



Nothing About Us Without US: Including Women and Racial Ethnic Minorities In Health Disparities Research

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Purpose:

- To demonstrate the value of research by and for women and minorities with disabilities by providing a personal account of the barriers I confronted as an African American woman with a physical disability conducting disability health disparities research.

Statement of the Problem

- Women and minorities with disabilities experience health inequality.
- Women and minorities with disabilities are a hard to reach population.
- Women and minorities with disabilities are underrepresented as researchers

Question: What impact does this have on the type and quality of research produced?



Standpoint Theory

- Derives from Marxist and Hegelian thought which assumed that the daily activities or material lived experiences of individuals structures ones understanding of their social world.
- Assumes that the knowledge expressed by dominant groups about oppressed peoples tends to be distorted or excluded in society. However, because of their social position, oppressed groups are more likely to produce knowledge that understands both the dominant groups, and the marginalized groups view.
- It challenges whiteness, maleness, able-bodiedness etc. as norm, preferable or superior to other ways of being in the world

Consequences

- People with disabilities often feel alienated by disability research; they often do not feel that the research reflects the realities of their lives. In turn, disability research sometimes provides irrelevant and inaccurate information about people with disabilities.

Disability Studies

- Draws on the Social Model of Disability
- From a social model perspective, Impairment is understood as the physiological, and disability as the social outcome, which is culturally, historically and geographically contextual.

Barriers to Intersecting Disability

- Disability Studies is dominated by white male scholars, with and without disabilities, who often:
- Discuss disability as the dominate identity of people with disabilities, and ignore the heterogeneity of the disabled population.
- Challenge disability oppression while simultaneously reproducing hegemonic ideologies about white, male supremacy

About the Study

- **Purpose of Study:** To fill a gap in the literature by describing the social, economic and health characteristics of a small sample of African American women with physical disabilities, and exploring what these characteristics reveal about their access to homeownership.
- **Primary Research Question:** What are the barriers and facilitators to homeownership for African American women with physical disabilities?

Sub-Research Questions

- a) What are the selective social (i.e. marital status, education level, age), economic (i.e. income level, debt, insurance coverage), and health characteristics (i.e. functional limitations and emotional wellbeing) of African American women with disabilities by homeownership status?
- b) What are African American women with disabilities' perceptions and experiences of barriers and facilitators to homeownership?
- c) What are African American women with disabilities' visions of their ideal living quarters and how does homeownership relate to their future goals and aspirations?

Methodological Approach

Exploratory Mixed Methods Research Design: Two Phase Sequential Approach

- Quantitative Phase I: Descriptive
 - Purpose: To address question (a) by examining and describing members of a little known population, African American women with physical disabilities ages 25-55 in Mid Atlantic Region and, to identify patterns that need further exploration
 - Sample: Snow ball of 32 (8 homeowners + 24 non-homeowners)
 - Recruitment: By disability rights organizations, disability related service providers, and relevant homeownership assistance programs and services
 - Instrumentation: 58 item self-administered questionnaire with items from the Medical Outcomes Study (MOS) 20 Item Short Form Survey Instrument (SF 20), the US Census 2010 Long Form Questionnaire, and items developed by the student researcher based on a 2008 pilot study

Methodological Approach Cont.

- Qualitative Phase 2: Exploratory
 - Purpose: To address questions (b) & (c) by informing the observed quantitative patterns and, to advance a grounded theory developed out of the data
 - Sample: Sub-sample of 30 (8 homeowners + 22 non-homeowners)
 - Recruitment: Sub-sample identified through an item at the end of the self-administered questionnaire that asks survey participants if they would like to participate in an approximately 60 minute follow-up interview
 - Instrumentation: In-depth semi-structured one-on-one follow up interviews with questions based on the literature review and a pilot study conducted by the student researcher in 2008

Barriers Experienced in the Field: The Participants

- **Accessibility of Research Instruments:** Some participants had trouble writing, so could not fill out the survey without help, or provide a signature for the consent form.
- **Speech disabilities** made interviews difficult to record, understand and also tended to last longer.
- **Presence of learning disabilities:** The follow up interview allowed me to review the survey with the participants and clarify any confusion they may have had about the initial questions.
- **Some participants may need frequent breaks** which will also lead to the interview taking a longer amount of time or having to conduct the interview in different parts on more than one occasion.

Barriers Experienced in the Field: The Participants

- Some participants relied on an assistant or parent to help provide answers to survey and interview. This may limit what the participant is willing to reveal in the presence of someone else, or bias the responses.
- Women and minorities with disabilities often have stressful lives due to health issues, economic limitations etc. This makes it hard to follow up with them or recruit them.
- Participants and interviewer had limited resources. Both depended on public transportation or para-transit. This lead to time constraints.
- The interview location must be accessible for researcher and participant. Sometimes the accessibility needs of the participant and the researcher with a disability conflicted.

Barriers Experienced in the Field: The Researcher

- Unique financial constraints: I needed to find funding for someone to transcribe for me. I relied on someone else to drive me to where I needed to go for interviews. Social Security penalized me for having money over \$2,000 in my account, including loan money. So, I could not work but so much. I kept my SSI because I needed insurance.
- People with disabilities tend to take longer to graduate. Yet, I was funded according to able bodied standards. Thus, I ran out of funding fast.

Barriers Experienced in the Field: The Researcher

- The cost of researching people with disabilities is high, and researching as a person with a disability may be a higher cost.
- Stress related to research can cause added health difficulties, which also increase time to degree. I was hospitalized 2 times since I have been in grad school.
- People with disabilities, women and people of color have a history of being exploited by researchers. This can lead to heightened researcher mistrust. More reason to include people with disabilities in the research process. Also could help improve participants self esteem by seeing a person with a disability as a researcher.

In Their Own Words:

So why did you decide to participate in this study?

1. ...if it could help like people like in power that make the laws or whatever they, you know, in terms of disabled housing or African-Americans in general, women, if it can help like change their minds or something about something, then hey, I'm there.
2. I'm not sitting at home drowning my sorrows about having Ol. There's too much life out here for that. I don't want him to have that either. Look at you. You weren't either.
3. ...one of the problems we've had, a person with a disability, and I'm sure you can relate also, having role models that look like you. That was a big issue for me growing up because growing up for me, I'm going to tell you, none of my role models were disabled except for one. .. for me, it's nice to be able to identify with a peer, and I think it will help you with your study