WOMEN WITH POLIO:

MENOPAUSE, LATE EFFECTS, LIFE SATISFACTION AND EMOTIONAL DISTRESS

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EXECUTIVE SUMMARY

With advances in health care, women with physical disabilities are living longer than previous generations and are making the transition through menopause in greater numbers than ever before.[1] Of the 30 million women with physical disabilities in the United States, more than 16 million are over the age of 50 years[2] constituting a large and growing population of women who have been relatively understudied with regards to their psychological and physical experience of menopause. As such, little is known about the unique biological milestones women experience as they age and the interaction of physical disability and these biological changes.

The primary objective of this study was to explore the relationship between menopause and late effects (or post-polio sequelae) for women with a history of polio in a large, community-based sample. In an effort to highlight the unique contribution of menopause, men with a history of polio also participated serving as a control group. By clarifying such relationships, better treatment recommendations can be made by those providing care to women with a history of polio and who are experiencing menopause. Additionally, a greater understanding of differences between women and men in their experience of aging and post-polio sequelae can inform treatment approaches for men as well.

Three main objectives guided this study: 1) to explore the relationship of menopause, late effects and physical functioning; 2) explore the relationship of menopause to life satisfaction and emotional distress; and 3) the efficacy of hormone replacement therapy in ameliorating menopausal symptoms and improving physical functioning, life satisfaction and reducing emotional distress. In addition to these hypotheses, the efficacy of hormone replacement therapy (HRT) was explored in two sub-samples of women. Selected aspects of health and well-being of polio survivors and differences between genders as well as U.S. population estimates (where available) also have been explored and are presented here. Finally, psychometric properties and factor structures of a newly developed scale to measure post-polio sequelae severity and a standardized menopause symptom rating scale were investigated.

In January 2003, letters of invitation to participate along with a response card were sent to 2,964 individuals from a mailing list provided by PHI. Potential participants were instructed to return the response card if they wished to receive a survey. In addition to this mailing, throughout the duration of data collection, we heard from a number of individuals who found out about the study through family or friends or press; they too were sent surveys if they wished to participate. A total of 1,548 individuals were sent surveys between February and April 2003. Most surveys were returned shortly thereafter, but continued to be received until fall 2003. Data collection officially was closed October 31, 2003. A total of 1,282 surveys were returned and entered into the database. The survey used in this study was comprised of standardized measures and non-standardized items. The survey addressed seven domains: polio history, sequelae and current problems, general health, physical functioning, physical activity, psychosocial well-being and menopause. Surveys for women and men were identical with the exception of the menopause section.

This study produced several significant findings related to menopause in women who are post-polio which lays an important foundation for future studies examining the interactions between menopause symptoms and secondary conditions and their impact on health as women with physical disabilities age. First among these findings was a significant relationship between the severity of post-polio sequelae and menopause symptoms. Further research is needed to understand the potential mechanisms of symptom or secondary condition exacerbation as well as limitations in measurement of symptoms, in particular their sensitivity and specificity all of

which requires careful scrutiny before definitive conclusions can be made. However, this is preliminary evidence that a relationship does exist that has the potential to impact the health of these women as they age.

The study of menopause in general is fraught with complications stemming from its basic transitional nature to limitations in measurement and conceptualization of a "menopause syndrome." As such, with the added complication of physical disability, this study is an important first step in what is surely a substantial yet vital undertaking. Two particularly important findings related to how menopause may or may not differ in women with disabilities is that contrary to speculation in the literature, women in this sample who had a natural menopause did so at the same age, on average, as their peers. However, they did undergo hysterectomies at a significantly higher rate than their peers, although the reasons for this disparity are not clear at this time.

In general, more than half of the proposed hypotheses were unsupported by our findings. Two (2 and 3) were fully supported suggesting an association between worse menopause symptoms and poorer emotional well-being and an association between menopause status and post-polio sequelae severity and lower physical functioning. The hypothesis that menopause symptoms would be significantly associated with post-polio sequelae severity and physical functioning was partially supported as there was no association between the latter and menopause symptom severity. This may suggest that either self-report measures of physical functioning are not adequately sensitive enough to detect differences in levels of physical functioning or that this relationship is moderated by years of adaptation to physical disabilities, such as was the case for most of the women in this study.

Although the remaining hypotheses did not receive support (4-7), using men as controls provides an interesting perspective to better understand the interaction of menopause status and disability related factors. The vast majority of studies examining menopause symptoms do not include men as controls, although the few that do have found little differences in report of symptoms commonly associated with menopause (except vasomotor symptoms). Specifically, while there were some differences on physical outcomes by menopause status, age-matched men were generally similar on these outcomes. Where there were gender differences, these tended to be among late postmenopausal women and their age-matched male counterparts. This may suggest an acceleration of decline for women compared to men in later years; this will require further investigation.

Despite the unknown risk-benefit ratio of HRT use by women with physical disabilities, who are likely to be predisposed to greater health risks by virtue of their narrower margin of health, women in this study use HRT at a significantly higher rate than their non-disabled peers, despite its lack of efficacy for mitigating nearly all but vasomotor symptoms. Interestingly, there were differences on severity of psychological symptoms by HRT within groups early and late postmenopausal women, despite evidence to the contrary from recent studies of non-disabled women. The reasons for disparity in HRT use rates are not known and recent findings about the safety of HRT have dramatic changes in usage, both discontinuing and resuming use and so estimates of current use are difficult to determine. Although there were few differences found among women using and not using HRT and their age-matched counterparts on physical outcomes, late postmenopausal women using HRT reported greater post-polio sequelae severity but simultaneously better basic ADL functioning.

Additional analyses performed on a standardized scale to measure menopause symptoms also sheds some light on measurement issues in women with physical disabilities given the overlap or interaction of symptoms. Our examination of the factor structure of the MSL indicated that while there were the common symptom clusters – psychological, somatic, and vasomotor – the two somatic clusters reflected two common problems in late polio – sensory loss and sleep disturbance. The fact that these factors were far less likely to differ by menopause status than were psychological and vasomotor factors suggests that they may be less sensitive due to substantial overlap with problems associated with the primary disability. The results of this factor analysis, the first of its kind in the published literature, suggests that great caution should be used when employing standardized menopause symptom rating scales developed with non-disabled women. It further highlights limitations in measurement with regard to sensitivity and specificity indicating a need for more research.

On the whole, as expected, these polio survivors were well-educated, married and were either working or had retired. Using national estimates from the Census Bureau and the Centers for Disease Control and Prevention on selected demographic and health factors, we were able to make comparisons to this sample to place them in the larger context of their fellow Americans. These comparisons suggested that, as has been largely believed, their rates of education were nearly three to five times greater than their similarly aged peers. The most marked differences in advanced degree rates were among the older participants suggesting that indeed, they stood out among their peers given the up-trend of advanced education over time during the 20th century. These participants also were married at similar rates suggesting that disability did not limit their ability to form close, intimate relationships. In fact, those in the 75 to 84 year old age group were married at a higher rate than their peers. While many had already retired for both medical and non-medical reasons and were employed at significantly lower rates than their similarly aged peers, for those over the age of 65 years, employment rates were similar.

Nevertheless, not all differences to their fellow Americans were positive. Middle aged participants reported substantially greater perceived stress than their similarly aged peers, although this difference dropped off in later years with the lowest rates of stress reported by older participants. These polio survivors also rated their health lower than their peers (although poor ratings of health were similar) with many falling in the “good” range, while their fellow Americans were more likely to rate their health in “very good” and “excellent” categories.

Implications of the major findings of this study suggest some association between menopause and post-polio sequelae and, as such, women who are post-polio, perhaps even more than their non-disabled peers, should be fully aware of the health changes associated with menopause and their own personal risk profile for co-morbid disease, such as cardiovascular disease. The further implications of the findings of this study are such that women who are post-polio should carefully weigh the known risks and benefits of HRT with their physicians given their narrower margin of health and vulnerability to co-morbid health conditions due to limitations in physical activity.

Because so little is known about menopause, a normal biological milestone in every woman’s life, and its unique characteristics in women with physical disabilities, women who are post-polio are, fairly or not, are put in the position of having to educate both themselves and their health care providers about how they may differently experience menopause. Fortunately, this study now provides them with some of the first solid evidence that their experience of menopause – physiologically, physically, psychologically – will very likely be different in some important ways than their non-disabled peers. Optimizing their health at all levels and knowing their own unique

risk profile as it relates to both menopause and aging is perhaps the most important message from this study's findings for these women as they transition through menopause. While there remains much to be learned about menopause in the context of disability, this comprehensive study – the first of its kind with such a large population of women with physical disabilities – has taken the important first step to what we hope will be the start of a generation of menopause studies that no longer ignore women with disabilities.

STATEMENT OF THE PROBLEM

With advances in health care, women with physical disabilities are living longer than previous generations and are making the transition through menopause in greater numbers than ever before.[1] Of the 30 million women with physical disabilities in the United States, more than 16 million are over the age of 50 years[2] constituting a large and growing population of women who have been relatively understudied with regards to their psychological and physical experience of menopause. Women with disabilities in general have long been neglected in rehabilitation research; in fact, research on aging and disability has addressed the experience of women only in the last 10-15 years.[3] As such, little is known about the unique biological milestones women experience as they age and the interaction of physical disability and these biological changes. As a result, treatment approaches to maximize health and functioning in women as they age are not as informed as they might otherwise be.

Physiological changes due to menopause and their effects on health in women can place women with disabilities at a higher risk for problems due to their narrower margin of health. For example, the accelerated loss of bone mineral density (BMD) associated with menopause places many women with mobility impairments at an even higher risk for osteoporosis and fracture. Autoimmune disorders, more common in women,[4] such as multiple sclerosis, have been shown to be influenced by estrogen.[5, 6] Treatment of some autoimmune disorders, such as rheumatoid arthritis, with cortico-steroids accelerates bone loss, especially in postmenopausal women.[7, 8] For women with epilepsy, declines in estrogen at menopause lower seizure thresholds.[9, 10] Estrogen loss also compromises collagen content and vascular profusion in the skin that can result in diminished skin integrity and tissue resiliency leading to skin breakdown and pressure sores in wheelchair users,[2] although the latter will also depend on level of injury, strength in upper body (for pressure relief) and wheelchair-type use (manual vs. power). The periurethral region of the bladder is sensitive to estrogen loss[2] and may exacerbate bladder dysfunction.

Compounding the problem of already diminished physical activity and sedentary lifestyle in women with mobility impairments and its adverse effect on cardiovascular health and body composition are declines in resting metabolic rates resulting in weight gain[11] and increased abdominal adiposity.[12] Type II diabetes has particularly adverse effects on lipid profiles in women, with higher trigylcerides and lower high density lipoproteins (HDL).[13] Proper nutrition and weight management also may be problematic for women who are dependent on personal care attendants for grocery shopping and meal preparation.[2, 14] Bone loss also occurs well before menopause in many women with mobility impairments because diminished mechanical strain and contraction of muscle around the bone, but little is known about the acceleration of bone loss in postmenopause in women with pre-existing bone loss due to mobility impairment.[3] Mood disturbance during peri-menopause and early postmenopause has been associated with stressful life events around middle age, such as bereavement, caring for children and aging parents and health problems.[15-18]

SUMMARY OF PROJECT GOALS AND HYPOTHESES

The primary objective of this study was to explore the relationship between menopause and late effects (or post-polio sequelae) for women with a history of polio in a large, community-based sample. In an effort to highlight the unique contribution of menopause, men with a history of polio also participated serving as a control group. By clarifying such relationships, better treatment recommendations can be made by those providing care to women with a history of

polio and who are experiencing menopause. Additionally, a greater understanding of differences between women and men in their experience of aging and post-polio sequelae can inform treatment approaches for men as well.

Three main objectives guided this study: 1) to explore the relationship of menopause, late effects and physical functioning; 2) explore the relationship of menopause to life satisfaction and emotional distress; and 3) the efficacy of hormone replacement therapy in ameliorating menopausal symptoms and improving physical functioning, life satisfaction and reducing emotional distress. Some terms used to refer to classification of women by their stage of menopause have changed since this application was originally written. Specifically, "presence of menopause" referred to women who were either pre-menopausal or who were transitioning through menopause; however there were very few pre-menopausal women in this study for group comparisons. This term was replaced by *menopause status* which refers to classification the menopause transition based on menstrual cycle characteristics (described in greater detail later in the report). *Menopausal symptoms* refers specifically to the severity of menopausal symptoms currently experienced, irrespective of menopausal status (e.g., peri or post-menopause).

Objective 1: Explore the relationship between menopausal symptoms and menopause, late effects and physical functioning.

- **H1**: Greater severity of menopausal symptoms will be significantly associated with decreased physical functioning and greater severity of post-polio sequelae.
- **H2:** Menopause status will be significantly associated with decreased physical functioning and greater severity of post-polio sequelae, controlling for age and gender.

Objective 2: Explore the relationship between menopause status, menopausal symptoms and emotional well-being.

- **H3:** Greater severity of menopausal symptoms will be significantly associated with lower life satisfaction and greater emotional distress and perceived stress.
- **H4:** Menopause status will be significantly associated with lower life satisfaction and greater emotional distress and perceived, controlling for age and gender.

Objective 3: Explore the relationship between menopausal symptoms and hormone replacement therapy use and post-polio sequelae, physical functioning, and emotional well-being.

- **H5:** Women currently using hormone replacement therapy will have higher physical functioning and lower severity of post-polio sequelae than women not using hormone replacement therapy.
- **H6:** Women currently using hormone replacement therapy will have significantly higher life satisfaction and lower levels of emotional distress than women not using hormone replacement therapy.
- **H7:** Women not taking hormone replacement therapy will have significantly greater severity of post-polio sequelae and lower physical functioning compared to age-matched men.

In addition to these hypotheses, the efficacy of hormone replacement therapy (HRT) was explored in two sub-samples of women. Selected aspects of health and well-being of polio survivors and differences between genders as well as U.S. population estimates (where available) also have been explored and are presented here. Finally, psychometric properties

and factor structures of a newly developed scale to measure post-polio sequelae severity and a standardized menopause symptom rating scale were investigated.

METHODOLOGY

Data Collection

In January 2003, letters of invitation to participate along with a response card were sent to 2,964 individuals from a mailing list provided by PHI. Potential participants were instructed to return the response card if they wished to receive a survey. In addition to this mailing, throughout the duration of data collection, we heard from a number of individuals who found out about the study through family or friends or press; they too were sent surveys if they wished to participate. A total of 1,548 individuals were sent surveys between February and April 2003. Most surveys were returned shortly thereafter, but continued to be received until fall 2003. Data collection officially was closed October 31, 2003. A total of 1,282 surveys were returned and entered into the database.

Preliminary examination of the database in September 2003 revealed missing data on many surveys (generally these were only several items; most commonly women did not complete the menopause symptom portion of the survey). This is to be expected on mailed surveys and because of the enthusiasm of the participants, we decided that rather than using statistical methods to approximate missing data, participants would be contacted and missing data obtained as much as possible. A total of 680 surveys were identified as having more than one missing response; for those surveys with only one item missing, participants were typically not called. A total of 592 participants were contacted by phone; the remaining 88 individuals were not called, could not be reached or had passed away (5 individuals had died after completing their survey). This process was completed in December 2003 and the database was finalized in January 2004. As a result of this effort, the rate of missing data in the database ranges, on average, from 1% and 3%.

Survey Design and Measures

The survey used in this study was comprised of standardized measures and non-standardized items. The survey addressed seven domains: polio history, sequelae and current problems, general health, physical functioning, physical activity, psychosocial well-being and menopause. Surveys for women and men were identical with the exception of the menopause section. Measures within each domain and the psychometric properties of standardized scales are described in Appendix B.

RESULTS AND DATA ANALYSIS

Before discussing analysis of the primary hypotheses, the sample is described in some detail. In order to place certain characteristics of these participants in a larger context, where data is available, comparisons are made to U.S. population estimates; between group differences (e.g., by age and gender) within this sample also are presented. These kinds of comparisons are particularly important in light of the primary aim of this study to see if and how women who are post-polio are different than their non-disabled peers with respect to menopause. Analyses of the primary hypotheses are then presented followed by analyses performed with selected sub-samples further exploring menopause. Finally, psychometric properties and factor structure of a newly developed scale to measure severity of post-polio sequelae and a standardized

menopause symptom rating scale are presented. Because of the volume of data collected in this study is considerable, many additional detailed tables are given in Appendix A in addition to those provided within the main text of this report.

DESCRIPTION OF PARTICIPANTS

1. Demographic Profile

A total of 1,282 polio survivors participated in this study. They were drawn primarily from members of Post-Polio Health International and represented 49 states in the U.S. and, for the most part, equally distributed among the four regions of the U.S., as shown in Figure 1. Seven women from four other countries also participated in the study; these figures are given in Table A.1 in Appendix A. As expected, the sample was primarily middle aged although the age range of participants was quite wide – the youngest was 34 and the oldest 99 (mean age was 64.5 ± 9.4 years). In general, participants were well-educated, Caucasian and the majority were women (N = 909; 70.9%). Demographic characteristics of the sample are given in detail in Tables A2 through A6 in Appendix A.

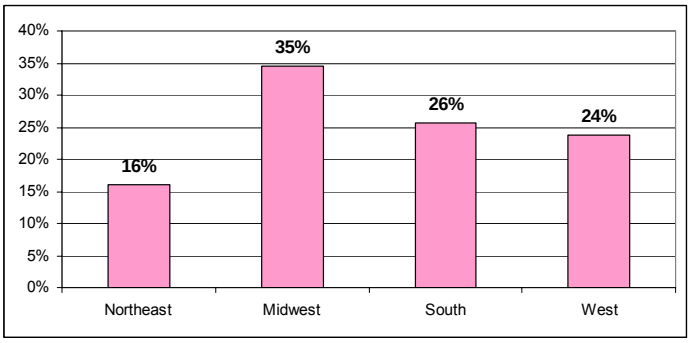

Figure 1. Distribution of Participants by U.S. Region

Much has been made of polio survivors being high achievers in educational and vocational pursuits, although to our knowledge this has not been directly tested. Although there is an inherent bias in most research because higher education is associated with greater participation in research, we explored this question further. Using U.S. 2002 Census Data, we compared rates of advanced degrees, marriage and employment to national averages. As shown in Table 1, these participants had substantially higher rates of advanced (post-bachelor's degree) education; it is particularly notable that older generations of polio survivors had similar rates of advanced degrees as younger generations, while the reverse is the case with national estimates. Rates of marriage were similar to national estimates, which the exception of participants ages 75 to 84 who were married at a slightly higher rate. Rates of current employment were significantly lower in age groups below 65 years, as might be expected given a third of the sample (36.2%) had retired for medical reasons; however contrary to expectations, the 65+ years old group had similar rates of employment compared to national estimates.

Table 1. Comparison of Post-Polio Sample to National Estimates on Education, Marriage and Employment

Area of Comparison By Age Group	***Post-Polio Sample %***	***National Average %***	***X^2***	***Sig.***
Educational achievement				
Advanced Degree				
25 to 55 years	24.0	9.3	56.22	<0.0001 (all)
55 to 59 years	28.9	12.1	63.22	
60 to 64 years	32.3	10.0	121.21	
65 to 74 years	27.5	7.1	221.89	
75 to 84 years	26.7	5.6	141.56	
85+ years	31.8	4.6	35.91	
Marriage				
Married				
55 to 59 years	64.5	69.4	2.98	0.08
60 to 64 years	73.7	68.0	0.25	0.62
65 to 74 years	62.8	63.7	0.11	0.74
75 to 84 years	60.0	48.6	11.10	<0.001
85+ years	31.8	26.3	0.35	0.56
*Employment**				
Currently employed				
55 to 59 years	42.7	70.0	85.45	<0.0001
60 to 64 years	28.0	50.4	45.54	<0.0001
65 and over	11.8	13.2	1.00	0.31

* Assumes employment in civilian labor force

2. Polio History

The year 1952 was the peak year participants contracted polio (N = 158) as shown in Figure 2. The average age at the time of contracting polio was 8.68 ± 7.4 years, ranging from <1 year to 49 years. Average months of hospitalization at acute polio onset was 4.63 ± 6.2; however a number of individuals were not sure how long they were hospitalized because they were too young to remember.

The majority of individuals reported having contracted spinal polio (N = 866; 67.5%) followed by a combination of spinal and bulbar polio (N = 264; 20.6%). A small minority (N = 111; 8.7%) were not certain about the type of polio they had as they were too

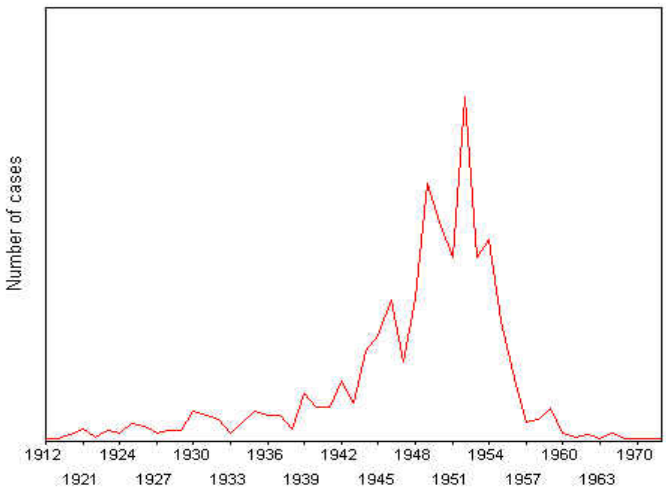

Figure 2. Year Participants Contracted Polio

young to remember (see Table A.7 in Appendix A).

3. Post-Polio Sequelae

Using the Index of Post Polio Sequelae (IPPS) developed for this study, prevalence and severity of 12 of the most commonly reported post-polio sequelae was collected. On average, participants reported a problem with 8 ± 2 post-polio symptoms (Table 2). As shown in Table 3, involved muscle weakness, fatigue and cold intolerance were reported by an overwhelming majority of the sample. Involved muscle weakness, fatigue and cold intolerance also were rated by respondents, on average, as being most severe. Average severity rating for each problem is given in Table A.8 in Appendix A.

Table 2. Post-polio Sequelae

	*N**	*Minimum*	*Maximum*	*Mean*	*Std. Deviation*
IPPS Total Score	1198	0	58	24.43	10.377
Number of Post-Polio Problems	1216	0	12	8.25	2.604
Average Problem Severity Rating	1072	1	5	2.90	0.656

* N's vary depending on missing data

Table 3. Prevalence of Post-Polio Sequelae

	N	*%*
Muscle weakness, involved muscle	1205	94.5
Fatigue	1170	91.6
Cold intolerance	1043	82.1
Muscle atrophy	985	78.0
Muscle weakness, uninvolved muscle	937	74.4
Muscle pain	916	72.2
Sleep problems	896	70.6
Joint pain	896	70.6
Contractures	779	61.9
Breathing problems	675	53.5
Swallowing problems	526	41.6
Carpal tunnel	480	38.4
Mean # of problems = 8.25 (2.6)		

Weakness in 8 specific body parts also was assessed. Severity of weakness was rated along 6-point scale, ranging from 1 (not weakened) to 5 (completely paralyzed). On average, participants reported some weakness in 5.2 ± 2.2 of the 8 body parts; only 10 participants reported no weakness in any of the 8 body parts (see Table A.9 in Appendix A). As shown in Table 4, legs (right and left) were rated, on average, as being most weakened and facial and swallowing muscles were the least weakened on average.

Table 4. Body Part Weakness

Body Part Weakness	*N*	*Minimum*	*Maximum*	*Mean*	*Std. Deviation*
Right arm weakness	1266	1	5	2.20	1.093
Left arm weakness	1258	1	5	2.19	1.124
Right leg weakness	1264	1	5	3.06	1.207
Left leg weakness	1266	1	5	2.99	1.214
Trunk muscles weakness	1250	1	5	2.40	1.104
Back/stomach weakness	1260	1	5	2.58	1.063
Facial/swallowing weakness	1253	1	5	1.54	0.858
Breathing muscles weakness	1254	1	5	1.70	0.956

4. Menopause Characteristics

As shown in Figure 3, the staging of menopause is primarily determined by self-report of menstrual cycle characteristics given the design of this study as a survey (therefore precluding the use of blood tests to measure hormonal levels in women). Peri-menopause is defined by menstrual cycle irregularity and experience of some symptoms and/or not yet 12 months since the final menstrual period (FMP). (Peri-menopause was not further delineated in this study as cycle length and variability data was not collected). Postmenopause is defined by a minimum of 12 months since the FMP; this is further delineated by *early* (< 5 years since FMP) and *late* postmenopause (≥ 5 years).[19]

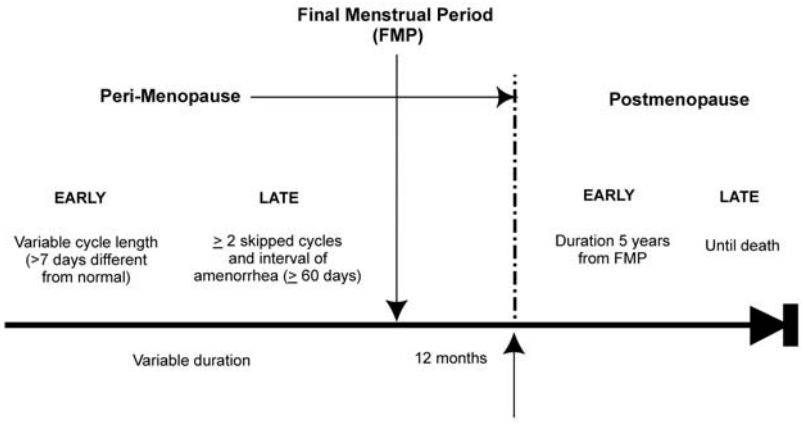

Figure 3: Diagram of Menopause Staging Criteria

Due to the demography of polio survivors in general due to the advent of the polio vaccine in 1955, the majority of women in this sample were postmenopausal. As shown in Table 5, few women were pre-menopausal or peri-menopausal.

Table 5. Menopause Status

	N	*%*	*Cumulative %*
Pre-menopausal	20	2.2	2.3
Peri-menopausal	89	9.8	12.6
Early postmenopausal	112	12.3	25.7
Late postmenopausal	640	70.3	100.0
Total	863	94.7	
Missing*	47	5.3	
Total	909	100.0	

* Missing FMP data did not allow for calculation of early or late postmenopause status

Reason for cessation menstruation, as shown in Table 6, was primarily due to natural menopause (43.2%). Although menopause characteristics of women with disabilities have not been studied to a great extent, it has been speculated that the FMP occurs earlier in women with disabilities although the rationale for this is not entirely clear. In this sample, for women who had a natural menopause, the mean age at the FMP was 50.3 $\pm$ 4.3 years which is the average among non-disabled women in the U.S.

In this sample, 34.7% of the women (N = 311) had had hysterectomies (either with ovary removal [N = 151] or without ovary removal [N = 160]). The average age at time of hysterectomy among these women was 40.6 $\pm$ 8.2 years. Reasons given for having a hysterectomy (not mutually exclusive categories) were fibroids (50.2%), heavy menstrual periods (41.2%), other reasons (32.4%), bleeding (15.8%), cervical abnormalities (8.7%), cancer (5.5%), and hygiene (0.3%). Nine women reported they were not sure of the reason they had a hysterectomy, but that their doctor had recommended it. The overall rate of hysterectomy in this sample was significantly higher than 2002 national estimates (Centers for Disease Control and Prevention [CDC], Behavioral Risk Factor Surveillance System [BRFSS], 2002; 34.7% vs. 20.8%, χ^2 = 48.31, $p \leq 0.001$).

Table 6. Reason for Cessation of Menstruation

	N	*%*	*Cumulative %*
Hysterectomy without ovary removal	151	16.6	16.8
Hysterectomy with ovary removal	160	17.6	34.7
Natural menopause	392	43.2	78.5
Hormonal medication	71	7.8	86.4
Other	20	2.2	88.6
Periods have not stopped	102	11.2	100.0
Total	896	98.6	
Missing	13	1.4	
Total	909	100.0	

5. Use of Hormone Replacement Therapy

Rates of prevalence of HRT use have varied considerably in the literature.[20, 21] A number of factors influence the use of HRT, such as age, type of menopause, ethnicity, education, socio-economic status, access to healthcare and geographic region, making overall prevalence rates difficult to establish. In general, well-educated, Caucasian women tend to use HRT with the highest frequency in the United States.[20-23] Given that the vast majority of HRT studies are conducted with non-disabled populations, little is known about the prevalence of its use among women with disabilities or other chronic illness or their reasons for using HRT.[24] Furthermore, there have been neither cross-sectional nor large, randomized controlled trials addressing HRT's potential risks and benefits for women with physical disabilities.

Findings from the Women's Health Initiative (WHI)[25] suggest risks of long term use of combination estrogen/progestin therapy (Prempro™) include invasive breast cancer, coronary heart disease (CHD), stroke and venous thromboembolism. Because of limitations in physical activity, many women with disabilities are already be at a risk for cardiovascular disease or thromboembolism and therefore potentially face an even greater health risk with use of combination HRT.[24, 26, 27] In addition, the WHI trial has suggested that HRT is efficacious only in treating menopausal symptoms and not mitigating the development of co-morbid disease or improving mood or quality of life.[27]

Although more than half of the women in the sample had used HRT (N = 649; 71.4%) at some time, beginning at an average age of 47.4 $\pm$ 7.6 years, less than half of the women were currently using HRT (N = 357; 39.3%). On average, those currently using HRT had done so for an average of 10.3 $\pm$ 9.8 years. Women using estrogen replacement therapy only had used it for a significantly longer period of time than women using combination replacement therapy (13.9 $\pm$ 10.5 vs. 7.5 $\pm$ 7.7 years; $t = 5.22$, $p \leq 0.001$). There were 291 women in the sample who had discontinued using HRT at an average age of 57.0 $\pm$ 9.4 years after an average 7.9 $\pm$ 5.3 years of use. The most common reason cited for discontinuing use was safety concerns (59.7%), followed by "other" reasons (31.0%), side effects (29.0%), and a lack of efficacy (7.3%). In comparison to a sample of Caucasian women from the Study for Women's Health Across the Nation (SWAN), women in this study used HRT at a significantly higher rate than their peers (39.3% vs. 23.8%; $\chi^2 = 100.67$, $p \leq 0.001$).

Among those women using HRT, less than half (N = 165; 46.2%) reported experiencing no side effects. For those who did, weight gain (26.8%) and breast soreness (11.2%) were reported at the highest rates. Interestingly, there is no empirical evidence to support weight gain associated with HRT use,[28, 29] although this is a pervasive belief among many midlife women. Furthermore, there were there were no significant differences in body mass index (BMI) among those who used HRT and those who did not (26.6 $\pm$ 6.1 vs. 27.1 $\pm$ 6.1; $t = 1.16$, $p = 0.27$). Efficacy of HRT in ameliorating menopause symptom severity will be discussed in the following sections reviewing testing of the hypotheses.

Table 7. Type of Hormone Replacement Therapy Used

	N	*%**
Estrogen Replacement Therapy	157	44.0
Combination Estrogen/Progesterone Replacement Therapy	110	30.8
Selective Estrogen Receptor Modulators	10	2.8
Topical Estrogen	46	12.9
Progesterone only	11	3.1
Using HRT, but type not specified	23	6.3
Total	357	

* Of HRT users only

6. Menopause Symptoms

The specificity and nature of menopause symptoms has been the subject of vigorous debate.[30, 31] Because of the spectrum of symptoms, ranging from those closely associated with hormone levels, such as hot flushes or vaginal drying, to more broad psychosocial symptoms, such as depression or anxiety, it is difficult to establish a true "menopausal syndrome."[32] Vasomotor symptoms, characterized by hot flushes, are the hallmark of menopause experienced by a majority of women (50-80%[33, 34]). The underlying mechanisms of hot flushes are not completely understood,[34] but have been associated with low estrogen and high follicle stimulating hormone,[35] warm weather and reduced sweating threshold.[34] Other factors such as ethnicity, socio-economic status and lifestyle also play a role in symptom frequency and intensity.[36] Depression, irritability, nervous tension, sleep disturbance and other somatic complaints have been more strongly associated with factors such as pre-morbid psychological disposition, stressful life events, social circumstances and attitudes.[15, 16, 18, 37-41] As shown in Table 8, women in this sample experienced a range of menopause symptoms. As shown in Table A.10, cold hands and sleeplessness were rated, on average, as the most severe.

Table 8. Prevalence of Menopause Symptoms

	N	*%*
Tension	720	85.3
Cold hands	728	80.1
Irritability	724	79.6
Sleeplessness	717	78.9
Early morning awakening	686	75.5
Excitability	672	74.9
Poor Concentration	679	74.7
Moodiness	641	70.5
Depressed	634	69.7
Headaches	623	68.5
Loss of sexual interest*	623	68.5

Table 8 (con't). Prevalence of Menopause Symptoms

Worrying	615	67.7
Constipation	610	67.1
Hot flushes	576	63.4
Numbness	558	61.4
Sweating	553	60.8
Shortness of breath	538	59.2
Pressure	537	59.1
Palpitations	533	58.6
Dry eyes	510	56.1
Weight gain	506	55.7
Crying	501	55.1
Loss of feeling	431	47.4
Poor appetite	368	40.5
Dyspareunia (painful intercourse)*	298	32.8

* Many women noted that lack of a partner as a reason for these items not being as problematic as others

6a. Menopause Symptom Factor Severity by Menopause Status

Four factors resulted from a factor analysis of the structure of the Menopause Symptom List; this analysis is presented in detail at the end of this section. Factor 1 (psychological) consists of eight items reflecting emotional distress such as depression, tension and anxiety. Factors 2 and 3 are a combination of items that generally describe somatic symptoms. Factor 2 (somatic - sensory) is comprised of two items related to sensory loss and two related to dehydration. Factor 3 (somatic - sleep) is comprised of two items related to sleep disturbance and two items related to vascularity. Factor 4 is comprised of two items that describe the core elements of vasomotor symptoms, namely hot flushes and sweating.

Severity ratings of these factors were compared by menopause status and then by HRT use within menopause status. Comparisons by menopause status (Table 9) suggested significant differences on factor 1 and factor 4, in general, and between each of the three menopause statuses, although these differences were generally small (eta^2 ranged from 0.009 to 0.031) and therefore unlikely to be clinically significant.

Hormone replacement therapy was efficacious primarily for relief of vasomotor symptoms for early postmenopausal women only, as shown in Table 10. Women taking HRT in early postmenopause had significantly lower psychological and vasomotor factor ratings (eta^2 = 0.06 and 0.07, respectively; a moderate effect size). For women taking HRT in late postmenopause, the opposite was true for psychological symptoms in that they were significantly greater than those not taking HRT; however this difference was quite small (eta^2 = 0.008, a small effect size) and unlikely to be clinically significant.

Table 9. Menopause Factor Severity By Menopause Status

Dependent Variable	***(I) Menopause status***	***(J) Menopause status***	***Mean Diff. (I-J)***	***Eta^2 (Sig. only)***
Factor 1 - Psychological	Peri-menopausal	Early postmenopausal	0.890	
		Late postmenopausal	**3.572**[a]	0.031
	Early postmenopausal	Late postmenopausal	**2.681**[a]	0.021
Factor 2 - Somatic/ Sensory	Peri-menopausal	Early postmenopausal	-0.204	
		Late postmenopausal	0.190	
	Early postmenopausal	Late postmenopausal	0.395	
Factor 3 - Somatic/Sleep	Peri-menopausal	Early postmenopausal	0.310	
		Late postmenopausal	**1.026**[b]	0.010
	Early postmenopausal	Late postmenopausal	0.717	
Factor 4 - Vasomotor	Peri-menopausal	Early postmenopausal	0.581	
		Late postmenopausal	**1.265**[a]	0.026
	Early postmenopausal	Late postmenopausal	**0.684**[b]	0.009

[a] = $p \leq 0.01$; [b] = $p \leq 0.05$

Table 10. Menopause Factor Severity by Menopause Status by HRT use

Menopause Status	***HRT Use***	***N***	***Factor 1 M (SD)***	***Factor 2 M (SD)***	***Factor 3 M (SD)***	***Factor 4 M (SD)***
Peri-Menopause	No	61	13.15 (6.2)	3.29 (3.0)	6.37 (3.1)	4.11 (2.5)
	Yes	23	13.09 (7.1)	4.13 (3.5)	6.26 (3.4)	3.83 (2.9)
Early Post Menopause	No	60	**13.65 (6.8)**[a]	4.38 (3.4)	6.28 (3.0)	**3.98 (2.0)**[b]
	Yes	48	**10.48 (5.9)**[a]	3.88 (2.9)	5.71 (2.8)	**2.77 (2.4)**[b]
Late Post Menopause	No	348	**9.04 (6.5)**[a]	3.68 (3.1)	5.12 (3.1)	2.90 (2.5)
	Yes	242	**10.31 (6.7)**[a]	3.87 (3.3)	5.59 (3.3)	2.59 (2.5)

[a] = $p < 0.05$; [b] = $p < 0.01$

7. Experience of Menopause

The experience of menopause among these women was, in general, positive (44.6%) or neutral (34.0); a small minority considered it to be a negative experience (17.2%). The majority of women had discussed menopause with their health care provider (71.6%) and of these, 22.9% initiated the discussion themselves, 31.4% did along with their health care provider, and 16% the health care provider initiated the discussion. Of those who did discuss menopause with their health care provider, 70.3% were satisfied with the information they received, 23.7% were somewhat satisfied and a small minority (6%) were dissatisfied. Finally, the majority of women

(78.6%) did not believe their disability limited their access to information regarding menopause, another 13.9% were not sure and a minority (7.5%) said it did.

8. General Health of Participants

In general, the majority of participants rated their health as good or better (70.4%). Comparing their current state of health to the previous year, the majority considered it the same or better (57.6%; see Tables A.11 and A.12). Using data from the BRFSS, self-ratings of health were compared to national estimates as shown in Figure 4. While poor health ratings were similar between groups, the majority of participants in this sample rated their health as good with far less rating their health in excellent or very good categories (all comparisons were significantly different with $p \leq 0.001$, except for poor health ratings). The distribution of participants' health rating is more normally distributed than national estimates, which are skewed to the left indicated higher health ratings overall. On the survey, participants were presented with a series of open-ended items referring to incidence of certain health conditions within eight categories (plus "other"): cardiovascular, respiratory, metabolic, neurological, autoimmune, gastrointestinal or urological, cancer and musculo-skeletal (excluding polio). As shown in Table 11, hypertension, osteoarthritis, osteoporosis or osteopenia, and hypercholestremia were among the highest incidence of co-morbid conditions by self-report.

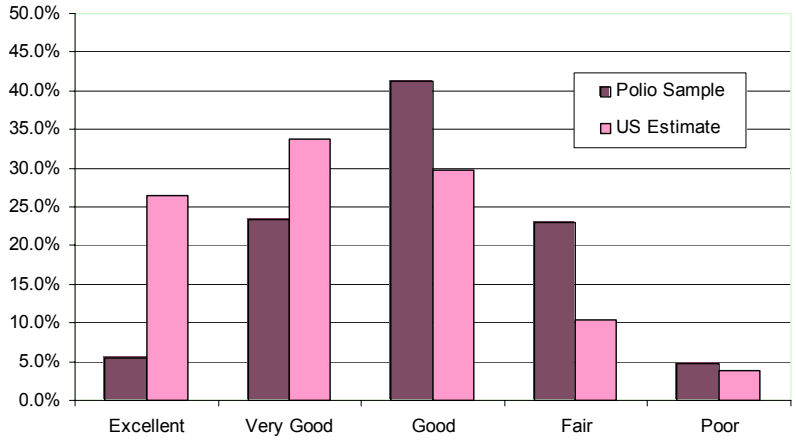

Figure 4. Ratings of Health Compared to U.S. Estimates

Table 11. Highest Incidence Co-Morbid Health Conditions

Co-Morbid Health Condition	*Reported Condition (N)*	*% of Total Sample*
Hypertension	491	38.3
Osteoarthritis	390	30.4
Osteoporosis or osteopenia*	337	26.3
Hypercholestremia	306	23.9
Thyroid disorders	168	13.1
Irritable bowel syndrome	154	12.3
Gastroesophogeal reflux disease	105	8.2

* In a related closed-ended item about whether they had been diagnosed with osteoporosis by a physician, 35.9% (N = 461) responded affirmatively.

The average body mass index (BMI) for the total sample was 26.8 $\pm$ 5.8 which is in the "overweight" classification, although 39% (N = 500) were in the healthy weight range and

another 3% were underweight. A small percentage (8.3%) fell into obese classification; see Table A.13 for distribution of BMIs for the sample.

9. Physical Functioning & Physical Activity

The ability to perform basic and intermediate activities of daily living (BADL and IADL, respectively) was limited to some degree for most participants. Using cut-scores of 88 for BADL and 78 for IADL, 49.4% and 83.0%, respectively, of the sample fell into the "warning zone" indicating some degree of difficulty with the ability to perform ADLs. National estimates of ADL limitations are available for the elderly (65+ years).[42] Limitations in ADLs are defined by activities related to personal care (e.g., bathing, dressing, eating). As shown in Table 12, a significantly greater proportion of participants in this sample reported some difficulty in ADLs compared to U.S. estimates. Although this is expected, it is interesting to note that contrary to U.S. estimates the older group of participants reported less difficulty with ADLs than the younger group (however this difference was not statistically significant).

Table 12. Limitations in ADLs – Comparisons between Polio Sample and U.S. Estimates

Age Group	*Post-Polio Sample %*	*National Average %*	χ^2	*Sig.*
65 to 74 years	65.4	3.4	3226.9	$p \leq 0.001$
75+ years	58.4	9.6	519.79	

The majority (79.4%) considered themselves to be somewhat or much less active than their peers outside of work (see Table A.14) which has implications for health and incidence of co-morbid health conditions. Walking ability was restricted for the majority of the sample (79%; see Table A.15). Finally, most of the sample (82.1%) used some type of adaptive equipment or devices; on average, participants used 2.33 $\pm$ 1.7 assistive devices. Shoe modifications (32.7%), electric wheelchair or cart (32.5%) and one cane or crutch (30.3) were used with the highest frequency in the sample; see Table 13.

Table 13. Use of Assistive Technology and Adaptive Devices

*Device**	*N*	*%*
Shoe modifications	419	32.7
Electric wheelchair or cart	417	32.5
1 cane or crutch	388	30.3
Leg Braces - Right leg/Left leg	347/340	27.2/26.5
Manual wheelchair	250	19.5
2 canes or crutches	219	17.1
Walker	184	14.4
Back brace or corset	150	11.7
Arm splint or brace - Right arm/Left arm	65/56	5.1/4.4
Breathing aides	56	4.4

*Categories are not mutually exclusive

10. Emotional Well Being

On the whole, the sample reported being slightly satisfied with their lives. However, as shown in Table 14, the sample was close to equally divided between dissatisfied and satisfied with their lives with no differences between age groups. Positive affect was rated higher, on average, than negative affect (32.89 vs. 19.07, $t = 41.05$, $p < 0.001$) and in general, positive affect rose with increasing age and negative affect declined with increasing age; see Figure 5.

Table 14. Life Satisfaction Ratings

	N	*%*	*Cumulative %*
Extremely dissatisfied	79	6.2	6.2
Dissatisfied	213	16.6	23.0
Slightly dissatisfied	230	17.9	41.2
Neutral	39	3.0	44.2
Slightly satisfied	232	18.1	62.5
Satisfied	329	25.7	88.5
Extremely satisfied	146	11.4	100.0
Total	1268	98.9	
Missing	14	1.1	
Total	1282	100.0	

Perceived stress in this sample was slightly greater than a National Probability Sample[43] by both gender and age, as shown in Table 15. Although all group comparisons were significant, differences between women and men polio survivors vs. the national sample are modest and therefore unlikely to be clinically significant. On the contrary, comparisons between 45 to 54 year olds had a rather large effect size; this suggests that middle aged polio survivors in this study reported a substantially, and therefore likely clinically significant, elevated perceived stress level compared to their peers.

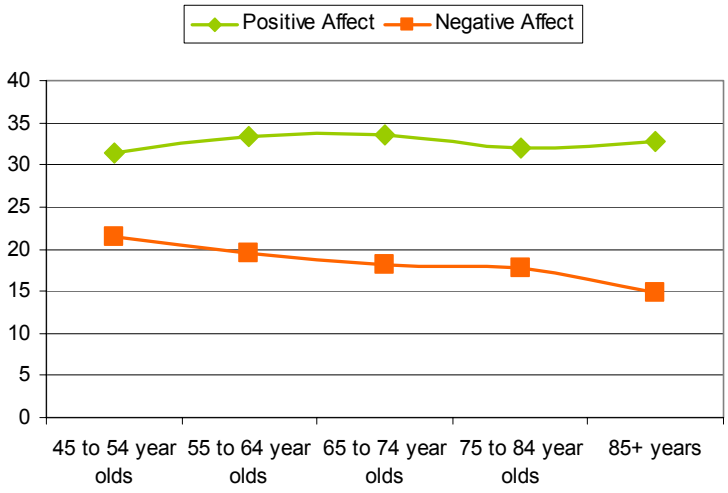

Figure 5. Age Group Comparison on Positive and Negative Affect

Within group differences also were explored. Women reported a significantly higher degree of perceived stress than men did, however this is unlikely to be a clinically significant as the effect size was very small ($eta^2 = 0.008$). Age group comparisons within the polio sample were all significant with effect sizes ranging from small (55 to 64 years vs. 65+ years, $eta^2 = 0.004$) to moderate (45 to 54 years vs. 65+, $eta^2 = 0.04$). As shown in Figure 6, there is a general downward trend of perceived stress from middle aged to elderly participants in this study.

Table 15. Ratings of Perceived Stress – Comparison to National Probability Sample

	Post-Polio ***M (SD)***	***National*** ***M (SD)***	***t***	***Eta²***	***Sig.***
Females	15.88 (6.8)	13.70 (5.9)	6.45	0.02	$p \leq 0.001$
Males	14.56 (6.9)	12.10 (6.6)	7.59	0.03	
45 to 54 year olds	17.74 (7.4)	12.60 (6.20	6.66	0.12	$p \leq 0.001$
55 to 64 year olds	15.59 (7.1)	11.90 (6.9)	7.05	0.06	
65 years and older	14.66 (6.3)	12.00 (6.3)	6.29	0.04	

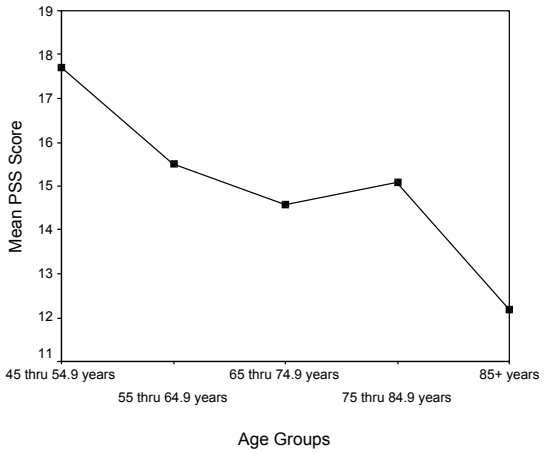

Figure 6. Age Group Comparisons on Perceived Stress

Hypothesis Testing & Additional Analyses

1. Hypothesis Testing

Bivariate correlations, independent sample t-tests and ANOVAs were used to test the hypotheses. Results of the hypotheses using only women are first followed hypothesis testing using men as controls which required considerably greater statistical complexity.

Women Only

H1:	*Greater severity of menopausal symptoms will be significantly associated with decreased physical functioning and greater severity of post-polio sequelae.*

Bivariate correlations were used to testing Hypothesis 1. As shown in Table 16, only post-polio sequelae severity was significantly correlated (bolded) with all of the menopause factors; only BADL was significantly correlated with Factor 2 (somatic/sensory). Therefore, Hypothesis 1 was partially supported by these findings.

Table 16. Bivariate Correlations between Menopause Symptom Factors, Post Polio Sequelae and Physical Functioning

		Factor 1 - Psychological	***Factor 2 – Som./Sensory***	***Factor 3 – Som./Sleep***	***Factor 4 - Vasomotor***
Post-Polio Sequelae	Pearson *r*	**0.295**	**0.394**	**0.354**	**0.216**
	Sig.	0.000	0.000	0.000	0.000
BADL scaled score	Pearson *r*	-0.037	**-0.083**	-0.064	-0.003
	Sig.	0.286	0.017	0.069	0.943
IADL scaled score	Pearson *r*	0.019	-0.033	-0.014	0.033
	Sig.	0.582	0.348	0.691	0.351

H3: *Greater severity of menopausal symptoms will be significantly associated with lower life satisfaction and greater emotional distress.*

Bivariate correlations were used to test Hypothesis 3. As shown in Table 17, all correlations were significant, with the largest correlations between Factor 1 (psychological) and Factor 3 (somatic sleep); other correlations tended to be modest, but significant. Therefore Hypothesis 3 was supported by these findings.

Table 17. Bivariate Correlations between Menopause Symptom Factors and Emotional Well-Being

		Factor 1 - Psychological	**Factor 2 - Somatic/Sens.**	**Factor 3 - Somatic/Sleep**	**Factor 4 - Vasomotor**
Perceived Stress	Pearson r	**0.565**	**0.250**	**0.316**	**0.207**
	Sig.	0.000	0.000	0.000	0.000
Life Satisfaction	Pearson r	**-0.315**	**-0.166**	**-0.150**	**-0.152**
	Sig.	0.000	0.000	0.000	0.000
Negative Affect	Pearson r	**0.535**	**0.206**	**0.309**	**0.187**
	Sig.	0.000	0.000	0.000	0.000

H5: *Women currently using hormone replacement therapy will have higher physical functioning and lower severity of post-polio sequelae than women not currently using hormone replacement therapy.*

Independent samples t-tests were used to explore differences in physical outcomes based on HRT use. No significant differences were found between women using and not using HRT in terms of severity of post-polio sequelae. Therefore, Hypothesis 5 was not supported.

H6:	Women currently using hormone replacement therapy will have significantly higher life satisfaction and lower levels of emotional distress than those not currently using hormone replacement therapy.

Independent samples t-tests were used to explore differences in emotional well being outcomes based on HRT use. No significant differences were found between women using and not using HRT in terms of life satisfaction, perceived stress or emotional distress/negative affect. Therefore, Hypothesis 6 was not supported.

Men as Controls

In order to use men as controls to test hypothesis 2, 4 and 7, a database of 694 women and men (347 age-matched pairs) was created. In order to test differences on outcomes by gender within each menopause status, men were provisionally assigned a "menopause status" to preserve the matched pair. In other words, a 50 year old female with a peri-menopausal status was matched to a 50 year old male who was then provisionally categorized as "peri-menopausal" for the purposes of running the analysis. One way ANOVAs were used to test differences between menopause status on physical outcomes (Hypothesis 2), emotional well being outcomes (Hypothesis 4) and HRT efficacy outcomes (Hypothesis 7).

H2:	*Menopause status will be significantly associated with decreased physical functioning and greater post-polio sequelae severity, controlling for age and gender.*

First, the effect of menopause status on these outcomes was examined for women only; this effect was not examined for men, because men were age-matched to women of varying menopausal statuses and hence their "status" is determined by an age-matched female. Second, differences on outcomes between women and age-matched men were examined at each menopausal status. These analyses allow an inspection of possible increased symptoms in women that are not attributable to simple increases in age. Statistically significant effects of menopausal status on severity of post-polio sequelae and basic and intermediate ADLs were observed. Peri-menopausal women differed from late postmenopausal women on post-polio sequelae severity; early postmenopausal women significantly differed from late postmenopausal women on basic and intermediate ADLs. Figure 6 graphically shows these differences.

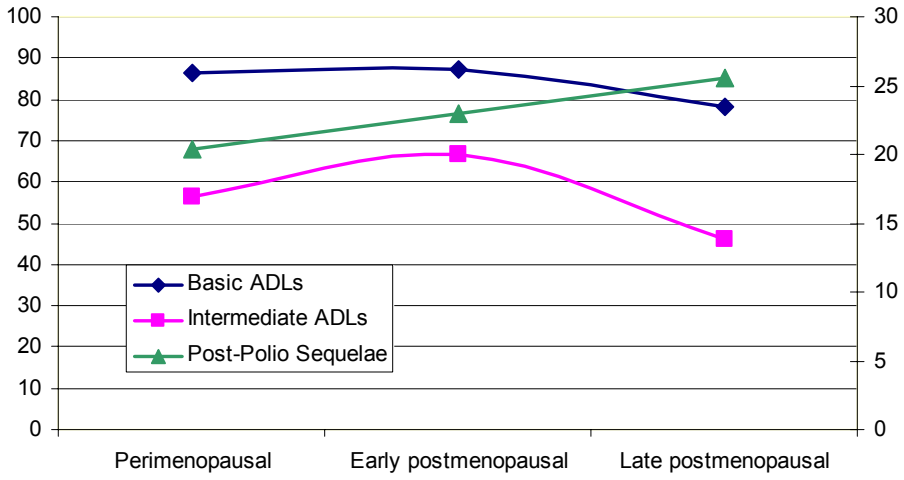

Figure 7. Menopause Status Comparison on Physical Outcomes

Examining differences between peri-menopausal and early postmenopausal women and age-matched men revealed no gender differences on any outcome variable in Hypothesis 2. When examining late postmenopausal women and age-matched comparison males, a difference was observed for post-polio severity with women reporting a higher severity than men ($t = 2.81$, $p = 0.005$). Therefore, Hypothesis 2 was supported by these findings.

H4: *Menopause status will be significantly associated with lower life satisfaction and greater emotional distress and perceived stress, controlling for age and gender.*

A similar analysis was performed to test Hypothesis 4 on emotional well being outcomes; there were no differences by menopause status on outcomes. Examining differences between peri-menopausal and age-matched men revealed significant gender differences on life satisfaction ($t = 2.13$, $p = 0.025$) and negative affect ($t = -2.04$, $p = 0.05$); these differences are displayed in Figure 7. No significant differences between gender were found for early postmenopausal women and age-matched men; the same was true of late postmenopausal women with the exception of perceived stress ($t = 2.18$, $p = 0.023$). Therefore, Hypothesis 4 was not supported by these findings.

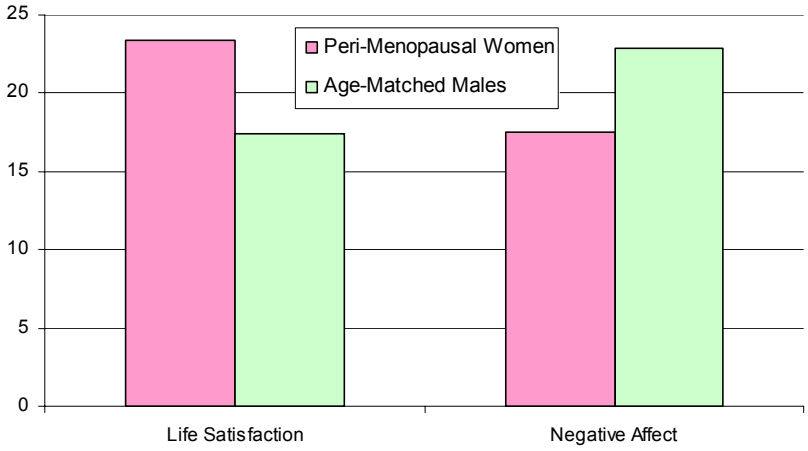

Figure 8. Comparison of Peri-Menopausal Women and Age-Matched Men

H7: *Women not taking hormone replacement therapy will have significantly greater severity of post-polio sequelae and lower physical functioning compared to age-matched men.*

To examine the effects of menopause status, HRT use, and gender on post-polio sequelae and physical functioning a series of one-way ANOVAs were conducted. First, the effect of menopause status and HRT was examined for women only. As stated above, for obvious reasons, men were not included in this analysis. Second, differences between women using HRT, women not using HRT, and age-matched men were examined at each menopausal status. These analyses allow an inspection of HRT status and gender effects that are not attributable to simple increases in age. The statistically significant effects of menopausal status reported above do not differ based on women's use of HRT. In other words, there are no differences on post-polio sequelae severity or activities of daily living between women using HRT and those not using HRT at any stage of menopause. The effect of menopausal status remains significant for post-polio sequelae and physical functioning (as presented above), but is not moderated by HRT status (use versus non use).

No statistically significant differences on outcomes were observed between women using HRT, women not using HRT, and age-matched men at peri-menopausal and early postmenopausal statuses. However, statistically significant differences were observed between late postmenopausal women using HRT, women not using HRT, and age-matched men at late postmenopausal status. Contrary to expectations, women using HRT had significantly higher post-polio severity ($p = 0.006$) and higher basic ADLs ($p = 0.024$) than men. Therefore Hypothesis 7 was not supported by these findings.

2. Factor Analysis of the Menopause Symptom List

The presentation and characteristics of menopause symptoms in women with physical disabilities has not yet been comprehensively studied. As a result, little is known about the interaction between physical disability and menopause symptoms or, more fundamentally, whether standardized scales, designed with non-disabled women, can be reliably used to measure menopause symptoms in women with physical disabilities. Therefore, the MSL was factor analyzed to examine its factor structure in a sub-sample of women in this study; to our knowledge this is the first analysis of its kind in the literature. The paper presenting these findings has been accepted for publication in *Menopause* (Kalpakjian, Toussaint, Quint and Reame), expected to be published in January 2005.

This sub-sample involved 190 women between 40 and 65 and who were not using current HRT; and naturally postmenopausal women. This sub-sample was selected to reflect the standardization sample used to examine the MSL. In this sub-sample, approximately a third was peri-menopausal ($n = 66$) with a mean age of 53.0 ($SD = 3.3$) years and two-thirds ($n = 115$) were postmenopausal with an average age at FMP of 50.52 ($SD = 3.9$) years. Of the postmenopausal women, 44.3% ($n = 51$) were early with a mean age of 56.3 ($SD = 3.2$) years and 54.7% ($n = 63$) were late with a mean age of 60.5 ($SD = 3.7$) years; one subject was missing FMP data.

The 25 items of the MSL were submitted to a factor analysis using principal components extraction. Factors were extracted according to Kaiser's criterion (eigenvalues >1) and rotated to oblique simple structure using oblimin rotation (delta = 0). Only significant loadings greater than or equal to 0.40 were used for interpreting the factors.[44] Although several extraction and rotation techniques were explored, principal components with oblique rotation provided the most interpretable solution.

Six factors were extracted that accounted for approximately 60% of the variance in the original MSL items. Factor loadings for each item are given in Table A.16. The first four factors showed acceptable levels of internal consistency (alphas 0.63 - 0.91), but the remaining two showed very poor internal consistency (≈ 0.0). Hence, the first four factors were examined and items loading highly on these factors (≥ 0.40) were summed to create factor scores. Factor 1 (psychological) consists of eight items that exactly replicate the psychological factor on the original MSL. Factors 2 and 3 are a combination of items that generally describe somatic symptoms. Factor 2 (somatic - sensory) is comprised of two items related to sensory loss and two related to dehydration. Factor 3 (somatic - sleep) is comprised of two items related to sleep disturbance and two items related to vascularity. Factor 4 is comprised of two items that describe the core elements of vasomotor symptoms, namely hot flushes and sweating. Because menopause symptoms range along different domains, as suggested by this and other factor analytic studies, an aggregate score has little meaning in and of itself[45] and may obscure important differences between symptom clusters,[46] a total score was not used in the present

study. This is particularly important given how little is known about menopausal symptoms in women with physical disabilities.

The psychological cluster (factor 1) in this sub-sample exactly replicated that of the MSL's standardization sample. However, items forming the vasomotor cluster (factor 4) were clearly distinct from any other factor. In the standardization sample, other somatic symptoms, such as palpitations, numbness and tingling and cold hands and feet, also loaded on the vasomotor factor. Additionally, hot flushes and involuntary sweating had the lowest loadings on the vasomotor factor in the standardization sample. That these symptoms showed low loadings on the vasomotor factor in the standardization sample suggests that they are not the best indicators of the factor. This is confirmed in our analyses showing that they load highly on a separate factor.

In summary, while total score internal consistency of the MSL in its original form was high, further exploration of the factor structure suggested that the underlying structure differed from the standardization sample. The factor analysis presented here was generally consistent with the extant literature supporting three primary clusters of menopause symptoms, namely psychological, somatic and vasomotor. In this sub-sample, somatic symptoms also clustered into two distinct factors. One was characterized by sensory problems and the other by sleep disturbance. Because incidence of sensory and sleep problems are quite high in many polio survivors, this distinction of clusters may suggest an influence of disability on the experience or expression of menopause symptoms. For example, the high baseline prevalence of sleep problems in polio survivors (75% in this sample) would limit its utility as a distinguishing characteristic of menopause, although it is commonly associated with frequency and intensity of hot flashes.

3. Other Selected Analysis on Menopause Factors

Two other analyses were performed on sub-samples and will be presented at two national conferences in 2004. The first (3a) will be presented as a poster at the Annual Conference of the American Psychological Association in Honolulu, Hawaii in July 2004 (Kalpakjian and Tate). The second (3b) has just been submitted for an oral presentation at the North American Menopause Society Annual Conference in Washington D.C. in October 2004 (Kalpakjian and Quint). Both analyses examine the efficacy of HRT in sub-samples of women.

3a. Relationship of HRT use and Post Polio Sequelae

To further examine the relationship of HRT to post-polio factors (described in the next section) a sub-sample of 319 women between the ages of 45 and 60 with a mean age of 55.1 (SD = 3.0) was used. Twenty-six percent of the sample were peri-menopause, 20% early postmenopausal and 54% were late postmenopausal. Thirty five percent of the sample (n = 82) was using HRT. The IPPS factors (described in the next section) of pain, muscle atrophy and bulbar symptoms and menopause symptom factors were compared using a two-way between-groups ANOVA. There was a statistically significant main effect for HRT use on vasomotor symptoms ($F = 12.79$, $p < 0.000$), however the effect size was small ($eta^2 = 0.041$). There also was a statistically significant main effect for menopause status on pain ($F = 4.36$, $p = 0.014$), however the effect size also was small ($eta^2 = 0.03$).

Post-hoc comparisons using the Tukey HSD indicated that the mean pain score of late postmenopausal women ($M = 12.88$, $SD = 6.4$) was significantly different from the early

postmenopausal women (M = 9.82, SD = 6.3) whereas peri-menopausal women did not differ significantly from either group (M = 11.63, SD = 6.0). Finally, there was a significant interaction effect for menopause status and HRT use on muscle atrophy (F = 4.41, p = 0.013) however the effect size also was small (eta^2 = 0.029). Further analysis using one-way ANOVA suggested that late postmenopausal women not using HRT (M = 9.24, SD = 2.9) report significantly greater muscle atrophy than early postmenopausal women (M = 7.23, SD = 3.4); this same relationship was not seen among women using HRT.

This analysis suggested that HRT reduced vasomotor symptom severity among all groups of women, regardless of menopause status, but did not appear to impact other menopause symptom factors alone. Pain scores were significantly worse among women who were late postmenopausal versus early menopausal with no differences by HRT use. Finally, a significant interaction between menopause status and HRT use on muscle atrophy suggested that late postmenopausal women taking not taking HRT experienced a greater problem with muscle atrophy than early postmenopausal women. Similar differences were not seen among women taking HRT. In general, differences by menopause status in this sample were seen between early and late postmenopausal groups, and not peri-menopausal.

3b. Efficacy of HRT among Early and Late Postmenopausal Women

To more closely examine HRT efficacy among early and late postmenopausal women, a sub-sample consisted of 273 women was used. This sample was comprised of early (EPM; N = 80) and late (LPM; N = 193) naturally postmenopausal women (mean age at FMP = 50.10 $\pm$ 4.2 years) between the ages of 47 and 71 years with a mean age of 61.2 $\pm$ 5.5 years. Of these, 30.4% (N = 83) were using HRT. The sample was further sub-divided into four groups: 1) EPM not using HRT (EPM – ; N = 51); 2) EPM using HRT (EPM +; N = 29); 3) LPM not using HRT (LPM – ; N = 139) and 4) LPM using HRT/ERT (LPM + ; N = 54). Groups were compared on the four menopause symptom factors, post-polio sequelae severity and selected emotional well being variables.

Results of the primary analysis suggested significant group differences on psychological and vasomotor menopause factors ($F_{3, 260}$ = 5.60, p = 0.001 and $F_{3, 260}$ = 3.26, p = 0.022). Post-hoc testing revealed significant differences on the psychological factor between EPM – and both groups of LPM women (p = 0.001 and 0.004, respectively) with higher severity ratings among EPM – women; no significant difference was found between EMP groups. No significant differences were found between EMP groups on the vasomotor factor. There was a significant difference between EMP – and EPM + women (p = 0.01) with the former reporting greater severity. No significant differences were found between LPM groups on any comparison. No significant group differences were found with regard to the severity of post-polio sequelae or psychosocial variables.

Results suggest that efficacy of HRT in this sub-sample was limited to psychological and vasomotor factors. Contrary to expectations, vasomotor symptoms did not differ significantly between EPM groups. It is also interesting that there were no significant differences between EPM and LPM women not using HRT with respect to vasomotor symptom severity which is expected to decline with age (LPM women were significantly older than EPM women, 56.3 vs. 63.2 years, p < 0.0001). It is unclear whether there is an overlay of sequelae related to physical disability that masks differences or potentiates vasomotor symptoms despite post-polio being a lower-motor neuron disorder and not being associated with thermodysregulation. It is also interesting to note that despite EPM women not using HRT reporting significantly greater

psychological symptom severity than both groups of LPM women, no other group differences were found on psychosocial factors or post-polio sequelae which itself may increase psychological distress. In general, the few group differences found in this sub sample were between EPM and LPM groups rather than within groups by HRT use suggesting that differences could be more strongly related to age or other omitted factors rather than HRT use.

4. Psychometric Properties and Factorial Structure of the Index of Post-Polio Sequelae (IPPS)

The manuscript (Kalpakjian, Toussaint, Klipp, and Forchheimer) describing the psychometric properties and factor structure of the IPPS, developed for use in this study, is currently in progress (submission to a peer-reviewed rehabilitation journal is expected in June). The development of the IPPS is described in detail in Appendix B. Briefly, the IPPS is comprised of 12 commonly reported post-polio symptoms rated for severity on a 5-point Likert scale ranging from 1 (slight) to 5 (extreme).

The 12 items from the IPPS were submitted to a factor analysis using principal components extraction. Factors were extracted according to Kaiser's criterion (eigenvalues >1) and rotated to oblique simple structure using promax rotation (Kappa = 2.5). Only significant loadings greater than or equal to 0.40 were used to interpret the factors. Oblique rotation was chosen since we expected that from the broad constellation of polio symptoms we would identify several unique but somewhat correlated factors. Three factors were extracted that accounted for approximately 53% of the variance in the original IPPS items. Factor loadings for each item are given in Table A.17.

All three factors showed acceptable levels of internal consistency (alphas 0.59 - 0.74), for short scales. Hence, all three factors were examined and items loading highly on these factors ($\geq$ 0.40) were summed to create factor sub-scale scores. Factor 1 (Pain) is comprised of six items (2, 4, 5, 7, 11, and 12) and is loaded most heavily by two items referring to muscle and joint pain. Factor 2 (Atrophy) is comprised of three items (1, 3, and 6) referring to muscle atrophy, involved muscle weakness, and to a lesser degree, fatigue. Factor 3 (Bulbar) is comprised of two items (8 and 9) referring to classic symptoms of bulbar polio, namely breathing and swallowing problems. Cold intolerance (item 10) did not load on any of the factors.

Score Distributions of the IPPS total score and factors: Total and factor scores were computed based on the results of the factor analysis and explored with regards to total score internal consistency and score distributions. Internal consistencies for the total score was within acceptable limits (alpha = 0.78) and normally distributed. Factor 1 (pain) scores were normally distributed. Factor 2 (atrophy) scores was negatively skewed indicating clustering in the higher range of scores. Factor 3 (bulbar symptoms) was positively skewed indicating clustering of scores in the lower range of scores. Examination of outliers for each of the factors and total score suggested that none substantially impacted mean scores.

Convergent Validity: Bi-variate correlations were performed on the IPPS total score and factors and measures of health and function variables to explore convergent validity. In general, associations between IPPS scores and health variables were modest to moderate at best, although nearly all correlations were statistically significant. Ability to perform basic and intermediate ADLs and self-rated health were consistently and moderately associated with factor 1 (pain) and factor 2 (atrophy), while associations with factor 3 (bulbar) tended to be weaker. In general, associations between the IPPS total score and measures of health and

function were equal or higher than the factor scores. Bi-variate correlations also were performed on the IPPS total score and factors and psychosocial factors to explore convergent and divergent validity. In general, the association between psychosocial variables and the IPPS factors ranged from modest to moderate at best. Perceived stress had the highest association with each of the factors, although these associations were moderate at best. Factor 1 (pain) had the strongest association with each of the psychosocial variables as compared to factor 2 and 3. Correlation coefficients are given in Table 18.

Table 18. Bivariate Correlations Between IPPS Factors and Health and Psychosocial Variables

	Total Score	***Factor 1 Pain***	***Factor 2 Atrophy***	***Factor 3 Bulbar***
Health Factors				
Basic ADLs	-0.39[a]	-0.33[a]	-0.34[a]	-.0.20[a]
Intermediate ADLs	-0.44[a]	-0.37[a]	-0.44[a]	-0.18[a]
Self-rated health	-0.47[a]	-0.41[a]	-0.31[a]	-0.36[a]
Physical activity	-0.24[a]	-0.16[a]	-0.31[a]	-0.10[b]
Psychosocial Factors				
Positive affect	-0.25[a]	-0.22[a]	-0.22[a]	-.0.12[a]
Negative affect	0.30[a]	0.32[a]	0.14[a]	0.16[a]
Life satisfaction	-0.35[a]	-0.33[a]	-0.22[a]	-0.20[a]
Perceived stress	0.39[a]	0.37[a]	0.26[a]	0.19[a]

Note: [a] $p \leq 0.000$; [b] $p \leq 0.005$ [c] $p \leq 0.05$

The results of this preliminary exploration of the psychometric properties and factor structure of the IPPS are promising suggesting that it is a reliable and useful tool to measure post-polio sequelae severity. Furthermore, examination of its factor structure suggests a core set of symptoms that cluster consistently into three well-defined factors: pain (muscle and joint pain and contractures); atrophy (muscle atrophy, involved muscle weakness and fatigue) and bulbar (breathing and swallowing problems). While the IPPS is a psychometrically sound measures of an individual's overall post-post sequelae severity, these analyses revealed that symptoms should be more appropriately be conceptualized as clustering into three core groups or dimensions. Furthermore, the underlying physiological processes producing such sequelae common among polio survivors also provide support for this clustering of symptoms.

The strength of relationships between the IPPS factors and other health and psychosocial factors were generally modest to moderate and in expected directions. In general, the pain factor had the overall strongest and most consistent relationship to self-care ability, self-rated health and physical activity. The impact of pain also was seen among the psychosocial variables. Future studies using the IPPS to explore factor structure differences in women and men are planned as little is known about the differential presentation of post-polio sequelae by gender. The reliability and factor structure of the IPPS also should be examined in other post-polio samples, such as clinic samples that may have a more severe presentation of symptoms and/or different demographic characteristics.

CONCLUSIONS

This study produced several significant findings related to menopause in women who are post-polio which lays an important foundation for future studies examining the interactions between menopause symptoms and secondary conditions and their impact on health as women with physical disabilities age. First among these findings was a significant relationship between the severity of post-polio sequelae and menopause symptoms. Further research is needed to understand the potential mechanisms of symptom or secondary condition exacerbation as well as limitations in measurement of symptoms, in particular their sensitivity and specificity all of which requires careful scrutiny before definitive conclusions can be made. However, this is preliminary evidence that a relationship does exist that has the potential to impact the health of these women as they age.

The study of menopause in general is fraught with complications stemming from its basic transitional nature to limitations in measurement and conceptualization of a "menopause syndrome." As such, with the added complication of physical disability, this study is an important first step in what is surely a substantial yet vital undertaking. Two particularly important findings related to how menopause may or may not differ in women with disabilities is that contrary to speculation in the literature, women in this sample who had a natural menopause did so at the same age, on average, as their peers. However, they did undergo hysterectomies at a significantly higher rate than their peers, although the reasons for this disparity are not clear at this time.

In general, more than half of the proposed hypotheses were unsupported by our findings. Two (2 and 3) were fully supported suggesting an association between worse menopause symptoms and poorer emotional well-being and an association between menopause status and post-polio sequelae severity and lower physical functioning. The hypothesis that menopause symptoms would be significantly associated with post-polio sequelae severity and physical functioning was partially supported as there was no association between the latter and menopause symptom severity. This may suggest that either self-report measures of physical functioning are not adequately sensitive enough to detect differences in levels of physical functioning or that this relationship is moderated by years of adaptation to physical disabilities, such as was the case for most of the women in this study.

Although the remaining hypotheses did not receive support (4-7), using men as controls provides an interesting perspective to better understand the interaction of menopause status and disability related factors. The vast majority of studies examining menopause symptoms do not include men as controls, although the few that do have found little differences in report of symptoms commonly associated with menopause (except vasomotor symptoms). Specifically, while there were some differences on physical outcomes by menopause status, age-matched men were generally similar on these outcomes. Where there were gender differences, these tended to be among late postmenopausal women and their age-matched male counterparts. This may suggest an acceleration of decline for women compared to men in later years; this will require further investigation.

Despite the unknown risk-benefit ratio of HRT use by women with physical disabilities, who are likely to be predisposed to greater health risks by virtue of their narrower margin of health, women in this study use HRT at a significantly higher rate than their non-disabled peers, despite its lack of efficacy for mitigating nearly all but vasomotor symptoms. Interestingly, there were differences on severity of psychological symptoms by HRT within groups early and late

postmenopausal women, despite evidence to the contrary from recent studies of non-disabled women. The reasons for disparity in HRT use rates are not known and recent findings about the safety of HRT have dramatic changes in usage, both discontinuing and resuming use and so estimates of current use are difficult to determine. Although there were few differences found among women using and not using HRT and their age-matched counterparts on physical outcomes, late postmenopausal women using HRT reported greater post-polio sequelae severity but simultaneously better basic ADL functioning.

Additional analyses performed on a standardized scale to measure menopause symptoms also sheds some light on measurement issues in women with physical disabilities given the overlap or interaction of symptoms. Our examination of the factor structure of the MSL indicated that while there were the common symptom clusters – psychological, somatic, and vasomotor – the two somatic clusters reflected two common problems in late polio – sensory loss and sleep disturbance. The fact that these factors were far less likely to differ by menopause status than were psychological and vasomotor factors suggests that they may be less sensitive due to substantial overlap with problems associated with the primary disability. The results of this factor analysis, the first of its kind in the published literature, suggests that great caution should be used when employing standardized menopause symptom rating scales developed with non-disabled women. It further highlights limitations in measurement with regard to sensitivity and specificity indicating a need for more research.

On the whole, as expected, these polio survivors were well-educated, married and were either working or had retired. Using national estimates from the Census Bureau and the Centers for Disease Control and Prevention on selected demographic and health factors, we were able to make comparisons to this sample to place them in the larger context of their fellow Americans. These comparisons suggested that, as has been largely believed, their rates of education were nearly three to five times greater than their similarly aged peers. The most marked differences in advanced degree rates were among the older participants suggesting that indeed, they stood out among their peers given the up-trend of advanced education over time during the 20th century. These participants also were married at similar rates suggesting that disability did not limit their ability to form close, intimate relationships. In fact, those in the 75 to 84 year old age group were married at a higher rate than their peers. While many had already retired for both medical and non-medical reasons and were employed at significantly lower rates than their similarly aged peers, for those over the age of 65 years, employment rates were similar.

Nevertheless, not all differences to their fellow Americans were positive. Middle aged participants reported substantially greater perceived stress than their similarly aged peers, although this difference dropped off in later years with the lowest rates of stress reported by older participants. These polio survivors also rated their health lower than their peers (although poor ratings of health were similar) with many falling in the “good” range, while their fellow Americans were more likely to rate their health in “very good” and “excellent” categories.

Implications of the major findings of this study suggest some association between menopause and post-polio sequelae and, as such, women who are post-polio, perhaps even more than their non-disabled peers, should be fully aware of the health changes associated with menopause and their own personal risk profile for co-morbid disease, such as cardiovascular disease. The further implications of the findings of this study are such that women who are post-polio should carefully weigh the known risks and benefits of HRT with their physicians given their narrower margin of health and vulnerability to co-morbid health conditions due to limitations in physical activity.

Because so little is known about menopause, a normal biological milestone in every woman's life, and its unique characteristics in women with physical disabilities, women who are post-polio are, fairly or not, are put in the position of having to educate both themselves and their health care providers about how they may differently experience menopause. Fortunately, this study now provides them with some of the first solid evidence that their experience of menopause – physiologically, physically, psychologically – will very likely be different in some important ways than their non-disabled peers. Optimizing their health at all levels and knowing their own unique risk profile as it relates to both menopause and aging is perhaps the most important message from this study's findings for these women as they transition through menopause. While there remains much to be learned about menopause in the context of disability, this comprehensive study – the first of its kind with such a large population of women with physical disabilities – has taken the important first step to what we hope will be the start of a generation of menopause studies that no longer ignore women with disabilities.

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APPENDIX A:
ADDITIONAL TABLES AND FIGURES

1. Demographic Profile

Table A.1: States and Countries of Participants (in alphabetical order)

State	*N*	*%*	*State*	*N*	*%*
AK	2	0.2	**NE**	12	0.9
AL	7	0.5	**NH**	7	0.5
AR	21	1.6	**NJ**	21	1.6
AZ	35	2.7	**NM**	13	1.0
CA	152	11.8	**NV**	6	0.5
CO	18	1.4	**NY**	76	5.9
CT	11	0.9	**OH**	61	4.8
FL	81	6.3	**OK**	17	1.3
GA	14	1.1	**OR**	24	1.9
HI	4	0.3	**PA**	52	4.1
IA	21	1.6	**RI**	4	0.3
ID	4	0.3	**SC**	4	0.3
IL	96	7.5	**SD**	1	0.1
IN	28	2.2	**TN**	28	2.2
KS	16	1.2	**TX**	65	5.1
KY	13	1.0	**UT**	7	0.5
LA	6	0.5	**VA**	26	2.0
MA	18	1.4	**VT**	6	0.5
MD	14	1.1	**WA**	24	1.9
ME	8	0.6	**WI**	40	3.1
MI	78	6.1	**WV**	1	0.1
MN	26	2.0	**WY**	3	0.2
MO	57	4.4	***International***		
MS	4	0.3	**Brazil**	1	0.1
MT	9	0.7	**Canada**	2	0.2
NC	25	1.9	**England**	3	0.2
ND	2	0.2	**France**	1	0.1

Table A.2: Age Groups

	N	*%*	*Cumulative %*
45 thru 54.9 years	210	16.4	16.4
55 thru 64.9 years	477	37.3	53.6
65 thru 74.9 years	382	29.8	83.4
75 thru 84.9 years	180	14.0	97.4
85+ years	22	1.7	99.1
<44.9	11	0.9	100.0
Total	1282	100.0	

Table A.3: Marital Status

	N	*%*	*Cumulative %*
Married	834	65.0	65.2
Separated	9	0.8	65.9
Divorced	163	12.7	78.7
Widowed	125	9.7	88.4
Never married	148	11.5	100.0
Total	1280	99.8	
Missing	2	0.2	
Total	1282	100.0	

Table A.4: Ethnicity

	N	*%*	*Cumulative %*
African American	9	0.7	.7
Asian	7	0.5	1.2
Caucasian	1228	95.7	97.1
Latina/Latino	15	1.2	98.4
American Indian	2	0.2	98.5
Other	6	0.5	99.0
Multiple Ethnicity	13	1.0	100.0
Total	1280	99.8	
Missing	2	0.2	
Total	1282	100.0	

Table A.5: Educational Attainment

	N	*%*	*Cumulative %*
Less than high school	20	1.6	1.6
High school or GED	201	15.7	17.2
Some college	346	27.0	44.2
College degree	356	27.7	72.0
Graduate degree	358	28.0	100.0
Total	1281	99.9	
Missing	1	0.1	
Total	1282	100.0	

Table A.6: Employment Status

	N	*%*	*Cumulative %*
Working, full or part time	372	29.1	29.1
Unemployed, looking	3	.2	29.3
Retired - not medical	335	26.1	55.5
Retired - medical	464	36.2	91.7
Homemaker	106	8.3	99.9
Retired both med and non-med	1	.1	100.0
Total	1281	99.9	
Missing	1	.1	
Total	1282	100.0	

2. Polio History

Table A.7: Type of Polio Contracted

Type of Polio	*N*	*%*	*Cumulative %*
Bulbar	38	3.0	3.0
Spinal	866	67.5	70.6
Bulbar and spinal	264	20.6	91.3
Not sure	111	8.7	100.0
Total	1279	99.8	
Missing	3	.2	
Total	1282	100.0	

3. Post Polio Sequelae

Table A.8: Average Severity Rating per Post-Polio Problem*

	N	*Minimum*	*Maximum*	*Mean*	*Std. Deviation*
Muscle weakness - involved	1272	0	5	3.16	1.206
Muscle weakness - uninvolved	1259	0	5	2.02	1.470
Muscle atrophy	1259	0	5	2.30	1.595
Joint pain	1268	0	5	2.22	1.702
Muscle pain	1265	0	5	2.22	1.642
Fatigue	1272	0	5	3.09	1.376
Sleeping problem	1262	0	5	2.05	1.630
Breathing problem	1258	0	5	1.37	1.535
Swallowing problem	1260	0	5	.89	1.270
Cold intolerance	1266	0	5	2.46	1.556
Contractures	1253	0	5	1.69	1.586
Carpal tunnel	1245	0	5	1.04	1.531

* In order as it appears on the IPPS questionnaire

Table A.9: Number of body parts weakened

# Body Parts Weakened	*N*	*%*	*Cumulative %*
No body parts weakened	10	0.8	0.8
1 body part weakened	84	6.5	7.3
2 body parts weakened	86	6.8	14.1
3 body parts weakened	111	8.7	22.8
4 body parts weakened	170	13.3	36.0
5 body parts weakened	124	9.7	45.7
6 body parts weakened	288	22.4	68.1
7 body parts weakened	171	13.3	81.4
8 body parts weakened	238	18.6	100.0
Total	1282	100.0	
Average number of body parts weakened: 5.24 $\pm$ 2.2			

6. Menopause

Table A.10: Mean Severity Ratings for Menopause Symptoms

	N	*Minimum*	*Maximum*	*Mean*	*Std. Deviation*
Tension	838	0	5	1.90	1.223
Excitability	838	0	5	1.54	1.192
Depressed	839	0	5	1.53	1.283
Moodiness	840	0	5	1.39	1.190
Irritability	839	0	5	1.64	1.153
Pressure	835	0	5	1.36	1.361
Crying	837	0	5	1.06	1.165
Worrying	836	0	5	1.29	1.173
Palpitations	834	0	5	1.15	1.192
Shortness of breath	835	0	5	1.26	1.264
Numbness	836	0	5	1.42	1.350
Loss of feeling	832	0	5	1.12	1.355
Dry eyes	839	0	5	1.30	1.347
Cold hands	843	0	5	2.35	1.451
Headaches	840	0	5	1.61	1.347
Sweating	837	0	5	1.39	1.404
Hot flushes	835	0	5	1.59	1.440
Weight gain	822	0	5	1.40	1.459
Sleeplessness	839	0	5	2.20	1.454
Loss of sexual interest	824	0	5	1.95	1.651
Poor appetite	827	0	5	0.67	.996
Dyspareunia	798	0	5	0.80	1.330
Poor Concentration	834	0	5	1.61	1.231
Constipation	837	0	5	1.40	1.289
Early morning awakening	838	0	5	1.69	1.323

8. General Health

Table A.11: Self-Ratings of Current Health

Current Health	*N*	*%*	*Cumulative %*
Poor	60	4.7	4.8
Fair	295	23.0	28.3
Good	528	41.2	70.4
Very good	300	23.4	94.3
Excellent	71	5.5	100.0
Total	1254	97.7	
Missing	28	2.3	
Total	1282	100.0	

Table A.12: Self-Ratings of Health Compared to Year Ago

Health Compared to a Year Ago	*N*	*%*	*Cumulative %*
Much worse	86	6.7	6.8
Somewhat worse	447	34.8	42.4
About the same	553	43.1	86.5
Somewhat better	121	9.4	96.1
Much better	49	3.8	100.0
Total	1256	97.9	
Missing	26	2.1	
Total	1282	100.0	

Table A.13: Body Mass Index

BMI Category	*Frequency*	*Percent*	*Cumulative Percent*
Lowest thru 18 (underweight)	38	3.0	3.0
18.5 thru 24.9 (healthy weight)	500	39.0	42.5
25 thru 29.9 (overweight)	426	33.2	76.1
30 thru 34.9 (obese, class I)	198	15.4	91.7
35 thru 39.9 (obese, class II)	68	5.3	97.1
40 thru highest (obese, class III)	37	2.9	100.0
Total	1267	98.8	
Missing	15	1.2	
Total	1282	100.0	

9. Physical Functioning and Physical Activity

Table A.14: Self-Rating of Physical Activity Compared to Peers

	N	*%*	*Cumulative %*
Much more active	45	3.5	3.5
Somewhat more active	117	9.1	12.7
About the same	126	9.9	22.6
Somewhat less active	228	17.8	40.4
Much less active	759	59.2	99.7
Not applicable	4	0.3	100.0
Total	1279	99.8	
Missing	3	0.2	
Total	1282	100.0	

Table A.15: Best Ability to Walk on Average Day

Able to walk …	*N*	*%*	*Cumulative %*
Unable to walk 100 feet	347	27.0	27.3
Over 100 feet, but use wheelchair	187	14.6	42.1
At least 100 feet, but not a mile	469	36.6	79.0
A mile with limp	139	10.9	90.1
More than mile with no problem	125	9.7	99.9
Total	1269	98.9	
Missing	15	1.2	
Total	1282	100.0	

Additional Analyses

Table A.16: Factor Loadings for MSL

Factor	*Items*	*Component*					
		1	*2*	*3*	*4*	*5*	*6*
1	Depressed feelings	**0.84**					
	Irritability	**0.82**					
	Tense feelings	**0.81**					
	Worrying needlessly	**0.81**					
	Moodiness	**0.79**					
	Crying spells	**0.78**					
	Feeling excitable	**0.76**					
	Pressure or tightness in head/body	**0.44**					
	Poor concentration						
2	Loss of feeling in hands or feet		**0.83**				
	Numbness and tingling		**0.81**				
	Dry eyes		**0.60**				
	Constipation		**0.45**				
3	Sleeplessness			**0.76**			
	Early morning awakenings			**0.62**			
	Cold hands and feet			**0.55**			
	Headaches			**0.40**			
	Loss of sexual interest						
4	Involuntary sweating				**0.83**		
	Hot flushes				**0.82**		
	Dyspareunia						
	Shortness of breath						
	Weight gain						
	Loss of appetite						
	Palpitations						
	Eigenvalue	*6.90*	*3.81*	*3.65*	*3.49*	*1.37*	*1.39*

Table A.17: Promax Rotated Factor Pattern Matrix of the IPPS

Items (#)		Component		
		1	2	3
Pain	Muscle pain (5)	**0.83**		
	Joint pain (4)	**0.83**		
	Carpal tunnel (12)	**0.55**		
	Sleeping problems (7)	**0.51**		
	Contractures (11)	**0.45**		
	Muscle weakness - un-involved muscle (2)	**0.41**		
Atrophy	Muscle atrophy (3)		**0.81**	
	Muscle weakness - involved muscle (1)		**0.77**	
	Fatigue (6)		**0.43**	
Bulbar	Breathing problems (8)			**0.85**
	Swallowing problems (9)			**0.83**
	Eigenvalue	*3.07*	*2.39*	*2.11*
	Coefficient Alpha	*0.74*	*0.59*	*0.66*

APPENDIX B: DESCRIPTION OF MEASURES

Demographics: Standard demographic information was collected from participants: date of birth, gender, ethnicity, marital status, education, occupational status and number of dependents in household.

General Health: Prevalence of co-morbid disease in the sample was obtained by a series of open-ended questions about incidence of conditions (not polio) in eleven categories: cardiovascular, respiratory, metabolic, neurological, autoimmune, gastrointestinal/urological, cancer, musculo-skeletal and "other." Those diseases with the highest prevalence were then dummy coded (reported vs. not reported) to establish prevalence rates of specific diseases within each category. A list of diseases and medications affecting bone health drawn from University of Michigan Health System "Guidelines for Clinical Care: Osteoporosis."[47] Other medications and dosage also were provided by participants. Having had a bone scan, diagnosis of osteoporosis or osteopenia, age diagnosed and family history also was asked.

Physical Functioning and Physical Activity: The *Functional Status Questionnaire (FSQ)*[48] was originally developed for comprehensive and efficient assessment of physical, psychosocial, social and role functioning in ambulatory medical patients. The two scales of physical functioning, Basic Activities of Daily Living (BADL) and Intermediate Activities of Daily Living (IADL), were used in this study. Both scales are rated on a Likert scale ranging from 1 (usually did not do because of health) to 4 (usually did with no difficulty). The BADL scale is comprised of 3 items referring to basic self care ability (e.g., bathing and dressing, walking indoors); the IADL contains 6 items referring to more demanding self-care activities (e.g., walking, driving a car, grocery shopping).

Total scores range from 0 to 100; scores falling below 88 on the BADL and below 78 on the IADL are considered to be in the "warning zone" suggesting reduced ability to perform ADLs. In this study, internal consistency (Cronbach's alpha) was 0.77 for the BADL and 0.87 for the IADL; scores were normally distributed. The FSQ also contains two items related to self-appraisal of health status. Item 1 refers to rating of health in general using a Likert scale ranging from 1 (poor) to 5 (excellent); item 2 refers to the current state of health in comparison to a year ago using a Likert scale ranging from 1 (somewhat worse than a year ago) to 5 (much better than a year ago).

The *Lipids Research Clinics Physical Activity Scale (PAS)*[49] is a brief, 4-item measure of physical activity. The scoring method used in the present study has been associated with cardio-respiratory fitness, body fatness and amount of leisure time physical activity. The four-point scoring method categorizes degree of physical activity into four levels, ranging from "highly active" to "very low active." This score combines self-report of strenuous exercise (yes or no) with a self-rating of degree of activity compared to peers. The latter is rated on a Likert scale ranging from 1 (much more active) to 5 (much less active).

Psychosocial Well Being: The *Satisfaction with Life Scale (SWLS)*[50] is designed to measure a global, cognitive judgment of one's life. Items are rated on a Likert scale ranging from 1 (strongly disagree) to 7 (strongly agree). Scores range from 5 to 35 such that *higher scores indicate greater life satisfaction*. In this study, internal consistency was 0.89; scores were normally distributed.

The *Perceived Stress Scale (PSS-10)*[43] is the most widely used measure of the degree to which situations in one's life are appraised as stressful. Items were designed to tap into how

unpredictable, uncontrollable and overloaded respondents find their lives. Items are rated on a Likert scale ranging from 0 (never) to 4 (very often) using a one-month time frame. Scores for the 10-item scale range from 0 to 40 such that higher scores indicate greater perceived stress. In this study, internal consistency was 0.89; scores were normally distributed.

The *Positive and Negative Affect Scale (PANAS)*[51] is a widely-used measure of positive and negative affect. Ten positive and ten negative affect descriptors are rated on a Likert scale ranging from 1 (very slightly or not at all) to 5 (extremely). Scores for the positive and negative scales range from 0 to 50, respectively, such that *higher scores indicate greater positive or negative affect*. In this study, internal consistency was 0.89 for the positive scale and 0.89 for the negative scale; scores for both scales were normally distributed.

Polio History: This section collected information with regard to the year polio was contracted, age at the time, length of hospitalization (if recalled) and the type of polio contracted. The use of assistive devices, walking ability on an average day and body part weakness also was assessed.

Post-Polio Sequelae: A new measure developed by the authors was used in this study to assess post-polio sequelae severity. The development of Index of Post-Polio Sequelae (IPPS) is described in detail below; assessment of its factor structure and psychometric properties is described in greater detail later in the report.

Initial Development of the Scale: The first version of the scale was used in a study of a wellness program for 183 female polio survivors conducted from 1996 to 1999.[52] The scale was patterned after the Seekins Secondary Conditions Questionnaire,[53] designed to assess secondary health problems in spinal cord injury. It was revised so that items would be applicable to polio survivors and was substantially shortened to reduce participant burden. The first version included sequelae frequently reported by polio survivors as well as broader content areas applicable to disability, such as environmental access, equipment failure, co-morbid disease, and social isolation. Each item was operationally defined (see Appendix) and was comprised of three parts: 1) diagnosis by a physician; 2) seeking medical care for problem; and 3) severity of problem rated on a 3-point Likert scale (mild, moderate, and severe).

In order to more closely target sequelae reported by polio survivors, the scale was substantially revised for a follow-up study with 106 (58%) of the wellness program participants in the 2002 NIH study. In the second version, items referring to broader disability issues were dropped, leaving eleven items. The IPPS items reflected the extant literature on the characteristics and prevalence rates of post-polio sequelae, as described above. Operational definitions were retained and each item was comprised of three sections: 1) occurrence of problem at any time since acute illness; 2) duration of problem (e.g., new, chronic, corrected but still a problem and corrected, and no longer a problem); and 3) current severity of problem rated on the same 3-point Likert scale. The duration of problem was further delineated by age problem started, worsened, or re-occurred. The change in focus of items was to ascertain, if possible, the relationship of onset or worsening of post-polio sequelae and menopause, the focus of the follow-up study.

Refining of the Scale: For this study, the IPPS was revised a third time. This third and (current) version contains the same eleven symptoms and operational definitions, however the pain item was been differentiated into muscle pain and joint pain resulting in the 12-item scale. Questions about duration of the problem were dropped because they were found to be problematic; subjects had difficulty recalling with some degree of precision the year or age of problem onset

or worsening of the problem. In addition, for the current version of the IPPS, the severity ratings were expanded from a 3-point (mild, moderate and severe) to a 5-point Likert scale ranging from 1 (slight) to 5 (extreme). The scale ranges were increased in order to improve the scale's internal consistency and sensitivity. Each severity rating also was operationally defined. These definitions were phrased such that they referred to the degree of severity of "change or sensation." Numerous participants indicated confusion over the word "change" as it implied relativity to some unknown benchmark. Thus the word was dropped from severity descriptions in the current version.

In its current form, total scores on the IPPS range from 0 to 60 *such that higher scores indicated greater severity of post-polio sequelae*. In this study, internal consistency for this new scale was 0.81; scores were normally distributed.

Menopause: The menopause section contained several subsections covering various aspects of menopause including: menopause status, use of hormone replacement therapy (HRT), other options for treating symptoms, experience of menopause and current severity of menopause symptoms.

Use of HRT: Various aspects of HRT use were assessed including current usage, who prescribed, age started, reason for taking HRT, the kind taken, and side effects. For women formerly using HRT, reasons for discontinuing use and age at time of discontinuing were collected.

Experience of Menopause: Communication with care providers about menopause, who initiated the discussion, satisfaction with the information received, other sources of menopause information, any limitations in access to information due to disability and their general experience of menopause was assessed.

Menopause Symptoms: The *Menopause Symptom List (MSL)*[54] is a 25-item scale of symptoms commonly associated with menopause. The scale's standardization sample was comprised of 40 women between the ages of 45 to 55 who did not use any form of HRT or oral contraceptives in the previous six months and who did not have a surgical menopause. Items were drawn from a pool of 56 symptoms generated from review of the literature and other symptom scales. A factor analysis on 39 items revealed three primary factors: 1) psychological; 2) vaso-somatic; and 3) general somatic, resulting in the 25-item scale. Each symptom is operationally defined and rated for frequency and severity using Likert-scaling. Frequency scores range from 0 (never) to 5 (almost always) and severity scores range from 0 (not applicable) to 5 (extreme). In scoring the MSL, items that load above a 0.70 on their respective factors are given a weight of 2 and the total score is a sum of severity rating multiplied by their weight. In its original form, total MSL scores range from 0 to 185 such that *higher scores indicate greater severity of symptoms.* However, we performed factor analysis of the MSL using a sub-sample of women in this study and a different factor structure was found as reported earlier.