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A Qualitative Analysis of Life Course Adjustment to Multiple Morbidity and Disability

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Abstract

The accumulation of limitations over the life course requires that women re-adapt to environmental barriers that they encounter over time. The purpose of this qualitative case study is to detail the life experiences associated with living with mobility, cognitive, and sensory loss experienced by a woman and her sister who participated in an on-going ethnographic study of mobility impairment in women. In-depth interviews were subjected to thematic, life course analysis. A family case study was interpreted as an exemplar for aging with early onset disability into multiple morbidity, which was described as a series of loss, recovery and re-engagement. Within the case study, the participant suggested that because her functional limitations were not accommodated earlier in life due to societal and family level disadvantage, functional limitations were more difficult to adjust to in later years.

Multiple morbidity, defined as having more than one illness with a focus on the total burden of impairment (Boyd, Ritchie, Tipton, & Studenski, & Wieland, 2008; Schoenberg, Kim, Edwards, & Fleming, 2007), has shown a steady increase in individuals in the U.S. over the age of 65. From 58% to 65% of American seniors have multiple morbidities according to 1998 and 1999 data (Wolf, Starfield, & Anderson, 2002). As of 2002, that number increased to 70% (Schoenberg et al, 2007), representing an average of 2.2 chronic diseases each among people over the age of 60. Among the population as a whole, 63 million Americans —23% of the population—report multiple morbidity (Vogeli et al., 2007).

For many women, morbidity leads to functional limitation and subsequent disability; over time this may evolve into multiple morbidity, which may take place in the context of disadvantage. Currently, beginning at age 18, women report significantly more disability over the life course than do men, with a prevalence of 24% and 19%, respectively (Brault, Hootman, Helmick, & Theis, 2009). Based on 2004 U.S. Census Bureau data, 12% of women age 18 to 44; 26% of women age 45 to 65; and 45% of women age 65 and older reported a disability—an accumulation of over 26 million women (Brault et al., 2009). When these numbers are examined more closely, of women 16 and older, 4.2 million have sensory limitations, 11.7 million have physical limitations, and 5.5 million have mental limitations, which results in 3.7 million women being unable to provide self-care and 7.9 million having difficulty going outside of their homes (Waldrop & Stern, 2003). Women with disabilities in the National Health Interview Survey have also reported less access to health care screenings, such as Pap smears and mammography, as well as medical and dental care than women without disabilities (Chevarley, Theirrry, Gill, Ryerson & Nosek, 2006). Further, people with disabilities have a significantly higher proportion of poverty

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than do their nondisabled peers; almost 9 million people with disabilities in 2000 reported low incomes. Among people 16 to 64, the low income rate among those with disabilities was nearly double that of those without disabilities (Waldrop & Stern, 2003). Among those unable to work, over half reported combined sensory, physical, or cognitive impairments.

The terms impairment, functional limitation, and disability were conceptualized based on Nagi (1965) and Verbrugge and Jette (1994) where the disablement process was defined as an avoidable path from an injury or pathology to the experience of being disabled. Impairment is medically defined cellular injury or deviation from what is considered normal organ system(s) function. A functional limitation is loss of the ability to carry out physical activities such as talking or watching. Disability is perceived inability to perform socially roles such as mother, and/or employer. From this perspective, it is theorized that each woman assesses her environment and interacts with it to achieve and enact roles (George, 1980). Because women with disabilities may be able to interact within their environments to create or change roles and/or modify the associated status of their roles, neither impairment nor functional limitation necessarily leads to a disability. According to Verbrugge (1990) the current statistical measurement of disablement misses information relevant to the socio-cultural context in which disablement occurs. An understanding of disablement is incomplete without information on how disability it is defined, experienced in socio-cultural context, and environmentally accommodated (Jette, 1995). This paper adds to this theoretical discussion by addressing the experience of multiple morbidity as accumulated over the life course.

The purpose of this paper is to describe two sisters' experience of managing multiple morbidity and functional limitations from a disablement perspective using a life course approach. In this paper, a glimpse is provided into the lives of two sisters living with multiple functional limitations due to multiple morbidity. We trace the life course of a woman with an early onset visual and mobility impairment due to multiple morbidities, along with that of her sister who aged into cognitive and mobility impairments later in life. We posit from a life course cumulative disadvantage perspective (Turner &Lloyd, 1995) that the onset of functional limitations in early life required continued and novel accommodation over time, and the success of the accommodation depended upon the environment and evolving needs of the woman. The manner and perceived success in which previous functional limitations were addressed over time accumulated to influence how functional limitations impacted the woman's life in later years.

Background

Having an early onset disability may create a position of inequality in American society and set women up to accumulate multiple diseases and disadvantage over time (XXXX, 2005). Early onset disability is defined as a permanent functional limitation prior to the age of 25 (XXXX, 2010). Women with early onset disabilities have reported the accumulation of disease at a faster rate than would have been the case had they aged without an initial functional limitation (Campbell, Sheets, & Strong, 1999). For example, women age 55 to 75 who aged with paralytic polio prior to age 14 described how their life course trajectories were affected by early onset functional limitations; role expectations taxed physical reserves with age despite significant and profound life accomplishments (XXXX, 2005). The women accumulated multiple diseases and functional losses with time, well before expected and well before retirement benefits were in place to support their needs (XXXX, 2006). The women with paralytic polio also described how the accumulation of functional limitations drove the women to the point of losing multiple roles as they aged. After all, as limitations increased, so did the challenges associated with managing daily life.

Women with *any* early onset medical diagnosis may be at risk for functional limitation leading to disability, not just those with paralytic polio. Several morbidities, including arthritis, cancer, diabetes, stroke, heart attack, and hip fractures, are all associated with the development of disability in women (Fried, Bandeen-Roche, Kasper, & Guralnik, 1999; Marengoni, et al., 2011; Markides et al., 1996). Moreover, when multiple pathologies create a situation of multiple morbidities, it is unclear which disease, if not all of them combined, may be causing the impairment, functional limitation, and/or disability (Steinhauser, et al., 2011). In this context, women may focus as much or more on managing multiple functional losses as on managing a specific disease process.

Aging with early onset disability from a life course cumulative disadvantage perspective provides the necessary lens through which to see how varying disadvantages in childhood and throughout life impact a person's psychosocial, physical, and biological outcomes (Ferraro & Shippee, 2009; O'Rand & Hamil-Luker, 2005). When one examines cumulative adversity throughout the life course, the focus is on the impact of events in the lives of individuals (O'Rand, 1996). Various adversities, unevenly distributed throughout society, can have an impact on an individual's health and well being (Hatch, 2005). Among these adversities are socioeconomic conditions such as poor living conditions, poor nutrition, and environmental exposures, as well as decreased health care access, abuse, and many other stressful events that may negatively affect the mental and physical health outcomes of elderly and disabled populations (Hatch, 2005). The effects of adversities accumulate over the life course and affect the dispersion of resources needed for a person to attain positive social standing (Hatch, 2005).

It is theorized that how women adapt to an early onset disabilities may influence the accumulation of adversity throughout the life course. Building on feminist perspectives on the disparities within the family, we posit that basic organizational characteristics of the family that were suggested to create women's subjugation (Firestone, 1997) may also impact women with disabilities. As originally described by Firestone (1997), the biology of the woman's body with associated illness and reproductive roles, the helplessness and dependency of the human infant on adults for survival, the interdependency of the child on its mother for psychological nurturance, and the division of labor creating a class structure all combine to impact women with a disability within the family and society. For instance, how the family and society respond to the infant girl with a disability and nurture her towards independent living using appropriate resources and skills to manage functional differences may impact future functional losses, or even perhaps, may prevent future losses over time (XXXX, 2010).

How women experience the accumulation of multiple functional losses over the life course has not been fully explored because the primary focus of research has been on disease; hence, this qualitative case study will add to the burgeoning dialogue on multiple morbidity by exploring the experience of managing multiple functional limitation and disability in the context of the family and society at large. It is from this perspective that a family case study, which includes two sisters with mobility impairment, is presented; the impact of aging with an early onset functional limitation and the accumulation of disadvantage from within a family are analyzed.

Method

The following analysis is based on data from a mixed-method ethnographic study designed to investigate reasons for health disparities in disablement outcomes among Mexican American women as compared with Non-Hispanic White women, while realizing that disparities in health and social outcomes may occur for all women with disabilities. After approval from the local IRB and the receipt of a certificate of confidentiality from the Department of Health and Human Services, recruitment was begun throughout the state of Texas targeting women known to the investigators and social agencies that provide services to midlife and older women with mobility impairment (XXX, 2011). Recruitment fliers with the office toll-free number were sent to agency leaders and to women known to the investigator, along with enrollment cards and stamped return envelopes. If a potential participant made contact with the office, a bilingual research associate would contact that person to screen for eligibility based on mobility impairment, age, gender, and ethnicity.

As of this analysis, the study was ongoing; 122 women enrolled for a total of 444 interviews on the experience of living with mobility impairment. The women (n = 60 Mexican American; n = 62 Non-Hispanic White) were followed over the course of four interviews per person. Each woman completed a demographic questionnaire and quantitative measures of impairment, function, disability, depression, and pain prior to the first interview. Thirteen of the women chose to complete the interviews in Spanish while all other chose to complete the interviews in English. At the first interview, a life history calendar was completed with a focus on time spent within the domains of impairment, functional limitation, and disability over the life course. During the next three interviews, the women discussed their experience of aging with disability and the use of accommodations, which were brought forth via topical biographical interview techniques (Nydegger, 1986). For instance, the women were asked to comment on their first experience around a person with a disability. And they were asked to discuss their first memories of disability in their own lives. Field notes were written at each interview and observations were made in the community and home where participants resided.

A total of 15 out of the 122 women who participated in the ethnographic study reported an early onset functional limitation; they indicated the loss of functional ability prior to the age of 25 (range birth to 23 years.) Their current age ranged from 59 to 74. Of these women, 5 were Mexican American and 10 were Non-Hispanic White. On average, using data calculated from their life history calendars (Scott & Harrison, 2011) the women reported spending 73% of their lives with a functional limitation, 83% of their lives with an illness, and 60% of their lives with a disability that prevented them from fulfilling a significant role in their lives. The women completed 3 to 18 years of education, and 33% were currently employed. Reasons for their early onset limitations included juvenile rheumatoid arthritis, depression, spinal muscle atrophy, paralytic polio, epilepsy, spinal cord injury, leg injuries and hypoxia with resulting neurologic involvement. The narratives of these women served as a guide for the interpretation of the experience of aging with a disability.

Two participants were selected to serve as exemplars for this family case study of aging with a disability and the accumulation of multiple morbidity. They joined simultaneously. They had learned of the study from the Area Agency on Aging. They were interviewed in their home four times each by the first author for a total of eight audio taped interviews. Each interview lasted 1 to 2 hr each. Consistent with the recommendations for flexibility in the make-up of qualitative family interviews (Beitin, 2008), the women were given the option to bring in their sibling during the interviews; the first two interviews with each woman were done with a focus on the individual sibling but both sisters were present. The third and fourth interviews with each were done alone with each sister. All eight interviews were done by the same interviewer. This provided both a joint and individual narrative of the family experience with disability.

The sisters presented for this analysis were selected because they exemplify the life course accumulation of multiple morbidity and subsequent disability in the context of family and social position. Their experiences provide knowledge about the issues surrounding disability that can be transferred for the purposes of assisting the lives of others. After all, it is unclear how widely known it is that disadvantage may accompany aging with disability, given that only 8 of 22 topics for measuring disparity domains defined in Healthy People 2010 included measurement of health disparities based on disability status (Truman et al., 2011).

Data Management and Analysis

The demographic data, observation fieldnotes, and narrative interview data from the two participants were used for an in-depth family case study of multiple morbidity over the life course. The tapes were transcribed verbatim into word documents, and the transcripts checked for accuracy by comparing them to the audio tape. A total of 459 double-spaced pages of transcribed data were produced from these eight interviews. The demographic data and narratives from the 14 other women with early onset disabilities, which included 56 interviews, were read, reread and coded for the purposes of understanding the patterns of multiple functional losses over the life course.

Consistent with the life course approach used, the family methodological assumptions included the belief that childhood experiences influence life course trajectories, which can be understood through in-depth interviews (Handel, 1996). Although the majority of family qualitative studies focus on marital or parent child relationships (Handel, 1996), this study was designed to capture how early onset impairment affected the lives of two sisters who depended upon each other. The case study was intended to contextualize the phenomenon of multiple functional limitations within the family and society for which it occurred (Yin, 2009). Consistent with an in-depth, descriptive approach to case study (Heidegger, 1962; Hentz, 2012; Yin, 2009) this study was designed to offer an understanding of how a family member experienced an early onset disability and how her subsequent accumulation of limitations were managed within the family. Heidegger’s position that a person must move out of sensory perception in order to understand he or she is truly present in the world framed the analysis. Movement is necessary for ontological understanding. With this in mind, the following steps were followed by two researchers (T.H. and J.T.) with the remaining researchers providing analytic insight into the analysis and discussion of findings.

1. The text was read as a whole for each sister.
2. The text was reread for meaning units based on developmental time periods and content. Then all text was coded in the margins based on content and developmental time period—childhood, adolescence, young adulthood, adulthood, and now.
3. The text was cut out and sorted according to developmental time period.
4. The data were sorted within developmental time periods into like categories.
5. Within developmental time periods, like categories were pulled together into themes for the first participant and then for the second. Themes were integrated based on coinciding developmental time period. Resolved complexity in experiences between sisters’ categories drove final theme development. In other words, the main thrust of the sisters’ combined narratives was resolved by understanding the main focus of combined voices.
6. Exemplars of themes and descriptive data were pulled from the field notes to supplement thematic analysis of the interview data.
7. Text from the 14 other participants were read and reread in relation to the accumulation of multiple functional losses.

8. Patterns of loss and accommodation were coded to assist with understanding the total experience.
9. The sisters' experiences were interpreted based upon the larger experience and their lives provided as an exemplar of that experience.
10. The names of the participants were changed to pseudonyms, and any identifying information was removed.

Findings

The findings of this case study, drawn from an ethnographic exploration, are presented in three sections. The setting and the sample are described first. These are essential for establishing the context of the narratives for the purpose of aiding in the interpretation and transferability of the findings. Next, the thematic analysis of common themes detailing childhood to present day experience is sequentially detailed.

Setting—Lucille and Jocelyn lived in a single story, 1920s style farm house. It was grey-white with paint chipping off the sides of the house, which is not uncommon in this area of Texas. Lucille said the house could get very cold because "the walls were plywood over bare boards to the outside." The lot on which the house sat consisted of 1.6 acres of land where a few of their goats could be seen grazing. There was a ramp leading up to the large porch where various items were scattered, including a grocery store cart, a wheel chair, potted plants, and boxes full of items to donate to the church. A van was parked half-way into the dirt drive and half-way into the dry, yellowing grass that surrounded the house. It was the start of summer in Texas, very little few plants remained. Once entering the house through a screen door, the inside consisted of a 1920's style antique chaise and a chair facing a fireplace. This is where the interviews were held.

Jocelyn and her sister were unemployed. Lucille, due to her longer work history, had acquired more financial resources despite less education, and she had bought their home with the sale of her condominium. Jocelyn did not have any resources; she qualified for Medicaid. Jocelyn's income was less than $10,000 per year. She and her sister had a combined household income of less than $25,000 (They lived in a small town of approximately 1,500 people where the median income of this rural area per household was $40,000.) The town where they lived did not have a doctor's office, a grocery store, transit service, or a social security office. The town was located in one of 80 Texas counties that experienced a decline in life expectancy for women from 1997 through 2007, which resulted in an average longevity lower there than what is reported for women in Estonia, Mexico, Cuba, and Albania (Roser, 2011; Kulkarni, Levin-Rector, Ezzati, & Murray, 2011). The following will describe the women included in this analysis by detailing the demographics and descriptive disability of each sister.

Sample—Lucille was 61 years old. She was of white race with graying blond, curly hair. She was 5 ft 2 in. tall and weighed 222 lbs. She moved slowly due to chronic back and leg pain and used a mobility cane and occasionally a walker. She said she had been diagnosed with arthritis, diabetes, and moderate kidney damage from long-term non-steroidal anti-inflammatory drug use. She also said she had a knee replacement and several back surgeries. She said she was unable to stand for 20 min, bend from a standing position, walk a quarter of a mile, or climb stairs. She said she had been incontinent since a hysterectomy was done in her mid 20s. She said she was unable to pull trash out of the can, mow her lawn, wash her dishes, hang up her clothes, or make her bed.

Jocelyn said she was 57 years old. She was of white race with blond, straight, short hair. She was 5 ft 5½ in. tall and weighed 250 pounds. She spoke of having a Bachelor's degree in English literature and a technical writing degree. She reported she had been divorced twice. She said she had been through menopause and never had children. Jocelyn said she was also visually impaired, and had lived with narrow angle glaucoma and optic nerve atrophy with associated visual loss since birth, which she characterized as legally blind. She said she was diagnosed at age 10. Jocelyn had reportedly lost abilities to perform many activities independently by age 35; up until that point she said she had been able to compensate for her vision loss and prevent further loss with the use of daily marijuana. She described herself as legally blind since childhood. Before moving to this rural region, she described frequenting known dealers in the urban area where she lived in order to obtain free marijuana. Once she decided to leave her husband, who she said abused and neglected her for being visually impaired, she believed she also left her marijuana contacts. Afterwards, she described losing all vision.

Themes—In order to portray the sisters' experience of living with multiple morbidity and functional limitations, we will briefly explain the major themes (Table 1) of their lives as they conveyed them from childhood to the present. Overall, the themes build to describe the sisters' perceptions of multiple morbidity and functional limitations, which was described as a series of losses, recoveries and re-engagement. Each loss of ability within a new functional category (e.g. sensory, mobility, cognitive, emotional) was unique and required a new skill set to manage. An exacerbation of a previous functional limitation was not the same experience as a new functional limitation. The tools for the management of an exacerbation were learned and in place. The tools for the management of a new functional loss were not yet established. In this case, acquiring a new functional limitation, while simultaneously managing or trying to cure prior limitations, was difficult to manage in the context of limited resources. The choice of how to adapt was critical along every step of the life course.

Childhood (~1953–1965)

Limited and Unwanted

Jocelyn and Lucille were "raised a very puritanical Christian by a mother who was a Nazarene and a daddy who was of the Church of God." They were taught "no smoking, no drinking, no dancing, no nothing. No cards, no swearing, and you didn't cut your hair, you dressed very modestly." Lucille stated that they "were raised like depression kids." They worked on the farm and ate what they raised. Lucille's memories were scattered, but Jocelyn's memories of childhood neglect were vivid.

Growing up, Jocelyn slept in a dresser drawer. Jocelyn said that her mother had "gotten rid of the crib. I didn't have a high chair because she had gotten rid of it, because she thought she had gone through menopause and she couldn't get pregnant." Later, when Jocelyn was discovered to have limitations to her senses, her mother ignored it because she believed that such problems could be attributed only to sin, and, if present, could be overcome by faith. Jocelyn, however, could not smell, and she had limited sight. In response, her family did not recognize her unique needs and often left her unattended. At the young age of 3 years, she drank a large amount of kerosene. She said, "I basically died. I can vaguely remember them making me vomit. I wasn't breathing and I basically died. And I remember coming back into my body—I didn't want to. It hurt!" To sum up her childhood, Jocelyn paused and said, "So you know, talk about your unwanted child."

Reconstituting Family

In response to Jocelyn's poisoning, Jocelyn said Lucille was "put in charge of me [at] about three or four years old to make sure I didn't get in trouble, I didn't get lost, or I didn't fall off the neighbor's porch and hurt myself anymore or pull something off on my head. She was kind of made responsible for me." Lucille said they "were a team" and had become Jocelyn's "sighted assistance to help me do my, my work. And uh, I was expected to work. It's just that, you know, sister [the nickname Jocelyn was given] needed more help." Jocelyn recalled going to Lucille for help more often than to her mother. She had developed an altered dependence on Lucille, who was only 4 years older than she.

Passing for Sighted

Jocelyn said, "My mother had this hard time accepting it. And so she'd say, "I'm not raising you to be a blind person. Well, I was, but I wasn't. You know what I mean? Put a lot of pressure on me." After all, she said, "it was a shame. It was a shameful thing. And she'd say, you're not blind, you just don't see very well." From this, Jocelyn learned to pass for sighted. Passing, however, left her feeling alone. It limited her abilities because she had to pretend that she was the same as everyone else. Passing encouraged self-neglect. Jocelyn had to claim a visual impairment to gain help with that impairment. Lucille was her only accommodation. She said, "I grew up just limiting myself to what I could accomplish on my own. It definitely limited me, socially and physically."

Adolescence (~1966–1975)

Finding their own Way

Jocelyn recalled that during her childhood she was kept away from mainstream culture. She referred to herself as a "straight arrow," an adolescent who did not represent the counter-culture of the 1960s. Instead, she thought of herself as someone a viewer might expect to "walk out of the 70s show *Little House on the Prairie*". She stated, "Between me struggling to do my schoolwork and being considered kind of a weirdo because of the way I dressed, and you know, in the sixties the psychedelics … I did not fit in." Lucille, on the other hand, described herself as a "farmhand" who smelled like "cow poop," someone she thought the opposite sex did not find attractive. In reaction to these feelings of estrangement from the world and a desire to fit in, Jocelyn said she left home at 18 and Lucille said she married the first man who came along. Jocelyn said,

> And see I fought this all my life this idea of my life being limited by my blindness. It is why I left home at 18 because I knew if I stayed at home I would never go anywhere, I would never do anything, I would never go to school. I would live out there on that farm and take care of mother and daddy and that would be it.

Young Adulthood (~1976–1983)

Just out of Reach

The two sisters were separated from their family of origin, including each other, during their young adulthood. Although this time was described as full of promise and many dreams, they were just out of reach for Jocelyn. While Lucille was establishing a family, a joint business with her husband, and a "wonderland of a home," Jocelyn was struggling to become educated and employed. She had been a nurse's aide in high school, but because of her vision she was not accepted into nursing school. When she went to college, she received a Bachelor's degree in English. After graduation, Jocelyn was eager for employment. She wanted a job working for a magazine. She said, "the only job I could get is in classified advertising, answering the phone and taking ads. Well, I thought okay, it's a job." She wanted to further her education by gaining a graduate degree, thinking life would improve with advanced education, but her loans had defaulted because of nonpayment. Her job paid poorly. She couldn't afford tuition without more student loans. Social relations were also difficult. She said, "I often offended a lot of people because they thought I was terribly rude because I didn't see them. Because they were fifteen feet away. 'Well, I waved at you but you didn't. You were looking right at me.' It's because I didn't see them." Jocelyn viewed life's benefits as just out of reach.

Adulthood (~1984–2005)

Looking for the Cure

Jocelyn tried to cure her blindness throughout most of her adult life. Her worst vision was in her left eye. Each time her left eye worsened, however, her right eye would worsen 6 to 8 months later. Researchers offered therapies; she said she enrolled in too many experimental studies to be remembered. Doctors offered surgeries, a total of four on one eye. Of the treatments she said,

> And sometimes I'll think, you know, when I used these real bad medicines I used to have to wait for the, the effects would make me blind. They'd take away, make my vision so blurry I couldn't see, so I'd have to wait until I got to where I could see better. And sometimes I'll think, I better not wait, what are you waiting for?

By the time of the last reparative surgery she said she was left with what she described as a "peephole." Through it, she said, she "could see like across the street but I couldn't see my hand." The peephole closed when she was 49 years of age.

Fighting Adversity

Many battles were fought by the sisters, the same fights many women have known. While Jocelyn was battling her vision and abusive relationships, Lucille was battling to overcome depression and to maintain a family and employment in the face of worsening mobility. After the birth of her son, Lucille experienced the onset of postpartum depression, which she said left her unable to care for her son. She also said she had difficulty maintaining relations with her spouse due to an infected episiotomy incision. And it was "not too long after my son was born I had a prolapsed uterus. And it was sticking out my bottom." She said, "We'd have sex but it, it really hurt. And, finally went ahead [crying] and had it taken care of, but by that time, it wasn't 6 months to a year after that. Everybody in the neighborhood knew it but me, the old story": Her husband had an affair and asked her to leave. He kept their home, business, and son. She recovered and began anew as a secretary.

Over the ensuing years, Lucille said her battle with depression never abated. Instead, it was made worse by osteoarthritis of the knees, a series of car accidents, and work place injuries, which left her functionally limited with chronic pain. She had multiple surgeries to maintain function. Eventually, she said she was forced out of her job by supervisors who viewed her injuries as trivial. On one memorable occasion, she said she was called into her boss's office to defend her physician's determination of workplace functional limitations. She said, "They kept pushing me and pushing me and pushing me. They made me feel like I really wasn't needed. So, I left."

Meanwhile, Jocelyn had married two men, one at 19 and the other at 35, both of whom were abusive. She said of her first husband, "The blinder I got, the worse he got." She found no support from him. She said, "And my husband came to pick me up from that appointment and I said, I told him what the doctor had said. I was, of course, very upset. She said he pulled over to the side of the road and he said, 'well, that just cuts it. I'm not going to put up.' And he left that night, and moved out. He left me. He left me." She said her second husband could not tolerate her vision loss either. She said he pushed her down stairs and refused to tell her when obstacles were in her path. And as her vision worsened, she thought, “and I was going through this vision thing. And I was losing my sight, bad enough, but I’m having to deal with this man that can’t handle it.” She said her husband thought she faked her blindness for attention. She quipped, “I’d say who would want to get attention falling over a newspaper rack. That doesn’t make any sense to me.” She said, “You don’t get mad at me because there’s a stain on your shirt that I didn’t see, because I can’t see it.” She described herself as desperate and nervous. She said she was losing the last of her pinhole of visual light and she said, “I want to do it in peace.”

When Jocelyn decided to leave her spouse, she said she made the decision to give up all expectation of vision. With the separation from her spouse, she abandoned the lifestyle that enabled her self-treatment with marijuana. Despite the prescription she carried with her, she knew it a risk. Although in the city she had access to a medical marijuana society, she no longer had that in the rural community. She feared arrest and marijuana contamination with other drugs. Further, financially she couldn’t afford it. She laughed, “It’s like, what if I get busted, the blind lady and her dog. Do I get to keep my dog?” So, she stopped the only therapy she believed maintained her vision and relieved her ocular pain. She said, “And when I moved out here, I also made a choice to get out of that life, that type of hang-out people that had access to that [marijuana] and a lot of good friends, and I just had to just, kind of ride off, because he was part of that life.” In the end, she said, “I just wanted completely out of those connections and that kind of sneakiness because I’m not a sneaky person.” She said she chose to live with her visual loss through accommodations.

Now (~2006–2010)

A Cascade of Illness

Not long after moving to the rural community, both sisters’ health and function worsened. Lucille described worsening problems due to acid reflux, a cholecystectomy, two knee replacements for osteoarthritis, neuropathy in her feet, worsening vision, and bilateral carpal tunnel syndrome from years of typing. She stated that her knees continued to ache after knee replacement surgery and that had it not been for Jocelyn’s assistance when she was confined to her bed, she would have perished. Lucille stated, “It takes me a long time to just go get a glass of water from the table or I have to ask my sister who is blind to get it for me.” Jocelyn, however, was also ill. She was diagnosed with colon cancer, diabetes, and congestive heart failure. A year earlier, she was gravely ill and hospitalized with sepsis. She stated, “Well, I used to say every time I’d go to the rehabilitation center for the blind, I’d come home and think, ‘ Oh, I’m so glad my life isn’t like that! Cause they all had these multiple health problems and usually people just aren’t blind, they’re blind and two or three other things’ which I am now.”

Loss of Resources

The sister’s lives were not as they had hoped. Although the cost of rural living was relatively low, they had little help with needed activities and little money for added expenses. The two sisters needed help. But the only available family support they had came from one another. While living in their new environment, and after the onset of Jocelyn’s mobility impairment coupled with both sisters’ multiple illnesses, they needed help with cleaning, bill paying, lawn care, bathing, and transportation. Jocelyn qualified for home health services after being on a wait list for 1 year. Once she was assigned a provider, however, nothing was done, or at least nothing was done well. Jocelyn said, “And then I’d go in there and I’d touch the floor and I can find stuff on the floor. I got tired of that.” Further, at one point, jewelry was stolen. Jocelyn said, “When I was in the hospital last year, even though I called them and said, look you know they [bills] were made out but they didn’t get mailed. I was like a day or two late and they raised my interest rate to like 27%.” She said, “I had a sister who could not walk, I was blind and I was not feeling well. And we couldn’t get any help from anybody.” She said she was told that they received too much in disability to qualify for other types of need-based services, and they were not old enough to qualify for elder services.

Jocelyn also said she felt that people misunderstood her visual impairment. Despite enactment of the Americans with Disabilities’ Act in 1990, she said she was asked to leave a restaurant after its passage because her guide dog was not allowed. She said she was also followed around an antique store and told that she must buy whatever she broke. Jocelyn supported her sister’s stories and she said she lamented the way her sister was treated.

Loss of Function

With their sense that the world had turned its back, Jocelyn said she stopped integrating herself into society and lost her sense of being in the world. “People are very reluctant to like ask me to do things, include me in things.” She went to church and to the doctor. Otherwise, she stayed at home. She stated, “it’s just too much of a physical challenge to get there, and when I get there it’s like I could have phoned this in, because I’m there but I’m not there, if you know what I am saying.” She used to love to shop, but now she buys all her clothes through QVC while watching television. “I can’t just enjoy the colors and the textures. I can’t physically stand there, and when you stand at a rack of clothes and you try to guess at what it is, it takes the fun out of it.” She no longer writes poetry. She turns on the computer then turns it off. She also gave up gardening. Most tragically, her guide dog died. “I had to have my guide dog put to sleep; it is going on three years ago now. And I miss her so much.” And her lack of mobility prevented her from getting another dog. Jocelyn stated, “When we moved out here, we wanted a place, I wanted a place, I had my guide dog and I wanted a place I could garden, which I can’t do now.” With loss of vision and loss of mobility, findings ways to remain active in society were a challenge.

Disengaged: Loss of Contact

Lucille stated that at one time she and her sister made up the function of one healthy person. The two of them made a team. But she no longer believed that. She felt they needed assistance. And she worried about Jocelyn’s health. Jocelyn’s thoughts were frequently devoted to the importance of “being” versus “doing.” She pondered whether her life had meaning without purpose, or whether her life was purely a matter of being in the world. Was being in the world a purpose in and of itself? She found few activities to keep her life fulfilled. She recalled having been given an activity to perform at church, where she introduced the hymns. After her illness, she was no longer invited to perform this activity. She said, “It’s just that when you’ve been doing something for over a year, and then suddenly nobody wants you do to do it anymore. It’s like, okay, maybe you were making that up for me to do.” Jocelyn admitted, “Yeah, I got my feelings hurt.” She struggled because, she said, “I find myself being dismissed many times because they don’t know what I can do.”

Re-evaluating Function

The women were gradually returning to the belief that their bodies and their movement did not have to be ideal. They only had to be alive and to move. Set within the range of perceptions of women with chronic disabling conditions, these sisters did not display evidence of optimism, which might have indicated expectancy for positive outcomes despite the negative events; indications they might have extracted a benefit from their adversity (Tennen & Affleck, 1999). They did, however, adapt. For instance, when Jocelyn ate her dinner she lamented dropping food on her blouse and not knowing it, but she ate. She said she failed to color-sort the laundry into the appropriate piles, which resulted in things such as white sheets turning pink, but she did the laundry. Her sister, Lucille, complained when Jocelyn had to pull the trash out of the trashcan or make her bed for her. Lucille also said she had to stop doing dishes in the middle of the task only to later become “bored from lying in bed watching the spiders on the ceiling”. At the same time, the sisters cared for two cats and multiple goats that lived in and around the house. Of these, the sisters stated, “We just love it: cats and goats.” Lucille had found and cared for a cat who was also disabled due to a dog fight. Although the cat was small and some of its fur was missing, she said she loved it. And although Jocelyn said she was unable to see and walk without difficulty; she used her mobility cane to find her way to feed her goats every day. We theorize that after multiple adverse events, the sisters stopped looking for perfection in their bodies and benefit in their adversity; instead, they started looking for pleasure in their relationships. They focused on their unique relationships with their God, each other and pets.

Discussion

This study is limited to the experiences of the women who participated. The sisters’ experiences are not representative of all women with early onset disabilities or their families. Given the severity of their life course trajectories, it might be suggested that these women represent the worst of cases. On the contrary, they do not represent exemplars of the worst cases among the women who participated in the larger ethnographic study. Women with far worse poverty, disability, and abuse enrolled, leading the principal investigator to visit women living in rural fields and condemned homes.

Multiple morbidity and accumulated functional limitation over the life course was described by the sisters as a repeated experience of loss, recovery and re-engagement. At the point in which the sisters were interviewed they were recovering from multiple losses and were trying to re-engage with their communities and family. Their attempts were not always successful. This produced a narrative that may be viewed as negative. This may be a product of where their lives are in the totality of the experience. Their narrative does not suggest that they were not resilient and will not learn to manage their current level of accumulated functional limitation and adversity with time. They had moved through loss, recovery and re-engagement in the past. They must do so again. Their obstacles at this juncture were, however, profound for multiple reasons. These included an internalized negative family and societal view of disability, early life course experiences with functional loss, and a reliance on previously acquired urban-based resources and learned skills to manage limitations, which are no longer available in their rural setting.

The sister’s early onset functional loss had been accommodated in multiple ways that were currently perceived as less beneficial given the accumulation of added functional losses in later life. This resulted in a perceived disadvantage for both sisters who were trying to assist each other in their later years. We posit that once multiple functional limitations accumulated, without the appropriate skill and management of previous limitations, the added impact was physically and psychologically overwhelming. This is consistent with the coping literature indicating that multiple stressors may deplete physical and psychological resources that require equal or greater strength to overcome (Baumeister, Faber & Wallace, 1999). We suggest that with time the sisters may be able to reengage if provided with appropriate resources while they build their strength.

How the women in this study internalized their families’ and society’s views of functional limitations influenced how they viewed treatment options and accommodations. Jocelyn attributed her early experiences with neglect to her visual impairment; likewise, her ongoing abuse from spouses was attributed to her visual impairment. She believed that her disability was a negative attribute that had to be overcome by “passing” as a sighted individual. In her later years, she said this was a mistake. She said she had tried multiple surgeries, various experimental therapies, and marijuana gained through illegal means. She placed herself in a situation of ongoing jeopardy to normalize. Once she decided to accept her vision loss, the irony was that she perceived life as harder and she thought society did not support her decision. It is consistent with the literature to suggest that life is more difficult for women who have functional limitations. Disparities in access to health care and social resources exist between women with and without disabilities (Chevarley, et al, 2006). Psychologically, however, studies support an association between acceptance of functional limitation and quality of life for people with disabilities (XXXX, 2004; Stuifbergen, Becker, Blozis, Beal & Park, 2008). This is not a resignation to loss but a positive mental attitude toward a new experience with their bodies; moving forward with a new level of function. Jocelyn said she felt socially isolated, discriminated against for her disability, and inferior. In this instance, the issue is not whether or not therapies such as medical marijuana should be legal but how disability is viewed and how far people will go to meet cultural standards for normality through medical or other treatments.

It would be tempting, but disingenuous, to suggest that the sisters' disadvantage was purely due to the functional limitation perceived in their bodies. From a feminist perspective (Firestone, 1997), social privilege is built over time through multiple factors that may include a family's reaction to a child's body, economic stratification based on perceived ability, and the nature of the nurturing experience initiated early in the life course. This might be helpful when examining the outcomes of the two sisters. Although both sisters had mobility limitations in later years, only one of the sisters had aged with an early onset disability. She faced multiple episodes of abuse and she was unable to find appropriate employment despite her education. Jocelyn, although more educated than her sister, had few resources available to her and had accumulated greater limitations with age. Lucille had more resources and was able to provide financial and housing support to both sisters. Their lives demonstrated how aging with an early onset disability might influence different life trajectories through an interaction of impairment with family and societal expectations.

Societal resources were perceived to influence the trajectories and accommodation to functional loss. Currently, the state in which the women reside is faced with budget constraint. The Texas Health and Human Services Commission outlined areas for budget cuts (Texas HHSC, 2011) where the Department of Aging and Disability Services suggested the need for "greater consistency in the authorization of Personal Assistance Service hours (Primary Home Care, Community Attendant Services, and Community Based Alternatives) for a given condition/situation. Currently, there are wide regional variations in the average hours of service authorized per individual. The focus of this option is on ensuring consistency." (Texas HHSC, 2011, p.7). The ladies in this report state they qualified for service after being placed on a wait list for one year. Again, women's life expectancy in this county of Texas is has diminished over the past 10 years and is now lower than what is found in Mexico or Cuba (Roser, 2011).

Jocelyn's need to learn new strategies to accommodate her limitations while managing new onset mobility loss was a challenge, at times it was overwhelming for Jocelyn; and this may have some relationship to the birth cohort in which she belonged. It is questioned if Jocelyn had experienced a stable and successful management of her early onset severe vision loss, would the mobility loss have been as difficult to manage in later life? Jocelyn's adaptation to unclear visual pictures through childhood, small amounts of light from early adulthood, and then no vision or light perception coupled with mobility loss during later adulthood was complex and without clear resolution. This was coupled with multiple life time stressors that she perceived were connected to her disability such as poverty, parental and spousal abuse. At the time she was adapting to the majority of these changes, the Americans with

Disabilities' Act of 1990 had not been enacted. She would not have begun to benefit from this legislation until she was 37 years of age. The support people with disabilities receive from this legislation was not in place for the majority of Jocelyn's young life when she was working and establishing her benefits. Many older adults aging with early onset functional limitations have lived through periods of time when society was less supportive and accepting of their functional limitations. Cohort differences should be considered in disability related adaptation research.

As Jocelyn accumulated multiple morbidity and as her ability to socially interact diminished, she questioned her place in the world. Consistent with the work of Heidegger on the experience of the body in time, movement in time was needed to understand the ontological experience of existence. Without movement, as indicated by a change in the position of mind and body in time, not only the body, but also perceptions of self seemed stagnant. This resulted in Jocelyn's ruminating over the losses that had occurred. Jocelyn also questioned her purpose in life. This was not uncommon. For many of the women, functional loss placed them in a position where they began to contemplate existential reasons for their lives. Once movement resumed, however, the women had a restored sense of engagement in their near world, usually through contact with those people or animals closest to them. Finding a psychological benefit to the multiple adversities women experience has been shown to give some advantage to women if they derive it for themselves; those that are "directed, imposed, or suggested benefits will almost surely fail to achieve their desired goals." (Tennen & Affleck, 1999, p. 298). From this case study it is theorized that the women gradually moved into a position where they experienced contact with selective aspects of their environment, which enabled them to experience positive feelings. We suggest that it may only be with time if at all that the benefits of those pleasurable interactions will be articulated as a means of maintaining aspects of health. This deserves further research.

Evidence from this case study suggests that support might be needed beyond the initial bio-medical loss of function. Jocelyn found pleasure with her environment through her relationships, but she needed support in order to find that pleasure for herself. Once experienced, she began to perceive the need for more engagement with her environment. It was clear that functional losses did not have to be eliminated prior to her re-engaging into society successfully. Finding the best accommodation to keep her moving and engaged was a challenge given the severity and repetition of loss, but it was possible. Supporting her until she found pleasure in her environment again may have been the best possible intervention. This suggested to us that allowing for a process of self-discovery in the context of functional loss may be beneficial and deserves further research.

Based on this case, it is suggested that health care providers might cushion the additive affect of multiple functional losses experienced by ensuring that previous functional losses are accommodated prior to the addition of any new losses. Clearly, further research is needed on adaptation to multiple morbidity and repetitive functional loss.

In conclusion, the narratives of two sisters who participated in an ongoing ethnographic study of mobility impairment were used to describe the vast impact of multiple morbidity and cumulative adversity over the life course. At this time, it was evident that early onset impairment placed one of the sisters in a position of disadvantage and led to cumulative adversity over time. The experience of loss, recovery and re-engagement was described at multiple points along the life course. The added impact, however, was made worse when appropriate accommodations were not in place in later life. When vision worsened it was difficult but when walking worsened before the vision problems were accommodated appropriately, both functional limitations seemed unmanageable. Future work on this project will address the added affects of ethnicity. It is suggested that further examination of cumulative adversity and its relationship to multiple morbidity will increase our knowledge and insight into the processes of aging (Ferraro & Shippee, 2009) and disablement.

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Table 1

Description of Themes

Developmental Time Period	Theme	Description
Childhood	Limited and Unwanted	Jocelyn remembered and described vivid memories of childhood neglect due to her visual limitations, which were also described by Lucille.
	Reconstituting Family	Lucille was placed in charge of her younger sister Jocelyn, who subsequently grew-up dependent on her as a sighted guide and mother figure.
	Passing for Sighted	Jocelyn was punished for her visual impairment and she made every attempt to pass as sighted.
Adolescence	Finding their own Way	Lucille and Jocelyn were raised outside of mainstream cultural values; viewed themselves as not fitting in with peers.
Young Adulthood	Making do with Functional Limitations	This was a time when the sisters were separated. Jocelyn became educated but was unable to reach goals due to visual impairment while Lucille established a family.
Adulthood	Looking for the Cure	Jocelyn tried multiple experimental and non-experimental therapies in order to maintain any available light for vision.
	Fighting Adversity	During this time, both sisters ended their relationships with their abusive spouses. They were also battling mental health issues that kept them in their relationships. Jocelyn stopped trying to pass for sighted with medical marijuana and both stopped trying to maintain employment.
Middle Adulthood / Now	A Cascade of Illnesses	Health and function worsened for both sisters after moving in together.
	Loss of Resources	The sisters were living in a new rural environment where resources were low.
	Loss of Function	As resources and function diminished a sense of being in the world also diminished.
	Disengaged: Loss of Contact	Jocelyn questioned importance of being vs. doing as meaningful to existence.
	Re-evaluating Function: Sometimes the white sheets are pink	The sisters were disappointed when their functional outcomes were not to their expectation but were beginning to see goodness in their lives again.