

**Adaptation Into Late Life for Persons with Long-  
Term Neuromuscular Disabilities:  
Lessons Learned from Polio Survivors**

**Final Report**

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**National Institute on Disability and Rehabilitation Research  
Research Fellowship Program  
Grant Award H133FO50039  
12/1/2005-8/31/2007  
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**December 2007**

## **Author Note and Dedication**

The author would like to acknowledge the gracious support and assistance of the following individual contributors and organizations:

### **Mentors**

Frederick M. Maynard, M.D.  
Jessica Scheer, Ph.D.

### **Advisors**

Denise G. Tate, Ph.D.  
Nancy Crewe, Ph.D.  
Julie Silver, M.D.  
Lauro Halstead, M.D.  
Judith E. Heumann  
Christopher Peterson, Ph.D.  
Claire Kalpakjian, Ph.D.  
Monika Ardel, Ph.D.

### **Personal Travel Assistants/Companions/Hosts/Collaborators**

Susan Rasmussen  
Eva Harris  
Jane Cairy  
Laurie Oliver  
Brenda and Scott Roller  
Holly and Kris Konecny  
Barbara Goldstein  
Sharon Antoniuc  
Dr. Werner Rink  
Els Eldersveld

### **University of Michigan Office of the Vice President of Research**

### **University of Michigan Department of Physical Medicine and Rehabilitation**

Joan Headley, Executive Director  
**Post-Polio Health International**

### **Post-Polio Support Groups**

Polio Epic, Inc. Support Group; Tucson, AZ  
Polio Survivors Association; Downey, CA  
San Diego Polio Survivors; San Diego, CA  
Riverside Area Polio Survivors; Riverside, CA  
Easter Seals Post-Polio Support Group; Ft. Collins, CA

Easter Seals Post-Polio Support Group Southern Colorado; Colorado Springs, CO  
The Polio Outreach of Connecticut; Southbury CT  
Florida East Coast Post-Polio Support Group; Ormond Beach FL  
Tampa Bay Polio Survivors Support Group. Tampa, FL  
Post-Polio Support Group of Charlotte County; Punta Gorda, FL  
Portland Region Post-Polio Support Group; Durham, ME  
Southeast Michigan Post-Polio Support Group; Troy, MI  
West Metro Chapter of Post-Polio Awareness and  
Support Society of Minnesota; Edina, MN  
Post-Polio Support Group of the Lehigh Valley; Allentown, PA  
Post-Polio Resource Group of Southeast Wisconsin; Milwaukee, WI

*A special thank you is extended to Monika Ardelt, Ph.D. and Claire Kalpakjian, Ph.D. who voluntarily performed the quantitative data analyses for this report.*



This report is respectfully dedicated to Bob Hudson and Beverly Solomon, two key participants who were designated to be “wise elders” by their support groups. Bob passed away in December 2006; Beverly in June 2007. Heartfelt condolences are sent to their families, friends and support group members. Their gracious contribution to this study was indeed a meaningful, valuable and appreciated opportunity to learn from their extraordinary life experiences.



Bob Hudson  
San Diego Polio Survivors;  
San Diego, CA



Beverly Solomon  
Post-Polio Support Group of the Lehigh Valley;  
Allentown, PA

## Expenditures

The total grant award was for \$55,000.00 for the one-year period. All grant funds were drawn down by August 31, 2006, with no balance remaining.

## Outputs

### Project Dissemination Products

#### *Presentations:*

Roller, S. (2006, May) Adaptation into Late Life for Persons with Long-Term Neuromuscular Disabilities: Lessons Learned from Polio Survivors. Oral presentation at the *NIDRR Mary E. Switzer Fellowship Meeting*, Madison Hotel, Washington, D.C.

Roller, S. (2006, November) Very Early Findings--Adaptation into Late Life for Persons with Long-Term Neuromuscular Disabilities: Lessons Learned from Polio Survivors. Oral presentation for the *Advanced Rehabilitation Research Training Program Seminar Series*, University of Michigan Health System, Ann Arbor, MI.

Roller, S. (2007, September) Inspiration and Wellness: How Spirit Affects Health. Oral Presentation at *Bay Cliff Post-Polio Wellness Retreat*, Big Bay, MI

Roller, S. (2007, September) Aging Well with Polio: Advice from Ginny and the Wise Elders. Oral presentation at the *Michigan Polio Network Annual Meeting*, Mt. Pleasant, MI

#### *Consumer Publications (See Appendix A):*

Roller, S. (November/December 2007) Aging Well with Polio: Advice from Ginny and the Wise Elders. *Florida East Coast Post-Polio Support Group Newsletter*, 15 (3), 6-7.

Roller, S. (November/December 2007) Aging Well with Polio: Advice from Ginny and the Wise Elders. *Post Polio Voice Newsletter*, 11(4), 6-7.

Roller, S. (November 2007) Aging Well with Polio: Advice from Ginny and the Wise Elders. *PPS Manager Newsletter*, 5-9.

#### *Planned Future Publications:*

Roller, S. (Winter 2008) Aging Well with Polio: Advice from Ginny and the Wise Elders. *SpecialLiving Magazine*.

## The Research Study

This report is divided into two parts. *Part One* provides the findings from the primary study of the 15 key participants and *Part Two* elucidates the findings from the sub-study on wisdom, which included both key participants and 93 members of linked post-polio support groups.

### *Part One*

## **Primary Study: Late Life Lessons Learned from Polio Survivors**

### **Abstract**

Even though people with a prolonged disability from causes such as poliomyelitis, spinal cord injury, spina bifida, and cerebral palsy are quickly emerging as a large elder population with accelerating needs, their patterns of adaptation into late life are ill defined. To describe late life success strategies, this investigation concentrated on the perceptions of a small and elite set of polio survivors--those who were designated the most highly regarded by their peer group as senior role models (or polio mentors), who were over 65 years of age and more than 50 years past disability onset.

The goal of this study was to expand knowledge about the late life physical, social and environmental adaptation experience of older individuals who contracted poliomyelitis between 1930 and 1955. To accomplish this purpose, specific physical changes, attitudes, coping techniques and adaptive behaviors facilitating improved quality of life over the life span and into late life were identified. To achieve the study objectives, the PI, a polio survivor herself,<sup>1</sup> employed qualitative social research methodology, complemented by quantitative measures to describe the sample and document perceptions.

The four research questions guiding the study addressed the following topics: (a) issues polio mentors faced at various stages of the life course; (b) how perceptions of life with a disability changed over time; (c) attitudes viewed as most valuable for coping well with new issues into late life and how these attitudes differed from past ways of thinking; (d) how polio mentors defined “successful adaptation” in late life.

Objective measures of stress and life satisfaction were used to describe the sample. From a national network of post-polio support groups, purposive sampling was used to select 15 study participants with 93 respectively linked support group members in five regions of the U.S. During the study year, in-depth, audio taped semi-structured interviews (in person or by telephone) were conducted with the 15 key participants, who also completed the objective measures noted above. Qualitative analysis was performed using standard qualitative techniques (constant comparative method). Quantitative analyses included descriptive and inferential statistics.

## Key Findings:

- Major issues throughout life included: achieving and maintaining independence which required diligent effort; fighting shame and creating a positive self-image with a disability; and reconciling social and functional losses
- Over time, perception of life with a disability from polio changed for this group. Before encountering the late effects of polio at mid-life, individuals operated and worked hard using their “lens of difference,” a self-perception that rejected the shame and prevalent social stigma of disability. High achievement was crucial. Later in life they became more willing to look at their lives through the “lens of disability,” more fully embracing their disability as part of their overall personal identity. In so doing, they found a new freedom to be more content with this new self-perception and life in their retirement years.
- Key coping strategies included having a strong social support system, enjoying life, being optimistic, self-acceptance, assertiveness, education and spirituality.
- Successful late life adaptation was defined as self-acceptance and adaptation, having the right resources, and being surrounded by loved ones.

## Introduction

With advances in health care, people who have chronic neuromuscular disabilities from poliomyelitis, spinal cord injury (SCI), spina bifida and cerebral palsy (CP) are living longer than previous generations, surviving the challenges that lifelong disability brings, and entering old age and old, old age in greater numbers than ever before.<sup>2</sup> An estimated 12 million people with various kinds of impairments are living into their late life years.<sup>2</sup> As part of the process, individuals with a variety of neuromuscular disabilities often experience profound changes in their health and function 15 to 20 years earlier than their non-disabled peers. This growing population of men and women with physical disabilities are said to face “fast-track” aging (with new functional losses occurring “prematurely” during mid-life).<sup>2</sup> For them, understanding and, more importantly, effectively dealing with the effects of aging and long-term chronicity are of paramount importance in maximizing health, maintaining physical functioning, independence and, ultimately, attaining the highest quality of life. Ironically however, as they encounter the mystifying gift of longevity for the first time in history, they also are confronted by a confusing combination of appreciation and bewilderment.

The first group to report that aging was not going favorably was the polio population.<sup>2, 7, 8</sup> There are an estimated one million individuals who had polio in the U.S.<sup>9</sup> Many of them have lived with a chronic disability for over 50 years and are experiencing new pain, weakness and fatigue, and a declining functional capacity as a result of these health problems.<sup>9</sup> Studies suggest that 60% or more of post-polio individuals experience at least one or more difficulties with secondary conditions, also referred to as PPS, polio sequelae or the late effects of polio.<sup>10</sup> In a June 2005 pilot survey conducted by this study’s P.I.<sup>1</sup> at the “International Polio and Independent Living Conference,” a sample of polio survivors (n=36) with an average age of 59 years was asked about the most important concerns they expect to face in the next ten years.

Functional loss and the availability of environmental supports ranked the highest. Sixty-one percent expressed some fear about their future neuromusculoskeletal and movement related functions (e.g., joints, muscles, involuntary movements). Fifty-eight percent were uneasy about changes in their mobility, while 44% said they were apprehensive about deviation or loss related to movement (e.g., neck, shoulders, arms, legs); compromised cognitive functions (e.g., intellectual, energy, sleep, emotional, etc.) was a worry expressed by 42%. Thirty-six percent responded that products and technology for personal and public use were important for them as they think about the years ahead.<sup>3</sup>

In spite of expressed concerns among consumers, little is known about the experience of living a very long time with a disability or the impact of disabling conditions on the transition into late life.<sup>4</sup> As a result, rehabilitation approaches that specifically target psychological, environmental and social factors associated with successful adaptation into the later years are not as informed as they could be. Also, as it stands now, young and mid-life consumers with a chronic neuromuscular disability and their families cannot be adequately educated in the area of late life planning about predictable needs for accessible housing, financial support, and long-term care, for example, because information in the literature is minimal. This information gap not only directly affects consumers and those in the field of rehabilitation, but public policymakers as well, who will be facing the needs of the population of disabled “baby-boomers” as they highlight new needs for community-supported health and medical services and insurance disability coverage, including long-term care. Legislators also will need to address this group’s concerns about housing, transportation, early retirement and long-term care.<sup>5</sup>

**The purpose of this study was to expand knowledge about the late life physical, social and environmental adaptation experience of older individuals who contracted poliomyelitis between 1930 and 1955.** The study sample consisted of 15 individuals who have lived with a chronic disability from polio for more than 50 years and are considered to be polio mentors by their peer group. For the purposes of this study, a *polio mentor* was defined as a senior person who has had a prolonged disability from polio and who served as a peer group identified role model for living well in late life. A polio mentor, further, was willing to teach/coach others about ways to successfully adapt to late life demands. As the study progressed, the key participants also came to be informally referred to as “wise elders.”

Specific study objectives were to: 1) Document how polio mentors perceive the physical, social and environmental changes that accompany moving into late life, including issues or dilemmas they have encountered at various stages along the life course; 2) Describe how polio mentors perceive both lifelong attitudes and newly acquired attitudes towards living with disabilities; and 3) Identify how polio mentors distinguish the coping techniques and adaptive behaviors used to facilitate a high quality of life over the life span and into late life. The life course and polio trajectory conceptual framework guided the collection of study data.

## Methods

Studying individuals' lives in narrative format is particularly useful for discovering personal meaning, social context and change. Hence, a qualitative research semi-structured interview methodology was used, complemented by quantitative measures that included perception of stress, life satisfaction and dimensions of wisdom.

### Sample Selection

Fifteen “polio mentors” living in different areas of the U.S. were recruited to participate in this study. The purpose of such sampling was to recruit polio survivors whose functional life experience included adaptation in a variety of climates and environmental contexts. To do this:

1. Leaders of semi-randomly selected support groups in five regions of the country were contacted. These regions included the South (Florida), the East (Connecticut, Maine, and Pennsylvania), the West (Colorado and Arizona), The Far West (California) and the Midwest (Wisconsin, Michigan and Minnesota). See Figure 1.





Using the Post-Polio Health International's (PHI's) support group directory, group leaders were contacted either at random or based on geographic feasibility for travel, and/or the group's previously stated willingness to participate until 15 groups agreed to participate—three from each region. Support groups were asked to nominate one polio mentor from their group to be considered for selection as a key study participant. Upon request after the initial contact, a condensed description of the study was emailed to the support group leader to share with their group and the potential study recruits. People were asked to consider (as listed in the study's consent form) the following criteria to select a polio mentor:

- Identified by support group leaders and their board of directors as a person who has demonstrated the following qualities of a mentor: shows compassion for others, effective in an interpersonal context; serves as role model, sometimes extending friendship; provides direction, support and stability; models lifelong learning; and can point out big picture and communicate hope and optimism.
  - Identified by the PI as a person who is articulate about personal experiences; is fifty or more years post polio onset; has a functional impairment; is 65 years old or more.
2. Once potential participants were nominated and agreed to consider participation, support group leaders provided telephone numbers for contact and initial screening. Screening for inclusion criteria took place during this initial contact.
  3. If the polio survivor met all criteria and was willing to participate, a consent form was reviewed with the individual on the phone and then mailed or faxed to them for signature and return to project headquarters.
  4. Once polio mentors were fully recruited into the study, support group leaders were also asked to identify other group members who would volunteer to participate, each completing a consent form and then the Three-Dimensional Wisdom Scale (3D-WS), as further described below.

### **Data Sources**

The principal source of qualitative data was the text of transcribed interviews from key participants. The sources of quantitative data for the main study were the following objective measures of perceived stress and life satisfaction:

1. *Perceived Stress Scale-10*: The PSS (Cohen, Karmarck, & Mermelstein, 1983; Cohen & Williamson, 1988) is a self-report questionnaire that measures a global perception of stress during the previous month. Its short version comprised of ten items asking the subject to rate how often they have perceived an event in their life over the last week. An example is "In the last month how often have you felt difficulties were piling up so high that you could not overcome them?" Response

options were assessed using a 5-point Likert-type scale: (0 = Never to 4= Very Often.) A total PSS score is computed by summing across all 10 items. The measure has the virtues of being widely used, general in nature, brief, and assessing stress response on a continuum from relatively mild to severe. To keep interview time from becoming too exhausting for participants, it was decided to use the similar 10-item scale rather than the originally cited 14-item scale.

2. *Satisfaction with Life Scale*: The SWLS (Diener, Emmons, Larsen & Griffin, 1985), uses five items to measure global satisfaction with life. Respondents were asked to rate their level of satisfaction on a seven-point Likert scale. Scores are calculated by summing the scores and dividing this number by the number of items.

During the first nine months of the study, two interviews were conducted with each of the selected participants.

1. **Interview One** was designed to collect background information, including basic demographics, medical history and quantitative information from the Perceived Stress Scale, the Satisfaction with Life Survey, and (for the pilot sub-study) the Three-Dimensional Wisdom Questionnaire. Originally, the Ways of Coping Questionnaire was also going to be included as an objective measure, but was dropped before interviews began due to concern about the length of the interview with respect to the participants' endurance levels balanced against the actual usefulness of this particular instrument.
2. **Interview Two** was guided by a semi-structured open-ended questionnaire designed to collect in-depth narrative information. (See Appendix B for all instruments.) The core of the interview consisted of a series of questions developed specifically for this study and designed to answer the research questions posed. Each participant was asked to describe his or her life in relation to the domain areas of personal health and well-being, daily life, social roles, quality of life, life story and recollections after polio, in addition to closing advice to others and thoughts about the future.

Interviews were carried out in person or by telephone if physical access to the participant's home or other physical meeting place was not possible. The interviews lasted an average duration of approximately 2.5 hours each. Photos were taken at the interview sight upon written permission and consent to release them from the participant.

### **Data Processing**

Both the first and second interviews were audio taped, with the second one sent to a professional service for transcription. As a check on accuracy and completeness, transcriptions were compared to audiotapes. Each line of the 15 transcriptions was examined and reviewed several times. Information was then sorted according to each of the four research questions.

Common answers emerged. Quantitative data was entered into the study's main database, an Excel file that could later be transported to an SPSS file for data analyses.

### **Quantitative Data Analysis**

Quantitative analyses include descriptive statistics to elucidate the elders' demographic, polio and functional characteristics as well as mean scores on measures of perceived stress and life satisfaction. Inferential statistics, specifically independent samples t-tests, were used to compare mean scores on the PSS to normative data.

### **Qualitative Data Analysis**

A major goal of any qualitative analysis is the identification of patterns and themes and the drawing of inferences about their meaning. Data analysis depends on the insight, intuition and methods that the investigators bring to the research process. The interpretive course of action is dialectical and goes beyond the conventional logic of quantitative methods. In combination, the analysis implies the back and forth movement between data, concepts and inferences. It is a reflective and iterative process in which new data continually inform emerging interpretations. In other words, data collection, analysis and interpretation emerge together. The definition of and categorization of common themes related to successfully adapting into late life was continuously considered and reconsidered. Early in the data collection process, an ad hoc group of four colleagues including the P.I., a public health researcher, a psychiatrist, and a consumer advocate gathered to share independently-drawn impressions of the information that was gathered on the first five cases, as a check for interpretive reliability.<sup>1</sup>

## **Results**

The results of this mixed-methods study are reported in two sections. Section A describes quantitative findings including the demographic characteristics of the sample. Fairly extensive medical information was also collected, which included current physical functioning, physical activity levels, polio history, a history of assistive device use and physical function, and medical status regarding the late effects of polio, general health, medications and co-morbidities. This report section also conveys the results of the perceived stress and life satisfaction measures. Section B reporting the qualitative findings is organized into subsections based on the four research questions originally proposed for the study. As such, each section documents the results of both quantitative and qualitative analyses that provide key findings for each research question.

### **Section A: Quantitative Findings**

#### **Demographic, Polio and Functional Characteristics**

All 15 participants had had polio for more than 50 years ranging from 54 to 80 years. Seven were women; eight were men. Their average age was 73, ranging from 65 to 86 years. Four walked with a cane or crutches and 11 used a wheelchair. (It is interesting to note that such

a high percentage of the sample was wheelchair users in light of the fact that this is disproportionate to the percentage of wheelchair users in the polio population as a whole. It could be speculated that this occurred either because those who use wheelchairs full time are seen as wiser due to the complications of severe disability or because such a disability really does elicit greater wisdom from life experience.) As a group they reported that their health ranged from good (75%) to very good (25%). All had experienced the late effects of polio and were living with some functional decline. Eighty percent reported a new disabling fatigue in recent years. Two have passed away since the study interview, from heart problems. Seven were married, six were either divorced or widowed and two were never married. All were living independently in their homes and had functional help doing so. Ninety three percent had a partial or full college education with 28% holding a post-graduate degree. Their average age at retirement was 58 years. All were doing volunteer work and enjoying leisure pursuits. Beyond mentoring people in their post-polio support groups, examples of their volunteer work included serving on community committees to address disability issues, participating in church/temple activities, and babysitting with grandchildren. Examples of leisure activities were watching T.V., traveling, shopping, socializing with friends over dinner, reading, going to concerts and the theater, and singing in the church choir. Selected demographic, polio-related history and functional characteristics are given in Table 1.

Table 1. Demographic, Polio and Functional Characteristics of Elders (N = 15)

<i>Demographics</i>	<i>Mean (SD) or Frequency (%)</i>	<i>Range</i>
Age (years)	72.93 (7.8)	65 to 86
Females	7 (46.7%)	--
Highest Academic Degree Obtained < High school Some college/College Post-graduate	1 (7.1%) 9 (64.3%) 4 (28.6%)	--
Marital status Married Divorced Widowed Never married	7 (46.7%) 4 (26.7%) 2 (13.3%) 2 (13.3%)	--
Age at retirement	57.8 (4.1)	51 to 65
Reside with spouse/child/caregiver	10 (66.7%)	--
<i>Polio History and Functional Characteristics</i>	<i>Mean (SD) or Frequency (%)</i>	<i>Range</i>
Years since polio onset	65.47 (9.7)	54 to 80
No. assistive devices used at functional stability	1.93 (1.8)	0 to 6
No. assistive devices used now	2.87 (1.8)	1 to 7
Walking ability now At least 100 ft. without stopping, no wheelchair Walk over 100 ft., but also use wheelchair Unable to walk 100 ft.	4 (26.7%) 1 (6.7%) 10 (66.7%)	--
Reported disabling fatigue in recent years	12 (80%)	--
Level of fatigue now (scale 1 – 10, 10 as totally disabling)	6.0 (1.7)	3 to 9
Reported new pain in recent years (joint and muscle)	11 (73.3%)	--
Level of pain now (scale 1 – 10, 10 as unbearable)	3.93 (2.9)	1 to 9
Reported new weakness in recent years	15 (100%)	--
Number of co-morbidities	2.8 (1.4)	0 to 6

## Perceived Stress and Life Satisfaction

This study sample's stress levels were about the same as other Americans their age. The mean score of the elders on the Perceived Stress Scale was 9.23 (6.7) with a range of 0 to 25. Using data from the L. Harris Poll of 2,387 respondents in the U.S., we compared the mean score of the elders to a nationally representative sample of 65 years and older adults (N = 296) and found a statistically significant difference (9.36 vs. 12.0,  $t = 1.65$ ,  $p = 0.05$ ). However the effect size was very small (0.01) and thus is unlikely to be a meaningful difference.

The mean score of the Satisfaction with Life Scale for the elders was 27.79 (5.3) with a range of 18 to 35. Although there are no nationally representative data as above, scores primarily ranged from slightly to extremely satisfied, with one elder being slightly dissatisfied; see Figure 2.

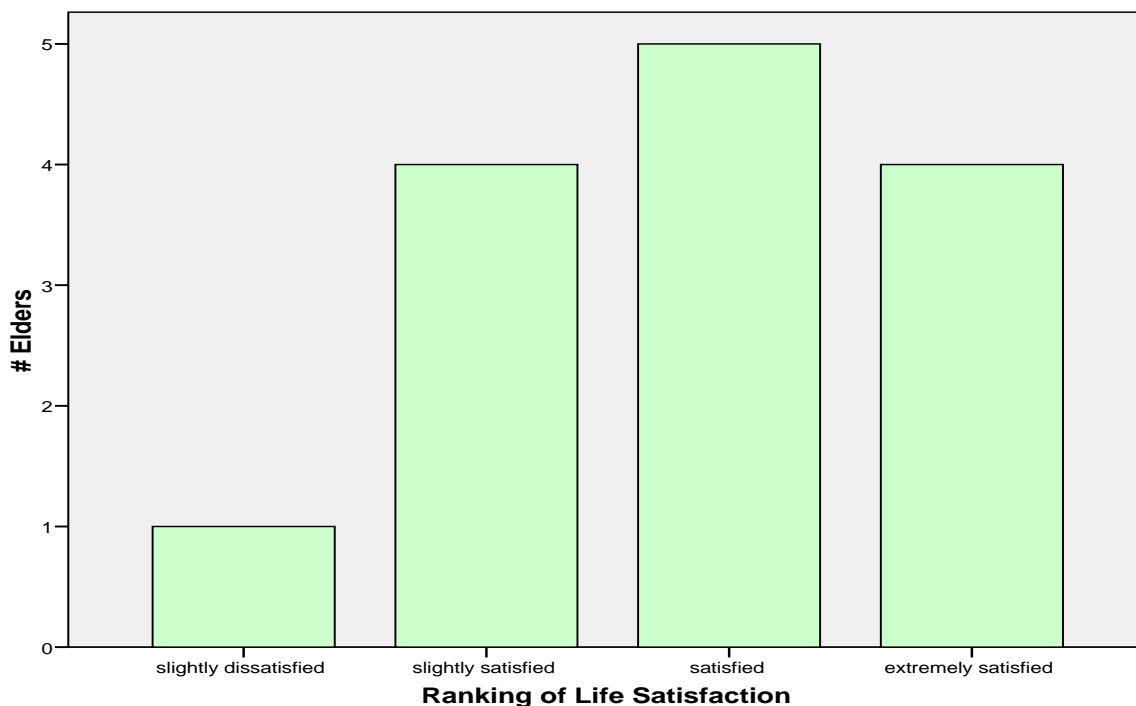


Figure 2. Life Satisfaction Rankings

## Section B: Qualitative Findings

### Lifetime Issues

*Research Question 1: What issues or dilemmas have polio mentors faced at various stages of the life course?*

The life course perspective is one lens used by this researcher to formulate questions in the structured interview guide and understand how the late effects of polio impacted the lives of these individuals who had polio during the epidemic years. The perspective suggests that



new meaning in late life. This concept seemed to mean both independence of thinking as well as in physical, living situations. People fought to disprove negative social stigma of being disabled and worked hard to earn a living to have an independent lifestyle. In their childhood, study participants often heard messages like “you can do anything anybody else can do...” One man shared that his father “ wanted me to get out and do my thing on my own. So he didn’t perpetuate a feeling of, you know, a cripple or a person that can’t do everything.” Another participant defined a need to *think* independently from the time she was a young woman. She described how she traveled alone around the country and made other decisions that seemed imprudent to her non-disabled social group. In later life, the term independence changed its meaning for her, from having an “I’ll show them” attitude, proving that she could be self-sufficient with an obvious disability, to becoming graciously *interdependent*, accepting more physical help from others as physical function declines. She went on to explain her meaning of independent thinking in the context of her later life years:

I still have control of my life, even though people are doing for me, I still—I am a type A person and I know that. But I still can control my life. The people that help me are wonderful but they will always ask. They never do things without asking. And I appreciate that. There’s also a lot you can do yourself and **be your own person**. The month I was in the nursing home was really an interesting one for me because they weren’t used to someone like me who wanted to handle their own problems and I can see how people who are in a nursing home can **lose their identity very quickly** because nobody wants to take the time. It takes time to be—to try to be independent and they don’t have that time. And so they do for you. Not always willingly, but they do it. I think that happens in families, too. And that doesn’t allow you to be yourself.

Several respondents mentioned a fear of helplessness or dependence in late life. This dependence often was defined in terms of needing intimate personal care as one woman explained, “When I have to have somebody come in and help me with bathing, going to the bathroom and doing things like that.” In fact, suicide was mentioned as a rational end to being overly dependent:

I don’t want people wiping my rear end and, you know, this, that and the other thing...(if I had a terminal illness and I couldn’t do anything for myself and I don’t want to go into a nursing home where they lay me down in bed and fill me full of pills and life support, whatever—I was talking about this to my friend Brenda, just last week we were talking. I would try to save up whatever pills they gave me and I would do away with myself.

### **Creating a Positive Self-Image with a Disability**

Self-acceptance was expressed as a major lifelong issue for this group. It was not until the Disability Rights Movement in the 1970s that the negative disgrace surrounding physical disability began to be challenged by American society. It is not surprising; therefore, that in the 1950s and 60s this study’s group of polio survivors felt forced, during their early and mid-life years, to fiercely battle the shame and guilt associated with having a socially obvious disability. This became a major lifetime issue that seems to have become more, but not completely, resolved in this group after the age of retirement. Several respondents reported that in their



childhood years, their families imposed a sense of humiliation and responsibility on them for being disabled, resulting in varying levels of disability denial and a sense of oppression. One woman reported that she always had to be behind everyone else in the annual family Christmas photo so her crutches and braces wouldn't show. Of her disability she shared, "I absorbed that this is really awful, that we can't even mention it. And it was never mentioned at all." Another man shared that as a young man, he was ashamed of his physique and was afraid to go out in public in shorts. When he first had to use a scooter in mid-life he once again struggled with a shame and grief that threatened a positive self-image. He had to ignore the stares of others. Another man told a story of needing assurance as a man in his young twenties about his sexual identity and actually finding an older woman to mentor him in this role. Adding to a sense of liability with the family, three women reported that, as children and young adults, they had to emotionally care for one of their parents who suffered from various emotional problems, including drug addiction, which added to the burden imposed by disability.

It is interesting to note that there were three study subjects who self-identified as "passers" who were intensely emotional--outspoken, angry and distressed--about the lifelong issues of shame they faced as people who were always hiding a minimal disability to pass for normal and how this is not resolved in later life. One woman still struggles with the burden of trying to reconcile a positive self-image. In spite of new disability in later life, she confided that she is still attempting to pass for non-disabled in her head. "It still feels like a family secret," she said. Passers feel both a sense of rejection among others with polio and with the public if disability-related help is needed. As background, many polio survivors who attend local and national post-polio conferences are comfortable with a model of coping styles developed by Maynard and Roller (1991). This model suggests that the post-polio population can be grouped into three categories: "passers", "minimizers" or "identifiers." Passers have had a hidden disability and could pass for normal. Minimizers coped by using a form of denial or the minimization of their obvious physical disability. Identifiers could not hide their disability and tended to more fully identify with it. One Midwestern woman revealed, "Being a passer has been another whole disability in itself...trying to explain to people why I can't do a certain thing...sometimes reluctant, embarrassed to ask for help. It would have been easier to be out of the closet." Two of them felt misunderstood and sometimes rejected or diminished by their post-polio support group peers in particular. One insightful study participant tearfully told the story of a support group member who used a wheelchair full time that protested that she be voted as group's "wise elder" for this study. Had she possibly endured as much as the other who had a severe disability?

## **Reconciling Losses**

One hundred percent of the sample expressed that adapting to losses has been a major life challenge, beginning with the first termination of normal physical functioning at polio onset. The average age of polio onset for the group was eight years. Most of the group (73%) had dealt with the loss of normal functioning to varying degrees since childhood, with acute polio onset time ranging from 10 months old to 12 years of age. Three participants acquired polio as teenagers; one contracted polio as a 23-year old adult. Loss of both function and the appearance of being an able-bodied ("normal") person in society precipitated personal struggles from childhood until retirement to achieve the highest possible levels of functioning—physically, educationally, vocationally, and socially. Ninety-three percent of this group had obtained a college education.

All, but one who had a lifelong severe disability, had been gainfully employed until retirement age, which for this group averaged 58, about four years earlier than the norm. Accepting early polio-related losses was difficult, and for some is still ongoing. One woman shared that she is just now dealing with her original polio losses: “I—it brings me back to seeing all those children in the ward that wouldn’t walk again. And I’ve never dealt with those images. [Sobs] Terrible!” By contrast, another man said that he sees his disability now as simply “a speed bump (or pothole) on life’s highway.”

Everyone in the sample was dealing with mid to later life losses that were both physical and social. The entire group reported having the late effects of polio. One hundred percent reported new weakness, 73% new pain, and 80% new disabling fatigue in recent years. All but one participant was experiencing at least one late-life co-morbidity; with the group mean at about three diagnoses per person. The most common co-morbidity was vascular in nature and included high blood pressure, edema, high cholesterol, and/or circulatory problems. One woman shares how losing her accustomed level of mobility was difficult: “I had to give up. I couldn’t defy nature anymore. It was harder than (after) the first battle with polio.” A combination of shame, grief, and relief was expressed at having to use new assistive and mobility devices. Several people specifically mentioned that they missed not being able to travel and cook as much as previously. Several individuals believed that in general their options decreased with age.

The other losses that key participants described as difficult to reconcile were social losses. It was the painful descriptions of social losses during the interviews that generated the most tears. One man was still grappling with the knowledge that his first wife divorced him partially because he contracted polio, which resulted in physical deformity as a young husband:

Well, my wife and I stayed married for about eight or nine years after I had polio. Things were working out pretty good but she—she would complain about the appearance of my body because of the atrophy in my shoulders and I was still able to do darn near everything and—but she had complained about—about my body a little bit so I’m sure it made a difference... It was a really devastating blow to me.

Additional social losses included the death of a spouse and/or friends, moving to new locations and leaving old friends and family members behind, and retiring from jobs. A few individuals mentioned struggling with financial losses after retirement.

### **Changing Perceptions of Life with a Disability**

*Research Question 2: Have polio mentors’ perceptions of life with a disability changed over time? If yes, how? If no, what perceptions have endured over time? What types and patterns of personal discovery have polio mentors made?*

## Early Perceptions

Over time, perception of life with a disability from polio changed for this group. Before needing to struggle with the late effects of polio, which typically occurred at mid-life, individuals operated and worked hard using their “lens of difference,” a self-perception that rejected the shame and prevalent negative social stigma of disability. There was a need to battle the negative often-repulsive social stigma of disability in the late 20<sup>th</sup> century. None wanted to “be a cripple,” so they perceived themselves as being different, not disabled. For this, high achievement was crucial and hard work was commanded. One man responded that life with polio could make a person “damn tough.” Their parents told them they could do almost anything that anyone else could do. One man who used crutches and braces when he was a youngster said that he really did not have a disability then because it did not interfere with his life. He relayed that because he uses a wheelchair now, he does have a disability...“yeah, well, naturally, if you use a wheelchair, there must be something wrong with you, right? If you don’t use a wheelchair, you don’t. Crutches don’t count.” One woman said she never thought of herself as disabled in her youth... “I was in such denial!” Another man in his formative years, felt held back because of polio because he never dated or felt accepted. But he relayed that he never considered himself handicapped, just a little bit different.

Like many, this group experienced major life turning points that affected their self-perception at various defining moments along the life course. These included times when they left home; went off to college; got jobs; changed jobs; experienced success beyond their expectations, such as worldwide travel; got married; had children; got divorced; contracted the late effects of polio; experienced the death of a spouse; developed a new co-morbidity; retired. Some referred to leaving home for the first time to go to college as a time to reinvent themselves to become more gregarious and socially self-assured. Several shared appreciation for adult mentors who helped shape their adult successes. One man described a spiritual experience that served as a crossroad for greater self-acceptance as a 20-year old man who had a visible disability when he prayed for a miracle cure asking to be completely healed, at a huge Canadian cathedral:

I had the attitude that...a miracle was going to happen to me and I got there and there was no service going on at the time. It was just an enormous cathedral with people sitting here and there on the seats and my friends sat with me and I started crying. [Sobs] I thought, oh, boy! People from nearby would see us...and would bring tissues to me. [Laughter] ...(The) miracle would happen, which I experienced later... or recognized later... *I accepted what was.*

## Late Life Perceptions

Having to deal with the late effects of polio and entering into their retirement status seemed to be the two major turning points in self-perception for most of these wise elders. First, about 30 years after their original struggle with the effects of acute polio, they were forced to deal with often debilitating new pain, weakness and fatigue, which the unexpected late effects

brought about. As a man from the far west expressed with amusement, “my 30-year warranty ran out!” One participant explained, “polio and other issues were not intertwined until post-polio issues emerged.” It was a new; yet unwelcome opportunity to look at themselves in functional decline and experiencing greater disability. This began for most in the early 1980s when American society was also beginning to see disability with a revised point of view. Additionally, one woman explained, that she has now learned that as a disabled woman, thanks to the women’s rights movement, social biases toward women have lifted and she can do more than she thought she could and what society told her in the 1950s and 60s. She added, “Like me, later in life, every polio survivor must come to a ‘moment of awareness’ that there is a new disability-related problem. The late effects of polio and new disability prompt a modification in thinking and confronting new issues in an ongoing way.” Another wise elder further explained that she has “moved from denial to the acceptance mode in the past 20 years.” Another woman exclaimed that it is important to “be who you really are.” She has finally given up trying to hide her disability and in turn, become an outspoken disability rights advocate in her community.

Many of the wise elders agreed that, in spite of new functional losses, life is somehow better now, than when they were younger and physically stronger. Perceptions have changed. There seems to be a new freedom that an evolved perception of disability and not being in the workforce both bring. When asked for a word or phrase that describes life for them now, their responses included:

- Comfortable
- Flourishing
- Grateful
- Excellent
- Open
- Wonderful, full, happy
- Satisfying, good
- Hopeful--filled with a sense of anticipation
- Good, fulfilling
- Better than expected--like a dream come true

One man revealed that he enjoyed flirting with women in grocery stores. He said “being older with a disability can give one license to ask for help and hugs...I’m an old guy and everybody thinks I’m not dangerous!” Another woman confessed, “I know deep down I’m a cripple and to be crippled doesn’t mean you are worthless.” A woman from the east coast shared that getting older doesn’t always mean getting worse. A new flexible schedule in retirement offers her the freedom to do what she wants, like browse for a long time in bookstores, even though financially life is a little more restrained. Several people shared that their perceptions of others who have a disability have changed in late life, due to their own greater self-acceptance—they are more compassionate and caring toward others than in their more competitive earlier years, when they had to “push, push, push--use it or lose it.”

## Valuable Coping Attitudes

*Research Question 3: What attitudes do polio mentors view as most valuable for coping well with new issues into late life? How do these attitudes differ from past ways of thinking?*

*Coping* denotes goal-directed behavior in response to a situation that is perceived as threatening, harmful or challenging.<sup>17</sup> Coping with polio has become a two-part process for survivors: dealing with the acute phase of polio and then, years later, dealing with the post-polio phase, which often involves a different repertoire of coping strategies than those used during the acute phase of illness.<sup>16</sup> This adaptation process involves frequent re-adaptation along the life course trajectory and often requires returning to rehabilitation after 20-40 years of physical stability.<sup>18</sup>

Coping strategies reflected in both the scientific and the consumer literature generally can be organized into four primary categories: social support focused, meaning-focused, problem-focused and emotion-focused.<sup>17</sup> Polio survivors in this study used all four of these strategies, with the most frequent being social support focused and emotion focused. Participating in support groups is an example of social support focused. Post-polio support groups have also aided with the process of information seeking, then considering and selecting alternatives for disability management, which is an example of problem-focused coping. Growing out of the 1980's post-polio sociopolitical movement, support groups have provided many polio survivors with reliable information and emotional encouragement in the face of new late effects in mid-life. For some, they have also been a way to rebuild a meaningful polio community they experienced in childhood rehabilitation centers like the one established by Franklin D. Roosevelt in Warm Springs, Georgia.<sup>19</sup> Meaning-focused attempts to cope involve finding significance and value in life events through a higher power or in the larger scheme of things. Prayer, drawing strength from adversity, going to church, and finding new faith are examples of this. Cited in the literature and once again in this new research report, common emotion-focused coping techniques polio survivors have used are positive reappraisal and finding humor in life.<sup>17</sup>

The polio mentors in this study were asked questions to elucidate how they cope now and have coped in the past. Sample questions included:

- How do you cope with the process of growing older? What do you recommend others do to cope well in later life if they are a person with a long-held disability?
- What were some of the biggest issues or dilemmas you have had to deal with since life with polio began? What did you do?
- What attitudes and values have served you well through life?

From this group of wise elders several coping strategies emerged as being most helpful. These included having a strong social support system, enjoying life, being optimistic, self-acceptance, assertiveness, education and spirituality. The most frequent answer was that it is important to build and nurture a *support network of friends, family and the community in general*. This was cited as indispensable to them both in the past and now. Adult mentors were essential in early life to guide the way as role models. One man described a group of young childhood friends who would pull him to school on a sled in the snow because he could not walk.

In late life important relationships included: an understanding spouse, children and grandchildren. Friends and siblings were especially important for single people. One woman said that she would advise making friends of all ages early in life “so you don’t run out in old age.” A woman in the South emphasized that it’s important to know who to call in a crisis. All of these elders were active post-polio support group members, which they found very satisfying.

They also emphasized that late in life it is very important to *enjoy life* and have fun. After working very hard earlier in life to achieve, retirement emerged as a time to simply enjoy life more. One man said, “when in doubt, go out for pizza!” Employing a sense of humor also was designated to be important for coping well. “Laugh at yourself a lot; become a fun-loving mentor,” one recommended. “Take your scooter and be where you want to be—never feel like you are in the way,” one elder directed. An attractive former college English professor and now a prize winning gardener and public speaker went on to say, “If you are paralyzed by polio, don’t be doubly paralyzed by life!”

Every study participant emphasized the importance of having a *positive attitude*. Many believed that being optimistic got them through life and continues to do so. Two believed that they were born with a genetic leaning toward optimism. Another reflected that her original rehabilitation experience had encouraged an attitude of hope. Feeling self-pity was not an option during childhood rehabilitation and was ill advised for late life. Comments noted were: “make the best of things”, “stay upbeat about life”, “dwell on the good memories in life”, “focus on life’s beauties that you appreciate.” Conversely, they warned against the negative: “don’t dwell on the negative”, “don’t hang around negative people”, and “don’t get stuck in depression and complaining.”

Fully *accepting life and one’s self* was another coping strategy that has been adopted by the wise elders. “Be real,” and “don’t do denial,” and “accept new limitations” was expressed in a variety of ways: “I say do what you can and that’s it. I have to accept what I can do and know what I cannot do”; “It’s much better to set your own parameters than for someone else to do it”; “Take the message from ‘The Gambler’ song.” Accepting both early and new disability-related physical/medical characteristics was deemed to be foremost in importance.

Being persistently *assertive* in the health care system, the community and at home to make appropriate adaptations was another coping strategy that was also highlighted as important for late life success. They repeated in a variety of ways that it is important to be empowered to go after what one wants and needs and not be afraid to ask for help. One woman qualified how to seek assistance—“in the community, I don’t demand, but I ask for help.” Living well still takes “a lot of drive and vision,” one woman commented. Taking the initiative to plan for accessible housing, transportation, financial comfort was cited as important also. Making adaptations also involved maintaining a flexible attitude—to be able to “go with the flow.” One woman shared “As rigid as I am, I am also flexible—there’s a balance between stability at home and making adjustments!”

As when they were growing up, *education* reigned high on the wise elders’ list of important coping strategies in order to adapt to later life with a disability. They were told as

children to use their minds to compensate for weaker bodies and many did. One man shared a story illuminating the role of reading for him when he was a child with polio:

...When I was in Children's Hospital, I learned to read and I grew up about a mile or two miles from the town and my mother used to go in town to the library and bring home books for me. I read the whole children's section in one winter and one day she came back, she says, "Well, the library guy says you've read all the children's books [Laughter] and he'll have to give you the regular books now." I said, "Okay."

One woman, who was constructing a family history book, believes that "wisdom itself is the ability to learn and to benefit from that learning-- to move ahead then and to grow out of each learning experience." "Learn! Go see things! Learn and know about your disability!" they conveyed.

Developing and building upon a *spiritual center* was another coping strategy used by many, but not mentioned by all of this study's key participants. Of the 13 who did cite the value of a spiritual life, seven were religious and active in places of worship while six autonomously looked to a higher power for moral guidance, often through prayer. Of his uncertain spiritual outlook, one elder shared,

I classify myself as a Christian agnostic with no belief in a supreme being but an understanding that Christ said, "love one another." I think that is all that is needed. On the other hand my devoutly religious friend keeps telling me I'm a very spiritual person. Go figure.

In contrast, another woman who became a devout and religiously active Christian in childhood and remains so today, was so connected to the power and joy of her enduring spiritual life that she did her doctoral thesis on the role of power and spirituality in polio survivors.

Another man expressed how he felt blessed throughout his life:

When I really tried to find something or buy something and I couldn't find it then out of the clear blue sky, I get an offer to buy my house or I get something ten times better than what I was looking for! And that's happened again and again and I don't know what's responsible for it, whether it's my guardian angel or a higher power or whatever you want to call it, but it doesn't happen by accident. That I'm convinced of.

### **Definition of "Successful Adaptation" in Late Life**

*Research Question 4: How do polio mentors define "successful adaptation" in late life for a polio survivor?*

A successful late life was described in close connection to the coping strategies explained above. According to the wise elders, self-acceptance and adaptation, having the right resources, and being surrounded by loved ones make for a successful late life. First it requires being

realistic and flexible. One must continuously and realistically accept oneself with a physical disability and one must manage new limitations, especially physical limitations related to post-polio decline. Participants shared: it is “realizing that as time goes on, your situation may go downhill more...and knowing that when that time comes, you’ll have to accept and adapt to that”; “...understanding new limitations and re-establishing roles that work.”

Successful adaptation also means having appropriate resources to support an acceptable quality of life. This includes having planned for retirement needs. Financial security was cited as a critical requisite for a good life after 65. One must have enough money to live on. Having the means and foresight to have convenient and accessible transportation and a home that is accessible were also considered to be very important. They said it is also important to have reliable communication tools (like computers), and the insurance needed to purchase medical care and medical equipment. Being able to pay for functional help to address personal and household care was another important sign of having adapted well to late life needs. Adequate resources can support one’s lifestyle freedom and opportunities to travel and further enjoy chosen leisure pursuits. One man declared that a good late life means, “having what you want when you want it.” He goes on to reveal of his life now:

In 80 years, I’ve seen a lot and if I think back, you know, and sometimes when I drive in the car and I see the palm trees, especially at night, you know... when your mind kind of wanders... I think back when I was a kid, (when) I didn’t have braces (yet). I was just crawling on the floor. And (now) here I am, not a worry in the world, driving a luxury car in the tropics. And if somebody would have told me that at that time, I would have said, “Man, you are crazy! You are absolutely crazy!” Yeah! Well—if that isn’t something, it’s—it’s like a dream.

Being surrounded by friends and loved ones was another key ingredient for happiness in late life. They found great comfort in good relationships with spouses and other family members, including grandchildren, yet some were distressed when their relationships were inadequate or filled with conflict. Several warned that it is important to surround oneself with happy, positive people whenever possible. Many felt it was important to contribute to society in some way, to be a positive force helping others by way of social connections and organizations.

## **Discussion**

This investigation explored successful late life adaptation in a small sample of 15 elder polio survivors. By using a combination of methodologies, both quantitative and qualitative, the researcher was able to begin to better comprehend the late life physical, social and environmental adaptation experience of older polio survivors. The identification of life-long “survival tactics” that are effective over time promise to better enable rehabilitation professionals to use these study findings to provide a variety of late life management advice and support to patients who are growing old with polio and similar chronic conditions. By examining participants’ definition



of success in late life, their self-perceptions, and coping strategies over time, several factors emerged as keys to late life success. What lessons did these polio survivors teach us?

Successful late life adaptation was commonly defined as an outgrowth of self-acceptance and adaptation, having the right resources, and being surrounded by loved ones. These guidelines were built upon earlier life lessons that were revised for success in later life.

Over the lifespan, this group's perception of living with a disability from polio had changed. The years with polio during childhood, adolescence and as an adult were not comfortable. Before encountering the late effects of polio at mid-life, individuals operated and worked very hard using their "lens of difference," a self-perception that rejected the shame and powerful social stigma of disability. High achievement was crucial. Later in life, due to changing societal attitudes and new public policy, and out of practical necessity, this group became more willing to look at their lives through the "lens of disability," more fully embracing their disability as part of their overall personal identity. Once retired, there was no longer, for example, a need to prove oneself in the mainstream workplace and keep up with non-disabled competitors. These polio mentors seem to have found a new freedom to make further disability-related adaptations and be more content with who they really were becoming, and what they needed to do to live well during retirement years. Ironically, growing older with greater disability has offered this group a fresh sense of not only comfort, but also liberation. In many important ways, life was reported as better in old age than it ever was in youth.

Looking back, the major issues for these particular polio survivors throughout life included achieving and maintaining independence, which required diligent effort; fighting shame in order to create a positive self-image with a disability; and reconciling social and functional losses. It is interesting to note that all of these peer-group selected wise elders were living independently in their own homes. Two had never married. One third of the group lived alone. Perhaps polio survivors still especially esteem the value of independence as a group, which could have been stressed as part of their original polio rehabilitation as children. It appears that these polio mentors had been able to maintain this long-held value by pragmatically re-learning that independence can mean a new interdependence and that asking for functional help at home is acceptable.

For the three "passers" in the sample, very intense feelings of not being understood by their disabled and non-disabled peer group as they struggled with greater disability were expressed in terms of loneliness, confusion and anger. To address these issues, additional focused research to investigate the specific late life plight of post-polio passers and the anger of being misunderstood for many years should be considered. For the twelve remaining elders with moderate to severe levels of disability, fighting the humiliation that new functional losses brought on in later life was an old battle that, although difficult, seemed a bit easier to wage than it was during childhood and in adolescent years. The shame and guilt associated with disability still existed but did not strongly govern behavior for so long. This may be because they found themselves not so alone—now being joined by their previously non-disabled peers in later life—for whom they could even provide some helpful counsel on how to adapt gracefully. It may also be because they have been allowed by society and their less demanding retirement lifestyle to let

go of outdated negative perceptions about being a “cripple”, which not only many have done, but also wholeheartedly advise to other aging polio survivors.

Another major issue throughout the life course was having to deal with the grief that early functional loss from polio brought on, as well as other losses wrought by normal life events. Divorce and bereavement of friends and loved ones were paramount sources of sadness. It seemed that some late life losses, especially dealing with new disablement due to the late effects of polio, spurred memories of early times in the hospitals with acute polio, which may have never been fully resolved. It remains unclear which of this group’s grief responses were based on life experiences with polio verses the typical process of aging that is common in the general population.

Key past and current coping strategies included having a strong social support system, enjoying life, being optimistic, coming to and possessing greater self-acceptance, demonstrating assertiveness, using education and relying on some form of spirituality. The most recent strategies employed by this group were enjoying life and embracing fuller self-acceptance. Many of these polio survivors had not had enough time or energy to enjoy leisure pursuits when they were working to earn a living and raise a family on top of the burden of a physical disability, so now, in their retirement years they seemed to be making up for lost time. *Carpe diem*, had become the new, highly valued mantra to help deal with life’s challenges. Additionally, greater self-acceptance had allowed a coming to wholeness of mind, body and spirit and offered a relaxed sense of personal peace, which in turn more quickly enabled elders to make new adaptations in late life.

This group, which was drawn from a national post-polio support group network, was selection-biased toward holding the value of a strong social support system from the start. As such, the group expounded upon the fact that supportive spouses, friends, grandchildren, and communities of people was critical for a healthy late life. They expressed deep-felt appreciation for those who loved, understood and supported them and worked conscientiously to keep those connections strong. Earlier in the life course, a vigorously influential social network whether positive or negative, shaped their working *zeitgeist*. This network included social and career mentors, teachers, parents, grandparents, and friends who were described as either critical to their success or were criticized as barriers that they had to overcome or cognitively reconstruct in their minds if they wanted to move forward in life.

Along with social networking, optimism was cited very frequently and intensely as crucial to success throughout the years. Life would not have worked without the “power of positive thinking.” People also emphasized that appropriate assertiveness skills are important tools to use for coping. One must be able to go after what one needs and wants in late life. The power of education was also a lifelong valued coping tool for this group, which was originally learned from parents and mentors early in life and promoted throughout life. Learning and achieving an education was physically possible. Knowledge became a necessary source of power in the midst of physical weakness. Finally, developing a spiritual core worked very well for almost all of these elders. As has been discussed in the literature, spirituality can help one transcend the limitations of physical disability and increase a sense of self-worth. It can also provide a sense of meaning and purpose in life. A religious life can additionally offer

opportunities for sense of belonging to a group of believers whose focus is not on physical prowess and strength.

Qualitative studies such as this one are conducted to lay the groundwork for future larger studies of the population. Upon reflection, several further recommendations emerge for forthcoming research on this topic of late life adaptation among people with chronic neuromuscular disabilities.

Because of their growing numbers, it will be important to compare this group to samples of non-disabled peers as well as other same-age groups with similar neurological disabilities for example, from stroke, multiple sclerosis, diabetic peripheral neuropathy, or spinal cord injury. It will also be helpful to investigate what is unique to this population compared to those who are typically aging. This might begin with an examination of the work of George Valliant, the Harvard researcher who describes successful aging in his book, *Aging Well: Surprising Guideposts to a Happier Life from the Landmark Harvard Study of Adult Development* which casts a spotlight on the behaviors that make for happy longevity and those that result in illness and early death. His generalization about a non-disabled sample is that there are six factors at age 50 that have a great deal to do with whether one will get to age 80. The six are having a warm marriage, possessing adaptive or coping strategies, not smoking heavily, not abusing alcohol, getting ample exercise and not being overweight.

Further studies of exactly how this group learned to be fiercely optimistic could be helpful for building such hopefulness in people who have a similar disability in preparation for later life. What were the sources and taproots for their practice of positive thinking throughout life? Was it genetics, parents, and/or their rehabilitation experiences? Engaging specialists in Positive Psychology might be helpful in formulating new research questions and hypotheses. A review of the work of Martin Seligman, starting with his book, *Learned Optimism*, could provide a promising contextual foundation. In this book, he writes that the ability of some people to bounce back from apparent defeat is not necessarily a 'triumph of the human will'. Rather than having an inborn trait of greatness, such people have developed a way of explaining events that does not see defeat as permanent or affecting their basic value. Nor is this trait something that 'we either have or we don't'; optimism involves a set of skills, which can be learned.

This study's findings also suggest that interventions/workshops designed by centers for independent living in conjunction with rehabilitation psychologists and other educators should be developed and tested. These educational formats would teach healthy assertiveness that could lead to accompanying feelings of self-worth and self-confidence during retirement years "with" a progressive disability rather than "in spite of" such a disability and could be helpful to polio survivors who may be approaching their late life years with misgivings. A retirement planning course to include preparation for accessible housing and transportation, health care resources, personal care requirements, and financial goals would also be advised. The theme of this intervention might be "plan for the worst and hope for the best." The fine art of how to create an adequate working social network of family, friends and community contacts could be a whole course in itself. How does one build reciprocal social support networks that work for him/her? How does one most feasibly contribute to the community in later life with a disability? It may be

that many people with a disability do not know how to do this, which could be explored by rehabilitation researchers as a relevant topic for future assessment.

Its small number of cases limited this study. It was heartening to this researcher to have witnessed key participants' great enthusiasm to take part in this study, however this may have helped contribute to one known flaw in the sample selection process. One participant, the youngest, out of practical necessity, was selected for geographic convenience. She was contacted and immediately volunteered her participation without asking her group for the nomination, although another polio survivor in her geographic area had recommended her based on the criteria, to the investigator. As group leader, the participant believed her support group would have selected her to be their polio mentor for the study, which may or may not have been the case. Due to financial and logistical constraints for fieldwork, the P.I. did agree to interview her. As it turned out, although she had issues similar to other key participants, she was experiencing the stress connected with dealing with polio's late effects at the time of the interview. All other key participants had been through this transition earlier; therefore she is viewed by the investigator as an outlier in the data.

In spite of the study limitations, these lessons learned from polio mentors have begun to serve the post-polio community. Through a September 2007 presentation at the Michigan Polio Network's annual meeting, and resultant support group newsletter publications of the speech's condensation (see above), post-polio consumers are currently being provided with a set of suggested guidelines about ways to successfully adapt into late life with a chronic neuromuscular disability. With this first publication (see Appendix A), several support groups (Colorado, Michigan, and California) have informally reported that they have engaged in lively group discussions about their own successful adaptation into late life and what can still be done to improve their individual quality of life.

Beyond these articles, this Switzer Fellow is organizing to write a book in 2008 for publication on the lives and advice from the study's 15 "wise elders." Plans are underway to contact potential publishers: either Jean Thomson Black at Yale University Press or Jackie Wehmueller at Johns Hopkins University Press. These were recommended by one of this study's project advisors, Julie Silver, MD, Assistant Professor, Harvard Medical School who is a widely published medical author and Chief Editor of Books, Harvard Health Publications. This book, which hopes to provide pointers from the study's participants on successful late life adaptation strategies with a physical disability, would also promise to present insightful guidelines for "growing old gracefully" to readers who are aging into physical disabilities for the first time in late life.

## ***Part Two***

### **Pilot Sub-Study:**

### **Describing Polio Survivors in Terms of Wisdom**

#### **Abstract**

Some authorities say that wisdom, rather than intellectual knowledge is crucial for aging well<sup>48</sup>, yet understanding and applying the notion of wisdom in the area of personal growth and successful aging among people with disabilities has not been attempted until now. To complement the larger study, a sub-study to explore characteristics of wisdom in this group and their polio support group peers was conducted. The purpose of this concurrent pilot study was to begin to describe polio survivors in terms of their individual perceptions about wisdom as well as Monika Ardelt's concept of wisdom. Ardelt's notion of wisdom is defined in terms of three separate, but interconnected ways of dealing with life: cognitive (intellectual objectivity), reflective (comprehending differing perspectives) and affective (empathy and compassion). The study's objectives were to document how polio mentors personally describe wisdom and its current role in their lives, and to describe the difference between Ardelt's measured wisdom levels in polio mentors and their support group peers. The total N for this sub-study was 108. A mixed-methods approach was utilized: qualitative inquiry complemented with use of the Three-Dimensional Wisdom Scale (3D-WS), Ardelt's quantitative measure. The primary study's sample of 15 key participants was 1) asked several questions about wisdom and 2) to complete the 3D-WS. After being invited by the groups' leaders, 11 of the 15 key participants' support groups volunteered to complete the 3D-WS, resulting in 93 responses. Qualitative analysis was performed using the constant comparative method. Quantitative data were analyzed using one-sample and independent samples t-tests to compare all elders to all support group members.

#### **Key Findings:**

- Key participants defined wisdom as a combination of education and knowledge, the ability to see situations from another's point of view, and the ability to actively help, listen and share with others. The role of wisdom in their lives was described as being directly related to actively assisting their post-polio peer group.
- As a group, key participants scored significantly higher than support group members on the wisdom scale in the area of reflective wisdom only.

## Introduction

Some experts say that wisdom, rather than intellectual knowledge is crucial for aging well<sup>48</sup>, yet understanding and applying the notion of wisdom in the area of personal growth and successful aging among people with disabilities has not been attempted. It may be that wisdom is a characteristic that could eventually be taught by rehabilitation professionals to their patients in order to enhance the life-long adaptation processes, much like other coping strategies. Even though *spirituality* and *expanding life philosophies* have been cited by Kalpakjian<sup>17</sup> as coping strategies utilized by polio survivors, there have been no studies of the similar construct of wisdom as defined by Monika Ardelt, in this population.

Wisdom has been defined by a variety of scholars as a concept that includes the following attributes: reflective ability, an integration of emotional and logical thought, life planning and decision making, the understanding of ambiguity and obstacles, problem-*finding* ability and extraordinary understanding.<sup>49 50 51</sup> Historically, the concept of wisdom has been viewed by the scientific community as not easily definable, accessible or observable, and therefore unsuitable for scientific research. This has kept wisdom as a fringe topic in research until recently.<sup>52</sup>

During the past seven years, Monika Ardelt, Ph.D., Department of Sociology, University of Florida, developed and tested a structured questionnaire, The Three-Dimensional Wisdom Scale (3D-WS), which is now considered to be a reliable and valid instrument and a promising measure of the latent variable, wisdom, in large standardized surveys of elder populations.<sup>53</sup> In developing the instrument, Ardelt was interested in creating a measure to understand better how some older people are able to deal with adversity and bounce back emotionally while others cannot. She has noted “successfully coping with crises and hardships in life might not only be a hallmark of wise individuals but also one of the pathways to wisdom.”<sup>56</sup> (See Appendix C.)

According to Ardelt, the definition of wisdom can be summed up in the well-known Serenity Prayer:

*“God grant me the serenity to accept the things I cannot change; the courage to change the things I can; and the wisdom to know the difference.”<sup>54</sup>*

Ardelt more specifically defines wisdom as a combination of cognitive, reflective and affective qualities. First, wisdom pertains to knowledge in the complexities and uncertainties of life and involves the ability to see reality objectively (i.e., cognitive). Second, wisdom involves comprehending the deeper meaning of generally known facts from different perspectives, rather than simply reacting to events (i.e., reflective). Third, reflective thinking and a diminished ego-centeredness lead to a deeper understanding of the contradictions and imperfections in human nature and can make a person more caring, empathetic and compassionate toward others (i.e., affective). Table 2 below further describes Ardelt’s three dimensions of wisdom related to the wisdom scale she has created.

Table 2. Definition and Operationalization of Wisdom as a Three-Dimensional Personality Characteristic<sup>57</sup>

Dimension	Definition	Operationalization
Cognitive	A deep and clear understanding of life and a desire to know the truth, that is, to comprehend the significance and deeper meaning of phenomena and events, particularly with regard to intrapersonal and interpersonal matters. Includes knowledge and acceptance of the positive and negative aspects of human nature, of the inherent limits of knowledge and of life's unpredictability and uncertainties.	Scale items and ratings assess: <ul style="list-style-type: none"> <li>the ability and willingness to understand a situation or phenomenon thoroughly</li> <li>knowledge of the positive and negative aspects of human nature</li> <li>acknowledgement of ambiguity and uncertainty in life</li> <li>the ability to make important decisions despite life's unpredictability and uncertainties</li> </ul>
Reflective	A perception of phenomena and events from multiple perspectives. Requires self-examination, self-awareness, and self-insight.	Scale items and ratings assess: <ul style="list-style-type: none"> <li>the ability and willingness to look at phenomena and events from different perspectives</li> <li>the absence of subjectivity and projections (that is, the tendency to blame other people or circumstances for one's own situation or feelings.)</li> </ul>
Affective	Sympathetic and compassionate love for others.	Scale items and ratings assess: <ul style="list-style-type: none"> <li>the presence of positive emotions and behavior toward others</li> <li>the absence of indifferent or negative emotions and behavior toward others.</li> </ul>

**The purpose of this concurrent pilot study was to begin to describe polio survivors in terms of Ardelt's concept of wisdom.** The study's objectives were to document how polio mentors, sometimes casually referred to as "wise elders" in their "polio tribe," describe wisdom and its current role in their lives, and to describe the difference between measured wisdom levels in polio mentors and their support group peers.

## Methods

### Sample Selection

This sample included the 15 elders and 93 support group members. The original methodology included PI attendance at a support group meeting while on location interviewing the group's polio mentor, and administering the 3D-WS to the members of the support group. It

was found, however, to be more practical for every group that participated to either complete the questionnaires individually or together at a later meeting, mailing them back to project headquarters. Hence, at the time of our interviews, copies of the measures were provided for support group distribution.

### **Data Sources**

To achieve sub-study objectives, a mixed-methods approach was used. Open-ended questions (such as “What does wisdom mean to you and what role has wisdom played in your life?”) were included in the primary study’s semi-structured interview with key participants. To test the hypothesis for the quantitative portion of this sub-study that **polio mentors will score higher on the 3D-WS than their peer group counterparts (both support group leaders and general members)** and to validate the peer group designation of these credible senior role models, both polio mentors and their support group members completed the 39-item 3D-WS. Subjects were asked to rate the level of importance on the first fifteen items and level of agreement on the second 24 items. A mean overall score between 4 and 5 indicates relatively high wisdom; between 3 and 4, a comparatively moderate level of wisdom; below 3, relatively low levels of wisdom. At or after a meeting, support group members in 11 of the 15-targeted groups completed the wisdom measure, which was return-mailed to study headquarters for analysis. (See Appendix B for the 3D-WS.)

### **Data Analysis**

Qualitative analysis for this sub-study was conducted by identifying, examining, sorting and comparing answers to open-ended questions in the semi-structured interview guide regarding wisdom and its role in participants’ lives. To address the hypothesis of this sub-study, one-sample and independent samples t-tests were used to compare all elders to all support group members.

## **Results**

### **Section A: Qualitative Findings**

#### **1. Defined Concept of Wisdom**

*Research Question 1: How do polio mentors define the concept of wisdom and the role it plays in their lives?*

To answer this research question, 13 of 15 participants were asked some or all of the following questions:

1. How would you define the concept of “wisdom?”
2. Is there anyone in the past or present public world whom you think is wise?
3. What are the characteristics of a wise person, in your view?



4. Do you have ideas about how a person becomes wise?
5. Do you think other people see you as a person with some wisdom? If yes, can you describe your own kind of wisdom? What is it that other people see? What kinds of things do people ask you for advice about?

## The Definition of Wisdom

Key participants defined wisdom as a combination of education and knowledge, the ability to see situations from another's point of view, and the ability to actively help, listen and share with others. They also used the term "common sense" quite often as they defined wisdom. Although the majority of key participants agreed on several basic characteristics of wisdom, there were conflicting opinions on how wisdom is acquired. A small minority believed that wisdom is either inherent at birth or a trait that cannot be developed, however, most agreed that wisdom is a characteristic that can be learned, especially from long life experience. As one respondent expressed, "Wisdom comes from actually living and experiencing things and also from people whom you take the time to talk to and get to know--who've lived a lot of life; people you respect." Further, wisdom involves action. It can be an iterative process of exchange between people that involves sharing ideas with others non-judgmentally, listening and finally, making firm decisions. One man expressed his need to actively share this way: "If we were to learn a (painful) lesson and don't share it and we die, it's a waste; it's a loss. It stopped with us. If we can convey it to other people so they can ...find shortcuts...the pain was well worth it."

Upon close examination, these elders unknowingly described wisdom in terms of Ardelt's three-dimensional definition. One participant when asked, "What is wisdom", immediately recited the Serenity Prayer (independently referred to by Ardelt in her articles) and further remarked, "a wise person sees the big picture." In terms of Ardelt's cognitive aspect of wisdom, elders commented that wisdom requires education: "academic knowledge," "the ability to learn" and "learning from past experience." One woman said, "wisdom comes from knowledge that you have gained through life experiences; your understanding of people and situations." Ardelt's reflective characteristic was most evident as participants' definitions of wisdom emerged. More than 50% said that one must see a situation from multiple perspectives. It is "looking at a broader spectrum of life, not just my narrow viewpoint...so that I have understanding of other people's kind of living, other people's illnesses, and other people's income level." Less than half of the respondents highlighted the affective aspect of wisdom. They commented that they try to empathize with others and that a wise person is "somebody that can laugh with you, that can be with you as a person of understanding." One man with a severe lifelong disability from polio articulated, "My wisdom is in choosing to be positive. I say you have choices. That doesn't mean everything's going to be good, but it's how you face the problems." The group additionally commented that wisdom involves using rational and practical or "common sense" approaches to problem solving.

## **The Role of Wisdom**

The wisdom they employed was described mainly in terms of a post-polio framework. They understood that they were viewed by their post-polio support groups to be wise because they were knowledgeable about post-polio issues and adjustment processes, but did not necessarily believe that they were wise in a more global sense. Hence, the role of wisdom in their life was described as being directly related to actively assisting their post-polio peer group. It is interesting to note that none of the key participants were sure that they clearly met their requirements of being “wise ” in an all-encompassing sense, but they did understand and agree that they had their own individual kind of wisdom, especially within their support groups and were willing to listen to others to try to help. One woman said, “I am not really a person of wisdom. I do what I can and do what I have to do.” Another explained, “My own wisdom is from things that I’ve experienced, places I’ve been, people I’ve known, things I’ve done.” They believed that their support groups designated them to be their “wise elders” in terms of their currently successful adjustments to disability, their knowledge about the late effects of polio including management strategies and their willingness to help group members. One woman shared of her group, “I think they view me as a stable kind of person. I’m there. I think they know they can use me.”

## **Section B: Quantitative Findings**

### **Measured Wisdom: Polio Mentors Versus Support Group Peers**

Eleven of the 15 support groups responded to the invitation to participate in the study, resulting in a total group n of 93. The support group return rate on the 3D-WS ranged from 13 questionnaires from a midwestern group to two from an east coast group. Submitted instruments were scored and entered into the study’s main database.

*Hypothesis: Polio mentors will score higher on the 3D-WS than their peer group counterparts (both support group leaders and general members).*

The study’s hypothesis was partially supported. Overall, there was not a significant difference between elders and their group on wisdom, except for the reflective dimension of wisdom. Independent samples t-tests were used to compare all elders to all group members on the total wisdom and subscale scores. As shown in Table 3, with Bonferroni correction to adjust for the chance of Type I error, elders scored statistically significantly higher only on reflective wisdom dimension compared to support group members. There were no significant group differences on cognitive, affective or total wisdom scores. This finding suggests that overall, support groups did indeed identify polio mentors who may demonstrate greater characteristics of reflective wisdom, (which indicates the ability to examine an event from multiple perspectives—to step outside oneself and understand another point of view), but not always so. It is expected that if the sample were larger, more differences would be found.

Table 3. Comparison of Total Wisdom and Wisdom subscales between Elders (N = 15) and Support Group Members (N = 93)

<i>Wisdom</i>	<i>Elders Mean* (SD)</i>	<i>Norms Mean* (SD)</i>	<i>t</i>	<i>p<sup>†</sup></i>
Total Wisdom	3.9122 .29729	3.6626 .3702	-2.482	.015
Cognitive Wisdom	3.9652 .49854	3.6449 .53366	-2.176	.032
Affective Wisdom	3.6718 .40020	3.6613 .41841	-.091	.928
Reflective Wisdom	4.0995 .33245	3.6816 .44930	-3.448	.001

\* Mean of the mean scores

† Bonferroni correction, significant  $p \leq 0.0125$

It is also interesting to note that seven of the 15 wise elders scored in the relatively high wisdom category (which is good for the scale). The remaining eight are in the moderate wisdom category. None were in the low wisdom category. Being a wise elder is positively related to the cognitive ( $r = .21$ ) and reflective ( $r = .32$ ) dimensions of wisdom, but surprisingly not to the affective dimension of wisdom. The affective dimension of wisdom also had a very low reliability, which suggests that the measure does not work very well for this population. The reliability of the cognitive and reflective dimensions was fine. Surprisingly, the affective dimension of wisdom is correlated negatively (although not significantly due to the small number of cases) with life satisfaction. Tables 4 and 5 below show the average scores in rank order of key participants on the 3D-WS (highest possible score would be 5) and Life Satisfaction Scales (highest possible score would be 7).

Table 4. Elders' Relatively High Wisdom Scores with Life Satisfaction Scores, in Rank Order

Elder ID	Total Wisdom Score	Cognitive Dimension	Reflective Dimension	Affective Dimension	Life Satisfaction
6	4.55	4.57	4.92	4.15	5.80
5	4.29	4.64	4.08	4.15	4.80
10	4.12	4.50	4.17	3.69	7.00
9	4.10	4.29	4.25	3.77	3.60
15	4.09	4.43	4.08	3.77	6.60
13	4.08	4.07	4.17	4.00	5.8
11	4.00	4.07	4.17	3.77	7.00

Table 5. Elders’ Relatively Moderate Wisdom Scores with Life Satisfaction Scores, in Rank Order

Elder ID	Total Wisdom Score	Cognitive Dimension	Reflective Dimension	Affective Dimension	Life Satisfaction
3	3.94	3.50	4.00	4.31	4.40
8	3.78	3.69	4.33	3.31	6.40
2	3.67	3.93	4.08	3.00	7.00
7	3.65	3.00	4.33	3.62	5.60
12	3.64	3.71	3.91	3.31	4.80
14	3.64	3.14	3.92	3.85	5.40
4	3.62	4.14	3.42	3.31	5.40
1	3.51	3.79	3.67	3.08	4.60

## Discussion

This sub-study represents an introductory exploration of wisdom as defined by Monika Ardelt relative to a small sample of 108 elder polio survivors. By using a combination of methodologies, both quantitative and qualitative, the researcher was able to gain a greater understanding of the definition, role and dimensions of wisdom in this group.

Upon reflection, the basic conclusion of this pilot study might be summed up as one wise elder said, “my own wisdom is from things that I’ve experienced, places I’ve been, people I’ve known. Things I’ve done. That’s absolutely the way I see my wisdom.” This group’s wisdom is real, but unique. This elite group of 15 polio survivors has lived with a chronic disability for more than 50 years, adapting so well they have become elected as “adaptation role models” by their observing peer group. When reviewing this preliminary information, several patterns about their distinctive form of wisdom have emerged.

Key participants defined wisdom as a combination of education and knowledge, the ability to see situations from another’s point of view, and the ability to actively help, listen and share with others. The role of wisdom in their lives was described as being directly related to actively assisting their post-polio peer group, which would, of course, be different than that of a cross section of elders in the non-disabled population. These elders did not necessarily see themselves as wise among all men, but they humbly agreed that they did have some type of wisdom based on their unique life experience with polio. Their support groups, by way of this study, had just verified that distinction for them. They could help and advise others from that perspective. It should be noted that one limitation of this study was that there was no direct question asked to further discover how they actually saw themselves more globally in terms of wisdom. Did they feel that the combination of their polio and overall life experience had offered them a wisdom that matched the wisdom levels of society’s other wise people?

It is interesting to examine this group's unique form of wisdom based on the results of Ardel's quantifiable measure. As a cluster, key participants scored significantly higher than support group members on the wisdom scale in the area of reflective wisdom only. In terms of compassion (affective) or thinking/knowledge (cognitive) levels, the 15 did not score any higher than the rest of the support groups as a whole. This may say that the sample of wise elders was selected because they were perceived by their peer group as understanding and able to view life from the perspectives of others, specifically them. They were the individuals who could step outside of themselves and offer an objective point of view to those who needed them. It may be that their ability and willingness to look at phenomena and events from different perspectives may have actually been a key coping tactic that had to be developed over the years to compete and thrive in a non-disabled society. It has been deduced in various writings that any member of a minority group in a diverse society that is led by a privileged majority must study the ways of the majority in order to interact with them well and succeed. For example, although this is changing, black people in the American culture have said they needed to study and understand white people's ways if they were going to do well in a white-dominated society. So this is also likely to be true for those who are disabled in a non-disabled culture. In order to get what one needs to fit in, to become part of the mainstream, the disabled person must take the initiative to understand the dominant majority. (What is valued and important to that person? What does he want to achieve? What emphasis does he place on his and others' physical strength and prowess? How patient is he? How helpful is he? What does he need?) Perhaps it is only seldom that an able bodied person needs to, or chooses to understand the person who is disabled, at least at first meeting. It may be that at least for these selected polio survivors, the responsibility of understanding the other's perspective was well learned throughout life and then easily applied to support group members now in later life.

It is also worthy of note that as a group on the 3D-WS, being a post-polio wise elder is not positively related to the affective dimension of wisdom. Their lowest scores were in this area. Not only that, but the affective dimension of wisdom was correlated negatively (although not significantly due to the small number of cases) with life satisfaction. Hence this group's strong suit was not necessarily sympathetic and compassionate love for others. It may be that for this group, because of their life experience with disability, survival goals often had to trump compassion. Early on they learned that they had to work through the pain they may have felt physically through the years and rise above it. They had no time to feel sorry for themselves if they wanted to make it in society. They had to "use it or lose it" and press forward with persistence when they did not feel like it. At times this may have even seemed a bit self-abusive. Rehabilitation professionals and parents were tough on kids with polio because they were seen as having much weakness to overcome. Hence this study's subjects warned others about not associating with negative people too much. They would drag them down. Because they had to go beyond their own self-pity to overcome disability, they did not approve of self-pity in others and expressed low tolerance for "whiners." As one participant said, life with polio could make a person "damn tough." Of this Ardel comments, "I think avoiding "negative" people might be a good strategy for one's own well-being, but truly wise people are not affected by the negativity of others and, hence, are able to spend time with them and even help them to feel better. They can truly love the enemy." But does this reflect the practical real life wisdom of survivors of disabling diseases such as polio? It would be interesting to investigate whether excellent health lends itself better to extending greater compassion toward others than does disability. It may also

be that the wisest of the wise elders are the ones who revealed that their experience with disability is now, in later life, making them more compassionate toward others with a disability, because they have grown in greater self-acceptance with their own disability.

It is intriguing to consider how to apply the concept of wisdom to the rehabilitation process of people who have a disability. Could increased levels of wisdom lead to greater late life satisfaction? To overcome the major limitation of this pilot study, future studies in this area should involve investigations of Ardelt's "latent variable" in much larger groups of others who have similar chronic disabilities to check for further reliability of the 3D-WS and to profile these groups in terms of wisdom. The instrument may need to be adapted for disabled populations. Interventions could then be created and tested in populations of individuals who are growing older with a disability to increase their wisdom levels, which could in turn provide them with greater ability to share what they have learned with others and contribute in new ways in the midst of their own progressive late life functional losses. Is wisdom teachable? Ardelt states,

I think wisdom is teachable. Practicing mindfulness meditation (or anything that encourages self-reflection, self-awareness, self-examination, and self-insight) is probably a way to grow in wisdom because it strengthens the reflective dimension of wisdom, which I consider essential to develop the cognitive and affective dimensions of wisdom. (Participating in) autobiographical writing workshops that encourage self-reflection, etc. and the perception of events from multiple perspectives might also be a way to grow in wisdom.

Future plans to disseminate the results of this pilot sub-study include writing an article for consumer publications such as Post-Polio Health International's Newsletter. The P.I. may also pursue future studies in this area with Dr. Ardelt or a group of interested rehabilitation researchers as the potential of this new research and teaching topic becomes deliberated.

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