

The Experience of Active Wheelchair Provision and Aspects of Importance Concerning the Wheelchair Among Experienced Users in Sweden

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Abstract: This qualitative study describes the experience of active ultra lightweight rigid frame wheelchairs (active wheelchairs) provision. Eleven interviews with experienced users showed that the wheelchair should support physical as well as social functioning, but that users experienced injustice and unfairness when negotiating their wheelchair needs and felt insecure within the system. Changes of attitudes and organization are suggested.

Key Words: negotiation, qualitative research, wheelchair prescription

Introduction

Active wheelchairs are a sub-type of wheelchairs mostly used by younger persons living active lives with career, family, and leisure activities. But, without an optimized wheelchair, everyday life activities become difficult to maintain (Batavia, 1998; Cooper, 1998). In Sweden, municipalities are responsible for the provision of assistive devices, such as wheelchairs (Arnell, 1999). However, as most wheelchairs are used by persons over 65 years of age, active wheelchairs represent only a fraction of all wheelchairs (Frick-Meijer, 2005). Meeting the demands of a small group of young active users, as compared to older persons with different demands, may pose a problem. Active wheelchairs have to meet other requirements than other manual wheelchairs, for instance, to facilitate active means of ambulating. Compared to other types of wheelchairs, an active wheelchair is less a tool for a person being transported (Cooper, 1998; Batavia, 1998; Bergström & Samuelsson, 2006). Active wheelchairs are more hard-wearing, can withstand higher strains than other manual wheelchairs and can be used for up to 16 hours a day, 365 days per year, a degree of usage few other devices are required to withstand (Cooper, 1998; Cooper, Boninger, & Rentschler, 1999).

In Sweden, 6.5% (or 575,000 persons) of the population between 16 and 84 years have a physical disability (defined as the inability to take a short walk); about 25% are under 65 years of age. Further, a person is considered severely physically disabled if an assistive device is needed for ambulation. About 1 % of the Swedish population (90,000 persons) uses manual wheelchairs. Among those, the proportion of active wheelchairs is unknown. There is no centralized gathering of data from the 21 county councils or 290 municipalities regarding prescription and utilization of models and brands of active wheelchairs (Arnell, 1999). However, in the year of 2004/05, the number of manual wheelchairs reported by the Swedish Handicap Institute (HI) as sold was 19,797, out of which 9.4% (1,579) were active wheelchairs. This data is not based on prescriptions, but on the reported sale by the manufacturers. There is no information concerning how the number of manual wheelchairs sold is distributed among the various brands or models (Frick-Meijer, 2005).

The Swedish system of government is based on strong and independent municipalities and county councils. Within their respective fields of responsibility, they are relatively free to decide upon taxes and the detailed content of specific services (Lindgren, 2006).

General guidelines for prescription are provided by the Swedish Health and Medical Care Act (HsL) (SFS, 1983). Decisions made based on this act cannot be appealed; neither does the act include any possible sanctions if its intentions are not fulfilled. Instead, HsL states that the obligations of the health-care system to supply the medical care and devices are deemed necessary by the profession. Thus, the legislation endows no rights to the patient to demand a specific medical treatment (or device) (Lindgren, 2006).

The assistive device is a loan and ought to be returned when it is no longer needed (Svensson, Ödegaard, & Persson, 2007). When a user moves from one municipality to another, the device is to be returned, and another device prescribed in the new municipality (Hjälpmiddelsinstitutet, 2008). Normally, counties are responsible for healthcare at large, and municipalities are responsible for assistive devices used in everyday life (e.g., active wheelchairs). In practice, only assistive devices deemed necessary for everyday life are supplied – assistive devices whose primary purpose is deemed recreational (e.g., a set of wider wheelchair wheels for a walk in the woods or on a sandy beach) are not supplied. The HsL does not regulate the interaction between county councils and municipalities regarding the assortment of devices and potential fees (SFS, 1983; NSH, 2003). Blomquist (2006) found variations between municipalities in the same county, as well as between counties, and increasing fees during later years.

Choices regarding the local selection of assistive devices are guided by recommendations by the Swedish Handicap Institute. One role of the Institute is to test and validate assistive devices, normally by commission of manufacturers, thus establishing a list of validated models (NSH, 2003; Rönnberg, 2005; Blomquist, 2006). The list includes 17 models from five distributors/manufacturers (Hjälpmiddelsinstitutet: Webb-HIDA, 2008). The local lists tend to contain fewer models due to economic reasons (Kittel, DiMarco & Stewart, 2002; Wressle & Samuelsson, 2004). However, no legal hindrances have been located regarding neither marketing nor prescription of CE-marked models (not validated by the Swedish Handicap Institute). Validation may therefore serve other purposes, such as a marketing argument.

Previous research has identified the main objective in prescription as the selection of the wheelchair that best allows the user to carry out daily activities and social roles (DiGiovine, Cooper, Boninger, Lawrence, VanSickle, & Rentschler, 2000; Routhier, Vincent, Desrosiers, & Nadeau, 2003), i.e., a satisfied user performing needed and desired activities in varied settings (Scherer, Jutai, Fuhrer, Demers, & Deruyter, 2007).

Wheelchair prescription requires knowledge in many disciplines such as mechanics, anatomy, physiology, kinesiology and technology, but also concerning everyday activities and movement function. Moreover, knowledge concerning available products is needed due to the constant expansion of available models. It is vital to allow the user to try different models during the prescription process. The wheelchair is an extension of the user's body, and therefore,

knowledge about the user's needs and priorities are of outmost importance for the prescriber. Thus, in theory, the most important factor is the user's personal priorities (Batavia, 1998; Cooper, 1998). However, a dilemma in prescription is the traditional view of users as patients, subject to expert assessment and prescription; not as individuals with a right to express preferences or allowed the possibility to choose (Sapey, Stewart, & Donaldson, 2004).

In Sweden, prescription is supposed to be based on the user's entire life situation. The prescriber has to make sure that the user priorities are understood; choice of product ought to be done together with the user, based on individual demands, needs, and priorities. However, this process does not imply that the user has a free choice. The final decision is always made by the prescriber, thus indicating an uneven distribution of power in the relationship. The availability of a certain device may differ between municipalities. Even though a specific device is available on a local list, it may prove impossible to obtain in reality (NSH, 2003; Lindgren, 2006; Svensson, Ödegaard, & Persson, 2007). DHR (2003), the Swedish National Confederation of Persons with Disabilities, conducted a survey concerning users' experience of assistive devices supply. Results indicated that the process was thought to be complicated. This was due to organizational decentralization and widespread responsibilities, making it difficult to find someone with an actual responsibility. Nevertheless, prescription of active wheelchairs in Sweden has only sparsely been focused in earlier research. This may be due to the comparatively small number of prescriptions, therefore a less common task for the average prescriber. Hence, the objective of this study was *to describe the experience of active wheelchair provision and aspects of importance concerning the wheelchair among experienced users in Sweden*. In order to gain a thorough understanding, a qualitative approach based on interviews was chosen.

Materials and Method

This study utilized qualitative methods for data collection and analysis; more specifically, a thematic qualitative content analysis, as described by Graneheim & Lundman (2004). Through this approach, themes and issues in the interview data were linked, forming a system of categories from which the subject was understood. By employing an inductive approach, the focus was on the "understanding of the nature of a phenomenon on its own terms" (Kilbourn, 2006).

The experiences of the first author as a wheelchair user (not mentioned when recruiting respondents) proved helpful during the interviews. A common ground of understanding emerged due to shared terminology and knowledge. One of the first respondents immediately expressed relief upon noticing the interviewer using a wheelchair and said it was great due to "speaking the same language." However, this also served as a reminder of the need to handle these issues in the following interviews by means of attempting to employ an enhanced naivety for example. This episode also increased awareness (as a form of reflexivity) of researcher triangulation, thus emphasized during the analysis.

Study Group and Participants

Experienced active wheelchair users can be described as those who are "healthy disabled," i.e., persons whose impairments are predictable and stable (for instance spinal cord

injuries), those who consider themselves to be healthy (as opposed to sick), and those who do not “expect to die any sooner than any other healthy person their age” (Wendell, 2001). An experienced user has passed primary rehabilitation and gained a width of experiences of living with a wheelchair as primary mode of mobility.

An experienced user utilizes the wheelchair in everyday life without specific concentration. Everyday life is “a series of ‘methodic appearances’ through which ‘doing being ordinary’ is mundanely, methodically and reflexively accomplished” (Sandywell, 2004), i.e. daily occurrences where social relations are (re)produced and activities are performed or from which desisted (Burkitt 2004). In this study, criteria for being included as an experienced user were: (1) considering oneself to live an active life with a range of family and leisure activities (e.g. sports or other hobbies); (2) perceiving oneself to be post-rehabilitation, having landed in a reshaped everyday life; and (3) engaging in at least half-time employment, studies, or similar, but preferably full-time. These criteria are based on persons within this group possibly having accumulated a width of experiences of active wheelchair use and provision in the context of an active life with a range of activities, having finished rehabilitation, and having some kind of daytime occupation, studies, or other. Another criterion was the absence of cognitive affect and/or drug abuse. In sum, the phrase “healthy disabled” designates active individuals whose only obvious difference compared to others is wheelchair use.

After establishing inclusion criteria, key persons in disability organizations in southern Sweden were contacted, suggesting potential interviewees. The first author contacted them to validate the fulfillment of the inclusion criteria. This form of community recruitment was complemented with respondent referrals (i.e., snowball sampling). Eleven respondents, eight male and three female, aged between 25 and 52 (median: 41; mean 38.6), and between three and 40 (median: 23) years of wheelchair experience were included in this study. All were gainfully employed or students. Four were civil servants, three were teachers/lecturers, two were students, one was an economist, and one worked with computers. The causes of impairments were spinal cord injuries acquired at birth or later.

The Interviews

A semi-structured interview guide was used during the interviews. Initially, a structured interview guide was constructed, but after two pilot interviews, this was revised. The interview guide consisted of ten topics concerning experiences of wheelchair prescription and utilization. Each interview started with a basic question of, “What do you do when you need a new wheelchair?” Thereafter, other interview topics were discussed. Please see below for a presentation of the topics:

- 1) What to do when a new wheelchair is needed
- 2) Repairs and maintenance of the wheelchair
- 3) The role of sports
- 4) Sources of wheelchair skills
- 5) Key features of an optimized wheelchair
- 6) The role of the wheelchair in everyday life
- 7) Sources of knowledge

- 8) Sources of news on modern wheelchairs
- 9) The interactional effect of the wheelchair
- 10) Financial factors concerning wheelchair use

During each of the interviews, ideas emerged about what to ask next when following up on specific issues. Sports served a role as a source of information concerning news on the international wheelchair market. Initially, sports was included concerning the personal development of wheelchairs skills, but this proved to be of lesser importance than as a source of knowledge in active wheelchair optimization. Finishing each interview, the informant was asked if something needed to be supplemented. This aimed at giving the interviewee more control of the content of the interview (Beazley, Moore, Benzie, 1997). Interviews were digitally recorded using an mp3-recorder or a mini-DV camera utilizing only the audio recording capacity. Consent from the interviewees was obtained in accordance with valid ethical guidelines. Valid Swedish legislation was followed when conducting this study (SFS, 2003; Gustafsson, Hermerén, & Petersson, 2006).

Analysis

Thematic qualitative content analysis seeks to link themes and issues in the interview data forming a system of categories from which the subject can be understood. In this study, the inductive analysis focuses the manifest, as well as the latent content, of the interview transcripts. Manifest analysis aims at the obvious and visible components in the text being analyzed, and latent analysis aims at interpreting the embedded and underlying meaning of the text. According to Berg (2001), manifest and latent analysis should be used in combination when possible. The detailed analysis was performed in several steps, the first step being readings of the whole text in order to gain an overall understanding of the text. After this, the meaning units in the text were identified, and the text was condensed and coded for content (Graneheim & Lundman, 2004). Thereafter, the second and last authors independently generated their own category system from the data, i.e., a form of researcher triangulation (Curtin & Fossey, 2007). The coding and interpretations of the text were discussed; thereafter codes with similar content were clustered and named based on their meaning, then assigned to categories. The last step was to confirm the categorization by means of comparing and contrasting the categories to the codes, and the codes to the text.

Results

The main and subcategories emerging from the interview data is presented in Table 1. Within the first part of the aim of this study (users' experiences of wheelchair prescription), one main category ("to negotiate") emerged, and within the second part of the aim of this study (aspects of importance concerning the optimal wheelchair), two main categories ("support physical function" and "support social function") emerged. In the following, the content of these categories are discussed in detail.

Table 1: Main and sub-categories of the interview data

Part of aim	Main categories	Sub-categories
Experiences of the wheelchair prescription	To negotiate	To experience injustice and unfairness To feel insecure within the system
Aspects of importance concerning the optimal wheelchair	Support physical function Support social function	Easy to handle Comfortable seating Stand high strains and be trusted Identity and self image Social capital and agency

Experiences of the Wheelchair Prescription

Interviewees described two main actors in wheelchair prescription: (1) the prescriber and (2) the manufacturer's sales representative. The sales representative was described as the one having deep knowledge in technical aspects, as well as a clear sales motive. The prescriber represented the municipality in the prescription process and was described as being in power, i.e., the gatekeeper of an optimal wheelchair, denying solutions outside the absolute minimum. Examples given included not being listened to, or even answered, when providing arguments for a wanted wheelchair. Other arguments could be answered as being outside the municipal budget, which evoked feelings of uncertainty and frustration. Users based their arguments on being post rehabilitation and having gained a range of experiences and knowledge. There were also examples of when a prescriber could support almost everything the interviewee said, and even ask the interviewee to gather information and arguments concerning various models. However, these experiences were most common when the prescriber was described to lack knowledge on even basic aspects of an active wheelchair:

“When the prescriber was demonstrating the wheelchair he read the manual and said... ‘back here, on the back, is a cord’ [...] ‘and when you drag the cord, the back is folded’ ... [laugh] [...] well, it has been like that on my seven latest wheelchairs... [laugh].”

The division of responsibility between the prescriber and the manufacturer was sometimes unclear during the prescription process. In some situations, the informants found themselves in a position of reaching a conclusion with one of them, a conclusion questioned by the other. In theory, the prescriber decided on the configuration and type of prescribed wheelchair, but in reality, parts of this decision seemed to be subject to negotiation between the interviewee and the manufacturer, leaving the prescriber outside.

To Negotiate

In general, interviewees found prescription to be a process of negotiating their needs:

“It is a negotiation, and if you are a poor negotiator you do not get anything.”

“The weird thing is...with the prescribers...at last, you often end up with what you wanted, if you are persistent and can really motivate.”

A negotiation with a prescriber was seen as problematic due to the prescriber not having the sufficient knowledge to be an effective counterpart. Interviewees saw arguments on municipal economy to be used when arguments based on technical knowledge were lacking:

“They do not know that much I think...you have to keep informed yourself...”

The personal cost in terms of invested energy in negotiating one’s needs was experienced as high:

“I experienced a radically decreased quality of life by this...this way of behavior.”

A general argument from the interviewees was that negotiations should not be needed at all if prescribers had sufficient technical knowledge and understanding of wheelchair needs. Different experiences of negotiations could be identified: (1) to experience injustice and unfairness and (2) to feel insecure within the system.

To Experience Injustice and Unfairness

An experience of injustice and unfairness in contacts with the prescriber was emphasized by many of the interviewees. Examples included experiences of a high cost in terms of personal energy when the expressed needs not were considered. To obtain a new wheelchair was described as a long and tedious process. Therefore, it was something to engage in only when it was needed. Informants expressed one reason for needing a new wheelchair to be the introduction on the market of a new model that might solve issues with the model used at present. Even so, the prescriber did not always accept arguments of a new wheelchair solving problems with the current one. Informants even expressed fears of a potential injustice for other active wheelchair users perhaps not persistent enough in fighting for their needs, thus ending up with wheelchairs less optimized. However, some interviewees expressed that they were generally uninterested with the wheelchair:

“So, I just drive on.... I think I get used to both how it works and how it does not work, and how poor I sit because it is nothing that changes from one day to another but gradually.”

The sense of injustice was also described in relation to economical prerequisites. Some of the informants with stable financial situations had abandoned the public system of prescription and bought wheelchairs themselves in order to avoid having to discuss every detail with the

prescriber. Interviewees stressed that already today the cost of rear wheel tires is, in many municipalities, a personal responsibility for the user. In many cases, interviewees with wheelchairs prescribed within the public system used alternative, and privately funded, rear wheels and hand rims. Other examples were privately funded ways of attending wheelchair service and maintenance.

Family members were described as a buffer in contacts with the prescriber. One informant described when a prescriber discussed matters of cushion covers with a family member, where the family member in vain tried to convince the prescriber of the need for a spare cushion cover.

To Feel Insecure Within the System

Interviewees described a sense of insecurity when in contact with the prescriber. To feel insecure and powerless was due to not knowing what to expect in terms of wheelchair optimization and assortment, or the prescriber's negotiation starting point, or how difficult the negotiation was going to be, i.e., the unpredictability of the process. Nevertheless, informants could contact the prescriber to discuss the need for a new and better wheelchair:

“I have hesitated all this time because, no one really likes to change wheelchair... due to it is so tough to change.”

Hesitance could be based on a new wheelchair taking time to get used to. Hesitance was further increased by the insecurity of not knowing what to expect. One informant described that the prescriber asked her/him to check what was available on the wheelchair market and then return with a decision. For the informant, this resulted in insecurity due to a feeling of not being taken seriously and the presumed expert's lack of expertise.

“The prescribers were very passive at the side... [...] it was more like a dialogue with the manufacturer sales representative.”

A further source of insecurity described by the interviewees was differences between municipalities. Some municipalities had widespread restrictions concerning active wheelchairs, adding to increased unpredictability:

“My experience here in [in this municipality compared to where I used to live] is not good... it is probably the worst I have experienced since I got injured.”

Another source of insecurity was when they tried to locate the prescriber in a system in which it was difficult to navigate. One informant described this as difficult due to not having had any contact with the prescriber for some time, the municipal organization was altered, new persons were employed, etc.:

“I started by calling my health care centre in X-town and then they wanted me to call the municipal local organization and then they told me to contact X [the prescriber] and then X came home to me, made a home visit, they like making home visits....”

However, one informant described the prescription of a new wheelchair as an easy and unproblematic process:

“Actually relatively easy... among the easiest I have been through concerning... the jungle of societal support... [laughs].”

Aspects of Importance Concerning the Optimal Wheelchair

A picture emerged in the narratives of how the optimal wheelchair should be constructed and what needs it should fulfill. The role of the optimal wheelchair was described as supporting: (1) physical function (technical aspects) and (2) social function (identity, self-image, and agency).

Supporting Physical Function

Technical aspects of importance were described as the wheelchair should: (a) be easy to handle, (b) have comfortable seating, and (c) stand high strains and be trusted. The prescriber was expected to give an account for these aspects. The technical perspective on wheelchairs involved mobility:

“It should make it possible for me to ambulate as freely as possible from my physical... prerequisites.”

An optimal wheelchair was described as tailor-made to fit the user perfectly. Some interviewees expressed plans of buying such a chair, built from personal measurements, as such a wheelchair was not prescribed within the Swedish prescription system.

Easy to Handle

An aspect of importance was that the wheelchair should be easy to handle in varying environments. One main criterion is that it should have low weight:

“It should weigh nothing, preferably minus...”

However, some informants expressed that the hunt for low weight seemed to have gone a little too far:

“I think it is ridiculous, this hunt for... hectograms of the wheelchair when you are sitting with...one of these...[points at his paunch] [laughs].”

Low weight was also associated with easiness of loading and unloading the wheelchair in and out of a car. Informants described that in relation to weight, a wheelchair that was a little heavier could still be easier to drive if it was better adjusted. However, when loading the wheelchair into the car, extra weight could cause problems.

To be easy to drive, the wheelchair had to be optimized to the user. Functioning friction hand rims were important for interviewees with limited hand function. Aspects of optimization included rear wheels, as lightweight fiber spoke rear wheels were lighter, easier to maintain, and more hard-wearing than other types. Cast magnesium rear wheels were preferred by a user wanting a narrower wheelchair in order to not smash into doorposts.

An optimal wheelchair was described as not having too many possibilities to adjust. Each site of adjustment tended to make the wheelchair heavier, and in time break easier. Less possible adjustments made the wheelchair more rigid according to some of the interviewees; a rigid frame makes the chair more stable, hence easier to operate.

Informants expressed that side guards could be too hot in the summer, but used during the winter to prevent clothes from being stained. For a user with lower hand function, side guards could be omitted due to being in the way during transfers, and being time consuming to remove or mount when loading/unloading the wheelchair in or out of the car.

Comfortable Seating

One key aspect emphasized by the interviewees was seating properties, including aspects of the cushion. Informants expressed that the wheelchair had to be adjusted in a way facilitating both driving the wheelchair and sitting in one place. This could lead to compromises – optimal seating positions when driving and when remaining in one place were different. For example, driving was easier sitting lower with the knees more flexed, whereas for static sitting, a more upright position was more practical. Nevertheless:

“Comfortable seating is almost never present in a wheelchair, but you can sit more or less stable and good.”

“Good seating is possible, but not as in an armchair... [laughs].”

The cushion was described as important for prevention of pressure ulcers and had to keep the rear parts cool and provide an even pressure. Other demands included low weight, easiness of putting in and removing from the chair when loading in or out of a car. Informants expressed that the cushion must be easily washed (both cover and cushion) in case of incontinence. Under these circumstances, an extra cushion cover was convenient.

However, a wheelchair not selected and adjusted from the beginning to fit the user was not easily optimized. Therefore, informants emphasized the need to keep informed about developments and new products. This included, but was not limited to, trade fairs, magazines (both local and international), as well as information obtained via peer-to-peer networks.

Stand High Strains and Be Trusted

Another issue of importance emphasized was that the wheelchair had to be trusted to stand strains from everyday use. In general, wheelchairs could stand many demands, but when the demands exceeded the capacity of the wheelchair, accidents could happen. One of the interviewees mentioned a travel abroad, where curbs were higher than at home, thus breaking one of the rear wheel axles of the wheelchair. However, accidents were described as generally rare, and were expressed as partly understandable due to the demands put on the wheelchair:

“When the frame... if it starts to crack, then it is time to get a new wheelchair, then the metal is exhausted and will soon start to crack also in other places...”

Interviewees expressed that rear wheel tires could be more or less sensitive. Some types, especially ones sold via the prescriber, were of low quality, prone to puncture. Therefore, more expensive, but less sensitive tires were preferred. One interviewee described a potential problem of tires being too knobby, thus bringing grit and gravel indoors during the winter.

The alternative to a one-hand operated two-wheel brake was brakes in a standard one per side configuration. However, these could widen the chair and be in the way, snagging clothes when lifting in and out of a car. Another problem was the one-handed brake sometimes coming loose during transfers to and from the wheelchair. Some interviewees preferred to not use any brake at all, and when needing to stay in one place instead placed a foot on the floor.

Supporting Social Function

The second perspective of the optimal wheelchair was to support social function in terms of identity and agency. Social functioning was also described in relation to technical aspects. For example, lightweight fiber spoke rear wheels were not only lighter and more durable. They were also considered to be better looking, nicer in color, and providing a more active appearance. A 12-spoke model of these rear wheels was expressed as the “top of the line,” even though they had to be privately imported at a high cost.

Identity and Self-Image

In general, the wheelchair could be a part of one’s identity and self-image, but the importance differed between the interviewees:

“It should not be seen, the wheelchair is not me; it is me who should be noticed.”

“It is still a part of me, even though it is not a part of my body.”

Interviewees saw the wheelchair as not only a means of mobility, but as a part of the presentation of self. A wheelchair had to be properly cleaned, e.g., hair around the front wheel

axles was seen as sloppy, and a stained cushion cover as disgusting. The cushion and its cover were washed once every month, sometimes a little less often.

A good-looking wheelchair was described to be as discrete as possible, but at the same time good-looking and signaling an active lifestyle. For example, a black wheelchair was described as easier to match with clothes. Colors and looks were generally described as important, and even though one interviewee saw matters of trends, colors, and image as being less important, this interviewee clearly expressed a will to not settle for any possible color without having the possibility to make an active choice:

“I will be using this chair almost 24 hours a day, well... almost... and, am I not supposed to have... to be satisfied with my chair then?”

Informants expressed differences between municipalities concerning both possibilities to choose color and making other choices. In some municipalities, the standard assortment consisted of only one or two models.

Even though a wheelchair should be perceived as discrete, some accentuation of design features was not negative. For instance, black tires were described as better looking than the ordinary “municipal gray,” whereas too wide or knobby tires made the whole wheelchair look clumsy. Nevertheless, informants emphasized that design ideals differ with age, insofar as they preferred more brightly colored wheelchairs when they were younger, but during later years had begun to use more discrete color and design.

Social Capital and Agency

Interviewees expressed that one social function of an optimized active wheelchair was to make activities and roles possible, i.e., increase agency. Among peers, agency could be expressed by the optimized wheelchair and the skills of the user, i.e., how to use the wheelchair as a means of living an active life. Agency was further understood and evaluated in terms of ascribed social capital based on individual prerequisites, for example, level of spinal cord injury (SCI). A lower level of SCI implied managing activities not expected with a higher level of SCI.

Interviewees explained that features ascribed to a high social capital were often features that increased optimization of the wheelchair, thus increasing personal function and agency in everyday life. On the other hand, features only meant to improve looks were considered ridiculous, for instance casters (front wheels) with built in flashing lights of different colors:

“Design is enormously important actually... Some [i.e. out-group] may not be conscious about the importance but I see the importance among, among... all, all conscious wheelchair pilots that the design is... and the function of course... they are of course intertwined the two... [i.e. design and function].”

Informants described the role of the wheelchair concerning how others treated the wheelchair user. Differences were described between peers and outsiders (persons outside the

group of conscious users). Reactions among peers concerned mainly functional aspects. Outsiders tended to react on the occurrence of a wheelchair *per se*, understanding the wheelchair as signaling absence of autonomy and agency. Interviewees referred to the wheelchair as a disabling attribute among outsiders, and an enabling device among peers.

An example of a negative impact on the social capital of an active wheelchair user can be to use an electric scooter:

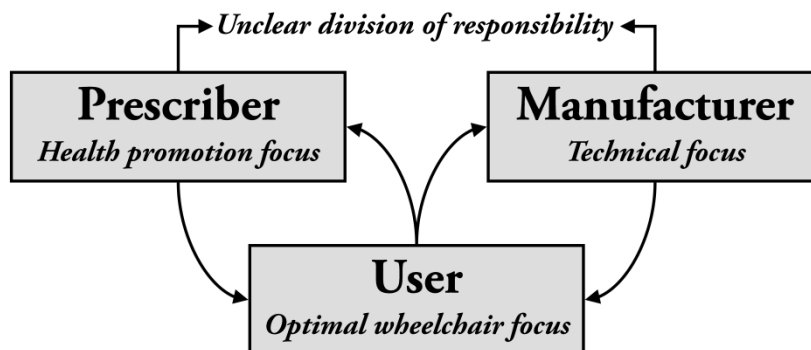
“... Some party in X-town ... where someone had used a moped ... electric scooter ... to get there ... [Interviewer: Right, yes...] and then it was the talk of the party of who's it was... it stood outside and no one wanted to admit [that it was hers/his] [laughs].”

To use an electric scooter was explained as to give up autonomy by making oneself dependent upon technology.

Discussion

The aim of this study was to describe the experience of active wheelchair provision and aspects of importance concerning the wheelchair among experienced users in Sweden. The process of prescription was experienced as a negotiation with a prescriber having the power to decide. During this process, feelings of injustice and unfairness were frequent, associated with feeling insecure and powerless within the system. The main aspects of importance concerning the wheelchair were supporting the user's physical as well as social functioning. Important aspects concerning the physical function were that the wheelchair should be easy to handle, provide comfortable seating, be easy to maintain, and stand high strains in order to be trusted to function, while important aspects concerning the social function were to support the identity and self-image of the user and be a means of agency.

Figure 1: Model of understanding user perceptions of negotiating needs



From a user perspective, the process of wheelchair provision can be seen as a triad of relations between the wheelchair user, prescriber, and sales representative as described in Figure 1. The goal of the wheelchair user was to obtain an optimal one. The goal of the sales

representative was described as proposing a wheelchair optimized for the user, thus also in many cases more expensive rear wheels for example. The goal of the user in this negotiation (to obtain an optimal wheelchair) and the goal of the sales representative (to sell) appeared intertwined concerning optimization. The goal of the prescriber was described to be health promotion and rehabilitation, which was not very well received by the users, as they considered themselves to be post rehabilitation, having landed in a reshaped everyday life, i.e., in line with the inclusion criteria of this study. The prescribers were further described to have a clear cost-cutting goal, in conflict with the users' needs and expectations. The informants instead expected the prescriber to have expert knowledge of technical aspects, e.g., material strength and pros and cons of a great variety of aspects. This can be seen as a role conflict for the prescriber to have a health promoting and rehabilitating perspective that is not requested and a cost cutting perspective that might contradict what the user deems optimal for his wheelchair. From the users' perspective, the division of responsibilities between prescriber and sales representative remained unclear.

For a wheelchair user, the prescription was a process of negotiating basic needs. Efring (1999) discusses assistive devices and needs as based on the desired activity of the user and the capacity of the device in this activity. The desired activity defined by the user, what remains to be negotiated with the prescriber is the capacity of the device. The optimal wheelchair fulfilling these demands can be a wheelchair with a high degree of useworthiness (Efring, 1999), i.e., a device perceived as not only possible to use, but also worth using due to the qualities of the device corresponding with the user's needs. This does not always mean a prescription of the most advanced chair or equipment as, "The most advanced application of technology is not necessarily the same as the application of the most advanced technology" (Childress, 2002). "Needs" have been discussed by Hallström & Elander (2001), utilizing a definition by Georg Henrik von Wright, i.e., as something "bad for the person to be without." By not recognizing perceived needs, the prescriber was seen as exercising power, repressing the functioning of the user. However, prescribers are an executive part of the municipal organization, not the ones making the rules they are following. The general argument from interviewees (that negotiations should not be needed at all if prescribers had sufficient knowledge) is therefore an argument pertaining to the societal organization the prescriber represents, and not only the individual prescriber. Consequently, even though a prescriber has the knowledge and wants to prescribe an optimal wheelchair, the prescriber may be hindered by regulations.

On a general level, societal organization of assistive devices supply is mainly arranged to facilitate the demands of persons with longstanding, sometimes progressing, diseases, and less to facilitate the demands of persons with stable conditions (i.e., "healthy disabled"). This is supported by findings from Wressle & Samuelsson (2004) including a random sample of adult wheelchair users where approximately four in five users were satisfied with their wheelchairs, indicating that today's municipal system is sufficient for persons with a more general demand of assistive devices supply. One way to handle the specific needs and demands of the group of "healthy disabled" could be to locate and/or construct an alternative track through the system, a track with optimal wheelchair provisioning as its only goal. Until the mid 1990s, specialized assistive devices centers existed within each county, but after assistive devices became a municipal responsibility, the centers were closed and competence disappeared. As this is a relatively small group, the supply can preferably be organized on a regional rather than a local level in order to enable provision based on specialized knowledge.

Differences described by the interviewees between in-group and out-group attitudes towards the wheelchair can be discussed in Goffman's (1990) terms of back stage and front stage, i.e., the back stage being where information can be exchanged freely among peers, and the front stage being where self is presented to others, i.e., out-group persons. Front stage, technical aspects could be emphasized from a perspective of physical function, with social aspects often left aside. Back stage, particular aspects are ascribed a certain value among peers, for instance, having a certain model of rear wheels or a wheelchair that is properly maintained. Persons not members of the in-group are neither aware, nor know of the existence of these values. According to the informants, outsiders tended to react on the wheelchair *per se* as signaling absence of autonomy and agency. Among peers, social capital emerged from the functional value of the optimized wheelchair and the skills of the user as a means of agency, where user skills were understood and evaluated based on individual prerequisites, for example, function based on the level of spinal cord injury (SCI). In sum, a person's agency can be understood based on both a physical level of ambulation based on personal prerequisites and optimization of the wheelchair, and a social level of self-image, identity, and social functioning in everyday life.

Thus, the combination of physical and social aspects is vital when optimizing a wheelchair as a means of agency. For an experienced user, the wheelchair has become integrated into the user's body image—a person's mental picture of her or his body. This was seen in a person's body image as a dynamic construction based on internal and external stimuli, understood as the compatibility between the actual and mental pictures of the body (Breakey, 1997; Desmond & MacLachlan, 2002). The body image of a wheelchair user can be affected by attitudes and values projected back stage concerning aspects of the wheelchair and parts thereof, as the wheelchair can be a means of expressing one's self. However, this was not mentioned as an aspect expressed to the prescriber during a process of prescription and thus remained undisclosed for the prescriber. Instead, the negotiation was mainly kept on a technical level by the interviewees, a level where prescribers were unable to respond due to lack of knowledge.

Some users had abandoned the public system of prescription as a consequence of not getting the expressed needs met. Instead, personal financial capacity was used to obtain an optimal wheelchair or complementing a prescribed wheelchair with other rear wheels, etc. This can be seen in Bourdieu's (1984; 1991; 1992) terms as a transformation of economic capital into social capital, where one's financial assets are used as means of gaining a higher degree of social capital valid among peers back stage, where matters of, for instance, rear wheels are ascribed a certain value. Consequently, a person without the financial capital is unable to obtain the social capital desired. On a general level, abandonment of the public system raises the question of financial differences within the group of users when a person's need of an optimal wheelchair becomes less important than her or his financial strength.

Methodological Considerations

There is a risk that the first author's experience as a wheelchair user has affected the interviews and the analysis of the interview transcripts. To balance this risk, two coanalyzers also generated their own category system from the data, i.e., researcher triangulation. The first coanalyzer (Ph.D. in Occupational Therapy) had experiences from a prescribing perspective,

while the second co-analyzer (Professor, Ph.D. in Nursing) had no previous experiences of the prescription process. Through comprehensive discussions, an increased awareness emerged where the included perspectives added to a wider understanding of the subject. Furthermore, personal experience of wheelchair use mainly proved positive concerning the possibility to gain a more thorough understanding of key issues, at the same time as increasing awareness of potential researcher bias *per se*. Other means of triangulation employed in order to enhance trustworthiness included attempts to make a “thick description” by providing extensive quotes from the interviews and a comprehensive description of the research process. Ultimately, triangulation aims at enhancing trustworthiness, i.e., establishing arguments for the interpretations most probable (Graneheim & Lundman, 2004).

Transferability of the findings in this study can be discussed from a wider perspective in terms of other types of assistive devices or other groups of users. As shown by Bergström & Samuelsson (2006), satisfaction in general may be higher when focusing a wider group of users. Hypothesizing that knowledge among prescribers of wheelchairs is roughly the same as indicated by the experiences among users in this study, one possible consequence is that the larger group of users utilize wheelchairs that are less than optimal.

Transferability to similar groups in other countries for example, countries where health care services and assistive devices are not financed through general taxes, can be discussed. The results may have limited transferability to countries where funding of assistive devices are based on insurances and/or private funding.

Conclusions

In general, experienced users of active wheelchairs were not satisfied with active wheelchair prescription. The process was described as negotiating one’s needs of an optimized wheelchair as a means of physical and social functioning. The counterpart in this negotiation, the prescriber, was perceived to have a low level of knowledge concerning important aspects of the wheelchair from both physical and social perspectives and was working within a cumbersome system of budgets and regulations. Prescribers emphasized a health promotion focus instead of a user requested technical focus. This left the user feeling insecure within the system. As a consequence, a question can be raised whether users have realistic expectations regarding the prescribers’ resources to meet their needs of an optimal wheelchair. Another question can be raised concerning prescribers’ knowledge of the social function of active wheelchairs, i.e. prescribers’ access to, and use of, back stage information in wheelchair prescription. In the interaction between the agents of the user-prescriber-manufacturer triad presented here, efforts by the prescribers to express and utilize knowledge of these conditions, purposes and norms therefore seem highly warranted. Even in a changed organization, to accomplish a better fit and satisfaction within the prescription process in the future, users, in turn, have to inform the prescriber about everyday life and personal needs, also back stage.

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Acknowledgements

We would like to thank everyone who participated in this study for sharing their experiences. We would also like to thank Kristian Bolin, PhD, Associate Professor, Department of Economics, Lund University, for valuable advice during the design of this study, and the Vårdal Institute, Lund University for financial support.

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