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## The Meaning of Gender while Aging with Paralytic Polio

Tracie Harrison, PhD, RN\*\* [Assistant Professor], Alexa Stuijbergen, PhD, RN[Dean, Professor], Janiece Walker, MSN, RN[Doctoral Student], Tiffany Scott, MSN, RN[Doctoral Student], and Robin Choban, RN[Graduate Research Assistant]

### Abstract

The purpose of this paper is to report the influence of gender on aging with childhood onset paralytic polio. The hermeneutic phenomenological exploration of gender was done using multiple qualitative interviews with 25 women, age 55 to 75 years of age, who had polio since before 14 years of age. We noted three themes: 1) The movement of her body, 2) Integrating body and gender, and 3) Gender discrepancies. Findings are discussed in the context of gendered expectations and the women's bodies.

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There's a restaurant to tell you about. I don't know if you've ever eaten there. It has the wheelchair sign on the side door. Well, you go there. You have to knock on the door because it's their delivery door. So you're coming in through the back. Of course, everybody has to look when you're coming in. So, like I say, they're meeting the ADA requirements the way they're written, but they need to be written better. They need to be updated. There's too much that they're 'doing their duty' by letting us come in their back door. But we haven't ... (pause) they seem to think that if you're in a wheelchair, gosh, you must be blind, maybe you're deaf, you're not real smart, and you have mental problems. That's the reaction that you get from people.

–Joan, age 54, polio survivor

In her phenomenological research, Furman wrote, “We repeatedly see that women's developing sense of their bodily selves is strongly shaped by the way they are perceived by others” (1997, p. 51). If the development of our gendered bodies is influenced by interactions with other people, the developmental trajectory of womanhood may be unique for women with early onset impairments. In the quote above, Joan, age 54, who had aged with the effects of paralytic polio since childhood, spoke about how the attention that was drawn to her body magnified her body's impairments. In fact, the very process of social interaction was altered; her body was allocated to the back door and given access to society only through obligatory legal means that stigmatized her. The meaning assigned to her body, as gender friendly as the cold steel the wheelchair sign was printed on, did little to bolster her on-going sense of womanhood as she aged. This example highlights the types of experiences that shape the gendered body for women aging with early onset impairment.

Through intensive life course interviews with women aging with the effects of early onset paralytic polio, it was our purpose to explore how women's gender affected their experience of aging and subsequent adjustment. Often neglected in the healthcare literature, gender, a process of understanding the continuum of femininity/masculinity by interacting with people in society (West & Zimmerman, 1987), deserves careful consideration for how it influences

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\*\*Corresponding Author, Tracie Harrison, PhD, RN, Associate Professor, School of Nursing, UT Austin, 1700 Red River, Austin, TX 78701, 512-471-9085.

the health of women aging with disabilities. In this paper, we present this gender analysis in three steps. First, we review the literature on aging with paralytic polio and gender, next we present our phenomenological analysis of gender, aging, and disability among 25 women with paralytic polio, and finally, we integrate our findings into current knowledge of gender and health. The paper concludes with our recommendations for future research consideration.

## Background

Poliomyelitis is still a common neurologic condition despite an immunization that has nearly eradicated the disease in developed countries (Trojan & Cashman, 2005). Approximately 440,000 people in the United States (National Institute of Neurologic Disorders and Stroke, 2010) and over 20 million worldwide (World Health Organization [WHO], 2008) live with the late effects of polio. From the 1950s through the 1980s, up to 350,000 cases were reported each year worldwide (WHO, 2008). Immunizations were fully released by the 1960s and the disease slowly became less common. From 2003 to 2005, however, 25 countries that were polio-free saw polio infections due to “imports of the virus” from endemic countries (WHO, 2008). Currently, only Afghanistan, India, Nigeria, and Pakistan continue to report new cases of polio at endemic rates (WHO, 2008).

Typically, paralytic poliomyelitis infected children under five years of age, although older people were also diagnosed (National Institute of Neurologic Disorders and Stroke, 2010). Symptoms characteristically started with a fever and headache, and then swiftly progressed to muscle weakness, as well as paralysis. For those who did not recover, permanent paralysis of skeletal muscles impinged on activities such as walking, breathing, reaching, grabbing, or holding the torso straight. This, coupled with on-going restorative surgeries and rehabilitation, became a way of life from an early age (Harrison & Stuijbergen, 2005). Polio resulted in a variety of functional limitations ranging from difficulty breathing and swallowing to difficulty in walking or both. It also required a variety of coping mechanisms from society, family and the individual. Given the varied biological and psychosocial effects surrounding living with paralysis related to polio, it is now considered an exemplar for aging with childhood-onset disabilities (Alexander, 1990).

Studies have explored the alterations in function and subsequent life patterns over time for those aging with polio-related paralysis. Research has focused on three main areas: the possibility of acquiring post polio syndrome (PPS), the development of co-morbid conditions, and the impact on social participation. PPS, which includes new muscle weakness, fatigue, and pain in muscles previously affected by polio, was reported by 25 to 60% of polio survivors as synthesized by a report from the National Institute of Neurologic Disorders and Stroke (2010). Twenty years after experiencing the initial effects of polio, survivors once more needed wheelchairs, iron lungs, and other assistive devices to stay employed and actively involved in society. Studies have also highlighted the elevated risk for co-morbid conditions that people with polio experience with age. For instance, cardiac risk factors were higher for people aging with polio than in the general population (Gawne, Wells, & Wilson, 2003). Further, persons aging with polio reported higher rates of hospitalizations for pulmonary disease, heart disease, gastrointestinal disorders, and musculoskeletal disorders than did age-matched contemporaries (Neilsen, Rostgaard, Askgaard, Skinhoj, & Aaby, 2004). Finally, polio survivors reported the inability to maintain social activities because their impairments increased with age (Yelnik & Laffont, 2010). Although polio survivors have mental health conditions comparable to the average population (Yelnik & Laffont), they may have difficulty with life satisfaction and depression if they view their disability negatively and report poor family function (Kemp, Adams, & Campbell, 1997).

What is missing from these studies is an exploration of how a woman's gender influences the experiences of persons who have aged with early onset polio. Women aging with polio provide knowledge on the experiences of disability from childhood. If disability has influenced their perception of gender and aging, it will be evident in their life histories, which may be different from those who age into a disability later in life. Gadow (1982), posited that people progress along four levels of relation between the conscious self and the body: the lived body, the object body, the harmony of the lived body, object body, and then finally the subject body exemplified in aging and illness. There is movement from an unconsciousness of the body, to the consciousness of disrupted being based upon normal then abnormal bodily function, to a final new aesthetic appreciation for the body in old age. de Beauvoir (1996/1970) further detailed the experiences of life in old age and disability. For women, she highlighted "the barren, flowerless days" in which "those who escape utter poverty or pinching want are forced to take care of a body that has grown frail, easily fatigued, often infirm or racked with pain" (p. 449). Most significantly, de Beauvoir pointed out that as a woman ages her physical losses potentiate the loss she may experience by societal withdrawal. The impact of disability, however, on a woman's life from an early age may not be the same as when it occurs late in (Harrison, Umberson, Lin, & Cheng, 2010). Given that the phenomenology of women's everyday lives in old age has been intertwined with the lived experiences of disability (de Beauvoir, 1996/1970; Gadow, 1982), it was our goal to understand the experience of gender and disability from a life course perspective (Elder, 1996).

## Methods

After approval from the local institutional review board, a hermeneutic phenomenological study was undertaken (Cohen, Kahn, & Steeves, 2000). The purpose of the study was to explore how the gender of women aging with paralytic polio was perceived to influence their experience of aging and subsequent adjustment. This was accomplished by collecting the life histories of 25 women with paralytic polio and interpreting those stories in a systematic manner. Prior to interviews, the women were sent a life history calendar to complete, which asked them to detail and rank significant events in their lives. During the interviews, the women were asked to start with their earliest memory of their lives and work forward to present day. The interviewer (TCH) would use probes to such as "go on" to continue the dialogue. After the collection of life histories, all text was analyzed to answer three research questions. This report reflects one of three questions pursued at the time of data collection. Specifically, we asked in this study: What is the perceived influence of gender on adaptation to aging with a childhood onset disability?

Line by line coding was done on close to 4,000 pages of text. The stories were analyzed by moving from the particular words in any given sequence to the entirety of the text within the hermeneutic circle. According to Dilthey, "Understanding must try to link words into meaning and the meaning of the parts into the structure of the whole given in the sequence of words." (1985, p. 163). Specifically, for this research question, data were identified that indicated that the women were conscious of their gender. In other words, women were usually unaware of themselves as being a "female" in the world. However, there were moments when their gender came to the forefront of their consciousness, when they spoke of times in their lives when they recognized the significance of their gender in society—of being or being perceived of as a gendered being. Those moments were understood by the researcher within the context of the entire text. It was "the expressions themselves and what they express as their meaning or sense" (Husserl, 1985, p. 174) that drove the analysis. Next, data were categorized into groups of like meaning and then synthesized into themes. The themes, subject matter that pulled together categorized descriptions of experiences, were the

common threads that linked words into a meaningful essence. The thematic analysis was guided by hermeneutic phenomenology (Cohen et al., 2000).

Hermeneutics and phenomenological philosophy formed the theoretical foundation of this study. Hermeneutics is the art and science of understanding written text and phenomenology is the philosophy behind understanding the essence of human experience. Hermeneutic phenomenologists “study how people interpret their lives and make meaning of what they experience”. (Cohen, Kahn & Steeves, 2000, p.5). Germaine to this study was the need to understand, albeit interpret, the stories that represent the “mental reality in a particular situation” (Dilthey, 1985, p. 162). It is the experience of being conscious of being a woman with paralytic polio, not the thought of what it might be, but the actual female body engaged with a physical world, that is the subject of this hermeneutic phenomenological investigation. The meaning of the language and the interpretation of the intent behind the language is analyzed in the process of understanding (Cohen Kahn & Steeves).

Given that the purpose of this study was to talk with women who had experienced aging with paralytic polio since childhood, community residing women throughout Texas were recruited based on age, self-reported diagnosis of paralytic polio, and gender. Briefly, each woman was interviewed two to four times, and each interview was audio-taped, then transcribed verbatim. The women’s names were changed to pseudonyms to protect their privacy. Procedures for data collection and management have been detailed elsewhere (Harrison, 2006; Harrison & Stuifbergen, 2005).

## Sample

The study included 25 women aged 55 to 75 years with polio onset from 3 months to 13 years of age. The women were highly educated with over half reporting a college degree, but only 4 (16%) were employed. Five of the women lived in rural areas while 20 resided in urban areas. Overall, 88% of the women reported a diagnosis of PPS. The women also had a high number of co-morbidities and secondary conditions. The most frequently mentioned were hypertension, diabetes, arthritis, sleep apnea, and osteoporosis. Other problems mentioned were cancer, pneumonia, depression, high cholesterol, and thyroid abnormalities. See Table 1 for a detailed description of the sample.

## Results

The influence of gender on aging with impairments was derived out of the women’s embodied experiences. As Patsy said, “I just love being a woman, but I don’t have to be frilly, I don’t have to be anything that I’m not. I can’t be anything else but me.” Throughout the study, the women expressed diverse views of gendered norms, which is common in society for women. The women’s ability to express their gender was altered due to polio. Overall, there was a tension within women with paralytic polio between normality of gendered expectations and their bodies’ impairment, which left a sense of unease in social interactions.

Our analysis of the women’s discussions of how their gender influenced their adaptation to aging resulted in three themes. The themes were: 1) The Movement of Her Body, 2) Integrating Body and Gender, and 3) Gender Discrepancies. These themes depict our interpretation of how gender was integrated into their lives to influence their experiences as women aging with the effects of paralytic polio.

Overall, the women noted discrepancies between their views of themselves, their needs, and the belief that the normal body should perform in some other way. Knowing that their bodies functioned differently than most women’s did not mean their gender roles and

expectations were different. Most important was the knowledge that aging with paralytic polio did not make the women different in their physical desires, ambitions, or pleasures, which came out of their gendered expectations for the female body regardless of impairment. The women's gendered sense of "self" developed with the same expectation for behavior and performance as any woman in Western society (Oksala, 2006). The exception was in her voluntary adaptation of a position in response to her body's ability, and in response to the actions of others.

### **The movement of her body: "Then the energy goes away."**

As the women aged, they moved from having adapted to childhood paralysis by using accommodations such as braces and crutches with altered movements to later adulthood, when movement and adaptation to loss of movement became more difficult. Along with their loss of movement came the loss of ability to perform activities. This theme describes the changes to their bodies' associated with age combined with progressive disability.

The women used their bodies in ways that best enabled them to work toward their life goals, but diminished energy and increasing pain with age slowed their progress. The effects of paralytic polio included paralysis, unequal leg length, scoliosis, weakness, fatigue, muscle atrophy, pain, and surgical scars. At times, the way that they moved their bodies was different than the way women without disabilities moved their bodies. For instance, to walk, women with leg paralysis braced their legs then rotated their hip to swing their leg forward and into position in a forward motion. This resulted in a noticeable difference in gait compared to someone without leg paralysis. The years of walking with paralysis and leg length variation led to pain and stiffness in their backs and legs. Jane described this as, "a stiffness most of the time, a stiffness. I felt like a tree trying to walk, completely stiff. When I get up sometimes in the morning, I'm just completely stiff and can't bend over. It takes me awhile to make my legs start." The intentions of their actions, however, were no different from any other woman walking forward. The difference was in the outcome. As Linda mentioned,

"You feel like you're well. You feel like there is nothing wrong with you. You could walk all over the mall if you had to, but if you tried, no. You couldn't walk very far at all. You just think you can because you have the energy. But if you walk very far at all, then the energy goes away."

Accommodations to assist in movement could be a threat to their femininity. The women mentioned shoes as a sign of femininity. The brown oxford, sturdy shoes that held their braces were a constant reminder in adolescence that they were not like other girls; they were different. The ability to discard unwanted shoes to wear the shoes that other girls wore was a sign of freedom, they could be feminine *if they desired*. Sharon commented,

I guess I was the first bionic woman. I think genetically engineered by my doctors. Let's make her this way. Let's make her that way. Let's do this, make her this way. Oh, let's make her that way. But I remember when I didn't have to wear buckle up shoes anymore. I just needed maybe an inch on my left leg. So, then I could buy sandals and beautiful shoes. Just had the heel built up and it was wonderful. It was freeing.

When negative events happened, the women with polio remembered previous doubts about their bodies' abilities and questioned their bodies' abilities. After a fall, Jessica stated, "I started crying like a baby. Went and got in my bed, you know, like it was going to go away. My arms were bleeding and stuff like that. I started crying. I said, 'I'm just not good for anything. I can't even bathe the dog.'" Then as the women aged, these movements changed or were lost all together. Lori stated,

When I was ambulatory, I would swing it from my hip. It's given a lot of, my hip, has given me a lot of pain. I think this is from all those years of walking and swinging this leg from my hip. The doctor said that's how I walked, was swinging that leg from my hip because now I can pull my leg when I'm laying down for the bed exercises, but I can't pull it back in.

Donna also added that:

I've always used my arms to hold me up with my walker and my arms are giving out. And [my husband] has called my attention to it, how I'm walking slouched over. And it's because my arms won't hold me up anymore.

The loss of physical movement meant changes in ability and activities of daily living. Doing independent activities required having physical abilities. Washing dishes required that a woman use her arms for reaching, grabbing, turning, and holding objects. Shelly stated, "Well, at the time, I could still wash dishes because I could reach over and turn the water off and on. See, I can't reach the water to turn it on and off with this weakness." The added loss of ability as the women aged required them to continue to find new ways of accomplishing necessary activities. It also had an impact on the meaning of their gender, which is discussed in the next theme.

### Enacting the Meaning of Gender

Early in their lives, the women recalled being raised to take on traits that had gender implications. The women described their gender-related options for self-expression and the implications those had for their bodies. The women described masculine characteristics primarily as the foundation for their psychological development while they described feminine characteristics as a more complex aspect of their bodies.

Masculine characteristics were described as strength, playfulness, and independence. Janice said, "I was always a tomboy growing up. I think also because of my disability, mother and dad always wanted me to be independent." Jackie and Tabby made similar statements when they said that they grew up as tomboys. Tabby said, "But I guess I kind of prided myself in being tough. You know, well, that may be part of that tomboy thing. My brother didn't want me to be crying, you know. Be tough. You can hack it. You can make it. And so maybe that's part of the difference." Kathy said she was a tomboy that never acted out the typical female roles. She became a pharmacist at a time when few female pharmacists existed. She wanted to be able to care for herself, and she was not sure that she would ever marry. The masculine characteristics enabled her to be strong and independent at a time when she was unsure of her future.

In a similar tone, three women used descriptors, such as "country girl". It was a way of communicating a degree of hardiness and strength in the face of a childhood onset disability. It must be remembered that the women underwent a severe illness where they lost control of their ability to move limbs and/or breathe and swallow. They were also removed from their families where they spent months in hospital institutions. Describing themselves as tomboys or country girls was a way of communicating a survival mechanism within each of them.

The masculine characteristics were a guide to self-sufficiency for these women, but they did not consistently have the ability or permission to do what they wanted. This contradiction did not alter their perception of their masculine traits. For instance, as children, they saw themselves as 'tomboys,' but they were not allowed to play sports, such as kickball, with other children. Their bodies remained impaired, which had cultural meaning, but that meaning did not conflict with the way they described their masculine traits. They described

themselves as tomboys but did not describe any conflict when they were not treated as tomboys.

Instead, the women remembered questioning whether their actions and appearances were appropriate for their female gender. This resulted in a self-appraisal of their actions as being more or less masculine or feminine in nature. For instance, Janice described how she was perceived as too strong a woman, which made work difficult. She said, "But now it's kind of like, and then in the last maybe 10 to 15 years or something, I seem to feel more so where this ego-centered world of men is. They feel threatened because of my strengths." Deborah was told by a work manager that she came across as too strong. In other words, the masculine traits, which enabled her to adapt to impairments, were seen as inappropriate traits for a woman in competitive situations, such as in childhood games or adult work places.

The women also discussed their ability to be compassionate, creative, and nurturing. They described these characteristics as parts of their feminine side, as well as part of their roles as women. These characteristics allowed them to express themselves as women and adapt to changing environments and their changing impairments. For instance, Tabby saw herself as having creative characteristics. She said, "It's cooler for a woman to be creative. I just knitted my granddaughter a cap, a winter cap. I had seen a girl with one similar at Wendy's. It was a cream-colored band with a green frog at the top of the cap and I said, oh, that is cool." Alita described having nurturing feminine characteristics. She said, "I've always been this way and it's too late to change. I think you either are or you're not. I think it's a character thing that you have. Some of us are giving people and some of us are not. Some of us are givers, some of us are takers."

The women felt like they possessed feminine traits, but their impairments threatened their ability to express themselves. For these women, their masculine traits were simply a matter of acting independent, but being woman required that they physically enact and display their femininity. Given their paralysis, this was more of a challenge. In other words, the women saw their feminine characteristics as being enacted through their bodies and the enactment could be altered by their impairments. When they were unable to enact the characteristics, it threatened their belief in their abilities as women. Charlotte said, "I always felt feminine. I always felt like, I didn't have problems that way. I just felt inferior over all." Later, Charlotte described how men would not allow themselves to love her because of her impairments.

I always knew that they did like me or they wouldn't have been asking me out. But then when the deficits started coming up and it became more apparent, they didn't want to date anymore... I mean it's possible somebody could fall in love with me and marry me with this, but you have to get to the point to fall in love. Men, most men that I've gone out with my age and a little older, they don't want any baggage in their life.

Joann said that an impaired body was harder to display as feminine because she was expected to physically enact her feminine characteristics. Enacting feminine characteristics was done by wearing make-up, wearing certain clothing, or wearing high heels. For example, Betty said,

I wanted to wear pretty clothes. I was the chubby, fat one that didn't have a waistline that couldn't wear hand me downs. I would just love to have had their hand me downs because to me they had beautiful skirts and blouses. I always had to wear a dress because I didn't have a waistline and my clothes would tend to fall straight down walking the way I did. So I never...I got new clothes, but I always wanted what they had.

At times, people's reaction to their bodies as they moved reminded them that their bodies were different. Gloria recalled her husband's comments upon first meeting her after corresponding by mail. He almost turned away after being shocked at her appearance. He told her, "Well, you didn't tell me you had braces on both legs and walked with crutches." She responded, "I just thought you'd look at that and not look at the person." It was his mother that told him to "give her a chance. You need to look through those braces and those crutches. See what kind of a woman she is."

Enacting feminine characteristics was described again when they accepted caregiver roles, which were difficult. The act of care giving required physical involvement. Alita described the physical requirements of being a caregiver to her mother, which she attributed to her physical decline.

But it was a lot of picking her up. She fell in the bathroom. I had to pick [her] up. She insisted that she had to take a tub bath. She would get in there, and I kept saying, you can't get out Mom. Once you sit down, I have to get you up. She'd get mad and she wanted to do it. So she'd stand there and then she couldn't get up, so then I had to pull her up. All the things I wasn't supposed to do.

### Gender discrepancies

The women had personal views about what it was to be women, which may or may not have been the way they lived their lives. Tension occurred when the women perceived their lives as contrary to their visions of womanhood. From the theoretical perspective of "doing gender" (West & Zimmerman, 1987), if the women were able "to do" their gender in a way that was consistent with their perceptions of self, then they were more satisfied with their perceptions of self. Given that gender is the "activity of managing situated conduct in light of normative conceptions of attitudes and activities appropriate for one's sex category" (West & Zimmerman, 1987, p. 127), it is clear how conflicts in the ability to manage one's life in a way consistent with one's gender created conflict and ill-adaptive behavior. To clarify the differences between the women's views versus their actual lives, and how that affected their ability to adapt to changes with aging, two examples are illustrated.

Patsy had a discrepancy between her ideal and actual development as a woman. She wanted to be a wife and a mother. She was both. The discrepancy came when her husband left her and her second husband abused her. She had to work and live in a shelter with her children. This was not her view of womanhood. She said that her view of being a woman was one who was married and gave herself to a husband who respected and cared for her.

As far as being a woman, I think a woman should be loved and respected, but I think she needs to be under the umbrella of her husband. She should not have all the burdens put on her. I think that's the reason that God said that we're to be obedient to our husbands and not for him to step on us or slap us around or be our boss, to be our helpmate. I think you're supposed to be as the husband is the head of the house, you're supposed to be in a place of honor. As far as women's rights, yeah. I think we have rights. We have rights to have fresh air. To breathe. We have rights to raise our children in a Godly manner. Do we have rights to our own bodies? To a degree. Bodies are not ours. If we're married, our bodies belong to our husbands.

Patsy adapted to the discrepancy between her life and her idealized view of her gender by pragmatically accepting that her experiences were unlike those that she wanted. She knew that she might never be married to and cared for by a man and that was a continual emotional struggle.



On the other hand, Jackie's life was similar to her view of how a woman should act and be treated in society. Jackie never wanted to marry nor have children. She wanted to have a career and a home. The ideal woman was independent and strong, but able to care for others. She became an army officer.

You don't need a man to, you know, be a woman...I just didn't have the endurance to continue, but I could do everything. But no, I knew I could be self-sufficient. I didn't want children. I didn't want to take care ... I didn't want to cook and clean for somebody else. I don't even do it for myself. I have a housekeeper you know. No. Never.

Jackie could physically perform activities but she lost the energy to continue to do them in a short period. This required that she not only plan-out her daily activities but also her future well-being. Jackie planned her life around her notion of what it was to be a woman.

Then I realized okay, I've got to have a future. I've got to take care of myself. I don't want to get married. What retirement am I going to have? Social Security? Forget that. You couldn't live off of that, so that's when I thought well, okay, military is pretty good. Ten years is the point you either stay in or you get out. Then I realized okay, I've got to have a future. I've got to take care of myself.

Jackie's strategies for adjusting to the changes with aging coincided with her view of womanhood. She had the resources that she needed for healthcare through the military and she said her needs for nurturing were met in her relationships with her cats and her nieces. This view of her gender was balanced with the way she lived her life, and she was satisfied with the way she was subsequently treated by others in society. This congruence resulted in a satisfaction with the way that she was treated as a woman in society.

The themes derived from the interviews of the women illustrate how varied the notion of gender can be among women with disabilities, which reflects the varied ways that gender is enacted among women. Frequently, however, the influence of gender was noticeable in their physical ability to enact their will as women.

## Discussion

Harriet McBryde Johnson (2005) wrote about her experience of aging with a neuromuscular disease that left her "thin flesh mostly vanished, a jumble of bones in a floppy bag of skin" (p. 1). In her memoir, she recalled the natural feeling of having other people's hands on her body, and rejoiced that there were other people available to assist her. She also answered the question most all women, regardless of gendered norms or sexual orientation, answer in some fashion or another:

What am I dreaming of? The sweet untouchable man who sent me one red rose this Valentine's Day, who loves me in most of the ways that I love him, who will be happy for me to tell him about this ordinary everyday awakening, who reminds me that there's more to touching and being touched, more to moving and being moved, than what bodies can do for bodies—and also yes, without doubt, who agrees with me that what bodies can do for bodies can be very very good (Johnson, 2005, p. 251).

Johnson's quote expresses the common desire that she has with other people for some form of pleasurable bodily sensation and romantic interaction. At the same time, the readers are aware that Johnson's body, like many with polio, moved and was moved in a way unique to her impairment. This tension within women with paralytic polio between normality of gendered expectations and their bodies' impairment leaves a sense of unease in social interactions, which is the crux of this paper.

As the women with polio lived and aged with their functional limitations, their social status as well as their beliefs about their bodies was influenced by their gender expectations in the context of their impairments. The women sensed that it took a strong personality to overcome their impairments that prevented them from moving as other women, but that strong and independent self was not always commended for acting that way—it was not always gender appropriate. They used masculine language to communicate their strength, their ability to survive. The need to have one personality that drove their ambition to move and another to interact with other people was notable among these women. This may be emphasized using the classic work of Cixous who wrote, “more so than men who are coaxed toward social success, toward sublimation, women are body” (Cixous, 1976, p. 886). The bodies of women with disabilities are often judged using the harsh rhetoric of medical abnormality.

The way a woman dresses, wears her hair, and walks conveys to others that she is a woman and indicates terms for contact in social situations (Goffman, 1979; West & Zimmerman, 1987). Almost any activity a person performs is judged according to the degree of womanly or manly characteristics that are involved in the action. The meaning assigned to a woman’s impairment for purposes of explaining her body within a culture, may influence her identity, roles, behaviors, and health (Kleinman, 1980). In our study, the types of shoes the women wore made a difference in their feelings of femininity, as well as freedom. Women described feeling excluded from a common experience with other women because they could not wear the same kind of shoes, for these women shoes were part of an expression of gender. The women did not discuss this in relation to canes or wheelchairs, only shoes. We posit that shoes were important because they bonded women with other women in society—a shared femininity—where other accommodations, such as canes and wheelchairs, only separated the women with disabilities from other women in society. The ability to use a more feminine cane would not make a woman with a disability more like other women.

Attitudes toward women with disabilities may be affected by how well they demonstrate their gender (Weisel & Florian, 1990); at the same time, the way women feel about their bodies may be influenced by how people interact with them. For instance, this dual nature of interaction can be noted when Charlotte stated, “I always knew that they did like me or they wouldn’t have been asking me out. But then when the deficits started coming up and it became more apparent, they didn’t want to date anymore.” It is within a culture that a person learns how to be a woman and others learn how to interact with her (de Beauvoir, 1952/1974). Yet, the rules for being impaired and being a woman are not clear. The ambiguity about socially appropriate womanly behavior left the women questioning how they were perceived. But they did not question the gender-related standards they were trying to achieve, which might reflect their age cohort.

One question that emerged from this analysis was related to the extremes of gender performance. We questioned whether the performance of femininity for women is as physically restrictive in our society as the performance of masculinity is for men. For instance, Betty exemplified many of the women’s discussions about their physical inability to enact their gender with shoes and clothing, as well as physical displays of femininity. Patsy exemplified the problem women had if they tried to hold feminine values that placed them as subservient to the needs of others. Clearly, the women adapted to the way that they were viewed and responded in a way that was commensurate with the resources society provided. Despite their values regarding femininity, women had to act in their best interest.

This is similar to the way that men, described by Smith and Sparkes (2008), had to adapt to their spinal cord injuries despite their views of gender or suffer the consequences of not doing so. According to Smith and Sparkes (2008), an *infiltrated consciousness* can damage a

man's body, identity, and emotions when he allows the negative and oppressive views of others about his condition to color his awareness of the world. As an example, they presented a case of a man with a spinal cord injury due to a sports-related injury. He internalized the negative views of others and decided that he would never be a good father or employee due to his injury. If women did not adapt they would suffer from a mismatch between beliefs and societies' response to them. We acknowledge that gender related beliefs are diverse and when the body is changed, it is unclear how it will affect the performance of gender and subsequent adjustment apart from sexual orientation or biological sex. It is clear that gender-related beliefs have implications for roles and activities of both men and women.

At no time during the interviews did gender lose saliency. Aging with disability from early in the life course did not infer gender neutrality, or androgen characteristics. At times, it conferred cumulative gender dissatisfaction, while in other more optimistic times, it conferred satisfaction. Further studies of the cumulative strain of discrepancies between gender expectation and treatment are needed. The dissatisfaction that women may feel with their gendered treatment may have long-term consequences for health. Our results indicate that it had effects on responses to life choices. Future research might also focus on the satisfaction that a woman has in the way that she is treated as a product of societal interactions and health outcomes.

It has long been theorized that women with disabilities may feel stigmatized due to a self-image that is in conflict with how society views women (Goffman, 1963). Feeling stigmatized has been reported to lower the self-esteem of women with disabilities and subsequently influence their ability to perform social roles (Nosek, Hughes, Swedlund, Taylor, & Swank, 2003). A woman is affected by how people see her and respond to her over time (Blumer, 1969; Goffman, 1963). Despite reporting discord between their sense of self and their sense of gender expectations women in this study did not report lower self-esteem or dislike for their bodies. In retrospect, they reported these feelings during adolescence and young adulthood. Respondents frequently discussed their adaptation in later years, treating the discrepancy as a fact of life, something they had grown to accept with time. According to Furman (1997), older women experience a systematic devaluation as they age. They are devalued as their hair turns grey and their bodies lose strength and agility. Perhaps the women in our study had aged into a period in their lives where they found commonality with women who were aging into disability.

The ways in which women "define and manipulate the symbols of femininity vary in accordance with evolving patterns of class" (Gill, 1993). Further, when people seek assistance from the health care system they are restructured into the status of a patient not by their symptoms but by their interactions with health care providers (Lorber, 2000). According to Lorber, men's complaints get more attention than women's from health care providers. Thus, there could be a survival benefit to the identification with a man's experience within the health care arena. The women in this study who survived from childhood with disabilities due to polio may have perceived that describing masculine traits produced a better response from health care providers.

Regardless, the gendered expectations of women with disabilities are similar to women without disabilities because they are living within the same society. The difference, however, may be in their ability to enact the norms associated with their gender, whether it is in the type of shoes they wear or in the type of tasks they perform. When gendered expectations and perceptions of treatment do not coincide, women perceive negative outcomes. When the women's lives coincided with their gendered expectations, the impact of their impairment on their lives was perceived to be minimal. This has implications for

policy and the allocation of resources to foster the well-being of women as they age with impairments.

From a public policy perspective, the integration of the needs of women aging with disabilities into larger women's health and social rights movement is needed. When we discuss the needs of women, the needs of women with disabilities should automatically be part of that discussion. When we relocate the needs of women with disabilities into the realm of "other women", we neglect the embodied experiences and expectations that come with being a woman and aging in everyday society. It is also probable that we ignore the reality of our current U.S. society when women with disabilities are discussed separately from the needs of women in general. After all, over 25% of low income mothers and 50% of Temporary Assistance for Needy Families (TANF) recipients have disabilities (Loprest & Maag, 2009). Granted, women with disabilities, such as polio, may have unique needs within society. We suggest that women without disabilities and society in general must broaden their views of how women's bodies experience the world and demand attention and equal services for women with all levels of ability at all ages. The same gendered expectations influence the lives of both women with and without disabilities; women with disabilities may just have more difficulty meeting those demands due to one-dimensional views of the female body.

To advance our position on the combined efforts of women for the good of women with and without impairments, the concept of positionality as posited by Alcoff (1997) is useful. Within this view, the woman is not an essentialist being, but a socially constructed person that has been defined by her from within the socio-historical context that situates her. The woman is defined by her perception of womanhood combined with her culture's influence on her perception set within an evolving point in time, not by her anatomy. This definition of woman emerges as a position from which to take action as a united group.

Alcoff's use of positionality (1997) along with Young's description of a social collective (Young, 1994) is important for use in this argument for women's solidarity for better treatment in society. To understand women in relation to a collective without placing them into a category of common attributes, such as a vagina with two moving legs, Young (1994) used Sartre's 'serial collectivity'. This work described how women, who are a series, might combine as a group over a self-conscious purpose that unites them. This would be independent of their separate identities of race, sexuality, or abilities. Through this analogy using Sartre's serial collectivity (Young, 1994), women could become a group combating a problem, such as those experienced by women aging with paralytic polio.

The problem is that when a woman with polio is denied access through a front door or fondled when fitted for a leg brace, a woman without a disability may not take this as cause for social action. It may not be until she ages into disability and is limited by both gender and disability that she understands the experience. She may not understand the commonality in gender that women share regardless of their bodies' abilities. The number of barriers faced by women with disabilities compared to women without disabilities are considerable (Chevarley, Theiry, Gill, Ryerson & Nosek, 2006). Using the concepts of positionality and serial collective, we assert that women without disabilities and women with disabilities might be viewed as one group with common interests in certain domains of social rights. These domains could unite women to help one another to overcome common health and social problems. These could include discrimination, healthcare, and abuse. However, if women do not recognize their commonality of experience, the serial based on positionality may not unite women.

Given that all women may not recognize their common struggle based on discrimination, abuse, and healthcare access, we propose that the key to binding women with and without disabilities in social action is an emotive response based in feelings and understanding, which can be highlighted through the use of phenomenological methods. According to Waldenfels (2008), feelings orient us to our position in the world and motivate us to action. The goal of this phenomenological work would be to arouse emotion and motivate to action. Through the use of phenomenological methods detailing both the commonalities and unique struggles that women with polio encounter, other women with and without disabilities can join together to create social change in domains of common interest.

This study was limited to the experience of these women aging with paralytic polio, a childhood onset disabling condition. The experience of women with other conditions and possessing varying beliefs regarding gender norms may report different experiences. Moreover, women with later onset impairments may report different experiences with gender. Men have not been involved in the development of this research, which would strengthen its theoretical foundations. Future work is planned to explore the impact of disabling conditions on gender from the perspective of men aging with childhood onset polio. Further, this work was limited to women between the ages of 55 and 75 years. Work exploring the impact of gender satisfaction on various age cohorts of women is needed.

## Conclusion

Women aging with early onset paralysis related to polio were interviewed to understand their experiences of gender. This hermeneutic phenomenological study was part of a qualitative dataset collected on the experience of aging with an early onset disability. Overall, the women in this study reported diverse expectations of how they wanted to be treated in society, which had implications for their satisfaction with how they were treated. When their expectations met their perceived treatment, they expressed more satisfaction. Perhaps the essence of gender is in the control of its expression. Women aging with paralytic polio had similar gender expectations as women in general. Women aging with polio were not foreign to the human experience. They were part of it. Reworded, being judged and excluded from how they wanted to enact their gendered beliefs was hurtful to them. We think that could be universal—or speak to many women's experience. Policies that include their needs within the needs of women in general might have the most impact for social change.

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**Table 1**

Demographic characteristics of women in study 1 (N=25)

Age	Mean 59.44 years Std Dev. 3.02 Range 55 to 65	Marital Status	Married: 16 (64%) Single: 5 (20%) Divorced: 1 (4%) Widowed: 2 (8%) Separated: 1 (4%)
Ethnicity	Anglo 20 (80%) Hispanic 4 (16%) African American 1 (4%)	Children	Yes: 17 (68%) No: 8 (32%)
Type of Polio	Bulbar 1 (4%) Bulbar-Spinal 6 (24%) Spinal 17 (68%) Unsure 1 (4%)	Employment	Retired: 9 (36%) Unemployed due to disability: 10 (40%) Employed: 4 (16%) Unemployed other reasons: 2 (8%)
Age of Polio Onset	Mean 5.24 years Std. Dev. 3.95 Range: 3 months to 13 years	Post Polio	Yes: 22 (88%) No: 3 (12%)
Length of Time Hospitalized During Infection	Mean: 8.44 months Std. Dev. 16.11 Range: 0 to 72 months	Current Assistive Device Use	Yes: 22 (88%) No: 3 (12%)