Home Is Where Their Wheels Are: Experiences of Women Wheelchair Users

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This paper reports on a qualitative study conducted with women with disabilities who use wheelchairs living in Toronto, Ontario. In this study we were concerned with homemaking and parenting issues for such women: we were interested in exploring how women give meaning and perform household activities including child care within the social and physical contexts of their homes. We chose to study the situation of women, since women with disabilities have been described as doubly handicapped, as gender intersects with physical impairments in circumscribing such women's opportunities (Dyck, 1995). In addition, in North American society, women bear the overwhelming responsibility for homemaking and caregiving activities (Angus, 1996; Morris, 1995; Thorne, McCormick, & Carty, 1997; Young, 1996). Further, although estimates indicate that over 200,000 Canadians utilize wheelchairs (Kirby, Coughlan, & Christie, 1995; Statistics Canada, 1991), the expectation that a wheelchair will improve personal independence and social participation in people who use them is not always achieved (Pierce, 1998; Smith, McCreadie, & Unsworth, 1995). Physical barriers such as poor planning and design of technology and environments interact with society's treatment of people with disabilities to hinder full participation in social and domestic life (Matthews & Vujakovic, 1995).

The study used focused, in-depth interviews to investigate women's experiences of their homemaking and parenting tasks, identifying issues that were important to them as they carried out their mothering roles at home. The study explored the interactions among the home environment, gender, and disability. In this study, 11 mothers who used wheelchairs on a full-time basis were interviewed concerning the ways in which they adapted to, or modified, their physical and social

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environments to fulfill daily homemaking and mothering responsibilities. The knowledge gained from this study has implications for broadening the vision of housing design practice in planning living environments that are more responsive to women who have mobility needs, and for theory development related to household life and person–wheelchair–environment relationships.

Overall the study questions were:

“How do women who use wheelchairs adapt and respond to their physical home environments to perform their daily household occupations?”

“How do women who use wheelchairs structure and restructure home social environments so that they can fulfill their occupational roles?”

The data reported in this paper addresses the first question. Another paper is currently being prepared that addresses the second question.

Housing, Homemaking, and Disability

The home as a context for living is no longer conceptualized purely in terms of its physical boundaries, but also as a psychosocial environment constructed through the activities conducted within it by occupants (Bowlby, Gregory, & McKie, 1997). The home is a repository for a very special space experience that has something to do with the fundamental sense of our being. Home has been described as that secure inner sanctity where we can feel protected and be ourselves (Heidegger, 1996). The aging literature notes that control and mastery are implicit dimensions of the meaning of home (O’Bryant, 1983). Ownership may become a symbol of status. In this regard the idea of home may transcend the physical setting and may remain as part of the individual’s self identity.

This expanded view of the home has implications for research that examines how home environments enable and constrain wheelchair users in fully engaging in domestic life. Linking housing design with barriers and facilitators to the in-home activities undertaken by people with disabilities is “a formidable task” (Chen, Baruch, Scharf, Tanner, & Edlich, 1990; Connell, Sanford, Long, Archea, & Turner, 1993, p. 9). A “new way of thinking about domestic environments and disability…goes beyond stair lifts and ramps” (Oldman & Beresford, 2000, p. 429) to explore the constraints of physical and social space upon family, homemaking, leisure, and employment participation.

The home has been described as the place where one carries out one’s daily activities and that these activities provide structure to one’s life (Tamm, 1999). Activities that are carried out as part of homemaking are lived through space and person–wheelchair–environment relationships.

“New way of thinking about domestic environments and disability…”

Oldman and Beresford (2000) argue that comprehensive literature exists on housing and disability from a medical rehabilitation perspective, however, information on the role of domestic space on the lives of disabled people is largely missing. Few empirical studies have been conducted to examine the perspectives of people who use wheelchairs on a full-time basis regarding the constraining or enabling aspects of their home environment and the consequences on their daily activities. The array of needs of parents who have disabilities, and specifically those of mothers, has not been fully assessed. Research suggests that domestic physical and social circumstances have a far greater influence on occupational performance than the ability or inability to perform a number of activities independently (Dyck, 1995; Jongbloed, 1994; Moss, 1997).

A few studies have explored issues that women living with arthritis and multiple sclerosis faced with respect to restructuring the physical spaces and social relationships in their homes in an attempt to carry out their daily activities (Dyck, 1995; Dyck & Kearns, 1995; Moss, 1997). These studies contribute to our understanding of how gender, the physical and social circumstances of the home environment, and sociopolitical and economic contexts interweave and influence the lives of women who are disabled and live at home. However, since the type of mobility device and its level of use varied significantly, generalizations to full-time wheelchair users cannot be made. Further, the centrality of homemaking and related responsibilities in the lives of disabled women was not a primary concern of the studies.

With chronic disability, both personal circumstances and environmental needs change; some discordance emerges in the person–environment fit that undermines this equilibrium and results in a need to make environmental modifications or to relocate (Rowles, 1987). The impact of physiological and health changes is frequently exacerbated by reduced income in many cases with disabled women. As housing needs change, women with disabilities typically adjust by modifying the use of their residence, for example they stop going into certain rooms (Rowles). The emergence of home care and attendant care services has allowed many women to manage daily routines in their homes, but even with this support many women still are faced with the need to find more suitable housing.

A study conducted by Rubinstein (1989) with the elderly describes a number of processes of linkage by which individuals construct and interpret external environmental phenomena. One such process is called person-centered.
This process is concerned with the individual’s life course as revealed in features of the home environment and includes such concepts as embodiment, that is, aspects of the environment that a person feels he or she cannot do without because it is subjectively part of himself or herself. For example, a personal attendant or a wheelchair may therefore be assigned the task, through embodiment, of carrying the load of personal meaning and thereby aid in the maintenance of self when it is threatened (Rubinstein). Another concept that is relevant here is called body-centeredness and refers to the relationship of the body to the environmental features that surround it. The concept of environmental centralization is key; this concept refers to a way in which the home environment is manipulated over time to accommodate increasing limitations of the body through closing off of peripheral areas and the concentration of living space in central zones. This is similar to Rowles (1987) perspective on environmental modifications.

A perusal of contemporary medical products catalogues finds that they are largely devoid of devices that assist disabled mothers in meeting the needs of their newborn, preschool, and school-age children. Women are often required to “reinvent the wheel” in terms of crib, child, and wheelchair adaptations or they are forced to make do with inadequate equipment (Somers, 1993). Care services often do not recognize women’s obligations as carers-of-others within the household. Thus, while personal care is relatively accessible and available to women, support for their roles as mothers is not. Further, inaccessible public spaces such as day care centers, schools, classrooms, libraries, community centers, swimming pools, and local parks prevent women from fully participating in their children’s education and leisure activities. This lack of community and institutional support is seen as particularly oppressive to mothers with disabilities (Furminger-Delisle, 1996; Morris, 1995).

The combination of paid employment with mothering responsibilities places further strain on women with disabilities. Women must deal with specialized transportation systems that are poorly organized, a lack of services designed to facilitate their roles as working mothers, and punitive income support programs that provide poorly for families and limit how much supplementary income women can earn (Dyck & Jongbloed, 2000).

Homemaking is a relevant issue for women with disabilities. Despite changes over the years in the gendered division of household labor, women, regardless of age and disability status, continue to assume most responsibility for activities associated with homemaking (Angus, 1994; Bowlby et al., 1997; Chandler, 1994; Morris, 1995). Because women, in part, enact their gender identity through household tasks, difficulty with housework holds profound significance for women (De Vault, 1991; McDonough, 1996; West & Zimmerman, 1991). Disruption of activities by disabling conditions creates disturbances in personal identity and social relationships (McDonough, 1996).

**Wheelchairs: Enabling or Constraining Devices?**

It is generally believed that a wheelchair is an enabling device (Cooper, Trefler, & Hobson, 1996). For example, wheelchairs have been proposed to impact on the user in terms of support for independence in personal care and functional mobility (Ferguson Pell, 1995; York, 1989), employability (Ferguson Pell), work performance (Troy, Cooper, Roberton, & Grey, 1997), leisure participation (Pluym, Keur, Gerriston, & Post, 1997), and parenting (Somers, 1993). However, other research has demonstrated that the occupational performance of people who use wheelchairs is often hindered by the presence of physical and social barriers in the environment. This small body of research has been focused on examining barriers faced by wheelchair users in the larger community (e.g., Ahn, McGovern, Walk, & Edlich, 1994; McClain et al., 1993; McClain, Cram, Wood, & Taylor, 1998; Pierce, 1998). There is a need for research that examines issues associated with wheelchair use in the home by homemakers.

In summary, the purpose of this study was to examine the ways in which mothers who use wheelchairs experience homemaking, and how they shape and respond to their home environments.

**Methods**

**Design**

A qualitative study using focused, in-depth interviews was conducted (Lincoln & Guba, 1985, Strauss & Corbin, 1998). We conducted interviews with 11 mothers with disabilities who lived in the greater Toronto area. Women were recruited for a purposeful sample using advertisements in disability-targeted newsletters and through local flyers. In order to be eligible for the study, mothers had to be English-speaking, between 20 and 55 years of age, a user of a wheelchair or scooter as the primary means of mobility, and care for at least one biological or adopted child who lived in the same household. Interviews were conducted after the study received ethics review board approval and we obtained informed consent. Following the audiotaped interview, a short demographic questionnaire was completed. A $25.00 honorarium was offered to mothers in acknowledgment of their time.
Description of the Mothers

The 11 mothers who participated in the study were on average 42 years old, with a range from 32 to 51 years of age. All women were white, the majority had a college or university degree (n = 7), and were married (n = 6). Three mothers had lived with disabilities since birth (cerebral palsy, muscular dystrophy, spina bifida), two women had acquired disabilities in childhood (rheumatoid arthritis, spinal cord injury), four women developed multiple sclerosis as adults, and two women were injured in accidents as adults that resulted in amputation or quadriplegia. The women had a mean of 1.45 children (total = 16), with one child less than a year old, two between 2 and 5 years, five between 6 and 10 years, six between 11 and 14 years, and 2 between 15 and 18 years. Six of the women identified themselves as full-time homemakers or unemployed; three women were reliant upon spouses, long-term disability funding or the Ontario Disability Support Program for income support. The other one third of the women worked outside the home, either full or part-time, at the time of the interview. Approximately one third performed community or volunteer work.

A little over half of the women rented their dwellings. Almost three quarters of the women resided in multifamily dwellings such as apartments or cooperatives or condominiums, while just over one quarter resided in single-family dwellings. Nine were satisfied with their living accommodations, and two women who were apartment dwellers were on waiting lists for subsidized or accessible housing. One woman had applied to the Ontario March of Dimes Agency for a home renovation grant. Eight women had made renovations to their dwelling, with the overwhelming majority of renovators making structural changes. On average, mothers had lived at their current addresses for 8 years, with a range from 1 to 18 years in length. Four women received home care attendant care or homemaking services and one woman had a health care aide.

Six mothers used power wheelchairs, three used standard or manual chairs, and two used a scooter. On average, mothers had been wheelchair users for 12 years, although this ranged from 1 to 35 years. Women had been using their most frequently used wheelchairs for approximately 3 years, and 9 women were generally satisfied with their devices. Three of the women identified problems with maintenance or overall design of the chair.

Data Collection

The qualitative interviews lasted from 45 min to 2.5 hrs. All interviews were conducted by the fourth author. Women were interviewed privately in their homes. Three infants or children were home with their mother, and in two cases home care attendants or nurses were in the home. Two of the interviews ended abruptly as one mother needed to attend to her crying infant, and another mother was concerned about missing her transportation van and being late for work. As a consequence, the mother with the crying infant sent two follow-up e-mails to augment the description of her dwelling and the types of assistance she received, and the other mother completed the demographic questionnaire by telephone. Descriptive and reflective note making about the environment in the home and the interviewer’s impressions was done throughout the interview phase.

Five topic areas guided the interview: (1) home and modifications; (2) activities (homemaking, parenting/caregiving, and leisure); (3) family, friends and support network; (4) neighborhood and community; and (5) wheelchair use and design. Although the interview guide was designed to facilitate comparative data analysis (Fry & Keith, 1986), all interviews were recursive (i.e., we probed issues as they were mentioned by mothers, rather than waiting for when that issue was outlined in the guide). As the aim of the interview was to obtain the informant’s point of view (Lincoln & Guba, 1985), open-ended questions were utilized. Mothers were able to express their viewpoints about the specific questions, and had the opportunity to discuss other issues of importance to them. Such flexibility led to women moving beyond the research focus on their homemaking experiences within private dwellings. Women indicated that attendant care, and public accessibility and attitudes were integral to any discussion of accessibility, or lack thereof, upon quality of life and the facilitation of their roles as mothers and homemakers.

Data Analysis

Mothers were assigned an identification number and a pseudonym to protect their privacy. Taped interviews were transcribed by a professional transcriber, then checked for accuracy, edited, and then coded into categories, by the research assistant (interviewer) with consensus from the investigators based on the research questions according to the constant comparative approach described by Glaser (1978) and further delineated by Lincoln and Guba (1985). Next, data within each code were organized according to thematic content, moving from lower-order to higher-order themes as the analysis progressed using the NUD*IST computer program (Richards & Richards, 1994). Global categories were created and these were later collapsed into new codes as themes began to evolve. Finally, a review of an unpublished final report that was written for the funding
agency, was conducted by two disabled mothers who were not part of the study and one woman scholar with a physical disability who used a wheelchair to support the authenticity of researchers’ interpretations and analyses. We chose independent, not previously involved women as reviewers in order to have an objective, non-biased perspective.

Findings

Three main themes emerged from the data that were related to housing and wheelchair issues. They were: (1) lived space restricting personal autonomy, (2) advocacy for strategies to secure appropriate housing, and (3) my wheelchair, my liberator, my sense of comfort. Two subthemes were also found: coping strategies and living in a small physical and social world. These themes represent the subject matter of statements made by informants and they represent basic interpretative groupings made by the project investigator that productively organized the statements for analysis. Certainly, other readings can be made for other purposes.

Lived Space Restricting Personal Autonomy

The women in this study were confined in their ability to do what was important to them when they wanted to do it and how they wanted to do it. This seriously constrained their autonomy and participation in daily activities. The home, which is for most people a place where people can shape their activities and events, and to a large extent the environment within its walls, may have less meaning for mothers who live in a wheelchair. In many instances the women could not fulfill typical parenting and homemaking roles. Cleaning their children’s bedrooms, doing the laundry, diapering the baby, doing dishes, and dusting were often not possible. As a result their personal autonomy and self-care manager role were restricted. In many instances they were forced into environmental centralization (Rubinstein, 1989), concentrating on lived space where doing things was possible for them.

Using a transactional definition of roles (Roscow, 1976; Schumacher, 1995; Stryker & Statham, 1985), the construct of role is conceptualized as the management of an interrelated set of behaviors into a routine that can be adapted in response to environmental expectations and resources, and individual identity and self-efficacy. The essential behaviors of the self-care manager role include coordination and control of medical management, health promotion, basic activities of daily living (ADL), related instrumental ADL, and system coordination.

Taking a shower and even using the washroom when some women wanted to was not possible. Jacque commented on her plans to remodel the bathroom, “Well right now it’s very hard to use the bathroom the way it is. To get in and out of the shower [the attendant] has to do a lot of lifting and transferring that makes it very hard for her. I feel that I can be more independent by having the wheelchair accessible bathroom.”

Others could not socialize with friends and family because of either not being able to access the elevator buttons from their wheelchair or not being able to enter people’s homes, which further restricted their personal autonomy. Autonomy is not a state of being, but rather something individuals develop in the course of their lives (Nordenfelt, 1993). Autonomy can be viewed as a continuous and personally unique variable that exists in different degrees, depending on a person’s circumstances. Autonomy was restricted for many of the women by aspects in their physical and social environments. Executional autonomy is defined as the ability and freedom to carry out decisions (e.g., actually dressing oneself as one wishes). Decisional autonomy is the ability to make decisions without external restraint or coercion (e.g., deciding when and how to get dressed). The first requirement for decisional autonomy is physical conditions that allow chosen actions to be carried out. Such conditions are difficult for people with a disability to achieve, even when care systems are well resourced. All too often, physical restrictions cause expectations to be lowered so that decisional autonomy is undermined. The second requirement for decisional autonomy is psychological conditions that allow choices to be made freely. A person requires psychological rather than physical independence in order to take control of one’s life, and to choose among options related to what life to live and what risks to take (Brisenden, 1986; Gignac & Cott, 1998; Miller, 1981).

In this study many women did try to overcome their restrictions, but with a certain amount of safety risk and with some loss to their dignity. Jennifer, who could not use her wheelchair in her small kitchen, had to use a walker to get around. She expressed her concerns, “The walker, it’s hard. If I don’t feel safe, then I’ll just use the walls and I’ll just do what I can.” Doing the dishes in the kitchen sink was not possible for Diane because it caused too much stress on her shoulder joints. She had to take the dishes to the bathroom sink which was not as deep, but all this rearranging took a lot of time and made the job tiring. Stacey had to find a way to go up and down stairs to get things done. “I had to go up the stairs on my behind because there was no landing to put a chair lift in so we didn’t have one, and when I came home from the hospital I got one of those Canadian Tire plastic slider mats and that got me around. And I could get into my kids bedroom that way but it
always hurt me because the floor was hard and I couldn’t reach anything anyway.”

The lack of space to the bathroom necessitated that Mary remove the bathroom door, which undermined her need for privacy. Installing hardwood floors and removing the padding under the carpet was a strategy many women used as it enabled them to have greater freedom of mobility. “I am going to have the under pad taken out because I feel like I’m in sand or something. Every time I go to move I get sort of trapped in it, like I sink into the carpet. It drives me crazy” [Rubiga]. In all of these example, the women enlisted as an ally an environment feature (walker, attendant, hardwood flooring, slider mat, small bathroom sink) that came to function as part prosthetic self to enable function (Rubinstein, 1989).

Coping Strategies

Women used several strategies to maintain as much control over their lives as possible. The installation of a roll-in shower allowed them to direct an attendant to bathe them with ease and in some cases allowed them to take a shower by themselves. Renovations to counters, closets, kitchens, and installing ramps allowed better mobility and access in the home that facilitated the women’s abilities to perform activities they wished to do. On average the women used a total of 11 assistive devices (Table 1). The women with arthritis and multiple sclerosis relied heavily on self-care, reaching aids and kitchen aids due to the weakness in their muscles and limited range of motion. Women with multiple sclerosis and cerebral palsy who did have some functional ambulation skills seemed happy to have a walker to allow them to get out of their wheelchairs and move about their homes. All women relied on ramps to get in and out of buildings, but the women with quadriplegia and amputation were most dependent on these.

Advocacy Strategies for Securing Appropriate Housing

Finding funding for renovations or to secure alternative housing arrangements was a constant source of frustration for most women. There were many reasons why participants needed to find better housing, including the participant’s deteriorating health, aging, changing functional status, children getting older, environment centralization, and deteriorating mobility.

Most women were proactive and quite knowledgeable about the avenues available to them for finding ways to get funding. Some had applied to charitable foundations for home renovation grants whereas others applied to government residential aid programs for subsidized housing and renovation grants. With all of these activities, a constant amount of advocating and negotiating was required by the women to keep the process moving forward. With many of the government programs, women were forced to meet a number of eligibility criteria before their application would be considered, which was a great source of stress. Many women were forced to remain in their current housing situation, which was clearly inadequate for their needs and that of their growing children. One example was with Kristan who was forced to negotiate with the transportation van to pick her up and drop her off at the side entrance of her building because of an inaccessible front entrance. Until she was able to negotiate this new arrangement, she had missed her transportation van because of the extra time it took her to maneuver her wheelchair out to the side of her building. She complained that the necessity of entering and exiting the building from the side entrance or the “tradesman’s entrance” was humiliating and demeaning to her.

Delays in finding the help that was needed further interfered with the autonomy of these women. Sabina described her frustration of not being able to find a willing architect who could do renovations in her home. She repeatedly made calls to many architects to secure their help but was unable to find help.

The challenge of finding affordable housing is real and reported in a recent report “Where’s Home” from the Cooperative Housing Federation of Canada. The availability of nonprofit and cooperative housing declined between 1994 and 1998 and it has been at zero for the last several years following the provincial government’s cancellation of the program in 1995. Gillian said:

My dream home is a house that is fully accessible, even if it’s a townhouse. I don’t see why the government isn’t build-

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<th>Number of Self-Care Aids</th>
<th>Mean</th>
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<tr>
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<td>11.5</td>
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<td>Number of Transform Aids</td>
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<td>Number of Vehicle Aids</td>
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<td>Number of Other Assistive Technologies</td>
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Table 1. Assistive Technologies (N = 11)
ing more accessible housing for disabled because I think over 50% of the people in housing have one disability or another and out of all the housing in Toronto, there is only 5% that is accessible, fully accessible, so you’re on a waiting list for God knows how long and it’s not fair.

As this quote illustrates, the participants spoke of the limited housing available to people with disabilities. Only one third of the apartments of a 40-unit building where one participant lived were designated as wheelchair accessible.

Those living in regular households spoke of other roadblocks that interfered with their needs. The city’s municipal rules in applying for renovations to be made to a house was one such roadblock. Kelly was required to apply to the city’s committee of adjustment in seeking permission to make the entrance to her home more accessible. The process required that the neighbors approve the changes to be made. This was perceived as unfair to Kelly as her neighbors appeared to hold the decision power over her housing needs.

Participants living in apartments were also affected by the institutional environment when they discussed how the building rules prevented them from making any changes to their living quarters, and how the owners refused to spend the money to undertake changes. Such changes included automatic door openers, built-in dishwashers, and accessible pools, which the participants commented would make their lives better. Being renters, and not being able to make changes to their homes, seemed to seriously undermined their sense of identity by the comments participants made.

A fear mentioned by participants related to their efforts involved in applying for better housing was the possible negative spillover effect. They were hesitant to move out of their housing area because they would lose the current services such as their homemaker or attendant care, which were provided. Therefore, they felt unduly restricted in the choices available to them for possible new housing. This is a major issue for many women because it took considerable time for them to find a reliable, trustworthy service provider, and if they moved from their region they would have to reapply for services in a new area. This is another example of how autonomy was further restricted.

My Wheelchair, My Liberator, My Sense of Comfort

Participants in the study used manual and power wheelchairs and scooters. Generally, they stated that they liked their wheelchairs and felt safe. Features they liked included collapsibility, the backward tilt mechanism, the basket on the scooter, the power feature of the wheelchair, anti-flat tires, and direct drive chairs that allowed for better wheel traction. With respect to power, the benefits were that it increased a sense of freedom, lessened fatigue levels, and increased their opportunities for independence. Other benefits described with wheelchair use included the improved posture and decreased body pressure that resulted in more comfortable seating. Maintaining good health status was very important to the women who were getting older. Participants recommended changes to their scooters to improve their comfort level. These included a larger basket, more legroom, and better shock absorbers.

Overall the wheelchair was viewed by the participants as a liberator. They described it as a device that enabled them to be more independent to perform the occupations that were relevant to them. The following quotes reflect this idea:

The wheelchair has given me more independence. A lot more independence…. I used it everyday for work. I could do things like shopping and things like that…. It has given me so much more independence. I love it. I do my shopping. I love the freedom…. This is really liberating [Karen].

Gillian spoke about how the wheelchair allowed increased opportunities for social participation. “I rented a scooter for the summer so that I could get around with him [son] and I found it to be great.”

The freedom to perform occupations that were previously not possible was also the result of using a wheelchair. “Before I got the wheelchair, I really didn’t do much at all because it was just too difficult and then if there was stuff on the floor, which there is, you know, that’s an added barrier for me…. and I would get the kids to clean up as best as they could so that I could come into their rooms but the reality is that they weren’t very good at doing that and you can tell if you just glance into the kid’s rooms, I mean things don’t get hung up, they get dropped on the floor. Now that I’m in a wheelchair, I can go into the rooms” [Lucy].

The use of power wheelchairs was highly accepted as it increased the participants’ sense of control. “Just having a power wheelchair has given me a lot more freedom…. with the wheelchair I mean they can’t keep up with me when we go out. They keep telling me to slow down cause I’m going too fast” [Diane]. The increased mobility was very liberating to participants who had lived with manual wheelchairs. “I was that much weaker that it was just too hard to push all those distances and it took an inordinate amount of time, it was silly, so I got an electric chair at that time, which I really liked. I felt like I was in a rocket” [Mary].

Some participants mentioned that they could not live without their wheelchairs—It was viewed as an extension of themselves. There was a real sense of dependency on the wheelchair for quality in their lives. The wheelchair provided them with a comfortable sitting position as well as a
means of mobility. One participant mentioned how she would be confined to bed if her chair was taken away for repairs. Her chair supported her neck and her posture, and without it she would have to be in bed. This seems like a clear example of embodiment by Rubinstein (1989).

Along with the sense that the wheelchair was a necessity for users, it was described as a safe place:

Now that I have it I use it all the time, which I don't know if that's the best thing except I feel safer with it and I think you know, I haven't had a fall cause I used to fall routinely at home even. Again, because I am not walking as much around the home, I don't have those risks anymore you know. I feel much safer with the wheelchair so I use it way too much. [Jennifer]

Living in a Restricted Social and Physical World

Generally participants described their neighborhoods as being acceptable in terms of accessibility. These women, however, were responsible for many neighborhood changes to ensure accessibility. They mentioned their roles in encouraging schools to put in ramps so they could visit their children's schools. In one case, the church renovated its entrance and installed a chair lift to make it more accessible. Grocery stores, libraries, and banks were generally accessible because of the automatic doors. There were some problems with accessibility faced by participants. Drug stores presented more problems because of steps and narrow aisles. Another participant complained about not being able to continue singing in the church choir due to a lack of a ramp to the podium.

Major mobility problems occurred in the winter with the snow and poorly shoveled sidewalks that prevented access. Not being able to propel the wheelchair restricted community participation severely. One participant was unable to access the dressing rooms at her son's hockey rink because of limited space.

Many women stayed at home and entertained in their homes because often other people's places were not accessible. The scheduling issues around transportation also caused them to stay at home. Although women regularly advocated for better accessibility, they were clearly restricted in their participation in social activities.

Discussion

Findings from this study show that women manage both mobility issues and barriers in their physical environment as they carry out their homemaking role. The resulting lack of choice and control is a unique vulnerability faced by women with disabilities as they perform their homemaking and mothering activities. For mothers with disabilities, women doing ordinary labor within the home is transformed not only by the addition of extra hands, such as that of attendants or homemakers, but through mothers' attempts to control the effects of those hands upon them, their homes, activities, and families (Dyck, 1995).

Women did not have the freedom or economic resources to seek out new living arrangements, nor to make modifications to existing environments. Nor did they have control over the type of mobility device they owned because they did not have the financial resources to pay for the ideal chair.

Rowles (1987) in reviewing the literature on the meaning of home, noted that the need for a home is a “fundamental human imperative” (p. 339). Within the home environment, I suggest certain practices and processes related to the person and body are expressed. The main concepts derived from the conversations with the 11 informants and their comments on their homes and their experiences within them are embodiment and environmental centralization. Embodiment refers to those aspects of the person’s environment that are depended upon to get the job done. Examples in this study were wheelchairs, walkers, transfer aids, ramps, and attendant care aides, all used by the participants. Environmental centralization was expressed in the ways the women changed their living space so that it was more possible for them to be able to do things related to their homemaking. In considering possible generalizability of these findings from the small number of informants, however, it seems prudent to suggest that these relationships be considered exploratory. What this study did find was that women do endow environmental features with meanings, based on their personal circumstances. This points to the fact that environmental features and the lives of disabled women are intertwined. It was clearly revealed that declining function or change in health status led these women to seek relocation to more supportive home environments and to alter the living spaces of their current living situation either through renovations or manipulating aspects of their homes.

Conclusion

Having a wheelchair was a necessity and viewed relatively positively by most women as it increased their participation in society. Power wheelchairs contributed significantly to the quality of life of wheelchair users as it provided them with increased freedom and speed.
Mobility restrictions were numerous as women struggled with the barriers and lack of space in their homes and their communities. Women developed many coping strategies to manage their dependency on their wheelchairs by making changes to their physical worlds and social routines. Also they attempted to make changes to stakeholders in the political and institutional environments by negotiating changes in policies related to housing and health care services. These strategies helped to preserve their sense of personal autonomy.

This qualitative study allowed exploration of factors affecting the mothering and homemaking experiences of women with mobility impairments. The study points to the importance of taking into account the physical and institutional environments in understanding the women’s home and community participation. These environments come into play as women struggle to negotiate the demands of caregiving and homemaking as wheelchair users. Consideration of these dimensions will increase awareness and suggest possibilities for change for those clinicians who assist women with disabilities.

The findings from this study suggest new directions for research. Exploring the interaction of environments on women’s labor in the home and workplace needs further study as we identify the role of changes and modifications have on women’s lives. Further, we need to explore how children and spouses deal with living with a mother and wife, respectively, with a disability who uses a wheelchair. Several issues arise such as the possible embodiment role they may play in these women’s lives. Other studies should be conducted to examine the changes in women’s lives as they get older and the meaning they attribute to their wheelchair and other aspects of their environments.

References


