used for self-protection over the years. Intolerable fears of criticism and failure are triggered when they contemplate lifestyle changes or the use of assistive devices (Bruno & Frick, 1991).

And yet, not all studies have found that those experiencing PPS also experience psychological distress. Schanke (1997) examines the emotional responses to PPS of 63 patients after completing in-patient treatment three to five years previously at the Post-Polio Program at Sunnaas Rehabilitation Hospital in Norway. Thus, unlike Bruno and Frick’s study, the population of PPS patients is more specified: by the time they participated in this study, all had lived with PPS symptoms for at least three years. Depression, anxiety, and Type A scores were found to be within normal range. Although 82% of subjects self-identified as disabled, compared to 58% three to five years previously, 49% of women and 25% of men reported improved psychological well-being compared to 3-5 years ago, although this was not a statistically significant finding. These individuals were slightly younger, were more likely to

have invisible disabilities, and to have experienced greater distress in the past, than those individuals who reported having similar or worse psychological well-being. Data did not show a correlation between psychological well-being and physical issues, but there was a positive correlation between previous emotional distress and invisibility of disability (Schanke, 1997). The differences in Schanke's findings regarding depression, anxiety, and Type A scores compared to other studies, such as Bruno and Frick (1991), is striking, particularly as the existence of a Type A personality in PPS patients is a fundamental assumption in their treatment model. Schanke suggests that these differences may be the result of differing study populations (Schanke's study is of Norwegian participants, while those she compares it to are American), type of study conducted, and the interval between the time of first symptoms and when the study was conducted (Schanke, 1997).

Westbrook & McIlwain's (1996) longitudinal, quantitative comparison of emotional responses among individuals with PPS at the onset of disability and five years later, yielded similar results. Unlike Schanke, whose sample was drawn from those hospitalized at the onset of PPS, Westbrook & McIlwain's sample was made up of members from recently formed post polio support groups in Australia. Their sample, therefore, may include a different level of disability from those Schanke's study, all of whom were initially hospitalized for their PPS symptoms. Five years after the first questionnaire, of the 280 respondents who originally replied, 176 completed the follow up questionnaire. Both questionnaires contained many of the same questions, and asked respondents about their level of disability, emotional reaction, and coping style. Like Schanke, after five years most respondents reported a significant decline in health. However, they also experienced significantly less anxiety, uncertainty, depression and helplessness, with feelings of anger being the one emotional component not diminishing

significantly. Coping strategies were grouped into four categories: treatment (i.e. massage, counseling, vitamins, special shoes), lifestyle changes, personal strategies (i.e. development of spirituality, learning more about PPS, greater involvement in interests the person can still pursue), and interpersonal strategies (i.e., asking friend to help, talking with family about PPS). Participants rated the efficacy of lifestyle changes to be the most effective, and interpersonal strategies the least. Furthermore, emotional response to PPS at follow up was significantly related to coping style. For instance, participants who expressed greater feelings of helplessness, depression, and anger were more likely to cope by focusing on their symptoms and attempting to maintain previous activity levels. The authors also note that “(s)trategies of personal change have received little attention in the rehabilitation literature” (Westbrook & McIlwain, 1996, p. 68). And yet, more than two-thirds of participants highlighted such strategies as useful coping devices, suggesting that current literature and treatment options may overlook important modes of coping that can be useful to individuals with PPS (Westbrook & McIlwain, 1996).

Level of disability may also play a role in the experience of, and emotional reaction to, PPS. Following Schanke’s results, Maynard & Roller’s (1991) quantitative, cross sectional study found that polio survivors with invisible disabilities are more likely to become emotionally distressed by post polio symptoms as the new physical issues threaten their self-image and identity as “not disabled”. One hundred polio survivors experiencing PPS symptoms were asked to complete a survey that asked questions regarding their attitudes towards polio and PPS. The authors found that polio survivors can be grouped into three groups: Passers, Minimizers, and Identifiers. Different coping styles, they argue, are used among these groups which then can create unique challenges when an individual experiences post polio symptoms (Maynard & Roller, 1991). For instance, individuals identified by the researchers as Passers, whose

disability “was so mild it could be easily hidden in casual social interactions”, had used denial to “put their disability out of existence mentally and physically” to avoid being stigmatized as a disabled (Maynard & Roller, 1991, p. 70). This group, the study found, was the most likely to become emotionally distressed and overwhelmed by physical changes resulting from PPS. The authors hypothesized that this distress stemmed from threats to self-image because such individuals might not be able to pass any longer and thus fear stigmatization. In order to cope, “passers often must alter their self-perceptions and life-style in order to continue successful coping” (Maynard & Roller, 1991, p. 70). Minimizers, on the other hand, whose moderate disability “was readily recognized by other people”, who “often used visible adaptive equipment or had to do physical tasks differently in order to optimally function” and who “typically minimized the importance of their physical differences”, minimize the effects of their disability on their lives. They have “adapted by de-emphasizing physical pain, deformity, and functional shortcomings.” (Maynard & Roller, 1991, p. 70) Identifiers, who “were severely disabled by acute polio”, who “generally needed wheelchairs for independent mobility”, and who “needed to fully identify with their disability in order to make major lifestyle adaptations and successfully cope”, have often coped by becoming involved in disability rights advocacy and working very hard to learn simple self-care tasks. Thus, “independence in daily living activities may be one of the most important accomplishments of their lives” (Maynard & Roller, 1991, p. 70). The authors suggest that health providers should be prepared for these different styles of coping and respond accordingly. Passers may “require an unexpected amount of understanding, patience and empathetic support...because of strong emotional reactions that are not only triggered by the impending public nature of their new disability, but also by memories of past polio-related experiences” (Maynard & Roller, 1991, p. 71). In engaging with Minimizers, treatment



providers should help them “to re-focus on what is important in life; to take another look at how to be successful; to set new goals and achieve them in new ways. Health care professionals must be patient in helping Minimizers work through understandable resistance, fears, and anger with re-rehabilitation” (Maynard & Roller, 1991, p. 71). Identifiers may need treatment providers to “recognize that their intense interest in autonomy and control of their environment is not pathologic” (Maynard & Roller, 1991, p. 71). Thus, the authors suggest that individuals who experienced different degrees of severity of polio, learned different coping mechanisms, which, in turn, currently influence their response to PPS symptoms.

Similarly, Scheer & Luborsky’s (1991) qualitative, descriptive study examines how the qualities and personal characteristics which helped polio survivors succeed in the past, can now help them cope with the physical and emotional effects of new disability brought on by PPS. However, rather than link coping behaviors with distinct levels of disability, they suggest that coping behaviors are linked to an interplay between the individual and the wider socio-historical context in which they live. The authors use multiple interview case studies from two National Institute on Aging projects (they do not specify how many interviews were used or the nature of these larger studies), and find that two themes emerge: “First, decisions about current disability-related issues are infused with broader concerns about personal identity and the fulfillment of personal and cultural ideals, values, and expectations. Second, early life disability experiences continue to be important in later life” (Scheer & Luborsky, 1991, pp. 1173-1174). The authors argue that an individual’s experience of second disability must be located and understood within these cultural contexts. Polio survivors with PPS symptoms were found to experience a disrupted life course, that is, they were not leading the life they expected to be living at that stage of life, they experienced changing relationships with family members and friends, and they

confronted new losses in physical ability. Furthermore, they were found to interpret disabling symptoms in the context of “polio traditions”, that is, social expectations that polio survivors internalized as young people as to how to live life with a disability. Chief among these traditions was the emphasis on the work ethic to minimize and overcome physical limitations and achieve goals. Secondly, polio survivors were encouraged to forget polio and deny and minimize the loss pain and discomfort. Finally, and more recently, the authors cite the emergence of the concept of a “polio personality”, that is, the unique characteristics that enabled them to pass and achieve in the mainstream. This signifier has, for some, created a sense of shared identity and is a “banner of pride, a way for survivors to reclaim aspects of their own personal histories” (Scheer & Luborsky, 1991, pp. 1175-1180). The authors suggest that traditions such as working hard to meet goals and overcome adversity, “can be translated to the task of life reorganization demanded by the onset of secondary disabilities” (Scheer & Luborsky, 1991, p. 1180). Ultimately, “clinicians must recognize each client’s perception of his or her biography, and the influence of cultural as well as personal values and ideals” (Scheer & Luborsky, 1991, p. 1180).

### **Identification of Strengths and Limitations**

The review of the literature above illustrates that there are conflicting findings regarding the emotional experience of PPS, use of coping strategies, and approaches to treatment. Even so, these studies provide insight into the forces which may shape an individual’s emotional experience of PPS symptoms. For instance, length of time since the onset of symptoms, as proposed by Shanke (1997) and Westbrook & McIlwain (1996), and level of initial disability, as proposed by Maynard & Roller (1991), appear to contribute to levels of emotional distress and approaches to coping. Scheer & Luborsky’s (1991) emphasis on the unique socio-historical context within which American polio survivors grew-up, usefully situates the PPS experience

within a person-in-environment framework, and suggests that the current emotional experience of individuals with PPS is shaped by values internalized from childhood experience. This concept might also explain why Shanke (1997) and Westbrook & McIlwain (1996), whose participants were Norwegian and Australian, respectively, may show lower levels of emotional distress than those in Bruno & Frick's (1991) study using American participants. Finally, the stage model approach to treatment locates the emotional experience of PPS symptoms as fluid and flexible, rather than static, suggesting that needs, attitudes, resiliencies, and coping strategies may be different depending on an individual's stage of acceptance of symptoms.

These studies by and large understand PPS and secondary disability from a deficit perspective: they focus on the feelings of grief, anger, depression, and anxiety due to loss of physical functioning and then give suggestions regarding how treatment providers might support those with PPS in reducing them. Shanke (1997), Westbrook & McIlwain (1996), and Bruno & Frick (1991), for instance, explore the emotional responses to the loss of functioning and strategies for coping with this loss. Maynard & Roller (1991) link the experience of PPS entirely around the individual's loss of ability from their first bout with polio, assuming that this shaped their sense of identity, coping style, and approach to living. The stage model approach to treatment advocated by Frick (1985) and Hollingsworth et al. (2002) assumes that there is an experience of loss and grieving resulting from a loss in physical functioning, and that the individual must come to terms with and accept a decline in physical functioning to re-achieve emotional well-being. Indeed, Frick states that individuals experiencing PPS will inevitably internalize negative stereotypes toward the disabled and devalue themselves with the advent of PPS symptoms. These studies suggest that polio survivors' sense of self worth is dependent on physical ability and a normalized body image. The identity of being disabled is assumed to be a

negative identity and one that is distressing. And yet, some studies have shown, in fact, that the opposite is true. For instance, in a study of university students with cognitive and psychiatric disabilities, Olney & Brockelman (2003) found that students identified positive aspects to their disabilities, such as the ability to think differently than others and problem-solve in unique ways. Many felt that their disability had made them a better, more insightful person than they otherwise would have been. They tended to conceptualize disability as difference rather than deficit. Positive attitudes towards disability were also documented by Dunn (1996) who explored responses to disability as the result of amputation. This study found that seventy seven percent of participants identified that something positive had happened as a result of their amputation. Furthermore, as Schanke (1997) and Westbrook & McIlwain (1996) show, individuals experiencing PPS are emotionally healthier after experiencing a decline in physical functioning over a period of several years. Although their level of disability has increased, emotionally they appear better off. This suggests that attitudes toward disability are complex, and that responses to declines in physical functioning cannot always be assumed to be only ones of distress, depression, and mourning. Thus, treatment plans that are founded on these assumptions may be misguided: polio survivors' attitudes toward PPS and disability may be different, and/or far richer, from those currently assumed in the literature.

Approaches to PPS treatment that take into account the social construction of polio in the 1940s and 1950s and unique social histories of polio survivors, also focus on loss. Scheer & Luborsky (1991) for instance, focus on the experience of loss of physical functioning due to PPS within this socio-historical framework. Bruno and Frick (1991) locates an individual's non-compliance with treatment recommendations on internalized ways of being and personality characteristics, which they argue are the result of their early, historically situated, polio

experience rather than questioning the model of treatment and assumptions underlying it as being appropriate to the PPS population. The goal of psychotherapeutic treatment is to challenge thought processes labeled Type A and to replace them with those that will facilitate compliance with recommendations to enhance physical functioning and decrease depression and anxiety. And yet, this approach to treatment does not appear to utilize the existing strengths which are likely present in polio survivors, such as a strong will, organization, and perseverance, which are often described as Type A characteristics (Shell, 2005). These empirical studies largely mirror the attitudes underlying the socio-historical texts, which argue that internalized values and attitudes from childhood have been largely detrimental to polio survivors now experiencing PPS.

In summary, studies show that loss and emotional distress can be an important component of the PPS experience for those confronting PPS. Furthermore, these studies highlight other factors that might contribute to differences in the PPS experience among individuals, for instance time since onset of symptoms and level of initial disability. The socio-historical context in which an individual experienced their initial bout with polio also may be an important factor in determining an individual's response to, and understanding of, PPS symptoms. Since recommendations for treatment are largely based on the understanding of disability as only a negative experience, treatment is focused on helping individuals accept secondary disability. Furthermore, recommended coping strategies are often highly focused on lifestyle changes that a decrease in physical functioning may call for.

Existing literature provides a starting place to understand what the experience of PPS might evoke in some people. However, the literature's underlying assumption that the advent of disability naturally evokes only distress and feelings of loss is limiting. The coping strategies put forward in past literature also tend to be too narrowly defined. The experience of PPS may

be richer than what these studies indicate. As Wiley (2003) suggests, a useful approach for understanding attitudes, experiences, and strengths, is by in-depth interviewing of individuals with PPS, which enables thick descriptions. She notes, and it is evident in the research reviewed above, that in the case of PPS this is an area where more work is needed. It is this work that this study undertakes.

## **Chapter III**

### **Methodology**

This qualitative study asks the question, “What are the experiences and attitudes among individuals experiencing PPS towards declining physical functioning and secondary disability, and what are the resiliencies and coping strategies they are drawing upon in confronting symptoms?” Sub-topics explored are experiences with systems of medical care, complexities of coping strategies, interconnectivity between self identity and physical functioning, and benefits to secondary disability. Data was collected from interviews with 16 polio survivors experiencing PPS symptoms. Interview questions were open-ended and followed up by probes when appropriate. The strength of this methodological approach is that it allowed for the capture of rich and varied experiences and attitudes, and thus provided insight into the strengths, coping skills, and unique treatment needs of this population. Furthermore, it allowed for the examination of both manifest and latent content put forward by study participants, which led to potentially richer observations. Limitations of this method include that results could be interpreted to reflect the personal biases, both conscious and unconscious, of the researcher, interviewee responses could be misunderstood, and interviewees could be less likely to provide candid answers to questions than in an anonymous survey.

### **Recruitment**

Participants for the study were located using a non-probability sampling technique of snowball sampling. After the study was approved by the Human Subjects Review Board of Smith School for Social Work in January 2011 (Appendix A), recruitment began in February 2011 and ended in March 2011. Leaders of five different polio support groups in the Bay Area

of California were contacted via email by the researcher asking if she could attend a meeting to present the study and recruit participants. Three leaders responded and set up a time for the researcher to attend a group meeting. At the meeting, the researcher gave a brief presentation of the project and asked interested individuals to provide their contact information. Participants were required to be adults and English speaking, as this is the language the researcher was comfortable communicating in. Participants were also asked to have either a medical diagnosis of PPS or to self-identify as having symptoms of PPS.

### **Sample**

The study sample included five men and eleven women who self-identified as experiencing indicators of the late effects of polio, post polio syndrome, or similar symptoms. All were members of PPS support groups in the San Francisco Bay Area. The age of participants ranged from 56 to 78 years old, with an average age of 69. Fifteen participants identified as Caucasian, and one identified as Hispanic. The sample encompassed various levels of initial disability from polio, from no lasting residual effects to significant weakness and/or paralysis of the legs and/or arms. For those participants that were physically affected after their initial polio experience, most did not have physical limitations that they felt were highly visible to others. While many participants used assistive devices, most commonly braces on their legs, during periods of time in childhood and/or adolescence and/or early adulthood, no participant had used assistive devices in adulthood for extended periods before the onset of PPS symptoms. The age of initial onset of polio ranged from two weeks to 23 years old, with an average age of 8 years. The study sample encompassed a range of symptoms of PPS, from fatigue and breathing difficulties to mobility issues caused by muscle weakness and paralysis. The goal of the study was to attempt to capture a range of experience, attitudes and resiliencies. Based on these



demographics, diversity in gender, physical functioning, and age was achieved. Diversity in ethnicity and race was not achieved due to the lack of diversity in the support groups.

### **Ethics and Safeguards**

Before the interview, each participant received an informed consent form via email or in person (Appendix B) which detailed the nature of this study and the potential risks and benefits to the participant for participating in this study. Participants were made aware that their participation was voluntary, that they could refuse to answer any question, and that they could stop the interview at any time. Participants could withdraw after the interview. The informed consent also described how confidentiality would be maintained. Participants were provided with a list of psychotherapeutic referral sources in the event that participation in the study brought on psychological distress (Appendix C). Prior to beginning the interview, the researcher collected signed consents and answered any questions. No participant withdrew from the study.

### **Data Collection**

Upon a participant expressing interest in being interviewed for the study, the researcher arranged, via email and/or telephone, an interview date and a mutually agreeable location to meet. Interviews were conducted in participants' homes, at cafes, and at support group meeting locations. Participants were interviewed individually, one time, between February and March 2011. Interviews ranged from approximately 40 minutes to one and a half hours and were semi-structured. The interview consisted of open-ended questions and probes that explored the experience of polio and PPS, attitudes towards secondary disability, coping strategies, identity construction, and potential residual benefits to the PPS experience (Appendix D). Participants were audio-recorded. The recorder was only turned on once the interview began, and thus any introductions, discussion of the study, or closing remarks were not recorded.

## Data Analysis

Interviews were transcribed by the researcher one day to one week after the interview using Microsoft Word. During this process, common responses to particular questions were noted by the researcher in short memos. The researcher also noted common themes which emerged in the interviews but were not necessarily explicitly stated by the participant. To ensure confidentiality, the tape recorder used to record interviews was placed in a secure locked box per federal regulations after the transcription process was completed. Data was de-identified by removing names from the transcribed interview files and assigning each interview with a letter and number.

Transcriptions were coded using the categorizing strategy of content analysis. As defined by Maxwell (2005), this is the process of “fracturing” the data and rearranging it into categories “that facilitate comparison between things in the same category and that aid in the development of theoretical concepts” (p. 96). Data was categorized first using organizational categories, that is, “broad areas or issues that you establish prior to your interviews or observations, or that could usually have been anticipated” (Maxwell, 2005, p. 97). These categories followed topics defined by the researcher prior to interviewing. Interview questions were structured around these topics. The first, *Historical Context*, was further divided into sub categories of Initial Illness and Treatment, Participants’ Response After Recovery, Family’s Response After Recovery, Community Response After Recovery and Societal Barriers, and Coping. The next category, *The Post Polio Experience*, was divided into the sub organizational categories of Post Polio Symptoms and Response to Post Polio Syndrome Diagnosis. The purpose of these first two organizational categories, which have been examined in previous studies, was to provide context for the third and fourth organizational categories, *Coping* and *Benefits*, which have not been

examined thoroughly in the research up to this point. Organizational categories were then further subdivided into substantive categories, defined by Maxwell as descriptive categories “that provide some insight into what’s going on...they are generally not subcategories that in advance you would have known would be significant” (p. 97). Substantive categories include “description of participants’ concepts and beliefs; they stay close to the data categorized, and don’t inherently imply a more abstract theory” (Maxwell, 2005, p. 97). For the organizational category of *Coping*, substantive categories that emerged from the data were further divided into two sections. The first, Concrete Coping, described concrete actions participants took to cope with PPS. These included Seeking Medical Care, Use of Assistive Devices, Worker’s/Disability Compensation, Pacing, and Connecting with Others Confronting PPS. The second, Internal Coping, described thoughts, reflections, and beliefs that participants were using to cope. These included “Faith and Spirituality, Gratitude and Appreciation, and Normalizing Declining Physical Functioning. The organizational category of *Benefits* examines the positive residuals to polio and post polio that participants have experienced. The substantive categories which emerged from the data included Empathy and Compassion, Perseverance, and Coping Skills as residual benefits of polio. The substantive categories of Self Acceptance, Sense of Community with Other Polio Survivors, and Self Care emerged as residual benefits of PPS.

During the coding process, the researcher documented her analytic thoughts and insights in short memos. After the completion of the coding described above, connections between categories were analyzed by the researcher. Maxwell states, “This connecting step is necessary for building theory, a primary goal of analysis” (Maxwell, 2005). The conclusions that the researcher drew from this process are described in the last chapter (Chapter V) of this thesis.

## **Potential Limitations**

Since subjects participated in this study on a volunteer basis, the sample of individuals are those who had the time, energy, and interest in participating in this study. As a result, those who were particularly physically and emotionally impaired, and/or suffer from co-occurring illnesses, as well as those with significant work and family responsibilities, may have been less likely to volunteer. Second, all study participants were associated with PPS support groups. Those who choose to join support groups may not be representative of the general population of survivors of polio confronting post polio syndrome. For instance, they may experience more physical impairment, may be more likely to reach out to others for support, and may be more pro-active regarding understanding and treating their symptoms. Furthermore, the polio support groups attended by the researcher tended to have a primarily Caucasian membership, which led to a primarily Caucasian sample. On the other hand, those in support groups may be more used to talking about their experience of PPS, and more comfortable in sharing their thoughts and feelings with others. Therefore, a sample of group members could potentially yield richer and more extensive data. Third, due to disparities in healthcare, the study sample likely does not represent the range in racial and ethnic identities, as well as socio-economic status, of those who experience PPS. People of color and those who are financially disadvantaged may not have access to systems of healthcare which would diagnosis PPS symptoms, helping the individual to be aware that they are experiencing the late effects of polio. Fourth, individuals interviewed live in the San Francisco Bay Area. The experience of individuals living in a large, urban, socially liberal area may be different from those living in other geographic areas. For these reasons the study is likely not to be representative of the general population of individuals experiencing PPS, which likely affects all segments of society. Finally, interviewees may have felt compelled to

answer questions in a particular manner, for instance, to give the answer they believe the researcher was looking for (acquiescence), or to give an answer that reflected well on them (social desirability).

## **Chapter IV**

### **Findings**

The following chapter describes the most significant findings gathered from sixteen interviews with polio survivors now confronting PPS. It is divided into four sections. The first, Historical Context, describes participants' initial experience of polio as children and adolescents. Although this study seeks to focus on the post polio experience of adults, to fully understand this experience and the coping strategies participants have developed in response to PPS it is important to contextualize them within participants' polio histories. The second section, The Post Polio Experience, examines participants' physical and emotional experience of post polio syndrome as adults. The third section, Coping, examines coping strategies utilized by participants in confronting the physical and emotional effects of PPS. This section, in turn, is divided into two parts. The first explores concrete actions participants have taken to cope. The second examines internal and emotional coping strategies. The fourth and final section, Benefits, explores positive residuals that participants feel they have derived from their experiences of polio and PPS.

#### **Historical Context**

For the sixteen participants interviewed, the initial polio experience, medical treatment received, responses and behaviors of the individual, family, and community after initial recovery, and coping strategies, varied widely.

**Initial illness and treatment.** Most participants described common physical symptoms while ill with polio, particularly flu-like symptoms and paralysis in the legs and/or arms or entire body. No participants had been placed in iron lungs, which was a common intervention for polio

patients to aid in breathing. However, the experience of the medical treatment participants received while ill with polio was highly varied. Some were quarantined in their homes by public health officials, along with their families, to mitigate the spread of illness. Some received treatment in their homes simply because the hospitals were full during the epidemics. One participant did not receive any treatment from medical professionals due to her family's attempts to keep her illness a secret from their community. Most participants were hospitalized, often for weeks or months, rarely seeing their parents due to hospital policies of the time which limited contact between parents and their hospitalized children. Frequently, these participants recounted vivid memories of fear and anxiety due to being separated from their parents and being placed in an unknown environment. One participant stated:

(T)he hardest thing, probably of the whole thing, was looking down (from the hospital window), seeing my parents who must have come there only once or twice, I don't remember, all I can remember is looking out the window...looking out on my mom, my dad, and my sister. And that was very, that was hard.

Another participant, who acquired polio at two years old, remembered a similar experience:

(M)y parents could only come and see me on Sunday afternoons for a couple of hours, they could only come in one at a time. They couldn't come in together, so that was hard... (T)hey had a little play room and the windows you could look out and see the cars go by, and I was waiting for my mother and I guess she got there kind of late, you know. And I thought she had forgotten about me, and they said, 'Your mother's here' and I ran to her and I wouldn't let go of her.

Treatment, too, could be a frightening experience. For instance, several participants remembered receiving spinal taps, a painful method used to diagnose polio. Some participants remembered the kindness of hospital staff, while others remembered particular treatment providers who were unempathic and demanding.

After recovering from polio, participants also varied in their experience of its residual physical effects. A few participants did not have any physical effects as the result of their initial illness. Others had paralysis or weakness in the legs and arms, a limp, atrophy, cold sensitivity,

and/or breathing issues. Most participants received various physical therapy treatments during the rehabilitation phase after recovering from polio, which were founded on the ideas and methods of Sister Kinney, a pioneering treatment provider of physical therapy to polio survivors. These were performed by professionals and parents, and included hot packs on the body, painful stretching, exercises, and water therapy. Many participants had braces on their legs for several months to several years to strengthen the legs and improve mobility. Some had legs placed in casts in an attempt to stabilize them and prevent atrophy. Surgeries, sometimes multiple times, to adjust for differentials in leg length and to strengthen and adjust the leg were common experiences during young adolescence for those polio survivors who had had polio as children.

**Participants' emotional experience after recovery.** After recovering from polio, some participants, particularly those who were not visibly physically different from others, described that after recovering from polio, they and their families put the experience in the past. Polio was conceptualized as over with and rarely discussed. As one participant described, "(I)t was just something like, it's over with, you know, it's in the past." Another participant said that she conceptualized her experience of polio as a child as "very matter of fact. Kind of like, well, one cousin had rheumatic fever so she had a weak heart, I think to me it was just one of those things that happened." Several participants remembered being somewhat clumsy and physically awkward as children, but not associating this with their history of polio. "I tried to ignore it like my folks did, I'd just get tired. I didn't really notice (it) as being polio tired, just over doing it, too much sports, too much dance classes". One participant, who did not feel particularly unique as a child, felt that polio had made her feel special. Being a polio survivor also helped her to feel connected with her grandmother, one of the few supportive adults in her life, who also had challenges with mobility.



However, participants who appeared physically different than their peers tended to experience more negative feelings. Wearing braces and specially fitted shoes that looked different from those of other children, for instance, made them feel like they stood out from others and that something was wrong with them. Similarly, those who appeared physically different due to muscle atrophy and limping often described feeling unattractive, embarrassed that they looked different and not “normal”. One participant remembered:

I was the one limping...and wearing clumping braces, I wore those until the surgery at thirteen. So all through grade school I was wearing these gigantic, hunking, clumping metallic and wood braces, that there was no way you could make them look graceful or feminine. And of course everyone wore skirts then, no girls wore pants... physical difference was always there for everyone to see. There was no chance of covering it up.

Several participants who had polio as adolescents described feelings of loss and disappointment in response to no longer being able to do activities that they had enjoyed in the past. Those participants who were young adults living independent lives when they acquired polio, returned to families of origin during recovery.

**Family response after recovery.** Just as treatment and the residual effects of polio were highly varied among participants, so too were the responses of their families. Most commonly, participants voiced that once they recovered from polio, it was not an experience that the family talked about. For these participants and their families, polio was considered over with once the child recovered from the initial illness, and life moved on. As one participant stated about her parents, “They were very much in denial, they didn’t want to face it. I was going to get better, this was just a little bump in the road, that’s how they dealt with it”. Almost every participant stated that they were not indulged or treated specially from other children by their families, particularly after they had recovered from their initial illness. Indeed, most stated that they were expected to participate in school and other activities just as any able bodied child would. One participant stated that her family “expected me to be the way I was before.” Some were pushed

by their parents to overcome physical obstacles they experienced: “Oh yeah, the doctors even said you need to work out, strengthen your leg, tap dance, ballet, sports at school, I couldn’t get out of it. ‘Oh no, you need to work on it, you need to build the strength in your leg.’” One participant stated that she was pushed by her father to become educated because he felt she would never marry due to her physical difference. Her mother, on the other hand, viewed polio as a punishment from God.

A minority of participants described family responses that were secretive and emotionally and/or physically abusive. One participant stated that her family initially accused her of faking polio, and demanded she get out of bed while she was ill. The family refused her medical treatment and then kept her experience of polio as a family secret during and after her recovery. Another participant stated that his family was so ashamed of him due to his physical limitations, he was kept in a room in the back of his house for years. One participant who had polio as a toddler after the advent of the Salk vaccine learned years later from her grandmother that her mother had refused to vaccinate her, which resulted in her contracting polio. When she approached her mother about her decision and her experience of polio as a toddler, her mother refused to discuss it with her. Another participant discovered as an adult that she had likely contracted polio from her sister, who was aware she had it at the time but had kept it a secret.

**Community response after recovery and societal barriers.** Although aware of the stigma that could accompany polio and being “crippled”, many participants stated that they did not experience overt discrimination in their communities. Several remembered particularly supportive responses by others. One participant, for instance, described being carried up the stairs at her school by her ex-volleyball coaches after she returned to high school from the hospital, while another remembered PE teachers establishing rules about how teams were picked

to protect him from being chosen last by the other children. Overall those whose physical difference was clearly visible tended to encounter more discrimination and social barriers than those participants who had no physical limitations or were able to pass as physically similar to others. Even those who could pass as able bodied were often physically weaker and less able, even though visibly they appeared similar to others. Some of these participants also experienced negative community responses once it became known that they had reduced physical ability.

The experiences of discrimination encountered by participants varied widely. One participant, who began kindergarten while still wearing braces, was placed into a special education classroom with other children who were either physically or mentally different from “normal” children. He remembered that there was very little instruction or learning that occurred. When his braces were removed in first grade, he was allowed to enter a mainstream classroom. One participant described high school as particularly difficult for her, because boys were not interested in her due to her physical appearance. Others remembered being stared at by others due to their braces and/or limp. One described being rejected from a service job which involved engaging with the public because of her visible disability which made her less physically attractive than other women applicants. Another remembered being rejected from a potential employer because the employer thought he was not physically capable of doing the job. Similarly, a college career counselor told one participant, who hoped to become a physical therapist, that she should find another career due to her physical limitations: “I thought I’d be a physical therapist and I was dissuaded by that by the (career) counselor who said you’re too weak, you’ve had polio. So ... they never gave me a chance.” Several participants described consistently being picked last for sports teams and other physical activities by peers because they were less physically able. One participant remembered:

I can remember, I couldn't play hopscotch very well, I couldn't jump very well, I would miss when I would play jump (rope). It didn't mean that I didn't do those things, but I was always the last one to be picked when it was like, Red Rover, because I wasn't very tough.

**Coping after recovery.** After recovery, participants described putting, or attempting to put, the experience of polio behind them and move forward with their lives and be "normal".

One participant described this mentality:

I think all polio survivors have a really strong will to go on and say there's nothing wrong with me, I can do anything that you can do. And so... most of us hid our disability as much as we could, we tried to be normal like everyone else.

Another stated:

People would stare, that probably bothered me more than anything, they would stare. Once in a while you might somebody say well what happened to your leg and that was not something I was going to talk about to anybody (because) I didn't want to be seen as different or less than normal...I think the word 'normal' for polio survivors is a very important word...(W)e were conditioned, I think, to strive to be normal. We have the polio and we had to go through all the rehab and all that stuff and our main goal was to be as normal as we could be. I think that's a common thread with polio survivors.

Most participants described trying to do all the things that their peers did and often pushing themselves to overcome their physical limitations:

It was just understood that you did whatever you had to do to keep up with, do as well as, everybody else. There were not going to be any corners cut for you and you measured up to that. I guess I never really thought that there was another way to approach this... (D)octors would talk to me, they would make it seem that the more you worked at this that the better that things could get. And of course what you absolutely wanted was to be 100% normal in whatever parts of your body had been affected. So you just assumed that the more I work at it, boy this is going to get back to normal. So of course you pressed yourself to do that, the goal was to get back to normal if you possibly could.

Participants who were young children when they had polio tended to identify themselves as high academic achievers. For some, this grew out of the isolation and loneliness they experienced as they recuperated from polio, with books being one of the few outlets for amusement. For these participants, interest in book learning and reading continued after their recovery. Others described becoming academic achievers as a way to be competent and

successful, as physical limitations from polio limited ability at physical activities: “I was a straight A student, all that good stuff, type A... (I)f there was someone who was going to get an award it was going to be me, because I was going to try to make up this other stuff.” Participants who contracted polio early on in life also described finding other ways to integrate themselves into able-bodied, life, such as becoming involved in school activities and developing close peer relationships.

The mentality of pushing to overcome obstacles continued as participants grew older, such as career and advocacy work for themselves and others. Indeed, many participants had highly successful careers and many were in the helping professions. Several identified their experience with polio as inspiring them to enter these professions while others were not sure this was a factor in their career choice. One stated, “I decided in college and I felt like I wanted to repay the therapists that had helped and all that sort of thing”. Several had to continuously confront and overcome societal intolerance directed at people with physical limitations by pushing themselves to prove themselves to others of their capabilities. As one participant, who had a visible physical difference as the result of polio noted:

(I)t was always a push. I always had to be the driving force. There was no one out there saying, ‘Oh, we really like you.’ And that has been a continuous pain in my life, not being desired or desirable. Being early judged. People would think you couldn’t hear because you couldn’t use your arm, or that you couldn’t think, that you were somehow not as good.

This participant described difficulty she encountered with getting a job due to this discrimination:

(H)onestly, in the real world, the fact is you have to be twice as good to be as good. That’s the fact. So I had to type 70 words a minute 65 to 75 words a minute to get a job. Somebody else who was cute, double armed, could do 40 or 45 and it would be ok because she looked good in the office. I knew from the very beginning that I had to be functional. I had to serve a purpose in an organization to be acceptable.

A “Type A” personality, that is, a personality characterized by a strong ambition, work ethic, tenacity, and unwillingness to give up in the face of adversity, was proudly identified by many participants as a significant part of their identity. Some felt that they had been born this way, while others felt that the physical limitations and societal barriers they had experienced as a result of polio, as well as doctors’ recommendations to push through physical limitations to regain physical functioning, had encouraged the development of these characteristics. One participant stated:

(Y)ou become kind of a type a person, a super achiever... you’re encouraged you can do it, you can get over this, there was a, it was kind of like, no excuses you can do this...And then you internalize it so the others don’t have to do it anymore. You do it yourself.

For several participants who lived in families that were unsupportive or potentially abusive, pushing themselves to be physically “normal” and regain mobility as much as possible was necessary for survival. Others felt that other personal experiences had helped shaped this aspect of their personalities.

### **The Post Polio Experience**

Participants characterized the experience of post polio syndrome as a process of confronting and navigating both its physical symptoms and their emotional reactions to its unexpected emergence.

**Post polio symptoms.** The most prevalent symptom of PPS experienced by participants, described by every participant except one, was intense fatigue and lack of stamina. Declining mobility due to muscle weakness in the legs was also experienced by almost all participants, although varied in severity among them. Some participants also described muscle weakness in the arms. Fatigue and muscle weakness were usually the first symptoms of PPS that participants noticed, although most did not initially link their symptoms to polio since PPS was virtually

unknown when most participants began having symptoms. Many participants reported aches and pains in various areas of the body. Tripping for no apparent reason, falling, and difficulties with balance were also common experiences, as was sensitivity to cold. Participants described sleeping problems related to difficulties breathing and several participants used a ventilator at night as an aid. A few participants noted memory issues. Most participants stated that their symptoms had increased slowly over time as they had aged, although two participants described gaining muscle strength in their legs from the use of custom braces. Several described plateaus in their symptoms at various times, in which symptoms stabilized for a period before declining further.

**Emotional Experience of PPS.** The majority of participants were not aware that polio symptoms could return in adulthood. Only one participant was warned by his doctor during his initial illness that he could experience problems related to polio later in life. One participant, who only recently began to have PPS symptoms, did not remember if he was aware of post polio beforehand. Indeed, although post polio was first documented in 1879, it was forgotten by the medical community until the 1980s (Shell, 2005). Thus, the possibility of the return of polio symptoms was not discussed with mid century polio survivors during or after recovery. As a result, when participants began experiencing post polio symptoms such as increased fatigue, muscle pain, and incidents of short term paralysis, they did not tend to attribute these symptoms to their earlier experience of polio. Rather, they assumed that symptoms were related to the stressors of middle age, such as having multiple demands of family and careers, or other health problems. Some were simply confused by the symptoms. Several participants stated that they were reluctant to pay attention to the symptoms and instead chose to ignore them. Several

sought medical attention, but in the 1980s and early 1990s, when most participants first experienced symptoms, doctors had few answers for them:

(W)hen it first came out there was so much denial by the doctors of there being anything, and you'd read literature here and one person would say it was nothing, it was just in everyone's heads, and that it really wasn't anything.

Indeed, most participants described learning of the existence of post polio through newspaper articles and television shows rather than through physicians, and self-diagnosing. Some heard about the post polio support groups through friends and local media, and attended looking for information. Others read books that aided them in understanding their symptoms. One participant described:

I got (a) book and started reading and it was like the world opened up. Then I could see exactly what was going on. It was amazing really the difference. One day I just felt in the dark and everything was falling apart and I couldn't understand what was going on, and the next it was like, wow, ok.

Once having received an official or unofficial diagnosis of post polio syndrome, commonly participants experienced surprise and shock that polio symptoms could return. For most, polio was something that had happened long ago. They had learned to live with any residual physical effects, and had assumed these would stay relatively stable through their lives. One participant, suffering from intense fatigue, described learning of the existence of PPS from a guest on Oprah. The guest

had been a nurse so, you know, she had been on her feet in her job, and she was completely disabled and in a wheel chair and needed a training dog, a rehabilitation dog. And they asked her ... 'what happened to you'? And she said, 'I have post polio.' And it floored me. I couldn't believe it that that could happen. I hadn't heard anything like that really happening. So it really brought my awareness that maybe this tiredness really is affected by the polio.

Approximately half of participants voiced that they went into denial when confronted with the diagnosis. Many were still in good health and were fully mobile, and couldn't fathom needing assistive devices or experiencing declining physical functioning as they aged. They



assumed that they could simply “push through” any physical issues they encountered, just as they had in the past: “I didn’t want to accept it, you know, and so I kept ignoring it and...I just kept working and doing what I had to do.” One stated, “I didn’t delve into it as much as I should have because I didn’t want to know all the details that might be. Ok, ok, it exists, I’m fine.” And another said, “There’s a long period, several years even when you just say no, this is not, this can’t be, ... it’s past, it’s over with, I’ve worked with this, I’m done. It’s a real in your face experience.” And yet, having a name with which to label symptoms was comforting to some participants. Indeed, six stated they felt “relief” to have a name for the symptoms they were experiencing and answers to why they were occurring: “(W)hen the name came, PPS came to me, then it gave me a better framework within which to fit the different experiences that I had had.” One participant described receiving a diagnosis of PPS after years of various health problems and felt “relief I think. Oh, so that’s why. I was like an ‘ah-ha’ moment.” One participant stated it was not a big deal to receive the diagnosis, and one stated she took the diagnosis in stride.

After the initial shock, disbelief, denial, and/or relief, the majority of participants described experiencing feelings of anger, frustration, anxiety, loss, and resistance. Anger and frustration were triggered by a variety of circumstances, most commonly from being unable to do activities and tasks that they wished to. One participant, who was facing knee surgery at the time of the interview stated:

(I)t is frustrating that I can’t do any of that heavy duty work out because of my knee. I want this knee to work because I want to be able to work out, I want to be able to go to my pilates class, I want to do stuff, that’s what’s aggravating me.

Another stated:

(T)he big item in the forefront was, ‘God damn it, I can’t go skiing, I can’t, you know, ride my bike up the hill anymore and get in the driveway and that type of thing. Then, when I would, I would be paying for it.

Commonly, participants described ongoing feelings of anger and frustration directed towards themselves for being unable to do the activities they used to do: “I get mad, not necessarily at other people, I get annoyed, I guess self-directed...I get mad at myself. ‘Why can’t you do this’?”

For several participants, anger and frustration arose from realizing that the future they had imagined for their later years would be very different from the one they had expected and planned for:

I gave up my entire adult functional years to work, and now that I’m retired I’m left with crap physically. Pretty much. So that’s part of the anger, definitely right there, because that’s not the way I saw my retirement at all. What I saw my retirement as was an opening up of all these opportunities, things I had never been able to do because I was working full time, all the time. So I feel cheated, definitely, there’s a lot of that.

Another participant in a similar circumstance expressed regret that she had worked so hard throughout adulthood and had not enjoyed life more, because she now was limited in what she could do.

Anxiety was also a response to declining physical functioning for many participants.

Anxiety arose from the knowledge that physical decline would likely continue as they aged, they would be further restricted in their mobility, and there was very little that the medical profession could do to help them. One participant, dealing with significant fatigue stated:

(T)he hardest thing about this is that I’m just 65, and... I blew polio away, I never thought anything about it and then it is getting worse and I think, if it’s getting worse what am I going to do? Be in bed the whole time? And that’s the part that kind of scares me because there’s not that much you can do.

To retain mobility, the knowledge that they would be required to use assistive devices more frequently and/or more restrictive devices such as wheelchairs and scooters was also anxiety provoking for many participants. For several participants, this possibility also meant making

structural changes to their homes to allow for wheelchair or scooter access or considering having to move at some point, leading to further feelings of anxiety.

Several participants described the emotional experience of PPS as a mourning process, similar to that experienced with a death, triggered by a loss in physical functioning and acknowledgment that they could no longer do what they once had:

(W)hen you start going through all this and facing it,...you have a mourning process you have to go through, you're letting go of these things you used to have. Some of these things are dying, you won't be able to do it anymore... (I)t's letting go of those memories of being able to do those things.

Anger, grief, anxiety, resistance, and acceptance were all experienced as part of this process.

Many participants described moving between multiple emotional states. As time went on, many participants described feelings of greater acceptance, less resistance, and less emotional distress.

Several participants stated that they had no particular negative emotional experience to their symptoms. Although one of these participants noted minimal physical symptoms of PPS, the others had symptoms that corresponded in severity to other participants'.

Another emotional stressor experienced by participants was feeling a lack of empathy and support from friends, colleagues, and family. One participant described developing a new social network because her old friends were continuing to do physically demanding activities and appeared unwilling to do other, less physically demanding activities that she could participate in:

I have changed groups of friends because of PPS. I find that I no longer have anything in common with women in particular whom I have known for decades ...because these are all people who plan things like, 'lets hike up Machu Pichu'. It is nothing that I can have anything to do with anymore... There is no sympathy there with what I'm dealing with... So I've found other groups of friends.

A couple of participants whose disabilities from PPS were not visible to others, described a lack of empathy and understanding due to this invisibility:

I don't like to talk about it to too many people because I know most people don't understand. I'll say, 'Oh, I have a health problem, I get fatigued.' But so many people

say, 'Oh, I get tired too'. They don't understand, so it's like I'd just as soon not talk about it to most people anymore.

Another said:

(P)eople didn't see me as being handicapped or slowed down, so when plans were made with friends they were things that possibly I shouldn't be doing because of the struggle to do it, and I'd tell people, but they didn't see anything handicapped about me.

This participant, a nurse, also described conflict at work because she needed special accommodations, and her co-workers resented this.

(A)t work ,when I was getting so tired and fatigued, ... I was giving TB skin tests and I needed a different kind of a chair, a chair with arms on it so I could get up and down, and they gave me a real bad time about that at work, just like I was pretending... And because they were told by higher up that they had to accommodate me, they were not happy. They made it very clear that they didn't appreciate it, they didn't think it was necessary, and co-workers were feeling I was getting special privileges.

Several participants stated that, although they could count on their adult children to help them if they really needed it, they felt that their children often did not fully understand the extent of their symptoms or empathize with the experience of debilitation caused by PPS. These participants wondered if the "can do" attitude which they had presented with as their children grew up, had inadvertently trained their children to be less empathic and attuned to their needs now. Most acknowledged that they rarely spoke to their children about the symptoms of PPS they experienced and that their history of polio had not been a topic of conversation in the past:

I was training my kids to think that I didn't need any help and one of the hard things is to ask for help and not get it. And that happens.... And its not that they're cruel (and) that they don't care...I think I trained them so well that I could do almost anything I wanted to that I'm having to gradually say look, things are different for me now. I need more help than I did before. But it was difficult for me to do that.

Another stated, "(O)ne thing I didn't teach them is empathy...I took on everything and they just expect that, well, mom will do it....they're not real empathetic kids ... I'm not asking for anyone to feel sorry, just to understand when I am tired". Another participant similarly acknowledged feeling conflicted about wanting empathy but not pity: "I think they understand but I don't think

they really get it. And I don't know if I want them to so much. It's kind of a, yes, I want that understanding, but I don't want you to feel sorry for me."

Finally, a significant component of the emotional experience of PPS for participants was negotiating identity construction as disabled, handicapped, or the equivalent. While rarely considering themselves disabled after the initial experience of polio, every participant except one currently identified as "disabled" (or used a similar term) or "becoming disabled" as a result of PPS. One preferred the term "other abled", one preferred "physically challenged" and one preferred "differently abled". For the majority of these participants, this shift in identity had occurred after they lost mobility and couldn't do particular activities that they had once done easily. Applying and receiving a handicapped parking placard was also noted by several participants as a significant step toward self-identifying as disabled. Identifying as disabled was a process of acceptance for many participants, and a difficult process given that normalcy was an important value many had strove for throughout their lives. One participant who had begun to encounter significant effects of PPS in the past several years, stated that being disabled is

a very hard thing to be. I never considered myself disabled and then when I went to (the doctor), he said 'You are disabled, it is a disability... you are disabled. Your breathing is bad you have this, it's a debilitating thing that's happening to you.' And it was a very hard thing to accept. And I still think I have not accepted it yet.

Several participants remembered the negative connotations with being disabled from when they were young, and particularly with the word cripple:

(I)n those years you weren't disabled, you were crippled. You didn't ever want to use that word... It connoted someone who couldn't walk, couldn't do this, couldn't do that...People were looked down upon, those people in wheel chairs, there was something really wrong with you. It's hard for people to understand today...It was a bad thing.

For several participants, identifying as disabled was a fluid process: they self identified as disabled to get needs met, such as a handicapped placard, but did not use the term to describe themselves otherwise. When asked if she identified as disabled, one participant stated:

Depends on who the audience is. Honestly, it's a political world, it's a political world. I mean, I've had an employer say to me, you got the job because you fit two bills: you're female and you're disabled. It was hard but I also thought, good. Good, because there were otherwise, there were eight men, eight white men in this agency and I thought, well if I'm the one to break this barrier that's fine with me. So anyway... I said in that respect I'd say, 'ok, I'm disabled.'

Another said,

I don't always pull the 'gimp' card because some days I feel really good and I don't need to. But I do have a blue placard in my car and I use it when my immune system is down (from another health issue) or my muscles are hurting or anything, and I do use it to board a plane to get on first...so I pull it when I need to.

## **Coping**

Whereas past studies have documented the physical symptoms of, and negative emotional responses to, post polio syndrome, very little research has explored the coping strategies that polio survivors have developed to confront it. The following section examines these coping strategies. Study participants had been coping with post polio symptoms from five years to four decades and had developed rich and complex approaches to facing both its physical and emotional effects. In the following, findings are divided into two sections. The first, Concrete Coping Strategies, describes concrete actions that participants have undertaken to cope. These include seeking medical treatment, using assistive devices, seeking worker's compensation and disability compensation, pacing, and connecting with others confronting PPS. The second section, Internal Coping Strategies, describes processes of thinking and belief that participants have used to face the physical and emotional consequences of PPS. These include faith, gratitude and appreciation, and normalization of declines in physical functioning.

The findings suggest that the process of coping can be complex and multi-faceted. First, strategies of coping, particularly concrete coping, often led to additional issues and difficult emotions that, in turn, had to be coped with. Thus, although these coping strategies had their benefits, they also had significant drawbacks. Second, finding and assembling coping strategies

was an intricate process of embracing particular old strategies, discarding others, and developing new ones. Some coping strategies were developed long ago, such as faith in a higher power, and had been utilized by participants throughout their lives. Others had to be developed after the advent of PPS to replace old coping strategies that were now no longer useful, such as pacing to replace pushing through. Some coping strategies, such as connecting with other polio survivors were entirely new experiences for participants. The process of coping with PPS, therefore, was a complicated one that necessitated flexibility, courage, and perseverance on the part of participants.

**Concrete coping strategies.** Participants commonly described utilizing concrete coping strategies. These included seeking medical treatment for PPS, adopting assistive devices to aid in mobility, seeking workers/disability compensation, pacing themselves, and connecting with others confronting PPS.

*Seeking medical treatment.* All participants had sought medical treatment at some point for physical symptoms related to post polio. Indeed, this was the most common of all coping strategies utilized by participants, although when participants sought medical advice varied. Some, when they began noticing increased fatigue and muscle weakness, sought medical attention immediately. Others ignored symptoms until they became more severe; they felt that the symptoms they experienced were not serious enough to warrant medical attention and/or they denied and pushed through them. Some participants had seen many physicians and specialists over the years, while others had seen only a few. Several saw acupuncturists and other providers outside of the Western tradition of medicine. Currently, most participants reported being a patient of a physiatrist in the community who specializes in post polio and/or of a couple of

physicians with knowledge of PPS through their Kaiser HMO insurance. Overall, these participants had been happy with the care they have received from these specialists.

However, common to almost all participants were frustrations that came from seeking help from a medical community that, overall, had little knowledge of PPS. At least eight participants were initially undiagnosed or misdiagnosed or told that symptoms were in their heads. Several were encouraged to do exercises which were ultimately detrimental to their physical well-being. Others received braces that were not particularly helpful to them. When receiving treatment for other medical issues, participants often experienced complications due to comorbidity with polio and PPS that treatment providers did not take into account. The lack of knowledge among medical professionals about post polio has continued to the present. Outside of the post polio specialists already mentioned, participants repeatedly stated that the medical professionals they saw knew almost nothing about post polio. One participant stated:

(Y)ou feel kind of lost about what you should and shouldn't do and you kind of feel like you're on your own because they (physicians) don't know anything. They just don't know anything, and not a lot of money is being spent on research for this stuff because they know we're going to die out.

Several stated that they felt that treatment providers, most commonly physicians, were unwilling to listen to the knowledge they had about their bodies and collaborate with them on treatment. This could be particularly frustrating for participants because most had extensively educated themselves on PPS: "You get into people's egos. Not all doctors are like that, but you get into people's egos and they think they know more about what's going on with you than you do." Another said, "(S)ome of them (physicians) are maybe too busy. They don't want to sit and listen to you. Physicians that I've seen in the last 20 years, maybe it's part of their education, but there's some that don't want to hear." Others described feeling like physicians did not know



what to do with them because their symptoms were complicated, often co-morbid with other health issues, and didn't fit into a clear cut, easily defined box.

Participants described coping with the lack of knowledge in the medical community in several ways. Many had attempted to educate their doctors and other medical specialists by talking with them about PPS, bringing literature to appointments, and recommending books on PPS. Some found physicians open to this, others felt that this encouragement to learn more about post polio “went in one ear and out the other”, ultimately leading to more frustration:

(A)fter I was diagnosed, and I got all this information together about post polio. I went to the doctor,... I put it in a folder, and labeled it 'post polio'. 'If you have free time, here's about post polio...the younger the doctor. the more narrow they are... I think they think they know it all. Because they haven't been around long enough to see any strange disease that does not work in their little book.

As another strategy for coping with the lack of PPS treatment knowledge in medical systems, some participants purposefully sought out experts in post polio, often receiving information from support group members about who to go to. This often required paying for care out of pocket.

Advocacy was another course of action taken by participants, particularly those who had difficulty getting their medical needs met. One participant, for instance, who needed a knee replacement to retain her mobility, was told repeatedly by her HMO that she would need to wait until after she was 65 so they would not have to eventually replace it a second time. Faced with a continuing decline in her mobility, she continued to push over a period of years until the HMO finally acquiesced to her request. Another participant described injuring her knee, leading to incidences of falling. She was denied an MRI from her insurance although she asked for one repeatedly due to her concern that there were multiple injuries that could not be detected otherwise. Finally, after seeing a post polio specialist who she paid for out of pocket, the specialist wrote a letter demanding an MRI for the participant. Her insurance then agreed to pay for one, after three years of self advocacy. On the other hand, participants sometimes found it

necessary to advocate for themselves against treatment. One participant described a physician pushing her to have surgery on her back who then became angry with her when she repeatedly declined treatment. Another participant noted that advocating for himself, questioning doctors, and pushing medical systems to give him the care he felt was warranted, had at times led to negative responses from physicians and a decline in the quality of care he received. A participant noted the difficulty with being proactive around medical care during periods of stress. Noticing that her leg was being cast incorrectly after breaking her ankle, she told the medical professional casting the leg that it could not be cast in the typical manner due to changes in her leg and ankle from polio. The professional reassured her that this would not be problematic for her and continued the casting. The participant continued to have doubts but felt simply too tired and overwhelmed by the experience to advocate for herself further:

I was too wiped to advocate for myself and I think that's a major, major issue ...for people with disabilities, is getting really sick and being too wiped to advocate for ourselves. It scared the hell out of me when this happened because...my knee became even more unstable from the cast they put on me.

When asked what they would change about the medical care they have received, a majority of participants stated they wished for medical professionals to be more knowledgeable about post polio syndrome and how to treat it. One stated:

It's almost like they are in denial of a whole group of people, apparently a million strong in the United States, who are dealing with all of these issues. It's almost like they're denying that muscular dystrophy exists. I mean, they don't do that so why do they deny that we have these chronic conditions, and this is an issue and they need to deal with it.

Many participants also voiced that they would like physicians in particular to be open to the knowledge they bring with them about their bodies and post polio syndrome, to be more willing to work collaboratively with them around treatment, and to express less surety around their recommendations, as there is much conflicting opinion in the medical profession around PPS and few clear answers. One participant who had several co-morbid conditions in addition to PPS,

felt strongly that there needed to be more interconnectivity between medical records so that a treating physician could see the patient's medical history, past procedures, and what treatments had and had not been successful. This participant also felt there was a disconnect between treatment providers, and wished there to be a cohesive team of providers on the same page. Another participant added that he would like to see more homeopathic and alternative treatments utilized in treatment. Indeed, several participants stated that they had used, or were currently using, acupuncture, meditation, and massage to treat symptoms and had found them to be helpful. Several participants expressed regret that these treatments, due to their unconventional nature, usually had to be paid for out of pocket, and thus felt limited in their ability to take advantage of them.

*Use of assistive devices.* While many participants had used braces and specially constructed shoes after their initial experience with polio, none had continued to use these devices until the advent of PPS. Fifteen of the sixteen participants were now using an assistive device to cope with post polio symptoms and aid in mobility. These devices ranged from special shoes to braces to walkers and scooters to vans with ramps. Although the use of a wheel chair is not uncommon for those with post polio, no participants interviewed were currently using a wheelchair regularly although several anticipated needing to do so in the near future. Some participants used assistive devices at all times, others only when engaging in physically stressful activities. A number of participants had multiple assistive devices available to them which they used depending on the activity. One participant, for instance, described using a scooter when she was required to stand or walk for long periods of time, such as at Disneyland or at Costco. At other times, she utilized a brace on her leg and a cane to aid in mobility. At home, she often simply wore the brace.

While utilizing assistive devices was a common coping strategy for confronting declining mobility, doing so after many years of near to full mobility brought up a variety of difficult feelings for participants. For every participant except one, having to use an assistive device was something they had not expected to have to do after fully recovering from polio. Anger, frustration and self-consciousness were common responses. Most of these participants had used assistive devices, particularly braces, as young people, and many associated them with feelings of embarrassment, abnormality, and unattractiveness. Thus, returning to the use of assistive devices often meant confronting these feelings again. One patient described her experience of returning to using a brace on her leg:

The biggest problem I had was coming to the realization that I needed to get a brace...I had trouble getting them in the shoe and I got angry and I threw the thing across the room because I was dealing with anger, I hadn't done that yet, I hadn't experienced it yet, because I tend to be kind of a stoic person, I tend to be controlled. My emotions, I don't want them to be out of control. So at that point I threw it and I felt better. So, each experience (of) an assistive device, it hasn't got me to the point where I'm in tears, I don't do that, ...but it upsets me, it upsets me. Well, why? Why do I have to do this, why?

Several participants described resisting using assistive devices because doing so made them feel older than their age. One participant described having to use a walker after knee surgery:

“(H)aving both my hands occupied I couldn't pick anything up, I couldn't carry anything. I felt like a little old lady 'cause I had to lean over because the damn thing was at the wrong height.”

One participant who was an occupational therapist described an interaction with her physician in which he asked her to walk down the hall:

I'm kind of ... holding on to (the wall). And he said, 'What would you tell a patient if they weren't using a cane and they were walking like you?' I said ok. It was like a cane means you're old... And now I've got one in each car, one by the front door, so I'm using it all the time now. Now they're on my case to get a walker.

Self consciousness was also a reason cited by participants for avoiding using assistive devices:

(Q)uite a few years ago the doctor I was going to... was willing to sign for me to get a scooter or something, but I always avoided that particularly because of the self consciousness of the scooter. I think I'd feel more handicapped if I had to use the scooter.

And yet, participants also acknowledged that using assistive devices was a key coping strategy that allowed them to remain mobile and continue to do many of the activities they wished to. They adopted these devices because the alternative was, at best, pain and fatigue, and at worse, loss of independence. One participant in particular described becoming much more optimistic and positive in her outlook after she switched to specialty braces and returned to greater mobility as a result. Self-identifying as a jock, she had been unable to lead an active lifestyle with her previous braces and was facing needing to begin using a scooter. This not only challenged her self-identity as an active, mobile person, but would also have required her leaving her home with stairs and her tight knit neighborhood. The new braces allowed her to stay in her home and neighborhood, and resume the physical activity that was key to her sense of self. She said, “(H)aving my braces has completely changed my life. I mean, I love these things ... And my friends keep commenting about the change in my attitude and the change in my optimism”. This participant had to make a significant financial sacrifice to purchase the braces, as her insurance did not cover them because they were deemed unconventional.

I was continuing to deteriorate (and the doctor) said, ‘Get a scooter.’ And I thought, yeah right. I’m going to do what I have to do to avoid being in a scooter. And, see, I’d heard about these braces, (and I wanted to) see if they would work for me. So I refinanced my house so I could pay for them. Out of pocket. Worker’s comp would have nothing to do with paying for the braces. I mean, they paid for the original knee brace and the original ankle brace but they would have nothing to do with paying for these because they were so non-traditional.

Indeed, several participants described needing to make financial sacrifices and advocate for themselves with insurance companies to receive particular assistive devices. Thus, the coping

strategy of adopting assistive devices was a complex process for participants, leading to difficult feelings and engagement with systems that required their own coping responses.

***Worker's/disability compensation.*** Post polio symptoms, particularly intense fatigue and muscle weakness, made it difficult for many participants to continue to work. Symptoms were often aggravated by job requirements such as extended periods of standing, physical exertion, and long hours. To cope with these symptoms, some sought to stop working temporarily or permanently and to receive workers compensation or disability compensation. Four participants had successfully filed claims and had retired. Another had successfully filed a short term claim and was planning to return to work after several months. One had applied for worker's comp but had been denied. Similar to seeking medical care and utilizing assistive devices, attempting to cope with physical symptoms by seeking workers comp and disability led to new stressors that required additional coping strategies. Most significant for participants was the bureaucracy involved in filing claims and dealing with the associated medical systems which had little knowledge of post polio syndrome. A participant denied worker's comp, for instance, had received a post polio syndrome diagnosis from a physician specializing in post polio, while the physician evaluating her for worker's comp disagreed with the diagnosis. As a result of the conflicting opinions of the physicians involved, she was denied worker's comp and is continuing to work full time for financial reasons, despite intense fatigue and muscle pain. Another participant, who when interviewed was on short term disability, described a similar experience with the insurance company who provided disability through her work. Although she had been diagnosed with post polio by a specialist, the insurance company had required her to see a physician of its choosing. The participant described feelings of frustration and stress when this physician appeared to have little knowledge of post polio and to doubt the debilitating nature of

intense fatigue she experienced. This participant found it necessary to advocate strongly for herself with the insurance company to have her claim accepted and anticipated having to do so again when her short term disability ended. Two participants described using the support group as a resource for coping with the bureaucracy of insurance systems and avoiding particular pitfalls when filling out the paperwork to receive disability compensation. Group members who had filed claims successfully in the past acted as advisors to these participants. One of these members stated:

(A) lot of people put in for social security disability and they get denied, I didn't, and I also had help from one of the people in our group in how to fill out the paperwork. And I've helped a few people do that and they've been accepted, and I was accepted right away. But some people aren't. And there are so many little things you have to be careful of when you fill out that paperwork ... there are a whole bunch of forms you have to fill out, and one of the forms is, 'What do you do from the time you get up in the morning to the time you go to bed?' ...I'm not going to put on there that I use a computer, that I go in there and get my email. Because you're leaving it open for them, you're giving them an opening to say, 'Well, if you can work on a computer, than you can work. So you have to be very careful how you do that. So I've helped a few people fill out that paperwork and they've gotten their disability without having to go through the appeal process.

Several participants who had worker's comp described ongoing frustrations with getting their medical needs met, particularly when they required unconventional treatment, and needed to advocate for themselves and develop alternative methods of maintaining their health. One participant said:

(Y)ou can't rely entirely on worker's comp because there is a limit they will allow you to do... So you say, that's not going to carry me in the long run. I have to think of another plan. So I have a lot of equipment in my house, ... I had a full gym, and I've tried to develop my own plan based on what I've learned on the web and from PT's, OT's and others. And I've parceled out what was workable and affordable and developed my own plan.

Another participant described trying to get workers comp to finance a lift chair after moving from Southern California to Northern California: "I've had to fight that system up here too, so it's been quite a struggle with medical care up here and I just get very frustrated and very tired

trying to get done what I need to get done.” She continued, “I told him (her physician) I wanted a lift chair, but he didn’t write enough in the report to explain it for worker’s comp, so now I’m trying to get him to write another letter. And so all of that is frustrating.”

***Pacing.*** Pacing, that is, limiting one’s activities and physical exertion to preserve physical functioning, along with seeking medical treatment and adopting assistive devices, was the most prominent coping strategy described by participants. Pacing took several forms. Most commonly, participants described doing less physical activity and taking more time to rest. Many participants reported being physically active throughout their lives and thus pacing themselves meant significant lifestyle changes. For example, one participant described camping as an important activity that had become too physically demanding for her to continue. Another found that she needed to scale back her daily walks due to leg pain. One participant had needed to relinquish cross country bike riding. For a number of participants, doing less also meant relying more on others and asking for help, such as with daily household activities. For some, this also meant confronting uncomfortable feelings of dependence and lack of usefulness. Realizing that it was difficult for herself to accept help, one participant described accepting help from others when they offered even if she did not necessarily need it, as a way to practice this coping strategy for when she was more physically limited in the future.

Many participants described planning their day to avoid taking on too many activities and responsibilities which could leave them fatigued and in pain. Several participants had noticed that they had more energy in the mornings than in the afternoons, and so planned their activities accordingly.

I have to plan my day, especially with cleaning house. Like, I know if I want to mop the floors or do something major I have to do it in the morning when my energy level is the highest. If I don’t do it first thing in the morning, it’s not going to get done. Because I poop out. Just from normally walking around and doing stuff.



One participant had developed a spreadsheet which allowed him to plan his activities by day, week and month as a strategy to balance activity with rest. He also described “sequencing” his movements, that is, planning his movements at a micro level, around the house, and on a larger scale in his community, to conserve energy as much as possible. Also to conserve energy, this participant took a small stool with him when he was out in the community so he could sit at any time standing was not necessary. In his home he had several rolling chairs that allowed him to move to different areas while sitting and he had structured his home so that he could easily reach for things as he sat. Several other participants, too, stated that they had made environmental adjustments in their homes to help them better pace themselves and allow for ease of mobility. Daily napping was noted by several participants as important to maintaining their well-being.

Many participants stated that it was difficult to learn to pace themselves, “slow down”, take on less, and rely more on others. Indeed, the majority of participants described themselves as Type A personalities who, in the past, had pushed through physical barriers and refused to accept physical limitations. This often translated into other areas of their lives, in which they overcame barriers and pushed through difficult circumstances. Independence was a key value for many of them. One stated:

(W)e tend to be a group of people that are type A personalities...My view of a type A person is a person who says, ‘I can do it and I’ll show you I can do it and I’ve succeeded in the past and I’ll succeed again in the future.’ And we push and we push and we push to the point until we hurt ourselves. It’s detrimental, we over do it, we make our bodies hurt from over doing it.

Pacing themselves by doing less, asking for help, and relinquishing activities, therefore, was antithetical to coping strategies ingrained in childhood, adolescence, and young adulthood, and also, many felt, to their personalities. For some participants, facing the prospect of not being able to do particular activities that they enjoyed caused frustration, distress and resistance. A participant who had been told by her doctor to garden while sitting in a chair stated:

(The physician) wants me to sit on a chair and do chair gardening. And I say, no that's not gardening that's deadheading flowers, that's not gardening. So I can't do that. I mean, I can't do that. I draw lines of what's acceptable, what's compromising to do, and I'm probably still in denial to a certain point but I'm drawing those lines that make me comfortable.

Pacing was also complicated by times when participants felt ok physically for brief periods, and resumed past levels of activities as a result.

I've learned to pace myself, but I get these little spurts when I feel I have more energy this morning and (think), 'Hey, I can do this.' I have energy (so I think), 'Okay, I'll just do a few little things.' ... (A)nd I know better, and we're all very big on telling other polio survivors, 'Would you sit down, you shouldn't be doing that' ... (W)e need to swallow our own advice.

For some participants, pacing could also be difficult since it required relinquishing exercise that they had used, in the past, as a coping skill to deal with stress, anxiety and/or depression unrelated to polio.

Asking for help was an important part of pacing for many participants, and a skill that often needed to be learned after years of caring for others and self-reliance. One participant described the experience of relying more on his wife as his physical functioning declined.

Another stated:

I just know that I'm happier if I ... learn to ask for what I need. And I'm not that kind of person. That's been hard for me. So they're (her children) willing to (help), but I have to put it out there square, I can't beat around the bush. And (they say), 'If you want something mom, just ask. We can't guess what you need.'

One participant, who after ankle surgery realized that she would need rides from neighbors during her recuperation, described organizing a brunch for her neighbors, during which she asked for their help. She received tremendous support and the neighborhood has continued to meet regularly, creating an important community for the participant. She described asking for help as

really, really hard to do, when I was really well-schooled on doing everything myself. My parents really drilled that in that you never ask for help, so that was a gift in a way, that's been a real gift to say 'Hey this is what I need.' It's been wonderful.

Several asked for help, particularly from family members, and did not always receive it at first:

I realized that what you have to do is figure out what you need, ask for that help 'cause you're not going to get it if you don't. You might not get it even then, but if you don't ask, it's for sure you're not going to get that...But initially be prepared for rejection because I got a lot of that. But not to be discouraged because of that rejection, just keep trying. Keep trying to get help, ok.

Indeed, just as participants needed to teach themselves to ask for help and voice their needs after living lives of full independence, so too did family members need time to learn how to respond when these needs were voiced. For instance, one participant stated that her son did not initially appear to understand and respond when she stated her need to take a daily nap. Over time, however, he became responsive to this need, and now assumes that he will have a few hours of free time in the afternoon when his mother stays with him for visits. Thus, pacing, described as one of the most useful and widely adopted coping strategies for participants, was also one of the hardest in and of itself to cope with.

***Connecting with others confronting PPS.*** Almost every participant cited the importance of connecting with others confronting PPS as an important coping strategy. Most participants were currently doing this through the PPS support groups, although a few in the past had connected with individuals with PPS on their own. Most participants stated that they had initially sought out others with PPS and attended the support groups to gain knowledge of PPS, treatment options, and information regarding navigating healthcare and insurance systems. One participant stated, "I wanted to know what this was, what is 'post polio'. I had never heard of it, nobody had ever told me about, nobody ever told me years down the road you're going to have problems." For a minority of participants, this continued to be the predominant reason for attending the support groups. However, ten participants cited that, in addition to information, the

group provided the opportunity to receive understanding, empathy and support from others in similar circumstances to themselves, as well as social camaraderie. One stated:

We have a commonality that holds us together, now let's support each other. You know, I can talk to someone with MS and I can sympathize with them, but I don't understand them. When I'm talking to someone with polio, ... I have a kindred spirit, a commonality.

Being with others with PPS also helped some participants gain perspective on their own physical limitations:

I am a huge advocate for support groups because you come in, you understand everybody, you don't feel like you're the one that has a disability. There's a whole lot of people who have disabilities who are worse off than you are. And you would miss an awful lot of nice, nice people.

The support group also provided opportunities for group members to "give back" and advocate for others. Several participants noted receiving guidance from group members in navigating the bureaucracy of applying for worker's and disability compensation. They were now helping others in the group do the same. Another member, who had learned from the group about specialized braces that had aided her mobility tremendously, was now combining her skills as a PT and knowledge as a user of braces to train other orthotists on how to make them. One group had developed a general fund which helped members who were financially stressed pay for needed personal items.

Finally, the support group was useful in supporting positive identity construction. Many participants voiced their admiration for the accomplishments that other group members had made during their lives and the obstacles they had overcome despite the effects of polio and PPS. This recognition, in turn, engendered feelings of pride and positive identification with being a polio survivor. As one participant stated:

I feel very proud to be part of this group of people because I feel like we're a family. This experience has made us like a family because of our common experiences and what we've achieved ... We were talking about what we've achieved in our lives (during a

group meeting) and finally came around to this lady, and she said, ‘Oh my gosh, this is amazing. All of these people and what they’ve gone through and look at what they’ve done with their lives.’ This is what you find with people who are survivors... (A) lot of our people are lawyers, they’re nurses they’re physical therapists, they’re engineers. I mean these people have accomplished a lot considering what they’ve gone through.

Another participant described a growth in the feelings of self-worth and self-efficacy associated with the positive responses and appreciation he had received from group members for the leadership activities he had engaged in as group president: “I see myself as having some real, real strong points, which I didn’t see before. I don’t feel like I’m a leader but here I am, the leader of that group, and people seem to respect that and appreciate what I do and how I’ve done it.”

Thus, for many participants the support group provided not only information, but an opportunity to give and receive empathy, support, and camaraderie, and to build positive self-identity as a survivor of polio. However, similar to other coping strategies, attending the support group also brought with it its own challenges. Many participants voiced that attending the groups, particularly in the beginning, were difficult experiences because they were confronted with seeing others with PPS who were in further physical decline than themselves. These participants, all of whom were fully mobile when they first attended group meetings, saw group members in wheelchairs and using walkers, and felt ambivalent about participating. They described feelings of fear and anxiety that they could someday be in a similar physical condition, and described feeling out of place because they were not physically compromised to the extent that others in the group were. One participant stated:

(T)he first post polio support group that I went to, I came and I saw all those people with electric chairs and walkers and ... I think I went home and freaked out. Because I figured that that was my future, an electric chair, not being able to get yourself around without a walker, or a cane or whatever, and I could feel me having to do that as I got older. And that’s a terrifying thing.

Another remembered:

I walked in the meeting and I said, what am I here for? I mean, here were people in crutches, here were people in braces, here were people with walkers....And I was ambulatory and walking around, and I thought, what am I here for?

Yet participants stated that the information they got from the groups about PPS initially encouraged them to continue to come to meetings, even though they could be emotionally stressful at times. Several participants stated they continued to feel ambivalent about attending group meetings for this reason.

**Internal coping strategies.** Unlike the concrete coping strategies described by participants, internal coping strategies did not tend to have the problematic residuals that then, in turn, needed to be coped with. And yet, internal coping strategies, although commonly utilized by participants, were not described as commonly as the concrete strategies were. Also unlike the concrete coping strategies, internal coping skills were not reactive responses to physical decline. Indeed, these strategies usually were not new to participants nor developed in response to PPS. Rather, participants described using these skills throughout their lives, both in response to polio, and when confronting other challenges and adversity. Internal coping skills used by participants included relying on faith and spirituality, a focus on gratitude and appreciation, and a process of normalizing declining physical functioning. The internalized nature of these coping strategies made them highly personalized to the individual participant, and yet provided similar benefits: comfort, peace of mind, and acceptance.

***Faith and spirituality.*** Half of all participants highlighted their religious faith and/or spirituality as a significant coping strategy used to confront the physical and emotional effects of declining physical functioning. Of the eight participants who highlighted faith as integral to their coping with PPS, six had been raised in families where faith was an important value and two had developed their beliefs in adulthood, prior to PPS. All eight participants noted that faith had been an important coping strategy that they had utilized before PPS when

confronted with adversity and hardship. A belief in a higher power helped these participants accept physical deterioration and the changes in their lives that accompanied it. These participants voiced that, regardless of what happened to them physically, they were not alone but rather had a higher power looking out for them. One participant stated that her faith “gives me the satisfaction that I always know that somebody is going to be there who is going to be on my side, that’s the Lord, and I know he’s the one that never lets you down.” Another stated, “I...accept pretty much what life throws at you and you do the best you can with it. And I think your faith helps you with that in doing the best you can.” Similar to this participant, another described how faith helped her with acceptance:

I think one thing that gives me strength through this whole thing is my faith, my faith in God really gives me strength... because each time I’ve had these hurdles to go over, it’s all been smooth when I get to that point where I’m accepting it ... So I think God has guided me and given me strength to get through all of these experience.

Faith provided these participants with comfort and appeared to reduce feelings of anxiety and increase feelings of acceptance. Several of these participants noted connections between their faith and feelings of gratitude for the positives in their lives: “I have my faith, and I know that I’m fortunate to be on this earth and walking and living alone and working and taking care of myself, and so if something comes up that’s a disappointment, that’s the way it is.” She continued, “I’ve been fortunate enough to have lots of good things in my life, and I have family and friends now...I’m just very fortunate. I have God who looks out after me.” Faith also provided perspective for some participants. One stated that his spiritual beliefs placed his experience of PPS in perspective for him as a minor event when compared to the vastness of God and the universe. For another participant, helping others less fortunate than herself through her church helped her put her own problems in perspective:

I try to do for others, which helps to take the focus of myself... And so as I say that’s how I cope, that’s how I get along because you can always find someone worse off. And

the church now that I'm attending feeds the homeless and overnight, there's a whole group in this town ... of churches that put up these homeless people every night and feed them every night. And I go and they're our guests in our church and we feed them dinner and we spend time with them and we eat with them. I've nothing to complain about.

***Gratitude and appreciation.*** Other participants who were not necessarily coming from a religious and/or spiritual perspective, also described focusing on, and taking in, the positives in their lives as an important coping strategy. Many participants noted feelings of gratitude for the supportive people in their lives. One participant stated about her son, "He's just a really awesome human being and, you know, some of my friends are just, they're just wonderful human beings and I feel so thankful to have this network of people who are so caring." For several participants, noticing the physical struggles of others with PPS in the support group helped them to develop feelings of gratitude for the physical functioning they continued to have. One participant described feeling "how fortunate I am because there's some people who are really in trouble here (in the group), and they're getting worse." Indeed, many participants stated in passing that they felt grateful for what they could still do physically. Another stated that he had learned to notice and be grateful for the small things in life that gave him pleasure, such as supportive friends, good food, and a devoted partner: "I have a few good friends, I'm grateful for whatever I have ... So life is full of little things, not big things, and if I didn't have (my partner) and good friends, I think life would be useless". This participant also described paying more attention to, and having a deeper appreciation for, the simple things life had to offer him: "Look at what's nice, enjoy what's nice, a beautiful day, smells in the air, good meal, good wine a good beer. Then it makes things you took for granted more important in life." He also had developed a new interest in art and design, in response to being more homebound. Another participant noted that he felt appreciative for the experience of PPS because it required him to sit more, allowing him to do more reading and writing, activities that he found



meaningful. He felt that if he was more mobile, he would feel obligated to do other activities which he enjoyed less.

I'd say I'm appreciative because I've been lately into something where I want to spend more time thinking and writing and I might have felt guilty by taking the time to do that if I wasn't forced to go sit down all the time, which has been a blessing for where I am right now. So I see it as a really cool thing.

One participant described feeling grateful for having opportunities in the past to do activities she enjoyed which she could now no longer do. "I'm glad I had all those years when I could do those things and I did them and it's the same way with travel. I'm so glad that I did that."

Another felt like she had developed a greater appreciation for childhood opportunities she had had:

I've learned to have great appreciation. I feel that I've been extremely lucky and very fortunate to have had the education I had in spite of the handicap. I mean, kids when I was little, if you had a handicap sometimes they'd put you in a school with retarded kids, whatever. ...I was blessed to have a family that did have religious faith and spirituality.... There was a sense of something bigger than yourself and a responsibility for something bigger than yourself and so that, I found out, is very important to me.

*Normalizing declining physical functioning.* A tendency to normalize changes in physical functioning was commonly implied by participants, although rarely highlighted as a conscious coping strategy. Some of these participants saw the physical issues they struggled with due to PPS as an example of challenges that all people at some point struggle with as part of the human experience. This was a coping skill that many had utilized throughout their life to deal with physical limitations and difference. As one participant put it:

I feel like I've been dealt a set of cards...everybody's got something. I think that was in my late teens, early 20s I realized ...even in Playboy Magazine those gals have pimples on their rear ends. And I remember thinking that... (S)o that's how I've looked at the world, you just have something I can't see. This is what I have.

Another participant stated, "Basically we're all the same. We're not that good looking, there's a male and female, there's not a hell of a lot of difference." Participants who engaged in

normalizing understood their physical issues as not separating them from others who did not have PPS, but rather unifying them. That is, most people are different from the mainstream in some way, whether this difference is visible or invisible, and physical difference was simply an example of this for these participants. Other participants normalized their physical challenges as an example of declines in functioning that most people experience as a part of aging: “I think the fact that a lot of my contemporaries who didn’t have polio have the same issues-Okay-So you know it’s just part of aging. So I don’t, you know, I don’t... waste worry over it.” She continued,

The truth is, is that almost everybody becomes disabled during some part of their life and it’s not generally a matter of if, it’s when. And I see having physical challenges ever since I was four years old as an advantage... because I learned to cope with it over time.

## **Benefits**

Different from previous studies, this study explored if and how participants felt they had benefited from their experiences of polio and PPS. Almost every participant noted significant benefits from one or both. Indeed, most participants described important qualities, values, characteristics, and opportunities that they felt had been shaped by their experiences of polio and/or PPS. Those benefits arising from polio had served participants’ over the course of their lives and often shaped their identities in profound ways. Those benefits which participants had derived from the experience of PPS had positively enriched their sense of self and feelings of interconnectivity to others.

**Benefits from polio.** Participants described developing greater empathy and compassion for others, perseverance, and coping skills as positive residuals from their initial experience of polio.

*Empathy and compassion.* A development of deep empathy for others who experienced hardship was the most common benefit participants described as coming out of their

experience of polio. For some, this empathy was particularly directed towards others with disabilities and/or with differences in physical functioning. One participant stated, “It made me more open to understanding handicap, and things that people couldn’t do, and it wasn’t just a matter of choice”. Another said, “I’m more compassionate, more tolerant, much more tolerant of people with disabilities because I understand some of the things they have to go through”. For others, they felt that their experience of polio had encouraged a growth in empathy for all people who were outside the mainstream and experienced intolerance, societal barriers, and other forms of oppression: “I...think it’s given me empathy for other people who have other kinds of issues, things that are beyond their control, people who live in war zones, people who are of a race or religion that because of that they’re ostracized or mistreated or whatever.” A capacity for empathy was also evident in choices many participants made in their careers and other activities in their communities. Several had held, or were holding, jobs in the helping professions, including physical therapy, social work, and occupational therapy. One participant highlighted how her experience with polio had been significant to her work as an occupational therapist: “I think it’s made me more compassionate, more patient with other people ...And I think that’s why I became a real advocate...to try to get the families to understand what the patient is going through.” One participant described becoming an advocate in her city government for people with disabilities when she was unable to get a handicapped parking space put in place by her home. Several described participating in church groups which served underprivileged people. One participant described the importance to her of passing along the values of empathy and understanding for those with disabilities to her daughter.

***Perseverance.*** Many participants stated that their initial experience of polio had taught them perseverance and determination not to give up in the face of adversity. One

participant stated it had made her “more determined, I guess, to prove whatever it is I think I need to prove.” Most felt that this attitude had overall been helpful to them in surmounting different challenges throughout life: “I’m probably a whole different person than I would have been if I had not had polio...I think that I was more determined that I wasn’t going to give up, that I could do just about anything that I put my mind to.” For these participants, a sense of mastery and identity as a capable person emerged through persevering and achieving in the face of adversity.

*Coping skills.* Several participants who had experienced multiple physical and emotional challenges related to polio as children noted that they felt these experiences helped them to develop coping skills that later aided them in dealing successfully with other hardships, including PPS. One participant described multiple hospitalizations from the time she was a young child through adolescence:

(B)asically you were on your own, you know, and it taught you to be self-reliant. It made you stronger. Those experiences made me a stronger person...because of coping skills. It gives you coping skills...(Y)ou’re thrown into a situation (and) you know you have to survive. You have to do what you have to do. I mean, that prepares you for real life ‘cause that’s what real life is about. You get out into the world and you’ve got to do what you’ve got to do to survive.

Another stated that one benefit to polio “was learning to cope over those years. You figure out, piece by piece by piece, ‘how do I deal with this?’ because it’s incremental ... And with post polio it’s been incremental as well, even more so”. Another participant noted that the judgments by others she had endured as a young person had helped her as an adult not to take the negative opinions of others personally. She felt that this skill, in turn, had helped her in her career as a manager.

**Benefits from PPS.** Participants described greater self acceptance, a new sense of community with other polio survivors, and a focus on self care as positive residuals developing from their experience of PPS.

*Self Acceptance.* For many participants, after living much of their lives pushing through obstacles, ignoring physical limitations, and accomplishing in their careers, post polio had engendered a re-evaluation of how they responded to themselves and their physical limitations. Now being told by medical professionals to “conserve it or lose it”, participants were warned of the physical hazards of continuing to respond to physical limitations with pushing themselves. Many participants experienced a struggle between old ways of dealing with obstacles by fighting and resisting and pushing, with new ways that focused on compassion for the self and self-acceptance. And yet, most described developing greater acceptance of themselves and their physical limitations related to PPS as time went on: “I’m learning that all the expectation I’ve put on myself to do everything perfectly, that it’s ok, that there is a reason that I have trouble with that, the polio was to blame for a lot of it... I’m starting to give myself more of a break.” She continued, “So I’ve eased up on myself because I’ve always been so hard on myself my whole life...(L)ike I can see it’s miraculous I did what I’ve done.” Another participant stated:

I’m more accepting of myself as someone who’s physically challenged because I feel like I’ve accomplished a lot in my life and I’m proud of myself for doing that. I know who I am, my disability does not define who I am. And if nobody sees that, then that’s really not my problem.

Although it was often a struggle, many participants described feelings of recognition and appreciation for what they had achieved in the past as well as being at peace with themselves in present. Several participants described moving back and forth between feelings of acceptance of themselves and their current physical capabilities, and wanting to fight and push through them.

The coping skills described above, particularly internal coping skills, were useful in helping participants move towards acceptance of, and tolerance for, themselves and their physical limitations.

*Sense of community with other polio survivors.* Most participants had not known other polio survivors before joining the support groups. Furthermore, most participants stated that polio was not a topic of conversation with family and friends after recovery. One participant stated that she and her college roommate had recently discovered, at their college reunion, that both had had polio. However, they had never discussed it with each other as young adults and so had been unaware that the other was also a polio survivor. With the advent of PPS, polio survivors began connecting with each other for information and support. Many participants, as already touched on above, felt that the support group provided them with an important community which they had not had before PPS. Indeed, several participants described the group as their polio “family”. Some participants noted that the group gave them an opportunity to share their story of polio with others for the first time, which they had not done in the past due trying to leave polio behind and lead a “normal” life :

I talked a little bit about my experience, which is not something that I had done in my life because (the mentality was that) it's over with, I did all that, it's over with, I've moved on in my life and what does that have to do with anything. I'm going to start living now, I'm going to make up for lost time and start living a normal life. So you don't talk about it. I don't ever remember meeting anyone who had polio and I probably did more than I know because polios didn't talk about it...(W)e weren't taught to really, you know, face it.

The development of a PPS community not only empowered participants with an importance source of information, support, and positive identity as described previously, it also provided gave them a community in which their stories could be heard and witnessed by others with a shared experience.

*Self care.* For many participants, the experience of PPS had inspired them to take better care of themselves. A new focus on getting appropriate exercise, nutrition, and sleep was commonly cited by participants. Most participants who had retired early due to PPS acknowledged they had greater energy and flexibility to do activities that they enjoyed. Retiring at a younger age was cited as a significant benefit for these participants that they would not have otherwise had if not for PPS. One participant stated:

If I didn't have the polio I'd still be working somewhere...I was able to retire and get disability sooner... If I didn't have it I probably would have stayed at the phone company longer even though ... it was so tiring getting up, driving to work, getting there, (working) all day, getting back in the car, and going home. It was a long day that wore me out. So thirty years is enough.

This participant noted that now that she had retired, she could structure her days according to her physical needs and requirements, and could focus her energy on enjoying herself. Another participant stated that, for her, the only benefit to PPS was "having to retire, and just loving retirement, being able to treat myself well if I want to." One participant, a physical therapist, described feeling the burden of responsibility for others lifted now that she had retired, and having the opportunity to respond to her own needs and wishes in ways she had not done in the past while working. She stated:

The energy it took for me to be in a care giving role or be in a role of helping people understand what they needed to do to make things better for themselves or their baby was exhausting, and I didn't know it because I'd been doing it for so long...I think that's just been awesome, it's been wonderful to do something because I want to do it, not because I need to be here, there, and everywhere for these other people and I've learned to say no finally.

PPS thus provided these participants with a sense of freedom and greater opportunity for self-fulfillment that they had not enjoyed while working.

## **Chapter V**

### **Discussion**

The findings suggest that polio survivors confronting post polio syndrome are utilizing a rich array of coping strategies to manage its physical and emotional effects. Some of these strategies had been derived from past experience, while others were newly developed. Some had replaced past strategies that are no longer useful. Some strategies participants had developed on their own, while others were learned from medical professionals and other polio survivors. Many of these strategies proved to be complex, necessitating further coping to deal with residual challenges that arose from their use. Coping, therefore, was often a complicated process for participants, and one that required flexibility, perseverance, and a willingness to face difficult emotions and navigate complicated family, medical, work, and other social systems. The intricacies involved in coping with PPS and the strengths and resiliencies necessary to successfully engage in the coping process, have, up to this point, been undocumented in the literature.

Furthermore, far from being purely negative experiences, polio and PPS had profound positive residuals for participants that contributed to feelings of mastery, pride, positive identity, and interconnectivity with others. Participants illustrated in their narratives another side of the experience of PPS that had not been sought out or documented in previous literature. The following chapter contextualizes study findings within the existing literature, locates its importance in the work of clinical social workers, and suggests opportunities for further research.



## **Contextualization of findings within the literature**

Study findings both followed those of previous literature in regards to the initial experience of polio, the negative emotional reactions to PPS diagnosis, and the stage model of coping as well as differed from the results of past studies. Findings also illuminated areas of the PPS experience that had not been explored in the past research, particularly around the themes of coping and positive residuals to the experiences of polio and PPS.

**Polio.** Participants' initial experience of polio often followed those documented in the literature which described a wide array of challenges, expectations, and barriers experienced by mid-century polio survivors. Some were fortunate to live in supportive families and communities and to receive good, empathic medical care, while others were not so fortunate. The distress arising for young children left in the hospital without their parents was a common theme described by participants who developed polio as young children and which has also been well documented in the past literature. Also similar to past research, participants often characterized themselves as having a type A personality, pushing to integrate themselves into society as able bodied, and focusing their energies on areas in which they could achieve, such as in academics and careers. A wish to be "normal", which has been contextualized in the literature with negative mid-century social attitudes towards disability, was also evident in participant's responses. These "polio traditions" described by Scheer & Luborsky (1991) who write, "early life disability experiences continue to be important in later life", were evident in the initial responses of many participants to PPS.

While findings tended to mirror the experiences of polio survivors described in the literature, they also contrasted with the recent meta histories of polio with their dominant narratives of struggle and conquest of polio by survivors and by the Salk vaccine. The findings

illustrate that the consequences of polio did not end after recovery for many survivors, particularly for those with visible physical difference and for those living in unsupportive environments. The psychological consequences and social barriers confronted by these polio survivors illustrated in the findings were present and repeatedly faced long after the illness subsided. Similarly, it is not altogether unsurprising that these historical narratives largely ignore PPS, referring to it only briefly and as a footnote to the polio conquest narratives. Indeed, the existence of PPS and the lack of knowledge about how to treat it within the medical community described by participants, challenges the faith in science and American ingenuity and heroism that these narratives of conquest offer. Ultimately, histories of polio put forward a myth that ultimately minimizes the complexities of polio that many survivors faced, and which many face today with the advent of PPS. The findings of this study give voice to these complexities and propose that these histories have overlooked polio survivors' experiences that may be incongruent with the values on which these narratives are founded. Findings also challenge the structure of these narratives themselves: the history of polio does not have a linear beginning, middle and happy ending, but rather is ongoing and rife with challenges.

**Emotional experience of post polio syndrome.** The findings challenge the suggestion in past literature that the PPS experience is simply one of emotional distress. The focus of these authors tends to be on the negative emotions that arise as the result of declining physical functioning, such as anger, depression, and anxiety. Furthermore, coping by pacing is described as particularly emotionally difficult for polio survivors to do because it can be experienced as a surrendering to physical limitations, which is contrary to coping strategies used in the past. The findings agree in part with these conclusions: many participants described feelings of distress related to PPS as well as difficulty with incorporating pacing into their lives after years of full

activity. And yet, findings also show that emotional responses are far broader than those described by these authors, and also are fluid, changing and evolving over time. For instance, feelings of gratitude, appreciation, acceptance, hope, and interconnectivity were also shown by the findings to be a part of the emotional experience of PPS. Furthermore, participants illustrated that they are not defined by, nor prisoners of, past internalized values as some of the previous literature has suggested. Although these values appeared to play a role, participants illustrated a capacity to be flexible in their understanding of themselves in relationship to PPS. This capacity allowed them to embrace pacing and other coping strategies, as well as to locate benefits to the PPS experience. Finally, findings illustrate that the emotional experience of PPS and coping choices are shaped not only by the past and by what is inside participants but by the present and what is outside. Systemic barriers to treatment, for instance, strongly influenced the emotional experience of participants as did receiving empathy and support from other polio survivors. It is important that emotional responses to PPS be understood as shaped by the reflexivity between the polio survivor and his or her environment.

**Stage model.** The findings mirror the literature suggesting a stage model of acceptance for declining physical functioning. Indeed, participants reacted early on often with denial, anger and anxiety, and tended to experience greater acceptance and other positive emotions over time. Furthermore, as time went on, participants were more likely to integrate the lifestyle changes necessary to retain physical functioning as much as possible. These findings support the research of Frick (1985) and Hollingsworth, Didelot, & Levington (2002), who suggest that, as polio survivors confront PPS, they move through several stages until they arrive at acceptance of the PPS diagnosis and secondary disability. With pacing as a central coping strategy, findings also supported Frick's (1985) assertion that an important part of the process of acceptance is

accepting what one can do within one's physical limitations. The findings found that, like past studies, peer support groups are helpful in facilitating the individual's movement through the emotional stages of PPS. Frick (1985) noted, for instance, that such groups decrease feelings of isolation, provide access to community resources and the coping strategies of others, and can be protective against the effects of stress (Frick, 1985). However, the findings also suggested that empathy, support and understanding from other group members were the most significant benefits.

The findings also show areas of contrast to previous studies. First, most participants appeared not to follow a linear model toward PPS acceptance. Rather, they often described becoming more accepting as time went on, but also continuing to experience difficult emotions and strong responses. For instance, using a brace again was a process for many of rejection and then gradual integration. This process occurred again when a new, more restrictive device was needed, such as scooter. A similar process occurred with the advent of new injuries, which appeared to spark a recurrence of difficult emotions and necessitate the process toward acceptance to begin again. Thus, for many participants, feelings of acceptance were not static, but vacillated with more difficult feelings, although these emotions seemed to become less prominent as time went on.

Secondly, past literature has overlooked how external systemic responses to those with PPS can create significant barriers towards moving towards acceptance and integration of declining physical functioning. For instance, study participants noted barriers to receiving adequate medical care, struggles with insurance companies, and challenges within family systems as significant stressors in coping with PPS. Whereas the stage model cites acceptance as an internal process, findings show that external systems with which those with PPS engage can

exacerbate the process of acclimation and acceptance. The process of acceptance is both an internal one as well as a reflexive experience between the person and their environment.

Third, according to Frick (1985), significant stages of acceptance are devaluing the physique so that the body is “not decisive in determining one’s worth” and “emphasizing and learning to value what persons can do within the limitations of their disability”. And yet, independence and mobility also appeared to be at the core of self identity, and loss of mobility and independence engendered the greatest feelings of anxiety and anger. An important part of acceptance for participants, therefore, was coming to terms with becoming more dependent on others, or the possibility of becoming more dependent on others in the future. Findings also showed that learning to ask for help and to accept help from others was a significant component of this process. Participants voiced that this was particularly difficult after living fully independent lives of full or near to full mobility. Thus, the process of acceptance of PPS is not just a process of coming to terms with doing less and, for some, no longer passing as able bodied, but also a process of coming to terms with a decline in independence and devaluation of independence.

Finally, the stage model fails to take into account that there may be differences in the process of acceptance due to personal history. As the findings from this study illustrate, polio survivors confronting PPS are a diverse group, particularly in this regard. Most significantly, perhaps, is the difference in experience among those with visible physical limitations and those without. Those without appeared to have an easier time integrating into society after polio due to being able to pass as a fully able-bodied person. Those with visible physical difference tended to report more feelings of distress, especially embarrassment, “abnormality” and unattractiveness, and encountered more societal barriers. A person’s history is often a significant indicator in how

he or she reacts to stressful circumstances. The stage model, therefore, should serve as a general structure and be held lightly. It ultimately must be subjugated to the polio survivor's narrative, which as Wiley (2003) states, reveals "(i)nnnermost thoughts, modes of thinking, personal ways of coping, person-environment interactions, and degrees of resiliency (pp. 39-40).

**PPS treatment.** Findings suggest that polio survivors are flexible with their coping strategies and not necessarily bound to past strategies that are no longer useful to them. Pacing was the most common of coping strategies, and although participants described difficulty relinquishing pushing behaviors utilized throughout their lives, they ultimately were able to use this coping strategy successfully. This is a contradiction with Bruno & Frick's (1991) study, which concludes that high non-compliance rates with treatment recommendations, particularly pacing, is a result of fears of relinquishing type A behaviors that polio survivors have used for self-protection over the years (Bruno & Frick, 1991). Part of traditional treatment is therefore focused on helping polio survivors relinquish type A behaviors, although even when initially successful, they tended to resume on follow up.

Although Bruno and Frick don't specify how long patients had been experiencing symptoms, lack of compliance with treatment recommendations could be more related to time since onset of PPS symptoms. Indeed, findings showed that most participants experienced more resistance to changing behaviors when first faced with diagnosis. Findings also showed, as already discussed, that the process of acceptance of declining physical functioning took time. This also consistent with Shanke (1997) and Westbrook & McIlwain (1996), who found that polio survivors showed lower levels of emotional distress and greater acceptance of declining physical functioning as they experienced with the passage of time. By not specifying time since onset of symptoms and/or diagnosis in their study population, Bruno & Frick (1991) may be

misinterpreting what is simply a natural process of mourning that begins with denial and resistance, and gradually moves towards acceptance, made perhaps more challenging due to past coping strategies.

### **Relevance of findings to clinical social work**

For social workers working with those confronting both the physical and emotional effects of PPS, study findings offer important information that social workers can utilize to help this population cope with declining physical functioning. First, there are rich arrays of coping strategies many polio survivors are using and which appear to be successful in helping them to navigate declining physical functioning. For polio survivors just beginning to confront PPS symptoms, these are strategies with which social workers can support clients in exploring for themselves. For those who have been confronting PPS for some time, findings can provide social workers and their clients with suggestions for coping that these clients may not have previously thought of and tried. Social workers should be aware that coping takes many forms, and can be a process of doing, such as seeking medical care, and as well as a process in which the client utilizes internal resources, such as faith and spirituality. These strategies both work to confront the concrete physical issues that the client is experiencing, as well as the emotional components. Together, the client uses these strategies to not only increase their physical well being, but also to make meaning out of the declining physical functioning they are experiencing. The social worker can be attuned to this meaning making process, and support clients in choosing coping strategies support meaning making that is most beneficial to them.

Second, findings showed that many with PPS do not have the opportunity to share their experience of polio and PPS with others in their families and communities. They lack opportunities to share their stories as well as empathy and understanding. Social workers,

therefore, should be attuned to this possibility with their PPS clients, and can provide a space for the telling of these narratives. Empathy and understanding on the part of the social worker is particularly important to emphasize in these interactions. The social worker may wish to encourage PPS clients to join support groups where they can receive information, empathy and understanding from their peers. Findings also showed that group engagement with others with PPS could also be helpful to developing a positive self-identity as a polio survivor. For PPS clients who have a particularly negative view of disability, this may be a significant benefit to joining a support group. Although study participants were all support group members and thus the findings supporting interconnectivity with others with PPS may be skewed, it makes intuitive sense that engagement with others confronting similar stressors could be beneficial to many clients. For clients who lack support groups in their communities, social workers in settings that allow for groups may wish to consider creating them for clients as part of treatment.

Third, social workers should be attuned to the possibility that their clients with PPS are experiencing, or have experienced in the past, disappointment and mistreatment by medical systems. As a treatment provider, clients may be skeptical of the social worker's ability to provide adequate care and services to them due to the lack of treatment options available for the physical effects of PPS. Social workers can provide a space for the discussion of these concerns and also support and encourage attempts at self advocacy on the part of the client. This would be particularly important if the social worker providing treatment was part of a medical system.

Fourth, positive self-identity related to being a polio survivor may be fostered by the social worker. Similar to the findings of Dunn (1996) and Olney & Brockelman (2003), the study findings suggest that many polio survivors confronting PPS do not view their experiences of these illnesses in purely negative terms. Rather, many participants felt that the experiences of



polio had profoundly shaped their identities in positive ways that engendered feelings of pride and competency. The PPS experience was also one from which some participants felt that they had benefited. Supporting PPS clients in creating richer, strength-based narratives around their experiences of polio and PPS may be helpful for clients whose identities may be shaken as the result of declining physical functioning and who may be focused on problem-saturated narratives. Through techniques of narrative therapy, social workers can help clients restructure negative dominant stories about themselves and disability to ones that are useful to them. For instance, as the findings illustrate, a disability identity is highly personalized, incorporated fully or fluidly or not at all. Social workers can support clients in consciously developing a relationship to this identity that is most useful to them.

Fifth, findings show that coping is often a complex process, bringing up additional stressors, and social workers should be sensitive to, and prepared for these residuals. They can prepare clients for the possibilities of these complexities in advance and support clients in forming additional strategies for meeting them. For instance, participants noted that attending support group meetings was often difficult in the beginning because they were confronted with seeing others with disabilities far more extensive than their own. This brought up feelings such as anxiety and grief as they imagined themselves someday in a similar position. Social workers can help prepare clients for the possibility of the emergence of these feelings, normalize them as natural responses, and support clients in processing these feelings.

Sixth, social workers should be aware of the presence of polio traditions that clients may bring with them into treatment, such as a strong work ethic, drive to overcome obstacles, and type A characteristics, and how these may influence clients' current coping strategies. For some clients, these polio traditions may translate into coping strategies such as pushing rather

than pacing. To support clients in relinquishing coping strategies that may no longer be effective for them, social workers can help clients explore social and familial expectations around disability that may have been internalized long ago. Furthermore, social workers can support clients in redirecting these polio traditions towards behaviors and cognitive skills that are more beneficial to them. It is important that social workers do not pathologize these traditions, but rather understand their source for the client and their significance in helping the client overcome social barriers and succeed in a mainstream society often prejudiced and unsympathetic to those with physical differences.

Seventh, social workers should be sensitive to the possibility that the PPS client's initial polio experience may contain significant traumas, stemming from the initial treatment experience, family and community responses, and societal barriers and prejudice encountered after recovery. Although the decision of how to work with these traumas will be based on the social worker's clinical judgment and on the individual's needs and wishes, it is important that social workers be aware of their potential presence during their work with this population. As the findings indicate, memories of the initial polio experience, whether traumatic or not, will likely be triggered with the advent of PPS, and influence the client's reactions and coping decisions. Clients may find discussing traumatic memories with others in support groups to be useful to them. These clients may also benefit from trauma focused work with an individual therapist.

Finally, as supported in the findings and in previous research, it is important that social workers be aware that the time since the client has been confronting PPS symptoms and/or diagnosis, will likely be a significant factor in their current response. In addition to time, the level of disability caused by polio and PPS may also play a role in the acceptance process.

While a stage model can be useful in understanding the process of acceptance, clients will, as the findings indicate, likely move between stages of acceptance non-linearly, triggered by new physical, systemic and emotional challenges they encounter. For instance, a client may, over time, come to accept braces, and then go through a cycle of difficult emotions again when confronted with needing to use a scooter. Social workers, when aware of where clients are on the continuum of acceptance, can formulate interventions sensitive to this.

It is likely that that these findings are applicable to social workers working with clients encountering other forms of illness re-emergence, such as the return of cancer previously believed cured. Furthermore, findings are also likely translatable to those encountering disability later in life due to illness, such as MS. However, it should also be noted that, due to polio's unique social construction in American society in the first half of the twentieth century and the apparent internalization of particular values around disability by many young polio patients during that time, there may be important differences. For instance, physical normalcy may not hold the same significance to other clients as to those with PPS. Furthermore, those with illnesses which lead to physical limitations will likely not have histories of encountering the illness in the past that polio survivors have and which can influence current responses. Another important difference is that PPS is usually not life threatening, as cancer and MS might be, and therefore polio survivors' anxieties are not focused around loss of life. Therefore, while there is likely overlap, there are also important differences in experiences to which social workers should be sensitive.

### **Future research opportunities**

Further research is needed to explore the differences and similarities in the experiences, attitudes and coping skills of those confronting PPS and those experiencing re-emergence of

other illnesses and disability acquired later in life due to illness. Additional research is also necessary to more fully understand the relationship of visible disability from polio to the experience of post polio syndrome. Do the needs and experiences of this population differ? Furthermore, how do the experiences of PPS differ of those whose initial experience of polio included trauma? As this population confronts PPS, how might their needs and coping strategies differ from those who did not experience trauma?

The participants in this study all belonged to support groups, raising important questions about the experiences, attitudes, and coping skills of those who are not part of groups. Those not in groups may be less disabled, for instance, less likely to seek the support of others, more likely to utilize denial as a coping mechanism, or less effected by the emotional and psychological stressors of PPS. They may also be less likely to verbalize their experiences of polio and PPS with others, and may be more isolated. The experiences of people of color with PPS are also an important area for further research. No studies have explored the possibility that the initial experience of polio may have been very different for this population, due to segregated systems of medical care, lack of medical resources available to some communities, and different cultural interpretations of polio outside of the dominant narrative referred to in this study. As the findings illustrate, the initial experience of polio can be significant to how polio survivors confront PPS today. Furthermore, this population may encounter similar experiences as they confront PPS. Therefore, the unexplored polio histories and current PPS experience of people of color is an important missing component in the literature. The lack of knowledge in this area creates barriers to care for social workers working with this population. Social workers must therefore be cognizant of these gaps in knowledge and be particularly attuned to the potential that they will diverge from the experiences, attitudes and coping skills described in this study.

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## Appendix A

### Human Subjects Review Application

**Investigator Name:** Arianna Opsvig

**Project Title:** Attitudes, Coping Skills, and Resiliencies: Polio Survivors Confront Post-Polio Syndrome

**Contact Address:** xxx

**Contact Phone:** xxx

**Email Address:** xxx

#### Project Purpose and Design

Polio survivors experiencing post polio syndrome (PPS), that is, a return of polio symptoms in middle and older age, are often confronted with declining physical functioning. Research has shown that, at times, emotional distress accompanies the onset of PPS symptoms (Hollingsworth, Didelot, & Levington, 2002). Research has also shown that treatment providers, both those providing mental health services, such as social workers, and those providing medical services, such as physicians, often encounter resistance from this population to medical and psychotherapeutic treatment recommendations (Bruno & Frick, 1991). The resistance encountered from PPS patients suggests that there is a disconnect between the model of treatment being offered and polio survivors' experience of themselves and their illness. In order to support those confronting PPS, it is vital that treatment providers understand this experience, so treatment can be molded to fit the needs of, and be palatable to, this population. Thus, my research proposal asks the question, "What are the attitudes among individuals experiencing PPS towards declining physical functioning and secondary disability, and what are the resiliencies and coping skills they are drawing upon in confronting this illness?"

Up to this point, much research has focused on the experience and treatment of emotional distress due to loss in physical functioning. These studies highlight factors that might contribute to differences in levels of emotional distress among individuals, for instance time since onset of symptoms (Shanke, 1997 and Westbrook & McIlwain, 1996), and level of initial disability (Maynard & Roller, 1991). Research has also sought to establish a connection between the socio-historical context in which an individual experienced polio and the individual's current response to, and understanding of, PPS symptoms (Scheer & Luborsky, 1991). Recommendations for treatment are largely based on the understanding of disability as loss. Thus, treatment is focused on helping individuals accept secondary disability and make the lifestyle changes that a decrease in physical functioning may call for. I propose a study that will hopefully yield a broader understanding of the PPS experience, one that assumes that secondary disability does not necessarily have to be constructed only as an experience of loss, anxiety, and trauma. By providing participants with a broader space to describe their experience of PPS, I hope to capture the resiliencies and strengths they bring to the experience of secondary disability, as well as how the experience may be a richer and more varied one than what previous literature has assumed.



My study will be qualitative and data will be collected from interviews with polio survivors experiencing PPS symptoms. I will employ a non-probability sampling technique, using convenience and snowball sampling. It will hopefully provide useful information so that those providing medical and psychotherapeutic services to this population may better tailor treatment approaches and, in doing so, encounter less resistance to them. This is particularly important now, as the number of those experiencing PPS is growing, and expected to continue to grow, as polio survivors age. There are, according to a 1987 study by the National Center for Health Statistics, at least 1.63 million survivors of polio in the United States. Of these, at least 240,000 are currently experiencing the effects of PPS, and it is predicted that the majority of polio survivors will experience at least some PPS symptoms as they age (Hollingsworth et al., 2002). This research will be used for the completion of the MSW Thesis at Smith School for Social Work. It may be used for publication or for presentation.

### **The Characteristics of the Participants**

My sample population will include men and women who self-identify as experiencing indicators of the late effects of polio, post polio syndrome, or similar symptoms. Participants must be English speaking, as this is the language I am comfortable communicating with. My sample population will be open to all levels of initial disability, in attempt to capture a range of experience, attitudes and resiliencies. I plan for my sample size to be between 12 and 15 participants.

### **The Recruitment Process**

I plan to recruit using two methods. First, I will contact the several local polio support groups in the Bay Area. I will contact support group leaders and request permission to distribute flyers about my study to group participants. I will mail or deliver copies of the flyer to the support group (Appendix A). I will explain the study to support group leaders and ask them to encourage those in their groups to participate. If email lists are available through the support groups, I will request permission to email the flyer to the list in order to contact potential study participants through this avenue as well. Although I hope to have an ethnically and racially diverse sample, I do not know if these groups are diverse themselves. Therefore, my study sample will be, in part, contingent on the diversity of these groups. Secondly, I will use personal contacts in the polio community to recruit potential participants for my study. I will ask these contacts to speak to potential participants and to distribute my flyer to potential participants. After a potential participant contacts me I will follow up with a phone call or email conversation in which I will screen potential participants to make sure they meet the selection criteria. Next, I will describe the study and if the potential participant agrees to be interviewed I will set up a time and send them a copy of the informed consent. I believe these recruitment processes are the most likely to capture the widest possible range of voices.

### **The Nature of Participation**

Participants will sit for an interview, consisting of open-ended questions, that explores their experience of PPS, attitudes towards second disability, coping mechanisms, and the resiliencies they are using to confront PPS (Appendix B). I will also collect demographic data on the participant's age, gender, race, ethnicity, and level of initial disability from polio, as this information may be useful in contextualizing the individual's experience of PPS. Interviews will be conducted in-person in a semi-public place, such as a café or public library. Interviews will

last approximately 45 minutes to one hour and will be audio-taped. I will prepare the transcription. Data will be coded using content analysis techniques.

### **Risks of Participation**

Revisiting the past can bring up painful memories and allow for re-experiencing of trauma. Speaking of current difficulties related to PPS may also be upsetting for participants. Thus, there is some risk that study participants could experience emotional distress as a result of participating in my study. To help mitigate this risk, I will inform participants before interviews begin that some questions may bring up difficult memories and emotions. I will also distribute a list of referral sources for services to all study participants, attached to the informed consent form (Appendix C). All identifying information will be held in confidence.

### **Benefits of Participation**

Research participants may experience a sense of empowerment and agency through telling their story and having their voice heard by an individual in the academic community. Results of the study will be offered to participants, which may be helpful to them in understanding their experience and locating it within the experience of cohorts. They may also feel good about providing information that could be of use to social workers and other health professionals providing care to them or others experiencing PPS. Financial compensation will be provided to participants: I will offer to purchase a cup of tea or coffee for the participant if the interview is held in a café setting.

### **Informed Consent Procedures**

The informed consent (Appendix D) will be emailed to study participants before the interview occurs, to provide them with information regarding the purpose of the study and what they can expect from the interview process. I will take two copies of the consent to the interview. Before the interview begins, I will review the consent form with the study participant in person and obtain their signature. They will receive the other copy of the consent to keep.

### **Precautions Taken to Safeguard Confidentiality and Identifiable Information**

To insure confidentiality, all documentation and tapes will be stored in a locked, secure file box and identifying information, including signed consent forms and participant contact information, will be kept separate from data. Once audiofiles are transcribed, code numbers will be used as file names. In addition, I will remove/replace identifiers such as names and addresses. Once identifying information has been removed, my research advisor will have access to the data. Illustrative vignettes and quoted comments will be disguised in the thesis, and any presentation, and/or publication so that participants will not be identifiable. Documentations and tapes will be stored for three years per Federal regulations. After three years, I will continue to keep this data securely until it is destroyed when no longer needed.

### **The Voluntary Nature of Participation**

Participation in this study is voluntary and participants can refuse to answer any question. They can stop the interview at any time. If they choose to withdraw from the study after the interview, they must do so by March 28, 2011. Participants will be informed of these guidelines. If a participant withdraws from the study, all materials related to them will be destroyed.

**Investigator's Signature:** \_\_\_\_\_ **Date:** \_\_\_\_\_

**Advisor's Signature (if applicable):** \_\_\_\_\_ **Date:** \_\_\_\_\_



SMITH COLLEGE  
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Smith College  
Northampton, Massachusetts 01063  
T (413) 585-7950  
F (413) 585-7994

February 2, 2011

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Arianna Opsvig

Dear Arianna,

Your revised materials have been reviewed and they are complete. We are now happy to give final approval to your study. But didn't you mean there would be no financial compensation? A cup of tea isn't really financial compensation. Perhaps you should put the "no" in both the Application and the Consent.

*Please note the following requirements:*

**Consent Maintaining Data:** You must retain all data and other documents for at least three (3) years past completion of the research activity.

*In addition, these requirements may also be applicable:*

**Amendments:** If you wish to change any aspect of the study (such as design, procedures, consent forms or subject population), please submit these changes to the Committee.

**Renewal:** You are required to apply for renewal of approval every year for as long as the study is active.

**Completion:** You are required to notify the Chair of the Human Subjects Review Committee when your study is completed (data collection finished). This requirement is met by completion of the thesis project during the Third Summer.

Good luck with your very interesting and useful project.

Sincerely,

Ann Hartman, D.S.W.  
Chair, Human Subjects Review Committee

CC: Kate Didden, Research Advisor

## **Appendix B**

### **Informed Consent Form**

Dear Participant,

My name is Arianna Opsvig and I am a graduate student at Smith School for Social Work in Northampton, MA. I am interviewing individuals in the Bay Area who are currently experiencing indicators of post polio syndrome or similar symptoms. In my study I hope to capture the experiences of individuals with PPS and particularly highlight the strengths and coping skills they are using. I hope my research will assist those in the helping professions develop better approaches for working with polio survivors confronting PPS. This research will be used for the completion of the MSW Thesis at Smith School for Social Work. It may be used for publication and/or for presentation.

If you agree to participate in my study, I will set up an interview with you at a convenient time and place. The interview should take from 45 minutes to 1 hour and will be audio-taped and later transcribed by myself. There is some risk that you could experience emotional distress as a result of participating in this study, as revisiting the past can bring up painful memories and speaking of current difficulties may be upsetting. To help mitigate these risks, I will distribute a list of referral sources at the time of the interview. On the other hand, you may experience a sense of empowerment through telling your story and having your voice heard. Results of the study will be offered to you, which may be helpful in understanding your experience of PPS and that of others. You may also feel good about providing information that could be of use to social workers and health professionals providing care to you or others experiencing PPS. There will be financial compensation for participation in this study: I will offer to purchase a cup of tea or coffee for the participant if the interview is held in a café setting

Confidentiality will be provided for in this research. To insure confidentiality, all documentation and tapes will be stored in a locked, secure file box and identifying information will be kept separately. Code numbers will be used in place of names. Once identifying information has been removed, my research advisor will have access to the data. Data will be accessible only by my research advisor and myself. Illustrative vignettes and quoted comments will be disguised in the thesis, a presentation, and/or publication so that participants will not be identifiable. Documentations and tapes will be stored for three years per Federal regulations. After three years, I will continue to store this data securely until it is destroyed when no longer needed.

Participation in this study is voluntary and you can refuse to answer any question. You may stop the interview at any time. If you choose to withdraw from the study after the interview, you must do so by March 28, 2011. If you withdraw from the study, all materials related to you will be destroyed immediately. In the case that you have additional questions or wish to withdraw from the study, I may be contacted at xxx-xxx-xxxx or at xxxxxx@smith.edu. If you have any concerns about your rights or any aspect of the study, the Chair of the Smith College School for Social Work Human Subjects Review Committee may be contacted at 413-585-7974.

**Your signature indicates that you have read and understand the above information and that you have had the opportunity to ask questions about the study, your participation, and your rights and that you agree to participate in the study.**

**Participant's signature:** \_\_\_\_\_

**Researcher's signature:** \_\_\_\_\_

**Date:** \_\_\_\_\_

Please keep a copy of this form for your records. Thank you for your participation in this study.

Sincerely,

Arianna Opsvig

## Appendix C

### Referral Sources

#### **For education, resources and support for polio survivors:**

San Francisco Bay Area Polio Survivors

[www.sfbaps.org](http://www.sfbaps.org)

[sfbaps@aol.com](mailto:sfbaps@aol.com)

(415) 440-5657

(650) 368-8185

Sacramento Post Polio Support Group

[www.sacramentopoliosurvivors.com](http://www.sacramentopoliosurvivors.com)

(916) 725-4077

(800) 215-0318

#### **For therapy services:**

Therapy Network Confidential Bay Area Therapy Referral Service

San Francisco and Marin: (415) 974-9779

East Bay: (510) 287-9225

[www.therapynetwork.net](http://www.therapynetwork.net)

Oak Creek Counseling Center

Located in Berkeley Pleasant Hill, and San Francisco

(888) 637-7404

[www.oakcreekcenter.org](http://www.oakcreekcenter.org)

*Fees based on a sliding scale*

San Francisco Psychotherapy Research Group

Located in San Francisco

(415) 677-7946

[www.sfprg.org](http://www.sfprg.org)

*Fees based on a sliding scale*

Susan Rosenblum Rabens, LCSW

Located in Albany, CA

(510) 526-6834

Arlene Rothchild, LCSW

Located in San Rafael and San Francisco, CA

(415) 567-7662

## **Appendix D**

### **Interview Questions**

#### **History**

What age were you when you contracted polio? What was your experience of the treatment you received for polio as a child?

What was your attitude toward polio growing up? What were the attitudes of your family toward polio? Friends' attitudes? How did these attitudes affect you?

#### **Experience of PPS**

How long have you experienced the symptoms of post polio syndrome?

Tell me about the physical effects of post polio syndrome you have experienced in the past and are currently experiencing.

Tell me about the emotional effects of post polio syndrome you have experienced in the past and are currently experiencing.

#### **Attitudes**

Can you describe how you felt after you recovered from your initial experience of polio? Has this feeling changed over time, and particularly since you contracted PPS?

Have you ever considered yourself disabled? If so, what does being a "disabled person" mean to you?

How, if at all, has your self-identity changed since you contracted PPS?

What, if anything, has the experience of PPS taught you about yourself?

Is there anything positive that has come out of your experience of PPS? If so, please describe.

#### **Coping**

I'd like to know about how you are coping with the physical and emotional effects of PPS. Can you describe the things you may be doing or the things you are thinking that are helping you.

How do you think you developed these coping skills/strategies?

Do you currently receive any kind of professional treatment for the physical and/or emotional symptoms of PPS? What have you found helpful, and what has not been helpful? If you were "in charge", what would you do differently?



Is there anything friends/family have suggested to manage your physical/emotional symptoms?  
What has been helpful? What has not?