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Health Disparities among Latinas Aging with Disabilities

Tracie Harrison, PhD, RN, FNP [Assistant Professor]

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

Tracie Harrison: tharrison@mail.nur.utexas.edu

Abstract

Latinas with disabilities report greater levels of disablement than Non-Hispanic, White women with disabilities. Over the life course, Latinas experience increased numbers of functional limitations, more difficulties with activities of daily living, and more unemployment due to impairments. The reasons for this health disparity are unclear. The purpose of this paper is to explore the empirical evidence surrounding health disparities in disablement among Mexican American women. From this exploration, recommendations are made, including moving beyond the correlational documentation of disparities to building a knowledge base that provides theoretical reasons for disparities amenable to intervention.

Keywords

disability; aging with disability; women with disabilities; Mexican American women; minority health

Disability, the inability to carry out salient roles due to the social impact of impairment,¹ is a growing problem among Latinas. Although all women with functional or sensory impairments, such as those with paralysis, low vision, or amputation, are at risk for poorer health and social outcomes than women in general,^{2–5} Latinas with impairments, estimated at over 3 million U.S. women,⁶ report greater risk than White, Non-Hispanic (WNH) women. Latinas report increased numbers of impairments,^{7,8} more difficulties with activities of daily living (ADL), and more unemployment due to disability than WNH women.⁹ The reasons for the disparity are unclear. Hence, the purpose of this paper is to propose a framework, based in empirical evidence, for the exploration of health disparities in disablement among Mexican American women compared to WNH women.

What is disability?

The terms *pathology*, *impairment*, *functional limitation*, and *disability* are conceptualized based on Nagi's¹⁰ and Verbrugge and Jette's¹ descriptions of the disablement process model. The disablement process is an avoidable path from an injury or pathology in the body to the experience of being disabled. *Pathology* is the presence of abnormal physiological measures based upon normal human parameters. *Impairment* is actual injury to or deviation from what is considered normal cellular or organ system(s) function. A *functional limitation* is the inability to carry out physical activities such as running, talking, or writing. *Disability* is a perceived inability to perform socially salient roles such as being a voter, mother, or employer due to functional limitation. Each woman occupies a certain status within society with associated roles; those roles have associated behaviors. Each woman assesses her environment and interacts with it to achieve and enact roles.¹¹ 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. Disability and the related concepts of

pathology, impairment, and functional limitation may be influenced by extra-and intra-individual factors, as well as gender, genetics, and age.

For women aging with disability, age-based cultural norms have a direct impact on the disablement process; the fulfillment of a role is not only dependent upon ability, but also upon what roles and behaviors are expected to be fulfilled given the age-based norms of the group. All cultures use age to differentiate members.¹² As people age, cultures have different expectations for behavior. For instance, at later stages of life, elders may be deemed most competent in spiritual counsel, food preparation, and ethnic counsel, but less competent in matters of financial exchange, community planning, and sex therapy.¹³ When impairment occurs, culture guides when it is appropriate to be reliant and if resources will be available to support members.¹⁴

What is a health disparity?

Health disparities are defined as “a chain of events signified by a difference in environment; access to, utilization of, and quality of care; health status or a particular health outcome.”¹⁵(p117) Health disparities are frequently seen under conditions of inequality and inequity due to differential access to resources and a heightened level of risk to worse outcomes.¹⁶

Given the growing rate of impairment among Latinas,¹⁷ Markides¹⁸ predicts that an increasing number of older Latinas will live poor and alone, that intergenerational connections will weaken, and that institutionalization will increase. This is posited to be due to impairment-related stress, causing strain on financial and caregiving resources within the family and society. The possible stress of living with functional impairments on Latinas and their families cannot be overstated. Gender, disability, and ethnic/racial status are powerful determinants of health and well-being with age that contribute to stratification in outcomes. Ethnicity alone has been a recognized risk factor for health disparities in the U.S. for over 40 years.¹⁹

Is there evidence for health disparities in disablement among Latinas?

Although social and health outcomes are often worse for those experiencing impairment in American society, further health disparities in disablement are found when Latinas are compared to WNH women. Specifically, differences in treatments and reactions to impairments were found when Latinas were compared to WNH women. Andresen and Brownson⁹(p200) hypothesized that “ethnicity may be part of a social context for disablement.” This indicates that Latinas may experience and adapt to aging with impairments in ways that are influenced by their socio-cultural context. For instance, although the prevalence of impairments reported by Latinas (16.2% of Latinas) has been lower than that reported by WNH women (20% of White, Non-Hispanic women),²⁰ Latinas have reported more severe impairment than WNH women.^{21,22} Moreover, recent data suggest that rates of disability in Hispanics may be surpassing that of WNH people.²³ Latinas have reported more problems than WNH women performing activities of daily living when both groups report similar levels of impairment.²²

What are the influences on disablement that might impact health disparities?

Based on the empirical data on disablement, 4 main categories of influences on disablement are presented that may explain where differences in disablement^{1,10} outcomes arise between Latinas and WNH women. In synthesizing these influences, the extant literature was

reviewed for factors within these major categories that influence disablement. The results describe biological, psychological, social, and cultural influences (Figure 1).

Biological influences on disablement are those physical attributes extraneous to the women's impairments, but when combined with impairments are perceived to influence disablement outcomes. Five attributes reported to influence disablement are menopause, weight, pain, timing of impairment, and age.

The need to consider how menopause and weight influence disablement was evident when the cadre of disabling conditions that increases in incidence as women age past menopause and undergo weight-specific changes²⁴ was examined. For instance, impairments causing immobility may heighten the risk for venous thrombo-embolism,²⁵ cardiovascular disease,²⁶ and osteoporosis²⁷; all of which cause additional functional limitation. Further, given the possibility of weight gain with muscle loss after menopause,²⁶ women who are non-ambulatory may have difficulty managing their weight, which increases risk for venous thrombosis.²⁸ In a study of 833 Mexican American and European American elders aged 64 to 78, weight was indirectly associated with function (knee range of motion) when considering pain and pain intensity, indicating that pain is a factor to consider in disablement.²⁹ Pain has been reported a unique contributor to disablement among older women.³⁰ Overweight rural Hispanic females have been reported as the most likely group to be mobility impaired.³¹ Moreover, timing of impairment is a factor, as those who lacked a medical diagnosis and had a mobility problem in their younger years were more likely to maintain it into their older years.³¹

As women age, function may worsen due to problems such as arthritic inflammation and pain,³² delicate skin, increasing weakness, and loss of bladder and/or bowel control.³³ After menopause, women may have a decrease in overall muscle mass and increased adipose tissue. For women with long-standing functional limitations, an increase in adipose tissue with decreasing muscle alters the ability to stay nimble and transfer without aid, which can decrease their activity level adding to weight gain and diminished socialization.²⁴ They may also be at risk for injury as transfers grow to be more involved and complex. Hence, there was evidence for the need to include how biological factors, such as menopause, age-related change, pain, timing of impairment, and weight, were perceived to affect the disablement process.

Psychological influences on disablement are women's mental or emotional attitudes that affect their ability to perform desired activities given their level of impairment. The specific psychological factors considered influences on disablement among Mexican American when compared to WNH women were competency, fear of injury, positive well-being, and anxiety.

Several psychological influences on disablement experienced by WNH women were reported.³⁴⁻³⁸ Overall, having a positive attitude³⁷ with lower levels of anxiety³⁵ and depression³⁹ and less fear of injury³⁴ predicted lower levels of disablement among older WNH women. Few studies specifically focusing on the psychological influences on disablement among Mexican American women were found. In a study of 109 Latinas with arthritis, the authors used a theoretical model of well-being to test the effects of illness, competency, and gender role saliency.⁴⁰ Competency, which was a combination of self-esteem and self-efficacy, mediated the effects of pain, identity, and illness intrusion on well-being. There was a protective effect of the motherhood role on illness; roles increased competency. This was followed by a study of the same 109 Latinas with arthritis over 3 years.⁴¹ The women were interviewed about their positive experiences with growth and thriving after being diagnosed with arthritis. An enhanced appreciation of life, hope,

strength, spirituality, empathy, and a philosophy of being patient were given as descriptions of thriving and these descriptions were the basis of a tool used to measure thriving. Personal, illness, and socio-cultural resources were measured to predict thriving in the sample. The socio-cultural and illness factors did not predict thriving, but competency and psychological well-being were predictors. Although the socio-cultural factors did not predict thriving, there is support in the literature for the assertion that they may impact disablement. The author pointed to the influence of psychological factors on well-being, but did not address disablement. Further work on psychological factors and disablement is needed.

Social influences on disablement are the crystallized social relationships among members that place them into groups and relate the groups to institutional activities.⁴² Examples of institutions are marriage and government. Examples of the crystallized social relationships are economic class, gender, educational level, and political ideology. Social structure is closely related to culture because social structure is the referent from which all social groups and activities are given meaning.⁴² Social influences are unique from culture in that social influences are aggregate, fixed relationships present across various locales. Cultural influences give meanings to those social hierarchies within those various locales. For instance, researchers can study the impact of different levels of income without knowing what the income structure means to the people living in that society.

For both Mexican American and WNH women with disabilities, age combined with socioeconomic class appeared to be risk factors for higher degrees of impairment and less ability to perform specified IADLs.⁴³⁻⁴⁷ In a sample of over 890,000 men and women age 55 to 84 years, social class predicted degree of functional limitation regardless of ethnicity.⁴⁵ Further, Rudkin and colleagues⁴⁶ studied functional impairment in over 3,000 Mexican American, Anglo, and African American men and women over age 65 years. The Mexican American women had higher rates of functional impairment than WNH women. Increased impairment was associated with lower income, lack of homeownership, and lack of private insurance. Those with greater degrees of impairment were more likely to be in a nursing home. The authors posited that decreased socioeconomic resources could exacerbate an existing disabling condition, which could ultimately deplete resources.

Cultural influences on disablement include relationships, objects, and events laden with meaning because of their use and distribution within society. These include the dynamic, changing social values, knowledge, and norms learned and applied through observation, demonstration, and discussion.⁴⁸ The meaning shared between members is the relevant aspect that defines cultural influences, and language can shape all observation, demonstration, and discussion because language shapes available articulation of meaning. Demographers interested in disablement report that cultural factors (family support, language, and accommodation preferences) were associated with functional limitation and disability in Mexican Americans—both men and women.^{47,49-51} For instance, researchers⁵² report that lower education, language barriers, and variation in medication ingredients from Mexico all influence disablement outcomes among Latinos in the U.S. Studies of culture and disability among WNH samples in the U.S. focused primarily on psychological adjustment to living with impairment within an able-bodied society.⁵³

Most intriguing from a potential intervention perspective, however, may be the cultural factors that influence accommodation use and selection among Latinas and WNH women. According to Luborsky,⁵⁴ the impact of accommodations for persons with disabilities has not been realized because it is not known how to situate accommodations into culturally diverse lives. Accommodations are personal and technological devices that women use to adapt to change in their abilities. Accommodations are given meaning as people interact with the technology within a given culture, and despite their ability to alter disablement

progression by allowing women to continue in desired roles, women choose if and how to use them based upon culturally derived meaning. A thorough knowledge of cultural beliefs is required before implementing any type of accommodation successfully.

There are 2 main categories of accommodations for women with disabilities: personal care help (PCH) and assistive technology (AT). The types of assistance used are often a matter of choice. PCH is aid given to women directly from another person. This can be skilled or unskilled services provided by people such as family members, attendants, nurses, or therapists, which include services such as transferring a woman from one position to another, bathing a woman, or reading a woman her mail. Evidence suggests that the lives of women with disabilities, both Hispanic and WNH, are affected by PCH, primarily due to the saliency of family relationships, which is the primary context for PCH.⁵⁵ After all, “self-treatment by the individual and family is the first therapeutic intervention resorted to by most people across a wide range of cultures.”⁵⁶(p51)

Differences in the use of formal PCH between Latinas and WNH women may be due to various social influences, such as income, or various cultural influences, such as the meaning given to seeking services without citizenship. According to Erwin,⁵⁷ Latino immigrants may fear obtaining care or assistance when they lack legal documentation for being in the country. Latinos in rural settings reported easier access than those in urban settings because providers in rural areas were more likely to barter for health services; they provided care in a less formal and costly manner with fewer obstacles. Women stated that their legal status and limited access to health care resources diminished their ability to advocate for themselves. Lacking health insurance has been a barrier to accessing services for Latinos.⁵⁸ In the U.S., 41% of Latinos and 70% of WNHs are insured.⁵⁹ Those in rural areas may have a higher likelihood of being uninsured due to employment in low-wage and low-benefit jobs.⁶⁰ Subsequently, differentiating whether accommodation use is indirectly related to social influences or directly related to cultural influences is difficult without observant, interactive research.

AT includes both assistive technology devices and services.⁶¹ AT devices include items such as a wheelchair, leg brace, or grab stick. AT services enable a person to choose, obtain, and use AT. AT can influence a woman’s perception of being disabled, given any degree of impairment or functional limitation. Technological accommodations may slow the rate of disablement in persons with impairments.^{62,63} People who use a device, such as a cane for mobility, are more likely to perform needed activities. Technological accommodations may also improve psychological outcomes.⁶⁴ Improvement in function extends to the ability to maintain an ADL when built environments are adapted to a person’s needs, which includes ramps and accessible toilets.⁶⁵ People who use more accommodations in their home need less help from others, allowing those with disabilities more control over their lives.⁶⁶

Despite ample numbers of technological accommodations, Latinos report less use than WNH people with disabilities. There are more than 29,000 different disability-related accommodations, the most common being canes, walkers, and wheelchairs.⁶⁷ It has been estimated that Latinos (38.7%) with disabilities used any type of assistive device less than Anglos (44.5%).⁶⁸ In this group of Latinos with disabilities, there were no reports of electric wheelchair or scooter use.

What is missing in the health disparities and disablement literature?

The first and most pressing issue that should be addressed is related to disability theory on health disparities. The literature is replete with documented associations between primarily socio-cultural independent variables and disability-related dependent variables. These

studies are largely population-level studies that only show that health disparities exist. Currently, however, theoretical explanations founded in empirical data are needed. Documenting an association within a sample and theorizing a fundamental cause of disparities in disability outcomes are different. In other words, health disparities have been documented in disability-related outcomes in women, but theoretical explanations for the differences in outcomes are missing.

It could be posited that a health disparity is a health disparity and one could apply any model of health disparities to disablement outcomes and reap a thorough understanding. In other words, health disparities models suggest that differential outcomes are primarily related to resource distribution and elevated risk.¹⁶ Accordingly, intervention work might focus on providing more resources and decreasing risk with the goal of diminishing inequity and inequality. However, this broad approach would ignore differences that groups uniquely use to adapt to disability that might provide them with advantage. It would also ignore the cultural meaning groups give to disability and accommodations. In other words, using a broad approach, it could be theorized that 1 group with impairment stays employed longer because they use more power wheelchairs. Then researchers could provide the other group, who are not staying employed as long, power wheelchairs. But without an understanding of how power wheelchairs are used, and if they are preferred by the second group, the researchers are at risk that their power wheelchairs would be rejected. Further, it may be that certain members of the second group are employed for a substantial period, but cease employment due to differences in the meaning of gender and disability in the context of age-based norms. Studies of influences on disablement suggest that factors beyond resources and risk reduction may be responsible for differences in outcomes between Latinas and WNH women. Resources may be a dominant social factor, but psychological, biological, and cultural factors also play a part.

A second issue that arises from this review relates to the description and classification of samples for comparison to uncover health disparities in these largely descriptive quantitative studies. The majority of studies report that the WNH racial group and women of Latin American descent are combined into 2 distinct groups for group-level comparison. Such groupings are a limitation when studying the influences of cultural beliefs and behaviors on health disparities. There are many group differences among Latinas based on nationality of origin and regional residence.^{69,70} Admittedly, researchers have begun to acknowledge these cultural distinctions among Latinas and have defined their samples with groups consisting exclusively of Mexican American women or compared outcomes among various groups of Latinas. Few researchers have gone so far as to examine the regional differences among groups with the same nationality of origin. Mexican American women aging with paralytic polio described regional differences among their experiences in a recent qualitative study.⁷¹ Further, it has not been considered what defines and leads the WNH group to manifest better outcomes. Race as a socio-cultural construct deserves further exploration in the context of disablement. This is especially true given that multiple indicators stratify women in society; the population of WNH people with disabilities in American culture has been characterized as vulnerable and marginalized when compared to those without disabilities.⁷² How ethnicity fits into the social stratification of women with disability requires a thorough understanding of all groups being compared.

A third issue that should be addressed is related to within group, or gender-specific, differences in outcomes among women. Frequently, studies compare population-level data obtained from men and women of varying ethnicity—allowing the reader to comb through results to find which groups have the best/worst outcomes based on gender and ethnicity. Fewer studies were designed to specifically explore disablement outcomes between Latinas and WNH women. In the third wave of feminist scholarship, researchers and philosophers

documented that the experiences of specific groups of women should not be generalized to all women.⁷³ They asserted that WNH women do not represent all women within society. Being able to view differences in women's outcomes based upon ethnicity works toward that goal. Further work on variations in women's health outcomes relative to women's varied position in society is needed. A focus solely on women's experience with impairment is necessary to follow trajectories of disablement influenced in culturally varied ways to develop a knowledge base built on diversity.

Fourth, disability occurs throughout the life course and the timing of the impairment may influence self-perception and skills developed to accommodate impairment. Further, ethnicity affects beliefs and values over the life course, not just in later life. Hence, the disablement process model, along with social, biological, cultural, and psychological influences, should be viewed from a life course perspective. The disablement process when viewed from a life course perspective^{74,75} assumes that disablement has trajectories and transitions that occur over time and are influenced by cultural beliefs.

Finally, these studies do not explore the protective nature of Hispanic culture in the context of disability outcomes. Twenty years ago, it was reported that the mortality rate of Mexican Americans in the Southwest was lower than what would be expected, given their socioeconomic status as a minority group.⁷⁶ Over time, this phenomenon gained support through national mortality indicators.⁷⁷ Hence, the phenomenon of increased survival for Mexican Americans aging as a minority population with fewer socioeconomic privileges than the WNH majority was labeled "the Hispanic Paradox." Negative outcomes of aging with a disability may be buffered by cultural practices and beliefs, but little work has been done to fully understand Hispanic culture and the meaning of disability.

What is needed at this juncture?

Qualitative research is needed to build the theoretical knowledge base on health disparities in disablement. One distinct methodology that would allow researchers to create the knowledge needed to address these issues is ethnography. Ethnography offers the means to explore lives in ways that explicate experiences with disability that are "difficult to capture through any other methodological means."⁷⁸(p346) Ethnographic data obtained by direct observation and assessment can support or elaborate self-reported claims of causality.^{79,80} Researchers could address additional questions, such as how long Mexican American women with impairments remain in the work force, what types of jobs they do before leaving work because of their functional limitations, and are these the same for WNH women? Further, do low-income Mexican American women use accommodations for impairments differently than low-income WNH women? Do Mexican American women with disabilities view their age-based norms for behavior the same as WNH women and what impact does this have on disablement? In other words, comparative studies could be conducted that explicate where health disparities exist between clearly described samples of women. Based on this work, concepts could be defined with clear relationships and theoretical assumptions.

Conclusion

Researchers have alerted healthcare providers to ethnic-specific differences in health-related outcomes in Latinas living with disabilities, but the reasons for these differences are absent from the literature. Ultimately, all women with disabilities may benefit from knowing about the age-related problems faced by women with disabilities from other cultures and how women routinely draw from their cultural backgrounds to solve the common problems they encounter. Researchers are currently at a crossroads with the current level of understanding

of health disparities in disablement outcomes. There is a choice. Work can continue to document disparities in outcomes or careful explorations of health disparities built on a clear knowledge of groups and firm theoretical underpinnings can be developed. Qualitative research, and specifically ethnographic studies, offers the means to develop the latter.

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Figure 1.
Influences on disablement documented in the literature (source: author).