

Aging Among Women with Disabilities

Dissertation Proposal

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## **Chapter 1: Introduction**

“No matter how much I was admired by others or by myself, there was still much more I had to face. “My Polio” and “My Accident” were not just my past; they were part of my present and my future” (Zola, 1982, p.84).

There are 53.9 million Americans with a disability (Jans & Stoddard, 1999); 28.6 million are women and their numbers are increasing (Gerschick, 2000). The increase is partly due to a longer lifespan for persons with disabilities, which is most pronounced among those aging with a disability since childhood (Campbell & Barras, 1999; Campbell, Sheets & Strong, 1999). For example, the average life span has increased for the nearly 700,000 with cerebral palsy and the almost 1 million polio survivors (Campbell, 1998). Regretfully, their increased life span has been accompanied by health and social problems (Campbell; Harrison & Stuifbergen, 2001).

Women with disabilities experience high rates of poverty, negative stereotypes, high rates of institutionalization (G. Frank, 2000) and increased secondary conditions and co-morbidities with aging (Harrison & Stuifbergen, 2001). These problems are costly to the individual, the family and society. The health risks associated with aging with a disability have prompted the U.S. Department of Health and Human Services to include the removal of health disparities amongst people with disabilities as one of its 2010 goals, which follows the goal to remove the disparities associated with gender (U.S. DHHS, 2000).

The research available on aging and disability in women has focused primarily upon aging as a process of biological decline. There is little understanding of the

experience of aging for women who have had disabilities since childhood; despite evidence from nursing, gerontology, sociology and developmental psychology that aging has physical, psychological, social, and cultural components (Elder, 1994; Moen, Dempster-McClain, & Williams, 1992; Sarvimaki, & Stenbock-Hult, 2000). Women age in complex ways, therefore, it is time nursing expand current understanding of aging to include the experience of women with childhood onset disabilities.

When society develops an understanding of the experiences of aging for a group, health care treatment and policy decisions can be tailored appropriately (Torres-Gill, 1992). By understanding the experience of aging, resources that promote opportunities for a high quality of life can be developed to anticipate changes and support women over their life course. If researchers do not understand more than the biological decline, which may be inevitable, few culturally appropriate interventions can be designed that help women with disabilities with their daily lives. Moreover, by understanding the psychological, social and cultural, as well as physical demands, preventive steps can be taken that may reduce the problems women with disabilities experience.

### ***Study Purpose***

The purpose of this study is to explore the meaning of aging for women with childhood onset disabilities. A hermeneutic phenomenological approach will be used to guide this interview study of a group of women who survived paralytic polio in childhood and are aging into late adulthood. Due to the varied cultural and societal experiences throughout the history of the United States for women of varied ethnicities, Anglo, Latino

and African American women will all be interviewed for their experiences of aging with childhood onset disabilities. Moreover, because perceptions of gender influence awareness of the body and social status, gender will be explored as an influence on perceptions of age related changes and subsequent adjustment.

The specific aim is to produce a life course description of the meaning of aging developed from the experience of living with a disability since childhood in a cohort of women age 55 to 65 who survived paralytic polio. Specifically, the researcher will:

- Explore the meaning of the changes women with childhood onset disabilities associate with aging as they enter into later adulthood—ages 55 to 65.
- Explore how women with childhood onset disabilities adjust to the changes they associate with aging.
- Explore how the women's gender impacts their experience of aging and subsequent adjustment.

## ***Background***

This is a study of the intersection of experiences surrounding the body when perceived through the eyes of women growing older with impairment related to childhood polio. The background for this study includes the historical context that influences the meaning of the women's experiences. This will form the basis for understanding the shared meanings of the group.

In order to understand aging for women over the life course the historical and cultural setting for the cohort will be explored. Cultural values have shifted over the 20<sup>th</sup>

century in relation to the position of women in society, and that must be taken into account. The lives of women have shifted over the past 100 years to give women longer lives, more complex roles and greater freedom in American society (Giele, 1993). In a review of multiple studies of women and their level of education in American society, Schuster (1993) classified studies from the early 1900s to the 1950s as typical of a Vanguard Era because women were only selectively gaining education and few entertained the idea of combining family responsibility and professional employment. The post 1950s period was described by Schuster as the Era of Limitations because women were encouraged to educate themselves but primarily for the purposes of gaining a suitable husband. This was followed by the Era of Transitions, which was typified by women struggling to find meaning in their lives through education and employment. This time period was considered a critical time for social change in American history. The Era of Liberation was described as the time period after 1965 when women began to enter the work force with multiple professional opportunities, but with new social stressors (Schuster, 1993). The changes within the social context are significant when studying the lives of women aging with the effects of paralytic polio.

Poliomyelitis is a very old disease; although the height of its impact on Western societies was during the first half of the 20<sup>th</sup> century. Poliomyelitis can be traced back as far as the Egyptian remains of a mummy found in 3700 B.C. (Mitchell, 1900). Heine reported the first clear description of the disease in 1840 (Frost, 1911), and in 1841 an epidemic was described by Colmer in a group of infants residing in Louisiana (Frost). Sources indicated that the epidemics of poliomyelitis were first recorded in Norway and

Sweden (Lavinder, Freeman & Frost, 1916), and in the U.S. from 1909 to 1915, the rate of polio was of endemic proportions (death rates ranging from 5,000 to 12,000 over the entire 6 year period (Lavinder et al.). In the year 1916, things began to change in the U.S.; polio became epidemic in the eastern US and contributed to over 6,000 deaths and 23,000 cases (Lavinder et al.). Afterwards, epidemics of polio sporadically occurred in cities and rural regions in the United States and throughout the world with increasing virulence (Sabin, 1949).

Currently, among women with disabilities, polio is one of the most common causes of paralysis after stroke (LeCompte, 1997). Polio related paralysis could range from minor muscle weakness to total paralysis requiring ventilatory support (Morag & Ogra, 1996). Prior to the use of the poliomyelitis vaccine, approximately 32 of every 100,000 children born in the world suffered permanent disability due to the polio virus (Bart, Foulds, & Patriarca, 1996). In 1952, 50,000 people were infected with polio in the United States alone (March of Dimes, 2001b). Today, approximately 640,000 people in the United States have some degree of impairment related to polio; 10 million polio survivors live worldwide (March of Dimes, 2001a).

In paralytic polio, the focus of this study, damage is related to cellular destruction. The lesions of destruction occur in the spinal cord, medulla, cerebellum, midbrain, pallidum and/or the motor area of the cerebral cortex. All other areas of the cerebral cortex are spared (Morag & Ogra, 1996). Three types of paralytic polio have been described correlating with characteristic patterns of the disease (Morag & Ogra). First, there is pure spinal poliomyelitis that involves tightness, weakness or paralysis of the



respiratory muscles without involvement of cranial nerves or vital centers. The largest degree of destruction involves the cervical and thoracic spinal cord segments. Second, pure bulbar poliomyelitis involves the motor cranial nerve nuclei with or without involvement of the vital centers that control things like body temperature and circulation. The third type, bulbospinal poliomyelitis, affects the respiratory centers and the cranial motor nerve nuclei (Morag & Ogra). The symptoms range from increased respiratory rate, inability to cough or sniff to inability to swallow, heart irregularities, flaccid paralysis, pain, incontinence, and decreased blood pressure (Morag & Ogra). This is followed by muscle atrophy due to disuse and denervation (Morag & Ogra). The only treatment is supportive care (Burns, Barber, Brady, & Dunn, 1996).

Although polio infection is no longer a public health epidemic within the United States, there are reasons to conduct this research with polio survivors. The experience of polio survivors can serve as a model for understanding the experience of aging with a disability (Alexander, 1990). This is the first time in history that people with major disabling conditions have lived from childhood to middle and late adulthood (Campbell, 1998) and the aging of polio survivors is largely responsible for this new phenomenon. Many women who are aging with polio were infected as children, rehabilitated and then lived within the community as productive citizens. The focus of polio treatment was on acute care medical issues and many of the long-term consequences of living with a disability over time were ignored (Kemp & Krause, 1999). The experience of aging with a disability can be understood by analyzing the stories of polio survivors.

Polio survivors have described how a disability since childhood has impacted their behaviors and emotions in later life. Research has indicated that polio survivors have made efforts to adapt to new disabilities and environmental problems as they arise (Hansson & Ahlstrom, 1999), and have frequently been able to maintain their self-esteem and quality of life in the face of worsening disability (Currie, Gershkoff, & Cifu, 1993). However, their values related to education, achievement and inner strength, which have been reported to help them normalize when they were young and forget their disability, have been less useful to them as they seek to cope with failing physical health in older age (Kuehn & Winters, 1994). Many of the difficulties associated with living with a disability since childhood have contributed to having a limited social life, not being able to live independently, unemployment, and a loss of access to the health care system after age 21 (Currie et al.). The life stories of polio survivors can provide evidence of how aging is experienced.

Most polio survivors are now in the age range of 40 to 70 years and are likely to enter the health care system at an increased rate as the years pass, which includes acute care settings. Although polio survivors have had on going experiences with health care providers, this has been primarily with rehabilitation professionals who may have a different approach to the care of persons with disabilities (Albrecht, 2001). Nurses in all settings need to be made aware of the rehabilitation needs of persons aging with disabilities. This was supported in an ethnographic study over 3 years with 153 persons with disabilities. From this study, researchers reported two case studies of the experience of how macro level policies impact the daily lives and care of persons with disabilities

(Albrecht). One participant, a 48-year-old male with PPS who was hospitalized with acute respiratory failure, reported that a nurse asked his wife “Why use high tech life support systems to prolong the lives of seriously disabled people who will have no life anyway and will be a burden on their families?”(Albrecht). The nurse and other acute care providers demonstrated little understanding of polio, how the participant had cared for his impairment over his life course, or what changes were anticipated for persons with disabilities as they age. The participant did not receive the instruction he wanted for discharge and the health care system did not understand the man’s past experiences with polio that shaped his current health care needs (Albrecht). Providers cannot remain ignorant to the way a disease shapes the body, mind and society.

The social reaction to polio is an exemplar of how a disease can have a world wide social impact. In a recent tour through a local university museum, the development of the polio vaccine was listed as one of the major societal developments of the 1950s. No other disease related development was listed for any of the time periods from the 1800s to present. Moreover, when scientists announced in 2000 that they developed a means of producing polio in a laboratory setting, the media reacted with outrage. And when persons infected with West Nile virus developed paralysis, it was immediately described as polio like symptoms, which conveyed the idea of an immanent threat. Although other diseases have been more prominent and resulted in the deaths of far more individuals worldwide, polio has invoked considerable societal response within the United States.

It was thirty years after the development of the polio vaccine that the World Health Organization devoted resources and began planning to eliminate polio in developing countries (Shiffman, Beer & Wu, 2002). This was partly due to the realization that people in these countries were suffering serious impairment related to polio despite being considered more prone to early incremental exposure, and it was partly because developing countries demonstrated they could mount effective vaccine programs to reduce the incidence of the disease (Shiffman, et al.). It was clear; however, that society had to come to the conclusion that polio deserved attention above other disease entities, not only a national level, but on a world wide level (Shiffman, et al.).

### ***Sensitizing Framework***

A framework that integrates symbolic interactionism and the life course paradigm will be used for this initial hermeneutic phenomenological study exploring the meaning of aging for women with disabilities. Within the life course paradigm, aging is viewed as a developmental process of changing events and socio-cultural meanings that move across time but within the historical and cultural context of the cohort (Giele & Elder, 1998). The life course paradigm incorporates four distinct areas of social life that when brought together tell a story of aging. The four elements, which make up the paradigm, are: 1) lives in time and place, 2) human agency, 3) the timing of lives, and 4) linked lives (Elder, 1994, 1996). These elements, which are based upon the premises of symbolic interactionism, combine to form the life course view of aging.

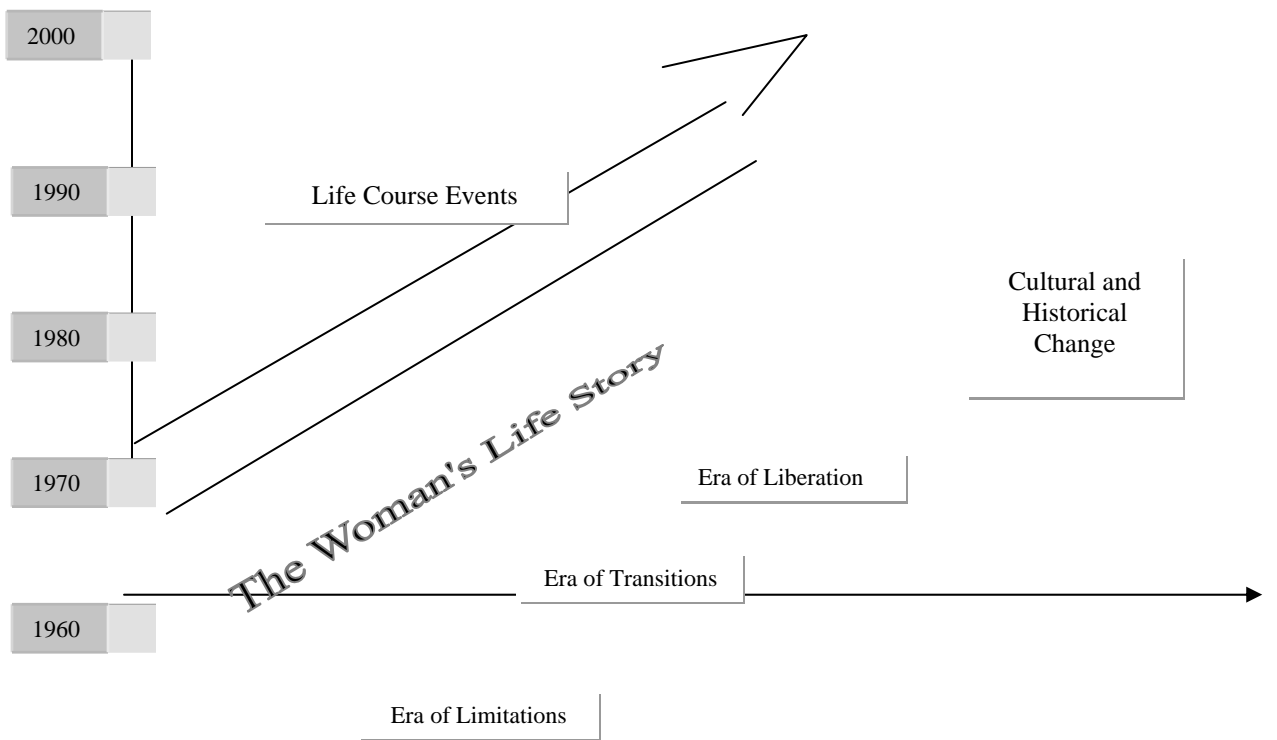
Symbolic interactionism (Blumer, 1969) is based upon three premises. According to Blumer, people act based upon the meaning objects and events have for them. Second, the meaning that is assigned is based upon their interaction with other people, and third, people select objects and events out of their environment, and they process them through time to make meaning. When a person is asked about an event in their childhood they tell a story that may appear random, but because it was selected it holds meaning to that person who has processed it over time. This indicates their story is not extraneous. It tells about their interaction with other people within a specified time and place. Those interactions are interpreted and conveyed through their stories, which provide information about their sense of human agency, how the timing of events affects them, and what the time and place they lived was like. The stories about how they chose to act or not to act throughout life provide a series of events and associated meanings that tell about aging.

The life course paradigm enables the researcher to understand the developmental changes women with disabilities experience. Harrison (In press) documented through a review of the historical and extant research on women with disabilities that four issues are important when understanding their development into older age: 1) Their lives are highly interdependent, 2) Institutions may shape or alter their life course development, 3) Cultural and historical context shape the meaning of gender and disability, and 4) There is a continued, not episodic, impact of impairment on social role development. The life course paradigm provides the researcher a useful tool for understanding the meaning of aging from the perspective of women with disabilities.

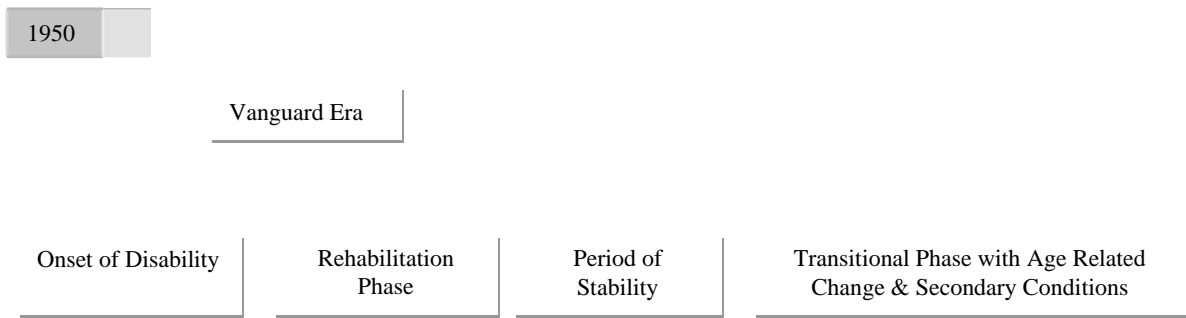
The life course paradigm is consistent with phenomenological views of time, which is highly relevant when studying the effects of aging. The major assumption of the life course paradigm, which is based on the importance of past events on present life pathways, can be explained with Husserl's description of how we shape our present and future based upon past perceptions. According to Husserl (1917/1999), when time is viewed as individual consciousness, it is the medium of existence that passes without regard in the present. It takes form through a stream of perceptions while allowing us to anticipate the future and bring the past into the present (Husserl). Our perceptions in the present ultimately become recollection and are brought forward as recollection but never as perception repeated (Husserl). The perceptions that have past remain in our past despite new perceptions, but the past perceptions become objectified within the mind (Husserl). The human function of objectifying past perception makes up our identity, reality, and history. Our every moment is placed in sequence by time with death reminding us of its end (Berger & Luckman, 1966). The objectification of past events as recollection makes the experience of events in time knowledge, and this knowledge forms our history and makes us aware of the limitations of our biology. Gertz, in his work with the Balinese, wrote that time could be marked in many ways to gain an understanding of its passage, yet the "most important is by the recognition in oneself and in one's fellowmen of the process of biological aging, the appearance, maturation, decay, and disappearance of concrete individuals" (1973, p. 389). After all, aging occurs with time, and time is the horizon in which all interpretation is made (Heidegger, 1962).

Understanding the impact of disability from a hermeneutic phenomenological view of the life course will advance our understanding of how aging is experienced from the standpoint of women with disabilities. According to Shakespeare & Watson (2001) there is a need for an understanding of disability that values impairment as part of the continuum of human experience instead of objectifying and dividing persons based upon categories of ability. In other words, disability should be contextualized as a lived experience that is dependent upon context and experience (Gabel 1999), but does not place people into stringent categories of disabled and able-bodied. When the body is no longer seen as ill or in a sick role, then the gaze must shift to viewing persons with disabilities within a context of aging that understands them as variations of the human body (Shakespeare & Watson). Within this context they are no longer the other or the excluded, but active members of society aging but within a different context. Just as women were reexamined when acknowledged to have a varied experience from men, women with disabilities must be explored--not as an extension of disease, medicine, illness or men with disabilities, but within their own lived experience. This view of disability is consistent with the view taken in other life course studies of aging women (Moen, et al., 1992).

The life course trajectory combined with a disability trajectory set within the historical changes experienced by women can guide the understanding of how disability affects women with disabilities. Based on the work of Scheer and Luborsky (1991), Schuster (1993), Campbell (1994) and Wenneberg & Ahlstrom (2000) the life course trajectory was adapted for women with disabilities and presented in figure 1.







**Figure 1.** Life course development for women with childhood onset disability. Adapted from the work of Campbell (1994), Scheer & Luborsky (1991), Wenneberg and Ahlstrom (2000), and Schuster (1993).

## ***Definitions***

Childhood onset disability is understood as a permanent functional impairment resulting from pathology and/or damage that occurred prior to age twelve and impacts adjustment over the life course.

Gender is a set of culturally prescribed attributes that characterize the degree of femininity and/or masculinity perceived by others and/or enacted by the individual.

Impairment is an objectively or subjectively determined alteration in the body's ability to function as determined normal. For example, the inability to move an arm or leg is impairment.

Disability is a contextualized and relative inability to meet the demands of the sociocultural environment. The loss of one's job due to the inability to sort papers, which was attributed to the arm paralysis, is an example of disability.

Culture is a set of meanings that are locally shared among people and enable them to communicate and advance their knowledge (Parsons, 1951; Geertz, 1973; Hall & Neitz, 1993).

Aging is a developmental process of changing events and biological and socio-cultural meanings that are set within a framework of chronological time and geographic location.

The life course is defined as the "culturally defined script of normatively expected stages and transitions for the socially defined group" (Scheer & Luborsky, 1991, p. 1174).

## ***Assumptions***

- People act based upon the meanings they gain from interaction within their environment and the derived meanings are processed over time. (Blumer, 1969).
- We can understand the meaning of experiences through communication, which may include facial expression, gestures and written or verbal expression (Gadamer, 2000; Polkinghorne, 1983).

- The most accurate interpretation of the meaning of experiences conveyed is gained through a precise understanding of the social, cultural and historical context in which they live out their lives (Gadamer, 2000).
- Early events within the life course impact later adult development (Elder, 1996, 1998). A person's biography influences how they react to and adapt to any new events (Elder & Liker, 1982; Elder & Chan, 1999).
- There are cultural meaning assigned to gender, ethnicity and disability, which influence health.

### ***Significance to Nursing***

Although this is not a study of the practice of nursing, it is designed to inform nursing praxis. Nurses are challenged to take the study findings and use them to guide the care of women with disabilities. This involves the care provided in acute, rehabilitation and community settings. It also involves the care given when influencing policy decisions and interacting with women on a daily basis. This is a study of women with childhood onset disabilities done to inform nursing praxis of the meaning found in aging. When historical shifts in the care of persons with disabilities are examined, the need for this understanding becomes clear.

In only four decades society has moved from celebrating the survival of persons with polio to contemplating assisted suicide for persons with disabilities that threaten quality of life (Koch, 1999). The American public, scientific community, government, and health care community are consistently faced with difficult choices surrounding the

use of technology and the subsequent formation of policy designed to care for those in need. One of the most controversial is the decision to prolong life in the face of disability and possible suffering. Other decisions include how to best distribute resources through entitlement programs to the elderly and/or need-based programs to persons with disabilities. All of these decisions surround the interpretation of the meaning given to the experience of aging and to disability, often by people who have not lived the majority of their life with a disability. Nursing has been viewed as one discipline that could guide the application of new technology respectfully into clinical practice (Newell, 2000), and help guide policy decisions designed to improve the lives of persons aging with disabilities. However, nursing must begin with an understanding of the life course experience of disability and aging. Without this information, society may waste valuable resources on health care policies and provisions not grounded in the lived experience of women aging with disabilities.

Life course stories have clinical application because nurses can use them in practice to guide care. According to G. Frank (1996), stories can be analyzed to capture the meaning of an experience for a group, which can be used by health care providers to make assessments and provide care that may indicate a need for further intervention. These stories will highlight what women with childhood onset disabilities find as beneficial while aging with a disability, and provide nurses a source to validate their own interpretations of their patient's experiences.

## ***Research Questions:***

The guiding question for this qualitative research study is: ***What is the meaning of aging for women who have lived with the effects of paralytic polio since before age 12 and are now entering later adulthood?*** Based upon the literature set within the experience of aging for women with childhood onset disabilities, I will answer the following questions:

- What is the meaning of the changes women with childhood onset disabilities associate with aging as they enter into later adulthood—ages 55 to 65?
- How do women with childhood onset disabilities adjust to the changes they associate with aging?
- How does the women's gender impact their experience of aging and subsequent adjustment?

## **Chapter 2: Review of Literature**

In order to examine the literature surrounding the meaning of aging for women with childhood onset disability, five major areas of literature will be reviewed. The first section of this literature review focuses on the meaning of aging, and it is followed by life course studies of aging women. Although this is not intended to be an exhaustive review, it provides an understanding of aging women within a life course context. The third section is a summary of studies that report on the experiences of aging with a disability. A fourth section narrows the report to the physiologic and psychosocial changes experienced with aging by polio survivors. In the final section, studies that represent experiences for women with disabilities and how these may impact the meaning of aging are presented within a life course perspective. This section was essential because few studies directly examined the experience of aging for women with disabilities.

### ***The Meaning of Aging***

Chronological age has been broken into stages of life that have associated tasks, meanings and roles (Neurgarten & Hagestad, 1976), and according to Erikson, Erikson and Kivnick (1959) the primary task of the later stage is to find meaning in past experiences. Persons are to look back over the events of their life to find meaning in what has come and gone. According to Adams-Price, Henley, & Hale (1998), older individuals are capable of integrating positive and negative events to find meaning in their later years. In fact, aging can emerge as a positive experience despite associated negative changes (Adams-Price, et al.). Interestingly, in a qualitative study older individuals did

not associate aging with any particular event nor did they recognize when it was that they became old (Adams-Price et al.). Moreover, Kaufman (1986) found in her in-depth qualitative interviews that the older individuals found meaning in being themselves, not in the experience of aging. Therefore, if people find meaning in being themselves and do not recognize when they become old, the last stage of life may not be a trigger for the process of finding meaning as described by Erikson and colleagues. Meaning may be found over the life course as events unfold and the identity formed—not as an activity chiefly for the later years of life.

In order to understand aging the continuity of self combined with the changes experienced must be incorporated into the phenomenon (Andrews, 1999). Aging means little when reduced to numbers, but it is the “transformation of the self which accompanies the new age which is of significance” (Andrews, p.312). A person may feel like the same person they have always been but have been changed mentally and physically due to their life experience (Andrews). The elderly person is the person of many experiences and events. Moreover, some elderly report that it would be a waste of time to have lived without the experiences to reflect upon (Andrews).

The individual’s perception of age is influenced by unique life events, but societies’ view of aging also influences the individual’s perception of aging. According to Goffman (1997) the moral career of a person is the change a person perceives in their self-image as others look at them over time. Our inability to accept aging due to the youth orientation of our society may force us to devalue the later years of life (Andrews, 1999). If the way people view us over time influences our self-image, a youth orientated society

could impact our perception of age as we grow old. The feeling of being stigmatized for aging may have created a desire not to age or to hide one's age. Moreover, Hepworth (1995) posited that the person is a combination of their physical self and outward appearance, and the ways others perceive the person influences their interactions. They may be perceived as negative, but that person could use negative perceptions as a resource for negotiations. In other words, looking young may be socially desirable, but a reduced physical condition associated with age could be used to gain favors from close relations. The image perceived and portrayed can be flexible, plural and diverse depending upon the goal of the interaction.

Neugarten (1968) proposed that identity changes very slowly as people age and that expected life events do little to change the person because they are given preparation. Certain events are expected due to cultural and societal norms. They are anticipated, good or bad, and their arrival is given preparation. Even death, if it appeared on schedule, is prepared for and perceived as a developmental milestone. Events that were not expected have had more of an impact due to the unsynchronized nature with society, however, as society has become less rigid regarding timing of events, aging and identity change has become more individualized (Neugarten).

Aging has diverse meaning depending upon the experiences and social context of the individual, which when prepared for may have a positive impact; therefore to understand aging, it has been proposed that researchers study the life course instead of cross sectional studies (Moen, 1995). The life course view of aging is a perspective that combines the age cohort that a person belongs to, their biological age, their social life



stage, and each person's unique context (Moen). Major turning points in life shape the outcome of the life course. Outcomes have been associated with the duration, number and timing of social roles. As an example, a life course exploration of the lives of men was done to understand the impact of family death and combat experience on successful aging. Crosnoe & Elder (2002) analyzed the data of 424 men involved in the Stanford-Terman study begun in 1922. These authors reported that four profiles represented the outcomes; the most successful with aging were described as well-rounded with higher economic resources and better health. Their life course paths seemed to lead them away from traumatic events and they held stable marriages. The least successful were those with the poorest health and lack of career, which was associated with combat experience and the loss of a child or spouse over the life course. The current marital status was not the predictor for successful aging, but long-term stability in marital status was the predictor, which indicated that researchers should strive to understand more than current role status (Crosnoe & Elder). This study is an exemplar of how aging is affected by social status and events over the life course; however, the research does not explore the meanings given to the events and social changes with aging.

### ***Studies of Aging Women: Life Course Perspectives***

As a starting point for the understanding of the perspective of the lives of women with disabilities, it is important to review what is known about the life course of women in general (Danek, 1992). In this section, selected life course studies focusing on aging women are presented. Using data from the Berkeley Longitudinal Study of normal

development, Elder and Liker (1982) did a quantitative investigation of the life course outcomes of women born from 1890 to 1910. It was hypothesized that loss during the 1930's would impact well-being in late life with health being a balance between loss and gain of resources over the life course. The results indicated that women's lives were shaped by the great depression, which was most evident in their emotional health in old age. Women of working class backgrounds, who experienced hard times during the depression, experienced poor emotional health and intellectual capability while women of middle class backgrounds, who also experienced hard times, became more self-assured and cheerful in old age. Interestingly, middle class women who did not experience hard times did not gain the same emotional benefits. It was posited that some women are more prepared for old age due to their life course experiences that strengthen their ability to adapt (Elder & Liker).

In a qualitative case study of three aging women using a life course approach, Shenk (2001) argued that women's late adult lives are influenced by the relationships they have with their family. The relationships influenced life choices and opportunities to mold how the late life was viewed. For instance, one woman who lived her entire life with her parents after having a child, found herself being their caretaker in old age. Later she became bitter with few interactions and lived alone in the family home. Her life choices were influenced by the out of wedlock birth of her child and her families' response. In late life, she became an emotionally isolated woman without contact with her own child (Shenk). The early life experiences of the woman were given meaning

through her interactions with significant others and these impacted her life as an older woman.

The different life course paths that women enter were explored in a sample of 313 wives and mothers interviewed in 1956 and 1986 (Moen et al., 1992). The rate of disability or severe illness experienced in persons who were healthy in 1956 was examined over the 30 year period. The duration and timing of adult roles were also examined. The researchers found that multiple roles in 1986 were associated with better health in 1956 and 1986. About a third of the women experienced some form of severe illness or disability over the 30 year period. Educational level or number of children was not significantly related to duration of health. The women who engaged in clubs and other organizations experienced a significantly longer period without disability or severe illness. The accumulation of roles over the 30 year period was positively associated with the women's appraisal of health in 1986 even when controlling for socioeconomic variables such as social class, husband's occupation and income. The authors posited that these findings indicated that women follow two distinct paths influenced by role acquisition and by health.

In a study of life course development in 68 middle age (33 to 56) women, Rossi (1980) investigated how the women coped with family and work responsibility as well as how it affected the meaning they associated with aging. This group of women was part of the baby boomer generation, which was characterized as an educated cohort of women who have participated in sexual freedoms and witnessed civil rights and feminist movements. Many of these women postponed motherhood and opted to further their

careers, which was unique to this cohort at that time in history. The results indicated that none of the women wanted to be older than their chronological age; most wanted to be around 6 years younger and wanted to live to around 75 years. Women with larger families and women who were older when their first child was born reported they wanted to be significantly younger than women with smaller families and women who were younger when their first child was born. Overall, women who perceived life was going well were satisfied with their age. Moreover, the more age related symptoms they reported the worse the relationship with their adolescent children. Rossi's study indicated that strain can occur in women's lives as the social change characteristic of their cohort is enacted in their daily lives.

In summary the literature indicated that women's lives are interconnected (Shenk, 2001) and affected by social events and the historical time period (Elder & Liker, 1982; Rossi, 1980). This can, in turn, affect their health, social activities, and ability to adapt to change in later life (Elder & Liker; Moen et al., 1992; Shenk).

### ***Studies of Aging with Disability***

Few studies have examined the effect of aging on the health status of women with disabilities. Coyle and colleagues (Coyle, Santiago, Shank, Ma & Boyd, 2000) studied the degree of secondary conditions in a sample of 165 women age 18 to 65 with varying types of disabilities. These researchers found high rates of secondary conditions that were dependent upon the type of initial disability, with the majority reporting fatigue, spasticity, pain, mobility problems and physical de-conditioning. The most severe

secondary problems were amputations and respiratory problems. A large proportion of women reported poor functional ability to complete everyday tasks. Other work has indicated that women with disabilities may be at increased risk of heart disease and osteoporosis after menopause due to inactivity and non-weight bearing activities (Vandenakker & Glass, 2001). Stuifbergen & Becker (2001) reported that women with MS who engaged in health promoting behaviors over time reported less functional decline than those who did not engage in health promoting behaviors. This work indicated that functional decline was not a purely biological necessity of aging for women with disabilities. A behavioral component exists, which may be influenced by the psychological, social and cultural context.

The psychosocial aspects of being women and aging with disability have placed women at risk for further health problems. The impact of disability, aging and gender create a triple jeopardy that place women with disabilities at risk of social marginalization and poor health beyond that of persons without disabilities or men with disabilities (Pentland, Tremblay, Spring, Rosenthal, 1999). Pentland and colleagues documented that women with disabilities were concerned about their changing bodies with age and how that affected their social roles. The loss of social roles placed them at risk of losing needed health benefits for access to care, thus increasing their risk for further health problems over time. Unfortunately, this work was limited due to the inclusion of participants with a wide age variation (age 25 to 71 years of age) without an exploration of the influence of culture, cohort, or timing of disability (Pentland et al).

Despite physiologic changes in the body, there are positive factors associated with aging. Researchers have reported that factors associated with decline are decreased in those who engage in health promoting life styles over the life course (Fries, Green & Levine, 1989). The prospect of a compression of morbidity--extension of life without disability-- has lead to theories of successful aging, which began with studies of elite elderly athletes and has culminated in a theory of selection, optimization and compensation with age (Baltes & Baltes, 1990). Other researchers have focused upon positive aspects of aging that include Neugarten's (1968) and Erikson, Erikson and Kivnick's (1986) theoretical work on mental growth in aging. This has lead to work indicating that self-esteem can be high in the elderly (Herzog & Rogers, 1986) and despite losses in health; the elderly frequently have optimistic views of themselves with a high sense of purpose (Mossey, 1995). The need for an insider view of the aging body, which is highly suitable for phenomenological methods, is often needed to integrate the lived experience of aging with the changes in the biological body.

Phenomenological work has given insight into the results of perpetuating the image of decline as synonymous with aging. In a phenomenological study of fourteen elderly individuals who spent time in a hospital, segregation and care organized around the philosophy of a conveyor belt were described as the result of biomedical images of the elderly as machines worn down from wear and tear (Koch & Webb, 1996).

Biomedical images of aging have also predisposed the word geriatric to mean mental and physical decay (Hepworth, 1995). These images have lead to the treatment of elderly

individuals as nothing more than expiring objects—“cared for but socially neglected” (Hepworth, p.17).

The impact of disability throughout the life course was examined in an ethnographic study of persons aging with the effects of polio (Scheer & Luborsky, 1991). The biographies of three people were set within a developmental and life course context that was influenced by historical change within society. The normative life expectation and developmental norms and the rehabilitation and recovery from polio influenced life course experiences. The influence of the historical movement surrounding polio was strong enough to sway the participants to label themselves as having a Type “P” (for polio) personality. The polio survivors were driven to normalize, and the main problem they reported with aging was not related to medically defined conditions, but with the premature loss of roles and goals for the future. This study was a contribution to our understanding of aging with a disability, but it did not address the impact of gender upon perceptions of aging.

The work by Scheer and Luborsky (1991) was followed by a dissertation study of fifteen purposively sampled polio survivors who experienced the disease as children (Lewis, 1992). The inclusion criteria for this study were paralytic polio prior to age 13 and intact cognitive function. Lewis’s research was based upon polio as an illness trajectory. The themes reported were the acute illness phase, recovery with a long plateau, unanticipated late effects, and further functional decline. Lewis (1992), like Scheer and Luborsky (1991) found that two life course themes dominated their biographies, but in this sample the cultural and developmental normalcy themes were

accompanied by themes of chronic and emotional distress with unending struggles. This work supported the need to contextualize disability within the life course, but persons with disabilities often criticize work that places them within a chronic illness perspective (Oliver, 1996). The view of the group as having unending struggles may have emerged due to the focus on polio as a chronic illness with associated sick role behavior.

Charmaz (1991) conducted interviews with 55 informants with chronic illnesses that ranged from neurologic impairments such as multiple sclerosis to those with circulatory diseases and cancer. Her study focused upon the construction of identity and time while experiencing chronic illness. All of the participants were white and ranged in age from early twenties to over seventy years of age. She conducted multiple interviews with the participants in order to gain comfort with disclosure. She wrote that her informants were able to understand the abstract nature of her study when they were given time to think about the nature of her questions. This also allowed her time to speak more in depth with the informants about issues that arose during previous interviews.

In regard to the proposed study, the most salient interpretations that Charmaz (1991) presented were related to time because time is a framework for aging. Charmaz provided a thick description of how chronic illness could change the way time is experienced. For instance, if people became primarily positioned in their past, they could lose the experience of the present. These people would reflect on past memories without attending to the present or future because only the past held meaning for them. She also found that if people became caught up in present activities of caring for their illness, they could hasten time. Others found themselves longing for a future that brought them



immortality and freedom from their failed physical beings, or they searched for a purpose in life that brought them immortality or lasting identity. These experiences of time were many of the ways those years were marked and remembered as events passed. However, Charmaz only interviewed Anglo Americans, interviewed a wide range of age cohorts, and made little attempt to understand disability apart from chronic illness.

The disability experience was analyzed by Wenneberg and Ahlstrom, (2000) who interviewed fifteen polio survivors. The five themes identified were the acute phase of severe illness, rehabilitation phase with restoration of capabilities, phase of relative stability, transitional phase where functional capacity is lost, and new dependence on medical technology. These individuals communicated stories of strength in overcoming their initial disability but found their new disabilities cannot be overcome in the same manner. The disability that arrived with aging required new resources from them and their memories of their childhood disability overwhelmed them—creating a sense of vulnerability. This work was similar to the prior studies but added to the literature because it explored themes related to adjustment to later life disability. Again, gender was not explored as an influence on the life course of these participants.

In a phenomenological study of the experience of aging for approximately twenty-seven men and three women with spinal cord injuries living in Japan, researchers reported that six underlying themes emerged (Iwakuma, 2001). First, the participants stated that time had been altered by their impairment. One participant stated that time had stopped since his accident and he was only reminded of its passage by a birthday card. Second, participants were concerned about how their bodies would adapt to changes associated

with aging, but contact with disabled elders was a calming source of feedback for them. By seeing others cope with the effects of aging, younger persons were better prepared for the future. Third, persons with disabilities felt they aged differently than non-disabled people. They reported that the opportunities for fulfilling life goals were altered by their disabilities. Fourth, many reported they were better prepared for the effects of aging because of their early onset disabilities. Impairment had altered their trajectories but prepared them better to appreciate life's gifts that occur over time; such as meeting new people. Fifth, the participants had concerns for their family—especially their wives because they relied so heavily upon them for their care. As their wives experienced physical changes with age, they feared what those changes might mean for them. Finally, they did not fear changes that were already present. They did not fear the loss of physical functioning that many without disabilities fear with aging. This study was limited due to its low number of women and lack of gender analysis, but it did provide a unique glimpse at the phenomenon of aging for persons with disabilities in Japan. It is unclear how the experiences of those in Japan will overlap with those in the United States.

It was not until Campbell (1994) did a quantitative study of impairment related outcomes based upon timing of disability in the life span that gender was considered an influence on the life course development of persons with disabilities. This study was done with three groups of persons aging with disabilities—those who have had polio, stroke, and spinal cord injuries. Again, this work supported the use of life course theory with persons aging with disabilities. They found that the time of disability onset was significantly related to the degree of impairment. Women who developed post polio

syndrome (PPS), which is characterized by new onset weakness and fatigue, had significantly more depressive symptoms than women without PPS. They also had higher depressive symptoms than men with or without PPS. Women were also more likely to have had to stop their education based upon their polio related impairment when compared to men. This study compared outcomes based upon gender using a life course theory approach. It indicated that further work is needed to understand how gender impacts the problems associated with aging and subsequent adjustment.

Frank (2000) reported the results of a twenty-year hermeneutic phenomenological life course study of one woman born in the United States with no arms or legs. Findings indicated that many barriers grew out of cultural stereotypes and influenced the participant's ability to become employed, stay married and remain living within the community. These cultural barriers combined with the historical time period, were a major influence on the participants development into mid life. Through the use of the life course methodology combined with a hermeneutic phenomenological interpretation of the experience of disability in our culture, Frank was able to report how researcher and participant co-construct the life course story of aging in American culture. However, this study did not follow the participant into later adulthood and was based on the experience of one Anglo American woman.

In summary, studies were found that examined the experiences of aging while living with a disability, but they did not examine the effects of gender on the experience (Albrecht, 2001; Iwakuma, 2001; Scheer & Luborsky, 1991; Trieschmann, 1987). Other studies examined the health experience of persons with chronic illness over time, but did

not make an attempt to understand disability apart from an illness experience (Lewis, 1992; Charmaz, 1991, Thorne, 1993). Frank's (2000) twenty-year case study of one woman provided a glimpse of how difficult experiences may be for women as they enter midlife. Yet, this study was not designed to incorporate shared experiences of women, nor did G. Frank follow the participant into later life. Another limitation of the literature was the lack of multi-ethnic samples of persons with disabilities.

### ***Aging with Polio/Post Polio***

Persons who survived polio have been the focus of neurological and muscular studies due to the occurrence of age related muscular weakness and fatigue. Twenty-eight to forty percent of polio survivors have reported age related symptoms known as Post Polio Syndrome (PPS) (Halstead, 1998; Lecompte, 1997). The pain, new onset weakness and fatigue associated with PPS are associated with factors associated with the acute illness (Currie, et al., 1993). Overall, PPS has resulted in decreased mobility (Willen & Grimby, 1998), a new need for ambulatory and ventilatory aids (Macdonald, Gift, Bell & Soeken, 1993), difficulty dressing, a new need for personal assistance, and a change or cessation in occupation (Jubelt & Cashman, 1987). The problems polio survivors have experienced with aging range from pain (Koh, Williams & Pohlsen, 2002; Widar & Ahlstrom, 1999) to respiratory problems (Macdonald, et al.; Weinberg, Borg, Bevegard & Sinderby, 1999). Table 1 represents a synthesis of age related problems experienced by polio survivors.

**Table 1. Studies of physical changes experienced by polio survivors with aging.**

Authors	Year	Design	Sample	Objective	Findings
Agre, Rodriguez & Franke	1998	Physiologic measures of muscle function.	25 persons with polio complaining of declining muscle strength, 16 without complaints and 25 controls.	The objective was to determine the time to recover muscle performance after exercise.	The recovery time from muscular exercise was greater in those with complaints of decline. The people with polio who had no complaints did not differ from the control group.
Agre, Rodriguez & Franke	1997	12 week longitudinal study of exercise intervention.	7 persons with history of polio and symptoms of PPS.	The objective was to test an exercise intervention.	The exercise intervention increased measures of muscle performance without increasing measures that would indicate nerve damage. No negative effects noted.
Allen, Gandevia, Neering, Hickie, Jones, & Middleton	1994	Physiologic measures of muscle function.	21 persons with history of polio 20 to 40 years previous and 20 healthy age matched controls.	The objective was to investigate muscle fatigue during exercise.	The group with PPS had more muscle fatigue. They also had impaired activation of muscles when not fatigued.

Chasens, Unlauf, Valappil, & Singh	2001	Self-report survey.	584 persons with PPS. Mostly women (69%) with mean age of 62.	The objective was to describe the sleep related breathing problems and nocturia.	75 % described recent onset of symptoms such as muscle pain and weakness. The women had increased levels of incontinence. 64% were bothered by nocturia. Poor sleep quality predicted an increased risk of PPS.
Ernstoff, Wetterqvist, Kvist, & Grimby	1996	Physiologic measures of muscles function and questionnaires in an exercise intervention.	17 persons with PPS at a University in Sweden. Age 39 to 49.	The objective was to determine the effects of the exercise intervention.	The training program increased muscle strength in select muscle groups and improved work performance in respect to heart rate.
Goerss, Atkinson, Windebank, O'Fallon & Melton	1994	Retrospective chart review	277 polio survivors' records looking for fractures since time of acute polio infection to date.	To determine the incidence of fractures in community living population.	87 people experienced 161 fractures. The cumulative incidence of fracture after 40 years was 48%. The risk of distal femoral and proximal humeral fractures was higher than among the general population.

Ivanyi, Nollet, Redekp, et al.	1999	Self-report questionnaires.	233 persons with polio in Netherlands. Age ranged from 39 to 77 years.	The objective was to determine the prevalence of new muscle symptoms, disability, and handicaps.	58% reported increase in muscle weakness. 56% reported increase in disabilities such as gait problems. 53% reported problems with occupation and social integration. They reported an increased need for adaptive devices.
Klein, Whyte, Keenan, Esquenazi & Polansky	2000	Longitudinal measurement of strength.	120 persons with Polio	The objective was to quantify the rate of muscle deterioration.	Muscle deterioration was present in the flexor muscles of the ankle, hip and knee, but it was not strongly related to age, time since polio, gender or history of residual weakness. The rate of deterioration was greater than what was expected with normal aging.

Koh, Williams & Povlsen	2002	Self-report survey	139 polio survivors	The objective was to assess the quality of the upper limb pain and its association with the use of mobility aids.	64% had upper limb pain and 74% used mobility aids. Those who used mobility aids were at increased risk for upper limb pain. The arms affected by polio were at less risk for pain.
Kumakura, Takayanagi Hasegawa, Ihara, Yano & Kimizuka	2002	Self-report Survey	662 post polio and 736 spinal cord injury survivors in Japan	The objective was to determine the time to secondary worsening of difficulties.	74.8% had some type of decline. PPS was estimated to be present in 53% of the group because they did not have another diagnosed disorder to cause the decline. The cumulative incidence of PPS was 60% by 60 years of age. The least amount of difficulties for polio survivors was during early life and began to decline 35 years post onset. Those with the most severe difficulties at onset had most problems with decline.



Lin, Liaw, Chen, Cheng, Wong, & Chiou	2001	Physiologic measures of respiratory function	44 persons with idiopathic scoliosis and 16 with Polio related scoliosis.	The objective was to identify factors of scoliosis that impact respiratory function.	Pulmonary function for the Polio group was related to scoliotic angle, kyphotic angle, location of the uppermost vertebra of the scoliotic curve and age. The respirator problems were restrictive in nature. Polio patients had a higher frequency of pulmonary function impairment.
McDalakas, Elder, Hallet, et al.	1986	Longitudinal measurement of muscle strength	27 persons with polio. Mean age of 50.6 and mean of 28.8 years since infection.	The objective was to determine the rate of muscle strength decline.	The rate of decline averaged 1 percent per year. The muscles showed evidence of chronic and new denervation. No loss of whole motor neurons but a slow disintegration of terminal nerve axons.

Macdonald, Gift, Bell & Soeken	1993	Physiologic measures of respiratory function	23 PPS persons with age and gender matched comparisons. They had a mean age of 55.	The objective was to determine the respiratory muscle strength and deterioration.	The mean maximum inspiratory pressure was significantly lower for the PPS group. The control group improved in respiratory strength over three trials but the PPS group did not.
Nollet, Beelen, Prins, et al.	1999	Self-report questionnaires and physiologic measures of muscle strength	76 polio survivors with PPS and 27 without PPS.	The objective was to determine the perceived health problems among polio survivors with and without PPS.	78% reported fatigue as the major problem followed by walking outside (46%) and climbing stairs (41%). Social and physical functioning not in measured muscle strength were predictors of differences in those with/out PPS.
Nollet, Beelen, Sargeant, de Visser, Lankhorst, & de Jong	2001	Self report questionnaires and physiologic measures	43 persons with polio (25 with PPS & 18 without). Also 12 controls.	The goal was to compare exercise ability of polio survivors with and without PPS to controls.	The exercise capacity of persons with Polio was reduced. No differences were found in the polio survivors with and without PPS.

Soreson & Windebank	2002	Questionnaires and physiologic measures using longitudinal design.	23 persons with history of polio.	The objective was to determine the prevalence and risk factors for progressive motor decline over 15 year period.	10 had symptoms of late progressive motor deficits. The rate of progression was uniform over time. Severe residual impairments were associated with symptoms of decline.
Stanghelle & Festvag	1997	Questionnaires and physiologic measures using longitudinal design over 3 to 5 years.	68 persons admitted to hospital with PPS. They had a mean age of 55.	The objective was to measure symptoms, pulmonary function and work capacity.	The lung function was a reduced restrictive type. Most reported increase in polio related symptoms but not a decline in mental abilities. Weight and symptoms related to polio increased over time.
Trojan, Cashman, Shapiro, Tansey & Esdaile	1994	Case control chart review study.	127 polio survivors with PPS and 39 without PPS.	The objective was to determine risk factors for PPS.	Increased age when presenting to clinic, longer time since initial infection, increased weakness with initial infection, joint pain, weight gain and muscle pain were predictive of PPS. Sex was not predictive.

Weinberg, Borg, Bevegard, & Sinderby	1999	Physiologic measures of respiratory function	5 men with PPS who were 42 to 58 years of age.	To determine the limitations of exercise and the respiratory adaptations.	The majority had normal blood gas values, but had ventilatory insufficiency when they exercised.
Widar, & Ahlstrom	1999	Self-report survey	37 persons with PPS. Age range 52 to 79. The mean of the years since polio infection was 52.9.	The objective was to assess how persons with PPS describe their pain and how it affects their lives.	Used Multidimensional Pain inventory to assess the perception of and effect of pain. The group had pain a mean of 19 years in a mean of 5 locations. The women had pain longer than the men. Most described their pain as an "ache", which occurred mostly in the back and joints. Many had "cramps" in their lower extremities.
Widar, & Ahlstrom	1998	Self-report survey and interview.	35 persons with PPS. Mean age was 65.	The objective was to find out the meaning of pain in the lives of persons with PPS.	Lower back (66%), knees (47%) and upper joints (38%) were common sites of pain. Most described it as dull & had it daily.

Willen & Grimby	1998	Self-report survey.	32 persons with PPS seen in a university hospital.	The objective was to provide a description of pain.	Over 50% experienced pain at least every day and it occurred most frequently during activity. Most had cramping pain in the lower limbs and aching pain in the upper limbs and trunk. Muscle weakness had no correlation with pain.
Willen, Sunnerhagen, & Grimby	2001	Physiologic measures. Pretest/posttest.	28 with late effects of polio. 15 to intervention and 13 to control group.	The objective was to test a water exercise intervention.	No negative effects of exercise. A decreased heart rate occurred in intervention group and they reported less pain and positive experiences.

Age related changes after years with a stable disability might alter the life course pathways of polio survivors, as well as the meaning they assign to aging. Persons aging with polio have reported higher levels of depressive symptoms when compared to non-disabled age matched controls (Kemp & Krause, 1999). Moreover, those who experience pain, weakness and fatigue associated with PPS have reported less satisfied lives (Burger & Marincek, 2000) and a poorer quality of life (Kling, Persson, & Gardulf, 2000) than those without PPS. This may be because their impairments have hampered their ability to socially integrate (Farbu, Rekeand, Aarli & Gilhus, 2001). A review of studies related to psychosocial changes while aging with polio is presented in Table 2.

**Table 2: Summary of Psychology and Sociological Studies of Persons Aging with Polio.**

Author	Year	Design	Sample	Objective	Findings
Burger & Marincek	2000	Self-report questionnaires	100 polio survivors in Ljubljana, Solvenia. Average age was 55.	The objective was to determine the effect of new symptoms on life satisfaction and independence.	69 out of 100 had symptoms of PPS. PPS decreased their ability to be active and social. It decreased their satisfaction with life. Life satisfaction for people without PPS did not change.
Creange & Bruno	1997	Self-report surveys	58 polio survivors cared for in a post polio treatment program.	The objective was to determine the effect of Type A behavior, self-concept and loneliness on completion of treatment.	They found few significant differences between completers and non-completers of the program. There was a significant negative correlation between age and completion of the program. Resting was negatively correlated with Type A behavior.

Farbu & Gilhus	2002	Self-report questionnaires	168 polio survivors (94 paralytic & 74 non-paralytic) and 239 siblings in Norway. Mean age of 61.	The objective was to determine to what degree they participated in education and professional life and how that related to their health.	Length of education did not differ significantly between those with polio and their siblings or between genders for those with polio and their siblings. Fewer patients than siblings were working by age 40 (55% of polio and 69% of siblings). 11 of the 14 on permanent disability were women. The majority of those who were working part-time and had no income were women. More women with polio than men were divorced or widowed. Significantly more siblings reported good health and life.
Farbu, Rekeand, Aarli & Gilhus	2001	Self-report questionnaires	149 persons with polio in western Norway with paralytic and non-paralytic. 98 persons in a control group. Age of polio survivors was 46 to 82 (mean of 57.)	The objective was to determine how polio influenced education, employment, profession, income, marriage and leisure activity outcomes.	Residual weakness was associated with not being married, however most polio survivors married at same rate as controls. Most persons with weakness reported that it interfered with hobbies, which was significantly more than the controls. Physical ability was associated with employment type. Of the polio survivors, 77% without & 50% with paresis were working. The majority of polio survivors were working past age 60.



Foster, Berkman, Willen, & Schuster	1993	Self-report surveys	268 polio survivors in Maine.	To determine the health care needs of persons with polio.	Many perceived no access to knowledgeable physicians or social and health care services, which interfered with their ability to cope with late problems.
Hansson & Ahlstrom	1999	Two Qualitative Interviews 6 weeks apart	24 people with PPS in Sweden with average age of 66, range 51 to 78.	The objective was to determine how people with PPS cope with their problems.	General weakness, fatigue and pain add to their distress in life. Illness related problems interfered with daily life activities. People coped by accepting their illness, preventing symptoms, changing activities, distancing, emotional reactions and seeking social support. Felt life was good despite health.
Kemp & Krause	1999	Self-report surveys	360 persons- 121 with PPS and 177 with spinal cord injury (SCI) plus 62 non-disabled age matched controls. PPS group had a mean age of 63.7	The objective was to explore and compare the level of life satisfaction and depressive symptoms in persons aging with PPS or SCI.	The control group was highest on all life satisfaction scales, the PPS group scored higher than the SCI group. Hispanics in the SCI group had highest depressive symptoms.

Kling, Persson & Gardulf	2002	Interview and observation by occupational therapist	150 polio survivors with mean age of 61 with age range from 20 to 82 in Sweden.	The objective was to explore activity level and use of aids.	The polio survivors were most independent with eating, daily hygiene and communication. They needed most help with housework. 57% used aids such as canes, crutches, walkers and wheelchairs. 91% needed their car to be adapted for them to drive.
Kling, Persson, & Gardulf	2000	Self-report questionnaires	150 persons with polio in Sweden. The mean age was 61 years, range 20 to 82.	The objective was to explore the perceived health related quality of life.	The groups reported that their perceived health was impacted by their post polio symptoms. When compared to a national sample, the polio survivors had worse functional status and perceived quality of life. The women with post polio had significantly more reported pain. They did not perceive that their family life deteriorated due to their health. Only in the oldest age groups (75-82) did the polio survivors begin to appear functionally similar to the general population.

Natterlund& Ahlstrom	1999	Self-report questionnaires	119 persons with muscular weakness; 33 with MD, 46 with myotonic dystrophy, and 40 with PPS. Those with PPS had a mean age of 65 with a range from 51 to 81.	The objective was to determine the types of coping used and explore the types of problems experienced.	The majority of problems occur in mobility, occupations, and transportation. People with MD had the greatest reported problems. The women used more aids and own solutions to problems than men with basic personal care activities, but men used more aids at work. People with PPS used more avoidance strategies with mobility/transportation problems.
Schanke	1997	Self-report questionnaires and physiologic measures.	63 polio survivors. (43 women and 20 men with mean age of 55.3 years)	The objective was to determine the psycho-social aspects of coping with late effects of polio after leaving an inpatient unit.	Level of work capacity (peak oxygen uptake) did not correlate with psychosocial variables. The participants were characterized by high adjustment and problem focused coping with low psychological distress.
Thoren-Jonsson	2001	Grounded theory	22 persons with late effects of polio.	The objective was to determine the process of adaptation.	The main category was coming to a changed approach in response to their changing bodies. They demonstrated flexibility & problem solving ability. They traded off independence and dependence depending activity type.

Thoren-Jonsson, Hedberg & Grimby	2001	Self-report questionnaires	113 polio survivors with a mean age of 57, range 15-84 in Sweden.	The objective was to determine the amount of distress related to physical mobility, pain and energy, and social isolation.	Women or men in the age group less than 44 had more emotional distress than men or women 45 to 64. Most health problems were in domains of housework, employment and leisure activities. Men reported more problems with house work regardless of age. Young men reported more problems with employment and social life. Persons who had problems with social life had more distress in energy, physical mobility, pain, emotions and isolation.
Walker	1998	Self-report questionnaires	341 persons with polio in Nova Scotia with mean age of 56 with range from 40 to over 80.	The objective was to determine the health, psychological and social problems of polio survivors.	25% diagnosed with PPS. No significant differences in sex for diagnosis of PPS. 11% also had diagnoses of arthritis, diabetes, MS, Guillan Barre, Paget's, cancer, DJD, Cardiac problems. Most were having problems with performing activities that required lower body use such as walking. They also reported high levels of fatigue.

## ***Research Surrounding Women with Disabilities***

Women with disabilities are at risk for social and health problems with aging (G. Frank, 2000; Pentland et al., 1999) that threaten their ability to adjust to late adulthood, but few studies have been found examining the meaning of aging into late adulthood for women with childhood onset disabilities. The life course paradigm (Elder, 1994; Giele & Elder, 1998) provides one way to organize the studies that have been done into a coherent whole. The following section is a synthesis of studies grouped according to the life course paradigm and focused upon women with disabilities.

### **Lives in Time and Place**

Since the 1960's researchers have understood that historical time and place affect life choices and subsequent aging. Ryder (1965) described this as a cohort effect. The approximate time and place of birth can affect what a group experienced when they were born and as they aged. Larger societal and historical changes experienced are shared with persons from the same cohort, which is traditionally viewed as no more than a ten-year birth span.

Elder (1994) stated that cohort effects are especially important when society is changing quickly, which has been the case for persons with disabilities. In the United States since the 1960's there have been 13 different civil rights laws passed that were directed toward persons with disabilities (Harrison, 2002). For instance, legislation written in 1975 ensured education for children with disabilities, and the Olmstead Act of 1999 required that persons with disabilities not be institutionalized when similar less

restrictive environments were available. The American's with Disabilities Act (ADA), which made discrimination against persons with disabilities illegal, has only been in effect for 12 years. Many of the laws passed over the last 50 years impacted the daily lives of persons with disabilities in the form of educational and residential environments that may impact health.

Economic policies toward women with disabilities, which are set within a specific time period, may also exclude them from society. In a study of how patients qualify for social security disability benefits, the work involved in gaining the benefits included waiting for as long as 72 months for benefits, hiring an attorney, completing multiple forms, and applying multiple times (Nasr & Welsch, 1996). The benefits provided, were important because they provided access to health insurance and cash that allowed for increased independence (Nasr & Welsch). Moreover, in a study of gender differences in social security disability awards, even after controlling for the type of impairment and the personal characteristics, women received social security disability awards at a significantly lower rate than men (Baldwin, 1997). Although men and women equally satisfied medical eligibility, women were less likely to meet vocational eligibility requirements. For women with disabilities, exerting the continued effort to qualify for benefits only to be rejected at an increased rate may prevent them from becoming independent members of society.

The government has responded to the needs of persons with disabilities, however, the response has historically favored men. The first national disability law was enacted for veterans of the Revolutionary war and followed by legislation to benefit military

merchant marines (Albrecht, 1997). Most government assistance has been either military or work related (Albrecht), which has excluded many women from gaining benefits. This has been compounded by the fact that social security benefits have been distributed with a heavy weight upon vocational and marital status, which has excluded many women with disabilities due to their low rate of marriage and employment (Meyer, 1996).

Living with a physical disability in the United States has been characterized as isolating. In the classic work of Goffman (1963), stigma due to disability was well documented with cultural accounts of discrimination and isolation of persons with disabilities. Murphy (1987) also added to our cultural understanding of disability in his studies of rites of passage. Murphy and colleagues ethnographic work reported that persons with disabilities in the United States were located in a liminal state--being viewed as neither ill nor well and unable to participate in American cultural norms (Murphy, Scheer, Murphy, & Mack, 1988).

Culture is more than something a society has; it is something that is done to each member (Agar, 1994). The individual is immersed within a culture that is not only where they interact but also where they learn how to interact (Agar). It is within a culture that a person learns how to be a woman and others learn how to interact with her (Beauvoir, 1974). Within American culture, femininity is part of the essential expression of what it is to be a woman (Goffman, 1979; West & Zimmerman, 1987). The way a woman dresses, wears her hair, and walks produces signs that are regarded as expressive behaviors that convey to others she is a woman and indicate terms for contact in social situations (West

& Zimmerman). Almost any activity is assessed to its womanly or manly characteristics (West & Zimmerman).

Women with disabilities may feel stigmatized due to a self-image that is in conflict with how society views what a woman should be (Goffman, 1963). Feeling stigmatized has been reported to lower the self-esteem of women with disabilities and subsequently influence her ability to perform social roles (Nosek, Hughes, Swedlund, Taylor & Swank, In Press). A person is affected by how people see them over time and the change in people's response to them based upon that image (Blumer, 1959; Goffman 1968).

The meaning assigned to a woman's impairment for purposes of explaining her body within a culture, may influence her identity, roles, behaviors and health (Kleinman, 1980). For instance, in an African society, the way the Songye explained the disability of a child determined how the child was treated and their subsequent roles in the community (Devlieger, 1995). The American view of the 'normal body' compared to the 'disabled body' has been rooted in scientific explanations of what is normal for the human body and what is deviant.

Women with disabilities have been described as "asexual, sick, retarded, handicapped, over sexed, and a burden upon society" (Anderson & Kitchin, 2000, p. 1164), and these images conflict with the slender sexually active modern woman that is promoted within American culture. Women with disabilities have voiced concern over their ability to meet the cultural demands of the ideal female body image (Ablon, 1996; Fine & Asche, 1988). In studies of body image, gender and disability, women have



reported being concerned about the physical alterations that occur and create a social stigma (Ablon). The cultural expectations can hinder the integration of women with disabilities into society and have been used to explain the differential treatment they receive in gender roles such as wife (Parker, 1993) and mother (Harrison & Stuifbergen, 2002; Thomas, 2001; Thorne, 1990).

The cultural image of the ideal female physique is difficult for most women to attain. This may have contributed to eating disorders and low self-esteem in many women (Bordo, 1993), but women with disabilities may be impacted more by these images. Adolescent girls with disabilities have reported significantly higher use of laxatives, diet pills, and vomiting for control of body physique (Neumark-Sztainer, Falkner, Beuhring, & Resnick, 1998). Moreover, in a study of the gender differences between young men and women with cystic fibrosis, girls were found to be highly concerned with meeting normative definitions of femininity (Willis, Miller & Wyn, 2001). The young women were less active, ate less, and had higher mortality rates than the young men. The women placed normative gender expectations above participating in practices that would promote their health. For example the girls felt that being thin was a good thing even though it was due to a mal-absorption of nutrients related to their disease process so they did little to correct the problem (Neumark-Sztainer, et al.). For women with mastectomies due to breast cancer, normative evaluations of the female body led many to choose reconstructive surgery although few found it satisfying and it placed them at risk of surgical complications (Kasper, 1995). The practices used to attain the feminine image

may be in conflict with the practices needed to maintain health when living with a disability.

The cultural images of women with disabilities may also impact interactions with the health care system. Studies have reported that women with disabilities do not receive adequate preventive and reproductive health care (Coyle & Santiago, 2002) with many reporting multiple barriers to an examination (Gans, Mann, & Becker 1993). Providers have been described as acting surprised when women with disabilities report their level of sexuality (Becker, Stuijbergen, & Tinkle, 1997). Furthermore, when a disease has been diagnosed predominantly in the female body, its existence has been questioned as a valid diagnosis (e.g. chronic fatigue syndrome and Fibromyalgia) (Thorne, McCormick, & Carty, 1997). The cultural image of women with disabilities as asexual, retarded, and invalid may have influenced what disorders providers screen for and how they offer services.

#### Human Agency

Human agency is concerned with the ability to adjust over time (Elder, 1994, 1998; Giele & Elder, 1998). As we adjust, life experiences are interpreted and meaning is made of them, which influences how we see our changing bodies and our roles within society over time. The ability to adjust to the changing body and socio-cultural environment is an essential part of aging.

It has been documented since the 1950s that women may have difficulty adjusting to disability. Watt (1955) found that women had more difficulty adjusting to disability when they had very little purpose in life or needed something to do. At that time, when

men were more preoccupied with careers, it was suggested that therapists provide women with hobbies to distract them from their physical complaints. In more recent studies, men have been found to have higher levels of acceptance of disability than women (Hampton & Crystal, 1999). For women, the severity of the disability has been less important than the ability to perform an expected activity (Nosek, Rintala, Young & Chanpong, 2001). The inability to perform valued activities and feeling stigmatized was reported to lower the self-esteem of women with disabilities and subsequently influence her ability to perform social roles (Nosek, et al. in press; Nosek et al. 2001).

#### The Timing of Lives

Events are interpreted depending upon when they occur in the sequence of life (Neugarten, 1968). When disability happens to a child, the reaction interpretation of the disability is different than when it occurs to an older person (Antonak & Livneh, 1995; Livneh, 2001). In a study of 1,266 persons in the U.S. with disabilities, the timing or onset of the disability affected the acceptance and adjustment to the disability (Li & Moore, 1998). In a study of young persons with spinal cord injuries age 15 to 29, the spinal cord injury affected their body image and left them preoccupied with being valued. They engaged in efforts to appear and function normal for their age (Dewis, 1989). This indicated the importance of affiliation within the cohort.

Timing of events is difficult to interpret with cross sectional data and often requires retrospective or longitudinal evaluations. For instance, in a study of impairment outcomes based upon timing of disability, women less than 60 years of age at onset of stroke were more likely than women over 60 to have poor adjustment to stroke related

disability (Campbell, 1994). This may be due to age or it may be due to the characteristics of those born into cohorts prior to, as opposed to after, 1934. Researchers must be careful when comparing characteristics related to age in cross sectional studies to avoid confusing age effects with cohort effects.

### Linked Lives

People are linked to one another in familial and social experiences. These linkages can provide or prevent opportunities that enhance quality of life. The importance of relationships while aging with disabilities has been emphasized in the literature. Kemp (1999) reported a positive correlation between maintaining active community ties and forming a positive quality of life throughout the life span for those with spinal cord injuries. Moreover, in the ethnographic/phenomenological autobiographical work of Frank, (2000) the participant had a positive body image despite having no arms or legs. She had two reoccurring worries of not paying rent and being unable to find a job because it would result in entering a nursing home, giving up her transportation, and losing autonomy. She also required more intense bodily interaction due to needed support from others. This study illustrated that women with disabilities require varied levels of interdependence in order to remain independent, and the risks of losing support is high. Women with disabilities can be vulnerable within their interactions due to unequal power distributions that may limit life choices as they age and put them at risk for poor health outcomes. Studies have shown abuse among women with disabilities to be different than that experienced by women without disabilities (Curry, Hassouneh-Phillips & Johnston-Silverberg, 2001; Watson-Armstrong, O'Rourke & Schatzlein, 1994; Young, Nosek,

Howland, Chanpong, & Rintala, 1997). Abusive interactions have included dismantling equipment, threats of abandonment, theft, sexual molestation, medication over dosage, and physical abuse (Powers, Curry, Oschwald, Maley, Saxton, & Eckels, 2002). Partners, family members, and paid and unpaid caregivers have perpetrated the abuse against these women. Women with disabilities have reported to stay in abusive relationships longer than women without disabilities, (Nosek, et al. 2001), and minority women with disabilities have reported more abuse from family members due to their higher use of unpaid familial caregivers (Powers, et al).

The type of interactions women with disabilities have with family can influence their life course and put them at risk for poor adjustment. For instance, marital status has been a predictor of positive health outcomes, and men with disabilities marry more often than women with disabilities (American Association of Neuroscience Nurses, 2001; Brown & Giesy, 1986). Women with disabilities have had higher rates of divorce than women without disabilities and men with the same disabilities (American Association of Neuroscience Nurses). When disability occurs after marriage, women with disabilities experience guilt about not taking care of their able-bodied husbands (Parker, 1993) despite evidence that husbands of women with disabilities had fewer burdens related to care giving than wives of men with disabilities (Bull, 2001). Moreover, in a study of mothers with disabilities, concern for how their disability affected their children was predictive of higher levels of depression. Interestingly, the depression was mediated by perceptions of higher social support (Harrison & Stuifbergen, 2002). No studies found addressed the health outcomes of women who never marry or never had children.

Provider relationships have impacted the ability of women with disabilities to age without secondary conditions and may have limited the opportunities they have had in life. Studies have reported that women with disabilities do not receive adequate preventive and reproductive health care (Coyle & Santiago, 2002), with many reporting multiple environmental barriers to an examination by a physician (Gans et al., 1993). Providers have been described as acting surprised when women report being sexually active, and stereotypes may be responsible for the inadequate reproductive care provided (Becker et al., 1997). In a study by Nosek & Howland (1997), 38% of the women with disabilities surveyed reported they had been refused treatment solely due to their disability. Women with disabilities also qualify for disability insurance less frequently than men (Baldwin, 1997). Providers do not make available to women with disabilities what they do not know or do not understand.

#### Summary

Studies have provided evidence that the elements of the life course paradigm--human agency (Nosek, et al. 2001; Nosek, et al., in press), timing of events (Dewis, 1989; Li & Moore, 1998; Livneh & Antonak, 1995), linked lives (Coyle & Santiago, 2002; Parker, 1993), and lives in time and place (Goffman 1963; Murphy, 1987; Murphy et al., 1988)--are highly applicable to the life course of persons with disabilities, but this is based on cross sectional studies of persons from varied cohorts without analyzing the effect of the social, historical and cultural context. This supports the use of this paradigm in women with disabilities, but a retrospective study that incorporates the full life course

is needed. Polio will provide the best exemplar of aging with disability at this point in time (Alexander, 1990).

## **Chapter 3: Methods**

### ***Research Design***

The purpose of this study is to explore the meaning of aging for women with childhood onset disability. The central guiding question is “What is the meaning of aging for women with childhood onset disabilities?” This existential question will be answered with a qualitative design that will consist of interviews, field notes, life course charts and specified demographic information.

The specific methodology that will guide the method of data collection, analysis and report writing, is hermeneutic phenomenology (Cohen, 2000). This methodology was chosen because the question is based upon the meaning of the phenomenon of aging set within the historical and cultural perspective of the cohort. A qualitative design is the most appropriate approach for answering the question because qualitative designs have been encouraged in areas of study where the voice of the group has been unexplored (Cohen, 2000; Smith, 1979); such is the case for women aging with childhood onset disabilities.

### ***Methodology***

Hermeneutic phenomenology (H/P) was chosen to give the phenomenon of aging in women with childhood onset disabilities a fuller and fairer understanding (Cohen 2000; Spiegelberg, 1960). It is the goal of H/P analysis, not to understand the linguistic use of the word aging, but to understand the intent and impact surrounding the experience (Spiegelberg). Therefore, when questions about the changes associated with aging are



asked, the women are free to speak of experiences that indicate what aging means to them. And when the women are asked how they have adjusted to these changes, they are free to tell stories about how the phenomenon has impacted their lives.

The H/P methodology is consistent with the overall design of this study, and it has been used with other life course studies (Tierney, 2000). H/P analysis has been described as a natural tool for use with the life course paradigm because life course descriptions are essentially phenomenological—they are stories of the lived experience; and the analysis allows for the interpretation of the life course placed into text format for analysis and interpretation of meaning (G. Frank, 1979, 2000). This way the lived experience, as it relates to the phenomenon of interest, emerges from the stories (Frank).

One potential criticism of the use of H/P with concepts of disability and gender is related to the consistent rejection of essential truths within disability and women's studies. It should be mentioned that the investigation of essences shared between culturally and historically situated individuals is not the same as an essential stereotype culturally branded upon a person based upon their gender or disability status (Frank, 2000; Spiegelberg, 1960). In fact, Kahn (2000) wrote that H/P was a non-essentialist methodology that viewed the essential themes as contextualized meanings that depend upon the shared horizon, not some universal truth or stereotypical essentializing, which is consistent with Simone deBeauvoir's, the existential feminist philosopher, view of women's experience (Beauvoir, 1974, Tong, 1998). Women with common life experiences share essences and essential relationships between essences and these will emerge from their stories (Spiegelberg).

Specifically, the methodology calls for interviews designed to draw out stories of the changes associated with aging and how women adjust to these changes. The four elements of the life course paradigm are used to bring shape to the study, which are consistent with the H/P emphasis on understanding the culturally and historically situated horizon that is shared by a group (Cohen, 2000). The individually defined events, the surrounding relationship and human agency issues, and the socio cultural and historical time period will be understood through conducting interviews and writing field notes of observations. The goal will be to elicit a story about the life course for each woman. Then the stories will be analyzed for how their roles, events and sociocultural meanings changed with aging and how they adjusted to these changes. Themes related to the influence of being women within the historical and cultural time period will emerge as the stories are analyzed.

## ***Methods***

The methods section includes the participant selection strategies, and the data management strategies for use in the study. The following sections outline the details of the strategies.

### **Participant Selection Strategies**

The participant selection strategies include the sample selection, sample size, recruitment and human subject protection. Each is outlined in detail in the following sections.

## **Sample Selection**

The sample will consist of 10 to 15 women who survived childhood onset paralytic polio. The inclusion criteria for this study are: (1) all participants will have physician-diagnosed paralytic polio before age 12, (2) belong to the age cohorts between 55 to 65, (3) be community living within the United States (4) have a disability related to paralytic polio (5) be able to speak English and (6) female. The main concern for participant selection in H/P studies is making sure the women have experienced the phenomenon of concern (Creswell, 1998). The inclusion criteria require that the women will meet these needs.

These women will have experienced polio at the height of the polio epidemic and have lived through similar social changes within the United States. By requiring that the timing of the disability be during childhood, consistency in timing of disability and its effect on aging is obtained. Moreover, since the social, historical and cultural experiences of women are different than for men, the unique experiences must be studied independently not combined into one analysis that neglects the unique experience of women. This will allow the researcher to understand how the women perceive their gender and its effect on the changes associated with aging and adjustment.

Based on population estimates from the 2000 census, there are approximately 37,000 female polio survivors in Texas. Due to the timing of the polio epidemic most of these women will meet the criteria for age. The sample will be recruited from the Texas Polio Survivors Association (TPSA). This is an informational organization for polio survivors in Texas that has contact with multiple support groups and maintains a database

of survivors across Texas. They may also be recruited from local support groups or Dr. Stuifbergen's study participants who have agreed to future studies. See recruitment for further discussion.

### **Sample Size**

Consistent with recommendations of Steeves (2000), who wrote that prior studies and empirical knowledge drive sample size selection; the sample is estimated to be 10 to 15 women. Kahn (1999) reached saturation, using a similar design with elderly individuals, after 15 intensive interviews. In a prior study of polio survivors conducted by the investigator, the participant was very eager to tell the story of her life at great length and detail. Subsequently, it is estimated that no more than 10 to 15 women will be needed for this study. This is stated knowing that sampling will continue until saturation is reached, the data is complete and minority representation is adequate. The researcher will know that saturation has been reached when each additional interviewee adds little to nothing to what is learned (Rubin & Rubin, 1995). Given the multiple interviews combined with observations, a large amount of data may be collected without need for a larger sample if the participants talk at length about their experiences (Morse, 2000).

### **Recruitment**

The TPSA has agreed to identify women who belong to their organization and meet our inclusion criteria. They will ask the women if the researcher can contact them about the study. If they consent to be contacted, the researcher will call them and explain the study in detail. If the women are willing to be interviewed and meet the inclusion criteria, a meeting time will be scheduled at their convenience at a mutually acceptable

time and place. Prior to the meeting a demographic sheet and a life course chart will be mailed to the participant for them to complete prior to the first interview. It is expected that most interviews will take place in the participant's home—however, other accessible sites could include a school, library or church.

Although multiple interviews will be conducted, attrition should not be a problem because the interviews will be conducted over a short period of time. Prior studies using this approach were successful in retaining their sample without need of special retention strategies (Kahn, personal communication, August 21, 2002).

### **Protection of Human Subjects**

The proposal will be sent to the Departmental Review Committee (DRC) of the School of Nursing and the Institutional Review Board (IRB) at the University of Texas at Austin. No informants will be involved in the study prior to the completion of the DRC and IRB review.

Approximately 10 to 15 women, who have survived polio since before age 12 and currently 55 to 65 years of age, will be included. All participants will be cognitively able to consent to participate in this research. No participant will be excluded based upon race, ethnicity or religion.

No major risks are anticipated for participants in this study. Inconvenience will be reduced by allowing the participants to arrange the time and place of the interviews. They may also terminate the interviews at any time and subsequently, reschedule or drop from the study without explanation. Each participant will be informed at each interview session that they can refuse to answer any question, talk about any topic or end the

interview session whenever they wish. The interview will be ended if the participant appears to be growing fatigued. No invasive procedures are included in the study. No existing medical records will be used. There are no alternative procedures of lesser risk than the interview format.

Confidentiality will be maintained for the subjects by changing their names to pseudonyms--non-identifying names. The pseudonyms will be used in all written records. Only the researcher, mentor and co-mentor will have access to the actual names, addresses, and phone numbers of the participants. These will remain in a locked cabinet in the mentor's research office. These will be destroyed 5 years after completion of the data analysis.

Participants will receive no monetary reward for participation in the study. They should not perceive any type of coercion to participate in the study. They will gain from contributing to the existing knowledge base and may gain some therapeutic benefit from narrating their stories (A. Frank, 1995). If the women develop emotional upset or fatigue during the discussion of their experiences, the interviews will be concluded. The women will be told in advance that they do not have to discuss any events or experiences that make them uncomfortable. The researcher has considerable experience assessing the health of persons with severe physical impairments and will be able to determine if the women are becoming compromised during the course of an interview. If necessary the participant will be referred for other forms of healthcare support. In sum, the risk/benefit ratio is favorable. The benefits to the individual and society outweigh the risks.

## **Data Management Strategies**

The data management strategies include the modes of data collection and modes of data analysis. The modes of data collection involve the interviews, demographics, life course tables, and field notes. The modes of data analysis include the description of the management of data, analysis and the strategies for bias reduction.

### **Modes of Data Collection**

An underlying premise of H/P is that people try to make meaning of their experience and the meaning made is contained in their stories (Kahn, 2000). Consequently, the aim of the interview is to bring out stories about their lives (Kahn, 2000). Since this is a study of the changes associated with aging and subsequent adjustment, a current and a retrospective approach will be taken. (See Appendix A for the interview questions). All interviews will be transcribed.

Consistent with H/P, three to five audiotaped interviews will be done with each participant. H/P recommends multiple interviews for the purpose of gaining the trust of participants so they will engage in open discussion (Steeves, 2000). The three to five audio taped interviews will give time to review and research prior interviews for clarification prior to the next interview. Interviews will be rescheduled within two to four weeks of the prior interview unless the participant needs more time. This will give the researcher time to reflect upon the stories.

If the participants become tired during the course of an interview, the interview will be stopped and rescheduled at their convenience. There will be at least 3 interviews

per participant taking 30 minutes to 1 hour per interview on average. The final interview will be used to validate the data heard during previous interview(s).

### **Interview Questions**

To answer the research questions, personal stories of their individual relationships, personal agency, the timing of the events in their life and the social-historical events will be gathered. For instance the participants may tell stories of work when asked about their life as a young adult. This will be considered in relation to the social and historical knowledge of work for persons with disabilities, which indicated that the majority of women with disabilities are unemployed (Jans & Stoddard, 1999) and often placed into low paying service-sector jobs (Gerschik, 2000); therefore, the type of work will be explored further. Moreover, in a prior study investigating the meaning of work for persons with disabilities, work was found to provide independence, and it balanced the dependence associated with being disabled (Conyers, Koch, & Szymanski, 1998), therefore their feelings of personal agency would be explored. They also found that persons with disabilities who work develop skills for negotiating, accommodating and becoming more assertive as the time past the initial disabling event increased (Conyers, et al.), therefore, their relationships with others would be explored. Social changes that occurred with passage of the ADA of 1990 offered new legal protection from work discrimination; therefore, the impact of the ADA would be analyzed by exploring the timing of their employment trends with societal changes. The timing of the work, the social and historical context of the work, their individual perceptions of agency, and the relationships that surround their work all contribute to the meaning the work will



have for them. By using life course paradigm and symbolic interactionism to guide the interviews and analysis, the participants will be able to state what is meaningful to them and rich descriptions of these events or objects will be developed. This will permit the researcher to develop thick description of specific content instead of superficial themes that do not situate the events in the life course. The interview guide is presented in Appendix A.

#### **Demographics**

Demographic data will be collected prior to the interview. The demographic collection tool is presented in Appendix B.

#### **Life Course Review Table**

The life course review table will serve as a tool to help the participant remember events prior to the interview. According to Clausen (1998), these charts are a useful way of obtaining life course information because they allow for the appraisal of the social and historical context by the researcher as well as the participant. The table will be sent prior to the study and reviewed with the participant at the first interview session. If it is not completed, the interviewer and participant will complete and discuss it together at the first interview. This table will be a prompt to help the participants to think of life course events that were meaningful to them and it will be analyzed as a part of the data using H/P. The sample life course review chart is presented in Appendix C.

#### **Field Notes**

Field notes are recommended to enhance the quality of data obtained (Emmerson, Fretz, & Shaw, 1995; Kahn, 2000). Information such as dress, body language, assistive devices and environmental details, as well as theoretical observations and documentation

of self-evaluations of the interview will be added to the field notes. This may also include descriptions or collections of pictures that represent memories of the past. The continued evaluations collected in the field notes will permit an on going reflective dialogue to help the researcher understand when saturation and completeness have been reached (Emerson, Fretz & Shaw).

### **Modes of Data Analysis**

The following section describes the data organization, analysis and bias reduction. It must be remembered that the strategies of data collection and analysis appear to be sequential, but they will be on going throughout the study.

#### **Data Organization**

The interviews and field notes will be transcribed as soon as possible after the interview. Next, the data will be checked for accuracy by listening and comparing it to the transcribed notes. The data will be merged into Ethnograph 5.0 for qualitative data analysis. Each audiotape will be transcribed and then destroyed. Transcribed notes and collected demographics will be kept within a locked cabinet at all times except when they are being analyzed.

#### **Data Analysis**

Philosophical Hermeneutics is concerned with the correct interpretation of human expression (Polkinghorne, 1983). Within hermeneutic analysis, the first step is to record what has been communicated in verbal and non-verbal form into a permanent written record (Steeves & Kahn, 1995). The text then becomes the “working ground for the study of socially constructed meaning” (Steeves & Kahn, p. 185). Understanding is the comprehension of meaning that goes beyond logical analysis (Polkinghorne) of the text.

The analysis occurs within the hermeneutic circle. There is no specified starting point or simple elements that must be present in order for understanding to occur. According to Polkinghorne it is a mental, integrative process bringing in the whole then the parts in a continual movement back and forth, and the understanding comes first in an unspecified, tacit sense.

Hermeneutic interpretation is possible because the text is supplying a meaning to a reader—it is not a non-intentional group of words without a reader (Crotty, 1998). It is more than semantics. Determination of meaning is more than relating work to an abstract theory. Hermeneutic interpretation is a combination of knowledge that comes from thinking something through and relating it to a sense of what is plausible (Crotty). The researcher must situate the text within culture and history (Crotty). Hermeneutics, however, is not a prescribed method, but a theoretical and philosophical starting point in which methodology can be based.

The analysis will begin with the bracketing of personal experiences and prior thoughts of the researcher in regard to women aging with disabilities. Kahn (2000) recommended that researchers critically reflect upon assumptions, preconceptions and prejudices prior to and during the study. The bracketing of these critical reflections is an important continual process throughout H/P analysis (Creswell, 1998; Spiegelberg, 1960).

Data analysis will continue in the field with interpretations recorded in the field notes. Field notes will be incorporated into the analysis process. Each Interview will be transcribed verbatim and compared to the audio taped interviews for accuracy. After the

data has been transcribed and checked for accuracy, the data will be read and reread. This immersion within the data with reading and rereading will help to create initial interpretations, which will also be entered into field notes for analysis. This will continue before and after each interview. This indicates a cyclical interpretation of the meaning of the experience, which is consistent with the hermeneutic circle.

Thematic analysis will be used to answer the specific aims, and it is based upon the recommendations of Cohen, Kahn, & Steeves (2000). The text will be read and reread to verify if it is representative of the experience. The transcripts will be read line-by-line and coded for specific phrases that indicate a salient aspect of the experience. The thematic analysis will be based upon the following steps, but in a non-linear fashion.

- Interview sections will be grouped based upon childhood, adolescence, young adulthood, middle adulthood and later adulthood.
- Line by line coding will be done by labeling phrases with code names. These will be small pieces of information that relate their perceptions of human agency, relationships, timing of events and events in time and place.
- Like code names from each area of the paradigm will be placed side by side together for further analysis and rules made as to how they relate, and then they will be called categories.
- Categories will be placed together for further analysis to discover the complex interrelations of the content drawn out from each element of the paradigm and rules will be made as to how they interrelate and called themes.

- Exemplars will be chosen to represent the themes. Exemplar themes will be connected throughout the life course to tell the story of how the meanings changed over time within each period of their life. This change over time in meanings and roles will represent aging. Exemplar themes will be pulled to express what the changes with aging have been, how women adjust to these changes, and how gender has influenced these meanings.

#### **Bias Control**

As recommended by Kahn (2000), the study will begin with bracketing of the researcher's view of aging in order to understand the preconceptions of the researcher prior to interpreting the experience of the participants. A journal of the study will also be maintained to document all research project decisions for continued tracking. It will maintain all preconceptions and prejudices as well as a log of all research project decisions. Moreover, memos will be generated from the analysis and given to the supervisors for verification. This will be available to all committee members for review. The supervisors will act as careful auditors for the study. The researcher will contact the supervisors for review of the transcripts, data transformation and analysis every month in order to maintain supervision.

## **Appendix A: Interview Questions\*\***

### Interview One:

- I find the best way to learn about how you have experienced the changes associated with aging is to start from the beginning. You may want to refer to the chart you completed before I arrived. It can help to remind you of events or experiences that were important to you over your life. At times I may ask you for further detail about certain things you mention. It is up to you to tell me as much as you feel comfortable with.
- Right now, I want to focus on the significant changes that have occurred in your relationships over time, but also those things that have influenced those relationships. So let's start back when you were a kid and what your relationships were like with parents, siblings and friends. Tell me what those relationships meant to you and how they affected you over time. Sometimes it helps to tell me a story about a significant relationship as an example. Then we can work forward to today.

### Interview Two:

- Last time we spoke, we talked about your relationships and how those changed over your life. Is there anything you would like to add that you didn't talk about last time?

- Again, you may want to refer to the chart you completed. Today I want to focus on the significant changes that have occurred in you and your ability to do the things you want. So, let's start back when you were a kid and what type of activities you engaged in and how you were able to do those things. Tell me what those changes meant to you? Sometimes it helps to tell me a specific story that describes how the changes affected you or to show me pictures of how things have changed. From there we can work forward to today.

#### Interview Three:

- Last time we spoke, we talked about you and how you have changed in your abilities to perform certain activities. Is there anything you would like to add that you didn't talk about last time?
- You may want to refer to the chart you completed before the first interview. Today I want to focus on how you feel society has changed around you and how that has affected you as a woman. Yet again, I want to start back when you were a girl. Do you recall what it was like to be a girl with a disability and what types of opportunities that were offered to you? Again, you may want to tell a story of what it was like to be a girl who had polio or show me pictures that you can describe. From there we can work forward to today.

- Right now I would like you to think about what aging means to you. Now, think back over your life. Was there ever a time when you felt aware that you had aged? Please tell me about this time in your life.

\*\*This is the tree and branch model of interviewing as described by Rubin and Rubin, (1995), which allows the interviewer to bring up a main question then branch out into the parts that make up the topic. This will enable the researcher to ask about meaningful events in each stage of the life course then branch into the categories of the life course that make up that complete picture. The questions above are based upon the format described by Clausen (1998), who used a similar format for life course interviews.



## Appendix B: Demographics

1. How old are you? \_\_\_\_\_
2. What is your marital status? \_\_\_\_\_
3. Do you have children? If so, how many?  
\_\_\_\_\_
4. What is the highest educational degree that you have completed?  
\_\_\_\_\_
5. What is your employment status? \_\_\_\_\_
6. How many hours a week do you work? \_\_\_\_\_
7. What type of work do you do? \_\_\_\_\_
8. What is your ethnicity? \_\_\_\_\_
9. How old were you when you contracted polio? \_\_\_\_\_
10. What year did you contract polio? \_\_\_\_\_
11. How long were you hospitalized when you had polio? \_\_\_\_\_
12. What type of polio did you have?  
\_\_\_\_\_  
\_\_\_\_\_
13. What part of your body was affected by polio during the first month of your illness? \_\_\_\_\_  
\_\_\_\_\_
14. How was your body affected by polio during the first month of your illness? \_\_\_\_\_

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15. Has a physician diagnosed you with Post Polio Syndrome? \_\_\_\_\_

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16. Are you currently using any assistive devices? If so, what kind?

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17. Do you have any health problems that require you see a physician or take medications on a regular basis? If so, what is that condition(s)?

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## **Appendix C: Life Course Review Chart**

### **Life Course Review Table**

#### **Instructions**

1. Identify the top area of the chart that has different events written across it. These events are social changes that may have affected you. Circle any event that you found very significant in your life.
2. Identify the area of the chart just below the social events that you circled. You may write in any event that was significant to you that were left off of the top of the chart. This can be any social event in your community or larger world that you wish to recognize.
3. Identify the area of the chart that is light gray. This is the life course events area of the chart. The higher you mark something in the light gray area the more significant it is to you. The lower you mark something the less significant it is to you.

4. Now fill in the chart with events that have occurred in your life that you feel are worth talking about or mentioning. Place the events that are very significant high in the gray box and place those that are less significant lower in the gray box. (See the example for more information, but you decide what is worth mentioning. What you think is significant is the point of this chart).
  
5. Identify the area of the chart along the bottom marked 'your age'. The corresponding boxes will be filled in with your age over time. Follow the instructions below.
  - Mark the spot on the chart above the year that indicates when you were born and label it birth.
  
  - After your birth, place your age in the square along the bottom of the page that corresponds to how old you were during that year.  
(See example for more information.)



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