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Timing of impairment and health-promoting lifestyles in women with disabilities

Tracie Harrison,

School of Nursing, The University of Texas at Austin, 1700 Red River, Austin, TX 78701

Deborah Umberson,

Department of Sociology, The University of Texas at Austin, Department of Sociology, College of Liberal Arts, 1 University Station A1700, Austin, TX 78712

Li-Chen Lin, RN, MSN, and

Graduate Student, School of Nursing, The University of Texas at Austin, 1700 Red River, Austin, TX 78701

Hsui-Rong Cheng, MSN, RN

Graduate Student, School of Nursing, The University of Texas at Austin, 1700 Red River, Austin, TX 78701

Abstract

The purpose of this study was to develop a substantive theory that explains how the timing of impairment in women's lives influences health-promoting lifestyles among 45 women age 43 to 79 years with impairments of varying onset across the life course. From this grounded theory exploration, we suggest that women created health-related lifestyles, which were comprised of changing abilities, roles, and rituals, in support of perceived self. The ultimate goal of a healthy lifestyle was healthy aging, which was self-determination in the support of positive relationships. Environment and resources had direct influence on perceived self. Our proposed substantive theory provides an understanding of how women develop a healthy lifestyle after the onset of permanent sensory or physical impairment. It also takes steps toward an understanding of how timing of impairment influences the perceptions women have of themselves and their health behaviors.

Keywords

aging; disability; grounded theory; health promotion; women's health, midlife

After the onset of permanent, disabling conditions, people change in both function and in the way they are perceived and treated by society (Gill, 2001). Moreover, the timing of disability affects long-term health outcomes. Those who are young when they become disabled might still be developing identity and subsequent health behaviors. On the other hand, those who are older when they become disabled might have a more stable sense of identity, lament the loss of function that supported an earlier identity and cling to previous health habits and patterns of behavior. In classic research on people with visual impairments, Scott asserted that early onset and late onset visual impairment were different phenomena primarily because others respond in very different ways depending on the age of individuals (Scott, 1981). Others have suggested that timing of impairment influences adjustment (Zink, 1992), types of rehabilitation offered (Brummel-Smith, 1992), legal benefits (Harrison,

2006), and identity formation (Kelley-Moore, Schumacher, Kahana & Kahana, 2006). The goal of the present study is to build a substantive theory to explain how the timing of impairment in women's lives influences health-promoting lifestyles. We accomplish this in three steps. First, we review previous theoretical and empirical work on health promotion and the timing of impairment and disability. Second, we examine support for this theory with results from a grounded theory study. Third, we discuss the implications of these findings for healthcare researchers and providers, including general practitioners, gerontologists and rehabilitation professionals.

Background

A healthy lifestyle is extremely important for the long-term health and well-being of individuals with disabilities (Stuifbergen & Becker, 2001). However, we know very little about what influences a woman with a disability to have or to develop a healthy lifestyle. Most work has focused on how to change people's behaviors, not on what makes people lead the lives they lead-healthy or otherwise. The vast majority of researchers use samples of individuals who have no significant disabilities. Carter and Kulbok (2002) reviewed the literature on motivation for health behavior change and found that two thirds of studies report that motivation to be healthy is a significant predictor of healthy lifestyles. The studies in this review reflected many different theoretical constructs and approaches, referring to at least seven different health promotion theories including The Health Belief Model and The Stages of Change Model, to study motivation for change in health lifestyles. Redland and Stuifbergen (1993) suggest that motivation, self-efficacy, barriers and facilitators are important concepts in the development of a health promoting lifestyle.

Few studies have focused on behavior change and the health promotion needs of those with disabling conditions. Some of these studies suggest that being motivated to change behavior and be healthy is an important factor in influencing health promotion. Motivation for change is a key component of an intervention designed to improve physical activity among Medicaid beneficiaries with impairments (Ravesloot, 2009). Ravesloot found significant improvements in activity levels among those in the intervention group that received motivational support. Ravesloot and colleagues (2007) also focused on health promotion for persons with disabilities in a study that stressed the importance of participatory action research and environmental change to effectively investigate health promotion. Furthermore, the health promotion in chronic illness model has been used to study health promotion among individuals with multiple sclerosis and post polio syndrome (Stuifbergen, Seraphine, Harrison, & Adachi, 2005). Severity of impairment, self-efficacy, resources, barriers, and acceptance of impairment were all predictors of a health promoting lifestyle. Tailored interventions for improving specific health behaviors have also been successful by focusing on personal feelings about the self and environment for persons with disabilities leaving rehabilitation (van der Ploeg, Streppel, van der Beek, van der Woude, van Harten & van Mechelen, 2008). Taken together, researchers stress the importance of environment, resources, motivation, acceptance of impairment, self-efficacy and personalized approaches when addressing the needs of persons with disabilities.

Although van der Ploeg and colleagues (2008), Ravesloot and colleagues (2007) and Stuifbergen and colleagues (2005) consider the experience of health promotion among those with permanent disabling conditions, they do not consider how the timing of impairment might alter a person's healthy lifestyle. Smeltzer and Zimmerman (2005) report significant differences between age cohorts of women with disabilities when surveyed regarding their interest in health promotion topics. The younger and older women had significantly different interests in stress management, parenting, juggling multiple symptoms and roles, and aging. It might be that women have different health promotion needs at different times in their lives

because disability affects their lives in unique ways at different points along the life course and because the responsibilities and demands in their lives vary over the life course.

The impact of impairment on social activities and role performance—for example, at work, as parents, and in education—is often age related; therefore, the timing of disability in women’s lives influences how activities and role performance are interpreted by women and by others around them (Verbrugge & Yang, 2003). As people age, social interactions influence personal lifestyles that might be health promoting or damaging (Maddi, 1998). When impairment occurs during adulthood, the person integrates their past perception of self into the future to organize how they see themselves as a person with a chronic condition (Charmaz, 1991). When impairment occurs soon after birth, women have reported an adult identity that is integrated with their disability; they do not need to adjust to the sudden loss of ability or a change in how people treat/perceive them (Harrison & Kahn, 2004; Harrison & Stuifbergen, 2005). These life experiences as a person with a disability, and the interpretation of these experiences, influence health behaviors over the life course (Harrison, 2004). Timing of impairment can also result in a change in health related behavior because rehabilitation teaches ritualistic health behaviors that support functioning with impairment and because disability culture provides behavioral guidance (Harrison & Kahn, 2004; Murphy, Scheer, Murphy, Mack, 1988). Moreover, those with younger onset impairment have reported “a greater potential for recovery than adults” (Magni-Manzoni, Pistorio, Labo, Viola, Garcia-Munitis, Panigada, et al., 2008, p.1159), which influences not only trajectories of function but how professionals approach their rehabilitation. At the same time, if providers do not respond in a supportive manner to people with early onset disabling conditions the young might find it difficult to adapt as they age (Thannhauser, 2009). Although variations exist in how people adjust to disabling conditions (Pinson, Ottens & Fisher, 2009) timing of impairment in the life course might have a strong influence on health behaviors (Campbell, 1994; Putnam, 2002; Zanjani, Schaie, & Willis, 2006).

The experiences of women with disabilities in acquiring long-term health behaviors might be unique to them because gender interacts with disability and age to marginalize women and alter their role performance, activities and subsequent health outcomes (Pentland, Tremblay, Spring & Rosenthal, 1999). Women who are aging with physical disabilities, when compared to women in general, might be at higher risk for osteoporosis (Schrager, 2004), asthma, and hypertension (Campbel, Sheets, & Strong, 1999; Harrison & Stuifbergen, 2000). Moreover, age becomes an issue in women’s healthy lifestyles because the longer a woman lives with one disabling condition, the more likely she is to develop multiple disabling conditions (Jans & Stoddard, 1999) such as muscle atrophy, fatigue, and pain (McNaughton & McPherson, 2003). In addition, the older a woman becomes, the less likely she might be to demand or expect independence, autonomy, or control and this can keep her from voicing her health needs (Zarb & Oliver, 1993). Given that the likelihood of co-morbid and secondary conditions increases with age, thereby adding to the complexity and cost of healthcare, how the timing of impairment over the life course influences health-promoting lifestyles is of importance to the whole of society. Policies and intervention approaches with women with disabilities might need to reflect the timing of disability in women’s lives. It is very important to establish not only what factors will promote healthy lifestyles among women with disabilities but also what factors best promote healthy lifestyles at different stages in the life course.

Consequently, we designed a qualitative study to build a theory of health promoting lifestyles based on an understanding of the life course of mid and elder life women with disabilities. The goal of this project is to understand what women perceive to have happened after the onset of a disabling condition that ultimately influenced their health behaviors. The

authors will use the resultant theory to provide tailored interventions to women with disabilities.

Theoretical Perspective

We used a sensitizing framework that integrated the life course paradigm and symbolic interactionism (Blumer, 1969) to structure a grounded theory study of aging in women with disabilities. (Figure. 1) A social interactionist perspective emphasizes that people act based on the meaning that objects have for them, that the meaning of objects and events is derived from interactions with others, and meanings are interpreted and then modified based on the on-going interpretations (Blumer, 1969). Over the life course, women accumulate experiences and their bodies change; they do not arrive at an older age without interpreting many years of experience. This lifetime of experiences shapes perceptions of self and one's behaviors. With time, an interpretation of experiences and changes accumulates; these experiences might be different across cultures and shared by individuals within a culture (Keltz, Hoffman, Ory, & Harden, 2000). When the shared meaning is negative, it might negatively influence long-term health with age (Levy, Slade, & Kasl 2002). For example, when people view aging as a loss of social and physical activity when younger, over time they might develop worse exercise habits and contact fewer friends, thereby creating the life they envisioned in earlier years. The developmental process of aging is made distinct by how social interactions lead to various lifestyles, which might be health promoting or damaging (Maddi, 1998). Hence, "aging is best understood within a life course perspective" (Keltz et al., 2000, p.143).

The life course paradigm (Giele & Elder, 1998) provided a broad framework to explore how timing of impairment in mid-life and elder women with disabilities influences health-promoting lifestyles. The framework was not re-created or tested using data from the study. The sensitizing framework served as a model to conceptualize health-promoting lifestyles for additional study. Within the life course paradigm, aging is a developmental process of changing meanings that move across time but within the historical and cultural context of a cohort of women (Giele & Elder, 1998). The timing of impairment in the life course is assumed a developmental milestone (Elder, 1996); therefore, the women were currently of adult age, but with impairment onset at variable times. The adult years were conceptualized as the time period judged or compared for degree of dependency and health responsibility with other periods of the life course (Priestley, 2003). In other words, degree of independence in childhood might be compared to degree of independence in adulthood with the theoretical knowledge that adulthood is considered a period of time when health, function, work and independence are climactic. Hence, by studying the life histories of mid and later life women the ways in which timing of impairment creates variations in perceptions of healthy lifestyles becomes evident.

Methodology

After approval from the local institutional review board, a grounded theory study using a constant comparative method of data analysis (Strauss & Corbin, 1990) was undertaken. The goal was to build a theory of health-promoting lifestyles based on an understanding of the life course of midlife and elder women with disabilities. Data were collected from 45 community-residing women living in rural and urban areas within the state of Texas. Data included 103 interviews lasting 1 to 2.5 hours each, field notes of observations, demographic sheets, and memos of theoretical insights. Data collection and analysis occurred over 3.5 years from 2005 to 2008.

Recruitment

Initially we recruited women purposefully based on self-reported disability. Women were asked to participate if they had a physical or sensory impairment that prevented them from living the life they would prefer.¹ They were recruited by word of mouth, flyers, and email communication with women with disabilities. Each woman was paid \$10.00 per interview. As the study continued and the theory developed, women were recruited based on timing of impairment and later recruited based on ethnic-racial and disability status. Later, we recruited in to complete the theory in a more culturally sensitive context. However, we realized that to be culturally sensitive to the issues faced by the varied ethnic-racial groups of women, a study of each group would have to include women of varied onset of impairment, which was beyond the scope of this study.

According to Corbin and Strauss, researchers should complete analysis on data collected before proceeding to the next participant to adjust the direction of data collection if necessary. We did not find this consistently feasible. The women with disabilities would volunteer to participate only if they could determine the time of their interviews. For instance, one woman called with interest in the study but when asked to wait for analysis to be completed, she decided not to participate. Hence, we used a modified recruitment and analysis procedure. That participant was the first and last participant lost during the recruitment phase; however, two women completed two interviews but declined a third interview. One declined because she had emergent open-heart surgery and another because she left the city. Because of these events, as women volunteered for the study they were enrolled and interviewed as soon as possible. Data analysis and recruitment were completed as quickly as possible but women were not asked to wait to be interviewed.

Sample

A sample of 45 women age 43 to 79 years participated. The study included 33 Non-Hispanic White, two Hispanic White, eight African American, and two Native American women. The timing of impairment among the women ranged from birth to 65 years of age with 51% of women having impairment onset prior to age 31.² All women reported a functional limitation because of mobility and/or sensory impairments. Twenty-six women (59%) had mobility impairments, seven (15%) had visual impairments, two (4%) had hearing impairments, eight (18%) had visual and mobility impairments, and two (4%) had mild cognitive and mobility impairments. All the women, including those with mild cognitive impairments, stated that they had the legal right to provide their own consent to participate in the study. We did not attempt to verify this information given they voiced understanding and agreement. The reasons for impairments included: macular degeneration, retinopathy of prematurity, post polio, traumatic brain injury, spinal cord injury, amputation, muscular dystrophy, stroke, spinal muscle atrophy, multiple sclerosis, ulcerative colitis with resultant

¹To be consistent with a definition of disability that considers the concept of impairment as separate from the concept of disability but at the same time let the women self identify as women with disabilities, we recruited women based on having perceived impairment that prevents them from doing something in their lives they would prefer to do. This did not necessarily make the women a more negative group of women concerning their impairments. We believe the sample varied in this respect. Many of the women were pragmatic about the facts that they could not do things because of their impairments. For instance, many of the women with visual impairments from childhood laughed when asked this question and said, "well, I can't drive". Other women were very concerned about the disabling affects of their impairments and the reason they participated in the study was that they wanted others to know just how disabling their impairments could be.

²In this study, we use the terminology later onset and earlier onset. These are not pre-defined objective terms. We recruited and studied women who had impairment onset over the life course. Theoretical sampling was devoted to recruiting those women whose impairments occurred at different points in their lives. Using this sample, we found that women with impairment that had an onset on or before age 23 integrated perceptions of self with their impairments while the women who had an onset on or after age 26 did not easily integrate perceptions of self with their impairments. This is specific to this sample. There were no women with onsets at age 24 or 25. We subsequently used the age of 25 to mark the cut off between the women in this sample, e.g. later onset refers to the women whose impairment occurs after age 25. We do not generalize this to all women with disabilities.

sexual dysfunction because of vaginal reconstruction and ileostomy, and genetic hearing loss. All of the women stated they used some type of assistive device or accommodation for their impairments. Most used wheelchairs (50%), computer aids (33%), personal attendants (31%), and modified vans (27%). Others used walkers (18%), power lifts (18%), sliding boards (11%), service or guide dogs (11%), and standing frames (9%).

Of the women included in this study, 29% were married and 40% were divorced. Sixty percent had children. The sample was also highly educated with 42 of the women reporting some college, and of those 42 women, 21 had a graduate degree. Despite the high level of education, 58% of the women had stopped working because of their disability with only 33% currently working for pay. Eleven women (24%) stated they were unable to meet their current financial obligations.

Data Collection

The grand tour question for this study was, “How does the timing of disability in a woman’s life affect her ability to promote her health as she ages?” We asked open-ended questions to collect data on the following: when and how the initial disability occurred, how the disability affected her life, and how and when any additional disability or illness occurred. In addition, we asked questions about how she perceived changes associated with aging, how the changes in her body affected her ability to function in society and promote her health, and how the disability affected her social relationships or vice versa. To answer the questions we conducted interviews, wrote field notes, and collected demographic information.

Multiple audio-taped interviews (2 to 3) lasting approximately 60 to 150 minutes each were conducted by the first author (TH, $n = 37$ participants with 87 interviews) and a research assistant (DJ, $n = 8$ participants with 16 interviews). Initial interviews were conversations about the topic of aging and health while living with a disability. The time between interviews varied from one week to three months. As we proceeded with data collection, we focused the recruitment and interviews on specific topics needed for the developing theory (Strauss & Corbin, 1990). For instance, we focused our recruitment more on those with adult onset physical impairments later in the study because these women were initially less interested because they were less likely to identify as women with disabilities than those who were born with impairments. We scheduled third interviews with women if we did not cover needed information for the developing theory during the first two interviews. The women controlled how much time we spent and how much information they shared. We have found that respect for the women’s time and emotional and physical fortitude as well as their knowledge of the experience is important for maintaining good relationships for retention, recruitment and data collection with women with disabilities. The final interviews validated data from previous interviews. Demographic data included age, education, employment history, onset of disability, marital status, number of children, and ethnicity. We wrote fieldnotes after each initial interview. Information such as dress, body language, assistive devices, and environmental details were included in the field notes. Theoretical observations and documentation of self-evaluations of the interview were added to the notes, thus allowing for ongoing reflective dialogue (Emerson, Fretz & Shaw, 1995). Data collection continued until the categories, a conceptual unit used in the theory’s structure, were saturated (Strauss & Corbin, 1990). We reached saturation when added interviews did not provide any new information to the categories.

Data Analysis

Grounded theory is a methodology designed for conducting qualitative research studies that focus on constructing substantive theories by performing inductive analysis of data (Bryant

& Charmaz, 2007). The substantive theory is built on a rigorous set of procedures by continuously interacting with data using the constant comparative method. Glaser and Strauss (1967) originally developed this methodology for the purpose of generating theories by connecting empirically derived data using systematic procedures of coding and hypothesis testing. Grounded theory methodology is a fluid design that allows participants to tell their own stories.

We analyzed data using the recursive constant comparative method as outlined by Strauss & Corbin (1990). In this method, there are three main forms of coding conducted repeatedly beginning immediately after the first interview: open coding, axial coding, and selective coding. Consistent with open coding, the first author did line-by-line coding of text by closely examining each word to understand the meaning conveyed. She wrote notes on each in the adjacent margin. Next, she identified concepts, which were the abstract phenomena that represented the building blocks of the emerging theory. She identified categories and subcategories by inter-relating the concepts to higher levels of abstraction. She described the concepts based on their properties and their dimensional range. Consistent with axial coding, the first author developed the categories and subcategories by examining the conditions, actions/interactions, and consequences of each. Moreover, relational statements describing how each category related to its subcategories were developed. Finally, consistent with selective coding, the first author formulated and refined the theory by describing the main idea of the research and identifying a core category that represented the main theme of the research. Next, other categories were related to the core category, as illustrated in Figure 2. Finally, the research team reviewed the theory for logical development and inconsistencies.

Findings

Overall, a lifestyle developed after the onset of a disabling condition through trial and error efforts to develop or maintain a perception of self, which was developed and given meaning based on interactions with other people. The women would interact with others, analyze the meaning and reflect on the consequences of that meaning for how they perceived themselves. The women developed a lifestyle in the context of their available resources and environmental supports in the hope that they would become or remain self-determined, which was a sense that they had control over their lives and the ramifications of their behavior.

Before turning to the theoretical constructs derived from the analysis, we clarify the phenomenon of time in the women's stories. All of the women, no matter the timing of the impairment, used certain types of time perspectives that we used to differentiate those with early vs. later onset impairment. The theory (Figure 2) developed from the stories of the women is set within two competing conceptualizations of time (Adam, 2004). The first conceptualization of time is circular. As women understood and presented their sense of self, they reached back for memories of themselves in the past. These memories reaffirmed the nature of who they believed they were as women, and what behaviors were consistent with that belief. This sense of time provided a sense of a permanent self. Those women who thought of themselves as non-disabled reached back for memories of themselves prior to their impairment onsets, whereas those women who had early onset impairments reached back for memories that included their disabilities. The second conceptualization of time was linear. The women's lifestyles were altered as events unfolded in a linear time sequence, taking into account current and future age, injury, and pathology-related changes. In other words, the women experienced changes in their physical abilities over time that allowed them to change their lifestyles depending on what was currently happening in their lives. These two conceptualizations of time allowed the women to be both permanent and changing beings having the potential to live out a self-determined lifestyle. The fundamental

differences in perceptions of self were based on the timing and meaning of the impairment in their lives, which is where the theory begins.

Timing of Impairment

Timing of impairment influenced actual skill development and perceived likelihood of skill development. The women recognized that our society teaches skills to people along a developmental time line. Society considers physical abilities prime for skill development at different points in the life course; therefore, professionals teach skills during those developmental periods. If reactions to impairment prevented skill acquisition because skills were not taught at a critical point in the life course, the women perceived the difference in how they were treated. For instance, a woman with a hearing impairment stated,

I have problems, too. I was pushed to be oral. I think most deaf children need a visual backup whether it is cued speech or signing. They need that along with the oral input because if you have just oral until you get to be 10, 11 years old, and then we go oh, your language is really far behind, it is too late. The critical time for learning language and complexities is before the age of 6.

The timing of impairment influenced perceived likelihood of skill acquisition for women. Women with impairment onset after the age of 50 years believed that rehabilitation providers did not teach new skills or did not offer to teach them as readily because women would be less likely to learn as older adults. Furthermore, some women did not want to learn new skills at older ages because they enjoyed doing things the way they always did them before. Despite the perceived likelihood of learning skills, women of all ages learned new skills out of necessity, which could directly influence the skill to perform specified health activities, such as running.

Meaning of Impairment

Women interpreted the meaning of impairment based on an appraisal of their abilities after the onset of the impairment and the reaction of others to them. The women who had early onset impairment grew up developing their abilities within the context of their impairments. The normal self just happened to be what others labeled as impairment. Only through the reaction of others did they realize they were impaired. However, this did not always cause them to think less of themselves or their abilities. For instance, Janice who was 56 years old with a retinopathy of prematurity realized that her lack of vision meant she was viewed differently, more fragile, by her peers' parents, but it did not change her behaviors or the meaning her body had to herself. She said,

And the other thing that I noticed was that they seemed to get more upset if something happened to me than if something happened to their kids, or even my sighted friends. So, what that causes is. You think, okay, well, I just won't let them see stuff.

The meaning of impairment was quite different for those with later onset impairment. The women shared the meaning of their impairment with those they socialized with in their environments. Gladys, who was 54 years of age and had multiple sclerosis since age 31, felt she knew what others were thinking when they saw how her abilities and appearance had changed. She said, "It's the elephant in the room. I am hyper aware of how people are going to react." If the women perceived that others viewed their impairment as a negative aspect of her, she was less able to maintain both her health and the relationship. For instance, Sarah, who was 60 years old with a diagnosis of a diabetic retinopathy with complete vision loss as well as kidney and pancreas transplants, stated, "And that's what finally happened in 1989 when it just got to be where I had to deal with my health issues. And sure enough, when it came down to that, he couldn't handle it and he certainly didn't want a sick wife." Sarah had

to make a decision to maintain either herself or her marriage when the illness meant she was functionally limited and her survival required that she change her lifestyle. She left her husband.

Confirming/Disconfirming Environments

An essential influence on the women's acquisition of a health promoting lifestyle was the built and attitudinal environments in which women existed following the onset of their impairment. These environments can be confirming in that they help to promote a healthy lifestyle or disconfirming in that they interfere with or undermine a healthy lifestyle. Women exposed to disconfirming environments found taking care of their health very difficult. Sammy, who was 55 years old and had been living with a diagnosis of muscular dystrophy since childhood, stated that she was unable to gain bathroom assistance at work: "They said that I had to take care of it. It was not a reasonable accommodation as far as they were concerned under the ADA (Americans with Disabilities Act). So employers do not acknowledge going to the bathroom as being necessary to work." She held her urine from the beginning of work until the end of the day when she returned home. Moreover, health promotion became difficult even if the environment was neutral, e.g. not disconfirming or confirming. A confirming environment, however, might introduce new possibilities for women with disabilities. For instance, Caroline, age 60 with spinal cord injury since age 16, said,

It took me about three years to really grasp that this is permanent, and I have to learn to live with it. Up 'til then I was in a deep depression, really struggling with wanting to die, thinking about suicide every day, trying to figure out well how could I do it. I wasn't very independent at the time, hadn't had any real rehab. I was going to be living in a dependent sort of existence with no real purpose.

She developed a sense of herself as an independent woman with a disability after connecting with the Paralyzed Veterans' Association.

Women exposed to confirming environments found health promotion easier or more natural. Joanie, who was 48 years old and had a spinal cord injury at age 18, had been an international Paralympics basketball player and received a professional degree that enabled her to support herself financially. She stated, "While I was at the rehabilitation center, I actually would go over... They had an underground tunnel over to this other building where the basketball team practiced. So even before I got out of the rehabilitation center, I was going over and playing basketball." Joanie continued to exercise and watch her weight, although she no longer played on an organized team.

When environments were disconfirming, the women had to make a choice to stay or to leave that environment. Elisa, age 52 years with a diagnosis of a spinal cord injury since age 29 years, made a decision to change her environment. Although she lived in a smart home that provided accessible living, she spent much of her time sedated with narcotics. Her boyfriend brought her essentials and encouraged her to remain sedated. She did not work, drive, or venture out of her home often. One day, after speaking to an attendant who was there to help her with her daily routine, she decided to taper off her medications and ask her boyfriend to leave. Today, she believes herself to be the most independent since her injury. She attributes this to the change in attitudinal environment. She said, "I think a lot of that is just trial and error. Right now, I am the most independent I've ever been. I am driving. I'm able to do more things for myself in terms of getting in and out of bed and needing a lot less." Without narcotics and the pressure to remain sedate, she has begun to learn how to care for herself again.

Resources

Women used six types of resources in their health-promoting lifestyles: emotional, cognitive, physical, technological, monetary, and relational. Women needed the resources to balance competing demands and personalities. For instance, to develop a health-promoting lifestyle, the women had to negotiate for services from health care providers who had power over the distribution of health care services. Hence, the women had to be careful negotiators to gain what they needed. Women stated they needed emotional resilience when denied services to overcome sadness and/or anger. Emotional resources were also important when they needed to control their anger in the face of rude health care providers. For instance, Judith, who was 44 years old with cerebral palsy since birth, stated, “You didn’t want to make them (health care providers) mad or they may not help you.” They needed cognitive resources to understand where to gain health advice and what health advice was best suited for them. They also needed cognitive resources to figure out how to promote their health when providers had little idea about how to advise them. The women needed physical and technological resources to request and access services, and monetary resources to pay for the services. They needed relationships with people who could support them when other resources were low.

The most difficult aspect about resources, however, was being able to maintain or replenish them as time passed. The women knew that all resources were time limited. As time passed, it took more energy from them to garner more resources. Candice was 47 years of age and had muscular dystrophy. She needed 24-hour personal attendant care. She stated,

Yea, she (personal attendant) has been very, very caring so I feel very blessed to have her. But, I know her time will come soon and you know, to where she’s going to be tired of taking care of me. So, it’s kind of like going through a divorce or something over and over and over again with attendants. But at least it’s not ugly because I am kind of a nice person.

Perceptions of Self

Perception of self was the core concept that led directly to a health-promoting lifestyle. It was distinctly different for the women with an impairment onset prior to the age of 25 than for those whose impairment occurred after age 25.² For those with early onset impairment, perceptions of self intertwined with the meaning of impairment and/or functional limitation. Joanne, age 50 with a retinopathy of prematurity, stated, “I had a name and blindness was just part of who I was.” That perception of self might be negative or positive. For instance, Maria was 44 years of age with muscular dystrophy and at times had to fight a negative perception of self. She was divorced and currently dating. She was college educated and lived independently with a hired attendant. She stated,

But you know of course even now at my age, there is the concern that I am getting older. There are fewer men out there. Are any of them going to want me? I mean, if able-bodied women are having trouble, it is going to be double hard for me. It will always be a worry I think in the back of my head. It always has been, especially since I grew up with my mom telling me that you know your brothers and sisters are all going to get married, but you will probably live here with me. You know, that kind of. With the implication being no one is going to want you.

For the women whose functional limitation occurred later in life, after age 25 years, the women’s perception of self was situated in the past, built on how they were prior to functional limitations. Women’s energy was often invested on hope; hoping “it’s not a permanent disability that I have.” The women, who had visible, later onset disabilities, reported a sense of dissonance between their perception and the way they way they were

treated by others. They perceived themselves as they were before their impairments; it was unnerving to be treated otherwise.

Health-promoting Lifestyles

The health-promoting lifestyle that developed after the onset of impairment was the way the women led their lives in support of their views of health. It was comprised of the roles, rituals and changing abilities that allowed them to function as capable women.

Roles—The women’s roles were “the behavior pattern and expectations associated with a particular status” (George, 1980, p. 140), which included the responsibilities and rights associated with the role. The women’s roles included wife, mother, activist, sibling, employer, employee, and volunteer. Within the context of impairment, disability occurred when the women were no longer able to perform roles as previously performed or with the expected degree of responsibility and rights. The women with early onset impairment aged into different roles just as any woman might. Roles were highly valued. They noticed when they did not obtain the same rights and responsibilities in their roles as women without disabilities and similar roles did. They fought to maintain their roles along with the appropriate associated rights and responsibilities.

Any change in role function, responsibility, and rights would come abruptly for those with older onset impairment. Frequently, changes in roles accompanied by changes in relationships threatened their sense of health. Anne, age 54 with multiple sclerosis since age 38, discussed how her declining ability to perform activities associated with her role as wife interfered with her marital relationship. She said, being a wife depended on performing her role in a way

That would mean doing little things that were contributing to how our marriage worked. He’s very traditional. He would go off to work at his office and I would stay at home. I know that as I become less able to do things around the house, after he comes home from work, it falls to him, where he didn’t used to have to do that. Laundry, dishes, pick things up—pick up the house. Those were things I did. They’re hard.

Antonia, age 60 with impairment since age 56, stated, “You know I’ve been in the role of helping other people and it’s difficult to have that role-reversal.” She had been a nurse her entire adult life and found it very difficult to be the patient.

Rituals—Rituals are the repetitive acts or behaviors performed in a meaningful way to support perceptions of self. We observed two main types of rituals: routine rituals and disability rituals. Routine rituals were those repetitive behaviors women did that were unrelated to impairment. For instance, women reported getting up every morning and reading the newspaper and drinking coffee before starting their day. This was important for their perception of self because it was a ritualized behavior done to support perceptions of self throughout their entire adult lives. Disability rituals were impairment-related repetitive behaviors. For instance, a woman would report getting up every morning on the left side of the bed because her strongest leg was the left leg. She could easily transfer if she could slide over and pivot on her left when getting into her wheelchair from the left side of her bed. She was upset when nurses did not understand this ritualized routine during a recent hospitalization. If she got up on the right side of the bed, she was more dependent on help and this did not support her perception of herself.

Both routine rituals and disability rituals were either rituals for rituals’ sake or rituals for roles’ sake. Women with early onset impairment described rituals for roles’ sake more often,

whereas women with later onset impairment described rituals for rituals' sake. A ritual done for rituals' sake was done because it was always done; but if the women did not perform the ritual, it would not prevent them from performing their roles. Dorothy, a 70-year-old woman with a visual and mobility impairment for 5 years, stated, "I mean the family is continuously here. Somebody comes by to see me or check on me or something like that, two or three people, and when I get ready to see them all at one time, I give a party. And that's the way I was before." She did this at least three times a year for her entire adult life. She stated that this routine ritual was very important to her. The ritual helped her by keeping family members together to support and check on her, but if not done, it would not prevent her from performing roles within her family. However, it would interfere with her perception of herself and her sense of health.

A ritual for roles' sake supported perceptions of self and was the only way the women could function in their current roles. For instance, Gloria, who was age 53 years with muscular dystrophy, described a disability ritual for role's sake. She ritualized her fluid intake because she and her attendant scheduled bathroom breaks for morning, noon, and night only. She could not work in a public place any other way. She stated,

Your body gets used to it though. But then, like you don't drink water. You don't drink coffee. You don't drink tea. You know you don't put foods into your body. A disabled person [sic] can pretty much schedule their body after a certain amount of time like this when you can go to the bathroom.

Women would maintain disability rituals for roles' sake to maintain salient roles within their lives. These types of rituals were flexible because the women valued the role more than the ritual. The women would always prefer to perform the ritual in their chosen method, but because of power imbalances, attendants or providers did not always allow them to do it their way. For instance, Leslie would get up every morning by 7 am and transfer to her wheelchair to get to work. She hired a series of attendants; each time a new attendant came along, she went through a new series of very stressful steps to get in her wheelchair—a necessary ritual on the way to leaving the house for work. Leslie, age 54 with cerebral palsy, stated,

When I get new attendants, they are used to doing things their own way and so usually on those transfers, I tell them, 'I like to be transferred this way.' They'll try it the first time, but then you know they'll revert back to their own ways after awhile, so it'll be me adapting to them.

Leslie admitted that it

Is always, always, always very stressful just because you don't know how it's going to go until it happens. But the security that they have a good arm, you know, grab around you, that your knees aren't just going to slide between their legs and stuff. So it's. The very first time is very stressful no matter who it is, even if it's a big strong looking guy. If they don't lift with their legs and they get hurt right in the middle, they could just drop you.

Changing Abilities—Whether from an accident, illness, or age-related change, the women perceived changes in their bodies over time that demanded a compensatory response. The women would need to readjust their patterns and rituals of behavior that supported their roles and comprised their health-promoting lifestyle after they recognized a change in function. The lifestyle, in essence, revolved around ability. Elisa, age 52 with a spinal cord injury since age 29, stated, "It has taken me years to figure out what my health needs are really. And then, of course, they do change, so over the years, of course, I've had a

variety of health problems and a variety of solutions.” Claudia, who was 54 years old and had multiple sclerosis for the past 20 years, stated,

I try to get around without any, you know... just going from furniture to furniture. I fell in here and hit my head on that doorway and started bleeding and had to go to the emergency room and be stitched up. So, after that is when we really, I needed to use it (walker) some time. It just wasn't worth going to the emergency room. It was a huge; that was a huge step.

Claudia walked without a walker because she had always walked without a walker. It was a ritual for rituals' sake. Claudia changed her ritual for rituals' sake because she perceived a change in ability. This internal shift resulted in a change in her health-promoting lifestyle.

Self-determination as Healthy Aging

We asked each of the women about their perception of health. The women began their explanations with the phrase, “being able to do”. Although all of the women wanted to enact their will to feel healthy, the women did not need to accomplish their goals through the same means. In other words, women who were able to enact their will physically did so to pursue their health. Those women who could not physically enact their will used proxies to enact their will. They would use accommodations—either personal care help or another type of technological assistance—to enact their will. The use of an accommodation meant the women remained self-determined because accommodations were a means to an end. For instance, Carol, a woman who used an electronic wheelchair and attendant care, stated, “I would just like to be able to take care of my own business and my own life.” She did this by asking attendants to do the things that she wanted. She did not have to be the one performing the activity to feel healthy.

The pursuit of health and the focus of the women's self-determination and feelings of health evolved around their relationships. As noted by June, a 78-year-old woman with a functional limitation after a car accident, stated,

I can take care of my own activities very good and I clean my own house. I have good relationships with other people, so in terms of health, you know I believe in God, so in terms of health, I consider myself healthy, very healthy, healthier than I ever felt before the accident.

Discussion

The findings of this study are consistent with previous health promotion theories for people with chronic disabling conditions, in that environment, (Ravesloot et al., 2007) resources and barriers (Stuifbergen et al., 2005) are prominent influences on the development of a healthy lifestyle. Exposure to a confirming environment was helpful at any time after onset of impairment; therefore, this is a strong area for potential intervention. Currently, there are programs that teach adjustment and skill acquisition to people with later onset impairment by people with early onset impairment. Based on these results we suggest that it might be difficult for the two groups to understand each other's experiences without careful teaching and exposure to the others' perceptions of self.

The importance of understanding health promotion from the context of perceived health, rather than biomedical health (Blaxter, 2004), was a dominant component of this theory. The women wanted to do things that supported their ability to be the women they perceived themselves to be, and they wanted to influence their environment in a way that was consistent with that perception. This is important for understanding why women with disabilities do things that might or might not support their health from a strictly biomedical

definition. If both their perception of health and their biomedical health status could be supported through a lifestyle choice this would seem the best option for these women. In this context, researchers could tailor health promotion interventions to the needs of these women. For example, the woman with a spinal cord injury exposed to wheelchair basketball immediately after her accident developed an active lifestyle that supported her biomedical health. She maintained a healthy lifestyle as she aged.

On the other hand, when trying to change a lifestyle, interventions should not ignore the abilities, roles, and rituals that comprise an individual's lifestyle. For instance, asking a woman with a disability to drink more water for better hydration would be fruitless if she does not increase her ability to access a bathroom during work hours. In this instance, work roles would have to change or rituals would have to change before she could drink more water. Regrettably, other components of a lifestyle might change before either of those things change; she might have a change in her body's ability to function or lose her job before she is able to increase the ritualized way in which she drinks water. This adds support to those interventions that tailor lifestyle change to personal and environmental determinants of health, such as planning an exercise routine based on how a person feels when they exercise (der Ploeg et al., 2008). It advances research interventions with people with disabilities by theoretically specifying how abilities, roles, and rituals work together to be salient aspects of a woman's lifestyle.

When designing interventions for health care providers, researchers might combine these findings with the intervention work of Stineman and colleagues (2009) who studied clinicians using recovery preference exploration. This intervention encouraged clinicians to imagine functional limitations with problem solving. If the providers combined imagined experiences with these actual experiences clinicians might begin to perceive the difficulties women with disabilities face when adapting provider recommendations.

The women ritualized their disability activities because they interpreted the cultural rules for how a body behaves within space and time and pushed their bodies to respond in kind (Bell, 1997). We noted that women ritualized routine behaviors differently after comparing how patterns emerged because of variations in timing of impairment. We suggest that the importance of these repetitive behaviors is in the way the behaviors routinely reaffirm and support perception of self, role, and health. Those involved in the women's lives should also recognize the importance of ritual as a function of health promotion. In understanding the rituals as reinforcements of self, health and role, providers can take steps to respect and support rituals when making lifestyle recommendations.

This study is unique in that it advances our understanding of how timing of impairment influences the development of a healthy lifestyle. It is limited to the experiences of the 45 women with disabilities who participated. Overall, timing of impairment was important for skill acquisition and women's perception of self. Time also influenced the meaning their impairment held for them. Women with early onset impairment in this study, those with impairment prior to age 25, did not discuss mourning the loss of their previous abilities to the extent that women with later onset impairment did. Those with earlier onset also discussed a willingness to alter their rituals frequently because they focused on their roles more than on the rituals. This might be because the longer the women lived with a disability the more opportunity to be exposed to environments that supported their perception of self as capable women regardless of degree of impairment. This might have made the women more likely to assert their selves and demand a better environment when needed. Perhaps the assertion that older women become less likely to demand or expect independence, autonomy, or control, which might keep them from voicing their health needs (Zarb &

Oliver, 1993), is more related to the newness of the experiences than it is to the essence of getting older.

From this study, it was obvious that the women needed resources and confirming environments to optimize outcomes. We suggest that rehabilitation services that provide job training and accommodations also assess how women perceives themselves and give meaning to their impairment when implementing services. In addition, roles acquired prior to impairment (e.g. spouse) might become strained after impairment in ways that create a disconfirming environment, and in ways that add stress and place demands on women's lives. Hence, policy should be written to afford women adaptive support services immediately after onset of impairment to best influence her long-term healthy lifestyle development. We have considered that it might be as much the timing of impairment in the women's lives as it is the timing of the resources and the confirming environment in response to impairment. This deserves study using other methods of inquiry.

A positive aspect of the design of this study is the inclusion of women with varying types of impairment. This inclusion enhances our understanding of how disability influenced health promotion and ensures that the theory has broader applicability. The women in the study solved problems in overcoming impairment-related difficulties on a trial-and-error basis. Women with varying types of impairments reported learning about strategies from other women despite having different types of impairments. Those women with fewer resources were not always able to find other women with disabilities to ask about solutions to everyday life problems. Health care providers frequently knew of ways to treat health problems, but they could not provide guidance on problems the women encountered in their daily routines. An area for more research involves the sharing of trial-and-error-derived expertise across groups of women with disabilities.

Using methods of purposeful and theoretical sampling, we were able to create a theory amenable for testing among women. This study is not, however, generalizable. Researchers need to test relationships among the variables using larger diverse samples. Of note, this study was limited because of the inclusion of primarily White women. As researchers and health care providers, we need theories that focus on the experiences of women of color. During recruitment, we realized that to be culturally sensitive to the issues faced by the varied ethnic-racial groups of women, we needed a study of each ethnic group that also included women of varied impairment onset within those ethnic groups, which was beyond the scope of this study. In a previous study of women aging with the effects of polio, we found we needed to design a separate study to explore the ethnic specific experiences of Mexican American women with childhood onset polio (Harrison, Angel, & Mann, 2008). Moreover, this study included women living within their community; those living in more structured institutions might have different experiences. Men were not included in the study. It should also be noted that a case existed that did not fit the model created in this study. There were two women with cognitive impairments. One of these women was unable to think in a linear time perspective to anticipate future changes. She focused only on past perceptions of self as a woman without a disability. Hence, this model did not fit her health promotion experiences. Furthermore, researches need work to understand how those with cognitive impairments perceive their health after the onset of impairment.

In conclusion, we conducted this qualitative study to understand how the timing of impairment influenced the health-promotion lifestyles of 45 midlife and elder women with disabilities. A life course perspective provided unique insights into the processes through which age and impairment onset influence implementation, maintenance and change in health promotion practices over time. Women with early impairment onset primarily discussed their identity as integrated with their impairment. This made a difference in how

they viewed their abilities, roles, and rituals that comprised their health-promotion lifestyles. Researchers should consider timing of impairment, perceptions of self, and meaning of impairment along with the type of environment and resources available when designing personalized interventions for women with disabilities.

Biographies

Tracie C. Harrison, PhD, RN, FNP is an assistant professor in the school of nursing at The University of Texas at Austin.

Deborah Umberson, PhD is a professor in the department of sociology at The University of Texas at Austin.

Li-Chen Lin, RN, MSN is a doctoral candidate in the school of nursing at The University of Texas at Austin

Hsui-Rong Cheng, MSN, RN is a doctoral student in the school of nursing at The University of Texas at Austin.

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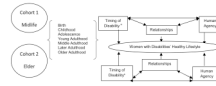


Figure 1.
Sensitizing Framework

^a Disability is a perception of an inability to do tasks and perform roles – usually related to a physical impairment situated within a non-accommodating environment. Because abilities vary over time, so do perceptions of aging and disability.



Figure 2.
Health-Promoting Lifestyle Depending on the Timing of Impairment