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Burden of Restraint, Disablement and Ethnic Identity: A Case Study of Total Joint Replacement for Osteoarthritis

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Abstract

Health disparities in total joint replacement have been documented based on gender and ethnicity in multiple countries. Absent are studies exploring the meaning of the procedures among diverse women, which is necessary to fully understand the impact of the disparity. Drawing on ethnographic data from a life course exploration of disablement among Mexican American women with mobility impairments, one woman's reasons for forgoing a joint replacement are considered. It is suggested that inequalities in disablement cannot be understood without considering the mulitple cultural conflicts and loyalties that push and pull women in multiple directions.

Keywords

Disability; Ethnic Identity; Aging with Disability; Mexican American; joint replacement; arthritis

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Health disparities have been reported in multiple countries including the United States (Tripp-Reimer, Coi, Kelley, & Enslein), Germany (Voigtlander, Berger & Razum, 2009), United Kingdom (Shelton, 2009) and Australia (Sabesan & Piliouras), just to name a few countries. One potential marker for the presence of health inequities in a society is the rate of elective total joint replacements (TJR) across racial and gender lines for the pain and disabling effects of osteoarthritis (OA). Countries such as Italy, Sweden, Norway, Finland, Denmark and Australia have set up registries to monitor outcomes and demographics associated with TJR (Stea, Bordini, De Clerico, Petropulacas & Toni, 2007). Gender and/or ethnic disparities in the rate of TJR for OA have been reported in the United States (Skinner, Weinstein, Sporer, & Wennberg, 2003) United Kingdom (Jedge, Welton, Sandhu & Ben-Shlomo, 2009) Australia (Wang, Simpson, Wluka, Urquhart, English, Giles et al., 2009) and Canada (Hawker, Wright, Coyte, Williams, Harvey Glazier & Badley, 2000) while researchers in New Zealand have reported variations in OA disease severity based on level of poverty (Eachus, Chan, Pearson, Propper & Davey, 1999). The treatment of OA has emerged as a potential international marker for health disparities based on race/ethnicity or gender. Research that addresses the reasons for differential rates in TJR is needed. Hence, the purpose of this manuscript is to report the findings of a qualitative investigation of the reason why a Mexican American woman living in Texas, USA refused TJR for OA. Readers will gain insight into why this woman believed that one procedure would not correct the inequities she has experienced in life nor would it relieve the burden of restraint associated with her ongoing health care. Suggestions for further research and health care are provided.

Arthritis is the most widespread cause of impairment with associated functional limitations and disability among aging women(Arthritis Foundation, 2008). Women and ethnic minority groups have higher rates of osteoarthritis (OA) with worse functional limitation and disability, e.g. the inability to carry out salient roles due to the social impact of impairment (Verbrugge & Jette, 1994), than Non-Hispanic White (NHW)men (Dunlop, Manheim, Song, Soh, Feinglass, Change & Chang, 2008; Steel, Clark, Lang, Wallace & Melzer, 2008; Skinner, Weinstein, Sporer, & Wennberg, 2003). Further, despite evidence suggesting improvement in pain, function, and disability for people with OA who receive total joint replacement (TJR) as a surgical treatment, there are ethnic and gender differences in the rate of TJR (NIH Consensus Panel, 2003). Defining health disparities 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” (Carter-Pokras & Baquet, 2002, p.117), there is a health disparity in the treatment of OA for Mexican American women. Statistically fewer Mexican Americans than NHWs receive TJR for OA (Dunlop, et al, 2008; Steel, et al, 2008; Skinner, et al, 2003).

There is a dearth of research exploring the beliefs regarding disablement and its treatment among Mexican American women (Harrison, 2009). The majority of research exploring health disparities in TJR for OA has been done comparing surgical rates and outcomes among African Americans as compared to NHWs participating in large epidemiological studies. In this paper, I explore the beliefs of a Mexican American woman with OA faced with the option of having TJR. This study takes steps toward an understanding of how health disparities in disability develop from the larger context of life course events. It is posited that health disparities arise not from any one single interaction within the healthcare system but instead arise out of alternatives and choices made from a life course position of disadvantage. Overall, a position of health equality cannot be gained from one single therapy, or in this case, one TJR.

Osteoarthritis is a chronic, degenerative disease of the joints affecting 27 million Americans (Arthritis Foundation, 2008) and costing individual patients over $8,000/year, which includes about $3,000 in direct costs for medicines and medical care and about $5000 in indirect costs for work days lost (White, Birnbaum, Janagap, Buteau, & Schein, 2008). The etiology of OA is basically unknown; a mismatch between the formation and degradation of articular cartilage is known to occur (Struyf, van Heugten, Hitters, & Smeets, 2009). The intra-individual factors that influence risk for OA are obesity and age (Felson, Lawrence, Dieppe, Hirsch, Helmick, Jordan et al.,2000), which makes OA an increasing concern as our population ages.

OA is disabling but not life threatening (Vignon, et al. 2006). Functional limitations from OA result from joint pain and stiffness (Stitik, Kaplan, Kamen, Vo, Bitar, & Shih, 2005). In early stages, the mobility limitations associated with OA may be transient and tolerable to the individual as the pain usually occurs primarily with movement and can be relieved with rest (Stitik, et al, 2005). The stiffness that occurs in early stages usually resolves within around 30 minutes of activity. It is in the later stages of the disease where individuals lose the ability to function permanently and become severely disabled. The pain of OA is characterized as both chronically aching and acutely stabbing; as the disease progresses little may be done beyond pharmacological intervention to ease the discomfort experienced with ambulation. OA patients are prescribed multiple pain relieving medications in addition to other medications frequently taken for multiple co-morbidities (White, et al, 2008). Ultimately, the treatment for OA is elective; treatment decisions are made by the patient after consultation with family and friends as well as the physicians involved, which may include a primary care provider, rheumatologist, and orthopedic surgeon.

Currently, the most effective treatment for OA of the hip or knee is TJR when individuals are not receiving adequate improvement with pharmacological and non-pharmacological therapies (Zhang, Moskowitz, Nuki, Abramson, Altman, Arden, et al., 2008; NIH Consensus Panel, 2003). Surgery should not be delayed regardless of gender, age or weight (Santaguida, Hawker, Hudak, Glazier, Mahomed, Kreder, et al., 2008). The primary reason given for TJR among those with OA is pain and difficulty walking (Hawker, et al., 2000). Overall, there are over 800,000 hip and knee replacements done annually in the United

States (Iorio, Robb, Healy, Berry, Hozack, Kyle, et al., 2008). Despite recommendations to the contrary, people may wait to have TJR until later phases of the disease when they perceive that the benefit outweighs any risk of surgery; NHW men tend to perceive less risk and have less pain and disability prior to TJR than other racial/ethnic groups and women (Gandhi, Davey & Mahamed, 2008). The pain relieving and functional improvement associated with TJR are diminished when the surgery is performed at later stages of the disease. Further, those who have TJR performed at low volume hospitals(e.g. hospitals that perform the surgeries less frequently)tend to have worse outcomes than people who have them at high volume hospitals(SooHoo, Zingmond, & Ko, 2008).

Mexican Americans have been reported to use low volume hospitals for TJR more frequently than NHWs, which puts them at higher risk for negative post-operative events such as pulmonary emboli and infection(SooHoo, Zingmond, & Ko, 2008). Women also opt for continued medicinal treatments rather than surgery because they contemplate worse surgical outcomes than NHW men despite their higher levels of disability (Gandhi, Razak, Davey, & Mahomed, 2008). Decreased access to care combined with poorer outcomes from delayed surgery and the possibility of using low volume hospitals, may all contribute to health disparities among Mexican American women with OA.

According to Nyamthathi and colleagues (2007), health disparities occur because some groups are at higher risk but have less access to resources. Further, the disadvantage must by ground in a social disadvantage that systematically and frequently, if not persistently, places one at risk (Braveman & Gruskin, 2003). The goal of health disparities research is the elucidation of “the individual mechanisms that are responsible for diseases and disabilities that contribute to health disparities.” (Thomson, Mitchell, & Williams, 2006, p. 24).

In understanding health disparities, considerable emphasis has been placed on the difference between equity and equality, as well as the need to not only count procedures but also study the impact of those procedures (Thomson, et al, 2006). In understanding the impact of discrepant rates of TJR for OA among Mexican American women, researchers need to go beyond counting the frequency of procedures. It must be considered if the lack of TJR placed an aging Mexican American woman at risk for worse quality of life than someone who received TJR. Moreover, it must be considered how the woman interprets her experiences and medical options.

When taking into consideration how a Mexican American woman comes to interpret the meaning of OA and TJR, the works of Kaufman (1981), Blumer (1969) Mead (1934) and Resaldo & Flores (1997) are useful. Consistent with tenets of symbolic interactionism (Blumer, 1969; Mead 1934), it is assumed that people act depending on the meaning of events, the meaning of events is derived from interactions, and meanings are subject to on-going interpretation and modified based upon reflections. The process of coming to understand cultural rules is reliant upon continued interaction with people and their cultural objects and interpretations to create a behavorial environment. It is within the behavioral environment that a person claims their ‘cultural citizenship’, e.g. the performative act of claiming Hispanic identity through aesthetic presentation(Rosaldo & Flores, 1997). Ethnic identity is the psychological and social meaning invested in the labels that describe their ethnicity (Quintana & Scull, 2009). The individual uses their biography to convey how culturally derived rules sequence their particular choices and subsequent way of life (Kaufman, 1981). I posit that this Mexican American woman used her biography to relay how she negotiated her place in the world through objects and private acts of aesthetic value, and these are of primary importance when understanding her disability and making treatment decisions.

In this paper, serious consideration is given to the issue of health disparities in disablement outcomes among Mexican American women as exemplified by the life history of Josie, a woman born and raised in Texas and currently living with the effects of OA. Her life story is part of data collected for an on-going ethnographic study exploring health disparities in disability related outcomes in Mexican American as compared to non-Hispanic White women, which currently includes a total of 46 Mexican American women and 28 Non-Hispanic White women.

Method

Life History Case Study Research

This life history research focuses on the topic of disablement within a feminist perspective. Life histories are used to investigate the cultural dimensions that influence a biography(Kaufman, 1981; Mandelbaum, 1973). As people narrate their biographies they speak within the context of the societal and cultural forces that give meaning to the interpretation of their lives. Kaufman stated that life history narratives inform readers of the “dynamics of individual life experience, such as the changing interpretations and meanings of different life stages, types and degrees of adaptation to social pressures, and fluctuations in self image, attitude and behavior” (1981; p. 58). In participating in the life history interview, women bring us into the sequencing of events that demonstrate how cultural and societal pressures are set in motion and build over time to push their health needs away from the primary interest of society.

From a feminist perspective, this research highlights the experiences of women and the significance of gender in social life, presents women’s way of viewing the world, challenges objective norms while legitimizing personal experiences as legitimate scientific knowledge, ethically attends to the position of women in the scientific process, and works toward the empowerment of women through research (Cook & Fonow, 1986). The researcher also acknowledges the fragmentation that exists in the category of ‘women’ (Butler, 1999), which requires that the experiences of women not be generalized across all women (Tong 1998). Variations in women’s health outcomes relative to women’s varied position in society must be understood as an intersection of experience(Kelly, 2009). In this instance, it is asserted that gender, when combined with ethnic minority status, creates a unique stance toward the experience of disablement in the context of OA and the option of TJR.

Sample and Participant Selection

The participant discussed in this paper was one of 74 women currently participating in an on-going ethnographic investigation of health disparities in disablement. After approval from the institutional review board and the issuance of a certificate of confidentiality by the Department of Health & Human Services, participants were purposefully recruited using targeted notification of agencies working with older women in various communities throughout Texas. Flyers that contained contact information and return envelopes for address cards were dispersed. Women interested in participating returned their cards through the postal service and they were contacted and screened for participation. Women were included if they lived in Texas, reported a mobility impairment, identified as Mexican American or Non-Hispanic White and were between the ages of 55 to 75 years.

Data Collection

The participant whose data is used for this analysis completed four individualized life course, topical biographical interviews regarding experiences with disability, life history calendars and structured interviews. The interviews, done by the PI (TCH), were open-ended conversational explorations of the women’s experiences with disability over the life course.

The open-ended topical biographical interviews were conversational. They started by asking the participants to recall their first experience with a person with a disability and relate what that person was like to them at that time. Next, they were asked to recall their own experience with disability and then describe their own experiences while working forward to present day. The four participant meetings lasted two to nearly four hours each. The first three meetings with this participant took place in a private meeting room of a senior center and the last took place in the participant's home. Participant observation was done as part of the interview process at the senior center as well as at her home, and field notes were written after each interview.

Data Analysis

The data collected from this participant was pulled from the larger data set and analyzed separately with the specific goal of understanding Ms. Josie's (pseudonym) decision regarding her OA treatment. First, demographic data was summarized, which may aid in the judgment of transferability of the interview data. The audio-taped interview data was transcribed verbatim, checked for accuracy and printed for hand, line-by-line coding. Both domain and content analysis of the interview data was performed. A domain analysis is a process of systematically identifying like items into typologies or meaningful clusters of symbols that fully describe a common referent (Le Compte & Schnesul, 1999; Spradley, 1979; 1980). The resultant domains are “large units of cultural knowledge” (LeCompte, 1999, p. 71). Aspects of disablement (Verbrugge & Jette, 1994) were understood through the domain analysis. Next, an inductive qualitative content analysis was done to understand Josie's treatment of OA and the influences on her disablement in the context of OA.

Results

Josie was a 74-year-old Mexican American widow living in a neighborhood she described as, “le barrio”. She grew up and married while living in the neighborhood, and she currently owned a one bedroom, white wooden home where she lived alone. She had no children. Josie was a reserved woman with a stern look with a seemingly careful approach to life in general and people more specifically. At five foot 2 inches, she weighed 243 pounds.

The last time I saw Ms. Josie, she stood on her porch wearing a skirt and blouse, the skirt waving in the wind. She looked down the street and recalled the dances and neighborhood parties she enjoyed. Then she turned to look the other direction and described the neighborhood gangs that had invaded a large building at the end of the street and the white couple who had invaded the home across from hers. She said, “I guess it's ok. I never really hear much out of' em.” The expression on her face, however, told me she did not care for either neighbor. There were neighbors she did enjoy. A Mexican American woman of 75yearswhose fenced yard was decorated with bottles, wind chimes and the Mexican flag was spoken of with admiration. A Mexican American gentleman, who walked by frequently and stopped to talk, made her blush. She appreciated his banter—banter that reminded her of who she was, which she summed up nicely by saying, “Some ways are Mexican, some ways are me.” She then said, “I live in the past.”

Josie's tie to her ethnic identity and past experiences influenced her present decisions to forgo a TJR for OA, which is described using three themes from the analyses. The qualitative themes of ‘The Cultural Burden of Restraint’ and ‘Body Aesthetics: “Don't give up – keep trying to look the best you can”’ illustrate what Ms. Josie values from her ethnic identity and how her illness, pain, function and treatment prevent her from participating in and effectively demonstrating the nuances of her cultural citizenship. She was disabled because she was deprived of full participation in her culture, which from a gendered perspective necessitates personal demonstration. The theme titled ‘A Series of Missteps’ describes her memories of the healthcare system and how a single act of having a TJR would threaten her immediate ability to maintain the remnants of culture that support her, while offering no perceived guarantee of support, improved pain or function and quality of life.

Disablement

As a child Josie had scarlet fever as well as other childhood illnesses. She remembered a diagnosis of mumps and tonsillitis, which she received special teas for from her grandmother. Josie also had a history of hypertension, high cholesterol and valvular heart disease caused from the childhood strep. Josie was quarantined during her childhood with only her grandmother to care for her during that childhood illness. Overall, 40% of Josie's life was spent with a diagnosed illness.

Josie was active in her youth but had lifelong issues with mobility restriction due to weight, illness and/or menstrual problems. Josie remembered that by age 22 she weighed 200 pounds, by age 30 she weighed 260 pounds, by age 45 she weighed 345 pounds. She said, "It's after I married this late husband of mine that I went all the way up to 345. It did not bother me at all." He was a thin man and his doctor instructed her to cook with more butter to help him gain weight. They both gained weight. By age 46 she was diagnosed with diabetes and a peripheral neuropathy in her feet. In her early 50's she became very sleepy and her vision worsened. She was told it was menopause. When she was 56and working as a cook for a day care center she experienced the effects of OA. Her memories are of weakness and pain in her knee. She stated, "I say why, why are my knees weak, or something like it? It would just sort of hurt a little bit, but I didn't pay much attention to it." At home, she accommodated this problem by holding on to her husband's arm. At work, she accommodated this problem by cooking on a stool despite her physician recommending she quit her job. Overall, 60% of her life was spent with some limitation inmobility and function. Primarily, she was limited by the pain she felt deep inside her knee when she walked. She was also stiff and would have liked more flexibility. She stated, "I don't get depressed because I'm alone. Ah, in fact, I don't get depressed but sometimes I, I feel like I just choke-up because I can't walk like I used to. I'm okay."

By age 64, Ms. Josie was feeling enough pain in her knee and shoulder that she stopped many extra activities, including work. Due to the withdrawal from activities over the past 10 years, it is suggested that14% of her life was lived with some experience of disability. She would, however, spend some time at the senior center with friends and she remained active in the center's activities of latch hook, bingo, and the annual diez y seis celebration. For mobility, she used a cane in public and a walker at home. She treated her pain with holy water, Marijuana Mexican salve, Darvocet and rest. Over the past 10 years, she has had two surgeries: the removal of a discolored spot from her toe and a heart valve replacement. Both surgeries had memorable effects on her ability to function. She required assistance from her now deceased husband after the first surgery, and assistance from one of her five sisters after the second. She stated that both surgeries left her with residual limitations and memories of needing assistance from people who were no longer available. About five years ago she was told she would need a TJR. She recalled, "I said, is it that bad already? He said, no, but it will be in later years." She refused the surgery. "My sister said why are you afraid, why are you afraid now, you weren't afraid of heart surgery? And I wasn't. When I went to heart surgery, to me, I didn't think about it at all." The following themes will shed light on Ms. Josie's decision to forgo TJR.

The Cultural Burden of Restraint

A tension existed between Josie's abilities and her ethnic identity. Her ethnic beliefs not only provided her with pleasure, as well as ideational support, but also compelled her to demonstrate those beliefs to bond with other Mexican Americans of her past and present. Those actions had a societal function of reproducing Hispanic culture, a psychological function of reaffirming her ethnic identity, and a social function of increasing her affiliations with past and present members. These physical acts demonstrated her beliefs and her role within her culture and without them she felt as though she was on the margins of society unable to fully participate. As her abilities diminished, like a chair slowly rocking back and forth until finally put to rest by force, she was removed from her compulsory drive to demonstrate her cultural beliefs by the pain and stiffness of OA. She felt she could no longer pleasure a man, sit and kneel at church, dance and cook; she was disabled. The performance stopped and the cultural citizenship was threatened because it was embedded in the act and in the belief, an intertwined aspect of mind and body.

Josie's ethnic beliefs contained both meaning and action within her personal space. She did not have to perform the acts of being a Mexican American woman in the presence of an audience for it to have the impact of affirming her cultural citizenship. For instance, cooking required a physical ability and the product of the act was nourishment and pleasure for the partaker. In providing these, Josie was able to reproduce her ethnic identity. As these ethnic-specific activities were taken away due to illness and loss of ability, all that was left was sustenance of futility. She cooked, but without taste or flavor. She remembered the love of her husband, but without bodily pleasure or future intent. She moved, but without rhythm or direction. She worshiped, but without passion or testament.

Although marriage, food, worship, and dance all pulled together to support Ms. Josie's cultural citizenship, I am limiting my discussion to food. Ethnic identity, food, acts of celebration and pleasure were warmly intertwined for Ms. Josie. For health reasons, she was told, however, to follow a diabetic diet, a low sodium diet, and a low fat diet. At 243 pounds, Josie was not without caloric intake. Regardless, she "longs for food" and had not recenlty felt a sense of satiety. She wanted to cook meals from her past; she was envious of the food enjoyment of others. She stated, "I was fed with love—not the best way." In this statement, she demonstrated the conflict between the emotion, belief, and action that represent her cultural beliefs surrounding food. Even if she were able to enjoy a full Mexican diet, she could not stand at the stove long enough to cook the meals she enjoyed in her past.

Ms. Josie currently explained her health problems in terms of food and a burden of restraint. The food that once gave her bodily pleasure and her life purpose while tying her to Hispanic culture now gave her fear. She explained that every illness had its own food restriction. Given her diabetes, she declared that "the pancreas is your enemy!" She feared the loss of body parts and function in relation to food. At times she was scared she would, in one meal, "eat the wrong thing and permanently damage my eyes or feet". She feared a stroke and the loss of speech from eating salt. She feared leg pain and cramps from eating too much sugar. She had lost not only the ability to cook, to nurture family with food, to celebrate with food and to make a living by cooking; she had lost the pleasure of her ethnicity. She sensed that she slipped away from what made her the woman she was. Ms. Josie did not believe that a TJR would relieve the burden of restraint.

Body Aesthetics: "Don't give up – keep trying to look the best you can"

As a part of Ms. Josie's cultural citizenship (Rosaldo & Flores, 1997), she had strong, albeit inconsistent, views of attractiveness. Despite her minority status under the influence of a majority's overwhelmingly biomedical explanation of the ideal female body she perceived aesthetic value to her body. She was aware that people judged her appearance as a Mexican American woman and she questioned her choices, but held fast to many values. For instance, a woman of 5′2″ and 243 pounds was considered obese in biomedical terms. She was fine with her weight when she was 345 pounds. At the same time, she thought arm flesh was unattractive, so she wore long sleeves. In fact, although she enjoyed her weight, she thought her fat should be unexposed. She said, "I see people with fat exposed and they seem happy. Not me, I care how I look." Further, she was aware that a surgical scar from TJR was considered necessary for function within biomedical terms. She considered knee surgery to be a source of disfiguring embarrassment. She commented, "There's this lady had it done and her knees just look grotesque." The thought of putting metal inside of her body to improve the ability to move was repulsive. She did not want it inside her. When a woman showed the world a bad appearance, "she is saying heck with it or I don't care." When pondering the possible benefit of TJR, she responded "all the people who know me are gone —who is there to see my shame?"

She found certain aspects of her body aesthetically problematic. She was upset by her incontinence and found it difficult to accept help from others because she did not wish to disclose this aspect of her body. She would slowly make her way from the bedroom to the bathroom at night to urinate, but frequently dribbled urine along the path. "The urine has come out. Oh, my God. And that's it. Sometimes by the time I sit on the commode, I release more fluid, more urine." She was, able to mop up her urine the next day when incontinent during the night; her ability to cover the smell allowed her to tolerate the failure of her body to hold her urine. "Oh my God, I don't know. I don't want people ever to come to my house and the house smells of urine, so I get my mop." The incontinence was aesthetically problematic to her and a reason not to have people come help take care of her after a surgery. From an aesthetics perspective, for Ms. Josie, TJR would not be an improvement, it would be deterioration.

A Series of Missteps

In their discussion of performance and cultural citizenship, Rosaldo and Flores (1997) wrote, "Experience is never neutral. It is the product of political negotiation, ideological motivation, and human desire, underscoring the problematic and processual dimensions of social life." (p. 125) Here I posit that Ms. Josie judges the performance of the healthcare system from her position of a Mexican American woman as a system of neglect and maltreatment. The missteps judged to have occurred within the healthcare system over the course of Ms. Josie's life were taken account of as performative evaluations of future acts to come. These were gradually discussed over the course of the 4 interviews and provided as evidential support for not having a TJR.

As Ms. Josie spoke, she recounted numerous acts of in eptitude on the part of the healthcare system. After her surgeries she felt uninformed, violated, with worse physical function than before surgery. She recalled that she was asked to sign a consent form for "removal of a small black spot on her toe". She was told it was minor surgery and necessary to prevent the spot from spreading. After the surgery she read the consent form and found a paragraph where she consented to an amputation that was not performed. She was very angry and felt uninformed. At her home, she was required to sit in her truck, parked outside her house waiting for the rain and wind to subside because she had no help ambulating into her home; meanwhile a tornado decimated a small town 30 miles away. She thought she could have stayed in the hospital another day. She was told she had to go home. On her follow up visit, she said she was cut by a scalpel to check her circulation. The provider happily stated, "You are bleeding like a stuck pig." She felt insulted. "Those remarks stick with you." After heart surgery, she said, "I felt violated. And I have no idea what they did. Did they damage areas of my body, a nerve?" She also thought she was left lying in her bed too long. When she was sent to physical therapy, she was left alone to exercise. She saw this as a waste of money. "I see no benefit to physical therapy, only bills."

Ms. Josie's negative appraisal of the health care system did not end with her personal experiences. She told how people were treated unfairly if they had the wrong insurance, how a niece died after receiving too high a dose of insulin, and how a friend was billed for doctor visits that never happened. She also recounted how friend after friend died; many she thought should not have died. She lost 3 ladies from the senior center in the past year. "Yeah, she's one of the old, old friends, a few, not too many, that I know that are left. Some, some of the girls are gone." Most devastating to her was the loss of her husband. He died in an emergency room. She was kept from being with him in his final moments. At the time of his death, she called her priest who came within the hour. She told him how her husband was dead and did not receive his last rights. She told the priest, as he went into see her deceased husband, how she was unable to comfort him or ensure he went to heaven. "And he came out, he said Ms. {Josie}, don't, don't worry cause he's at rest. He said he is so peaceful, he's with God. So, we, you know, that helped me some." She did not trust that her husband had been cared for appropriately; he was a Mexican American man who did not speak English.

Ms. Josie was given clearance by her physicians to have a TJR. In considering the healthcare systems ability to do the TJR she said, "Hurt won't go away with surgery. Go for surgery because of pain but it won't be the solution. I will still have pain." She also added, "Having bad knees won't kill you but surgery could." "They can't stop at just one knee." The series of missteps that were viewed as failures of the healthcare system built up to marginalize Ms. Josie from its possible therapeutic effects. At the same time, this researcher wonders if she is not able to survive because of her reserved appraisal.

Discussion

In this paper, I posited that a woman used her biography to relay how she negotiated her place in the world through private acts of personal aesthetic value. In this case, Ms. Josie relayed through the context of her biography the reasons to not have TJR despite mobility impairment, pain and disability. She told of how her mobility impairment interrupted her cultural performance of ethnic identity in private and public spaces. However, her personal aesthetics combined with her experiences with the health care system led her to manage her mobility impairment through other means.

Authors have repeatedly asserted that TJR for OA is optimal treatment when other therapies are not alleviating symptoms. In this case, however, Ms. Josie decided not to have a TJR. It may or may not seem that her reasons are founded. It is not always the decision that is of primary importance but how women arrive at their decisions that are most telling for the study of cultural influence. How a woman responds to disability is culturally determined and socially influenced. Perceptions of the disabling effects of OA and a woman's treatment decisions in response to OA must be understood from within the context of her life.

There is a dearth of work exploring disability among women of varying ethnic backgrounds. The intersection between gender and ethnicity can influence the cultural response to disability within a society where resources may seem unpredictable. Overall, a woman's ability to control what is done to her body in the name of illness and improved function, despite the consequences of that decision, is a culturally influenced personal decision, which may be justifiable only to her in the context of her life course.

In her process of deciding to forgo a TJR, Ms. Josie recounts numerous problems with the healthcare system. She not only rejects TJR, she rejects the culture of the health care system while remaining an on-going participant in it for treatment of her diabetes and cardiomyopathy secondary to valvular heart disease. She does not drop all health care. She denounces one procedure. Criticism of a culture by various groups within it is not uncommon. People "often criticize the very institutions they endorse." (Narayan, 1997, p. 400). Narayan suggests that we need to re-define what it is to be at home in a culture as well as our ideas of loyalty, infidelity, and esteem in ways that allow for improvement in the care of diverse members. As a Mexican American woman Ms. Josie is not denouncing the healthcare system, she is criticizing its maltreatment of her and its inability to understand or fix her life through one procedure.

It was documented in the literature that women prefer continued medicinal treatments rather than surgery because they contemplated worse surgical outcomes than NHW men despite their higher levels of disability (Gandhi, Razak, Davey, & Mahomed, 2008). This case study provides details on the thought processes that went into this decision. This work offers a "self-reflective conversation with human kind" (Geertz, 2000, p.137) in hopes that Mexican American women are not seen as victims 'afraid of a procedures'. In this case, mobility problems impacted Ms. Josie's ability to assert her cultural citizenship in the context of the majority's biomedical influence, but having a TJR was not the solution to many of the more overwhelming burdens she endured. Yes, the procedure scared her but she did not find it the solution for her burdens of restraint.

In the study of health disparities among women, researchers must not "fail to see how complicated are an individual's relationships to powerful influences that shape both their conformities and their conflicts, fail to see the closeness between us and the cultural contexts in which we have become both daughters and feminists" (Narayn, 1997, p. 400). In other words, the inequalities and inequities that women experience in health care cannot be understood without taking an account of the cultural conflicts and loyalties that push and pull women in directions they may and may not chose. At the same time, is it a sign of enculturation into a healthcare culture, when members feel free to rebuke its performance? It is up to the health care system to listen.

Ms. Josie mentioned that a member of their community became a nurse and helped her to understand the death of a niece. She mentioned this as helpful because she trusted the nurse who was a member of her community. She mentioned other healthcare providers who were members of her race/ethnicity as non-trustworthy. Hence, the cultural security she felt was because of shared cultural meanings and a shared past, not because of their shared Mexican American ethnic background, although it may have helped. Providers of all racial and ethnic backgrounds sincerely interested in reducing health disparities in treatment outcomes are capable of investing the time and effort to correct past perceptions of mal-treatment, which will require understanding past problems. This will not be easy. It will take an investment in understanding why women, such as Ms. Josie, refuse care then consistently being available to support them. It will, however, take more resources then time and personal effort to overcome health disparities in TJR. Women, such as Ms. Josie, need in-home care after surgery. The Mexican American family is not always available to provide care. Ms. Josie, like other widows, has limited family support and would need care to recover. Care would need to be carefully arranged prior to any procedure so that she would be able to remain in her home after the surgery.

Limitations of Present Study

This study is limited to the experiences of one Mexican American woman as she considered the possibility of having a TJR. Other women may make other decisions based upon different data. In order to understand the common overarching influences further work is needed directly studying those with OA considering TJR. Meanwhile, this study takes steps to toward understanding disablement and how the life course biography is shaped and used to defend an overall reason for forgoing a therapeutic procedure.

Conclusions

Without knowledge of variable responses to disablement researchers and healthcare providers cannot effectively impact health disparities in disability related outcomes, for which OA is an example. It is not sufficient to document a disparity; qualitative work must be done to thoroughly explore the mechanisms that lead to the gender and ethnic variations in outcomes.

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