Permanent link to this version:
http://urn.kb.se/resolve?urn=urn:nbn:se:umu:diva-100820

Title: Living with an electric wheelchair - the user perspective

Corresponding author
   Stenberg, Gunilla, PT, PhD
   Dept. of Community Medicine and Rehabilitation, Physiotherapy
   Umeå University
   S-90187 Umeå
   Sweden
   gunilla.stenberg@physiother.umu.se

   Catharina Henje PT, Interaction Designer
   Umeå Institute of Design
   Umeå University
   S-90187 Umeå
   Sweden
   catharina.henje@umu.se

   Richard Levi, MD, Professor
   Dept. of Community Medicine and Rehabilitation, Rehabilitation Medicine
   Umeå University
   S-90187 Umeå
   Sweden
   richard.levi@rehabmed.umu.se

   Maria Lindström OT, PhD
   Dept. of Community Medicine and Rehabilitation, Occupational therapy
   Umeå University
   S-90187 Umeå
    Sweden
    maria.lindstrom@occupther.umu.se

Abstract

Purpose: To explore the experiences of using an electric wheelchair in daily living.

Methods: Fifteen participants, eight women and seven men, living in different parts of a Nordic country were interviewed. The interviews were conducted in the home or workplace. Open-ended questions were used. The data were collected and analysed according to grounded theory.

Results: Analysis resulted in one core category: "Integrating the electric wheelchair—a manifold process", describing a process commencing from initial resistance against use of an electric wheelchair, to acceptance with various extent of integration. Six categories emerged that represent this core process: incorporating the electric wheelchair into the self-identity process, calculating functional consequences, encountering the reactions of others, facing duality in movability, using proactive strategies, and being at the mercy of the system.

Findings indicate that the integration process is complex and manifold. Practical, personal, and social dimensions were intertwined and significantly involved.

Conclusions: Integrating an electric wheelchair is a process closely connected to symbolic value, usability, community mobility, and identity. These aspects should be considered in the production, prescription, and adaptation processes.

Introduction

The United Nations Convention on the Rights of Persons with Disabilities [1] addresses disability in the context of human rights, i.e., from the viewpoints of inclusion, participation, personalization, and enabling active citizenship.

Participation in daily activities and life-situations can influence health [2], and when associated with a sense of personal meaning, purpose, and belonging, has the potential to be health-promoting [3]. Participation in such activities is dependent on personal engagement and goes beyond the act of performing something itself [4]. Benefits such as social inclusion, choice, and engagement, occurring because of participation, may potentially be achieved by many different activities [5, 6]. However, mobility is crucial to participation in most activities [7].

Community mobility is linked to several individual and shared meanings such as socialization and freedom, and closely related to participation [8]. Community mobility choices are influenced by physical, social, and attitudinal environmental factors, including barriers and facilitators, personal and intersectional factors [2, 5].

For persons with physical disabilities that lead to ambulatory problems, the wheelchair is arguably the most important piece of technical equipment for achieving mobility in daily living [9]. The modern wheelchair, whether manual or electric, enables its user to enjoy a degree of freedom in exploring and negotiating the environment. Multiple technical aspects thus must be considered [10]. The activity and contextual profile of the user, with considerations of biomechanical [11-13] and psychological variables [14-18] need to be accounted for to maximize the wheelchair-person-activity fit. Caregivers should strive to identify potential performance challenges [19]. Such challenges are not exclusively rational or technical.

Seating tolerance, pressure relief, and pain management are well–researched areas of wheelchair performance. Enhanced ease of access to physical location, which facilitates social interaction, has been elucidated. Beneficial effects on daily activities are also well described, e.g., personal care and functional mobility, employability [20, 21]; work performance, leisure participation [22], and parenting [23]. In contrast, socio-cultural implications are seldom a research focus [24].

Many stakeholders are involved in electric wheelchair development, production, prescription, adaptation, and use. Among these, user views must be considered of particular relevance. Nevertheless, few studies focus on the user perspective. Thus, the present study aims to explore the experience of using an electric wheelchair in daily living.

Methods

Interviews were conducted and analysed by Grounded theory [25], a qualitative method with an emergent design. The method was chosen to elucidate the user perspective, and particularly the processes involved.

Context

The study was conducted in Sweden, where people who need an electric wheelchair are entitled to borrow one from the healthcare authority. The professional responsible for prescribing the assistive technology is typically an occupational therapist who does an initial assessment of the individual's needs. After approval by an assessment group, the prescriber

selects an appropriate wheelchair in collaboration with the user, an assistive advisory officer, and a technician.

The community council legislation mostly allows one electric wheelchair per individual. Thus, users typically choose a wheelchair with both outdoor and indoor capabilities. This inevitably means a technical and functional compromise. An electric wheelchair is always supplemented with a back-up manual wheelchair.

Participants

Inclusion criteria for study participation were aged 18 to 70 years, ability to manoeuvre an electric wheelchair independently, sufficient cognitive and communicative capacity, and no rapidly progressive or terminal disease.

Medical professionals in various healthcare facilities informed potential participants about the study, and asked them to participate. Thereafter, one member of the research team made contact by telephone or email and provided additional information. Two participants were recruited through other participants (snowball sampling). Thematic interviews were carried out with 15 participants (eight women and seven men) aged 20–66 years. Prior to interview, participants gave written informed consent.

Participants were chosen purposively and consecutively, as data interpretation progressed. To obtain as rich data as possible, the sample was chosen to provide variation according to diagnosis, duration of wheelchair use, age, marital status, education level, type of wheelchair, geographical location, and sex. All participants except one were using electric wheelchairs at the time of the study. The non-user was due to receive an electric wheelchair in the near

future, and was chosen to capture prior apprehensions related to this change in ambulatory aids.

The climate in Sweden involves snowy, cold winters and hot summers, with significant regional variation. For this reason, participants were recruited from different parts of the country. All participants except two lived in urban areas. One of the rural dwellers lived in a small village and one in the countryside.

One participant operated the wheelchair by chin control, one with chin and neck controls, and the remainder with a joystick. Additional pertinent background data are given in table 1.

Insert table 1 about here

Data collection

The research group constructed an interview guide. The guide was then revised during the data gathering process, according to the concept of emergent design [25]. Each interview started with the open-ended question: "What are your experiences of living with an electric wheelchair?" The interview guide was primarily used to remind the interviewer of which topics to include, and was not adhered to strictly. The first author (GS) conducted all interviews from May to November 2012. Interviews were carried out in the participant's home or work place, according to the participant's wishes. Interviews were 30 minutes to two hours, audiotaped, and transcribed word for word.

Data analyses

Analyses of interview material were made in accordance with grounded theory research methods [25]. Thus, a preliminary analysis was done after reading each interview. If new primary categories emerged and new questions were posed, these were included in subsequent interviews. For initial open coding, a software package was used (OpenCode 4.0. Umeå: Umeå University; 2013. ICT Services and System Development and Division of Epidemiology and Global Health). Open codes were sorted into sub-categories and categories to find emerging constructs of patterns of processes, and to identify an overarching core category (table 2). Axial coding identified relations across categories. Theoretical saturation [25] was reached after 11 interviews. Additional four interviews were conducted and analysed to confirm that no additional categories emerged. The final findings are presented as a model (figure 1). The open coding was performed independently by three of the authors (GS, CH, and ML).

Insert table 2 about here

To ensure credibility further, analyses were scrutinized and negotiated between the researchers. The findings were presented and discussed in seminars with other researchers in occupational therapy and physiotherapy. Direct quotations from the participant interviews are presented with each category to confirm that the theoretical concepts are grounded in empirical data.

Ethics

The study was approved by the regional Ethics Committee (Dnr 2012-220-31M).

Findings

One core category emerged, and is expressed as "Integrating the electric wheelchair—a manifold process". Six categories representing processes that influence this core process also emerged. These categories were (table 3): 1) incorporating the electric wheelchair into the self-identity process; 2) calculating functional consequences; 3) encountering the reactions of others; 4) facing duality in mobility; 5) using proactive strategies; and, 6) being at the mercy of the system. These categories will be elaborated below.

Insert table 3 about here

Integrating the electric wheelchair- a manifold process

This core category reflects a process that starts with initial resistance to becoming an electric wheelchair user, and proceeds to acceptance and integration. Findings indicate that the integration process is complex and manifold, comprising more than merely the rational substitution of a more technically advanced mobility aid and, loss of walking ability, or use of a manual wheelchair. Intertwined practical, personal, and social dimensions are involved and significant. Participants described factors that could promote or obstruct electric wheelchair integration in each of those dimensions. These factors are presented as the six categories underlying the core process (figure 1).

Insert figure 1 about here

Incorporating the electric wheelchair into the self- identity process reflects how deeply the electric wheelchair affects self-identity processes. C*alculating functional consequences* (of

using electric wheelchair) started before the wheelchair was actually prescribed, and is closely connected with the psychological adaption of not being a walker any longer (or a manual wheelchair user). After starting to use the electric wheelchair, participants are *facing duality in movability*, and *encountering the reactions of others*. *Facing duality in movability* can encompass feelings of happiness and freedom, as well as frustration. Newfound possibilities in daily living lead to the possibility of new elaborations of self-identity.

Encountering the reactions of others also includes mixed emotions. Together with physical barriers to ambulation, this led the need of *using proactive strategies* in daily living. Finally, *being at the mercy of the system* reflects the frustration created by authorities and regulations that govern the technical aid system, e.g., restrictions in prescriptions and service. This category also includes a feeling of gratefulness for the new possibilities made accessible by the electric wheelchair. "The system" could symbolize the rigidity of the larger society, or a felt lack of independence (illustrated as a burden in figure1).

Participants who used wheelchairs since childhood, as well as those more reliant on wheelchairs, had integrated them into their lives to a greater extent than those who obtained the electric wheelchair as an adult or who were part-time users.

A detailed description of the categories and subcategories is below.

Incorporating the electric wheelchair into the personal self-identity process

Personal self-identity was closely connected with, and an important aspect of, how participants integrated the electric wheelchair with themselves and their lives. Participants describe self-identity processes in different ways depending on their individual experiences.

The wheelchair influences the self-identity process as regards acceptance of being an electric wheelchair user, different role fulfilments, and the process of considering the electric wheelchair as a body part.

Participants describe initial resistance from a perceived stigmatizing effect of the electric wheelchair, but also because they could not accept the progression of disability that necessitated electric wheelchair use. The process of resistance and acceptance relates to an on-going process of changing self-identity. Participants did not want to be identified as "an electric wheelchair user". Initially, the electric wheelchair was viewed as a concrete symbol of severe disability, and thus overt proof of a negative life change. Once they started to use it and experience its benefits, many were positively surprised. At least for some, the electric wheelchair became a symbol of freedom. In the acceptance phase, participants attribute various meanings to the electric wheelchair as they try out their approach and relationship to it. One participant describes his wheelchair as "the most important object" in his life. Others talked about it as a friend. However, feelings related to the wheelchair were often ambiguous.

No, but it's…you see, it's a hate object too. It's both. It's a bit like life, somehow. That is, it's a bit like…I could compare it to a marriage, it's up and [it's] down.

Participants expressed fear of not being regarded as "the person they really are". They were afraid of being overshadowed, to "disappear" as unique individuals, in the bulky wheelchair. They felt that the appearance of the electric wheelchair, as well as their seated posture while in it, influenced their self-esteem and the image they convey to others.

I think it matters, depending on the person, how it is perceived. I think it can depend on how the wheelchairs are designed.…If you sit up straighter, a bit higher up, the chair

looks better. So I think you give a more, what should I say?....(hesitating) Composed impression. That is, professional....It looks better, and I think that in some way that has an effect too.

Those who were electric wheelchair users since childhood articulated that attitudes towards disability at large among family and relatives played a major role in how they had come to perceive themselves, including how they perceive themselves as electric wheelchair users.

Some participants described difficulty relating to gender stereotypes. Being perceived as a "strong man" or an "attractive woman" while being an electric wheelchair user, was seen as problematic. For example, construction of the electric wheelchair precludes users from wearing short skirts and high heels, as one's legs spread apart while sitting and footplates cannot be easily adjusted to prevent this from happening. Conversely, some participants reported positive effects in building fruitful personal relationships because of being an electric wheelchair user. The electric wheelchair made it easier to socialize independently, find a partner, or spend time with friends.

I'd *be much more dependent on help if I only had a manual wheelchair, and [I] feel that … you know, this thing with meeting someone [partner] and having relationships, to be able to do that by yourself. To not alw*ays *have someone [assistant] around you [is important].*

The electric wheelchair made it easier to participate in children's play, interests and day-care, and school activities, and thus promoted parenting. The electric wheelchair was seen as a fundamental enabling device in the professional role, as it made users more autonomous at work.

Some participants describe their electric wheelchair as a part and an extension of their body—not only functionally, but also in appearance, sound, and movements. In this way, the wheelchair constitutes a concrete physical part of oneself:

The peculiarities of the wheelchair become a big part of my identity as well....all her noises... this is sort of me.

Consequently, influencing the properties and appearance of the wheelchair was important.

I feel offended by the chair beeping....[or)] when they put black lights on a blue chair. It is a part of my personality, of me, of who I am, and of my life. I will go places where everyone can see me with it. That's why I don't want it to start twinkling all around me, or have people stumble over me, or things like that.

However, not all participants said that they had incorporated their wheelchair. One participant expressed worry about letting the wheelchair become an extension of his body.

Sometimes I sit in an armchair or something. It can be good to use that, to have a more diverse feeling, to avoid be firmly rooted in this [electric wheel] chair. Because...when I describe it as legs, it could indicate that you are rooted, or joined with it, but it is not really that way. However, it is not so far away [either]. And then, the question is, what are the consequences for body image?

Another participant described accepting the wheelchair as an extension of the body only if it operated in the desired way. Once it malfunctioned, it ceased to be an extension of the body.

By contrast, some participants did not relate to the electric wheelchair as an extension of their body. They explicitly made a distinction between themselves and the device.

> I'm not feeling at one with it [the electric wheelchair]; rather....I think I am sitting **on top of** it. (smiling)

Calculating functional consequences

This category corresponds to how participants scrutinized the long and short term functional consequences of electric wheelchair use before accepting the device. For some, this encompassed a way of processing the sad fact that they had to give up being a walker or a manual wheelchair user due to progressing disability.

Participants expressed fear of feeling more disabled when using an electric wheelchair, and thought about the balance between rest and physical strain. There were varying thoughts on the importance of trying to continue walking at all costs. Some participants reported that some of their healthcare providers advocated trying to continue walking rather than choosing an electric wheelchair—even in circumstances when this was clearly not a functional option.

> It was strange; all the healthcare staff thought it was so important [for me] to walk all the time. I found walking painful and strenuous, and I could not walk so much anyhow.

Participants could more easily accept the electric wheelchair when it fulfilled needs in addition to ambulation (e.g., standing and tilting functions to reach and/or for pain relief). Some part time users were convinced that the electric wheelchair could help save energy, to be used in tasks other than ambulation.

I walk better since I got the electric wheelchair because I use it those days I am not feeling well. Now I can promise things [give a lecture], that I could not before. But now, I promise to go there because I can always use the electric wheelchair and go.

Encountering the reactions of others

Participants were well aware of the varying reactions of others to the electric wheelchair, and reported expressions of curiosity, insecurity, admiration, degradation, and pity.

Young children were especially likely to react with curiosity rather than prejudice. Children were felt to be more open-minded than adults were. Adults were often felt to exhibit insecure behaviours in the presence of an electric wheelchair user. Insecurity could be expressed as a disproportionate interest in the technical specifications of the electric wheelchair, presumably to defuse emotional unease with the situation. Another reaction, possibly reflecting a similar uneasiness, is the exaggerated manner in which some people were felt to yield when the wheelchair approached on the street.

Participants had experiences of being inadequately "upgraded" or "downgraded" during encounters with others due to their electric wheelchair. For example, one participant told about being admired bystanders for being able to "handle such a big machine" independently. Conversely, they reported that others interacted as if they were mentally retarded, or addressed the accompanying personal assistant. Reactions of pity ("Oh, poor you") also were mentioned, and such comments were considered negative and degrading.

There will not be a real encounter [on equal terms] as long as it is only out of pity. I think you have to meet a person as he/she is.

Participants experienced prejudice and stereotypic views from others, e.g., wheelchair users should be "grateful, happy, not interested in shopping, heterosexual, and less than intelligent".

Participants thought it was a challenge for others to relate spatially to the wheelchair. This was reflected in descriptions of how others would walk into the chair, apparently without seeing it, or, how others had difficulty estimating how much space the electric wheelchair occupies. This made participants feel that they were often in the way.

Comments and controversy were common about whether the electric wheelchair really needed as much space as participants claimed.

> *If you say "you have to back off a little because I will run over your feet otherwise",*
> *then they back maybe three inches and stand there, waiting for you to drive by, but it's*
> *not enough. I can see that if I drive now, I will run over them. But they believe that the*
> *space is sufficient, and do not move, even if they have noticed me [looking]. They say*
> *"yes, but you can [go]."*

Participants noted a positive change in attitude toward disability over the years, both within society and in their personal views. In particular, they saw that their own brighter attitude toward disability and being an electric wheelchair user likely help promote a more positive attitude in others. They observed a relation between a more wheelchair-accessible society and increased openness for cultural differences in a more pluralistic society.

Facing duality in mobility

Most participants confirm that the electric wheelchair is an important tool for independent movability, and they testified to the importance it has in their daily living. Nevertheless, they felt restricted and frustrated because of a less-than-accessible community.

Participants describe a strong sense of freedom of movability once they started to use the electric wheelchair. Regained movability comprised the whole spectrum from moving the chair (and thus the body) "an eighth of a turn" to driving 30 kilometres.

I could even go through the potato field, you know. I just didn't see how I could drive it outdoors [in the potato field] (laughter). Of course, it's sand, but it was packed in such a way that I felt like, hey, this actually works, and I just went and went. If I had stopped, I would probably have gotten stuck (laughter). [I] made large figures of eight all the time. It was fun. That's freedom somehow.

Participants appreciated the newfound opportunity to get into the countryside, take longer trips similar to walking or biking tours, and told about reaching a "bigger world". They valued the ability to move autonomously and without a helper. This also led to a sense of freedom.

If possible, one needs to be as independent as possible, even if it's just driving [the wheelchair] yourself, being able to move around independently, and things like that. To be able to choose that....now I'd like to go to the bathroom, or get some air or...whatever it might be. So, you see....yes....no, I actually think my life had been completely different....but...well, it would have been different, no doubt. Clearly different.

The electric wheelchair offered new possibilities for daily activities and social life, e.g., working, shopping, doing household work, taking part in leisure time activities, or being able to spend time with friends. Still, participants reported frustrations due to many, sometimes unforeseeable, obstacles such as limited accessibility in the streets, shops, restaurants, cafés, trains, busses, airports, and public buildings.

Another barrier to ambulation was difficulty driving outdoors in a cold climate. Some participants mentioned how difficult joystick handling became when their impaired fine motor skills deteriorated further in cold ambient temperatures. Gloves reduced sensitivity when driving. Metal parts of the chair retained a low temperature for a long time after coming indoors, leading to prolonged cooling, e.g., of the feet. The wheelchair brought snow and mud indoors when the weather was bad.

Using proactive strategies

The confrontation with physical environmental barriers, as well as attitudinal barriers from society and individuals necessitates continual development of a set of strategies to handle daily living.

One such strategy, used when meeting with strangers, is to avert excessive focus on the electric wheelchair by using humour, taking the initiative when talking to others or with distinctive appearance to avoid focus on the wheelchair:

" I have always tried to stand out from others and as you already do [as a wheelchair user] I can do it even more. You know when I distinguish myself in that way, it will take the focus away from the electric wheelchair."

The participants describe a consciousness about their seated posture when in the electric wheelchair. In order to give a good impression, they adopt an upright, straight seating position. Others use the raising or lifting function to reach the same level in interpersonal interactions.

Participants developed a strategy to prepare constantly for potentially risky situations in daily living, for protecting themselves and other people. Planning and control is constantly needed for life to work smoothly. Participants explained how they could easily drive into pedestrians, fall out of the chair if they came to a dead stop, get the joystick hooked into the clothing of passers-by, if they were not planning and controlling their environment.

It's a heavy machine, you know. It weighs 180 kg, the machine itself, and then I am 70 kg, that's 250 kg. So I could become a dangerous missile on the sidewalk, that's why one has to be careful when driving around people.

Sometimes, participants stretched the recommended specifications of wheelchair handling in order to manage daily living. For example, they made their own adaptations in order to have a mobile phone or a purse within reach, or for an assistant or child to ride on the wheelchair.

Using proactive strategies involved efforts on a political level. For example, some participants engaged in patient associations to fight for better accessibility in society, rehabilitation efforts, conditions, and dissemination of knowledge. Others adopted a pragmatic outlook toward obstacles that remain, and had an inner negotiation on whether or not to fight for something. As a man told very ironic:

There are still shops that are not available, but…but they're not *places I have to get into.*

Maybe because I have never entered them (laughs)

He meant that he did not know if he needed to get into those shops because he had never been there.

Being at the mercy of the system

This category reflects the powerlessness participants felt within society, especially as regards the technical aid prescription process and health organisation system. While grateful for having obtained an electric wheelchair, participants nevertheless expressed frustration at being dependent on "the system" (i.e., rules, regulations, bureaucracy, long lead times, lack of flexibility) connected with the prescription, delivery, adjustments and repair of electric wheelchairs. Participants felt they were at the mercy of the professional experts, while they themselves were the experts in living with the disability. They experienced a lack of sympathy from service staff concerning how dependent they were on their electric wheelchairs. The importance of improved support, information, and dialogue during the prescription process was articulated.

Most participants regret the lack of aesthetic and functional choices. They want options of colour, upholstery, and customized functions. Some wished for optional "luxury" accessories such as "pimped" hubcaps or lacquered hoods.

It should be ok to repaint, if you pay for it yourself…(laugh) I want to have pink and

blue flames on a black base. And if they [the Center for Assistive Technology] want it

back, it can be redone. The wheelchair should be something personal, like clothes,

shoes and hair colour.

Being at the mercy of the system also included feelings of being a "second class citizen". This was clearly exemplified by mirroring their situation in light of other discriminated groups within the society.

Imagine yourself, if…homosexuals, Sami people, and Jews would have to take the

backdoor. It would be unthinkable. But people in wheelchairs, they have to be grateful

for getting in at all.

Not only is accessibility to restaurants and public buildings problematic at a local level, but traveling by public bus, train, or airplane depends on national and international regulations and systems.

Discussion

The electric wheelchair represents much more than just a vehicle, or a technical device for overcoming or negotiating disability and impairment. The resultant increased independence and freedom has a more general positive impact on the user's *self-identity*. Sometimes the user even embodies the electric wheelchair. This fact creates possibilities and potential problems. The wheelchair must be treated with ethical considerations. As this study makes

apparent, the electric wheelchair is not to be regarded as something you "drive", but rather as an orthosis or prosthesis. The electric wheelchair is a part of its user's body and person, while simultaneously an ambient factor. In our study, the wheelchair was perceived as an extension of the body. Winance [26] states that a wheelchair is a part of the user's world from the start, but eventually becomes more integrated with the user's body, and it becomes a link to the world. The user acts through this link [27]. According to Merleau-Ponty [28] there is no separation between body, mind, and world; they cannot be understood without each other. They are intertwined and all human experience is built upon the unit of "the lived body" [28]. This may explain the user experiences of the wheelchair as an extension of the body.

The participants in our study viewed and integrated the electric wheelchair in different ways. Integrating wheelchair and person is a continuous process and involves material and emotional adjustments. The wheelchair becomes part of the body and person in that it adjusts the way the person perceives, moves, and relates to the world [27]. Electric wheelchair users who experience their electric wheelchair as an extension of the body had the most suitable electric wheelchairs in one study by Blach Rossen et al. [29]. In order to optimize the link to the world for people dependent on an electric wheelchair, it is important to put considerable time and effort into the material and emotional adjustments [27].

A significant and recurrent finding is that the electric wheelchair has an important role in the self-identity process. Self-identity is shaped by appraisals—by oneself and others [30]. Our results confirm those of previous studies. The electric wheelchair may be perceived as a stigma [29, 31, 32]. Additionally, some participants shared the impression that the electric wheelchair is a symbol of severe disability.

Participants were reluctant to be categorized as electric wheelchair users, belonging to "*that group of people*". This confirms previous works [29, 32]. In our study, self-identity was built on aspects other than the electric wheelchair use or disability itself. In a study on identity and disability, Watson [33] concluded that there is no such group identity among disabled persons. Self-identity is something disabled people do, not built on discourse about how other people identify disabled people. Disabled people did not negate the impairment, but embraced it and built their identity on conscious actions, on agency of their bodies [33]. Furthermore, identity is closely connected with, and dependent upon, interaction. This is where much of the self-appraisal and appraisal of others occurs [34]. This aspect is verified in our study. Other studies have shown that non-disabled persons react with a mix of sympathy, fear, discrimination, and uneasiness when encountering wheelchair users [35-38].

Participants in our study formed strategies for meetings with strangers to avert focus from the electric wheelchair. For example, they took the initiative and were aware of their posture. Hulme et al [39] underscored the importance of increased social interaction skills as a solution to coping with being confined to a wheelchair. According to Strauss [30], posture, intonation, speech, pace, and modes of interaction are ways to take control over interactions and force others to respond in desired ways that are appropriate to the desired status. Our study confirms the importance of attitude and mind-set among electric wheelchair users in order to gain acceptance in society.

Major life changes lead to questioning one's self-identity and raises questions of "who I really am" [30]. It is proposed that a person undergoing notable life changes risks losing him/herself and become located between "danger and discovery", thereby in need of finding and challenging new self-identities [30]. This is in accordance with our results, as participants initially had difficulty in accepting the life change for which the electric wheelchair became

symbolic. Once they started to use the electric wheelchair and experienced its practical benefits, they started to reformulate the symbolic value of the wheelchair and it became a symbol of freedom and independence. They challenged the feared passive and stigmatized identity as they developed new paths of self-identity, e.g., parental, working, or partner roles.

On a negative note, the electric wheelchair could hinder paths of self-identity such as difficulties in connecting with gender expectations of being a woman or man. Technology and gender can generally be seen as social constructs [40, 41]. Even if the electric wheelchair is not supposed to be gender coded, the communication of technology and electric engines signals masculinity more than femininity [42]. In Sweden, more men than women are prescribed electric wheelchairs [43], and more men than women work with design, technology, and production. Pettersson et al. saw in their study on electric wheelchair and scooter users that there were different needs among women and men [44]. Scherer and Dicowden [45] state that it is important to take gender and culture into consideration when it comes to technology and rehabilitation, and not allow women to be left behind. In our study, the self-identity of being an attractive woman was said to be difficult in a wheelchair. This was seen in other studies where the electric wheelchair is a burden for women whose interests in shopping, clothing, and appearance are more difficult in a wheelchair [42]. In contrast, men using electric wheelchairs found new identities in new leisure time activities like sports, shooting, and work [29]. Facilitating different types of self-identity for women and men in electric wheelchairs is important to let individual needs, not stereotyped gender roles, guide the future. This was also requested in our study through wheelchair aesthetics and design.

As in other studies [29, 31, 42, 46], our participants were afraid to let the electric wheelchair take attention away from them as individuals. They were frustrated that they could not make the electric wheelchair more personal and allow it to express more of whom they are. This

was seen in another Swedish study on persons using active wheelchairs [47]. In our study, influence on appearance was more important for those who integrated the electric wheelchair as an extension of their body; as the wheelchair represents a part of them. Considering appearance is important when designing new models, repairing, or prescribing new electric wheelchairs [42].

Participant perspectives on how the system functioned were another significant finding. 'Being at the mercy of the system' raised multiple, concerns in relation to societal, social, psychological, and practical issues. Participants expressed gratefulness and frustration with the system and their dependence on it for an electric wheelchair. They emphasized the joy and burdens of life as their main focus, rather than the burdens of having a wheelchair. Although they developed numerous strategies to handle concerns related to 'the system', they repeatedly reflected on the convoluted circumstances they must deal with.

Participants thought that professionals had a poor understanding of how dependent users were upon a functioning wheelchair. This lack of understanding was strongly reinforced the sense of 'being at the mercy of the system'. They felt that the professionals are higher in the hierarchy because of their professional expertise. The greater the relationship with the professionals, the more participants felt they were heard. They underscored the significance of good support, information, and the importance of sound interaction throughout the prescription and user processes.

Overall the findings also point to important aspects related to participation and health. This is interesting in relation to the ongoing, international dialogue about the relationship between occupation, participation, justice, and health.

Participants did not directly comment on the impact the wheelchair had on health, however, in several of the categories they highlighted aspects of great importance for participation in central life situations, which could be interpreted as impacting on health. According to Wilcock [3], recognition of how participation and engagement in life activities contributes to health status is poorly understood. In deeper aspects, Pörn [47] defines health as an ability to act in relation to adaptedness, goals in life, and the environment. Participants in our study described how the electric wheelchair contributed extensively to their ability to act in different areas of their lives. To further facilitate ability to act, and in that sense reinforcing health, there is still much work to do, as described in our results. For example there is much that can be done regarding the environment and the less accessible society as the participants stated in our study; this has also been explored in another recent Swedish study [44].

Community mobility is raised as a main benefit of the electric wheelchair related to social participation in life situations and society. This has been recognized in some research [49-51], and is evident in the present study when users expressed manageability and sociality.

Being at the mercy of the system encompasses how society is governed [52], how power relations influence daily activities and circumstances, injustices and health inequities, and embodies the underpinning of many societal contexts. This exposes complex contextual influences on life situations, expectations and opportunities for meaningful daily activities, system promises and hindrances at the local level, and attitudes among professionals specifically, and citizens in general. For instance, participants conveyed different feelings and discourses linked to their childhoods, and continuing reflections on why their lives turned out as they did. Those who received disability early in life recounted parental influences over their life prospects. Those affected in later life reported the importance of family, friends, work, and a well-functioning system for provision of technical aids. Experiences captured

gratefulness *and* frustration, evoked a concept of struggles with benefits and hindrances in many life situations. In the present study, perspectives such as limited accessibility are underscored by the users. However, they made a conscious choice not to focus too much on these issues, and interpreted this choice as a coping strategy. The impression and consciousness that body, identity, context and circumstances change constantly are highlighted throughout the stories. These perspectives are also related to 'being at the mercy of a system' because of how the system-scheme works long term and in relation to unique needs of individuals and their environment. The changing disability-policy that occurs over time, affects users and their families, friends, workplaces, aid organizations, professional conditions, et cetera. A welfare state such as Sweden would like people with disabilities to be independent and autonomous through the public welfare system [53]. The community relies in created opportunities for independence, but these findings show that there are not enough; people still encounter disabilities on a daily basis. Moreover, independence may not be the ultimate value for every individual. For some, it may be the ability to act in connection with the social and physical environments, the system, and the local community [54]. The disability movement and social model [54] have long emphasized that disability can be adjusted by altering the surrounding environment. This has led to increased awareness, and policies in Sweden such as physical access to all public spaces [53]. However, the entire material collected in this study illustrates a multipart and complex picture. The study indicates the importance of well-functioning systems, listening to the unique individual experiences of a changing body, identity, and context, and what these mean for individuals and their life situations.

The electric wheelchair users voiced concern about being excluded from the design processes for new products, the development of societal accommodations or systems, and their own prescription processes and related services. These are also highlighted in other studies, which

points to lack of user influence on decisions regarding the design and development of facilities [42, 55]. Incorporating users in the design process is the quickest, most reliable way to capture the needs and requirements of users [56]. Co-creation, active involvement of users across the whole span of a design process, is today practiced when designing new products and services, not least within health care [57]. It is shown to be commercially viable [58] and govern for more sustainable ways of living in the future [59].

Methodological considerations

Informed by the work of Bourdieu and Foucault, Biggs [61] proposed a narrative approach to the study of social policy. This is a primary reason why our study findings are interesting from a societal perspective. A narrative approach involves viewing policies as the construction and conveyance of stories that citizens are encouraged to live by. Holstein and Gubrium [62] discuss how normative ideas about what people should and should not do, in relation to steps of development, can inform decisions by parents and professionals. This kind of research helps understand how norms and knowledge guide the ways people can choose, handle, and engage in daily occupations, how a certain professional vocabulary is used, and thus influences norms and prospects for a rich life of the electric wheelchair user.

Informants in present study were generally talkative, reflective, and open-minded in sharing their stories. Overall, we collected rich and various experiences.

During the analyses, it was challenging to isolate disability issues from wheelchair use issues. The questions were based on the wheelchair use, but answers about the wheelchair could not

always be separated from issues about disability, because disability and wheelchair use are so closely entwined.

Having a research group that consists of different professions was a strength during the study analyses and permitted different perspectives on the findings. To strengthen the findings, colleagues were asked to reflect on them at different stages of the analyses. We could have involved users in the research process, and this would have further strengthened the work.

This study acquired the perspective of the most talkative electric wheelchair users. In the future, there is a need to deepen our understanding of the user perspectives and specifically study groups with more complex needs, e.g., children, persons with cognitive impairment, and the elderly.

All of the participants are native Swedes. The same study, conducted in a society with different technology, aid system, or other norms about disability, may yield different findings.

Conclusions

The present study provides an empirical example of how electric wheelchair users experience many processes, from self-identity to system perspectives.

The process of integrating an electric wheelchair is closely connected to symbolic value, usability, community mobility, and identity. These factors should be considered in production, prescription, and adaptation processes. These findings strengthen the theory that surroundings have a large impact on a user's opportunities for living a full life, and highlight the need of increased awareness and focus on how to support participation in society over time.

References

1.   UN. Convention on the Rights of Persons with Disabilities. In: UN, editor: United Nations Secretariat for the Convention on the Rights of Persons with Disabilities; 2006.

2.   World Health Organization. International classification of functioning, disability and health. Geneva: World Health Organization; 2008. iv, 373 s. p.

3.   Wilcock AA. An occupational perspective of health. Slack Incorporated; 2006.

4.   Whiteford GE, Pereira RB. Occupation, inclusion and participation. Occupational science: Society, inclusion, participation 2012:185-207.

5.   Hammel J, Magasi S, Heinemann A, Whiteneck G, Bogner J, Rodriguez E. What does participation mean? An insider perspective from people with disabilities. Disability & Rehabilitation 2008;30(19):1445-1460.

6.   Law M. Participation in the occupations of everyday life. The American Journal of Occupational Therapy 2002;56(6):640-649.

7.   Stalvey BT, Owsley C, Sloane ME, Ball K. The Life Space Questionnaire: A measure of the extent of mobility of older adults. Journal of Applied Gerontology 1999;18(4):460-478.

8.   Cresswell T. Towards a politics of mobility. Environment and Planning D: Society and Space 2010;28:17-31.

9.   Frontera WR. DeLisa's Physical Medicine & Rehabilitation: Principles and Practice. Wolters Kluwer Health/Lippincott Williams & Wilkins; 2010.

10.   O'Young B, Young MA, Stiens SA. Physical medicine and rehabilitation secrets. Hanley & Belfus; 2002.

11.   Gayle G, Davis G, Pohlman R, Glaser R. Track Wheelchair Ergometry: Effects of Handrim Diameter on Metabolic Responses. Adapted Physical Activity: Springer; 1990. p 101-107.

12.   Masse L, Lamontagne M, O'riain M. Biomechanical analysis of wheelchair propulsion for various seating positions. Journal of rehabilitation research and development 1991;29(3):12-28.

13.   Okawa H, Tajima F, Makino K, Kawazu T, Mizushima T, Monji K, Ogata H. Kinetic factors determining wheelchair propulsion in marathon racers with paraplegia. Spinal cord 1999;37(8).

14.   Bates PS, Spencer JC, Young ME, Rintala DH. Assistive technology and the newly disabled adult: adaptation to wheelchair use. The American journal of occupational therapy : official publication of the American Occupational Therapy Association 1993;47(11):1014-21.

15.   Cahill SE, Eggleston R. Managing emotions in public: The case of wheelchair users. Social Psychology Quarterly 1994;57:300-312.

16.   Gitlin LN, Luborsky MR, Schemm RL. Emerging concerns of older stroke patients about assistive device use. The Gerontologist 1998;38(2):169-180.

17.   Henderson KA, Bedini LA, Hecht L. 'Not just a wheelchair, not just a woman': self-identity and leisure. Therapeutic Recreation Journal 1994;28(2):73-86.

18.   Miles-Tapping C, MacDonald LJ. Lifestyle implications of power mobility. Physical & Occupational Therapy in Geriatrics 1995;12(4):31-49.

19.   Hebert D, Rudman D, Reid D. Wheelchair use and occupational performance: Stroke survivors' and caregivers' perspectives. 2000. p 13-15.

20.   Ferguson-Pell M. Jay Medical Lectureship: Seating and wheeled mobility research–The key to our future. 1995.

21.   York J. Mobility methods selected for use in home and community environments. Physical therapy 1989;69(9):736-747.

22.   Pluym SM, Keur TJ, Gerritsen J, Post MW. Community integration of wheelchair-bound athletes: a comparison before and after onset of disability. Clinical rehabilitation 1997;11(3):227-235.

23.   Somers MF, Garant A. Addressing the unique mobility requirements of parenting from a wheelchair: Case Report. Journal of Neurologic Physical Therapy 1993;17(4):11-13.

24.   Reid D, Laliberte-Rudman D, Hebert D. Impact of wheeled seated mobility devices on adult users' and their caregivers' occupational performance: a critical literature review. Canadian Journal of Occupational Therapy 2002;69(5):261-280.

25.   Strauss AL, Corbin JM. Basics of qualitative research : techniques and procedures for developing grounded theory. Thousand Oaks, Calif.: SAGE; 1998. xiii, 312 s. p.

26.   Winance M. Pain, disability and rehabilitation practices. A phenomenological perspective. Disability and Rehabilitation 2006;28(18):1109-18.

27.   Winance M. Trying Out the Wheelchair.The Mutual Shaping of People and Devices through Adjustment. Science, Technology, & Human Values 2006;31(1):52-72.

28.   Merleau-Ponty M. Phenomenology of perception. London: Routledge; 2002. xxiv, 544 s. p.

29.   Blach Rossen CS, Bodil. Würtz Jochumsen, Bente. Wind, Gitte. Everyday life for users of electric wheelchairs – a qualitative interview study. Disability and Rehabilitation: Assistive Technology 2012.

30.   Strauss AL. Mirrors & masks : the search for identity. New Brunswick, N.J.: Transaction Publishers; 1997. vii, 188 s. p.

31.   Hjelle KM, Vik K. The ups and downs of social participation: experiences of wheelchair users in Norway. Disability and Rehabilitation 2011;33(25-26):2479-89.

32. McMillen A-MS, S McMillen A-M, So¨derberg S. Disabled persons' experience of dependence on assistive devices. . Disabled Persons' Experience of Dependence on Assistive Devices. Scand J Occup Ther 2002(9):176-183.

33. Watson N. Well, I Know this is Going to Sound Very Strange to You, but I Don't See Myself as a Disabled Person. Identity and disability, Disability & Society 2002;17(5):509-527.

34. Mead GH. Mind, self, and society: From the standpoint of a social behaviorist. University of Chicago press; 2009.

35. Stephens MAP, Kinney JM, McNeer AE. Accommodative housing: Social integration of residents with physical limitations. The Gerontologist 1986;26(2):176-180.

36. Stiles BL. Benevolence as deviant behavior: A test of the sympathy effect. Deviant behavior 1995;16(1):81-92.

37. Viemerö V. The effects of somatic disability or progressive illness on psychological and social well-being. Psychotherapy and psychosomatics 1991;55(2-4):120-125.

38. Weinberg N. Social equity and the physically disabled. Social Work 1983;28(5):365-369.

39. Hulme JB, Poor R, Schulein M, Pezzino J. Perceived behavioral changes observed with adaptive seating devices and training programs for multihandicapped, developmentally disabled individuals. Physical therapy 1983;63(2):204-208.

40. Lohan M, Faulkner W. Masculinities and Technologies : Some Introductory Remarks. Men and Masculinities 2004;6:319-329.

41. Cockburn C, Silverstone R, Hirsch E. The circuit of technology: gender, identity and power. Consuming technologies: Media and information in domestic spaces 1992:33-42.

42. Ravneberg B. Identity politics by design: users, markets and the public service provision for assistive technology in Norway. Scandinavian Journal of Disability Research 2009;11(2):101-115.

43. Hjälpmedelsinstitutet. Statistik om hjälpmedel för förflyttning och kognition. Inköpskostnader och förskrivningar. Hjälpmedelsinsitutet; 2010. Report nr 11349-pdf. 39 p.

44.   Pettersson C, Iwarsson S, Brandt Å, Norin L, Månsson Lexell E. Men's and women's perspectives on using a powered mobility device: Benefits and societal challenges. Scandinavian journal of occupational therapy 2014(0):1-9.

45.   Scherer MJ, Dicowden MA. Organizing future research and intervention efforts on the impact and effects of gender differences on disability and rehabilitation: The usefulness of the International Classification of Functioning, Disability and Health (ICF). Disability & Rehabilitation 2008;30(3):161-165.

46.   Lupton D, Seymour W. Technology, selfhood and physical disability. Social science & medicine 2000;50(12):1851-62.

47.   Pörn I. Health and adaptedness. Theoretical medicine 1993;14(4):295-303.

48.   Krantz O, Persson D. The experience of active wheelchair provision and aspects of importance concerning the wheelchair among experienced wheelchair users in Sweden. Review of Disability Studies 2011;7(2):21-37.

49.   Fristedt S. Occupational participation through community mobility among older men and women. 2012.

50.   Shirado O, Shundo M, Kaneda K, Strax TE. Outdoor Winter Activities of Spinal Cord-Injured Patients: With Special Reference to Outdoor Mobility. American journal of physical medicine & rehabilitation 1995;74(6):408-414.

51.   Siösteen A, Lundqvist C, Blomstrand C, Sullivan L, Sullivan M. The quality of life of three functional spinal cord injury subgroups in a Swedish community. Spinal cord 1990;28(8):476-488.

52.   Foucault M. Power/knowledge: Selected interviews and other writings, 1972-1977. Random House LLC; 1980.

53.   Office SG. En strategi för genomförande av funktionshinderpolitiken 2011-2016 (A strategy for implementing disability policies 2011-2016). 2011.

54.   Barnes C, Mercer G. Implementing the social model of disability : theory and research. Leeds: Disability Press; 2004. vi, 233 s p.

55. Pierce LL. Barriers to Access: Frustrations of People Who Use a Wheelchair for Full-Time Mobility. Rehabilitation Nursing 1998;23(3):120-125.

56. Essén A, Östlund B. Laggards as innovators? Old users as designers of new services & service systems. International Journal of Design 2011;5(3):89-98.

57. Capire/HCM. 2013 Design av tjänster inom hälsa, vård och omsorg – en kunskapsöversikt. Stiftelsen Svensk Industridesign (Swedish Industrial Design Foundation) http://www.svid.se/kunskapsoversikt2013 . Accessed 2013.

58. Eikhaug O, Rådet for Industridesign (Norway), Innovation for All Programme. Innovating with people : the business of inclusive design. [Oslo]: Norwegian Design Council; 2010. 96 p. p.

59. Sanders EB-N, Stappers PJ. Co-creation and the new landscapes of design. Co-design 2008;4(1):5-18.

60. Biggs S. Toward critical narrativity: Stories of aging in contemporary social policy. Journal of Aging Studies 2001;15:303-316.

61. Holstein JA, Gubrium JF. Constructionist perspectives on the life course. Sociology Compass 2007;1(1):335-352.

Table 1. Background information on participants

Participant	Age	Sex	Married/ cohabiting [# children at home]	Type of accommodation	EPW type	EPW usage	EPW, time used (years)	Diagnosis	University education
P1	44	M	No	Apt	C500	Full	20	Progressive spinal muscular atrophy	Yes
P2	49	F	No	Apt	Mover 85	Part	10	Chronic pain from trauma	Yes
P3	37	M	No	Apt	C500	Part	7	Charcot-Marie-Tooth	Yes
P4	39	F	Yes [1]	Apt	C500	Full	30	Rheumatoid arthritis	Yes
P5	20	F	No	Student housing	C500	Full	18	Cerebral paresis	No
P6	53	M	No	Apt	-	-	-	Multiple sclerosis	No
P7	38	F	Yes	Apt	C500	Full	35	Osteoporosis	Yes
P8	26	F	Yes	Apt	K2000	Full	14	Charcot-Marie-Tooth	No
P9	23	F	No	Apt	Trax	Part	16	Juvenile dermatomyositis	No
P10	63	M	No	Apt	Hexior Trax	Part	36	Rheumatoid arthritis	No
P11	24	F	No	Apt	C500	Full	20	Cerebral paresis	Yes
P12	66	M	Yes	House	C500	Part	0,9	Spinal cord injury	No
P13	43	F	Yes [2]	House	C300	Part	0,25	Multiple sclerosis	No
P14	40	M	Yes [2]	Apt	C500	Full	28	Cerebral paresis	No
P15	44	M	Yes	House	C500	Full	10	Spinal cord injury	Yes

EPW=Electric powered wheelchair, P=Participant, M=Male, F=Female, Apt=Apartment, Full=Full time, Part=Part time

Table 2. Subcategories and examples of open codes in the category "Calculate functional consequences"

Category	Subcategory	open code examples
Calculate functional consequences	Calculate long term function	Frustrating, with unpredictable prognosis
		Hard to realize the extent of the disability
		Fear that you will feel sicker in wheelchair
	Balance between rest and physical workload	Afraid of being worse when using electric wheelchair
		Electric wheelchair to conserve strength
	Advocating gait	No choice of continuing to walk
		The professionals insist that one should walk
	Different needs control choice of electric wheelchair	Electric wheelchair as backup
		Electric wheelchair as the first choice
		Electric wheelchair as a tip board
		Electric wheelchair as a pain reliever

Table 3 Core category, categories and subcategories

| Core category	Categories	Subcategories
Integrating the electric wheelchair- a manifold process	Incorporating the electric wheelchair in the self-identity process	From resistance to acceptance The electric wheelchair as symbol Impact of electric wheelchair design on user image Electric wheelchair impact on self-identity processes The electric wheelchair as a friend The electric wheelchair as a body part
	Calculating functional consequences	Views on the value of walking Multiple surplus benefits influence choice Balancing between rest and exercise
	Encountering the reactions of others	The value-laden wheelchair evokes reactions The electric wheelchair signifies upgrading or downgrading Challenge for others to relate spatially to the electric wheelchair Changing attitudes towards disability
	Facing duality in movability	Unexpected opportunities The electric wheelchair as enabler of ADLs Limited availability, a barrier to independence The climate as barrier
	Using proactive strategies	Taking charge of the meeting Constant readiness Adopting a useful mind-set Stretching the limits of electric wheelchair use
	Being at the mercy of the system	The power of being expertise Lack of functional and aesthetic choices The stress of technical dependence Experiencing powerlessness in an inaccessible society
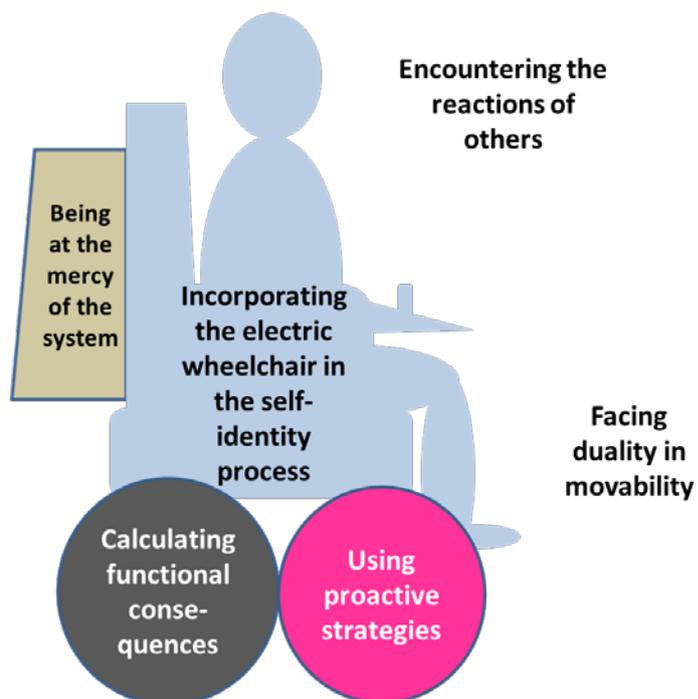
Figure 1. The relations of the categories