Acceptance and Meanings of Wheelchair Use in Senior Stroke Survivors

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The purpose of this qualitative study was to gain understanding of the lived experience of senior stroke survivors who used prescribed wheelchairs in their homes and communities. The study involved semistructured, in-depth interviews that were conducted with 10 participants, ages 70 to 80 years old, who had used a wheelchair for a mean of 5.6 years. A constant comparative inductive method of analysis was performed.

Three different categories of acceptance of wheelchair use were identified; reluctant acceptance, grateful acceptance, and internal acceptance. Increased mobility, varied social response, and loss of some valued roles were common to all three wheelchair acceptance categories. Aspects of level of burden, freedom, and spontaneity varied in degree among the three acceptance categories. As the wheelchair provided opportunity for increased continuity in the lives of these stroke survivors, it appeared to be accepted more fully and viewed more positively. Prestroke lifestyle and values need to be carefully considered in order to maximize acceptance of wheelchair use among senior stroke survivors.


Stroke survivors experience numerous losses due to cerebral damage (Mumma, 2000; Secrest & Thomas, 1999), however the loss of mobility is one that has been found to be of paramount importance to the survivor (Mumma). The use of a cane, walker, or wheelchair for mobility provides the stroke survivor with the opportunity to be more mobile than would otherwise be possible.

In addition to practical reorganization of various aspects of their lives that are necessary for wheelchair users, such as changes to living arrangements and transportation, there is also an emotional adjustment that occurs, including the recognition of new or increasing disability and incorporation of a new image of oneself (Gitlin, 1998; Spencer, 1998). A dearth of research literature attests to the fact that there is insufficient knowledge with regard to the psychological and emotional adaptation that takes place with the advent of the need for assistive devices, including wheelchairs, among people with mobility impairments. The purpose of this study was to examine how stroke survivors accept and view their wheelchairs, what it means to them to use a wheelchair, and how the wheelchair affects their life course and activities (Barker, 2001). This paper examines all these aspects of wheelchair use, although specific factors related to community participation were discussed in an earlier paper (Barker, Reid, & Cott, in press).

In one of the only studies that addresses acceptance of mobility devices and stroke survivors, Gitlin, Luborsky, and Schemm (1998) found that stroke patients expressed concerns about social acceptance and personal identity with regard to mobility devices, even though these devices were also viewed as providing an opportunity for independence. For other health populations, there are many factors that have been found to affect acceptance of mobility devices, including initial
prejudice toward the device (Bates, Spencer, Young, & Rintala, 1993), attitudes of others and stigmatization (Cott & Gignac, 1999; Rush & Ouellet, 1997). Genuine acceptance of mobility device usage often comes with seeing the need for the device, testing it out, and seeing the benefits such as the expanding of the user’s spatial boundaries and maintaining independence, which preserves self-integrity and self-identity (Cott & Gignac, 1999; Pippen & Fernie, 1997; Rush & Ouellet, 1997).

Acceptance of the wheelchair or mobility device for health populations other than stroke have been found to take years in some cases, due to the emotional adaptation that takes place, often involving new body image (Bates et al., 1993). The use of mobility devices has been found to alter self-identity in many cases (Bates et al.; Lupton & Seymour, 2000; Rush & Ouellet, 1997), and maintain self-identity through independence and increased mobility in others (Cott & Gignac, 1999; Rush & Ouellet). In speaking of wheelchair use specifically, Lupton and Seymour identified positive aspects such as increased mobility and increased social interaction, as well as negative aspects such as the wheelchair being seen as a signifier of disability, detracting attention away from identity and individuality of the user.

Aside from use of mobility devices, stroke survivors must deal with many changes in their lives. The concept of “biographical disruption” involves the disruption of lives and plans of those with chronic illness. It was first introduced by Bury (1982) in his study of people with rheumatoid arthritis but further developed by others (Charmaz, 1987, 1995; Corbin & Strauss, 1987; Williams, 2000). Studies have found that the advent of a stroke brings about numerous changes, disrupting the normal course of the individual’s life, bringing losses in many aspects of life, including loss of activities, abilities and characteristics, and independence (Becker 1993; Kaufman, 1988; Mumma, 2000; Secrest & Thomas, 1999). These losses can bring about changes in self-identity and self-concept (Becker; Ellis-Hill & Horn, 2000), depression (Singh et al., 2000), decreased subjective well-being (Wyller, Holmen, Laake, & Laake, 1998), and decreased quality of life (Astrom, Asplund, & Astrom, 1992; King, 1996). Pound, Gompertz, and Ebrahim (1998) challenged the assumption of the concept of biographical disruption that the lives of the chronically ill have previously been untouched by crisis or struggle, as they found that stroke was not such a disruption to the lives of the elderly, socially disadvantaged stroke survivors in their study.

Stroke can be viewed also as a disruption to continuity of life. Continuity Theory is a theory on aging and was developed in an effort to explain the common research findings that older adults, despite significant changes in health, functioning, and social circumstances, show considerable consistency over time in their patterns of thinking, activity profiles, living arrangements, and social relationships (Atchley, 1989). Becker (1993) found that people unanimously viewed stroke as a profound disruption to their lives. The poststroke year was a time of life reorganization. The stroke survivors focused on everyday tasks that had provided them with a basic template for daily life in the past and had given their lives meaning. It was also found that those who suffered severe strokes struggled to regain a sense of continuity because they could not resume even simple tasks of everyday life. Gitlin et al. (1998) discussed the findings of their study of assistive device use and stroke survivors from the viewpoint of continuity and discontinuity. They found that the devices provided a mechanism for continuing valued roles and activities. However, they found device use simultaneously contributes to the emotional, physical, and social disruptions experienced in the stroke survivor’s life.

In addition to the disruption in the life of the stroke survivor, the advent of stroke changes roles and relationships within the family life of the stroke survivor (Jongbloed, 1994). Research has also found that business and other social networks are disrupted after stroke (Burton, 2000). Disruption in the life of the stroke survivor requires work and time to recover some sort of balance and continuity in life (Buscherhof, 1998). To date, there has been no research to investigate the impact of wheelchair use on the biographical disruption of those with chronic illnesses and the effect of issues of continuity of life on acceptance of wheelchair use.

Research that specifically examines the life-course disruption, psychological and personal adjustments, and continuity of life in elderly stroke survivors who use wheelchairs postdischarge from the hospital is lacking. Issues of perceived losses, differing views and acceptance levels of assistive devices, and altered self-identity that have been found in previous studies need to be explored more fully with all wheelchair users to assist health care providers in prescribing appropriate equipment and responding to needs and concerns of the users. This study adds further understanding to these issues with the senior stroke survivor population.

Methodology

Research that is exploratory or descriptive and that stresses the importance of context, setting, and the participants’ frames of reference is well served by qualitative research methods (Marshall & Rossman, 1989; Strauss & Corbin,
This qualitative study involved in-depth interviews with a subsample of respondents obtained from an original study examining occupational performance of elderly stroke survivors who use prescribed wheeled mobility systems in the home environment (Reid, Rudman, & Hebert, 2000). The original study, using qualitative and quantitative means, examined practical occupational performance issues from the wheelchair users’ and caregivers’ perspectives. In contrast, this secondary study explored the lived experience of wheelchair users.

Participants

The inclusion criteria for stroke survivors in the original study were as follows. Subjects had to be more than 65 years of age, living at home, using a prescribed wheeled mobility system for at least 1 year, needing assistance with their daily activities, living in a metropolitan area of Canada, speaking and understanding the English language, and cognitively competent to use a wheelchair and report their evaluation of its use in an interview. Due to the qualitative nature of this study, the subsample invited to participate in this study were those participants who expressed themselves well in the primary study. Ten stroke survivors participated in this study, 8 males and 2 females. Participants ranged from 70 to 80 years of age with the mean being 75.5 years. All participants were married and living with a spouse. Two participants were Black and 8 were White. Time since stroke ranged from 2 to 16 years with a mean of 5.6 years. Eight participants had right-sided stroke and two had left-sided stroke.

Approval was received for the primary study and this present study, from the Human Subjects Ethics Review Committee at the authors’ university. Informed, written consent was obtained from all participants. Pseudonyms are used throughout this paper to ensure confidentiality of participants.

Data Collection

All interviews were semistructured (see appendix interview guide) and in-depth and took place in the participants’ homes with the exception of one interview that took place in a private room of a rehabilitation hospital. In performing the interview, the interviewer positioned herself as a learner, asking the participants to give their “expert” opinion on life as an elderly stroke survivor using a wheelchair in their home and community (as seen in Sword, 1999). All interviews were audiotaped, and lasted approximately 1 1/2 to 2 hours. After the qualitative interview was completed a data sheet was filled in and a photograph of the wheelchair was taken to aid in recording wheelchair characteristics. Field notes were generated immediately after the interview, denoting any information and observations deemed to be important, such as emotional responses, interview environment, and interruptions. Interviews were transcribed verbatim as promptly as possible after the interview was completed. Interviews were conducted from March 6, 2000, to August 16, 2000.

Data Analysis

Data analysis involved an inductive approach, using a constant comparative process (Creswell, 1998). The transcribed interviews were coded by analyzing whole sentences or paragraphs. Open coding was done initially, identifying concepts, with their properties and dimensions. The utility and appropriateness of this initial coding were assessed by the first and third authors independently coding pages of text with subsequent comparison and consensus of coding. A qualitative computer software program (QSR NUD*IST 4, 1997) was used to assist in the coding and retrieval processes. Axial coding, involving reassembling the data relating categories to their subcategories, was then undertaken. Categories were integrated and refined. Analytical and conceptual memos, both written and diagrammatic, were used throughout the analysis to help clarify and develop and explore emerging themes.

Process files (Kirby & McKenna, 1989), kept in a journal, allowed for recording of progression of research, thoughts of the researcher, development of themes, and other information deemed relevant and important to the research process. As themes emerged, questions were added to pursue these concepts and ideas with remaining participants.

After all interviews were completed, data were analyzed and themes developed. A member check was performed (Rowan & Huston, 1997) allowing participants to respond to the recorded findings, analysis, and themes. A summary sheet of the findings outlining meanings of wheelchair use, issues affecting acceptance, and other research questions, was mailed to 2 participants who represented different acceptance levels and after 7 to 10 days, a final telephone interview was conducted with them. The input and feedback from these telephone interviews, such as clarification and priority of issues, was incorporated back into the analysis.

Results

Generally speaking, the wheelchair and its use were viewed positively by the participants. Specifically, there were three views of the wheelchair. Each view represented a category of acceptance of wheelchair use. Figure 1 illustrates these views and acceptance categories, with the three views of the
wheelchair on the x-axis and the corresponding acceptance category of wheelchair use on the y-axis. Table 1 shows the characteristics of those participants in each of the acceptance categories of manual wheelchair users.

**The Wheelchair Is a “Necessity”: Reluctant Acceptance**

The participants in this category expressed the view that they would rather not use a wheelchair but recognized that in view of their physical problems and dependence on others, it left them no alternative but to use the wheelchair—it was a “necessity”: “Without it [the wheelchair] I couldn't get anywhere. Without the chair, I'd just have to put up with it. It's a necessity” (Mr. K. L.). So while these participants could list benefits of wheelchair use, and felt positive about the wheelchair, they did not speak at length of it as an asset or aid for their daily lives.

These participants who viewed the wheelchair as a necessity seemed to reluctantly accept their need for a wheelchair. This is seen in the words of one such participant when asked how he felt about the fact that he needed to use the wheelchair: “Not a thing I can do about it. I've come to accept it. That's it. I don't like it but...maybe I...I figure my age and what has happened to me made me where I am” (Mr. S. T.).

**The Wheelchair Is a “Great Asset”: Grateful Acceptance**

For participants in this category the wheelchair seemed to be viewed as a “great asset” in addition to being a necessity. These participants spoke more of the benefits than the problems with wheelchair use. They expressed thankfulness for the wheelchair and for what it allowed them to do: “Well, using the wheelchair doesn't make my life

As shown in Figure 1, the first view of wheelchair was as a necessity only. This view represented reluctant acceptance of wheelchair use. The second view was that the participant viewed the wheelchair as not just a necessity but also as a great asset. The corresponding category of acceptance for this view was grateful acceptance. The final view of the wheelchair was that the participant viewed the wheelchair as a part of him or herself in addition to viewing the device as a necessity and as a great asset. The corresponding category of acceptance for this view was internalized acceptance.

**Figure 1. Views of wheelchair with corresponding categories of acceptance of wheelchair use.**

<table>
<thead>
<tr>
<th>Acceptance Category</th>
<th>Number of Participants</th>
<th>Gender of Participants</th>
<th>Mobility of Participants</th>
<th>Manual vs. Power Wheelchair Users</th>
</tr>
</thead>
<tbody>
<tr>
<td>Reluctant Acceptance</td>
<td>4</td>
<td>4 Males 0 Females</td>
<td>0 Required wheelchair for full-time mobility 4 Able to walk with walking aid inside the home (3 Used wheelchair inside the home in addition to outside the home)</td>
<td>3 Used Manual Wheelchair only 1 Used Manual Wheelchair and Power Scooter</td>
</tr>
<tr>
<td>Grateful Acceptance</td>
<td>4</td>
<td>3 Males 1 Female</td>
<td>1 Required wheelchair for full-time mobility 3 Able to walk with walking aid inside the home (3 Used wheelchair inside the home in addition to outside the home)</td>
<td>3 Used Manual Wheelchair only 1 Used Manual Wheelchair and Power Scooter</td>
</tr>
<tr>
<td>Internal Acceptance</td>
<td>2</td>
<td>1 Male 1 Female</td>
<td>1 Required wheelchair for full-time mobility 1 Able to walk with walking aid inside the home (1 Used wheelchair inside the home in addition to outside the home)</td>
<td>2 Used Manual Wheelchair only 0 Used Manual Wheelchair and Power Mobility</td>
</tr>
</tbody>
</table>
harder. Using the wheelchair makes my life easier....But now I use the wheelchair I feel that I have conquered my illness” (Mr. I. J.).

The wheelchair appeared to be gratefully accepted and seemed to have become an accepted part of life and daily routine with those expressing this view. The wheelchair appeared to bring increased security and confidence in mobility, and was necessary for proper seating and for indoor and outdoor mobility. One participant expressed this grateful acceptance in this way: “If I didn’t have the wheelchair I’d be lost. It’s the thing...it’s a necessary thing for anyone that’s crippled. You know, that can’t walk very much. It’s a must to have it—it’s a must. It’s a great asset. It’s a great asset.” (Mr. A. B.). As evident in this quotation, the wheelchair was seen as both a necessity and as a great asset.

Two of the participants owned and used powered mobility devices in addition to owning and using manual wheelchairs. Although both participants could identify some negatives aspects of the use of power mobility devices, they generally spoke extremely positively about their power mobility devices: “[With the manual wheelchair] you’re confined enough where you go. Now [with] the electric chair...it would take you 25 miles. That’s quite a distance.”

In placing powered mobility users on Figure 1, it would seem that both participants viewed the powered mobility device as a great asset. They could be put in the grateful acceptance category. However, the grateful acceptance of the powered mobility users differed from that of the manual wheelchair users’ in that they did not seem to also consider the device a necessity. The powered wheelchair users seemed to view the wheelchair as more of a luxury item; the manual wheelchair that each also used appeared to be the necessity for them. Although the powered mobility was part of the daily lives of these participants, they seemed to view the device as primarily a method of transportation outside the home, almost as they might have previously viewed a car.

The Wheelchair Is “a Part of Me”: Internal Acceptance

With this final view, the wheelchair appeared to be not only a part of a routine of daily living, a necessity and a great asset, but was “a part of” the participants themselves. The participants acknowledged the decreased abilities of their physical bodies and seemed willing to substitute the use of the wheelchair for their impaired body parts. Two of the participants expressed this idea. One participant said: “[The wheelchair] gave me an extra leg...gave me a little more strength, confidence to move about, to be more mobile” (Mr. E. F.). The other participant, after speaking of the benefit of mobility and comfort in the wheelchair, and the wheelchair “accommodating” her, said, “So the wheelchair is a part of me now” (Mrs. G. H.).

The views of wheelchairs presented above represent the participants’ views of wheelchair use at the time of the interview. While this was not a longitudinal study and thus we could not examine actual change in views of the wheelchair and its use over time, the respondents did speak retrospectively on how they viewed the wheelchair initially. When speaking of getting used to using a wheelchair, one respondent said, “You gotta grow into it (laughing)” (Mr. E. F). Participants spoke of how their attitudes affected their adaptation to stroke and acceptance of wheelchair use, mentioning life-long patterns of attitudes and values. Self-concept also appeared to have an effect on adaptation to stroke and wheelchair use. One participant spoke of being a “fighter” and of fighting the deficits brought on by the stroke. Others felt that they were “determined” or “a survivor.”

The need for and use of the wheelchair led to many changes necessitating coping and adapting on the part of the participants. Positive coping resources that were mentioned by the participants were: family support and encouragement, a positive attitude, religiousness, perseverance, attending community support groups, and keeping busy. Seeing other wheelchair users in the rehabilitation hospital also appeared to help the participants accept wheelchair use while in the rehabilitation hospital. However, on transition from hospital to home, participants spoke of the physical changes that had to take place in their homes in order to accommodate the wheelchair, and of the increased effort required to perform routine daily chores. These changes were upsetting to the participants, however, the benefits of wheelchair use were also recognized, leading participants to continue to speak positively overall about the wheelchair as they reflected on these times.

Acceptance of Wheelchair Use Over Time

For participants in all acceptance categories, the use of the wheelchair meant that they had increased their mobility within or outside their homes or both. All participants in this study appeared to value
mobility highly. One participant expressed the importance of mobility to him in this way: “Cause once your mobility is affected you feel like you’re a dead person. This [the wheelchair] gives me an opportunity to still move.” (Mr. E. E.). Mobility, at least to this participant, meant life. Being capable of moving around, even if it was at a slower pace, was extremely important to all participants: “...It makes my life easier to get around. I can go downstairs, visit my friends. I just jump in it, and pull myself” (Mr. A. B.).

The 2 participants with power mobility spoke of the improved outdoor mobility with these devices. Although the manual wheelchair increased outdoor mobility, it did not compare with the amount and type of mobility that the power device offered as expressed by the power mobility users. Overall, participants spoke of the wheelchair increasing mobility within the home, the community, and travel within and outside of Canada.

**Level of “Burden” on Caregiver.** Wheelchair use to some participants meant the opportunity to lessen the burden on a spouse and was expressed by one participant in this way: “I’m not a hindrance, let’s say. I’m not a burden to anybody. The wheelchair accepts that burden. Not my wife” (laughing) (Mr. E. E). Another participant stated: “...and it’s my only means of helping [spouse] cope with what I’ve got.” (Mr. O. P.). Clearly, in these cases, wheelchair use meant less reliance on others, which was important for the participants.

In many cases, especially for those in the reluctant acceptance category of wheelchair use, participants mentioned the increased tasks and responsibilities of their caregivers and their dependence on them because of wheelchair use. Reliance on others increased because of additional tasks specific to wheelchair use, such as pushing the manual wheelchair, putting the wheelchair in and out of the trunk, and opening nonautomated doors. The wheelchair allowed many participants to be independent in mobility inside their homes, however difficulties with maneuvering and pushing the wheelchair led all participants to rely on caregivers for outdoor mobility in the manual wheelchair.

“Freedom” and “Confinement.” Participants expressed feelings of “freedom” and “confinement” with wheelchair use, with responses varying among acceptance categories. Participants in the reluctant acceptance category spoke more of confinement with wheelchair use, while more freedom was mentioned by those in the grateful acceptance category (with the exception of one participant who was blind). Interestingly, there was no mention of freedom or confinement by those in the internal acceptance category.

The wheelchair for 3 participants allowed freedom to do things that they wanted to do, when they wanted to do it, expressed this way by 1 participant: “You need a wheelchair—it makes you freer. Free to do things, you know. You know, you can go shopping, you can wheel yourself around in the summer time.” (Mr. A. B.).

Five participants expressed that they did not feel freedom in using the wheelchair, only confinement. One such participant expressed this feeling in this way: “I get confined. Um, sometimes it’s a lot of effort for what you...you’re getting out of where you’re going and what you’re doing” (Mr. S. T.). Another such participant said: “I don’t feel that freedom of movement I had when I wasn’t in the wheelchair” (Mr. I. J.).

**Decreased Spontaneity.** Three participants, 1 in the reluctant acceptance category and 2 in the grateful acceptance category, spoke of the fact that they could no longer do things on a spontaneous basis. Outings needed to be planned ahead of time, from beginning to end. Often disabled transit needed to be arranged, caregivers needed to have time to ready the participant for the outing as well as accompany them on most outings, wheelchair accessible washrooms and other facilities had to be confirmed as being available, and timing due to fatigue factors had to be taken into account. All these factors added together to produce the need to carefully plan outings and activities.

One participant spoke this way about how his life was different since he had to use the wheelchair and said: “Well, before the wheelchair I would say, ‘Well, I’m going down here,’ or ‘I’m going out here.’ But now I have to change that to ‘Can I go to such and such a place?’” (Mr. I. J.). Another participant spoke of this loss of spontaneity: “I miss the ability to go where I want when I want. I was never still” (Mrs. Q. R.).

**Varied Social Response.** Society response to wheelchair use was seen to be varied, however all participants felt that wheelchair use was socially acceptable and was not stigmatizing. Participants in all three wheelchair use acceptance categories spoke similarly about social response.

Wheelchair use, in spite of the difficulties it brought to family life, seemed to be generally acceptable and there appeared to be increased kindness and consideration from family members. The majority of participants thought that their family members treated them very kindly and appropriately and were very supportive. Responses from friends to wheelchair use was also viewed to be positive for the most part. Most participants felt that friends treated them well, generally as no different than prior to wheelchair use. Two participants did mention that they felt that their friends felt sorry for them when they thought of what they were capable of previously.

The majority of the participants felt that the general public was kind and helpful towards them as wheelchair users. Many mentioned that they felt that wheelchair use
was now more acceptable than it had been previously and attributed this to the public’s increased understanding of disability and increased exposure to those with disabilities. Some participants felt that people “felt sorry” for them or were “ignorant” or “nosey,” and some felt that people were overly helpful, to a fault. One gentleman, when asked how people reacted to him in a wheelchair said: “...Kindly, mostly. Patronizing some. Little kids, scared to death” (Mr. O. P.). Another participant said: “I’ll place [the religious magazines] on the street as I meet people. And what I find, uh, is that they accept more literature off me now then when before I got the stroke. Because I think they feel sorry for me. Probably” (Mr. A. B.).

Loss of Some Valued Activities and Roles. Certainly, participants had to deal with many losses since their strokes and did speak of these losses. However, they also spoke specifically about losses related to wheelchair use. Loss of some valued activities due to wheelchair use was mentioned by all participants, although participants in the reluctant acceptance category spent the most time talking about it. Losses were due to environmental barriers or to the amount of effort required by the stroke survivor or the caregiver or both to participate in the activities. These losses included: going to the cottage, going to places of worship, visiting the homes of family and friends, gardening, vacationing in other countries, and attending bridge club. One participant spoke of the fact that she could no longer attend her church, “I don’t get to my church because it’s not wheelchair accessible. And I was a church woman. I was president of my UCW and all that stuff. I was in church, “I don’t get to my church because it’s not wheelchair accessible. And I was a church woman. I was president of my UCW and all that stuff. I was in church work for many years. But I can’t get to it” (Mrs. Q. R.).

Discussion

Life-course disruption and discontinuities were certainly evident in the lives of the participants in this study, as found previously (Becker, 1993). The wheelchair, although it brought some discontinuities, was seen by the participants as a tool for continuity, allowing them to continue with some of the activities that brought meaning to their lives. As the wheelchair provided opportunity for increased continuity in the lives of these stroke survivors, it appeared to be accepted more fully and viewed more positively. Powered mobility devices, used by 2 participants, appeared to allow further continuity in activity levels and social roles and were valued highly by the participants that used them. These devices were used in conjunction with the manual wheelchair to allow optimum independence and activity and ultimately, continuity with the prestroke life.

The value participants placed on mobility prior to stroke seemed to affect their view of the wheelchair and acceptance of wheelchair use. For example, a former truck driver and frequent traveler was very frustrated at his low level of mobility in his manual wheelchair and was in the reluctant acceptance category. All participants valued mobility highly, as has been found previously (Mumma, 2000), but some were more content to be less mobile, and this contentment seems to have a more positive effect on their view and acceptance of wheelchair use.

Self-concept, attitudes, and values attributed to mobility and independence, seemed to contribute to the category of acceptance of wheelchair use, and the meanings associated with its use. Some participants spoke of using similar strategies of adaptation to wheelchair use as they had used for adaptation to other changes in life that they had encountered. Reciprocally, the stroke and need for a wheelchair for mobility seemed to affect the self-concept of at least some of the participants. This interrelatedness of meaning and self-identity is similar to other findings where the meaning of illness was integrally linked to perception of self, the social context, cognition, and behavior (Fife, 1994). As each participant has her or her own identity and cognitive response to using a wheelchair, he or she responded in a unique way, in the context of his or her past life and activities and the present social atmosphere.

Most participants in this study felt that they were the same person as prior to wheelchair use, even though some activities and roles had changed in their lives. Although participants recognized the limitations in activities and loss of social roles, most did not think that they had undergone a change in self-identity. This finding is in contrast to previous studies that found that mobility device use altered self-identity (Bates et al., 1993; Rush & Ouellet, 1997) and to studies that found that, mobility issues aside, the stroke event itself caused changes in self-identity (Becker, 1993; Ellis-Hill & Horn, 2000). It is possible that these participants had used a wheelchair long enough that the process of change in self-identity had occurred many years previous and they did not view it as notable or significant, or that the use of a wheelchair was not the threat to their self-identity that they had previously expected (Gitlin et al., 1998). It is also possible that for most of the elderly participants in this study, self-identity was well established and not challenged to as great an extent as it might be for some younger person confronted with the need for a wheelchair. In addition, wheelchair use may have helped to maintain self-identity through aiding independence (Cott & Gignac, 1999; Rush & Ouellet).

Goals for some participants remained consistent with goals of their prestroke life, while others had developed new goals related to living with the effects of a stroke. Two of the participants actually spoke about reevaluating life after the
stroke occurred. One participant, with reluctant acceptance of wheelchair use, had a personal goal to improve his ambulation so that he did not have to use a wheelchair anymore. In contrast, another participant who showed grateful acceptance of wheelchair use, seemed to be more content with his situation and spoke about the fact that he was endeavoring to be the same person he was prior to wheelchair use. Another participant with internal acceptance of wheelchair use seemed to have a personal goal of helping others deal with the onset and consequences of a stroke, volunteering with stroke support organizations. A desire to continue on with the spiritual aspect of their lives appeared important among many of the participants as they kept up contact with places of worship and other religious affiliations even when wheelchair use made continuity in this area somewhat problematic. Family relationships appeared to be extremely important to all participants. Consistent with previous findings, interdependency patterns among family members had changed (Jongbloed, 1994) due to the advent of the stroke and the need for a wheelchair. However, it appeared that the goal of continuing the evolution of ongoing family relationships was maintained.

The value of a mobility device in increasing independence, in other studies, led to increased acceptance and use of the device (Cott & Gignac, 1999; Pippen & Fernie, 1997; Rush & Ouellet, 1997). For many of the participants in this study, the same relationship between independence and acceptance might exist, but not for all, as some did not have independent mobility with the wheelchair. However, it could be said that as the wheelchair decreased the dependence or perceived “burden” on the caregiver, usually the spouse, wheelchair use was accepted more fully.

As in previous studies, power mobility devices allowed users to pursue previously valued roles, enact new and old roles that brought meaning to their lives, increased independence, decreased dependence on others, and widened their world (Buning & Schmeler, 1999; Miles-Tapping, 1996). The participants in this study mentioned the need for both mobility devices, manual and power, to enjoy both indoor and outdoor activities as they desired. Power mobility devices were viewed very positively and accepted swiftly. This is in contrast to other study findings (Miles-Tapping, 1996) in which power mobility device users regarded a switch from a manual to a power mobility device as a progression of disability or deterioration that is fought against and avoided as long as possible. This difference might be explained by the fact that stroke is a nonprogressive event, with a one-time effect on mobility, whereas those in the aforementioned study had progressive diseases.

Participants in all wheelchair use acceptance categories felt that the wheelchair brought varied, but overall positive social response. It is not clear whether this positive society response may have been a factor in the overall positive view of the wheelchair shown by all participants. Certainly, this study did not show attitudes of others to be a factor in mobility device acceptance as found in other studies (Cott & Gignac, 1999; Rush & Ouellet, 1997).

Overall, the wheelchair seemed to be viewed by the participants in this study more as an aid, rather than a visual reminder of loss (Gitlin et al., 1998; Lupton & Seymour, 2000). Participants in this study used many assistive devices and had altered limb use that would also remind them of losses without even considering the wheelchair. With the length of time using wheelchair being 2 years and greater, it could be that participants had already dealt with issues of loss and now looked on these devices as aids to compensate for losses rather than as reminders of losses.

It is thought that emotional acceptance of the wheelchair occurs gradually over years of use (Bates et al., 1993). Histories of participants in this study ranged from 2 to 16 years of wheelchair use, with the mean years of use being 5.6 years. It is possible that emotional acceptance of the wheelchair took a number of years, with initial acceptance only being out of necessity. For example, those who saw the wheelchair as a necessity only, accepting wheelchair use reluctantly, had the lowest mean years of wheelchair use and thus may not have the level of emotional acceptance of the device that those who had grateful and internal acceptance of wheelchair use did. It is possible that these are not static categories of acceptance, but evolving. This hypothesis would require further investigation, using a longitudinally designed study performed over many years.

Moderate activity decline, as compared with prestroke lifestyles, appeared in all categories. Participants in the internal acceptance category showed moderate activity decline in the quantity of activity but continued for the most part with engagement in similar activities as prior to wheelchair use. Participants in the reluctant acceptance category appeared to have a more dramatic decline in level and similarity of prestroke activity. Power mobility devices appeared to allow the participants who used them to pursue interests and lifestyles to which they had previously been accustomed. It is possible that acceptance of wheelchair use was linked to the continuity or discontinuity of activity patterns of the participants.

Conclusion

Due to the nature of this qualitative study and the in-depth interviews required, the number of participants was not large. Participants were all recruited from the same metropolitan area. Men and women were not equally rep-
resented, with only 2 of the 10 participants being female. The ability of the participants to verbalize their feelings and experiences was of paramount importance in this qualitative study. This meant that those with aphasia or any type of communication difficulties could not be included as subjects in this study. In spite of these limitations, themes and concepts were generated that would allow for further exploration in later research, to explore the transferability of the findings to a range of settings.

Some of the concepts explored, such as adaptation to wheelchair use and continuity or discontinuity of activity level, could be examined in more depth by use of a longitudinal study with an accurate index of activity levels past and present. Also, a longitudinal study, exploring acceptance categories of wheelchair use among stroke survivors, could help to discover whether these categories are progressive or static.

The benefits of powered mobility devices needs to be explored in more depth. Only 2 of the 10 participants in this study owned and used powered mobility devices. Research is needed to explore more fully the benefits and drawbacks of these devices in this population, exploring issues such as continuity or discontinuity and quality of life.

In prescribing wheelchairs for senior stroke survivors, this study provides evidence that prestroke lifestyle and values need to be carefully considered in order to maximize acceptance of wheelchair use. Beyond measurements for ensuring physical “fit” of the wheelchair, the prescribing therapist needs to explore social roles and desired levels of activities with the user to ensure maximum lifestyle “fit” of the wheelchair and to assist in continuity of life of the senior stroke survivor.

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References


Appendix

Interview Guide

Interviewer Introduction: “The purpose of this study is to understand more fully the experiences of stroke survivors who use a wheelchair in their home and community. I specifically want to hear from you concerning issues such as how you adapted to wheelchair use, whether there have been changes to your self-identity since having a stroke and using a wheelchair, and what your level of community participation is. If you do not wish to answer any question during the interview, you are free not to do so. I appreciate your willingness to partner with me in this project by spending this time with me. If you have any questions for me at any time, please feel free to ask.”

Please tell me about when you first received your wheelchair.
Probe: when, how, who helped with fitting, training

(a) Has your life changed since you started using a wheelchair?
Probe: in what ways?

(b) What is your life like with the wheelchair?
Probe: positives and negatives

Can you tell me if using a wheelchair makes your life harder?
Probe: inside or outside your home, specific examples

Can you tell me if using a wheelchair makes your life easier?
Probe: inside or outside your home, specific examples

Can you tell me if using a wheelchair has made you feel differently about yourself?
Probe: how, why

If you didn't have this wheelchair, can you tell me and how things would be different for you?
Probe: inside your home, outside your home

What advice would you give to someone who is just beginning to use a wheelchair?
Probe: any necessary adjustments