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Maneuverability Experiences Faced by Individuals Who Use Wheelchairs in Rural Settings: A Qualitative Analysis

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Abstract: People who have never been in a wheelchair do not understand how difficult simple tasks such as going to work, school, or completely daily living tasks can be. Many studies have discussed the experiences of those who use wheelchairs for mobility. This study qualitatively examines the daily experiences those who use wheelchairs face, despite the advances in policies to accommodate for people who have disabilities. The purpose of this study was to address this social problem by interviewing those who use wheelchairs in order to identify the day-to-day challenges that these individuals face. The sample derived from young adults living in a rural community in the Midwest. Using qualitative methods, this study demonstrates how the minimum disability accessibility laws do not always accommodate for all of the unique needs of those who use wheelchairs.

Keywords: rural social work, wheelchair, accessibility

People who have never been in a wheelchair do not understand how difficult simple tasks such as going to work, school, or completely daily living tasks can be. Many studies have discussed the experiences of those who use wheelchairs for mobility. This study qualitatively examines the daily experiences those who use wheelchairs face, despite the advances in policies to accommodate for people who have disabilities. The purpose of this study was to address this social problem by interviewing those who use wheelchairs in order to identify the day-to-day challenges that these individuals face. The sample derived from young adults living in a rural community in the Midwest. Using qualitative methods, this study demonstrates how the minimum disability accessibility laws do not always accommodate for all of the unique needs of those who use wheelchairs.

Literature Review

It is estimated that at least 30 million individuals in the United States have a physical disability (MacElman, 2001). People who have spinal cord injury, lower extremity amputation, paralysis, Cerebral Palsy, and other conditions limiting the use of their lower extremities are all apart of a the disability population that utilizes wheelchairs (Shechtman at al., 2003). The use of wheelchairs often limits their accessibility to many public buildings. Physical barriers that create unique maneuverability difficulties for individuals who use a wheelchair include stairs, high curbs, long inclines without a resting place, steep hills, narrow spaces, and uneven surfaces. These physical barriers can immensely impact the maneuverability by those who use a wheelchair, thus making it a social problem (Beale, Field, K., Briggs, D., Picton, P., & Matthews 2006).

Barriers Presented in Accessibility Policies

Due to the physical inaccessibility faced by individuals who use a wheelchair, legislation

has helped to promote equal physical accessibility for individuals who use wheelchairs. The Americans with Disabilities Act (ADA; 1990) has, for example, policies relating to recreational, public service, and public access accommodations in order to promote equal access for individuals who use wheelchairs. However, these are minimum standards that do not suit the unique maneuverability needs of all individuals who use a wheelchair. Despite ADA policies, Maneuverability experiences and challenges are still a social problem among individuals who use wheelchairs when trying to gain physical accessibility. Wee and Patterson (2009) stated, “One person’s definition of accessibility is not the same as another’s. Places may be accessible to some, but not to others. The greater the physical impairment, the greater the accessibility barriers one faces in a non-universally designed environment” (p. 178). In other words, even though the ADA implements minimum accessibility standards, physical inaccessibility still exists because the standards do not meet the unique maneuverability needs of all individuals who use a wheelchair.

Types of Wheelchairs and Their Unique Maneuverability Experiences

In order to understand the maneuverability experiences faced by individuals who use wheelchairs, it is important to understand the unique maneuverability experiences faced depending on different types of wheelchairs being used.. There are two common types of wheelchairs – manual and electronic. The following is a description of maneuverability experiences that are specific to each type of user.

Manual Wheelchair Maneuverability Experiences. Manual wheelchairs are used by individuals who have arm mobility and are able to push the wheels themselves. Maneuverability experiences associated with manual wheelchairs involve the level of strength it takes to physically maneuver up steep ramps, over curbs, and other physical obstacles. These wheelchairs are not always built to overcome physical obstacles, such as bumps, curbs, and rough terrain. However, manual wheelchairs are easier for other people to assist individuals who are using a wheelchair. For example, manual wheelchairs are lightweight and easy to lift and push, thus making it easier for others to assist the individual using the wheelchair (Bartolac & Rukavina, 2008). The manual wheelchair creates unique maneuverability experiences when trying to gain physical accessibility in comparison to other chairs due to their structure.

Active manual wheelchairs are sub-type of manual wheelchair. Active manual wheelchairs present unique maneuverability experiences compared to other manual wheelchairs. Active manual wheelchairs are built with a lighter, more flexible frame in order to make maneuverability more convenient for the individual using the wheelchair and for the caregiver aiding the individual using the wheelchair. Active manual wheelchairs are typically meant for individuals who are more physically active or are maneuvering their wheelchair on rougher terrain. For example, individuals who participate in wheelchair sports often times utilize the active manual wheelchair for its more flexible maneuverability (Krants, Edberg, & Persson, 2011).

Electric Wheelchair Maneuverability Experiences. Electric wheelchairs are typically used by individuals who have less arm mobility and strength, such as individuals who are quadriplegic. These wheelchairs are motorized with an electronic steering device. Accessibility

experiences presented for individuals using an electric wheelchair are similar to those using a manual chair. These chairs have less vertical mobility, thus can make it difficult to go up steep ramps, over curbs, and other physical accessibility obstacles (Pellegrini, Bouche, Barbot, Figère, Guillon, & Lofaso, 2010). Another maneuverability experience the electric wheelchair presents is that it is very heavy and hard to physically lift or push, thus making it more difficult to navigate in more rural settings. Unlike the manual wheelchair, the weight of the wheelchair causes it to be difficult for other individuals to aid the wheelchair user in maneuverability. Individuals who want to physically aid the electric wheelchair user are unable to lift it due to the wheelchair's weight, thus making maneuverability and physical accessibility more difficult for the individual using the wheelchair and for the individual aiding them (Blach Rossen, Sørensen, Würtz Jochumsen, & Wind, 2012; Pellegrini et al., 2010; Bartolac & Rukavina, 2008).

Maneuverability Experiences in Daily Living Tasks

Depending on the severity and unique circumstances of one's disability, many individuals who use wheelchairs are not able to physically perform daily living tasks on their own due to maneuverability challenges. Hence, many individuals who use a wheelchair must rely on family members, friends, or professional caregivers to help with basic daily tasks (Jackson, 2008). Many individuals who use a wheelchair grow up in homes and schools that provide accommodations to assist in the individual's maneuverability in daily living tasks, however; many of these daily living accommodations are no longer present once the individual is living independently. For example, schools provide professional aids and adaptive technologies that are no longer available for the individual using a wheelchair once they living on their own (Johnson, Dudgeon, Kuegn, & Walker, 2007). This creates unique maneuverability experiences for individuals in wheelchairs when trying to complete independent daily living tasks. Having to physically depend on others for maneuverability in daily living tasks limits a person using a wheelchair to experience life independently.

Teresa and Amaral (2009) demonstrated that the inability to complete daily living tasks independently due to maneuverability challenges creates negative emotional and physical experiences. Negative emotions found their study included feeling a sense of helplessness from having to rely on others to complete daily living tasks. Such dependency may also result in limited opportunities to live independently. When living independently, individuals who use a wheelchair need to take into consideration safety issues and accident prevention, such as falling. For example, the individual who uses a wheelchair needs to take into consideration their physical maneuverability experiences when completing daily living tasks when deciding to live on their own.

Maneuverability Experiences in Housing

Maneuverability challenges are just as likely to be found in homes as they are in public places. Individuals who use a wheelchair are going face unique environmental barriers if their homes are not physically accommodating for their maneuverability needs (Greiman & Ravesloot, 2016; Olkin, 2002). Finding housing that can meet the physical accessibility needs for individuals who use a wheelchair can be difficult. A few physical accommodation examples needed in housing for individuals who use a wheelchair include wide enough doorways and

hallways for the wheelchair to fit through, physically accessible bathrooms and shower stalls, elevators/lifts, low countertops, ramps, and flat patios. Also, the terrain surrounding their housing must be flat so they can efficiently maneuver when leaving and entering their home (Greiman & Ravesloot, 2016; Badreddine, 2013; Rudman, Hebert, Reid, 2006). Finding a home that meets all the physical accommodations needed in order for the individual using a wheelchair to maneuver can be difficult, especially in rural settings where homes are less updated and the terrain is rougher. As a result, many individuals who use wheelchairs experience hesitation to move out of their current living situation in fear of losing their current accommodations, thus giving them less physical accessibility in finding a desired home that meet their unique maneuverability needs (Wee & Paterson, 2009).

Maneuverability Experiences in Employment

Employment opportunities present unique challenges for those who use a wheelchair. Their place of employment must also have appropriate maneuverability and physical accessibility accommodations, such as elevators and ramps in order to allow the wheelchair user to access and maneuver in the building (Wee & Patterson, 2009). As mentioned previously, The ADA requires all public buildings to have minimum accommodations for individuals who use a wheelchair, however; these accommodations must be useable by the individual who uses a wheelchair. For example, the ramp provided by the building cannot be too steep or narrow for the employee who uses a wheelchair. Since every type of wheelchair and person who uses a wheelchair is different, the employee who uses the wheelchair must ensure that the type of accommodations provided by their place of employment meets their unique maneuverability needs.

Relevance of the Study

Past literature has been written to provide a picture displaying the different aspects of maneuvering with a wheelchair. Bartolac and Rukavina (2008) provide a detailed description through second hand observation of the different aspects of maneuvering using different types of wheelchairs. This study intends to expand on those findings by analyzing the first hand accounts of individuals who use electric, manual, or both types of wheelchairs in rural settings. The first hand accounts provided by the interviews demonstrate the gaps in ADA policies for those who use wheelchairs for maneuverability in rural locations. The qualitative findings also provide first hand accounts so rural social workers working with this population can understand their unique challenges.

Method

Participants who met specific criteria for participation in this study were interviewed about their maneuverability experiences in various settings located in a rural location in the Midwest. A selection process to obtain participants was implemented in order to gain a convenience sample. Data was then collected and analyzed by transcribing and coding interviews to find common themes among key variables. Key variables included maneuverability experiences at participants' place of employment, their colleges, and their homes.

Data Collection Procedures

A convenience sample ($N = 5$) was utilized by selecting participants residing in a rural location in the Midwest. Volunteers using electric, manual, or both types of wheelchairs all qualified for this study. Allowing participants who use electric, manual, or both types of wheelchairs provided a better representation of their experiences and challenges. All participants were over the age of 18.

The method of inquiry for this study was structured interviews. Interviews allowed individuals who use wheelchairs to share their personal experiences when using different types of wheelchairs in various settings. Data was collected through structured interviews through email. All interviews utilized the same questions in order to also ensure validity. Before the interview began, the informed consent form was reviewed. Participants were then asked open-ended questions pertaining to their maneuverability experiences using wheelchairs in various settings. The questions used for the interview pertained to key variables. Examples of key variables were maneuverability experiences using different types of wheelchairs at their places of employment, their at academic settings, at their homes, and when performing daily living tasks. Participants were told that they did not have to answer questions that they were uncomfortable answering. In order to ensure the participants' confidentiality, their names were not included in the transcriptions. The use of pseudonyms was used to refer to respondents.

Data Analysis

After all transcriptions were completed, the scripts of the interviews were manually coded. In order to code, a content analysis was conducted in order to establish themes. This included common phenomena among participants who use manual and electric wheelchairs in various settings. Key variables included common phenomena among participants using different types of wheelchairs at their place of employment, academic settings, their homes, and when performing daily living tasks.

Results

Two phenomenological themes were identified when examining the maneuverability experiences faced by individuals who use wheelchairs in rural settings. These themes reflected maneuverability obstacles referenced by all five participants. These themes were mobility issues and difficulty with daily living tasks (e.g., bathing, getting dressed, and getting out of bed). Both those who use electric and manual wheelchairs discussed these unique experiences within both of these themes. Within the theme of mobility issues, three subthemes were found. The subthemes within mobility issues were the steepness of the ramps, lack of width space, and rough terrain. All of the participants referenced a paternal figure that aided them for maneuverability assistance at some point in the interview.

The first theme was accessibility challenges pertaining mobility issues. Within this theme, a subtheme emerged pertaining to the incline degree of the wheelchair ramps in public settings. Settings in which this theme immersed included college campuses, places of employment, and other public buildings in the participants' communities. Participants who used

electric wheelchairs expressed the wheelchair ramps provided in these settings were often difficult to maneuver in because their chairs did not have enough power to go up the ramps due to the steepness of the incline. The participants who use electric wheelchairs referenced needing additional assistance from other people in order for their chair to make it up the incline. Within the subtheme pertaining to the incline degree of wheelchair ramps, safety issues and quality of life issues emerged.

Participant Sally: The ramps at my college are annoying. I put my electric chair on the highest settings and it still rolls backwards. People have to help push me up it a lot.

Participant Eva: The ramp at the place I work is ok. Sometimes my chair moves very slowly up it because it's steep.

Similar to electric chairs, individuals who use a manual chair for maneuverability also referenced having mobility challenges due to difficulties utilizing public ramps. This was also due to the degree of the incline. Participants using manual wheelchairs referenced needing assistance from someone to maneuver up the ramps due to the degree of the incline.

Participant Kayla: It's so tiring to get up the ramps around town. The ramps require a lot of work to get up. I'm always so tired once I get inside my school for class.

Participant Sally: I hate using my manual chair. I usually only use my electric chair because it moves on its own. It's too hard to go up a lot of the ramps in a manual chair because my arms aren't strong enough. Usually I have someone around to help push me.

The second subtheme that was found within mobility issues was a lack of width space when maneuvering in various settings. This included doorways, ramps, and hallways. Both electric and manual wheelchairs shared common themes. However, none of the participants mentioned needing assistance from another person when maneuvering in tight spaces.

Participant Mary: It's actually kinda funny. I always get stuck on this ramp at my school. The ramp is very narrow and zig zagged and I run into the walls.

Participant Kayla: The hall ways at my school are pretty small. There's not a lot of room and I always feel like I'm running over people.

Participant Eva: One of the offices at my work has a really skinny doorway. I always bump into it.

Maneuvering in rough terrain was the third common subtheme within the theme of mobility issues found. Those who used electric wheelchairs discussed getting "stuck" in the terrain. This required them to need assistance from another person in order to maneuver through the terrain. Since their electric chairs are very heavy, it is hard for people to aid in pushing them through rough terrain. The assistance identified was administered by a parental figure.

Participant Eva: I live out in the country and I always get stuck in our yard. Luckily my dad is strong enough to help me, but my mom usually isn't strong enough to get me out of bumpy spots.

Participant Sally: I hate being in the grass after it rains. My wheels get caught on the mud. I have no control over the wheels with my electric chair. My wheels just spin and get mud all over.

Participants using manual wheelchairs also had similar struggles maneuvering in rough terrain. The need for assistance from another person was identified when maneuvering in rough terrain.

Participant Kayla: Grassy areas can be tricky to move through. I always feel like my chair is going to get stuck and flip over.

Participant Sally: At home I use my manual chair because I'm with my parents. The electric one is too heavy to go in the yard. Going through the yard in my chair is hard on my arms, so my parents usually just push me around.

Participant Eva: Luckily my house is in an addition where there are sidewalks so I don't have to be on uneven ground too often.

The second theme experienced by participants was the difficulty completing daily living tasks. Both electric and manual wheelchair participants expressed this difficulty. Daily living tasks included bathing, getting dressed, and getting out of bed. This theme deals with the fact the participants needed specific accommodations and aid to complete these tasks. Daily living tasks were experienced uniquely by each participant, despite the type of chair that they used. Even though each participant experienced them uniquely, all of the participants mentioned having some form of physical accommodations made for them. All of the participants also mentioned having a parental figure assist them to get out of bed and when getting dressed. Seventy-five percent of participants mentioned having a parental figure assist in bathing.

Participant Sally: I have a special [shower] that was created specifically for me. My chair can roll into it, so I don't need help. The shower nozzle is removable, which is helpful.

Participant Kayla: My mom helps me bathe. She also has to help me get dressed after I bathe because it's too hard to do on my own.

Participant Kayla: My dad has to lift me out of bed and into my chair in the morning. I used to be able to crawl, but not anymore.

Participant Eva: I'm able to get from my bed to my chair if it is correctly positioned near me.

Participant Eva: I can shower on my own because I have a handicapped shower that is big enough [and has] a bench for me to sit on.

Discussion

Past literature demonstrates that individuals who use wheelchairs face unique maneuverability challenges in their everyday lives. MacElman (2001) discusses how almost 30

million people in the United States have a form of disability, and many of those are restricted due to it. The results of this study support past literature that finds individuals who use wheelchairs are restricted, despite the efforts made to make accessibility equal for those who use wheelchairs. Even accommodations, such as ramps, are unable to meet all of the needs of those who use wheelchairs for maneuverability. Both electric and manual wheelchair user expressed similar maneuverability obstacles. Many studies that have been conducted on individuals who use wheelchairs were based on second-hand observation (e.g., interviews with family members and case workers). This study provided a first-hand account of the maneuverability experiences faced by individuals who use a wheelchair, providing this population with a voice about their maneuverability experiences. The participants of this study corroborated past literature that found that maneuverability is still difficult for individuals who use wheelchairs, despite accessibility accommodations.

The findings in this study demonstrated that, despite the policies made in order to ensure convenient maneuverability for those who use wheelchairs, these accommodations did not always address their unique needs. Even though there were wheelchair ramps provided at many of places the participants were trying to access, many of them still had difficulty maneuvering across them. This was due to spaces being too narrow and ramps being too steep. Both those who use manual and electric wheelchairs encountered experiences where the ramps were too narrow or too steep. Even though the Americans With Disabilities Act (ADA) has gone to great lengths to try to ensure equal maneuverability access in public settings, these minimum requirements do not always meet the needs of all people requiring the use of a wheelchair. Not only do people who use wheelchairs struggle maneuvering using public accommodations, but they also struggle completing daily living tasks in their homes. Many of them have personal accommodations set up for them in their homes, but still experience difficulties despite the personal accommodations they have arranged for themselves. Both those who use electric chair and manual wheelchairs expressed a need to have another person assist them when utilizing public maneuverability accommodations and home setting accommodations, thus limiting them and hindering their quality of life. This is something that needs to be considered when creating accommodations for individuals who use wheelchairs. Many of the current accommodations offered in public settings and in home settings are still difficult for these individuals to utilize by themselves.

Many of the studies conducted on individuals who use wheelchairs have taken place in urban settings. Very few studies provide a representation of the difficulties experienced in rural settings, where wheelchair accommodations are not always present (Jackson, 2008). This study demonstrated that maneuvering around rural settings is a common phenomenon among individuals using wheelchairs. Rough terrains, such as grass and uneven ground, were common obstacles experienced by participants who used wheelchairs in rural settings. Both manual and electric wheelchair users expressed similar maneuverability difficulties in rough terrain, thus hindering their quality of life due to maneuverability limitations. The participants who encountered these obstacles mentioned needing assistance from others in order to maneuver through them. This is an issue that cannot be easily addressed, because the ADA cannot change terrain in rural settings; however, it needs to be taken into consideration when working with this population.

Implications for Social Work Practice

This qualitative study aids social workers in better formulating methods for helping individuals who use wheelchairs. By hearing the participants' first hand experiences, social workers can understand daily maneuverability challenges of this population. Social workers must formulate methods of serving wheelchair clients that are convenient and accessible to them, despite their maneuverability challenges. They can do this by ensuring they provide services at locations with appropriate accommodations to better serve this population (e.g. meeting them at more accessible locations and ensuring that building entrances are accessible).

The ADA sets standards that all public buildings must follow in order to ensure equal access for everyone who enters the building. For example, in order to address maneuverability needs for those who use wheelchairs, the ADA requires that there are wheelchair ramps at every entrance that incorporates stairs. This study supported past literature in finding that these ramps are not always built in a fashion that is equally accessible. Despite the efforts social work has made through the ADA to assist individuals who use wheelchairs, these minimum standards are not meeting the needs of all individuals who require the use of a wheelchair. Social workers must understand this gap in policy, and tailor their services to meet the needs of this population. Social workers can advocate for policy change that makes the minimum ADA requirements for wheelchair ramps to have less of an incline and that other wheelchair accommodations are wider in space.

Study Limitations

A limitation of the research design was a lack of participants due to the regional focus of the study coupled with convenience sampling, which resulted in a smaller sample size. Another limitation experienced during this study was all of the participants were female. This also may impact the quality of common phenomena found due to the lack of well-rounded gender representation of the population that uses wheelchairs for maneuverability. Men typically have stronger arms than women, and maneuvering up ramps and through rough terrain may be easier for them, than it is for women who use wheelchairs.

Conclusion

Overall, this study confirmed the findings of past literature suggesting individuals who use wheelchairs experience difficulties maneuvering, despite their accommodations in public settings and their homes. This study demonstrated that individuals who use wheelchairs require more maneuverability accommodations than the minimum requirements mandated by the ADA. This study also shows that even though the ADA mandates minimum accessibility standards, such as ramps, many individuals who use wheelchairs must have assistance from others in order to utilize them. Lastly, this study demonstrates that individuals who use wheelchairs have struggles beyond what is observed in public. They experience struggles at home when performing daily living tasks that often require assistance from a caregiver. This limits individuals in wheelchairs and impedes their quality of life. This study allowed individuals to have a voice and share the difficulties they face in rural settings where they often go unseen.

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Maneuverability Experiences