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BARBARA ANN BARTON

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THE RELATIONSHIP BETWEEN ADAPTATION TO DISABILITY, AND SEXUAL AND BODY ESTEEM IN WOMEN WITH POLIO

Barbara Ann Barton

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ABSTRACT

THE RELATIONSHIP BETWEEN ADAPTATION TO DISABILITY, AND SEXUAL AND BODY ESTEEM IN WOMEN WITH POLIO

By

Barbara Ann Barton

Sexuality in women with long-term disabilities and chronic illnesses is an emergent focus of inquiry in the fields of disability and aging. Rehabilitation counseling and counseling practice in general often neglect this important quality of life area. Women with visible disabilities also confront the challenges of a change in physical appearance that has, historically, characterized them as asexual in media portrayals and by health care practitioners. The internalization of impressions of how she looks to others can cause a change in body image and limit engagement in intimate relationships. This can be further compounded by any physical limitations that restrict functional activities, such as the capacity to adequately take care of personal needs or engage in sexual activities. The purpose of this study was to investigate the relationships between adaptation to disability and functional status on sexual and body esteem in a national sample of women with polio. The additional variables of length of time since polio diagnosis, self-reported visibility of disability, and history of sexual abuse were included as well, since theory indicates that these could be factors that also affect sexual health.

Polio survivors represent a unique population. Not only are women with polio better educated than the general population, but the advent of Post-Polio Syndrome occurs decades after the initial diagnosis and often results in adjustment to a variety of new and severe secondary disabilities.

This investigation is one of the first in the field of rehabilitation counseling to utilize Structural Equation Modeling (SEM) as a method to analyze some of the multidimensional components that affect sexual and body esteem in women with disabilities.

Results of the study indicate that functional status, as measured by the Activities of Daily Living subscale of the Functional Status Questionnaire (Jette & Davies, 1986) is a significant predictor of sexual and body esteem, as is the capacity for women with polio to view the disability in perspective, and not a characteristic that defines or limits her potential to achieve goals, or expand her values beyond a self-comparison to other women without disabilities (Acceptance of Disability Scale-Revised, Groomes & Linkowski, 2004). Visibility of disability, length of time since polio diagnosis and history of sexual abuse were not seen as significant predictors of sexual and body esteem in this study.

The examination of sexual and body esteem in women with disabilities is a research area that holds great promise for scholarship that will enable rehabilitation counselors to more effectively help consumers enjoy a heightened quality of life.

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Kites fly only against the wind, not with it.

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Introduction

According to the Chartbook on Women and Disability (NIDRR, 1997), there were 28.6 million women, or 21.3% of the female population in the United States who live with a disability or chronic illness. Women with disabilities face unique issues regarding their sexuality, sexual esteem and body image, and how these factors are influenced by adaptation to disability and level of physical functioning. Three of these constructs (sexual esteem, adaptation to disability, and body image) are multidimensional and involve internal processes of self-perception as well as external and environmental influences (Cash & Pruzinsky, 2002; Livneh & Antonak, 1997; Mona et al., 1994).

Milligan and Neufeldt (2001) state that research on sexual esteem is a fairly recent area of scholarship that has been initiated both by clinicians and people with disabilities. Sexuality is an important and emergent quality of life factor that warrants further research. A woman's self-esteem, as well as how she functions in interpersonal situations, have both been associated with efficacious and satisfactory sexual functioning (Cole & Cole, 1999). The relationship between adaptation to disability, body image, and sexual esteem has not been often explored in women with disabilities, or in women with polio (Taleporos & McCabe, 2002; Cash, 2002). Correlational relationships have not been empirically demonstrated although much anecdotal evidence links the three together. One of the few notable studies was conducted by Nosek, Young, Rintala, Howland and Chanpong (2001) who examined the issues of body image, sexual esteem, and adaptation to disability in their national study of sexuality and women with disabilities, and determined that there are many factors that impact the sexuality of women with disabilities. Intrinsic factors such as self-esteem and body image schema combined with other issues such as sexual abuse history affect how women view their sexuality and capacity to engage in intimate relationships.

Historically, people with disabilities have been viewed as asexual (Cole & Cole, 1999; Nosek, Howland, Rintala, Young, & Chanpong, 2001; Taleporos & McCabe , 2002). This is likely due to the cultural portrayals of what represents the perfect body and media representations of what is physically attractive and desirable. For a woman with a physical disability, there can be concomitant areas of concern. Physically, a woman's body may not respond in the same way as the woman who does not have a disability. The alignment of a woman's self-identity might not be consistent with what are considered normative standards of body ideals. Some women are able to reconcile their body image with the disability and how it compares with other women. However, for others, the image of themselves as defective or flawed in some way may prevent them from fully expressing themselves physically in an intimate situation due to self-consciousness and concern over their appearance. For women with polio, a lifelong adjustment to the effects of polio re-emerges as additional secondary disabilities to which the women must adapt (Maynard, 1995).

The socialization of women born with their disabilities, or who have disabilities that are frequently diagnosed at a young age like polio, affect how they experience and express their sexuality as adults, according to Cole and Cole (1999).

There is research to indicate that issues related to sexuality are different for those women with congenital disabilities (such as cerebral palsy) versus those who have an acquired disability (Cole & Cole, 1999; Rybarczyk & Behel, 2002). Gender identity and sexual role development begin in childhood and are shaped by parental value systems and socioenvironmental factors. Women with congenital disabilities are reported to receive information regarding their sexuality at a later age than their non-disabled counterparts, begin dating later than individuals without disabilities, and marry at a later age than women without disabilities (Nosek, 2001). Women who acquire their disabilities in adulthood face a transition in sexual identity and how they fulfill social roles and expectations. Prior to the initiation of the disability a woman may have developed patterns of behavior regarding how she interacts with others in the social environment and how she acts in a relationship. The onset of disability can produce a desexualizing response as care and attention shift to the management of the effects of the disability and any intrusive medical procedures. How she relates with and behaves in an intimate relationship may change as the woman's level of independence shifts. For women with relatively stable disabilities, such as spinal cord injuries, this may mean finding creative, different ways of sexual self-expression with a partner and incorporating the attendance to personal care issues into an intimate encounter. Planning becomes a more important part of dating as transportation and accessibility issues impact spontaneity.

Women with non-stable, or progressive disabilities, such as multiple sclerosis or polio, may experience different issues. Given that she has little or no control over her disease or illness, she may experience that loss of control in other areas of her life, including her role in sexual relationships with others (Cole and Cole, 1999). Her self-concept may be unaffected during the stable periods of her disability, only to change with an exacerbation of the illness or disability particularly if it results in increased dependency on others. Rybarczyk and Behel (2002) indicate that the change in body image can be especially difficult for women with acquired physical disabilities. The former self-schemata of one who has an average degree of satisfaction with her body changes when that body is altered due to accident, disease, or illness.

Moss and Dyck (2002) indicate how the experience of women with invisible, cognitive, or psychiatric disabilities can affect their self-concepts. The disability acceptance issues may be, but are not necessarily, different with these populations, and problems associated with cognition could impact how they view themselves and others. Symptoms of some disabilities are hidden (for instance the experience of fatigue or pain), and some women may try to pass as non-disabled since they feel their disability is not socially legitimized.

Body and sexual esteem are two important aspects of life satisfaction, and the spread of a negative self-image may extend beyond interpersonal relationships into other life areas such as vocational functioning. Ducharme and Gill (1991) reported that despite the importance of this quality of life area, few rehabilitation counselors include it as part of the rehabilitation plan. Drench

(1994) highlights the need for rehabilitation professionals to understand the issues related to the changes in body image and esteem following an injury or illness. Drench stated that it is important for practitioners to help individuals with such disabilities adjust to feelings of loss, anxiety, and depression. Negative consequences of a lowered body image can include impaired social relationships, reduced self-confidence, and feelings of incompetence—all of which can affect work performance.

Body image concerns affect women in general and women with disabilities in particular. Comparisons to magazine and television ideals may leave many women distressed about their appearance and lead to feelings of shame and avoidance of many social and intimate experiences (Tiggemann, 2002). For women with disabilities, this feeling of “not being comfortable in one’s skin” can result in social isolation and further the stigmatization of people with disabilities as socially inept and sexually undesirable. Women with acquired disabilities face an added challenge: their “skin” has changed. It’s not uncommon for women with acquired disabilities to dissociate from their bodies and disengage from existing or potential relationships until they adapt to their changed body and disability, and re-form their identity as a woman who enjoys sexual expression-- who just happens to have a disability. Feminist theorists have characterized such a situation and process as learning to *be* through the embodiment of our bodies, whether this is through the sociocultural experiences we engage in or in health, illness, or disability (Moss & Dyck, 2002).

There are several different words that characterize the response to disability. Shontz (1975) used the terms pre-impact, impact, and post-impact stages to describe an individual's reaction to disability. Moos and Schaeffer (1984, cited in Livneh & Antonak, 1997) stated that the response to a life crisis such as a disability is dependent upon three mediating variables: 1) personal characteristics such as age and socioeconomic status, 2) illness factors such as the visibility of the disability and degree of pain, and 3) physical and environmental factors such as the degree of social supports and vocational status. Moos and Schaefer identify three stages of coping: appraisal-focused, problem-focused, and emotion-focused. They also described two kinds of adaptive tasks: those that deal with the specific management of the illness or disability, and tasks related to the general adaptation to the disability such as the change in self-image. Theorists such as Livneh (2001) indicated that adaptation to disability research has primarily involved three models. The first model claims that disability adaptation progresses through linear stages. The second model views adaptation as a series of recurrent cycles. The third model views the adaptation process as idiosyncratic, or as an individually unfolding model. This adaptation process is determined by the interaction between psychodynamic and disability triggered phases of adaptation, and biological, social, and environmental factors. Livneh and Antonak (1997) presented a model for a dynamic, psychosocial adaptation process. In this model, early reactions to disability or chronic illness include feelings of shock, anxiety, and denial. Intermediate reactions to the disability involve depression, internalized anger, and externalized hostility. Later reactions in include acknowledgement and acceptance, and adjustment. Livneh and Antonak presume that adaptation to disability differs from acknowledgement of disability. The former is viewed as a more conclusive state, where acknowledgement is viewed as one step in the journey to adaptation. What is limited in the literature is the use of any instruments to measure the positive adaptive mechanisms to chronic illness and disability, not just the negative constructions—although contemporary research is using the phrase "response to" disability in lieu of polarized terms such as one's "adaptation to" disability, or "consequences of" disability.

Purpose of the Study

The purpose of this study was to evaluate the relationship between disability adaptation, physical functional abilities, and sexual and body esteem in a sample of 837 women with polio who had been previous study participants in research conducted by the University of Michigan. Rather than consolidating the adaptation response into two categories, either adapted or maladapted, specific qualities of adaptation (containment of disability affects, enlargement of the scope of values, subordination of the physique, and asset versus comparative values) were analyzed in this sample and measured by the AD Scale-Revised (Linkowski & Groomes, 2004). Study participants were asked to self-scale their functioning in Basic and Intermediate Activities of Daily Living by using the Functional Status Questionnaire (Jette & Davies, 1986). Sexual and body esteem were assessed through participants' responses to the Physical Disability and Sexual and Body Esteem scale (Taleporos & McCabe, 2002).

There are many different models of coping and adaptation. This study used Linkowski and Groomes' (2004) Adjustment to Disability Scale- Revised. This instrument contains four subscales which measure four characteristics of successful adaptation to disability developed by Beatrice Wright (1960): containment of disability affects, enlargement of the scope of values, subordination of the physique, and asset versus comparative values. It was felt that this multidimensional measurement of psychosocial stages would capture the heterogeneity of the women's responses to disability.

Body and sexual esteem were measured by utilizing the Physical Disability Sexual and Body Esteem (PDSBE) Scale developed by Taleporos and McCabe (2002). This instrument was developed to assess respondents' capacity to feel positively about their sexuality and their body while living with a disability or chronic illness. This is the first and only instrument developed to measure these two quality of life areas.

Respondents' physical functioning was correlated with the above measures using the Functional Status Questionnaire (FSQ) first used by Jette and Davies (1986). This self-report instrument is an evaluation of an individual's self- perceived level of competence with activities of daily living, such as bathing and grooming, ambulation, and doing light household maintenance. The survey also contained two items in which respondents were asked to rate their general health. The FSQ has been used in primary care settings as well as within rehabilitation contexts.

Six research questions and four hypotheses were addressed in this study.

Research questions

1. Do women who have a high level of disability acceptance as measured by the Acceptance of Disability-Revised (AD-R) scale have higher degrees of body and sexual esteem, as measured by the Physical Disability and Sexual and Body Esteem (PDSBE) scale?

2. What are the correlations between the AD subscales (Transformation from Comparative Status to Asset Values, Containment of Disability Effects, Enlargement of the Scope of Values, and Subordination of Physique) and the PDSBE?

3. What is the relationship between the visibility of disability and sexual and body esteem?

4. What is the relationship between the length of time since polio onset and sexual and body esteem?

5. What is the effect of the relationship of a woman's functioning level, as measured by the Functional Status Questionnaire (FSQ) on her sexual and body esteem, as measured by the PDSBE?

6. 1 What is the effect of a woman's sexual abuse history on her sexual and body esteem?

Hypotheses:

1. There is no difference in sexual esteem and body image between women who have high levels of disability acceptance as compared to those who have low levels of acceptance.

2. The level of a woman's functional status does not impact her sexual and body esteem.

3. The visibility of the disability does not impact sexual and body esteem.

4. A history of sexual abuse does not impact her sexual and body esteem.

The use of Structural Equation Modeling and the AMOS software package will allow statistical analysis of the relationships, correlations, and dependencies between the constructs of this study as measured by the AD-R summary and subscale scores, the PDSBE single score, and the scores for basic and intermediate activities of daily living (ADL) as measured by the FSQ. The relationships were also diagrammed through a visual path analysis.

The importance of this study has application to rehabilitation counseling as well as to other counseling professions. The examination of body image, adaptation to disability, and sexual esteem has received limited study. Any one of these constructs reflects the quality of life for women with disabilities. If a woman has an unsatisfactory body image, her self-confidence, self-esteem, and social presentation can be adversely affected. This can lead to impaired psychosocial and relational functioning. The various adaptive responses can individually, or as a group, be isolated to analyze which, if any, has an affect on a woman's sexual esteem and body image. And lastly, the relevance of sexual esteem to a woman's quality of life is quite important for her own satisfaction and that of her partner. One unique characteristic of this study was the attempt to apply concepts of body image to a specific group (women with progressive disabilities) that has not often appeared in the literature. Prior research on body image has been confined to disordered eating and with limited application to the self-concept of women who have had mastectomies, ostomies, or amputations. Significant clinical insight and treatment approaches can improve life satisfaction through the contribution of this study to the body of knowledge on sexuality and body image in women with acquired physical disabilities and progressive disabilities.

Definitions

Brief definitions of terms used in this study are found below.

Sexuality- the World Health Organization provides a comprehensive definition of sexuality: "Sexuality is a central aspect of being human throughout life and encompasses sex, gender identities and roles, sexual orientation, eroticism, pleasure, intimacy and reproduction. Sexuality is experienced and expressed in thoughts, fantasies, desires, beliefs, attitudes, values, behaviors, practices, roles and relationships. While sexuality can include all of these dimensions, not all of them are always experienced or expressed. Sexuality is influenced by the interaction of biological, psychological, social, economic, political, cultural, ethical, legal, historical and religious and spiritual factors." SIECUS (Sexuality Information and Education Council of the United States) sends a clear message regarding sexuality and persons with disabilities: comprehensive education, sexual health care services, and the policies and procedures of service delivery systems should support opportunities for socializing and sexual expression to all individuals.

Sexual health- This definition, also constructed by the World Health Organization, includes a biopsychosocial component. "Sexual health is a state of physical, emotional, mental and social well-being related to sexuality; it is not merely the absence of disease, dysfunction or infirmity. Sexual health requires a positive and respectful approach to sexuality and sexual relationships, as well as the possibility of having pleasurable and safe sexual experiences, free of coercion, discrimination and violence. For sexual health to be attained and maintained, the sexual rights of all persons must be respected, protected and fulfilled."

Sexual esteem- Sexual esteem is defined by a positive regard for and confidence in an individual's capacity to experience his or her sexuality in a satisfying and enjoyable way (Taleporos & McCabe, 2002, pg. 159). For the purposes of this study, the important aspect of sexual esteem is not merely the level of sexual activity. The multidimensionality of the concept can involve the meta-components of communication style, relational abilities, and social engagement.

Body esteem- refers to the overall positive or negative evaluation of the body (Talaperos & McCabe, 2002, pg. 159). Cash (2002) defines body image as the cognitive, behavioral, and emotional importance of the body for self-evaluation. It is internal dialogue, body image emotions, and self-regulatory emotions that influence an individual's perception of life events in relation to his or her physical body. The terms body esteem and body image will be used synonymously in this study. According to Taleporos and McCabe (2002) "... research has also suggested that having a body that is not capable of responding as one would want, and that responds in a different way from that endorsed by societal norms, can lead to a lack of sexual satisfaction, frustration, and a reduced enjoyment of sexual activity (pg. 160)."

Disability adaptation- for the purposes of this study the terms adaptation, adjustment, and response to disability were used synonymously. Origins of the phrase can be traced back to Dembo, Leviton, and Wright (1956, as cited in Livneh & Antonak, 1997) who saw the process of successfully adapting to a disability as one of "coping". This construction was thought to have six characteristics: 1) it emphasizes the person's skills and abilities, 2) an individual feels empowered to direct his/her own life, 3) personal accomplishments are recognized, 4) the person with a disability is successful at negotiating negative life experiences, 5) physical and environmental barriers are minimized, and 6) the individual feels unconfined to participate in, and enjoy, life activities.

Ineffective adaptation to disability was referred to as "succumbing" to the limitations imposed by the disability and feeling unempowered and hopeless.

The definition of "adaptation" that was used in this study was developed by Livneh and Antonak (1997). They regard psychosocial adaptation to disability as "... an evolving, dynamic, general process through which the individual gradually approaches an optimal state of person-environment congruence" (page 8) which is marked by several milestones. The first is the person's participation in major life activities, such as social, recreational, and vocational interests. Secondly, the person demonstrates successful mastery of the physical environment. And third, the person is aware of her strengths and skills, as well as any functional limitations.

An additional variable in the study is a woman's history of sexual abuse. What makes this a difficult concept to measure is that there is not one commonly accepted definition of sexual abuse, although there are shared similarities in any definition. The American Psychological Association (retrieved from http://www.apa.org/releases/sexabuse/ on July 15, 2005) states that common to any definition of sexual abuse is the presence of coercion of an individual into any form of sexual activity including fondling, touch, penetration, and pornography, and could involve adults as well as peers. Researchers from the University of Minnesota indicate that the risk of abuse for people with disabilities is at least twice as high and may be five or more times higher than the general population (retrieved from http://ici.umn.edu/products/impact/133/over5.html on July 17, 2005). Furthermore, Sobsey & Doe (1991) reported that persons with developmental disabilities may experience an abuse rate as high as 90%, for those who have been institutionalized. Polio is considered a ‘developmental disability’ since the age of onset is prior to age 22 in most cases. The survey for this study did not ask participants if they had ever been institutionalized and there were no qualitative comments made on any of the survey responses that indicated a history of institutionalization Research reports indicate that a history of sexual abuse is often more of a factor in satisfactory sexual expression and adjustment than any single characteristic of disability (Nosek, et al., 2001).

Chapter 2

Literature Review

This literature review is organized into three parts. Part one discusses relevant literature on body image with special attention paid to the body image of women. The focus of part two is on sexuality with an emphasis on disability. Part three deals with adaptation to disability, its models and theories, and additional information on post-polio syndrome.

Despite what might seem like an important area of research, little has been done to evaluate adaptation to physical disability, sexuality and sexual esteem, and body image or body esteem (Taleporos & McCabe, 2002; Cash, 2002). Theoretical incongruence regarding disability adjustment and adaptation models inhibits a consensual definition of adaptation to disability. The definition of sexuality is dependent on the context in which the term is used.

Sexuality and disability have been included in the rehabilitation literature for many years (Vash, 1981; Wright, 1983). Despite the importance of this quality of life area, professionals often neglect the sexuality of their consumers. According to Ducharme and Gill (1991) rehabilitation counselors often do not include sexuality as part of the rehabilitation plan. Seventy-nine percent of rehabilitation workers indicated that sexuality is as important to a client as other functional areas, but only 9% actually include it in the rehabilitation plan. Mulligan and Neufeldt (2001) report that investigators, clinicians, and people with disabilities have drawn professional attention to the importance of sexuality to both the emotional adjustment and general functioning of people with disabilities.

Body Image and Body Esteem

Thompson and Van Den Berg (2002) categorize the attitudinal dimensions of body image into four areas. *Global subjective dissatisfaction or disturbance* refers to the general satisfaction or dissatisfaction with one's appearance. *Affective distress regarding appearance* characterizes the emotional responses to one's image such as dysphoria, anxiety, and shame. *Cognitive aspects of body image* refer to positive or negative body image schemas and the thoughts one has about his or her body. *Behavioral avoidance reflective of dissatisfaction with appearance* reflects the avoidance of social situations due to body image concerns. Another approach construes this through multiple perspectives. For example, Streigel-Moore and Franko (2002) refer to body image as a multidimensional construct that includes perceptual, attitudinal, and affective components.

Body image research is based on the foundational literature found in psychology and mediated by environmental variables. As noted by Cash (2002), "Most contemporary research on body image derives directly or implicitly from cognitive and/or behavioral paradigms in psychology (pg. 38)." Cash indicates that the cognitive-behavioral elements of body image are influenced historically, through past events, attributes and experiences. It is these historical dimensions that influence how people feel about their bodies. He also states that cultural socialization, interpersonal experiences, physical characteristics, and personality attributes are important and relevant co-factors. And, through social learning theory, these variables instill "... fundamental body image schemas and attitudes, including dispositional body image evaluations and degrees of body image investment (pg. 38)." Cash defines body image investment as the cognitive, behavioral, and emotional importance of the body for self-evaluation. It is internal dialogue, body image emotions, and self-regulatory emotions that influence an individual's perception of life events in relation to his or her physical body. Rosen (1995) defines body image as an individual's "... mental image and evaluation... of appearance and the influence of the perceptions and attitudes on behavior."

Rybarczyk and Behel (2002) indicate that "... body image changes (are a central issue in the adjustment process faced by individuals with an acquired disability (pg. 387)." They indicate that over time individuals develop stable self-perceptions, although these may not always be considered positive. In a study with individuals with amputations Rybarczyk and Behel (2002) concluded that if a person receives negative social feedback and stigmatizes his or her own disability with the co-occurring emotions of shame or embarrassment, the result can be self-imposed activity restriction. The researchers also point out that the developmental stage at which the disability was acquired is important.

Disabilities acquired in adolescence, according to Rybarczyk and Behel (2002) pose less adjustment issues than disabilities acquired in early or mid-adulthood. They indicate that during the formative years, the integration of the self as a person with a disability is easier than for individuals who have a stronger developed sense of self. Rybarczyk and Behel say "... longitudinal and path analysis studies are needed to establish whether body image concerns are a direct causal factor in adjustment or serve a mediating or moderating role (pg. 393). Path analysis will be utilized in this dissertation, and the correlation and dependencies between the various values changes (Wright, 1983) that can occur in adjustment to disability, and body image and sexual esteem will be two of its variables.

Cash (2002) states that "one of the new frontiers of scholarship is the elucidation of the challenges to body image associated with physical diseases and disorders (pg. 10)". Despite the proliferation of research involving body image that emerged in the 1990's, studies involving the concerns of body image as it relates to women or men with progressive physical disabilities have not been developed. Pruzinsky and Cash (2002) indicate that there are many variables that affect a patient's assessment of his or her quality of life, and that body image has not been integrated into the quality of life literature "...despite consistent observations that changes in physical appearance, function, and body integrity are central to the experience of illness and medical treatment." (pg. 171)

Comparative research has also been done in women with and without disabilities. Watson (1999) analyzed body image concerns of ten women with visible physical disabilities. Body image concerns of the women with disabilities were comparable to those of women without disabilities. Both groups expressed dissatisfaction about parts of their bodies, their weight, and size, but were generally satisfied with their overall self image. She discovered that the group with disabilities also experienced the need to focus more on appearance to compensate for their physical limitations.

Many concepts can be interrelated and impact the degree to which a woman feels comfortable with her body. Not all of these are related to her physical presence, but involve interplay between the person and the environment. Gibson (1997) studied the self-esteem, body image, social interaction and adjustment to disability of college-age women with physical disabilities. While the sample size was small (34 women), her findings were consistent with the results of other larger studies: adjustment to disability and self-esteem were positively related to social interaction and these three variables were important when assessing sexual esteem.

The importance of person/environment interaction was further explored by Williams (1993). He indicated that one's dissatisfaction with his or her own body can be a negative influence with social relationships, and that the person with a disability is at risk for becoming reclusive and isolated. He stated that professional intervention should focus on re-building a positive self-image and sexual identity rather than on the physical aspects of sexuality.

In a small but unique study, Ketz examined the sexual self-concept and body image in lesbian and heterosexual women with disabilities. Heterosexual women with disabilities reported lower sexual self-concepts than lesbian women with disabilities, but both groups were equivalent on body image assessments. Lesbian women valued body image traits such as facial and physical attractiveness less than heterosexual women. While lesbians did express some body concern issues, they were less of a comparative nature with regards to normative and cultural ideals of beauty. Ketz also indicates that body image was the best predictor of sexual self-concept and a higher degree of positive body image for both heterosexual and lesbian women.

The study of human sexuality coincided with the various civil rights movements of the 1960's and 1970's. As late as 1976, however, research on sexuality had yet to become integrated into counseling and psychological practices. Sue (1976) states that "... sexual behavior is associated with so many taboos and prohibitions in our society that free discussion of sex and its systematic research is prohibited in many situations (pg. 348)." Freedom of expression and a more sexually permissive society helped stimulate the inclusiveness of sexuality into contemporary and mainstream psychosocial therapies, although Freud's psychoanalytically-based drive theory served as the forerunner.

The cognitive-behavioral basis of body image is not the sole theoretical paradigm. According to Malkah-Notman (2003), Wilson (2003), and Krenke-Seiffge (2002) there is a renewed interest in the psychoanalytic aspect of sexuality and body image. This has forced a reevaluation of the female body in relationship to "femininity" and feminine body image. The development of the body and the ego has an important, mutual relationship, as occurs in adolescence. Focus on the body is integral in adolescent maturation, and pressures from peers and popular culture help define the body image of a young adult. Across the lifespan, body image is seen as an evolution from the primary mother-baby relationship to the awareness of human mortality. The adult with a disability is a product of increasing autonomy as experienced developmentally throughout her life, and is further shaped by contemporary sociocultural norms. Blumberg (1975) argues that the psychodynamics of personality and ego development are related to motor development and that body image, important for normal psychological performance, is often impaired by somatic or cerebral deficits found in disabilities.

One of the primary perspectives on body image involves the constructing of body image as a developmental process. Krueger (2002) uses the term "body self" to refer to the "... combination of the psychic experience of body sensation, body functioning, and body image" (pg. 30). He indicates that body image is the evolving developmental and mental representation of the body self. Elements of this include the early psychic experiences of the body, defining body surface boundaries and distinguishing the body's internal states, and the definition and cohesion of the body self as a foundation for self-awareness. Additional research on the impact of an individual's developmental stage on body image was conducted by Ben-Tovim and Walker (1995). The researchers specifically analyzed the influence of an individual's developmental stage at the time of acquiring a disability that can affect body image. They conclude by indicating that these stages must be considered when assessing adjustment of an individual's modified body image. The issues of body image are different for congenital versus acquired disabilities, and hidden versus visible disabilities.

Society places enormous positive value on having an attractive, perfect physique. Unfortunately, social constructionists rarely portray individuals with disabilities as well-rounded, and socially and sexually competent. Ubiquitous unidimensional representations of people with disabilities serve to perpetuate stereotypes, such as the martyr-like person in a wheelchair, the heroic individual with a developmental disability who accomplishes a superhuman feat, or a fearsome blind person with a prosthetic arm. Such images are not necessarily representative yet form society's perceptions of people with disabilities (Norden, 1994). The Centers for Disease Control estimate that only roughly 10% of women match the social ideal for the female body profile as portrayed in media images. Weight and attractiveness standards are similarly misaligned with the model female image. For women with visible physical disabilities, the combination of what may seem like unachievable physical beauty and the sociocultural pressure to conform can be degrading and devaluing.

Sexuality and Disability

Cole and Cole (1999) indicate that, in addition to the media reinforcement of having a perfect body, there is a lack of positive role models with disabilities. Regarding sexuality, people with disabilities are either asexual or "...overlooked in the sexual spectrum of life (pg. 247)."

Women with physical disabilities are often viewed, too, as asexual and void of any appeal or desires. Physical imperfections adversely affect self-esteem, one's comfort with her body, her capacity to experience her sexuality in a satisfying and enjoyable way, and ultimately the degree to which she has successfully adapted to her disability. (Cole & Cole, 2001; Nosek, Howland, Rintala, Young, & Chanpong, 2001; Taleporos & McCabe, 2002). In the case of an acquired disability or an unstable chronic disease process, the body-self may change over time. The physical identity a woman previously maintained may have been altered by the disease course, a sudden injury, or onset of an illness of disability. Without precept, limbs that she has always expected to perform a certain way may have changed their functional capacity. She may feel that the visual appeal of her body will be undesirable to a partner. Scars, disfigurement, pain, and fatigue are further contributors to negative body esteem.

A large comparative study involving women with and without disabilities revealed that satisfactory sexual esteem and body image were predictive of intrapersonal functioning. Taleporos and McCabe's study (2002) investigated the association between sexuality and psychological well-being in 1,196 people with physical disabilities. The results demonstrated that sexual esteem, body esteem, and sexual satisfaction were strong predictors of self-esteem and depression among people with physical disabilities as compared to a group of non-disabled individuals. This was the first study in which these three constructs were measured. The methodology of the researchers resembles that of Nosek et al.'s study (2001), where responses on various measures of sexuality, body image, and self-esteem were compared against the scores of women without physical disabilities.

Another factor to consider is a woman's perception of herself as a sexual being, how she views her sexuality and her perspective on her sexual functioning. There are studies to indicate that these are influenced strongly by self-perceived levels of physical attractiveness. Wiederman and Hurst (1997) presented a self-report measure of women's sexual self-schema, or cognitive view of the self regarding sexuality. Results indicated that two areas of significance were self-rated facial attractiveness and social avoidance due to concern about looks. This study confirms the results of other research. If a woman perceives herself as unattractive she is less likely to extend herself into her social environment and engage others in any type of relationship. A key outcome of this study was that a woman's view of other parts of her body may be unsatisfactory, but it is her self-perception of her facial attractiveness that is remarkable.

The influence of disability can comprehensively affect a woman's interpersonal functioning. Benefield and Head (1984) contend that women with a disability undergo a revision of self-concept, disruption of role patterns, and a period of adjustment imposed by the disability. This study also reported notable changes in how a woman views her body image and its influence on her identity. When disability is introduced into a woman's lifestyle, role changes and role fulfillment may shift. Previous feelings of competency may be replaced by feelings of poor self-worth and failure. The effects of disability were also found to radiate to the environmental context. The researchers report that females with disabilities experience greater discrimination than males in life areas such as housing and locating personal assistance services, although both are adversely affected. Benefield and Head's conclusions state that if counselors become more aware of potential discrimination against females with disabilities, their influence can help the women with disabilities, their families, and other professionals who work with them.

The social construction of an ideal body type has been driven by sociocultural risks and benefits. Much like the idealized standards of beauty have business and “bottom-line” implications and the visibility of disability can be compared to having a negative business influence. Wendell (1996) argues that the principle of normality (a “non-deviant”, non-disabled physical form) creates an idealization of body image that ultimately has its roots in economic reward. Idealized standards promote not only comparison, but also act as an oppressive and inegalitarian system of sexual subordination for women.

Opportunity for sexual expression and sexuality education are two areas that are often limited for people with disabilities. Milligan and Neufeldt report that the impression of the asexuality of people with disabilities can be associated with two lines of thinking. First, for people with physical disabilities, because of actual or presumed sexual dysfunction, gratification opportunities are minimized or absent. Second, individuals with psychiatric or intellectual disabilities are thought to have limited social judgment and lack the capacity to engage in responsible social relationships. As a result, sexuality education is limited or absent for many people with disabilities. Not only is education affected, but the promotion of sexuality as a pleasurable, natural, and important activity is ignored (Tepper, 2000).

Tepper argues that, historically, sexuality has had a biological component and that society’s focus has been primarily on sexuality only as it relates to reproduction. Traits of people with disabilities were undesirable and individuals were encouraged not to procreate, and in some cases people with disabilities were manditorily sterilized. In the survival-of-the-fittest mentality, what is young, beautiful, healthy, and vigorous is good and is deserving of reproduction. For the person with a disability whose body might not be healthy or beautiful, the internalization of such normative thinking can result in decreased self- esteem, impaired body image, or even dissociation from one's body.

Schneider wrote of the suppression of the sexual needs of "handicapped persons" in 1976: "... suppression of the handicapped begins when they are exposed to and start operating in the so-called normal society. There the handicapped individual tends to be judged as being on a lower mental level and of an inferior sexual capacity (pg. 378)."

Sexual expression is merely one facet of sexuality. Equally as important is the internal process of self-assessment as a sexual person and her interpersonal relatedness. Sipski and Alexander (1997) indicate that any discussion regarding sexuality must consider the broad picture, beyond purely sexual behaviors. Expression of a person's sexuality involves the way one dresses, the way one carries oneself, the way one looks at self and others, and sensory information in how one intra- and interpersonally relates. Ducharme, Gill, Biener-Bergman, and Feritta (1993) indicate that sexuality might just be the most important part of rehabilitation because of the relationship to self-esteem and body image, as well as other factors.

One way to conceptualize sexuality has been offered by Cole and Cole (1999). They grouped issues related to sexuality into four categories: 1) sexuality and developmental disabilities, 2) sexuality and acquired disabilities, 3) reproductive issues, and 4) issues pertaining to the aging process. Each developmental life stage, they propose, has distinct psychosexual issues. This dissertation is principally concerned with the second category: sexuality and acquired disabilities. The experience of disability involves not only the woman herself, but also affects how she functions in a partnership. Cole and Cole indicate that gender roles may become blurred, "... past sexual patterns of activity may impede creativity needed after a disability, and medical experiences may have a desexualizing effect upon self-esteem and libido (page 242)." Because of alterations in physical functioning, a couple's approach to sexual activity and its expression may change. Prior to the onset of the illness or disability a woman may have felt completely independent and in control of her body and, for the most part, its sexual responses—which lead to a sense of mastery and control over the environment. Needing to depend on a personal assistant or partner for positioning can change the mood and spontaneity of an encounter, which can result in feelings of disempowerment and inadequacy.

As noted above, the psychosocial sequelae differ in acquired versus congenital disabilities. Acquired disabilities are typically characterized as either stable (i.e.- a spinal cord injury), or progressive and variable (i.e.- multiple sclerosis or polio) conditions. Psychosexual considerations are different for each disability pattern. Cole and Cole state that the lack of control over the medical course for those with progressive disabilities may impact an individual's self confidence and feelings of control in sexual situations.

Amundson (as cited in Wendell, 1996) distinguishes chronic illness from either an acquired or congenital disability. He states: "... unlike ill people, disabled people are not typically globally incapacitated except insofar as the environment helps to make them so." He refers to the medical treatments that often can suppress the manifestations of a disability, such as anti-epileptic medicine to prevent seizures. Also mentioned is the capacity of some disabilities to present in remitted states, again, such as multiple sclerosis
so that the individual's appearance is "normal". Such presentations influence an individual's response in sexual and social situations. If the disability is apparent, feelings of inferiority, shame, and loss of control are more likely to occur.

Wendell (1996) refers to this as the 'myth of control.' She postulates that there is a pervasive perception that if an individual takes care of him or herself, he or she can avoid disability, and thus can maintain control over most if not all aspects of his or her sexual and social experiences.

One area of sexuality and disability that has been researched and well-documented is sexuality, body image, and women with breast cancer. The studies have contributed richly to the empirical base of sexuality and body image with this population. (Andrade, Baxter, & Semple, (2001); Fine & Asch (1988); Fortune, (1979); Hensen, (2003); McGarvey, Baum, Pinkerton, & Rogers (2002); Owens & Tepper, (2003). Body image was evaluated as was sexual health outcomes such as sexual interest, sexual dysfunction, and sexual satisfaction. Research indicates that at a time when a woman's greatest need for closeness and intimacy occurs, a changed cosmetic appearance and decreased energy level impair full expression of sexuality. Results indicate that both the diagnosis of breast cancer and its subsequent treatment are intrusive both for the woman with cancer and her partner. A significant finding in the McGarvey, Baum, Pinkerton, and Rogers study was that women with alopecia as a result of their cancer treatment reported lower self-esteem, poorer body image, and negative effects on sexuality as compared to those women who did not experience hair loss as a function of treatment.

Additional research has focused on specific disabilities and sexuality (Sipski & Alexander, (1997); Owens & Tepper, (2003). For example, Rousso (1982) describes some of the key social and sexual issues facing people with cerebral palsy. Individuals with cerebral palsy have had their disabilities since birth and are likely to have been socialized into a disabled, asexual role, often struggling to put their disability into perspective to demystify sexuality, develop a positive body image, master essential social skills, and understand sexual functioning. The researcher recommends that counselors sensitively address these issues while being aware of their own attitudes and stereotypes. Gutweniger, Kopp, and Gunther (1999) studied the perceptions of body image and sexuality in women with rheumatoid arthritis. Their results suggested that women with severe rheumatoid arthritis dealt with anxieties regarding health, and have sexual concerns and dissatisfaction.

Richards, Tepper, Whipple, and Komisaruk (1997) identified sexuality and relationship issues among with women with spinal cord injuries. The results of their study indicated that there was a degree of cognitive-genital dissociation immediately post-injury, which they refer to as “shutting down” and “shutting out” sexual or intimate encounters due to the increased focus on activities of daily living. Their phenomenological study included comments from women such as: “I didn’t relate to sexuality because my priority was my body (pg. 276).” The researchers also report that body image in relation to sexual self esteem was a concern to the women: “I was not attracted to men in wheelchairs, so I don’t know how anyone could be attracted to me (pg. 277).” Sexuality and women with psychiatric disabilities is an emergent research area (Cook, 2000, Nelson, Ochoka, Griffin, & Lord, 1998). For individuals who reside in institutions, expression of sexual needs and desires can be severely restricted.

People with mental illness who have a history of childhood and adult abuse are especially vulnerable to mental illness and have psychiatric characteristics that may prevent them from fully expressing intimate feelings and emotions. Literature was cited by Cook (2000) that indicates that anywhere from 36% to 85% of women mental health consumers in the public system have experienced traumatic abuse including physical and sexual abuse as children or adults (pg. 200). Stigmatization and the effects of psychiatric behavior on sexual identity and practices are important considerations in working with this population. Karlen (2002) evaluated the positive sexual effects as reported by women with systemic lupus erythamatosus. For some women, despite physical and emotional problems, coping with lupus improved sexual functioning and relationships principally as a result of increased communication and the transient nature of symptoms.

The evaluation of body image in people with visible disabilities may be different from that of people with hidden or non-visible impairments. Fauerbach, (2000) analyzed body esteem in individuals who have sustained disfiguring physical injuries. They found that measurement of this construct and quality of life was best accomplished through disability-specific instruments rather than general scales. An instrument that was specifically designed to measure body image in people with significant cosmetic injuries was the Satisfaction with Appearance Scale, which assessed body image among burn-injured patients (Lawrence, Heinberg, Roca, Munster, Spence, & Fauerback, 1998). Burn injuries and its medical consequences are often the most visible of physical disabilities. Extending beyond cosmetic appearance, burn survivors often experience severe negative effects on their self-esteem. It is not infrequent for social isolation to play a prominent role in the life of people with disabilities, and this should be a key consideration in the assessment of individuals and the development of rehabilitation plans.

Limb loss is another area in which there may be issues related to an individual's quality of life. Ryzbarczyk, Szymanski, and Nicholas (2000) state that sexuality is one area that professionals do not adequately address in the rehabilitation of individuals who have had amputations. Williamson and Wallace (1996, cited in Ryzbarczyk et al., 2000) found that only 9% of individuals who underwent amputation received information or the opportunity to ask questions regarding sexuality. Amputation is primarily considered a stable disability in the research, unless it is the result of a primary disability, such as diabetes.

Research has also considered the effect of Charcot-Marie-Tooth disease on sexuality (Crabtree, 1997). Charcot-Marie-Tooth disease is also known as hereditary motor and sensory neuropathy and affects one in every 2,500 persons. The researcher indicates that the clinical expression of this disease includes hand muscle atrophy, and lack of sensation in the legs and arms from the knees and elbows down, which can impact sexual performance, expression, and body image.

Women with Disabilities

There may be a gender differentiation in how sexuality is addressed. According to Mona (1998), less attention has been focused on the sexual lives of women with disabilities. Because historically female sexuality has been explored less often than male sexuality, and because disability status has often carried the stigma of asexuality, Mona indicates that little is known about the sexual expression of women with disabilities. Historically, social comparison theory regarding women's body image in relation to the appearance and features of others has been propelled by sociopolitical pressures. Also, the standards of physical attractiveness are variable by culture. This influences how others respond to the individual: people respond differently based upon the attractiveness or unattractiveness of a person, no matter what culture. These can negatively or positively contribute to self-esteem and feelings of self-worth (Jackson, 2002). Jackson also indicates that the majority of research on attractiveness has been done on facial attractiveness. She cites three reasons for this: first, early research focused on the perception of others regarding attractiveness, second, facial attractiveness is seen as more stable than body appearance, and third, early research confirmed that overall attractiveness was confirmed by facial attractiveness. These tenets hold true regarding others' perceptions of an individual's attractiveness, but the research on an individual's self perceptions focus on the body. Jackson, again, remarks on how important cultural ideals are regarding self and other perceptions of attractiveness.

McKinley (2002) states that "current feminist theory contends that women's normative body dissatisfaction is not a function of individual social pathology but a...systematic social phenomena" (pg. 57). She further discusses that women and girls objectify their bodies as a result of internalizing the social construction of the role, function, and appearance of women's bodies. If a woman does not achieve the internalized body image standards, body shame results and is an important factor in the subsequent development of eating disorders and various body image pathologies. She states that women with disabilities are among the groups of women for whom we know relatively little, as compared to the body image issues of Caucasian, female college students, which comprise the subject pool of most studies. The convenience of this population for researchers, as well as the primary focus of body image research being disordered eating, limits the generalizability of research results to populations with dissimilar demographics.

Perhaps the most comprehensive study on sexuality and women with disabilities was conducted in the mid-1990's. Nosek, Rintala, Young and Foley (1994) reported on the first part of their three year NIH-funded study of sexuality and women with physical disabilities. The qualitative portion of the study (interviews with 31 women with physical disabilities) revealed several activities that can result in satisfactory sexual health and relationships. Their results highlighted the need for women to engage in health-promoting sexual and physical health behaviors. Women with disabilities should also pursue congruity between desires, values and sexual behaviors. Women also need to manage their physical environments to promote privacy for intimate activities, strive for satisfaction with the frequency and quality of sexual encounters, and communicate freely with partners about any limitations and devices and about what is sexually pleasurable.

The second phase of the study involved comparative responses between women with disabilities versus those without disabilities on issues related to sexual functioning. 1,150 women with disabilities were given two copies, and each was asked to give one copy to a friend that didn't have a disability. The response rate was 45% and the researchers received a total of 946 women: 504 of whom had disabilities and 442 women who did not.

Several major findings emerged from the study (pg. 7):

1. Compared to women without disabilities, women with disabilities were less satisfied with how often they date and perceived more constraints on attracting dating partners.

2. Even when women with disabilities were outgoing with strong social skills and many friends, their friendships were less likely to evolve into romantic relationships than for able-bodied women.

3. The large majority (87%) of the women with disabilities had had at least one serious romantic relationship or marriage. Fifty-two percent were involved in a serious relationship at the time of the study, 42% of the women said they weren't in a relationship because no one had asked them. Only 27% of women without disabilities listed the fact that nobody had asked them to engage in a partnership as a reason for not being in a relationship.

4. More than half of the women with disabilities believed that disability was not a major cause of the ending of a marriage or other serious relationship.

5. Only 38% of the women with disabilities in this sample had borne children compared to 51% of women without disabilities.

6. Women with disabilities were significantly more likely than those without disabilities to stay in a bad marriage for fear of losing custody of their children.

Other issues related to sexuality, as reported by Nosek et al. indicated that in women with physical disabilities, self-esteem is more strongly influenced by social and environmental factors than by the fact of having a disability. Other conclusions stated that abuse and sexual abuse is a serious problem, that the opportunities for sexual activity for women with disabilities occur less than the opportunities for women without disabilities, and that barriers to general and reproductive health care can be substantial.

Krotoski, Nosek, and Turk (1996) edited a comprehensive book on the sexual health of women with physical disabilities. The book discusses the psychosocial, sociocultural, historical, and political aspects of sexual self-definition and sexual expression of women with disabilities—broadening the conceptualization of sexuality. The multidimensionality of the sexuality construct in women with disabilities has emerged in recent years. Areas such as reproductive health, pregnancy and childbirth, lesbianism, and sexual abuse of women with physical disabilities are subjects of recent studies. These topics will not be discussed in this paper in order to keep the subject focused.

Another significant study recently analyzed the sexual esteem, sexual satisfaction, and sexual behavior of people with disabilities. McCabe and Taleporos (2003) examined these issues in a sample of 748 men and women with disabilities and 448 participants who did not have disabilities. They concluded that the more significant an individual's disability, the lower his/her sexual esteem and sexual satisfaction were—and the greater their sexual depression. In evaluating the gender differences between men and women with disabilities, Taleporos and McCabe (2003) found that women with physical abilities had significantly more positive feelings about their sexuality and more sexual experiences than their male counterparts. The researchers also expressed that both men and women who experienced their disabilities for a long period of time reported more positive attitudes about their sexuality than individuals for whom disability was a more recent status change.

In the general population there have been dramatic differences in the past 20 years in the way men and women rate their overall dissatisfaction with their body image. In 1972, 15% of men and 23% of women reported body image dissatisfaction. In 1985 those numbers increased to 34% of men and 38% of women feeling dissatisfied; and by 1996 the figures significantly rise to 43% of men and 56% of women reporting dissatisfaction with their body image. (Berschied, Walster, & Bohrnstedt, 1973; Cash, Winstead, & Janda, 1986; and Garner, 1997). Cash (2002) reports at length about the methodological problems from which the various percentages were derived, referring to errors of measurement and conceptual definition discrepancies. While the data may be inconsistent it is abundantly clear from media representations and popular culture that the promotion of set standards for attractiveness influences both men and women. Tiggeman (2002) states that there are contradictory studies on what media venues are most likely to promote body image satisfaction or dissatisfaction. A summary of these studies reveals, according to Tiggeman, that print media is more influential in general than television; but that the images communicated specifically in music videos have the greatest influence. She indicates that "... there is no sufficient evidence to conclude that brief exposure to idealized media images (less than one night's viewing or a single issue of a fashion magazine) does have short-term deleterious effects on mood and body satisfaction (pg. 95)." She continues to say that even brief media exposure does, however, continually reinforce levels of insecurity regarding body image.

Adaptation to Disability

Contemporary scholarship on adaptation to disability has its foundational roots in the model proposed by Dembo, Leviton, and Wright (1956), and further supported by Wright (1983). Adaptation to disability is promoted by an individual's recognition of the disability and the integration of the impairment into a person's life. Furthermore, Wright (1983) indicates that there can often be a value shift that reduces the "spread" of the disability into other aspects of an individual's life. Four principle changes in values that Wright proposes include these factors:

1. Enlargement of the Scope of Values. When a disability appears, and before other values are often initiated, the person progresses through a continuum of coping with the perceived loss. Attention becomes more acutely focused on what is important in life outside the management of the disability effects.

2. Subordination of the Physique Relative to Other Values. Wright referred to this as the realization that although one's body does not fit the "ideal" in terms of physical perfection, there are still other important life

areas, such as vocational interests, family roles, and friendships that become more important than physical capacities.

3. Containment of Disability Effects. The onset of a disability should not infer impaired functioning in other areas, such as social, intellectual and emotional domains. The impact of the disability is “contained” to the direct effects on the body of the illness or disability.

4. Transformation of Comparative-Status Values to Asset Values. This involves a transformation from comparing oneself to a non-disabled norm into seeing aspects of disability adaptation as promoting independence through successful negotiation of challenges presented as a result of the disability. An example of this would be the use of adaptive equipment to promote independence and facilitate recreational, social and vocational goals.

Wright indicates that a person can either cope with, or succumb to, the experience of disability and that adjustment can be framed using the above value changes. Wright has contributed richly to the literature involving the somatopsychology of the adaptation process. Cook (1998) states, in discussing Wright’s influence, that in addition to the potentially devaluating effects of disability, Wright says a person with a disability may assume an inferior social status position due to (p. 310):

1. Having a dual identity with the disabled and non-disabled populations.
2. Engaging in behavior “as-if” they did not have a disability.
3. Revere non-disabled standards to the extent that the individual pursues the unattainable standards.
4. Areas of impairment are focused upon, rather than individual assets.

General criticism of Dembo, Wright, and Leviton (1956) concern the lack of operationalization of, and measurement problems with, the value shifts. Second, disability adaptation literature has primarily focused on physical disabilities. Consideration of the adjustment process for those with sensory and non-physical disabilities has been limited.

Keany and Gluechauf (1999) promote the evaluation of disability adaptation according to a model proposed by Rokeach (1973). In this model, Rokeach defines a value as “an enduring belief that a specific mode of conduct or end-state of existence is personally or socially preferable to an opposite or converse mode of conduct or end-state existence” (p. 5). Rokeach classified values into two categories: terminal and instrumental. Terminal values are associated with desired traits such as wisdom and a peaceful world. Instrumental values are those which enhance behavior to reach terminal goals. These can include logic, a positive outlook, and competence. He sees the disability as possibly altering terminal values that were formerly regarded as highly important and changing instrumental values. Acceptance of disability involves re-ordering of the terminal and instrumental values to reflect what a person highly regards, with the knowledge that these values might have changed as a result of the onset of the disability.

One of the most influential contemporary scholars in the field of psychosocial adaptation to disability is Hanoch Livneh. Livneh's model (1986) of adaptation consists of five stages. The stages vary from those that involve denial of the disability (initial impact and defense mobilization) to those that reflect disability acceptance (initial realization, retaliation, and reintegration). In the *initial impact* stage, the individual may depersonalize the disability in order to manage shock and the loss experience. Anxiety shortly follows in which there are periods of feeling overwhelmed by the disability and how to cope with it. In the *defense mobilization* stage, bargaining and denial keep the individual's mood stable while ignoring the realization of the functional impact of the disability and the potential psychosocial and emotional impact of the illness or disability. The *initial realization* stage involves feelings of sadness and loss, internalized anger, and obsessive thought processes regarding how the diagnosis of a disability might significantly alter one's quality of life, or limit the length of one's life. The *retaliation* phase involves the external projection of anger and hostility to others who are close to the individual. *Reintegration* involves the cognitive process of acknowledgement of the disability, a realistic appraisal of how it will impact one's life; followed by acceptance of the disability and perhaps the limitations imposed by the disability—and the final stage of *adjustment* where an individual's life plan and goals are made in consideration of disability effects along with other factors, but the disability is not necessarily attributed more power than what is practical and realistic.

Livneh (2001) expands his adaptation theory to address the conceptualization of other psychosocial issues related to chronic illness and disability. He states that there are three classes of interacting variables that mark the adaptation to disability process. The first are *antecedents* or triggering events that initiate the process. The second class involves individual *reactions* to disability, which are seen as a dynamic, evolving process. The final class involves the *psychosocial outcome categories* in which an individual's psychosocial adjustment to disability is assessed and measured.

Livneh further indicates that adaptation is determined by the interaction between the psychodynamic and disability-triggered phases of adaptation, an array of biopsychosocial and individual factors, sociocultural factors, and environmental factors. Quality of life measures include assessments of functioning along these domains.

Livneh and Antonak's (1997) definition of "adaptation" will be applied throughout this study. They regard psychosocial adaptation to disability as "… an evolving, dynamic, general process through which the individual gradually approaches an optimal state of person-environment congruence" (page 8). The researchers argue that adaptation is not a linear process, but can be cyclic and irregular. The cyclical stages, and those that are measured in Livneh's Reactions to Impairment and Disability Scale (RIDI) are: shock, anxiety, depression, denial, internalized anger, externalized hostility, acknowledgement, and adaptation. A person may experience any of these stages and can cycle through any of the stages more than once.

Polio and Post-Polio Syndrome

Perhaps no disease was feared more greatly during the first half of this century than poliomyelitis (polio). In the polio epidemic of 1952, over 20,000 Americans developed paralytic polio (Jubelt & Drucker, 1999). With the introduction of the Salk inactivated polio vaccine in 1954 and the Sabin oral polio vaccine in 1961, paralytic polio was virtually eradicated in the United States (Jubelt & Druker, 1999). Decades later, following a period of prolonged stability, many patients may experience secondary functional disability related to polio, which has been identified as post-polio syndrome (PPS) (Jubelt & Cashman, 1987; Kidd, Williams & Howard, 1996; Maynard, 1995).

The psychological effects of long-term experience with polio can have an adverse impact on individuals, and can often be diagnosed as a psychoemotional disorder such as depression and post-traumatic stress syndrome (Maynard, 1995). After decades of relatively stable health, the diagnostic process and presence of new symptoms can leave individuals anxious, fearful, angry and depressed, especially if a physician can find no specific secondary condition and communicates uncertainty about the diagnosis (Maynard, 1995). Tate et al. (1994) examined distressed/depressed polio survivors to non-distressed/non-depressed polio survivors. The former were found more likely to be living alone, to be experiencing new health problems, to seek professional help, to view their health as poor, to report greater pain, to be less satisfied with their occupational status and life in general, and to exhibit poorer coping skills in relation to their disability. Positive coping factors included positive self-acceptance, information seeking and sharing about disability, and social activism.

The long-term effects of polio emerged as a distinct and potentially disabling consequence of the disease in the late 1970's. Survivors of paralytic polio began to notice new health problems that included fatigue, pain, mobility impairments, cold intolerance, swallowing problems, decreased upper limb function, decreased respiratory capacity, impairments in activities of daily living, and new weakness that eluded diagnosis by medical practitioners (Jubelt & Drucker, 1999). Complaints from individuals with polio histories span a range of physical and emotional sequelae. Health concerns such as fatigue, muscle and joint pain, reduced exercise tolerance, impairment of activities of daily living, and limb atrophy that are frequently presented to the physician (Dalakas & Hallett, 1988). The new constellation of symptoms was referred to as "post-polio syndrome (PPS)." The delay in onset between acute poliomyelitis and PPS ranges from eight to 71 years, with the average interval being approximately 35 years. The more severe the acute polio, the earlier new symptoms are likely to occur (Jubelt & Cashman, 1987).

It is difficult to distinguish PPS from a host of other neurological and neuromuscular disorders and diagnostic criteria for PPS are often ambiguously defined. Jubelt and Drucker (1999) reported the criteria for diagnosis of PPS from the results of the Post-Polio Task Force: 1) a prior episode of paralytic poliomyelitis with residual motor neuron loss (which can be confirmed through a typical patient history, neurologic examination, and electrodiagnostic exam), 2) a period of neurologic recovery followed by an interval (usually 15 years or more) of neurologic and functional stability, 3) a gradual or abrupt onset of new weakness or abnormal muscle fatigue (decreased endurance), muscle atrophy, or generalized fatigue, 4) exclusion of other medical, orthopedic, and neurologic conditions that may be causing the symptoms.

Jubelt and Cashman (1987) identified nine possible causes of PPS: 1) chronic poliovirus infection, 2) death of remaining motor neurons with the normal aging process, 3) premature aging of cells permanently damaged by the polio virus, 4) premature aging of the remaining normal motor neurons due to an increased metabolic demand, 5) loss of muscle fibers in reinnervated motor neurons as a function of age, 6) predisposition to motor neuron degeneration because of glial, vascular, and lymphatic damaged caused by the polio virus, 7) poliomyelitis-induced vulnerability of motor neurons to secondary insults, 8) genetic predisposition of motor neurons to both poliomyelitis and premature degeneration, and 9) and immune-mediated mechanism. There is no specific diagnostic test for PPS, which continues to be a diagnosis of exclusion in an individual with symptoms and signs of the disorder (Trojan & Cashman, 1997).

In a recent study of post-polio syndrome, researchers at the University of Michigan surveyed over 1,200 individuals with PPS (Kalpakjian, Tate, & Quint, 2004). They found their sample to have a higher rate of educational achievement as compared to the national average as reported in census data. In most cases, over 25% of the sample had advanced degrees, as compared to approximately 10% of the national average. Another significant finding was that, in general, older participants expressed greater positive and lower negative mood and perceived stress (pages 21-22).

Because of the presence of a second disability in women with polio who experience post-polio sequalae, the construct of acceptance of disability was viewed as a relevant measure of psychosocial functioning because this sample of women may need to re-define their self-schema in the face of new limitations and health challenges.

The advent of a disability can often change how a woman perceives herself and can result in a change in her degree of sexual esteem. Physical body changes lead to comparisons against media-influenced ideals of women. Not only is the woman with a disability experiencing insecurities, as most women do, when they fail to match the "ideal" weight and shape—but for the woman with a disability this can lead to feelings of negative self- and body esteem. The level of acceptance of disability and degree of physical functioning have not been studied to evaluate the influence of various internal and external factors on the sexual health and body esteem of women with progressive disabilities.

While there has been research on women's experience of, and reaction to, disability (Nosek et al.1994; Nosek et al., 2001; Wendell, 1996; Moss & Dyck, 2002), there has not been an exploration of how disability adaptation directly affects the body and sexual esteem of women (Taleporos & McCabe, 2002). Nor has research examined how a woman's functional physical status contributes to her feelings of body self-satisfaction and the degree to which she is satisfied with the expression of her sexuality and her ability to engage in intimate relationships. There is limited research in the areas of body image, functional status, and sexuality in women with disabilities, and the measurement of these constructs are the backbone of the purpose of this study. How is sexual and body esteem affected by a woman's level of acceptance and adaptation to disability, and functional status level? What is the mediating effect of a history of sexual abuse, the length of time since polio onset, and visibility? This study will attempt to explore these relationships.

Chapter 3

Methodology

The purpose of this study was to examine the relationships among acceptance of disability, physical level of functioning, as evidenced through the individual's capacity to engage in various activities of daily living, and sexual and body esteem of women with polio. This chapter describes the research questions and hypotheses, the design of the study, the recruitment of subjects, instrumentation, and the data analysis procedures.

Research Questions

Six research questions and four hypotheses will be addressed in this study.

Research questions

1. Do women who have a high level of disability acceptance as measured by the Acceptance of Disability (AD) scale have higher degrees of body and sexual esteem, as measured by the Physical Disability and Sexual and Body Esteem (PDSBE) scale?

2. What are the correlations between the AD subscales (Transformation from Comparative Status to Asset Values, Containment of Disability, Enlargement of the Scope of Values, and Subordination of Physique), and the PDSBE?

3. What is the relationship between the visibility of disability and sexual and body esteem?

4. What is the relationship between the length of time since polio onset and sexual and body esteem?

5. What is the effect of the relationship of a woman's functioning level, as measured by the Functional Status Questionnaire (FSQ) on her sexual and body esteem, as measured by the PDSBE?

6. What is the effect of sexual abuse on sexual and body esteem?

<u>Hypotheses:</u>

1. There is no difference in sexual esteem and body image between women who have high levels of disability acceptance as compared to those who have low levels of acceptance.

2. The level of a woman's functional status does not impact her sexual and body esteem.

3. The visibility of the disability does not impact sexual and body esteem.

4. A history of sexual abuse does not impact sexual and body esteem.

Analysis

This study used Structural Equation Modeling (SEM) to analyze the relationships among the independent variables and one dependent variable (sexual and body esteem) to determine causal as well as correlational relationships. Additionally, a number of demographic and descriptive questions were included as covariables. Results were represented statistically as well as diagrammatically using the AMOS statistical program.

The independent variables include the subscale responses to the AD-R: High Acceptance/Low Acceptance scores on the subscales of Containment of Disability Effects, Subordination of Physique, Asset Versus Comparative Values, and Enlargement of the Scope of Values. Two independent variables were Basic and Intermediate levels on functioning in Activities of Daily Living. The two remaining independent variables were self-reported visibility of disability and length of time since polio onset.

The dependent variable of body and sexual esteem were represented by the single score on the Physical Disability Sexual and Body Esteem Scale (PDSBE).

The third area of analysis was demographic and descriptive data. Demographic survey questions included age, marital status, and geographical residence. Descriptive questions included inquiries regarding sexual abuse history and sexual orientation.

Subjects

Participants were solicited through a census sample of 837 women who are enrolled in the women's post-polio program at the University of Michigan Medical Center in Ann Arbor, Michigan, who have participated in previous research studies at the University of Michigan, and have indicated their willingness to participate in future research. The women in this population had an 83% response rate to mail surveys in previous U-M studies. The age range of the women with polio in the U-M sample is 42 years of age to 92 years of age. Forty-one percent of the women are between the ages of 55 years and 64.9 years, and 28% are between the ages of 65 years and 74.9 years. The ethnic background of the women is Caucasian (96%). More than half of the women are married (62%), while 14% of the women are divorced, 11% indicate they are widowed, and 12% report never being married. There is a high degree of educational attainment in these women with polio, with 57% indicating that they either have 'some college,' or a 'college degree.' Advance degrees were obtained by an additional 24% of women. In this sample, most of the women are retired for either medical or non-medical reasons (58%), while 41% of the women remain employed and working at least part-time at the time of this study.

Instrumentation

The multidimensional nature of sexuality is affected by many factors. For women with disabilities, how adequately they have adjusted to their disability status and their functional levels are two primary influences. Women who have lived with the effects of polio find themselves experiencing new, and often severe, secondary disabilities that are manifested decades after the initial polio diagnosis. For this reason, this study incorporated a measure of acceptance of disability as one of the factors that could impact sexual and body esteem. Sexual self concept can be further challenged by body image self-schema, sexual abuse history, and visibility of disability. The research questions in this study addressed how these factors impact the body and sexual esteem of women with polio.

Three self-report instruments were combined in one survey which was used in the analysis. One instrument is the 32-item AD-R Scale (Linkowski & Groomes, 2004), the second instrument is the 10-item Physical Disability Sexual and Body Esteem Scale (PDSBE) (Taleporos & McCabe, 2002), and the third instrument is the 11-item Functional Status Questionnaire (FSQ) (Jette & Davies, 1986). There was an additional set of questions that captures participants' demographic and descriptive characteristics related to measurements such as age, marital status, length of time since polio diagnosis, sexual orientation, ethnicity, educational level, sexual abuse history and the visibility of the disability.

Disability can impact how comfortable an individual feels about experiencing her sexuality in a satisfying way. Body esteem refers to how she, overall, feels about her body. Taleporos and McCabe (2002) indicate that that "… there are currently no scales available that are specifically designed to evaluate these two dimensions (sexual esteem and body image) among people with physical disability (pg. 160)." Taleporos and McCabe developed the

Physical Disability Sexual and Body Esteem Scale (PDBSE) to specifically measure these two constructs in people with disabilities. This inventory consists of 10 questions with five Likert-scaled response categories. The scale has just recently been developed and the researchers have four studies which evaluate its psychometric properties. The first study was a principal components exploratory factor analysis which ultimately revealed a three factor solution that Taleporos and McCabe identified as subscales: Sexual Esteem subscale, Attractiveness to Others subscale, and Body Esteem subscale. Items in the original instrument that indicated high multicollinearity were removed, leaving the final scale with ten items. In analyzing the three factors of Sexual Esteem, Attractiveness to Others, and Body Esteem, Structural Equation Modeling analysis revealed acceptable goodness of fit indices.

The researchers' second study, a confirmatory factor analysis, produced results nearly identical to the exploratory factor analysis in the first study. The third study examined the retest reliability of the PDSBE scale over a four-week period. The Pearson correlation coefficient was found to be .78, indicating a moderate degree of reliability.

Study four further examined the reliability and validity of the PDSBE and established norms for a non-clinical population of people with physical disabilities. An item analysis examined the means, standard deviations and item-total correlations for each item. The means ranged from 1.82 to 3.23 and the standard deviations ranged between 1.14 and 1.48, indicating a good distribution. Analysis of the correlation coefficients did not indicate that a high degree of multicollinearity was present, indicative of good convergent validity. Divergent validity analysis was also strong. One interesting finding was that men generally scored lower than women on the overall indexed scores on the PDSBE; however, this was not the case for the Body Esteem subscale where there was no significant difference between men and women. The researchers speculated that physical disability has a greater deleterious effect on the sexual esteem of men and on their perceived attractiveness to others. The PDSBE has a Flesch-Kincaid grade level readability index of 11.1 and given that most of the women with polio in the U-M population have "at least some college," concern over literacy level is not an issue for this study.

The Functional Status Questionnaire (FSQ) was developed by Jette and Davies in 1986 as a measure of physical functioning and an individual's ability to engage in self-care activities. One section of this instrument consists of an 11-item questionnaire. Two items require evaluative self-reports of one's health status, and nine items reflect various activities of daily living and the degree to which an individual has or doesn't have difficulty with accomplishing the task. It is this part of the FSQ (the nine item "activities of daily living" (ADL) subscale of the FSQ) that was used in this study. The FSQ ADL subscale is comprised of six questions, three questions which measure basic ADL functioning (i.e.—"Taking care of yourself: eating, dressing, bathing") and six questions which measure intermediate ADL functioning (i.e.—"Walking several blocks"). Respondents indicated their functioning on a five-point Likert Scale that ranges from a zero value, no response ("Usually did not do for other reasons") to a four, which referred to accomplishing an activity with "no difficulty." The maximum value on the Basic ADL scale was twelve points, and the maximum value on the Intermediate ADL scale was 24, for a combined value of 36 points. The FSQ has a Flesch-Kincaid grade level readability index of 12.0.

The third instrument that was included in the study measured the construct of disability acceptance and adjustment and is called the Acceptance of Disability Scale-Revised (AD-R) by Groomes and Linkowski, 2004. This inventory was revised from an earlier Acceptance of Disability scale developed by Linkowski in 1969 (Linkowski, 1971). There have been no published reports on the psychometrics of the 2004 AD-R. The original scale that was developed in 1969, as well as the 2004 revision, is based on the research of Dembo et al. (1956) that characterized the feelings of loss associated with disability and how these were experienced by individuals. The organizing framework in both the 2004 version of the scale, and in the one published in 1971 by Linkowski, corresponds with Beatrice Wright's (1960) values change theory. The four components of values change of the theory are: 1) Containment of Disability Effects, 2) Subordination of Physique, 3) Transformation from Comparative to Asset Values, and 4) Enlargement of the Scope of Values. The original instrument was widely used but criticized for its absence of significant psychometric data, inconsistencies in validity data, and the declining professional opinion regarding the theoretical framework from which it was derived, specifically the theory of loss proposed Dembo et al.(1956) (Livneh & Antonak, 1997). The 2004 version was developed to address some of these concerns, and pilot studies conducted by Groomes and Linkowski have strong reliability data. Also, the preservation of Wright's theory of value changes and the four components of subordination of physique, containment of disability effects, transformation from comparative to asset values, and enlargement of the scope of values are the subscales in the 2004 AD-R. The AD-R is a 32-item, Likert-type scale that results in a summative score of Low Acceptance of Disability, Medium Acceptance of Disability, and High Acceptance of Disability. The four values subscales are totaled individually, and then combined for a total AD-R score. Despite the concern over its psychometric properties, the AD scale remains popular and Wright's values change theory is still prominent in contemporary rehabilitation literature. Because of this time-tested relevance of Wright's theory and the popularity of Linkowski's 1876 AD scale, the AD-R scale was selected for use in this study. The AD-R has a Flesch-Kincaid reading level of 12.0, but given the educational background of the women in the sample it is unlikely that this will present a problem.

Two important limitations regarding the use of these instruments were: 1) the lack of documentation of the utilization of the PDBSE and the AD-R in contemporary research, and 2) the relatively high readability grade level of the three instruments. It was expected that analysis of the demographic data of this study would reflect that participants have an above-average educational level, as reflected in the demographic data previously cited from U-M studies.

Participants were also asked to report their age, length of time since polio diagnosis, scale the visibility of their disability (1 = low to 10 = high), marital status, sexual orientation, ethnicity, and educational level. Due to the fairly large number of individuals who were invited to participate in the study, it was felt using a mail survey methodology was the most efficient and cost-effective method to collect data. Survey methodology has been determined to be an important method of gaining information from individuals.

Trochim (2004) stated that mail surveys offer respondents a measure of privacy when responding to an item. He added that mail surveys allow for more in-depth responses, longer response categories, easier data analysis, and a cost that is lower relative to other survey forms. Due to the sensitive nature of the topic, a mail survey approach was used in this study. It is thought that this approach promoted reflective responses and assured the respondents' privacy and confidentiality. Surveys provide statistical descriptions of people "... by asking questions, usually of a sample. Surveys meld sampling, question design, and data collection methodologies (Fowler, 2002, pg. 1)."

Procedures

A study announcement letter, a postcard, and a postage-paid return envelope were sent to the women with polio who have all participated in previous studies at the University of Michigan and have indicated a willingness to participate in future studies. This letter was jointly signed by the researchers from the University of Michigan and Michigan State University, and announced to the women that they have an opportunity to participate in an important study that will help other women with disabilities, and the professionals who work with them, understand issues related to acceptance of disability, and how they feel about their capacity to engage in intimate relationships. The letter also stated that participation is entirely voluntary, that they may choose not to answer any questions that make them uncomfortable, and that they will not be asked any highly personal information about their sexual activities. The return of the postcard indicated their willingness to participate in the study, and upon return of the postcard, the participants were mailed a survey packet that included an Informed Consent form that was jointly approved by the IRBs at U-M and MSU. This protocol had been utilized by U-M previously in their studies involving this group of women. The issue of study participation remuneration was discussed and rejected. It was felt by the U-M researcher that the U-M population was comfortable participating in studies and did not need incentivizing. Due to time and financial constraints, and the typical high survey return rate for this population, a second reminder mailing did not occur.

Prospective participants were assured that their responses will be held strictly confidential, and that all information would be reported only in an aggregate format. Additionally, they were informed that their participation will help professionals who work with women with disabilities on these important quality of life areas, and that their decision to participate, or not, in the study was entirely voluntary and in no way would influence the services they receive from the University of Michigan Medical Center or in other services they may receive from any disability organization or service.

Data Analysis

Structural Equation Modeling (SEM) is the only analysis that allows complete and simultaneous tests of relationships in multidimensional data (Ullman, 1996). A hypothesized model of causal relationships can be analyzed in SEM through two representations of the data: 1) through a series of regression equations; and 2) the relationships between variables can be presented pictorially as a path analysis (Byrne, 2001). The statistical software that was used was AMOS Graphics (Arbuckle, 1999) and SPSS.

Summary scores on the PDBSE, total and subscale scores on the AD-R, and the variables of sexual abuse history, the self-scaled score on visibility of disability, and the length of time since polio diagnosis were correlated, and associations and dependencies reported and diagrammed using the SEM method. Numerical representations of the data from the confirmatory factor and path analyses were reported, such as correlations and regression equations. A key metric in SEM is the array of fit statistics that allow the researcher to assess how well the data fits a hypothesized model and reflects, sample characteristics. The visual displays of data provided through the AMOS software program are comprised of straight lines with arrows, which indicate a dependent relationship, and curvilinear arrows which represent correlational and associative relationships. SEM is essentially a multivariate extension of the multiple regression model with one dependent variable.

There are three main assumptions which govern the use of SEM. The first is an adequate sample size. A good rule is fifteen cases per measured variable. The second is that dependent and mediating variables (SEM refers to these as endogenous or downstream variables) are continuously and normally distributed, although SEM has a method to manage data that are not continuously distributed. Outcome variables not continuously distributed and nominal variables are not appropriate for SEM analysis. SEM requires that each model be *identified*, which means that there is at least one solution for each parameter estimate in an SEM model. Models in which there is just one possible solution for each parameter is said to be *just-identified.* Models for which there are an infinite number of possible parameter estimate values are said to be *underidentified.* Identification is a structural requirement in order for an SEM analysis to occur.

A correlation matrix was developed using the independent variables, dependent variable, and responses to the sexual abuse history, length of time since polio diagnosis, and visibility of disability variables to examine if any factor or factors contributed to a higher score on the PDSBE, or was correlated with the AD-R total score.

CHAPTER 4

RESULTS

The purpose of this analysis was to assess the appropriateness of the hypothesized model as a description of the relationships among Acceptance of Disability, Functional Status as measured by an individual's ability to participate in Activities of Daily Living (ADL), presence of a Sexual Abuse history, self-reported Visibility of Disability, and the Length of Time Since Polio Diagnosis in predicting body image and sexual health.

The results of all analyses conducted in this study are presented in Chapter 4. Included are characteristics of the sample, demographics of the respondents, the results of the SEM analysis which will focus on the fit of the data to the hypothesized model using three identified fit indices, and a discussion of the dispersion of the data.

Respondents

A letter of invitation to participate in the study was sent to 832 women with polio who were previous study participants in the Post-Polio and Menopause Study conducted by the University of Michigan (U-M). An additional 193 invitation letters were sent to other women with polio who were not participants in U-M's Menopause Study, which brought the total number of invitations to participate in the study to 1,025 women with polio. The invitation letter was jointly signed by MSU and U-M. Potential participants for this study were asked to return the enclosed postage paid postcard to receive the survey packet and consent form. The consent form and the study protocol were jointly approved by the Institutional Review Boards (IRBs) at U-M and MSU. U-M assigned an identification number to those women who requested survey packets. If they were previous participants in U-M studies, they were given the same identification number to facilitate consistency in past and future research. The women had all been previous participants in U-M research and were most comfortable with surveys that were administered in hard-copy format that included many opportunities for them to express their opinion. Due to the advanced age of the sample, the technology of Scantron-type surveys was viewed to be too unfamiliar to the women, so the survey was designed using a somewhat larger font size and a more traditional layout.

The overall response rate for this study was 36%, with 374 women completing and returning their surveys and consent forms. Four invitation letters were returned as ‘undeliverable’ and one invitee was deceased. An additional invitee did not wish to participate in the study due to her fear of repercussions from an abusive spouse. Fifteen surveys were returned minus the signed consent form, thus these women’s surveys were not entered in the survey database. Age and response frequency distributions for the fifteen women who were missing the consent form, and demographics and response frequency distribution for the total sample are in Appendix A. A summary of the basic demographic characteristics of the study’s sample, the fifteen women without consent forms, and data from the 2000 U.S. Census are contained in Table 1. Note the variable range in published reports of women who have experienced sexual abuse.

Table 1: Demographic Characteristics

	Sample	U.S. Census
Women >65-years of Age	45.2%	14.7%
Caucasian Ethnicity	97.1%	84.7%
Educational Attainment (some college, college/post-graduate degree)	33.2%	24.4%

Table 1: Demographic Characteristics (continued)

	Marital Status	Abuse History	Length of Time Since Polio Polio Diagnosis
Sample	65.1% Married 14.2 % Widowed 8.6% Divorced	13.3%	54 years
No Consent	80% Married 6.7% Widowed 6.7% Divorced	13.3%	53 years
Census	58 % Married 11% Widowed 11% Divorced	25%[1] 50-90%[2]	X

[1] retrieved from: http://www.medicineau.net.au/clinical/psychiatry/SexualAbuse.html on July 17, 2005.

[2] retrieved from: http://ici.umn.edu/products/impact/133/over5.html on July 17, 2005.

The demographic data for the women with polio in this study suggest that participants have a slightly higher mean age than the mean age of the total United States population of women, the marital rate of the women in this study is higher than the national average, and the women with polio in this study reported a slightly decreased rate of sexual abuse; although this measure seems to have the greatest range of possible responses, which mirrors the definitional and reporting issues that surround what is considered sexual abuse, the rate of which is considered to be two- to five- times higher for people with disabilities than for the general population (retrieved from http://ici.umn.edu/products/impact/133/over5.html on July 17, 2005). The great disparity in the reported incidence rates of sexual abuse cited in the above table is not atypical. Depending on how 'sexual abuse' is defined greatly impacts how it is reported, and if it is reported. The figures for sexual abuse in the table were used to demonstrate the polarity in the measurement of this construct.

. Data collection was open for eight weeks after the mailing of the survey packets. Approximately 30 surveys were returned after the close of data collection and were not entered in this study. These responses will, however, be included in subsequent analyses that will occur after the completion of this dissertation.

The 36% response rate, while generally acceptable, is lower by approximately 45% relative to the previous studies the invitees had participated in through U-M. Possible explanations are speculative, and could include the sensitivity of the topic (sexuality), the eight- week response window, and disinterest in the topic. The researchers' letter was very sensitively-worded and clearly indicated that participants would not be asked any questions regarding their sexual activity, and that they could choose not to respond to any question(s) that made them uncomfortable.

Approximately ten women declined to answer some of the questions, or scales, in the survey. These women noted reasons such as "I'm widowed and these questions do not pertain to me" (regarding the Sexual and Body Esteem Scale), "I can do some of these things some of the time" (in reference to the Activities of Daily Living scale), and "I am happily married and have no reason to gauge how sexually attractive I am to others." Mean replacement values for missing responses were used in the analysis, as opposed to imputing values, due to the rather large sample size.

A power analysis was conducted using the website: calculators.stat.ucla.edu/powercalc/correlation, because of the large sample size required for a valid SEM analysis. With .8 power at a 95% confidence level (a .05 significance level) in order to detect a correlation of .2 or larger, a sample size of 154 was required. The sample size for the study was 373 women with polio which exceeds the estimate for adequate power. One additional respondent was the only individual to score "low" on the disability acceptance scale and was deleted from the analysis, since one case does not constitute a data set appropriate for analysis using SEM.

Approximately 70% of the respondents utilized the blank lines and other empty space on the survey form to make some very insightful and personal comments. A qualitative component of this study was added at its mid-point to capture some of this very rich data. Since this type of analysis was not included in the proposal for this dissertation, the results of the qualitative component will be reported separately at a later date.

In general, the respondents' comments on the purpose of the study were very favorable and indicated appreciation that the topic of sexuality was being addressed. Eight women stated that they thought the questions were too basic and had wished that there were in-depth questions on sexual behavior. Since the purpose of this study was to address how a woman feels about her capacity to engage in intimate relationships (and not the nature of the relationships) the comments indicated that there was an interest in going more in-depth on the components of sexuality and sexual activity.

The dispersion of the responses for the variables in the study is reported in Table 2, and a response summary for non-continuous variables is in Table 3:

Table 2: Data Dispersion

Variable	Minimum	Maximum	Mean	Standard Deviation
Respondent Age	42 years	92 years	62.77 years	8.37
Visibility of Disability	1 (low)	10 (extremely)	6.81	3.25
Years since Polio Diagnosis	1 year	91 years	53.36	12.67

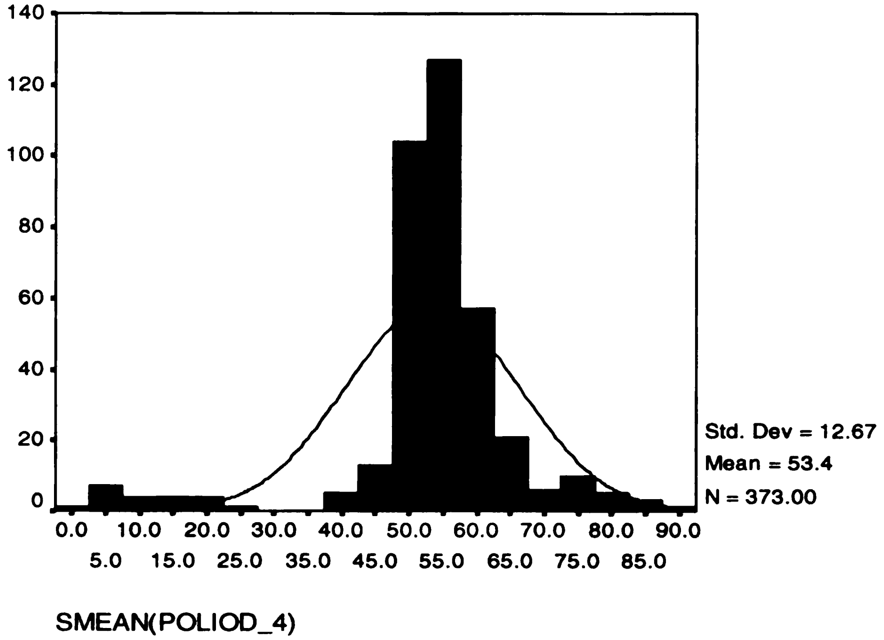
Table 3: Summary of Other Response Data:

Variable		Response Summary (in percent)
Sexual Abuse:	No	87.1%
	Yes	12.9%
Ethnicity:	Caucasian (n = 362)	97.3%
	African-American (n = 3)	.3%
	Hispanic (n = 3)	.8%
	Asian/Pacific Islander (n = 3)	.8%
	Native American/First Nation (n = 1)	.3%
	Other (n = 2)	.5%
Marital Status:	Married/in Partnership (n = 243)	65.1%
	Never Married (n = 6)	1.6%
	Divorced (n = 32)	8.6%
	Separated (n = 39)	10.5%
	Widowed (n = 53)	14.2%
Sexual Orientation:	Heterosexual (n = 352)	97.8%
	Lesbian (n = 3)	.8%
	Bisexual (n = 5)	1.4%
Educational Level:	High School (n = 52)	13.9%
	Technical/Trade School (n = 94)	25.2%
	Some College (n = 103)	27.6%
	College Degree (n = 99)	26.5%
	Post-Graduate Degree (n = 14)	3.8%
	Other (n = 2)	.5%

The respondents resided in all states of the United States. A frequency distribution of the respondents by state is contained in Appendix B.

The reported average number of years that the women had been diagnosed with polio was 53.4 years, and ranged from 1 – 91 years. It is suspected that 3% of the sample (who had stated <20 years since diagnosis) may have interpreted the question as the number of years since post-polio diagnosis (which occurs some decades after polio onset), rather than initial polio diagnosis. A histogram of the dispersion of the number of years since polio diagnosis of the respondents is displayed in Figure 1:

Figure 1: Length of Time Since Polio Diagnosis in Years



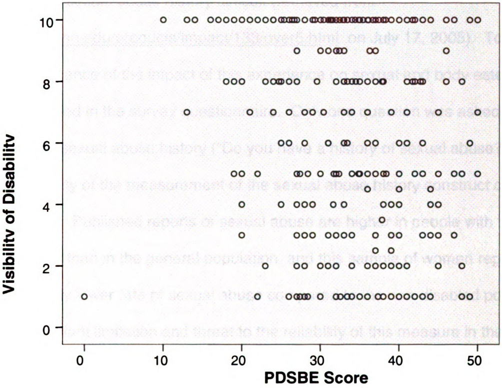
A frequency distribution of the age of respondents as well as those who returned surveys without Informed Consent Forms is contained in Appendix C. The mean age of study participants (n = 373) was 62.8 years of age, and the average age of those not included in the study because surveys were returned absent consent forms was 57.5 years.

A majority of the women in the study, 97.8% (n = 353), indicated that they were heterosexual while 2.2% replied that they were either lesbian or bisexual, which is slightly greater than the estimated national rate of 1.51% of the female population (U.S. Census, 2000). Even though the number of women not included in the survey was small, none indicated a sexual orientation other than heterosexual. This study contained a distinctly Caucasian sample with 97.3% indicating this as their ethnicity (n = 363). Three respondents indicated their ethnicity as Hispanic; three women replied they were of Asian/Pacific Island descent, while Native American/First Nation and African-American ethnicities were identified by one woman each. Two women indicated they were of "other" ethnicities. The reported ethnicity of the women who did not supply consent forms paralleled that of those in the study.

Consistent with the data in U-M's Polio and Menopause Study and with information from the National Center on Health Statistics, the women in this study have a higher level than average educational attainment. Twenty-seven percent of the sample had at least "some college," while 30.3% had at least a college degree or a post-graduate degree. The higher education background of this sample of women, therefore, equates to 57.9% of the total sample with at least some college experience compared to 24.4% of the general female population. Research question #3 addresses the issue of how obvious to others the women feel their disability is ("What is the relationship between the visibility of the disability and sexual and body esteem?") While 57.3% of the women reported a score of 7.5 or higher on a self-reported scale where a response of 1 = low visibility, and 10 = extremely visible), SEM analysis revealed that visibility was not a significant predictor of sexual and body esteem (r-square = .04). There appears to be a flat relationship between these two factors as presented in Figure 2: the self-reported visibility of disability (on a scale of 1 = low visibility, to

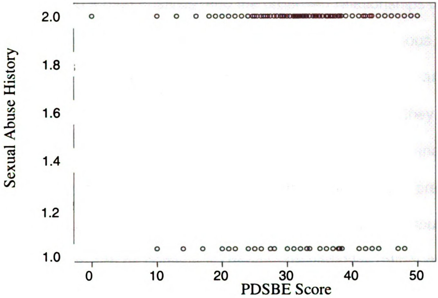
10 = extremely high visibility) does not seem to influence how a woman with polio views her body image and sexual esteem.

Figure 2: Relationship between Visibility of Disability, and Sexual and Body Esteem



. A mediating variable in the degree of a woman's capacity to develop positive intimate relationships is history of sexual abuse. The American Psychological Association (APA) reports that the definition of sexual abuse is very broad, and data on its incidence is difficult to collect because of underreporting and lack of a concise definition (retrieved from http://www.apa.org/releases/sexabuse/ on July 15, 2005). The women in this study reported an incidence of sexual abuse that is much less than the national average; just over 12% of this sample (12.4%, n = 46) claim they have been sexually abused. EndAbuseNow (retrieved on June 16, 2005) reports that over 33% of women experience sexual abuse in their lifetime, yet studies conducted by the College of Education at the University of Minnesota indicate that just 3% of women who experience sexual abuse report the occurrence, which makes estimating sexual abuse history difficult (retrieved from http://ici.umn.edu/products/impact/133/over5.html on July 17, 2005). To confirm the significance of the impact of this experience on sexual and body esteem, it was included in the survey questionnaire. Only one question was asked regarding sexual abuse history ("Do you have a history of sexual abuse?"), thus the reliability of the measurement of the sexual abuse history construct cannot be confirmed. Published reports of sexual abuse are higher in people with disabilities than in the general population, and this sample of women reported a significantly lower rate of sexual abuse compared to the non-disabled population. One important limitation and threat to the reliability of this measure in the use of the variable 'sexual abuse history' in this study, is that the survey did not provide a definition of what constituted sexual abuse, and only one question was used to measure the construct ("Do you have a history of sexual abuse?"). The scatterplot in Figure 3 demonstrates that sexual abuse history (1 = yes, 2 = no) does not have much impact on sexual and body esteem (scores range from 0 = low, 50 = high). There is a substantial cluster of scores in the 25 – 40 point range on the Physical Disability and Sexual and Body Esteem Scale, but a comparison against the general population of women who have and have not been sexually abused is not available.

Figure 3: Sexual Abuse History (1 = yes, 2 = no), and Sexual and Body Esteem



Structural Equation Model Specification

There are a number of factors that can affect how a woman with a disability perceives her physical self and her sexuality. Theory supports that body image is impacted by how obvious the disability is to others (as measured in this study by the self-scaled response to the question “How visible is your disability?”), and this in turn can inhibit expression of intimacy not only because of possible self-consciousness, but also because of physical limitations as a result of extensive physical disability. Additional research (Nosek, et al, 2001) has reported on the influence of the adverse effect of a sexual abuse history on sexual development. And, the length of time a woman has lived with a disability can also impact body and sexual esteem. Coefficients for the path model were estimated by AMOS and missing data was managed through mean replacement. The hypothesized model is an *a priori* first-order design. The schematic representation of the full structural equation model contains a confirmatory factor analysis (CFA) and a path analysis, and the proposed relationships between the variables were diagrammed. In SEM parlance, the five endogenous variables that are measured in this model are termed *observed* or *manifest* variables and the survey responses are considered indicators of the construct they purport to measure. The two types of variables that are considered in SEM analysis are *exogenous,* which are considered to function like independent, or predictor, variables that influence other variables in the model; and *endogenous* variables which, most simply, can be considered dependent variables, although in Structural Equation Modeling they could influence other variables. The hypothesized model contains four observed, exogenous variables and one unobserved, endogenous variables. The variable structure is presented in Table 4.

Table 4: Hypothesized Model, Variable Types

Name and Type of Variable
Observed, endogenous variables:
1. Sexual and Body Esteem (PDSBE)
2. Containment of Disability Effects ("Acceptance of Disability" subscale)
3. Subordination of Physique ("Acceptance of Disability" subscale)
4. Transformation from Comparative to Asset Values ("Acceptance of Disability" subscale)

5. Enlargement of the Scope of Values ("Acceptance of Disability" subscale)

Observed, exogenous variables:

1. Length of Time since Polio Diagnosis (Polio Dx.)
2. Functional Status with Activities of Daily Living (ADL)
3. Visibility of Disability (Visibility)
4. History of Sexual Abuse (Sexual Abuse)

Unobserved, exogenous variables (as error terms):

1. eSexual and Body Esteem (ePDSBE)
2. eContainment Sub-Scale (eCS)
3. eSubordination Sub-Scale (eSS)
4. eTransformation Sub-Scale (eTS)
5. eEnlargement Sub-Scale (eES)
6. eAcceptance of Disability (eAD)

Unobserved, endogenous variable:

1. Acceptance of Disability

The model is *recursive*, which means that the relationships between the variables are unidirectional—as opposed to *non-recursive* in which there is a reciprocal relationship between the variables. A visual portrayal of the hypothesized Structural Equation Model used in this study is provided in Figure 4.

Three instruments were incorporated into the survey to measure the constructs of functional capability to perform activities of daily living (ADL), acceptance of disability, and sexual and body esteem: the Activities of Daily Living (ADL) subscale of the Functional Status Questionnaire (FSQ) (Jette and Davies, 1986), Acceptance of Disability-Revised (AD-R) as measured by a summative score on the instrument and its four subscales (Groomes and Linkowski, 2004), and the Physical Disability and Sexual and Body Esteem Scale (PDSBE) (Taleporos and McCabe, 2002) were the three instruments used in this study.

There is a greater range of responses to the questions that measured a woman's functional ability to participate in skills that require more independence, endurance and strength (Intermediate ADL) than in the basic self-care skills (Basic ADL). A limitation in the measurement of Basic ADL functioning is that the instrument developers only included three questions to measure this construct. The distribution of scores is presented in Table 5.

Figure 4: Hypothesized Full SEM Model

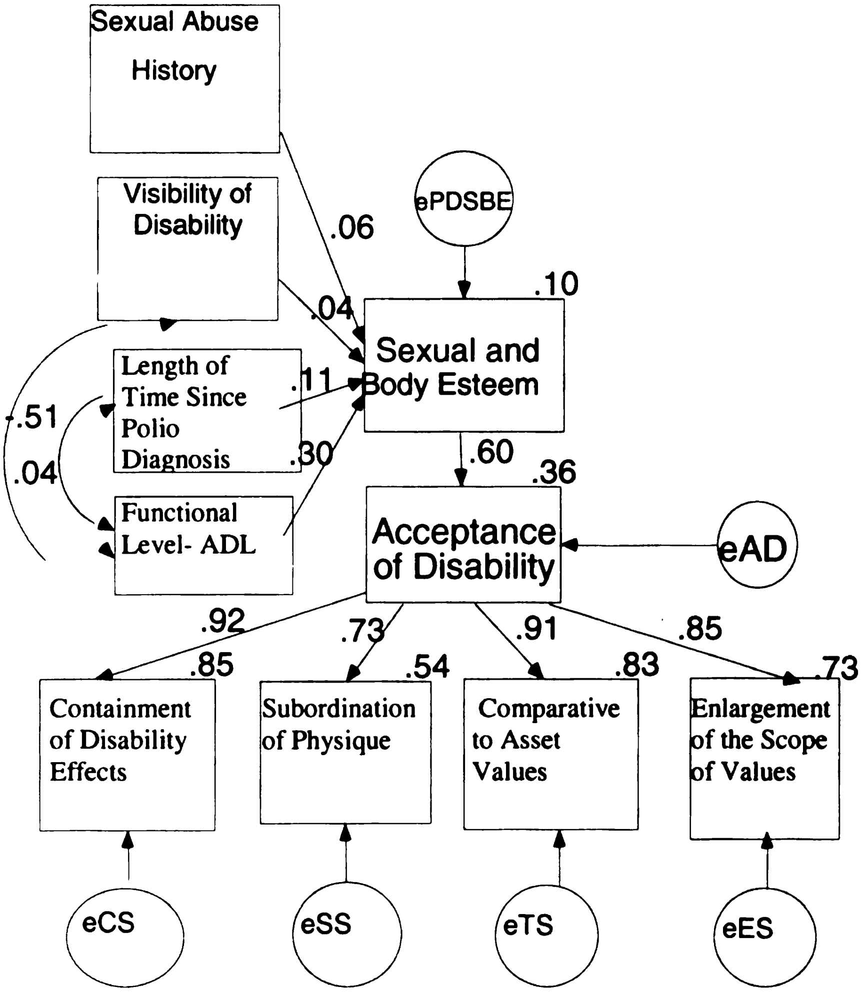
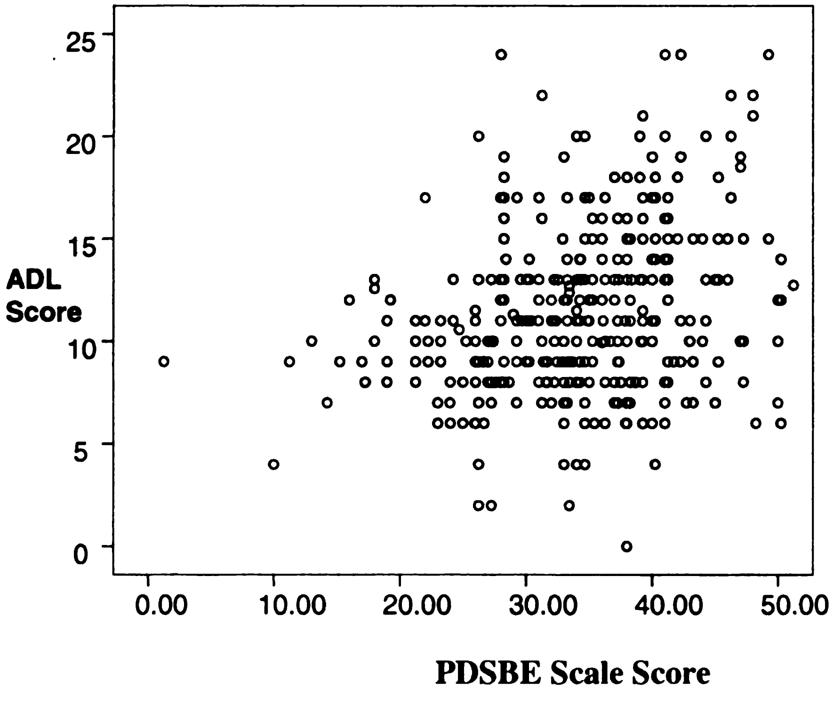


Table 5: FSQ “Activities of Daily Living” (ADL) Subscale Results (N = 373):

Functional Level	Possible Range	Mean	Standard Deviation
Basic ADL	12 points (3 questions)	7.94	2.22
Intermediate ADL	24 points (6 questions)	11.30	4.05

The distribution of scores for Basic ADL is dispersed very broadly (Figure 5), and there appears to be a slight negative correlation between a woman's basic ability to care for herself and how she perceives her body and sexual schemas. The responses seem to be evenly distributed around the mean score on the PDSBE (33.42).

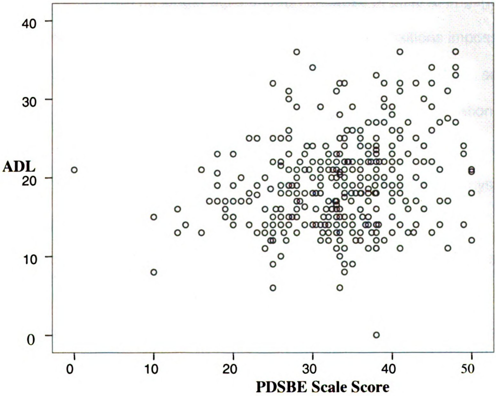
Figure 5: Basic “Activities of Daily Living” (ADL) and Sexual and Body Esteem



The dispersion of the scores when Intermediate ADL is graphed with Sexual and Body Esteem did not indicate the presence of any kind of relationship.

The plotting of the total profile of ADL scores (Basic and Intermediate combined) indicates that there is a small degree of negative skew between the degree of functional ability a woman that is necessary for her to complete basic and intermediate activities of daily living skills, and her feelings about her sexual and body esteem (Figure 6). It appears that the capacity to take care of oneself and to report a moderate degree of ability to perform ADL tasks that require more effort, lead to increased sexual confidence and appraisal of a woman's body image.

Figure 6: Total ADL Functional Status, and Sexual and Body Esteem



Research question #5 addresses the variables that resulted in the strongest relationship ("What is the effect of the relationship of a woman's functioning level on her sexual and body esteem?") Given the many assistive and adaptive devices, it cannot be assumed that a woman's subjective measure of the degree of her disability would necessarily reveal a poor level of ability to complete some activities of daily living, decreased disability acceptance, or impaired sexual health. Additionally, it appears that based on several written comments made by the participants, a metric that takes into account the capacity to specifically engage in sexual activities of various degrees was felt by many women to be an important indicator of sexual health. Some participants in this sample of women viewed a satisfying sexual self-image as the capacity to physically engage in sexual activity. An example of comments that were typical of some of the remarks, were: "I am no longer agile enough because of polio to engage in intercourse," and "My shriveled leg makes most sexual positions impossible." Perhaps future studies could include measures of ability to engage in sexual activities as a measure of ADL functioning. It is possible that education on the multi-dimensional aspects of sexuality did not occur for this generation of women who may have interpreted any question on sexuality purely from a physical capacity perspective.

The subjects had an overall ease with accomplishing basic ADLs as evidenced by the combined scores to the three questions that measure Basic ADL; between 86.8% and 99.2% of the women could accomplish the Basic ADL tasks with "No Difficulty," to "Some Difficulty." Only 10.2% (n = 38) of the women stated that they couldn't attain the Basic level of ADL functioning and responded, "Usually Did Not Do For Health Reasons."

Intermediate ADL functioning refers to skills such as walking several blocks, climbing a flight of stairs, doing light home maintenance, grocery shopping, driving, and doing vigorous sporting activities. With the exception of driving, in which 9.7% of survey participants said they "Usually Did Not Do For Health Reasons," the women appeared to be challenged by these intermediate activities of daily living. The greatest difficulty was with any type of vigorous activity, and 80.4% of the women could not participate in those activities due to health reasons. The remaining intermediate ADL's proved, on the average, to provide "Some-to-Total" difficulty for 57% - 80% of the women. Internal consistency reliability coefficients were calculated for the Basic ADL Scale and the Intermediate ADL scale, which indicated a high degree of reliability that exceeded previously published reports. All reliability data (Table 6) that refers to this study was calculated with the combined two groups of Basic- and Intermediate AD-R.

Table 6: FSQ Reliability

Scale Reliability	Published Reliability (alpha)	This Study (alpha)
Basic Activities of Daily Living (ADL)	>.75	.83
Intermediate ADL	>.80	.84

Single-item response questions were also used from the FSQ. Respondents were asked to describe their work situation, the number of days that illness or injury kept them in bed the past month, days of activity restriction in the prior month, their level of satisfaction with their sexual relationships, how they felt about their health, and social activities. A presentation of the results to these questions follows below.

Survey Question 1: Which of the following statements describes your work situation during the past month? There were six response categories to this question, ranging from working full- time to retired for a reason other than health. Approximately 20% of the women were working full time and 30% were unemployed and looking for work. Only 7.4% of the women indicated they were retired due to health reasons. This is clearly an active and industrious group given that the majority of the sample (mean age slightly older than 61 years) is engaged in employment at least part-time, or is looking for work.

Survey Question 2: During the past month how many days did illness or injury keep you in bed all or most of the time? Over 71% (71.5%) of the women said "zero" days. The range of responses extended to 25 days.

Survey Question 3: During the past month how many days did you cut down on the things that you usually do for one-half day or more because of your illness or injury? The percentage of women who were limited in their activity from zero to three days totaled 55.2%.

Survey Question 4: During the past month, how satisfied were you with your sexual relationships? Over half of the respondents (52.4%) indicated that they did not have sexual relationships, although 65.2% of the women indicated they were married or in a partnership. The level of sexual satisfaction seems mostly unrelated to the visibility of disability, years since polio diagnosis, ADL functioning level, and how the women feel about their health.

Survey Question 5: How do you feel about your health? The majority of the participants were either dissatisfied or very dissatisfied (67.2%) with their health. An area of additional future exploration would be to analyze the low level of sexual satisfaction reported in this study with the reported degree of dissatisfaction with their health. Those that replied they were satisfied or very satisfied with their health comprised 22.5% of the sample.

Survey Question 6: During the past month, about how often did you get together with friends or relatives, such as going out together, visiting in each other's home, or talking on the telephone? There did not appear to be severe social limitations with this sample of women. Nearly 47% of the respondents reported socializing one time or more per week and 40% replied that they socialize two to three times per month. One respondent indicated that she felt extremely isolated and 'in prison' due to the severity of her disability

The AD-R was used to measure the acceptance of disability construct. In the analysis, a combined single score is calculated to indicate overall acceptance of disability and is divided into three categories: High Acceptance of Disability (scores of 94 – 124 points), Medium Acceptance of Disability (scores of 61 – 93 points), and Low Acceptance of Disability (scores of 28 – 60). It should be noted that there was only one individual that scored in the "Low" range (participant identification number 563). Structural Equation Modeling and AMOS cannot run results with a single case as a variable, so #563 was eliminated. The scores on the four subscales of the AD-R were also calculated and correlated to determine the direction of the relationship between variables and the predictor variable, physical disability and sexual/body esteem. All respondents scored in the High range on the disability acceptance subscales; the High scoring range is 94 – 124 and the mean response in this sample of women was 101.49. A complete presentation of the AD-R scoring scale is presented in Table 6. It should be noted that one item in the Enlargement subscale was accidentally omitted in the formatting of the survey. Personal communication with the instrument co-developer, Dr. Darlene Groomes and statistician Dr. Mark Reckase indicated that it was acceptable to proportionately adjust the scores in the Enlargement subscale and the total scale by four points (the value of the missing item) since there were eight items remaining in the Enlargement subscale.

Table 7: Acceptance of Disability Instrument Scoring:

Range	Indicator
Total AD-R Scale (124 points):	
93-124	High Levels of Acceptance of Disability
61-92	Medium Levels of Acceptance of Disability
28-60	Low Levels of Acceptance of Disability
Transformation from Comparative to Asset Values Subscale (36 points):	
27-36	High Levels of Transformation
18-26	Medium Levels of Transformation
9-17	Low Levels of Transformation
Containment of Disability Effects Subscale (36 points):	
27-36	High Levels of Containment of Disability
18-26	Medium Levels of Containment of Disability
9-17	Low Levels of Containment of Disability
Enlargement of the Scope of Values Subscale (32 points):	
23-32	High Levels of Enlargement of Scope of Values
14-22	Medium Levels of Enlargement of Scope of Values
5-13	Low Levels of Enlargement of Scope of Values
Subordination of the Physique Subscale (20 points):	
16-20	High Levels of Subordination of Physique
11-15	Medium Levels of Subordination of Physique
5-10	Low Levels of Subordination of Physique

Despite the presence of secondary disability as a result of post-polio syndrome, it appears that the women in this study, as a group, have satisfactorily adjusted to their changing health status. Ninety-three women fell within the scoring range of Medium Acceptance of Disability, and 275 women scored in the High Acceptance of Disability range. Descriptive data for the responses to the AD-R and its subscales is reported in Table 8.

Table 8: Descriptives for Acceptance of Disability (AD-R) Instrument and its Four Subscales (N = 373).

ADR-R	Minimum	Maximum	Mean	Standard Deviation
Total AD-R	62.00	123.00	101.49	12.76
Containment	12.00	36.00	28.10	4.70
Subordination	7.00	20.00	16.98	2.45
Transformation	15.00	36.00	30.14	4.00
Enlargement	16.00	32.00	26.31	3.55

The highest mean score on the AD-R subscales was the Transformation from Comparative Status to Asset Values subscale, which is a measure of how well an individual perceives her strengths and abilities instead of comparing herself to others. Satisfactory sexual adjustment would indicate a certain level of self-confidence and self-efficacy. Containment of Disability Effects provided the most variability in responses. Containment of Disability Effects is defined by the perspective a person with a disability has to limit the impact of the disability to a realistic appraisal of one's limitations and not generalize the devaluation to other aspects of her life. For example, just because an individual has a severe physical disability does not mean that disability status should influence other life areas, such as an individual's ability to be successful in building friendships or pursuing vocational goals. A dysfunctional body does not imply dysfunctional social skills. The total results for the full 31-question AD-R scale are contained in Table 8. All items are scored on a Likert-type scale, with values that range from 1 = Strongly Disagree to 4 = Strongly Agree.

Table 9: AD-R Responses

Item	Mean	S.D.
1. With my disability, all areas of my life are affected in some major way.	2.76	.89
2. Having my disability, I am unable to do things like people without disabilities do.	3.01	.75
3. Disability or not, I am going to make good in life.	3.46	.64
4. Because of my disability, I have little to offer people.	1.42	.67
5. Good physical appearance and physical ability are the most important things in life.	1.85	.73
6. A person with a disability is restricted in certain ways, but there is still much s/he is able to do.	3.48	.68
7. No matter how hard I try or what I accomplish, I could never be as goodas the person who does not have my disability.	1.77	.84
8. It makes me feel very bad to see all the things that people without disabilities can do that I cannot.	2.05	.80
9. The most important thing in this world is to be physically capable.	1.67	.71
10. Because of my disability, other people's lives have more meaning than my own.	1.48	.66
11. Because of my disability, I feel miserable much of the time.	1.56	.72
12. Though I have a disability, my life is full.	3.36	.67
13. The kind of person I am and my accomplishments in life are less important than those without disabilities.	1.44	.64
14.A physical disability affects a person's mental ability.	1.67	.86
15. Since my disability interferes with just about everything I try to do, it is foremost in my mind practically all of the time.	2.02	.81
16. There are many things a person with my disability is able to do.	3.43	.65
17. My disability in itself affects me more than any other characteristic about me.	2.12	.83
18. There are many more important things in life than physical ability and appearance.	3.32	.67
19. Almost every area of life is closed to me.	1.35	.58

20. My disability prevents me from doing just about everything I really want to do and from becoming the kind of person I want to be.	1.55	.70
21. My disability affects those aspects of life that I care most about.	1.89	.79
22. A disability such as mine is the worst possible thing that can happen to a person.	1.29	.55
23. You need a good and whole body to have a good mind.	1.28	.56
24. There are times that I completely forget that I have a disability.	2.99	.79
25. If I didn't have my disability, I think I would be a much better person.	1.63	.74
26. When I think of my disability, it makes me so sad and upset that I am unable to do anything else.	1.43	.64
27. People with disabilities are able to do well in many ways.	3.53	.68
28. I feel satisfied with my abilities and my disability does not bother me too much.	2.85	.74
29. In just about everything, my disability is annoying to me so that I can't enjoy anything.	1.55	.68
30. Physical wholeness and appearance make a person who s/he is.	1.55	.69
31. I know what I can't do because of my disability, and I feel that I can live a full life.	3.40	.66

The statement that the women in this sample disagreed with the most was question #23: "You need a good and whole body to have a good mind." The mean score for the responses to that question was 1.28 (1 = strongly disagree). Several questions had responses that indicate that the women in this sample had very positive perspectives on their abilities and overwhelmingly viewed their futures as bright. The question that generated the most positive response was #27: "People with disabilities are able to do well in many ways."

Since the AD-R is a new instrument, internal consistency reliability statistics for the responses to this study's Acceptance of Disability subscales were compared to the reliability data published by the instrument developers (Table 10).

Table 10: AD-R Subscale Internal Consistency Reliabilities

Subscale	Published Alpha	This Study's Alpha
Containment	.88	.86
Subordination	.71	.72
Transformation	.88	.61
Enlargement	.82	.71

Research indicates that disability adjustment and sexual role development is more consistent for those with early developmental disabilities, which are disabilities that occur before the age of 22 years. In most cases, polio onset occurred at an early childhood age. Theorists (Cole & Cole, 1991) have supported the notion that early diagnosis of disability in a person's life can result in better adaptation since gender roles and socialization experiences are learned with a 'disabled self' at a young age. Adjustment to disability for those with acquired or adventitious disabilities that occur in adulthood is often a complex interplay between interpersonal traits and characteristics, and the degree to which a person's environment facilitates or hiders a person's full participation in the community.

A diagnosis of polio straddles both developmental frameworks. Initial onset of disability is usually in childhood, yet people with polio frequently experience secondary disability decades later in the form of new symptoms referred to as 'post-polio syndrome.'

The 10-item Physical Disability and Sexual and Body Esteem (PDSBE) is the first instrument to measure the impact of physical disability on how a person feels about their body and their capacity to engage in, and enjoy, elements of intimate relationships. Reliability coefficients in this study (alpha = .85) were comparable to the value of the published reports by the authors (alpha = .87), which indicates strong internal consistency reliability of the PDSBE. The scale was scored out of a cumulative value of 50-points. The sample mean was 33.42, s.d. = 7.83, which was higher than the published data (Taleporos & McCabe, 2002) of mean responses = 27.13, s.d. = 9.45. This suggests that the women with polio in this sample scored favorably compared to the instrument developers' normed averages on the constructs of sexual esteem, attractiveness to others, and body esteem. Data on the individual items in the PDSBE scale are contained in Table 11. There is a minimum score of one point ("Strongly Agree") to five points ("Strongly Disagree") per item, for a total of 50-points. The total mean score on the PDSBE scale in this study was 33.42/50 points, with a standard deviation of 7.75.

Table 11: PDSBE Results

Question	Mean	Standard Deviation
1. I feel that my disability interferes with my sexual enjoyment.	2.24	.99
2. It is harder to find a sexual partner when you have a disability.	2.11	.75
3. I would like to hide my disability as much as possible.	3.60	.73
4. I feel sexually frustrated because of my disability.	3.25	.73
5. I feel that my disability is likely to prevent me from satisfying a sexual partner.	3.23	.84

6. My sexual expression is limited by my disability.	3.65	1.21
7. I feel that people are not sexually interested in me because of my disability.	3.23	. 84
8. I envy people with 'normal' bodies.	3.01	.80
9. I believe that I experience rejection from potential sexual partners because of my disability.	3.33	.71
10. I would do a body swap with an able-bodied person if I could.	3.52	.67

SEM Model Fit Indices

There are over thirty fit indices in the Summary of Models produced by AMOS, although only a few key indicators of fit will be presented here. Model fit statistics will be represented the value of CMIN/d.f. (degrees of freedom), which provides a chi-square statistic, and the value should be <3 to indicate a good fit of the model to the data; a larger chi-square value would indicate that the model fit could be improved. The chi-square statistic for this study is 111/25 (d.f.), p<.000. DELTA1 NFI (Bentler-Bonett Normed Fit Index) was the criterion of choice for many years, but has tended to underestimate fit in small samples (Byrne, 2001). It is still a valuable measure of fit, however, and indices >.9 demonstrate a well-fitting model. Since this study has a fairly large sample with adequate power, it is not anticipated that sample size will not be an issue. The DELTA1 NFI value was .91 in this study, which is adequate for a good fit. The final metric that will be used is RMSEA (Root Mean Square Error of Approximations), which is considered an excellent measure of covariance structure modeling. An RMSEA index <.05 indicates that there is not a high degree of multicollinearity in the data. The RMSEA value in this study was .096, which indicates that there is an adequate fit of the model.

Significant in this study, however, were the Modification Indices (MIs) and their corresponding Parameter Change (Par Change), which reflects the degree to which the model has been appropriately described. Byrne (2001) states that the MIs that AMOS provides for each fixed parameter is an indication of the estimated change, in either direction, that could improve the fit of the model. Table 12 presents the MIs and Par Change for the model in the current study.

Table 11: Modification Indices and Parameter Changes for Fixed Parameters

		Mod. Index.	Par Change
Length of time since Polio Diagnosis	<--> Visibility	5.102	4.123
eTransformation	<--> Polio dx.	5.611	-3.602
eSubordination	<--> Visibility	14.675	1.069
eSubordination	<--> ADL	4.969	-1.123
eSubordination	<--> eTransformation	22.748	1.098
eContainment	<--> Polio dx.	7.890	4.672

The MI data reveals that there is a potential for correlated error in the indicator variables for Acceptance of Disability, specifically with the subscales of Subordination of Physique (eSS) and its relationship with Visibility of Disability; and the highly correlated subscales of Subordination of Physique (eSS) and eTS.

SEM analysis tests normality of the data is observed through analysis of the skew and kurtosis figures. Ideal kurtosis values should be < 10, and the skew metric should be close to zero and <3 (Kline, 1998). Skew statistics in this study range from a negative skew of -2.29 (Abuse History) to - .44 (PDSBE), and kurtosis values range from .28 (ADL) to 5.95 (Polio Diagnosis). Abuse History is, however, a dichotomous variable and would be more appropriately represented in a correlation coefficient. Taking Abuse History out of the normality considerations, the remaining continuous variables approximate a normal distribution. A boxplot revealed four outliers in the Acceptance of Disability group. In reviewing the raw data, three of the cases scored extremely low on the PDSBE, and the other case declined to answer questions on the PDSBE portion of the survey and noted on her survey that she's "... been happily married for 38 years, so I have no reason to care how sexually appealing I am to others." Because of the large size of the sample, it was decided to leave the outlying data scores in since their influence on the total results would, most likely, be negligible.

The combined group CMIN/d.f chi-square statistic for this study is 111/25 (d.f.), or 4.44, p<.000, which shows a fairly large and significant chi-square, which appears to be a compromise of fit since a value of <3 indicates a good fit of the data to the model. The DELTA1 NFI = .91, indicates a good fit since the index result is >.9, the ideal criterion for fit. The RMSEA of .096 also reveals an adequate fit of the hypothesized model.

The Squared Multiple Correlation (r-squared) is a metric that identifies the percentage of the variance in the dependent variable (in this case, PDSBE) that can be explained by the independent variables. If the R-Square value is close to one, the model explains most of the variation in the dependent variable (PDSBE); R-Square values close to zero indicate that the model explains little of the variation. Table 13 presents the R-square values for the variables in this study.

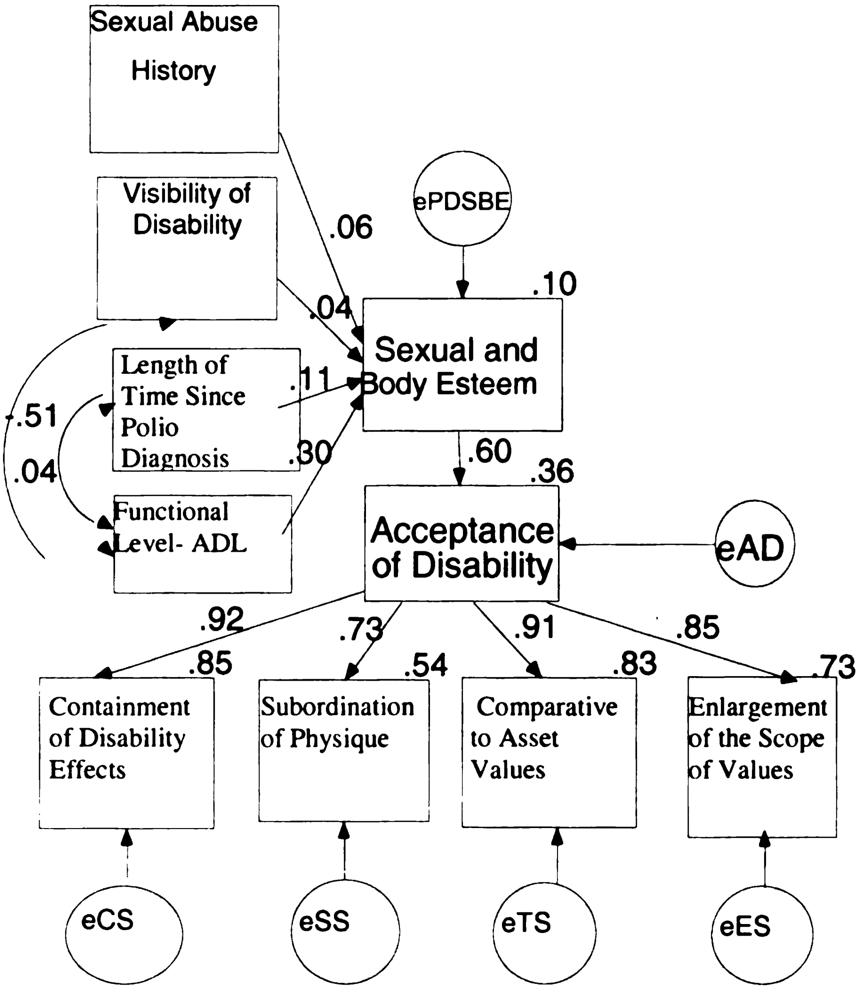
Table 13: R-square Values

Variable	R-Square
Sexual and Body Esteem	.098
Acceptance of Disability	.413
Enlargement Subscale	.646
Transformation Subscale	.738
Subordination Subscale	.415

With the exception of the Subordination of the Physique subscale, the remaining variables estimate a fair degree of the variance in esteem.

The hypothesized full structural equation model with regression weights is again presented in Figure 7.

Figure 7: Full Hypothesized Structural Equation Modeling



The Standardized Regression Weights (path coefficients) observed in Figure 7 above, corresponds identically with the AMOS Output statistics in Table 14, which is an important SEM metric.

Table 14: Standardized Regression Weights

Relationship			Estimate
Esteem	<---	Sexual Abuse History	.059
Esteem	<---	Visibility of Disability	.040
Esteem	<---	Length of Time since Polio Diagnosis	.114
Esteem	<---	ADL	.299
Acceptance of Disability	<---	Esteem	.643
Containment Subscale	<---	Acceptance of Disability	.908
Transformation Subscale	<---	Acceptance of Disability	.859
Enlargement Subscale	<---	Acceptance of Disability	.804
Subordination Subscale	<---	Acceptance of Disability	.644

The path model diagram (Figure 7) indicates that the functional ability of women with polio is the strongest predictor of sexual and body esteem (.30), followed by the length of time since polio diagnosis (.11). For every one unit increase in PDSBE all variables will increase by their reported Estimate in Table 13. Strong predictions were also observed with the relationships between sexual and body esteem and general acceptance of disability (.64) and the relationships between acceptance of disability and its subscales. Since the four subscales define acceptance of disability, it is expected that there is a strong relationship between the general acceptance of disability construct and its defining subscales.

The first two research question in this study addressed how women with polio were adjusting to their current level of disability and if their reported level of acceptance of disability affected their sexual and body esteem. There were three issues to be considered: 1) if women who reported a lower degree of acceptance of disability were less inclined to have satisfactory sexual health, 2) did a lower degree of body and sexual esteem demonstrate that women were not accepting of their current disability status, and 3) did any of the scores on the AD-R subscales correlate with satisfactory sexual and body esteem?

Relationships emerge between the variables in the review of the correlation matrix in Table 15.

Correlations for the variables in research question #1 ("Do women who have a high level of disability acceptance have higher degrees of sexual and body esteem?") revealed a positive correlation (.60) between acceptance and esteem, which indicates that the more a woman has accepted the impact of the disability on her life, the more positively she feels about her capacity to engage in personal relationships. The regression equation, also, points to a strong relationship (.64) between these two factors.

Research question #2 addressed the relationship of the various factors of adjustment to disability: ("What are the correlations between the four AD-R subscales and sexual and body esteem?") The four AD-R subscales were also positively correlated with esteem: Containment of Disability Effects (.61),

Table 14: Correlations

		Esteem	Total AD-R	Int. ADL	Basic ADL	Total ADL	Containm.	Subordin.	Transform	Enlargem.	Do you have a history of sexual abuse	How many years has it been since your polio diagnosis	How would you rate the visibility of your disability
Esteem	Pearson Correlation	1	.602(**)	.232(**)	.274(**)	.277(**)	.614(**)	.343(**)	.503(**)	.552(**)	.088	.117(*)	-.094
Total AD-R	Pearson Correlation	.602(**)	1	.180(**)	.204(**)	.209(**)	.921(**)	.731(**)	.909(**)	.854(**)	.064	.106(*)	-.049
Int. ADL	Pearson Correlation	.232(**)	.180(**)	1	.720(**)	.878(**)	.233(**)	-.029	.167(**)	.174(**)	.030	.005	-.430(**)
Basic ADL	Pearson Correlation	.274(**)	.204(**)	.720(**)	1	.965(**)	.259(**)	-.038	.210(**)	.182(**)	.055	-.047	-.509(**)
Total ADL	Pearson Correlation	.277(**)	.209(**)	.878(**)	.965(**)	1	.267(**)	-.037	.208(**)	.192(**)	.050	-.031	-.515(**)
Containment	Pearson Correlation	.614(**)	.921(**)	.233(**)	.259(**)	.267(**)	1	.561(**)	.776(**)	.733(**)	.069	.151(**)	-.118(*)
Subordination	Pearson Correlation	.343(**)	.731(**)	-.029	-.038	-.037	.561(**)	1	.636(**)	.485(**)	.044	.052	.176(**)
Transformation	Pearson Correlation	.503(**)	.909(**)	.167(**)	.210(**)	.208(**)	.776(**)	.636(**)	1	.684(**)	.023	.042	-.063
Enlargement	Pearson Correlation	.552(**)	.854(**)	.174(**)	.182(**)	.192(**)	.733(**)	.485(**)	.684(**)	1	.082	.096	-.074
Do you have a history of sexual abuse	Pearson Correlation	.088	.064	.030	.055	.050	.069	.044	.023	.082	1	.098	.064
How many years has it been since your polio diagnosis	Pearson Correlation	.117(*)	.106(*)	.005	-.047	-.031	.151(**)	.052	.042	.096	.098	1	.138(**)
How would you rate the visibiity of your disability	Pearson Correlation	-.094	-.049	-.430(**)	-.509(**)	-.515(**)	-.118(*)	.176(**)	-.063	-.074	.064	.138(**)	1

** Correlation is significant at the 0.01 level (2-tailed).
* Correlation is significant at the 0.05 level (2-tailed).

Subordination of Physique (.34), Transformation from Comparative to Asset Values (.50), and Enlargement of the Scope of Values (.55). The strongest correlation (Containment) would mean that the women are able to realistically appraise the role and impact of disability in their lives and not over-generalize the effects of disability on other areas of their lives, principally sexual and body esteem. The regression weights for each of these subscales also points to a strong predictive relationship with esteem: Containment (.90), Transformation (.86), Enlargement (.80), and Subordination (.64).

The correlations associated with research question #3 ("What is the relationship between the visibility of disability and sexual and body esteem?") pointed to a very slight negative correlation (-.09) between this variable and esteem, and the regression weight also reflected a weak relationship (.04). In fact, the greatest correlated relationship existed between visibility and functional capacity to complete activities of daily living (-.51) which suggests that the more visible a disability is the more difficulty a woman will have in completing various self-care activities. There is a limitation in the reliability of the visibility construct: only one question on the survey was used to measure this: ("On a scale from 1 = low to 10 = extremely, how would your rate the visibility of your disability?").

There is a slight positive correlation (.12) between the length of time since polio onset and sexual and body esteem (Research Question #4:"What is the relationship between the length of time since polio onset and sexual and body esteem?"), which appears to mean that the length of time a woman has lived with polio does affect her body and sexual esteem. The regression coefficient (.11) also supports that a relationship exists between these two variables. The years since polio diagnosis also has a significant positive correlation with the variables of Acceptance of Disability (.11, p<.05) and the Containment of Disability Effects subscale (.15, p<.01). The Containment subscale also reflected the greatest dispersion of responses to the questions that measured that construct (Table 5). It appears that the degree to which a woman is able to prevent the spread of the impact of disability into other areas of her life is based also on how long she has lived with polio. The Containment of Disability subscale is the only AD-R subscale shown to have any correlation with Length of Time since Polio Diagnosis (.151, p <.01), which suggests that the longer a woman lives with polio, the greater her ability might be to limit the impact of her disability into other aspects of her life, rather than "containing" its influence on just the physical dimension of self.

There appears to be a strong positive relationship (.28) between the variables in Research Question #5 ("What is the effect of the relationship of a woman's functioning level, as measured by the Functional Status Questionnaire (FSQ) on her sexual and body esteem?"). The variable of Total ADL (which is the functional ability of a woman to participate in various activities of daily living) has a significant relationship to all measured variables, but especially with visibility of disability (-.52).

The variable Sexual Abuse was revealed not to have any significant relationship with any of the other variables. A one-sample T-Test was run to see if there was a difference between the mean values of a history of sexual abuse and its effect on sexual and body esteem. Table 16 reports the results of this analysis.

Table 16: T-Test Sexual Abuse History, and Sexual and Body Esteem

							95% CI	
Sexual Abuse History	t	df	sig.	Mean Score (PDSBE)	s.d	s.e.	Lower	Upper
Yes	24.34	45	.000	31.61	8.81	1.30	28.99	34.23
No	79.91	324	.000	33.68	7.60	.42	32.85	34.51
Missing (imputed)	67.00	1	.010	33.50	.71	.50	27.15	39.85

The T-Test examined the effect of the variable abuse history on sexual and body esteem, as measured by the PDSBE instrument. The results of both groups are significant and it appears that whether a woman has an abuse history or not, it is not a distinguishing factor in sexual and body esteem, given that the PDSBE scale scores and standard deviations are approximately equivalent across groups.

The length of time a woman has been living with polio ("Polio dx.") is significantly and positively correlated at p<.05 (.12) with sexual and body esteem and also with total acceptance of disability (.11, p<.05). The regression coefficient is also predictive of a relationship (.11). There is a statistically significant and stronger positive relationship (p<.01) between length of time since polio diagnosis and the Containment of Disability Effects subscale of the AD-R (.15), and the self-reported visibility of disability (.14). Results indicate that the longer a woman has been living with polio the more likely that she will experience a positive body image and sexual esteem, and contain the spread of the disability effects despite what might be significant visibility of the disability.

The visibility of disability is strongly and positively correlated with a number of variables, although there was not a significant correlation with sexual and body esteem (-.09). The significant correlations were found with ADL (both Basic and Intermediate) (-.52), and the Containment of Disability Effects (-.12) subscale as well as the Subordination of Physique (.18) subscale, suggesting that how externally visible a woman's disability is could mean that she has difficulty limiting the effects of the disability solely to the physical limitations she experiences. This somewhat contradicts the small positive correlation reported on the Subordination subscale, since the Subordination of Physique refers to the ability of a person to see value in other personality and character traits beside just her physical abilities.

Observation of the correlated relationships with the variable Sexual and Body Esteem in Table 15 revealed significant positive correlations that exist between all but two variables (Acceptance of Disability and its four subscales, Activities of Daily Living, and Years since Polio Diagnosis); positive correlations range from .12 between the length of time since polio diagnosis and esteem, to .60 for overall acceptance of disability. The factors of history of sexual abuse (.09) and visibility of disability (-.09) appear to have a negligible and statistically insignificant impact on a woman's body image and sexual self-schemas.

With regards to the acceptance of disability construct, a history of sexual abuse and the self-reported visibility of disability appear to have no relationship to a woman's ability to accept and adjust to elements of living with polio (.06 and .35, respectively). Since the reliability of the measurement of these two variables is suspect, given that only one question appeared on the survey regarding each of these factors, the true relationship between visibility and history of sexual abuse, and sexual and body esteem, is inconclusive in this study. Additional research that measures the various components of visibility and abuse and how they influence a woman's view of her sexual and body esteem will provide greater detail on the relationship between these factors.

The degree to which a woman is able to take care of her self-care needs as well as perform general light household work and maintenance is positively correlated with the all measured aspects of acceptance of disability ($r = .21$ to .27) and negatively correlated with the visibility (-.52) variable, suggesting that acceptance of disability is related to the successful performance of various ADLs and may depend on the visibility of the disability. The accomplishment of activities of daily living appears to be a strong predictor of sexual and body esteem (regression weight of .299) and is also reflected in the significant ($p<.01$) positive correlation between Total ADL performance and Esteem (.277).

Effect sizes appear negligible in evaluating the influence of History of Sexual Abuse and Visibility of Disability. Small effect sizes were observed for the Activities of Daily Living (ADL) and Length of Time since Polio Diagnosis variables. Large effect sizes are noted for the variable of Sexual and Body Esteem across the variables of Acceptance of Disability and its related subscales. Table 17 contains the Standardized Total Effects for the variables.

Table 17: Standardized Total Effects

	Abuse	Visibility	ADL	Polio Dx.	Esteem	Acceptance of Disability
Esteem	.059	.040	.299	.114	.000	.000
Acceptance of Disability	.038	.026	.192	.074	.643	.000
Enlargement Subscale	.031	.021	.154	.059	.517	.804
Transformation Subscale	.033	.022	.165	.063	.552	.859
Subordination Subscale	.025	.016	.124	.047	.414	.644
Containment Subscale	.035	.023	.174	.067	.584	.908

Examination of the rather large values of the Modification Indices (MI) in the SEM AMOS output, reveals that an adjustment to the hypothesized model could be made to improve fit. Specifically, the relationship between the two error terms for the Subordination of the Physique AD-R subscale value and the Transformation from Comparative to Asset Values AD-R subscale value (MI = 22.75). It has been suggested that there may be a "halo" effect when respondents completed the survey (personal communication, Mark Reckase, July 21, 2005).

CHAPTER 5

DISCUSSION

The purpose of this study was to investigate factors that influence sexual and body esteem in a national sample of 373 women with polio. Structural Equation Modeling (SEM) was used to analyze the relationships between the factors of length of time since polio diagnosis, functional capacity regarding participation in activities of daily living, the self-reported visibility of disability, history of sexual abuse, and the degree of acceptance of disability. Several instruments were used to measure the constructs: Acceptance of Disability-Revised (Groomes and Linkowski, 2004), Functional Status Questionnaire (Cleary and Jette, 2000), and the Physical Disability and Sexual and Body Esteem Scale (Taleporos and McCabe, 2002). The findings indicate that there are significant predictive relationships between the variables and the measure of sexual and body esteem. Only one of the variables, Sexual Abuse History, appeared to have no significant correlative relationship to other variables and had a very weak predictive relationship (regression weight = .059) on sexual and body esteem. Previously cited research indicated that sexual abuse history could be a mediating factor in women's sexuality. The Visibility of Disability also was statistically insignificant in influencing sexual and body esteem and all measures of Acceptance of Disability, although a strong negative, and statistically significant, correlation was present in the relationship between Visibility and all four of the very specific AD-R subscales (Containment of Disability Effects, Subordination of the Physique, Transformation from

Comparative to Asset Values, and Enlargement of the Scope of Values). Interestingly, there was not a significant relationship between Visibility and the total measure of Acceptance of Disability.

One would expect that the degree of physical limitation (as measured by Activities of Daily Living- ADL in this study) would impact the sense of sexual self-efficacy and acceptance of disability experienced by long-term polio survivors who may have recently acquired new, and possibly severe secondary disabilities. The data demonstrated that ADL ability is a significant factor in esteem and acceptance of disability—but is uncorrelated, counter-intuitively, with the length of time a woman has polio. This suggests that functional disability can occur at any point in the continuum of living with the disease, and that physical restrictions and limitations could affect important quality of life measures such as sexuality. Positive enhancement of one's ability to cope with the loss associated with disability appears to be identified with Wright's (1983) modification of personal values that enhance disability acceptance. The study identified some areas of resiliency in disability acceptance and adjustment as represented on the AD-R subscale scores. This chapter presents additional discussion of the results of the study and its implications.

Sexual and Body Esteem Indicators

Body and sexual esteem are intricately interwoven for people with disabilities since there is vast social stigma associated with disabilities that visibly affect appearance and a pervasive belief that people with disabilities are asexual. The variable of a self-reported measure of how visible to others a woman feels her disability is, was included to test whether or not a greater degree of visibility of polio impacted how a woman viewed her sexual health and capacity to engage in intimate relationships.

Women with polio have been categorized as having a higher-than-average degree of educational attainment. This is confirmed by the results of this study: a majority of the women have college degrees and/or advanced graduate degrees. Initial analysis of the reading level of this investigation's survey instrument revealed a Flesch-Kincaid reading level of over an 11th-grade level. Given the academic history of the women in this sample, it is not believed that difficulty in understanding and interpreting survey questions was an issue.

The dimensions of Acceptance of Disability are framed by the theory of disability adjustment proposed by Wright, 1983. She identified four distinct aspects of adjustment that determine whether a person is "coping or succumbing (pg. 59)" to the influence of disability: 1) Containment of Disability Effects, addresses what Wright refers to as the concept of "spread," meaning that an individual blankets the elements of her worldview from a disability perspective. Disability status is the context from which everything is defined, viewed, and interpreted; 2) Subordination of the Physique, refers to the minimization of the various physical skills, abilities and appearance in lieu of a changed belief system that maintains that there is more to personal worth than physical capacity; 3) Transformation from Comparative Status to Asset Values, means that an individual who assesses their strengths and gifts in relation to others develops the ability to intrinsically identify personal skills and abilities that she may not have been able to identify and focus on prior to the onset of disability; and 4) Enlargement of the Scope of Values addresses the expansion of self-identity when confronted with disability so that the individual is able to broaden her concept of what is important in life despite the adverse affect of disability that may have diminished aspects of what an individual formerly (prior to disability onset) viewed as necessary. In this study, the women had high scores on all these subscales which indicate a satisfactory level of acceptance of disability despite the intrusion of what may be new disability-related characteristics as a result of post-polio syndrome. Of the sample size of 373 women, 275 of the women scored in the "High" Acceptance of Disability range, while 98 of the women scored in the "Medium" Acceptance of Disability category. One additional survey respondent scored in the "Low" category and for the purpose of this study, her data was not included and the "Low" category was eliminated.

The Physical Disability and Sexual and Body Esteem scale is the first instrument to concurrently assess how disability status influences an individual's perception of their physical self and their sexual health. The women's scores on the scale indicated a mostly positive-to-very positive self assessment of themselves and their status as a sexual being. Two questions had scaled responses that ranged from "Don't Know," to "Strongly Agree," and a third question triggered some thoughtful comments from participants:

> #2—"It is harder to find a sexual partner when you have a disability." 49.3% reported either "Agree" or "Strongly Agree." An additional 32% reported that they "Don't Know."

#8—"I envy people with 'normal' bodies." This question clearly conflicted some of the women. As noted previously, a majority of the respondents took advantage of the ability to write personal comments on the survey. Several women noted that they would like a different physical body, but would like to maintain their current personality and character traits.

#10 on the PDSBE was "I would do a body swap with an able-bodied person if I could." This question caused ambivalence in a substantial segment of the sample; over 31% percent of the women responded "Don't Know."

Other comments on the survey included content about how respondents didn't know themselves as a person without a disability so they had no idea if they would have the same quality of life. One woman said that in every dream she's ever had "...I'm always disabled. I don't think I'd be me without having gone through polio."

Many participants who included comments referenced their sexual activity level and their relationship with their partner. Over a dozen women indicated that the limitation in their sexual expression was a function of their spouse's impotence due to a chronic health condition (i.e.—diabetes, prostate problems) rather than as a result of any limitation imposed by their disability. It is clear that there is a need for (and interest in, at least with this sample of women) to explore issues related to sexual activity and performance more in-depth. It was a specific decision in the design of this study to purposefully exclude any questions that referenced sexual activity and to highlight this fact in the study's invitation letter to prospective participants. Since this topic had not been the focus of any prior research these women had participated in at U-M, and given their advanced age, it was decided to approach the issue of sexuality rather conservatively.

Limitations

This study's results and conclusions should be viewed with several limitations in mind. The 36% response rate for the survey was satisfactory and adequate for running an SEM analysis, however an extremely high percentage of the respondents were white (97.3%). Due to the homogeneity of this sample, no generalizations to other ethnic groups can be made. The four-fold discrimination issues that could arise in women, who happen to have a disability, who may be of non-Caucasian ethnicity, and who are older adults could be significant factors.

A second limitation involves the potential misinterpretation of a critical variable that is included in the SEM model. The survey question "How many years has it been since your polio diagnosis?" may have been understood by a few women to mean "how many years has it been since your *post-polio* diagnosis?" There is not a complementary question in the survey that asked participants to state the length of time since post-polio diagnosis. Given that polio has been essentially eradicated since the 1960's in the United States, survey responses that state a polio diagnosis <40 years is suspect.

A third concern is with the age of the sample (mean = 61.8 years). The generational issues regarding sexual orientation and openly talking about sexuality could have influenced the honesty of responses. Public health measures and polio vaccines will, more than likely, keep polio under control in the United States, but it remains a significant health problem in underdeveloped countries. Thus, studies on younger women with polio will be more likely to occur in countries where polio is not controlled.

Fourth, this survey focused on women with polio. Generalizing the results to males with polio could be problematic. Men with disabilities, and men in general, have a more positive body image self-schema than women. Responses to the PDSBE could be significantly different.

And finally, there are some limitations regarding the instruments. The FSQ (ADL measurement) scale has been normed for use mainly in primary care settings. It is a consideration that the FSQ was administered to a population that won't get 'better,' since polio is a chronic, often progressive, and lifelong affliction. The AD-R is a recent revision of an older instrument and there is very little information regarding its psychometric properties. Regarding the PDSBE, a limitation lies in the brevity of the instrument (10 items), and while a number of studies have validated its internal consistency reliability alphas, the instrument developers indicate that there are three subscales in the PDSBE with one subscale containing only three items. The three subscales, however, were not distinguished or specifically measured in this study. Finally, the reliability of two of the measures is questionable: only one question was asked of participants regarding their sexual abuse history, and one question was asked of participants to self-scale the visibility of their disability. No definitions were provided for these two constructs, leaving the questions open to subjective interpretation by the respondents.

Implications for Education and Training

Ducharme and Gill (1991) reported that while 79% of rehabilitation counselors thought sexual health was important, only 9% included it in their plans with consumers. Cash and Pruzinsky (2002), pioneers in the field of body image, state that body image and physical diseases and disorders are the "...next frontier of scholarship." Unfortunately, some still view sexuality as a taboo topic that can be further constrained by the cultural mores of the counselor and consumer. There is tremendous potential to infuse sexuality into many aspects of rehabilitation counseling. Sexuality is a multidimensional construct that combines elements of self-schema, degree of adjustment to and acceptance of disability, the visibility of the disability to others, and the physical and mental capacity to engage in sexual activity. Too often sexuality has been given token representation in counseling by focusing on 'it' for a counseling session or two. By acknowledging the many facets of sexuality that incorporate inter- and intra-personal, and environmental factors, sexuality can be addressed throughout the counseling process at many different points. Addressing the components of sexuality in people with disabilities should not just fall to the professional realm of social workers or psychologists but should involve a multi-disciplinary approach just as other parts of the rehabilitation process does.

The need to make the topic of discussing sexuality with consumers more palatable can be illustrated by the following brief story. If you, as a counselor, are in a meeting and someone asked you to say a little bit about your family—most of us could think of a few things to say without being too revealing. However, if you were asked to turn to your neighbor and discuss your most recent sexual experience, chances are you wouldn't do it, or would be extremely guarded and perhaps a little untruthful. Yet, that is what we as counselors ask our clients to do when we isolate the construct of sexuality solely as sexual activity in our counseling sessions.

There is opportunity to develop measures to enhance scholarship regarding the measurement of the inter-relatedness of disability, body image, and sexuality. Also, quantitative tools to assess disability, social desirability, and the experience of sexual expression in people with disabilities could be developed. Existing instruments frame the language of the questions from the perspective of someone who is not limited in their physical capacities and whose body functions "normally." These inventories are extremely limited in their applicability and relevance to someone who has a physical disability.

Rehabilitation counselors could actively work to influence media perceptions and public impressions of people with disabilities regarding the capacity of people with disabilities to live a full quality of life with success at work, socially, and interpersonally.

Although this study does have some important limitations, the contributions to the scholarship regarding the exploration of issues important to long- term polio survivors and their body and sexual esteem made by this study are useful. The perspectives that this sample had on some issues have the ability to be generalized to other populations of women with disabilities who live with a long-term disability. While no new theories emerged, this study did have implications for all helping professionals: women with disabilities experience the same events, such as sexual abuse, as women without disabilities; they have the same (although heightened) concerns about how they look and how they are perceived by others; and they also seek mutually satisfying and reciprocal intimate relationships. It appears that women with and without disabilities have more in common than they do differences. As rehabilitation counselors and scholars it may be time to bring women with disabilities into the research fold on the issue of sexuality for *all* women so that disability adjustment and attitude can be integrated into training and counselor training curricula, rather than as an isolated topic.

Implications for Future Research

There is a tremendous opportunity for research on the topic of women with disabilities and sexuality to examine some of the mediating variables that impact successful sexual adjustment, especially in older women with disabilities. The field of aging and disability is a relatively new area of inquiry, and quality of life measures like sexuality and adjustment to functional losses are emergent topical areas that deserve consideration, especially as the ‘baby boomer’ population of the United States experiences limitations that can be a natural component of the aging process.

The area of body image and women is a topic that has long been researched as the awareness of eating disorders has increased. However, modifying any of the instruments that are currently being used to evaluate body image would require changing some questions and re-wording them in a disability-friendly language. A woman can have experienced a significant loss, such as amputation, and still retain a positive body image. Most existing instruments assess this loss of a limb as a dysfunction and a cause for maladjustment. Disability status is still viewed as a problem, and therefore a person with a disability must experience problems in adjusting to their "non-normal" bodies.

Rather than framing adjustment and sexuality in people with disabilities using a deficits perspective (which is common to the medical-model view of disability), researchers could focus on identifying positive, facilitative skills that promote positive sexual health and adjustment, and evaluate the presence of character traits and environmental factors that allow an individual to transcend any physical (and cognitive) limitations imposed by the disability.

Reproductive health care in women with disabilities is a current area of research. The lack of accessible Ob-Gyn facilities and examining tables cause many women not to take care of this very important area of their health. Anecdotal reports from women with spinal cord injuries relate horror stories of being "heaved up" onto the examination tables by two office staff using a sheet as a sling. Women with disabilities who become pregnant often face an entire pregnancy without their weight being measured, due to an inaccessible scale. One can only assume that these issues further propagate the notion that women with disabilities are asexual.

And finally, education of physicians on how to work with women with disabilities should begin in medical school and should be infused into the curriculum to avoid segregation of disability that addresses disability as an "issue" that is presented in one lecture of one class in one term of medical school. Ongoing education and training of all health and allied healthcare providers should be ongoing, and the topic of sexuality should be included in any assessment and treatment plan for people with disabilities.

Summary and Conclusions

This study did not generate any new theories or hypotheses, but did confirm existing research and identify areas of inquiry for future exploration. The factors that influence sexual and body esteem seem to be more complex and interrelated than just isolating adjustment, history of sexual abuse, visibility of disability, and the length of time one has been living with the disability.

The incorporation of a non-disabled control group who would have answered the same questions on sexuality could have enhanced knowledge, although a non-disability specific measure of sexuality would need to be used. Specific scales regarding body image were reviewed prior to the beginning of this study. All were found to contain items that would, by the wording of the questions, automatically group people with disabilities into a dysfunctional status. There are many people, including those with severe disabilities, who have found a way to form very mutually satisfying intimate relationships. By focusing future research on individuals with disabilities who have successfully negotiated sexuality as an important quality of life issue, researchers can help eliminate the ubiquitous perceptions that sexual health is unimportant to those with disabilities.

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APPENDICES

APPENDIX A- Informed Consent Form

Informed Consent Form

A Study to Examine the Relationships between Adjustment to Disability, and Sexual and Body Esteem in Women with Polio.

You are being asked to give your voluntary consent to participate in this research study by completing a survey that analyzes the relationships regarding adjustment to disability, physical functioning, and how women with polio feel about their bodies and sexual relationships. The purpose of this research study is to further the knowledge about this important quality of life area for women with disabilities, and to assist professionals in understanding some of the needs and issues expressed by women with polio concerning how they feel about their level of disability and how this relates to their feelings about intimate relationships. This is a collaborative study between Michigan State University and the University of Michigan. This research study is being led by Barbara Barton, MSW, a doctoral candidate in Rehabilitation Counselor Education at Michigan State University, and Claire Kalpakjian, Ph.D. a Research Associate in the Department of Physical Medicine and Rehabilitation at the University of Michigan.

If you agree to participate in this study, the following will occur:

1) You will be asked to complete a survey that will ask you questions about how you feel about your disability, how you perform various activities of daily living, and how you feel about yourself as a woman with a disability in relation to your role in sexual relationships. Other questions will ask about your age and work status, visibility of your disability, length of time since polio onset, whether or not you have a history of sexual abuse, and your gender orientation. You may decline to answer *any* of the questions that make you uncomfortable or that you do not wish to answer.
2) The survey will take approximately 20 minutes of your time to complete.
3) The completed survey and this signed Informed Consent form should be returned in the enclosed business reply envelope. This address is: Women with Polio Study, 300 N. Ingalls, NI 2A09, Ann Arbor, MI 48109.
4) You may decide at any time to not complete the survey, or decline to answer any of its questions.

Participation in this study, or your decision not to participate, will in no way affect any services you may receive from the University of Michigan.

Confidentiality of Subject Records

All personally identifying information will be kept confidential and your privacy will be protected to the maximum extent allowed by law. Participants will be assigned an identification number and your name will not appear anywhere on the survey. All study materials will be kept in a locked file cabinet accessible only to the researchers. For more information about these policies, ask for a copy of the University of Michigan Notice of Privacy Practices. This information is also available on the web at http://www.med.umich.edu/hipaa/npp.htm.

A Certificate of Confidentiality has been issued by the Department of Health and Human Services (DHHS) in Washington, D.C. This Certificate will protect the investigators from being forced to release your name or other information that might identify you, even under a court order or subpoena. This protects you from being identified in any civil, criminal, administrative, legislative or other proceedings whether federal, state or local as a result of agreeing to release this information as part of this study. This protection, however, is not absolute. The researchers may report certain communicable diseases and if we have reason to believe a child is being abused. When results from this study are published, your identity will not be revealed. This Certificate of Confidentiality does not represent an endorsement of this research project by the Secretary of Health and Human Services.

Signing this form gives the researchers your permission to obtain, use, and share information about you for this study, and is required in order for you to take part in the study. You also give researchers permission to use data previously collected in the *Menopause and Aging Study* in which you participated in 2003. This data will be used to further explore relationships between health and well-being factors and what is learned in this study.

There are many reasons why information about you may be used or seen by the researchers or others during this study. Examples include:

- The researchers may need the information to make sure you can take part in the study.
- The researchers may need the information to check your test results or look for side effects.
- University and government officials may need the information to make sure that the study is done properly.
- Organizations that are funding the study may need the information to make sure that the study is done properly.
- Safety monitors or committees may need the information to make sure that the study is safe.
- Insurance companies or other organizations may need the information in order to pay your medical bills or other costs of your participation in the study.
- The researchers may need to use the information to create a databank of information about your condition or its treatment.

The results of this study could be published in an article, but would not include any information that would let others know who you are.

Information about Risks and Benefits

The only possible risks are in this study are psychological: discomfort as a result of describing your physical functioning, mood, attitude toward disability, sexuality and body image. There are no risks of physical injury. As with any research study, there may be additional risks that are unknown or unexpected. Remember, you do not have to answer any question if you do not wish to. The researchers have taken steps to minimize the known or expected risks. However, you may still experience problems or side effects, even when the researchers are careful to avoid them. If you believe that you have been harmed:

1) Do not complete the survey, or the questions that you find distressing.
2) Speak to either of the researchers, who are both trained clinicians, and who would be happy to talk about your concerns with you: Barbara Barton, 517/355-8090, bartonba@msu.edu, or Claire Kalpakjian, 734/763-9374, clairez@umich.edu.

Although there is no direct benefit to you from participating in this research project, you may gain an increased awareness of how your disability affects you and how it impacts how you feel about your sexuality. Additionally, the information you provide could help rehabilitation practitioners and other professionals better understand how to meet the needs of, and explore the issues of, women with polio and other disabilities.

We again want to state that your participation in the study by completing the survey is voluntary. You have the right to choose not to participate at all by not completing the survey. There will be no consequences to you if you decline to participate. If any of the questions on the survey are too stressful, sensitive, or difficult to answer, you may feel free to not answer them.

If you have any questions about the study or the survey, please contact any of the following:

Michael Leahy, Ph.D., CRC- Principal Investigator
Michigan State University
463 Erickson Hall
East Lansing, MI 48824-1034
Phone: 517/432-0605
E-Mail: leahym@msu.edu

Barbara Barton, MSW, Co-Investigator
935 C Cherry Lane
East Lansing, MI 48823
Phone: 517/355-8090
E-Mail: bartonba@msu.edu

Claire Kalpakjian, Ph.D., Co-Investigator
Project Manager
Model Spinal Cord Injury Care System
Department of Physical Medicine and Rehabilitation
University of Michigan Health System
NI2A09, 300 N. Ingalls
Ann Arbor, MI 48109-0491
Phone: 734/763-9374
E-Mail: clairez@umich.edu

If you have any questions regarding your rights as a study participant, or are dissatisfied at any time with any aspect of this study, you may contact, anonymously if you wish, the University Committee on Research Involving Human Subjects at Michigan State University, Peter Vasilenko, Ph.D. (phone: 517/355-2180, e-mail ucrihs@msu.edu), or the University of Michigan Medical School Institutional Review Board (phone: 734/763-4768, e-mail irbmed@umich.edu), or contact the University of Michigan Compliance Help Line at 1-888-296-2481.

You indicate your voluntary agreement to participate in this study by completing the enclosed survey by signing the Informed Consent form below. Please return this signed form with your survey.

____
Name of Participant (please print)

____
Signature of Participant

____
Date

APPENDIX B- Study Invitation Letter

University of Michigan
Health System

ADJUSTMENT TO DISABILITY, AND SEXUAL AND BODY ESTEEM IN WOMEN WITH POLIO

A New Collaborative Study By
THE UNIVERSITY OF MICHIGAN &
MICHIGAN STATE UNIVERSITY

Dear Potential Participant,

The Investigators of the ***Menopause and Post-Polio Study*** conducted in 2002-2003 at the University of Michigan Department of Physical Medicine and Rehabilitation are joining the Office of Rehabilitation and Disability Studies at Michigan State University in a new collaborative study to explore another important, but neglected area of health for women with disabilities. Specifically, this new study is exploring how women who are post-polio feel about their bodies, and how this affects their intimate relationships.

As with many issues unique to women's experience of disability, these are important quality of life areas that have received little attention in research. For women who are post-polio and the health care professionals who work with them, very little information is available that can help women with varying degrees of disability feel comfortable with themselves the way they are in terms of their sexuality. As you may guess, discomfort with how a woman feels about her body can have a dramatic impact on her ability to form and enjoy intimate partnerships, which can lead to lower life satisfaction and negative emotional consequences.

In order to better understand this area of women's health, we are inviting you to participate in this new study. You are being invited to participate because you expressed interest in being contacted for future studies. Nevertheless, as with any research, your participation is completely voluntary and you may withdraw at anytime without penalty. The questions in this new survey will be general in nature and will not ask you any questions related to your level of sexual activity. Rather, we are most interested in finding out how your disability has affected you and how you *feel* about yourself in intimate relationships. Should you decide to participate; the survey will take approximately 20-minutes of your time to complete. And you may decline to answer any question that makes you feel uncomfortable. If you have any questions or concerns, please contact either of us at any time.

If you would like to join this new study, please completely fill out the enclosed postcard and return it in the stamped envelope. We thank you for considering joining this unique, collaborative project... and we hope to hear from you!

Sincerely,

Claire Z. Kalpakjian, Ph.D.
Co-Principal Investigator
University of Michigan
734-763-9374
clairez@umich.edu

Barbara Barton, M.S.W.
Co-Principal Investigator
Michigan State University
517-355-8090
bartonba@msu.edu

APPENDIX C- Survey

(NOTE: Survey has been slightly re-formatted for space considerations in this dissertation)

I.D. Number: ________________

Adjustment to Disability, and Sexual and Body Esteem in Women with Polio

We thank you for your participation. If at any time you have questions or comments, please contact us: Barb Barton, 517/355-8090 (bartonba@msu.edu), or Claire Kalpakjian, 734/763-9374 (clairez@umich.edu).

Activities of Daily Living-- This section refers to how easy or difficult it is for you to accomplish everyday tasks. Please place an "X" beside the response that characterizes your functioning. (Functional Status Questionnaire (1986), Jette, A. and Davies, A.)

Activity	Usually did with no difficulty	Some difficulty	No difficulty	Usually did not do because of health	Usually did not do for other reasons
1. Taking care of yourself: eating, dressing, bathing?					
2. Moving in or out of a bed or chair?					
3. Walking indoors, such as around your home?					
1b. Walking several blocks?					
2b. Walking one block or climbing a flight of stairs?					
3b. Doing work around the house, such as cleaning, light yard work or home maintenance?					
4b. Doing errands such as grocery shopping?					
5b. Driving a car or using public transportation?					
6b. Doing vigorous activities such as running, lifting heavy objects or participating in strenuous sports?					

Comments:

Please answer the following questions by placing an "X" next to your response:

1. Which of the following statements describes your work situation during the past month?

_____ working full-time
_____ working part-time
_____ unemployed, looking for work
_____ unemployed, because of my health
_____ retired, because of my health
_____ retired, for some other reason

2. During the past month how many days did illness or injury keep you in bed all or most of the time? _________ DAYS

3. During the past month, how many days did you cut down on the things that you usually do for one-half day or more because of your illness or injury? ___________ DAYS

4. During the past month, how satisfied were you with your sexual relationships?
_____ very satisfied
_____ satisfied
_____ not sure
_____ dissatisfied
_____ very dissatisfied
_____ did not have any sexual relationships

5. How do you feel about your health?
_____ very satisfied
_____ satisfied
_____ not sure
_____ dissatisfied
_____ very dissatisfied

6. During the past month, about how often did you get together with friends or relatives, such as going out together, visiting in each other's home, or talking on the telephone?
_____ every day
_____ several times a week
_____ about once a week
_____ 2 or 3 times a month
_____ about once a month
_____ not at all

The next section addresses questions about how you feel about your level of disability.
(AD Scale-R (2004), Groomes and Linkowski)

Read each statement below and circle the number that indicates to what extent you agree or disagree with the statement.

	Strongly Disagree	Disagree	Agree	Strongly Agree
1. With my disability, all areas of my life are affected in some major way. C	1	2	3	4
2. Having my disability, I am unable to do things like people without disabilities do. T	1	2	3	4
3. Disability or not, I am going to make good in life. E	1	2	3	4
4. Because of my disability, I have little to offer other people. T	1	2	3	4
5. Good physical appearance and physical ability are the most important things in life. S	1	2	3	4

	Strongly Disagree	Disagree	Agree	Strongly Agree
6. A person with a disability is restricted in certain ways, but there is still much s/he is able to do. E	1	2	3	4
7. No matter how hard I try or what I accomplish, I could never be as good as the person who does not have my disability. T	1	2	3	4
8. Because of my disability, other people's lives have more meaning than my own. T	1	2	3	4
9. Because of my disability, I feel miserable much of the time. C	1	2	3	4
10. Though I have a disability, my life is full. E	1	2	3	4
11. The kind of person I am and my accomplishments in life are less important than those of persons without disabilities. T	1	2	3	4
12. A physical disability affects a person's mental ability. S	1	2	3	4
13. Since my disability interferes with just about everything I try to do, it is foremost in my mind practically all of the time. C	1	2	3	4
14. There are many things a person with my disability is able to do. E	1	2	3	4
15. My disability in itself affects me more than any other characteristic about me. C	1	2	3	4
16. There are many more important things in life than physical ability and appearance. E	1	2	3	4
17. Almost every area of life is closed to me. T	1	2	3	4
18. My disability prevents me from doing just about everything I really want to do and from becoming the kind of person I want to be. C	1	2	3	4
19. My disability affects those aspects of life that I care most about. C	1	2	3	4
20. A disability such as mine is the worst possible thing that can happen to a person. T	1	2	3	4

	Strongly Disagree	Disagree	Agree	Strongly Agree
21. If I didn't have my disability, I think I would be a much better person. T	1	2	3	4
22. When I think of my disability, it makes me so sad and upset that I am unable to do anything else. C	1	2	3	4
23. People with disabilities are able to do well in many ways. T	1	2	3	4
24. I feel satisfied with my abilities and my disability does not bother me too much. E	1	2	3	4
25. In just about everything, my disability is annoying to me so that I can't enjoy anything. C	1	2	3	4
26. Physical wholeness and appearance make a person who s/he is. S	1	2	3	4
27. I know what I can't do because of my disability, and I feel that I can live a full life. E	1	2	3	4

Comments:

____

____

This final set of questions asks you about how you feel about your body and sexuality. You may skip any questions that make you uncomfortable, or that you don't wish to answer. (Physical Disability Sexual and Body Esteem Scale (2002), Taleporos, B. and McCabe, M.)

Question	Strongly agree	Agree	Don't know	Disagree	Strongly disagree
1. I feel that my disability interferes with my sexual enjoyment.					
2. It is harder to find a sexual partner when you have a disability.					
3. I would like to hide my disability as much as possible.					
4. I feel sexually frustrated because of my disability.					
5. I feel that my disability is likely to prevent me from satisfying a sexual partner.					

Question	Strongly agree	Agree	Don't know	Disagree	Strongly disagree
6. My sexual expression is limited by my disability.					
7. I feel that people are not sexually interested in me because of my disability.					
8. I envy people with 'normal' bodies.					
9. I believe that I experience rejection from potential sexual partners because of my disability.					
10. I would do a body swap with an able-bodied person if I could.					

Comments:
____
____

And finally, please tell us about yourself:

1. Age: _____________ years

2. How would you rate the *visibility* of your disability? 1 = NOT VISIBLE, 10 = HIGHLY VISIBLE: __________

3. Do you have a history of sexual abuse? ______ yes
   _______ no

4. How many years has it been since your polio diagnosis? _____________ years

5. What is your marital status:
   - _____ married/in partnership
   - _____ divorced
   - _____ widowed
   - _____ never married
   - _____ separated

6. How would you identify your sexual orientation?
   - _____ heterosexual
   - _____ bisexual
   - _____ lesbian

7. What is your ethnicity?
   - _____ Caucasian
   - _____ Hispanic
   - _____ Native American/First Nation
   - _____ African-American/Black
   - _____ Asian/Pacific Islander
   - _____ Other: ______________

8. What is the highest educational level you've completed?
   - ______ high school
   - ______ some college
   - ______ college degree
   - ______ post-graduate degree
   - ______ technical/trade school
   - ______ Other: ______________

9. What STATE and COUNTRY do you live in? State: _______ Country: _____

General comments about the survey: ____

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Thank you for taking time to participate in this project. Please return your completed survey and Informed Consent Form in the enclosed addressed envelope, or mail it to:

Women with Polio Study, 300 N. Ingalls, NI 2A09, Ann Arbor, MI 48109.