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Research Paper

Health care experiences and perceptions among people with and without disabilities

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Abstract

Background: Little is known about health care experiences among people with and without disabilities.

Objective: We sought to explore perceptions of people with and without disabilities related to their health care experiences.

Methods: Nineteen persons with and without disabilities participated in one of four focus groups. Focus groups were conducted in the physical world in Milwaukee, WI and in the virtual world in Second Life® with Virtual Ability, a well-established community designed by and for people with a wide range of disabilities. A grounded theory methodology was employed to analyze focus group data. Inclusion of physical and virtual world focus groups enabled people with a wide range of disabilities to participate.

Results: While some participants described instances of receiving good care, many discussed numerous barriers. The main themes that emerged in focus groups among both persons with and without disabilities related to their health care experiences including poor coordination among providers; difficulties with insurance, finances, transportation and facilities; short duration of visits with physicians; inadequate information provision; feelings of being diminished and deflated; and self-advocacy as a tool. Transportation was a major concern for persons with disabilities influencing mobility. Persons with disabilities described particularly poignant experiences wherein they felt invisible or were viewed as incompetent.

Conclusions: Both persons with and without disabilities experienced challenges in obtaining high quality health care. However, persons with disabilities experienced specific challenges often related to their type of disability. Participants stressed the need for improving health care coordination and the importance of self-advocacy.

Keywords: Disability; Access to care; Patient-provider communication; Barriers to health care; Online communities

A national agenda to "close the quality gap" in health care between those with and without disability has become a top priority for the U.S. Department of Health and Human Services.[1] Persons with disability experience access barriers, have unmet health care needs, and are more dissatisfied with care.[2] A careful literature review documents that disparities in health services related to disability are complex and inconsistent.[3–8] Overall, persons with disability have been found to receive fewer preventive services such as dental care, mammograms, or fecal occult blood tests compared to persons without disability with the same chronic conditions.[9–12] However, people with mild disabilities were more likely to receive influenza vaccines than persons without disability, while those with the most severe

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Conflicts of interest: None.

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disabilities who experienced the greatest need and access barriers were less likely to be vaccinated.[11,13,14] The complex relationship between disability and receipt of services may be due to greater medical needs interacting with hampered abilities to obtain care. Other investigators reviewing the literature related to the quality of care for persons with disability identified several important issues related to the provision of health care services: physical barriers, transportation, communication, client and provider attitudes, and coordination.[15]

Studies utilizing qualitative methods have also been conducted among persons with disability recruited from community centers for independent living, resource and advocacy centers, agencies that provide services, informal social networks, as well as clinical settings.[16–23] Most qualitative studies focus on specific groups of persons with disability, for example persons who are deaf,[16,17] persons who are blind,[18–20] rural residents with disabilities,[21] persons with a psychiatric disability,[22] or women with disabilities.[23] Participants in these studies discussed difficulties with effective physician-patient communication and obtaining adequate interpreter services, finding physicians who were knowledgeable about particular conditions, and overcoming physical and financial barriers to care. All of these studies have been performed in face-to-face settings, thus missing the input of persons with disability who are less able to participate due to disability-related access, travel, and communication barriers. Although website content has been analyzed to provide corroboration with focus group results,[19] no study to date has been conducted with virtual world focus groups. Not all forms of internet-mediated communication are identical. Unlike websites, virtual worlds allow for an innovative kind of ‘‘face-to-face’’ setting that may have important implications for the access, travel, and communication barriers experienced by many persons with disability.

Our objective was to explore experiences and perceptions of persons with and without disability related to health care as provided in the physical world. We sought to assess perspectives through focus groups in the physical world in a community center as well as in the virtual world in an online community because persons with disability may face significant barriers to participation in either setting. Conducting groups in both the physical and virtual worlds enabled participation of persons with a wide range of disabilities.

Methods

Setting

Focus groups were conducted in the physical world at a community center in Milwaukee, WI and online in the Virtual Ability community in Second Life®. The purpose of recruiting from both the virtual and physical worlds was to ensure enrollment of persons from diverse socioeconomic circumstances and across the broad spectrum of disability type and severity. Second Life is a free-to-access virtual world, an online, 3D environment in which residents create avatars and engage in a range of activities.[24] Virtual Ability, Inc. (VAI) is a well-established virtual community in Second Life that was designed by and for people with a wide range of disabilities. People come from many diverse cultures across the age spectrum, and frequently share innovative grassroots solutions to living autonomously, making the virtual world ideal for community-engaged research. However, access to VAI requires the ability to access and use a computer, as well as a broadband internet connection. Given that VAI is not available to a fully representative population of persons with disability, we also recruited from low income integrated supportive urban community housing projects run by a social service agency in Milwaukee, WI. This second cohort included a high proportion of ethnic minorities with educational challenges and low computer literacy.

Sample characteristics

Nineteen persons with and without disabilities participated in 1 of 4 focus groups in the virtual and physical worlds conducted between March and July 2014. Characteristics of study participants according to focus group location are presented in the Table 1. Participant’s gender, age range, and focus group type (virtual or physical world) are shown in Table 2.

Sampling technique

Sampling was purposive to ensure enrollment of people from diverse socioeconomic circumstances and across the broad spectrum of disability type and severity. Inclusion criteria for both physical and virtual world focus groups were age 21 years old and older, living in a US community, and ability to communicate and participate in small group dialog online or in the physical world with or without an Americans with Disability Act (ADA) accommodation. Participants for the online VAI groups were recruited through membership of over 900 persons with disability, building on protocols established and applied extensively in Second Life®. Participants in the physical world focus groups were recruited by community newsletters and community meetings.

Data collection methods and procedure

The physical world focus group included 4 persons with disabilities and 1 without. All 4 people with disabilities in the physical world group had disabilities related to medical problems, 3 reported a psychiatric disability, 2 expressed a physical component, 2 had speech and language difficulties, 1 had blindness or low vision and 1 had a learning disability. The first virtual world group included 5 persons with disabilities. All 5 had contributing medical conditions,