Significance of Assistive Devices in the Daily Life of Persons with Stroke and Their Spouses
Significance of Assistive Devices in the Daily Life of Persons with Stroke and Their Spouses
The overall aim of this research project was to explore and describe the significance of assistive devices in daily life. The project involves two qualitative and two quantitative studies. Three of these studies were from the perspective of persons with stroke and one from the perspective of spouses of persons with stroke.

A hermeneutic phenomenological lifeworld approach was used in the qualitative studies and data was obtained through conversational interviews with the two study groups, 22 persons with stroke and 12 spouses of persons with stroke, after the devices had been used for about a year.

The results indicated that the lived experiences of assistive devices in respect of the different lifeworld existentials (lived body, lived space, lived time, lived human relation) are closely interconnected in both study groups. The lived body existential included aspects of habits, feelings and the incorporation, figuratively speaking, of the devices into their own bodies. Lived space concerned the gradual development of a new view of the environment and the devices’ role as a prerequisite for being able to live at home. The devices brought about a changed relation to lived time with respect to the temporal perspectives of past, present and future. To be able to take control of one’s own time was an important experience that the devices facilitated. Assistive devices were an integral part of the lived human relation between the couples in the study groups, as well as between the disabled persons/spouses and other people, including the health-care professionals. The devices contributed either to the maintenance or the change of social roles, but they sometimes also gave rise to the experience of being stigmatised. The results in the case of both study groups showed that the use of different devices is complex and often contradictory, especially when it comes to persons with stroke. Overall the persons’ experiences of the advantages of the devices overshadowed their experiences of the disadvantages.

The quantitative studies included a pre- and post-assessment design. Thirty-two persons with disabilities after stroke were included. The impact of an outdoor powered wheelchair on activity and participation (IPPA, WHODAS II) and quality of life (PIADS, EQ-5D) was measured. Statistical analysis with mainly non-parametric tests was used to determine significant within-group and between-group changes after intervention. The conceptual framework ICF was used in one of the quantitative studies when classifying the participants’ stated problems.

The results showed that the outdoor powered wheelchair is an essential device for persons with disabilities after stroke with regard to overcoming activity limitation and participation restrictions in everyday life. Furthermore it mostly has a positive impact on such users’ quality of life. However, it is also important to highlight the negative experiences of a few with regard to the use of powered wheelchairs. In sum, these results will enable prescribers to better understand the individual experiences of using assistive devices and the individuals’ and the families’ need for support in connection with the prescription of assistive devices, the particular example being powered wheelchairs.

Key words: stroke, spouse, next of kin, assistive devices, assistive technology, powered wheelchair, lifeworld, phenomenology, lived experience, activity, participation, quality of life, outcome, ICF, IPPA, WHODAS II, PIADS, Euroqol-5D, occupational therapy
ORIGINAL PUBLICATIONS

The present dissertation is based on the following four studies, which will be referred to in the text by their Roman numerals:

**Study I**

**Study II**

**Study III**
Pettersson I, Törnquist K, Ahlström G. The effect of an outdoor powered wheelchair on activity and participation in users with stroke. Disability and Rehabilitation: Assistive Technology; Accepted for publications.

**Study IV**
Pettersson, I, Ahlström G, Törnquist K. The value of an outdoor powered wheelchair with regard to the quality of life of persons with stroke: A follow-up study; Submitted.

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ABBREVIATIONS

EQ-5D      EuroQol-5D
ES         Effect size
HRQoL      Health-Related Quality of Life
ICF        International Classification of Functioning Disability and Health
IPPA       Individually Prioritized Problems Assessment
MRS        Modified Rankin Scale
MMSE       Mini-Mental State Examination
PIADS       Psychosocial Impact of Assistive Devices Scale
QUEST       Quebec User Evaluation of Satisfaction with assistive Technology
WHO        World Health Organization
WHODAS II  World Health Organization Disability Assessment Schedule II
SAMMANFATTNING

Betydelsen av hjälpmedel i vardagslivet för personer med stroke och deras närstående

Bakgrund


I *Studie III* var syftet att beskriva och jämföra aktivitets- och delaktighetsbegränsningar hos personer med stroke, ur deras eget perspektiv, före och efter användningen av en elrullstol för utomhusbruk. Vid första mätställlet och vid uppföljningen 4 månader senare användes två instrument: ”Individually Prioritized Problem Assessment” (Instrument för bedömning av individuellt prioriterade problem) (IPPA) och ”World Health Organization Disability Assessment Schedule II” (Världshälsoorganisationen, Instrument för bedömning av funktionshinder) (WHODAS II) i intervjuer med 32 deltagare. Statistisk analys med huvudsakligen icke-parametriska metoder användes för att fastställa signifikanta skillnader mellan före och efter användning av elrullstolen. Resultatet visade att elrullstolen hade en stor positiv effekt enligt IPPA. De 32 deltagarna bedömde att aktivitets- och delaktighetsbegränsningar i vardagslivet till stor del blev reducerade eller eliminerade. När det gäller klassificeringen av deltagarnas aktivitets- och delaktighetsproblem (*n=118*) enligt ”Internationell klassifikation av funktionstillstånd, funktionshinder och hälsa” (ICF), visade resultatet att de flesta problemen (*n=52*) tillhörde domänen ”Samhälls- och gemenskapsliv”. Denna domän inkluderar i huvudsak deltagarnas problem i relation till


Slutsatser
Livsvärlden hos personer med stroke (Studie I) och deras närstående (Studie II) påverkas av hjälpmedlen som de använder och som har funnits i deras hem under ett års tid. Resultatet visar att både personer med stroke och deras närståendes livsvärld påverkas av hjälpmedlen. När hjälpmedlen
kommer till hemmen ger de upphov till existentiella frågor angående den levda kroppen, den levda tiden, det levda rummet och levda relationer. Ett huvudresultat är upplevelsen av en dubbelhet när det gäller hjälpmedel som tar sig i uttryck av både positiva och negativa betydelser, ofta samtidigt (Studie I och II). Dock upplevs positiva erfarenheter i större utsträckning än negativa. Betydelsen av hjälpmedel är komplex och hjälpmedlen kan sägas vara icke-neutra produktioner. De livsvärldsexistentiell som användes vid analys och beskrivning av resultat visade sig vara användbara vid studierna om betydelsen av hjälpmedel och medverkade till en ökad insikt om hjälpmedlens betydelse. Elrullstolen för utomhusanvändning visade sig vara ett viktigt hjälpmedel när det gäller att övervinna olika aktivitets- och delaktighetstidsbegränsningar i vardagslivet (Studie III). Vidare har den för det mest en positiv effekt på olika aspekter av livskvalitet hos användare med stroke (Studie IV). Instrumenten IPPA och PIADS rekommenderas vid användning av utvärdering av hjälpmedelsförskrivning men även ICF för förståelse av vilka faktorer som kan inverka vid användning av hjälpmedel. Som helhet kan resultatet i denna avhandling bidra till ökad förståelse dels för förskrivare av hjälpmedel att förstå dels hur olika individer upplever hjälpmedel, men även individernas och familjernas behov av stöd i samhåll med förskrivningen av hjälpmedel, därmedel, elrullstolar för utomhusanvändning. Fortsatta studier med longitudinell design rekommenderas av användning av elrullstol för utomhusanvändning, men även psykometriska studier med instrumenten PIADS och WHODAS II. Vidare är det värdefullt med ytterligare studier av närståendes upplevelser av hjälpmedel.
INTRODUCTION

Assistive devices for the management of everyday life are to be found in an increasing number of homes, and they play a part in human interaction and in the interaction between the person and the environment. The focus of this dissertation is on the significance such devices have both for the persons using them and for the next of kin.

When I set out as an occupational therapist I gave little thought to what deeper significance assistive devices might have. In prescribing them I thought of them simply as what their name indicated: devices that assisted – that assisted people, that is, to perform daily activities they would not otherwise have been able to perform. Thus I saw the devices in a purely positive light: they meant that people with disabilities were able on their own to for instance go to the toilet, have a shower or go for a walk. The right device at the right time could change dependence on another person in everyday life into independence.

After I had worked as an occupational therapist for a number of years it was clear to me that assistive devices are not always regarded in a purely positive light. For certain people, for instance, such a device is a symbol of being ill, and they do not want to show themselves in public with it. In the course of time it came home to me more and more that an assistive device is an object with many meanings and that one and the same device can have different meanings for different persons in different situations. In my work I commonly encountered people with different neurological illnesses, stroke being one of them. Where there was impairment or restriction of activity because of the stroke, these people were often in need of extensive rehabilitation involving several occupational categories. One of a number of rehabilitation measures was making it possible for the people in question to perform the daily activities by which they set great store. The prescription of assistive devices was a means to this end. The clinical experience that the use of an assistive device in everyday life is not always regarded as purely positive and straightforward forms the background to this dissertation, and this is a part of my pre-understanding.

Moreover, a survey of the literature revealed few studies concerning persons with stroke in relation to assistive devices, and there is thus an evident need for further knowledge in this area. In addition, particular attention is paid in this dissertation to the perspective of the spouse with regard to assistive devices since no previous study exists in this area. The results of this study will, hopefully, improve the process of prescription of assistive devices to person in need of such devices.
BACKGROUND

Stroke — from the perspective of persons with stroke

Adjustment and rehabilitation go hand in hand in persons who have had a stroke and therefore knowledge and understanding of these persons’ life situation is vital. A study investigating the experiences of persons recovering from stroke showed that they felt their bodies become objectified. Then they no longer had a sense of a whole body: bodily integration was missing and the brain/mind and body were spoken of as separate entities (Doolittle, 1992). They said that after a time there was a plateau in their recovery, a difficult period because earlier in the recovery process there had been a fairly rapid return of functioning. Furthermore, about six months after the stroke the persons were going through a period of testing their physical abilities, accepting challenges such as walking without a walker. Mastery led to new hope, failure led to disappointment. Recovery for these persons meant that they were able to take up activities that mattered to them and gave them back an identity. At the end of six months, which was the end of the study period, the persons still experienced the body as an object, but were struggling to regain the sense of a whole body (Doolittle, 1992). In another study, Kirkevold (2002) studied patients’ experiences of bodily changes, the biographical impact of the consequences of stroke in everyday functioning. In the later phases of the rehabilitation at home, the person focuses on psychosocial and practical adjustments, such as developing a daily structure and testing the body’s functioning in the home environment. In the semi-stable phase, “going on with life”, about six to twelve months after the stroke, changes occur more slowly. During this phase the most important thing is to get on with one’s life, including adjusting to activities or developing new activities as a substitute for the activities one is no longer able to perform. The main conclusion of the study was that an increased understanding of the complexity of the process of adjustment in the case of stroke is necessary (Kirkevold, 2002). In addition, other qualitative studies have shown that a stroke is an intensely personal experience restructuring the individual’s world (Burton, 2000) and that people’s post-stroke experiences include a disrupted sense of embodiment and loss of self, including invisible emotional difficulties (Ellis-Hill, Payne, & Ward, 2000; Kvigne & Kirkevold, 2003; Murray & Harrison, 2004; Pound, Gompertz, & Ebrahim, 1998; Rittman et al., 2004; Tham & Kielhofner, 2003). Other difficulties are connected with the management of time, involving for instance challenges to the temporal order of daily routines, disruptions in the sense of self and the strategies needed to manage time (Rittman et al., 2004). Furthermore, the experience of living a life with stroke has been described in terms of having to face the fact that abilities previously taken for granted now
present a challenge (Burton, 2000). The challenges and difficulties noted in one study were to a great extent related to such things as getting out of the house, leisure activities, housework and walking (Pound, Gompertz, & Ebrahim, 1998).

Information from quantitative studies provides additional knowledge and understanding of this patient group. Stroke affects approximately 30,000 individuals per year in Sweden, 20,000 of whom are affected for the first time (Riks-stroke, 2005). In the area of central Sweden from which most of the subjects under investigation in this dissertation were recruited, the crude incidence rate for persons with first-ever stroke is 314/100,000 inhabitants per year, which is fairly comparable to the rates for populations in Northern and Eastern Europe (Appelros, Nydevik, Seiger, & Terent, 2002). Owing to the increased proportion of elderly people in the population, 30% more persons will be affected with stroke in 2010 if the incidence rates remain the same as for the year 2000 (Socialstyrelsen, 2000).

Using the terminology of International Classification of Functioning, Disability and Health (ICF) (WHO, 2001a), persons with stroke may have a wide range of impairments, ranging from mild to severe. Body functions – including mental functions (e.g. consciousness, emotions, perception, experience of self and sense of time), sensory functions and pain, genitourinary functions, neuromusculoskeletal and movement-related functions (e.g. muscle power and tone) — may be restricted after a stroke (Appelros, Karlsson, Seiger, & Nydevik, 2002; Glader, Stegmayr, & Asplund, 2002; Hulter-Åsberg et al., 2004; Socialstyrelsen, 2006; van de Weg, Kuik, & Lankhorst, 1999; Widar, Samuelsson, Karlsson-Tivenius, & Ahlstrom, 2002; Young, Murray, & Forster, 2003). Restrictions may also include daily activities and participation in everyday life (D’Alisa, Baudo, Mauro, & Miscio, 2005; Young, Murray, & Forster, 2003). The greatest restrictions, in the case of 73 persons with stroke recruited to a rehabilitation unit, occurred in mobility, physical independence and work or leisure activities (D’Alisa, Baudo, Mauro, & Miscio, 2005). Almost a third of a study group of 115 persons with stroke living in their homes were not getting out on their own without supervision (Lord, McPherson, McNaughton, Rochester, & Weatherall, 2004). Severe restriction in the participation in leisure activities was also found in a review. The barriers that hindered a relatively normal life were physical and environmental in nature, in addition to inadequate social support (Young, Murray, & Forster, 2003).

The results detailed above highlight the difficulties with mobility and participation in society in persons with stroke. Therefore it is important to study the value and effects of assistive devices, such as powered wheelchairs and other mobility devices, in enhancing the levels of participation in the different activities of regular community life.
Stroke — from the perspective of the next of kin

Stroke is a disease with a rather substantial rate of spontaneous recovery, but it is also well-known that stroke causes severe consequences in terms of remaining impairment and of restriction of activity and participation. Persons with stroke may therefore end up being dependent on spouses and other family members, which is a great burden for the relative (Hulter-Åsberg et al., 2004), causing stress that may lead to depression (Han & Haley, 1999), a lower level of life satisfaction (Forsberg-Warleby, Moller, & Blomstrand, 2004), a lower level of emotional functioning (Jonsson, Lindgren, Hallstrom, Norrving, & Lindgren, 2005) and poorer psychological health than in the case of the general population (Low, Payne, & Roderick, 1999). This is a matter of grave concern since carers taking care of persons with the most severe emotional, cognitive and behavioural impairments also suffer the most negative consequences of having to shoulder the role of being a carer (van den Heuvel, de Witte, Schure, Sanderman, & Meyboom-de Jong, 2001). With respect to stroke, a postal survey in Sweden answered by 2,300 relatives two years after their partners had had a stroke showed that 30% of the persons with stroke managed on their own without supervision half a day at the most. Furthermore, 52% assisted their partners with one or more activities of daily living, most commonly in conjunction with transportation, and 62% had taken over many activities their partner performed earlier (Hulter-Åsberg et al., 2004), adding to the pressure of taking care of a person with stroke.

Often the role of the spouse is to establish new routines in daily living, including re-establishing former activities that the persons with stroke are able to perform with the aid of a relative (Rittman et al., 2004). A phenomenological study showed that spouses (n=2) and other family members (n=2) of persons with stroke experienced a heavy impact on their daily life such as reversal of roles and uncertainties/doubts about what they could expect (Hunt & Smith, 2004). Uncertainty about stroke patients’ needs was also a main finding in an interview study with structured measurements of 115 partners. Other findings with regard to these partners were the sense of shouldering a heavy responsibility, constant worries, restraints in social life and the feeling that the stroke patient could only rely on their care (Scholte op Reimer, de Haan, Rijnders, Limburg, & van den Bos, 1998). Another study showed that lack of social involvement was frequent and was the most difficult for the more depressed carers (Hartke & King, 2002).

A review of the evaluation of the effectiveness of different intervention programmes for carers of persons with stroke has shown a variety of results (Visser-Meily, van Heugten, Post, Schepers, & Lindeman, 2005). The
reduction of depression and burden of care, improvement in understanding of the care situation, satisfaction with care given, increased family functioning, enhanced quality of life, problem-solving skills, social activities and social support have all been reported as positive outcomes. However, negative outcomes have been reported from three intervention studies. The authors of one study emphasise that the individual needs of the carers should be prioritised (Visser-Meily, van Heugten, Post, Schepers, & Lindeman, 2005), but there is also a need to gain a deeper understanding of the personal experiences of the families (Hunt & Smith, 2004). Since the next of kin provide considerable assistance at home, they must receive the appropriate attention and support in order to be able to cope with the situation (Bakas, Austin, Jessup, Williams, & Oberst, 2004; Socialstyrelsen, 2000).

As the spouses of persons with stroke often seem to be under considerable stress when caring for their partner, assistive devices have been described as a way to reduce the impact of the spouses’ burden. These devices are as much part of the spouse’s home as the disabled partner’s home, and therefore there is a need to also take into account the spouses’ perspective. A survey of the literature has revealed no study of spouses’ lived experience of assistive devices prescribed to their partner with stroke.

A lifeworld approach and the meaning of tools in everyday life
The lifeworld is the world in which people live their daily lives and it is always present. It is related to how a person perceives the world, but it is also characterised by the lived relations that exist between human beings and the world. Consequently each person experiences his or her own lifeworld, but their lifeworlds are also shared with other persons’ lifeworlds (Bengtsson, 1999; Dahlberg, Drew, & Nyström, 2001; van Manen, 1997). In this social world there are different things which also are part of our lifeworld. The meanings of different things or tools are often implicit or tacit and how we interact with these things in our environment is crucial to understanding them. In addition, it is crucial how we share the experience of the things with other people (Bengtsson, 1999; Dahlberg, Drew, & Nyström, 2001). Generally the lifeworld is taken for granted and not usually questioned in everyday life. This means that the lifeworld is pre-reflective and pre-scientific (i.e. precedes our knowledge) (Bengtsson, 1999; Dahlberg, Drew, & Nyström, 2001; van Manen, 1997). We have access to the world and our experiences through our bodies since these bodies are inseparable from the world and our lived experiences exist in time and space and in relations to other people, who also are perceiving the world (Bengtsson, 1999; Dahlberg, Drew, & Nyström, 2001; van Manen, 1997).
The basis for how we perceive things and their characteristics has to do with how our bodies encounter and engage with them (Kielhofner, 2002). When engaging in different activities, e.g. reaching for a cup of coffee, we do not objectively know about the specific movements, our concern is the subjective experience of the activity. If we concentrate on the movements of the hand and arm when drinking this coffee, that will interrupt the performance: “Learning to do something means that we must grasp the experience – to learn how it feels” (Kielhofner, 2002, p. 87).

Every object that we are using is associated, according to Heidegger (1996), with other useful objects. He mentions pen, ink, paper, table, lamp etc. All cultural objects, among them different kinds of tools, inherently manifest their origin and meaning as some form of human activity (Bengtsson, 1999; Schütz, 2002). Heidegger describes a product in terms of its user, with the implication that everything exists in a larger context (Heidegger, 1996).

Certain philosophers have described the meaning of using ordinary things in the home environment — things which are part of the lifeworld of most people. A well-known, often-cited example, originates from Heidegger and concerns using a hammer. His father was a cobbler and used one. When the hammer is in use it is not just an object but also a tool. With the acquisition of experience of using a tool, it becomes “transparent”, becomes incorporated in the action. Therefore, all things belong to a totality of useful things, but also to the material and the user at the same time (Heidegger, 1996; Ihde, 1993).

Merleau-Ponty (2002) emphasises that things can be seen as an extension of the body, and gives examples like cars and canes. Things become embodied in the sense that they, through habit, are incorporated into the experience of the body. When the telephone is mastered we do not attend to it but to the person we are talking to (Leder, 1990). The telephone is incorporated into the body and thus supplements the body by being its “artificial extension”. Leder says that incorporation is the result of a rich dialectic process, where the world transforms the body and the body transforms the world.

The psychologist Csikszentmihalyi has written about people, things and objects. The things that exist in our surroundings are inseparable from what we are. Things “embody goals, make skills manifest, and shape the identities of the user” (Csikszentmihalyi & Rochberg-Halton, 1981, p. 1). Furthermore, the philosopher Don Ihde (1990) asserts that technology transforms experience and that this is a token of its non-neutrality. He describes how the vision of the world is mediated through contact lenses as compared with glasses. They are closer to the body than glasses, which may change...
the experience in the form of improved eyesight. However, negative experiences may also be incurred since the contact lenses touch the eyes directly. Dust particles that previously were unnoticed may now be tactiley magnified and start to irritate the eyes instead (Ihde, 1990).

Assistive devices as tools or objects in relation to the lifeworld of the people using devices, is of interest in this dissertation. Berndtsson has described the use of devices, particularly in persons with reduced vision or blindness, from a lifeworld perspective. She discusses devices such as a white cane or a computer in relation to the lived body and in relations to other people. The cane is often a contributing element in a stigmatising process while the computer is a tool where the people who use them are seen as able and competent (Berndtsson, 2005).

Thus the concept of the lifeworld is central in hermeneutics, phenomenology as exemplified above. Empirical research performed in this tradition of knowledge is directed towards expanding our understanding of the lived experiences of everyday life (Bengtsson, 1999; Benner, 1994; Dahlberg, Drew, & Nyström, 2001; van Manen, 1997). However, we have to remember that the lifeworld cannot be fathomed in its completeness by any research approach since the lived experience of any person or group of persons is extremely complex and diverse in nature (Todres & Wheeler, 2001). With the concept and perspective of the lifeworld, interesting and novel research questions can be posed. Tools in the form of different assistive devices for daily life may have a profound impact on the user. For this reason the experience of persons with stroke and their next of kin with regard to assistive devices should be further investigated. The lifeworld approach is used in two of the studies in this dissertation and the framework of ICF, described below, is used in one of the other two studies.

ICF in relation to rehabilitation, occupational therapy and assistive technology

The International Classification of Functioning, Disability and Health (ICF) is a global conceptual framework of health and health-related states (WHO, 2001a). The aim is twofold: to present a unified language with which to understand and describe health and outcomes, and to provide a coding scheme for health information systems. A worldwide implementation of ICF is now on the agenda. Areas of importance are effects of intervention and the assessment and application of ICF-based instruments in different fields, including health care and education (Stucki, Ustun, & Melvin, 2005; WHO, 2005).

ICF is presented in the form of a model where the interactions between the different components of the model are included: body functions and
structures, activity and participation, and contextual factors (including environmental and personal factors). The activity and participation component comprises nine domains (Learning and applying knowledge, General tasks and demands, Communication, Mobility, Self-care, Domestic life, Interpersonal interactions and relationships, Major life areas, Community, social and civic life). These domains may be expressed and related to activity and participation in a positive or negative way. The positive aspects of activity are described as “execution of a task or action by an individual” and of participation as “involvement in a life situation”. The negative aspects at the personal level are described as activity limitation (difficulty in executing activities) and at the societal level as participation restriction (problems an individual may experience in life situations) (WHO, 2001a). In the case of the environmental factor (comprising the domains Products and technology, Natural environment and human-made changes to environment, Support and relationships, Attitudes, Services, system and policies), facilitators improve functioning and reduce disability, e.g. accessible environment, relevant assistive technology and positive attitudes of others. Barriers have the opposite effect.

ICF is proposed as a useful conceptual framework of clinical practice and outcomes in rehabilitation research (Stucki, Ewert, & Cieza, 2003; Ustun, Chatterji, Bickenbach, Kostanjsek, & Schneider, 2003; Walsh, 2004). The research so far has to a large extent examined the link between different measurements and ICF (Cieza & Stucki, 2005; Geyh, Kurt et al., 2004; Scheuringer et al., 2005), in addition to the development of different core sets for a diversity of diagnoses (Grill, Stucki, Boldt, Joisten, & Swoboda, 2005; Stamm et al., 2005), including stroke (Geyh, Cieza et al., 2004).

A few articles on ICF have recently been published within an occupational therapy perspective. It has been proposed that occupational therapists should support ICF as it embraces a universalistic perspective of disablement (Vrkljan, 2005), and that ICF should be incorporated into the professional terminology (AOTA, 2000; McLaughlin Gray, 2001). ICF has also been proposed as a research tool for occupational therapists, but the framework’s professional language is not yet sufficiently developed (Haglund & Henriksson, 2003). Further, the need to reconsider the concept of occupation in the light of ICF has been discussed. It is argued that the concept should be considered as the process of doing with meaning, and that activity and participation should be the observable outcomes, which would be consistent with ICF (Royeen, 2002). Recently, ICF has influenced the definitions and descriptions of occupational therapy (WFOT, 2006). The World Federation of Occupational Therapists (WFOT) has adopted ICF in definitions and descriptions of occupational therapy, and ICF is considered to be a
landmark with respect to the professional development of occupational therapists (Sinclair, 2004), but is also important in the revisions of WFOT’s minimum standards for the education of occupational therapists (Hocking & Ness, 2004). In addition, the conceptual framework of ICF has been used to link occupation-based measures to different ICF categories, which has been proved useful (Stamm, Cieza, Machold, Smolen, & Stucki, 2004). However, Hamell (2004) maintains that occupational therapists have embraced ICF without sufficient consideration of the fact that an outcome of classification is the possible marginalisation of people. Furthermore, the concept of participation in ICF needs to include subjective experience of meaning and autonomy (Hemmingsson & Jonsson, 2005).

Concerning research in the field of assistive technology, ICF has been described as one of six relevant conceptual models (Lenker & Paquet, 2003), that provides a holistic, theoretical framework when communicating with the family in conjunction with the prescription of adaptive seating system to children with cerebral palsy (which prevents a deformity or reduces undesirable muscle tone) (McDonald, Surtees, & Wirz, 2004). Furthermore, ICF has been used to categorise participants’ stated difficulties before and after the provision of mobility devices (Wessels, de Witte, Jedeloo, van den Heuvel, & van den Heuvel, 2004). The utility of ICF has been discussed as a means to organise relevant rehabilitation including assistive technology interventions (Scherer & Glueckauf, 2005) and to develop interview questions for young persons using a powered wheelchair (Wiart, Darrah, Cook, Hollis, & May, 2003). As only a few studies in the field of assistive technology have been performed with a theoretical base in ICF, there is a need for further research to elucidate its utility in this field. In the present dissertation the ICF concepts activity and participation are in focus in relation to the devices included in the environmental factor.

**Definitions and descriptions of assistive devices and assistive technology**

There is no generally accepted formal definition of assistive technology or assistive devices. But when definitions are given they often include some sort of description of the impairment of people who use the devices. The desired outcome is stated in different ways – sometimes it is a question of reducing or compensating for a disability, sometimes a question of a capacity to perform activities of daily living. The definitions described below differ from the description of tools within the lifeworld perspective explained above.

In official documents, such as that of the International Organization for Standardization (ISO), “technical aids” are defined as “any product, instrument or equipment or technical system used by a disabled person,
especially produced or generally available, preventing, compensating, monitoring, relieving or neutralizing the impairment, disability or handicap” (International Organization for Standardization, 2002, p. 2). However, the term technical aids is rarely used in the research literature. Further, ICF defines assistive products and technology as “any product, instrument, equipment or technology adapted or specially designed for improving the functioning of a disabled person” (WHO, 2001a). An often-cited definition is from the US Assistive Technology Act of 1998: “Assistive Technology device: Any item, piece of equipment, or product system whether acquired commercially off the shelf, modified or customized, that is used to increase, maintain, or improve functional capabilities of individuals with disabilities” (Cook & Hussey, 2002, p. 5). Furthermore, a definition is presented on the Web page of the Swedish Handicap Institute: “Assistive devices are products which people with disabilities need in order to: prevent future losses of function or ability, improve or maintain function or ability, compensate for impaired or lost function and ability to cope with day to day life” (NSH, 2004, p. 49).

In databases providing information from allied health areas there are different wordings for assistive devices. In CINAHL the subject heading “Assistive technology devices” covers “devices used by persons with functional deficits as alternative ways of performing actions, tasks, and activities”. In Medline the corresponding MeSH heading for assistive devices is “self-help devices”. The scope of “self-help devices” is more narrowly defined as “devices, not affixed to the body, designed to help persons having musculoskeletal or neuromuscular disabilities to perform activities involving movement”. The concept of self-help devices is used in Medline for assistive devices and assistive technology. Finally, the database AMED uses the term “Disability aids” without a defined scope.

In the Swedish Health and Medical Services Act assistive devices are seen as including devices used to aid in daily life as well as for care and treatment. For the purposes of this dissertation the main assistive devices are those being used in daily life. “Assistive devices aim to assist individuals to carry out the following tasks themselves or with the help of someone else: meet basic personal needs (getting dressed, eating, personal hygiene), move around, communicate with society, function both in home and in the local area, find their way around, carry out day-to-day tasks in the home, go to school or college, take part in normal leisure and recreation activities” (NSH, 2004, p. 50). Orthopaedic devices and devices for enhancing vision or hearing are not included in this dissertation. The term assistive device is the one mostly used in the dissertation, but the term assistive technology is also used when referring to a broader range of technology and services.
Most of the assistive devices in two of the studies are regarded as low-tech (examples are a wheeled walker and a reacher), whilst the powered wheelchair included in the other two studies is regarded as high-tech (Bain & Leger, 1997).

Activity, participation and quality of life in relation to assistive devices
Concerning activity and participation, these concepts are also included in definitions of assistive technology in terms of engaging in, maintaining, grading or enhancing activities (Brooks, 1991; Field, 1999; Hocking & Wilcock, 1997) or of participation in activities (Hammel, Lai, & Heller, 2002). Furthermore, a few descriptions include devices as a substitute for care or as easing the family’s burden of care (Cowan & Turner-Smith, 1999; de Klerk, Huijsman, & McDonnell, 1997; Gitlin, 1998), or as bridging the gap between the demands of the physical environment and the individual’s capacity (Gitlin & Levine, 1992; Roelands, Van Oost, Depoorter, & Buysse, 2002).

Quality of life is a concept not included in ICF. However, Ueda and Okawa (2003) consider that there is no reason to conceptually separate quality of life from ICF. Quality of life is described as a multidimensional concept (Bowling, 2005; Fayers, 2000; Post, de Witte, & Schrijvers, 1999) which means different things to different people. Mostly, quality of life includes emotional well-being, physical and mental health, the physical ability to do the things you want, relationships with friends and family, participation in social activities and recreation, living in a safe neighbourhood, good services, having enough money and being independent (Bowling, 2005). In addition, quality of life should be assessed by asking the persons themselves (Fayers, 2000).

Assistive technology is sometimes defined in terms of the improvement of quality of life (Jedeloo, De Witte, Linssen, & Schrijvers, 2002; Jutai, 1999). Jutai (1999, p. 3) defines an assistive device as one that “will promote good quality of life for the user to the extent to which it makes the user feel competent, confident, and inclined (or motivated) to exploit life possibilities”. Another dimension of quality of life, which mainly refers to disease-related functioning and well-being, is health-related quality of life (HRQoL) (Bowling, 2005; Fayers, 2000), but it is also sometimes used as a synonym of quality of life (Fayers, 2000). Psychosocial impact is a further factor included in the concept of quality of life, and it has been found important when evaluating assistive devices (Cook & Hussey, 2002; Day, Jutai, Woolrich, & Strong, 2001). Psychosocial impact is defined as “factors within the person and factors attributable to the environment that affect the psychosocial adjustment of individuals who have a disability” (Jutai &
Day, 2002, p. 107). Further, Cook and Hussey (2002) describe psychosocial function as being a question of identity and motivation, related to the person’s acceptance of disability and ability to interact successfully with a device. In this dissertation quality of life, HRQoL and psychosocial impact are all used, the particular use depending upon the particular context.

By way of summary, activity, participation and quality of life are concepts relevant to the evaluation of assistive technologies (Cook & Hussey, 2002; Fuhrer, Jutai, Scherer, & Deruyter, 2003). In this dissertation, two of the studies with quantitative design use these concepts in the evaluation of powered wheelchairs. In one study, activity and participation, components of ICF, are core concepts and the ICF definitions are used (see p. 24). In the other study quality of life is central, in particular HRQoL and psychosocial impact.

Provision and frequency of assistive devices
In Sweden assistive devices are provided as an integral part of health care, and they are to a great extent financed by the national health system. The devices are prescribed when deemed necessary by a prescriber (e.g. occupational therapist, physiotherapist, district nurse). This means that the device is prescribed regardless of age or financial situation, almost free of charge. The prescription process comprises the following stages: assessing the need for assistance; trying out an appropriate device; instructing, training and informing the user; and following up with an assessment of the function and benefit for the user (Blomquist & Nicolaou, 2000; Lilja, Mansson, Jahlenius, & Sacco-Peterson, 2003; NSH, 2004). A criterion for being provided with a powered wheelchair is being unable to meet one’s need for transportation with a manual wheelchair.

It is estimated that 800,000–850,000 people in Sweden use assistive devices, a prevalence rate of about 9.5% of the population. Commonly used devices are manual wheelchairs, wheeled walkers, bath boards and raised toilet seats (Hjälpmedelsinstitutet, 2005; Lilja, Mansson, Jahlenius, & Sacco-Peterson, 2003). The prescription of powered wheelchairs has increased during recent years in Sweden. In the 1990s the number of powered wheelchairs (including both indoor and outdoor) almost trebled. In 2002, 226 per 100,000 inhabitants possessed a powered wheelchair, and in the same year 59 new powered wheelchairs were prescribed per 100,000 inhabitants. This same year, the mean distribution of prescribed powered wheelchairs was 55% to men and 45% to women (Hjälpmedelsinstitutet, 2004).

Many persons are in need of assistive devices to enable or facilitate ordinary daily activities after discharge from hospital following stroke. A
Danish study showed that 75% (n=116) needed assistive devices and/or environmental modifications upon discharge. Six months later that proportion had increased to 81%. The mean number of assistive devices/environmental modifications upon discharge was 4.4. Bath seats, wheelchairs, wheeled walkers and other mobility devices were most common (Sorensen, Lendal, Schultz-Larsen, & Uhrskov, 2003). Comparable Swedish results showed that about 80% of a study group with stroke had on average about four devices twelve months after discharge (Gosman-Hedström, Claesson, Blomstrand, Fagerberg, & Lundgren-Lindquist, 2002). In a study of perceptions of assistive devices in relation to rehabilitation, the subjects (n=103) had been provided with an average of eight devices intended for daily life (Gitlin, Luborsky, & Schemm, 1998). Other results showed that on average nine “physical” assistive devices were used one year after the stroke (Mann, Hurren, Tomita, & Charvat, 1995).

During the last ten years the use of assistive technology has become more common in Sweden, this because of an increasing number of elderly people who often receive care in their own homes instead of in hospitals (Hjälpmedelsinstitutet, 2005). In addition, the prognosis is that stroke is going to increase in Sweden (Socialstyrelsen, 2000). This implies that the demand for assistive devices will increase (Hjälpmedelsinstitutet, 2005).

Experiences and outcomes of the use of assistive devices

When assistive devices are necessary for performing daily activities, they naturally have a considerable meaning for a disabled individual. The assigning of personal meanings to assistive devices has been studied to a greater or lesser extent with different study groups and with different kinds of devices (Aminzadeh & Edwards, 1998; Haggblom Kronlof & Sonn, 1999; Louise-Bender, Kim, & Weiner, 2002; Lund & Nygard, 2003; Lupton & Seymour, 2000; Mc Millen & Söderberg, 2002; Sapey, Stewart, & Donaldson, 2005). These studies have in some respects indicated a twofold meaning of assistive device use, pointing to both positive and negative qualities. From the perspective of persons with stroke, Gitlin et al. have described assistive device use in early rehabilitation (Gitlin, Luborsky, & Schemm, 1998). The results showed mixed perceptions with regard to physical, personal and socio-cultural issues in relation to different low-tech devices.

Only three studies have been found that investigated assistive devices from a lifeworld perspective. Berndtsson (2001) showed, as part of her dissertation using a lifeworld and learning approach, that the use of a cane is a complex issue for persons with severe visual impairment or who are blind. There is a social dimension of the cane use in relation to their own identity as a person. Extending their space of influence in the form of physical
activity can be both supported and prevented by assistive devices. In another study, researchers have examined how persons with visuospatial agnosia following stroke experienced the physical environment (Lampinen & Tham, 2003). Part of the results indicated that the persons experienced devices such as wheelchairs as clumsy – the wheelchairs had not yet become a part of their bodies. Furthermore, a study of electronic aids to daily living used in a training flat showed how participants with acquired brain damage were able to incorporate the electronic aids into their daily life (Erikson, Karlsson, Soderstrom, & Tham, 2004).

Many factors interact in the use of a powered wheelchair: human abilities, technology, environment and the activity of driving. A review by Field (1999) has indicated the existence of interactive and multifaceted factor effects. There has been little research on the subjective impact of powered wheelchairs on activity, participation and quality of life, and there is little in the way of specially designed measures for the outcome of assistive technology.

In one study eight participants using a powered wheelchair were interviewed with the aid of the Psychosocial Impact of Assistive Devices Scale (PIADS) and a positive psychosocial impact on adaptability, competence and self-esteem was seen (Buning, Angelo, & Schmeler, 2001). Further, in another study almost all users of powered wheelchairs (n=19) described the value of the chair in promoting quality of life (Mortenson et al., 2005). Research employing the instrument Quebec User Evaluation of Satisfaction with Assistive Technology (QUEST) and other items on the ability to be active showed that the 30 users of powered wheelchairs perceived a predominantly positive influence of the device on daily living (Wressle & Samuelsson, 2004). Brandt and co-workers have shown an increased level of activity and participation in 111 users of powered wheelchairs (Brandt, Iwarsson, & Stahle, 2004). Moreover, the instrument Individually Prioritized Problems Assessment (IPPA) and ICF was used in a study of 59 persons with outdoor mobility devices and the results indicated that the devices were used for shopping, social visits and leisure. The effect was shown to be large. However, other research showed no significant improvement of quality of life as measured by EuroQol-5D (EQ-5D) in 51 persons using an indoor or outdoor powered wheelchair (Davies, De Souza, & Frank, 2003).

With regard to persons with stroke, an evaluation of powered mobility in the case of two persons with unilateral neglect has been performed (Dawson & Thornton, 2003). The results revealed that the participants learned to drive the wheelchair regardless of the training intervention and despite persisting neglect. In a study involving ten wheelchair users with
stroke, two of whom used powered wheelchairs, the lived experience of wheelchair use was explored. Different categories or levels of acceptance was found with regard to having to use a wheelchair (Barker, Reid, & Cott, 2004). In a further study three out of eight participants were stroke patients. The author found that activity and participation were enhanced by the powered wheelchair (Evans, 2000).

Even though some studies have recognized the experiences of using different devices in daily life, there is still a need to explore the experiences of assistive devices from a lifeworld perspective in persons with stroke. As the previously mentioned studies on stroke patients focused on the early stages of rehabilitation, there is also a need to explore the later stages when the person with stroke again has accommodated to a life in the home environment with the help of such devices as powered wheelchairs.

Rationales for the study

To summarise, this dissertation will focus on the experience of the person having to use and live with assistive devices after stroke, as well as on the experience of the spouse as the devices are part of their home too. Persons with stroke often have difficulties with mobility and participation in society and as a result their next of kin also seems to be under considerable stress. Therefore assistive devices may be considered as tools to assist both the person with stroke and his/her spouse to increase their participation in daily activities at home and in society.

A search of the literature before the start of this project showed that a considerable part of the research on the use of assistive devices in the field of assistive technology had been undertaken from a biomedical or physiological perspective. Few qualitative studies had been performed in this area and no study had been undertaken with a focus on outdoor powered wheelchairs in the case of persons with stroke or on the meaning of assistive devices from the perspective of the next of kin. Although some attention has been given to the issue of activity and participation and quality of life in persons using powered wheelchairs, no study had addressed this issue with respect to a group consisting entirely of persons with disability after stroke using outdoor powered wheelchairs. Against this background, the present dissertation has a broad research perspective with regard to persons using the devices in the home environment. It aims to procure knowledge that will facilitate health professionals’ encounter with persons with disabilities in need of assistive devices and their next of kin.
AIMS OF THE STUDIES

The overall purpose of this dissertation is to explore and describe the significance of assistive devices and the use of different assistive devices in daily life. The project involves four studies, three from the perspectives of persons with stroke and one from the perspectives of spouses of persons with stroke. The specific aims are:

I. To explore how people with a disability following a stroke describe their personal meaning and lived experiences associated with the use of assistive devices.

II. To explore how spouses of persons with a disability following stroke describe their lived experiences regarding assistive devices in everyday life.

III. To describe and compare activity limitations and participation restrictions in persons with stroke from their own perspective, before and after using an outdoor powered wheelchair.

IV. To describe characteristics of persons with stroke that are using an outdoor powered wheelchair and to evaluate the impact of the wheelchair on quality of life. A further aim was to compare the impact on quality of life with respect to age, gender, different disability characteristics, and living conditions.

The concept of significance is used in the dissertation as an overall notion for the participating persons’ own experience of assistive devices and the meaning and value such devices has for them. This concept of significance may appear in the form of positive, negative or neutral aspects.
MATERIALS AND METHODS

Research design

This dissertation includes empirical studies of qualitative (Studies I, II) as well as quantitative design (Studies III, IV) to explore and describe the significance of assistive devices (Table I). The different approaches can be said to complement each other (Allwood & Eriksson, 1999; Brannen, 1992; Nilstun, 1995). Therefore this combined approach was chosen so that the significance of assistive devices could be investigated with the aid of different methodologies in order to acquire deeper knowledge of the field (Brannen, 1992; Nilstun, 1995).

The qualitative studies (Studies I and II) emanate from an ideographic view of reality, a holistic view where the individual in his or her unique context is the basis of understanding (Nilstun, 1995). These studies have an explorative focus directed towards understanding the significance of assistive device use. A phenomenological lifeworld approach, involving the world of lived experience (Bengtsson, 1999; Dahlberg, Drew, & Nyström, 2001; van Manen, 1997), is used in order to gain a deeper understanding of the meaning of assistive devices in the individual participants’ everyday lives. The studies are mainly inductive but a minor deductive element is involved in the analysis of the data from the lifeworld perspectives. A hermeneutic phenomenological method (van Manen, 1997) was used when interviewing the persons with stroke (Study I) and their spouses (Study II), one year post-stroke, and in the subsequent data analysis.

The quantitative studies (Studies III and IV) originate from a nomothetic view of reality (Nilstun, 1995). Here knowledge is gained from a group of people through statistical analysis. These studies include a pre- and post-assessment design and a follow-up design with different questionnaires (IPPA, WHODAS II, EQ-5D, PIADS) where the impact of an outdoor powered wheelchair on quality of life, activity and participation is measured. Although the measures have predefined categories and in that respect are quantitative, an attempt has been made to find and use subjective measures based on concepts in order to understand the significance of assistive devices from a group perspective. The conceptual framework ICF is used in one of the quantitative studies and it is used deductively when identifying the participants’ stated problems and analysing the results quantitatively.
### Table I. Overview of the four studies in the dissertation

<table>
<thead>
<tr>
<th>Study</th>
<th>Design</th>
<th>Participants</th>
<th>Methods of data collection</th>
<th>Methods of data analysis</th>
</tr>
</thead>
<tbody>
<tr>
<td>I</td>
<td>Qualitative Explorative</td>
<td>22 persons with stroke using assistive devices</td>
<td>Personal visit Conversational interview grounded in a lifeworld approach</td>
<td>Hermeneutic phenomenological (van Manen)</td>
</tr>
<tr>
<td>II</td>
<td>Qualitative Explorative</td>
<td>12 spouses of persons with stroke included in Study I</td>
<td>Personal visit Conversational interview grounded in a lifeworld approach</td>
<td>Hermeneutic phenomenological (van Manen)</td>
</tr>
<tr>
<td>III</td>
<td>Quantitative Descriptive Prospective Before and after</td>
<td>32 persons with stroke (referred to an assistive technology centre for provision of an outdoor powered wheelchair)</td>
<td>Two face-to-face interviews with structured questionnaires on: -activity and participation problems in daily life related to assistive technology (Individually Prioritized Problems Assessment, IPPA); -activity limitations and participation restrictions (World Health Organization Disability Assessment Schedule II, WHODAS II)</td>
<td>Descriptive statistics Non-parametric statistics: -Wilcoxon signed ranks test; Parametric statistics: -Effect size; Deductive analysis: ICF</td>
</tr>
<tr>
<td>IV</td>
<td>Quantitative Descriptive Comparative</td>
<td>32 persons with stroke (the same study group as in Study III)</td>
<td>Two face-to-face interviews with structured questionnaires on: -health-related quality of life (EuroQol-5D); -psychosocial impact (Psychosocial Impact of Assistive Devices Scale, PIADS)</td>
<td>Descriptive statistics Non-parametric statistics: -Wilcoxon signed ranks test, -Mann Whitney U-test; Parametric statistics: -Effect size</td>
</tr>
</tbody>
</table>

### Participant selection

The participants in the four studies were identified in two ways: (a) through a previous study involving a community cohort of 253 patients still surviving one year after the stroke event and at that point in time participating in a follow-up investigation (Appelros, Nydevik, Seiger, & Terent, 2002) (Studies I, II) and (b) through a consecutive selection of persons who were going to be prescribed and provided with an outdoor powered wheelchair (Studies III and IV) (Table II).
The population in Study I were adult survivors of stroke at one-year follow-up from a community cohort of 253 patients (Appelros, Nydevik, Seiger, & Terent, 2002). The inclusion criteria were as follows: (1) participants should have a score within the range 22–30 on a Mini-Mental State Examination (MMSE) (Folstein & Folstein, 1975) (this to ensure cognitive function); (2) participants should have moderate to severe disability including assistance with Personal or Instrumental Activities of Daily Living (P-ADL, I-ADL), which represents a score within the range 3–5 on the Modified Rankin Scale (MRS) (van Swieten, Koudstaal, Visser, Schouten, & Van Gijn, 1988); (3) participants should have no or only slight communication problems, e.g. be able to independently take part in an interview. Through the careful selection of participants on the basis of the information gained from the cohort study database, these three inclusion criteria were fulfilled (Appelros, Nydevik, Seiger, & Terent, 2002). Further, the final inclusion criterion was that (4) participants should possess two or more assistive devices for daily life and be registered at the assistive technology centre in Örebro, Sweden. The selection of participants on the basis of this inclusion criterion was accomplished through the information contained in the database at the centre. Out of the 26 possible participants who fulfilled these four inclusion criteria, 22 (85%) agreed to participate. All spouses (n=12) of this study group of persons with stroke were asked whether they would participate in the research project (Study II), and all consented (Table II).
In the case of Studies III and IV, the participants were recruited consecutively from three assistive technology centres, each situated in a county council area in central Sweden. The inclusion criteria were that participants (1) had had a stroke, (2) were going to be prescribed an outdoor powered wheelchair, (3) were able to independently take part in an interview (e.g. had no or only slight communication and/or cognitive problems) and (4) had not previously possessed an outdoor powered wheelchair. Forty consecutive persons were asked whether they were willing to participate in the study. Three of them declined and five dropped out after the first interview (Table II). The remaining 32 persons (80%) participated both in Study III and in Study IV.

Participants
In Studies I, III and IV the majority (about 70%) of the participants were men (Table III). In the study of spouses of persons with stroke (Study II), there were consequently more women (83%). The mean age of persons with stroke (m=67) in Studies III and IV was somewhat lower than in Studies I and II (m=75). Time since stroke onset was in Study I about 12 months. In Studies III and IV the mean time was 56 months (md 24, range 6–300 months). In Studies III and IV the frequencies of the side of body paresis were almost equal (left n=15, right n=16, bilateral n=1). In Study I this information was not obtained. Other demographical data are presented in Table III.

Table III. Demographic characteristics of participants with stroke (Studies I, III, IV) and spouses (Study II)

<table>
<thead>
<tr>
<th></th>
<th>Study I</th>
<th>Study II</th>
<th>Study III, IV</th>
</tr>
</thead>
<tbody>
<tr>
<td>Participants (n)</td>
<td>22</td>
<td>12</td>
<td>32</td>
</tr>
<tr>
<td>Mean age (range)</td>
<td>75 (35–86)</td>
<td>75 (36–80)</td>
<td>67 (43–85)</td>
</tr>
<tr>
<td>Gender (n)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>female</td>
<td>6</td>
<td>10</td>
<td>10</td>
</tr>
<tr>
<td>male</td>
<td>16</td>
<td>2</td>
<td>22</td>
</tr>
<tr>
<td>Marital status (n)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>– Married or cohabitant</td>
<td>12</td>
<td>12</td>
<td>24</td>
</tr>
<tr>
<td>– Single</td>
<td>10</td>
<td>0</td>
<td>8</td>
</tr>
<tr>
<td>Location of housing (n)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Living in countryside or small villages</td>
<td>2</td>
<td>2</td>
<td>14</td>
</tr>
<tr>
<td>Living in places with &gt;8000 inhabitants</td>
<td>20</td>
<td>10</td>
<td>18</td>
</tr>
<tr>
<td>Work status (n)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Working full- or part-time</td>
<td>0</td>
<td>2</td>
<td>1</td>
</tr>
<tr>
<td>Retired or on sick-leave</td>
<td>22</td>
<td>10</td>
<td>31</td>
</tr>
</tbody>
</table>
Concerning available assistive devices in the case of persons with stroke, this was recorded in Studies I and II. Table IV show the categories and numbers of devices included in Studies I and II. The most common device in Study I was a shower chair/stool (Personal care) and a wheeled walker (Mobility). In Studies III and IV assistive devices besides the outdoor powered wheelchair are not studied.

**Table IV. Category and number of assistive devices possessed by participants with stroke (Studies I and II)**

<table>
<thead>
<tr>
<th>Category of device</th>
<th>Study I (Assistive devices included) n</th>
<th>Study II (Assistive devices included) n</th>
</tr>
</thead>
<tbody>
<tr>
<td>Personal care</td>
<td>51</td>
<td>25</td>
</tr>
<tr>
<td>Mobility</td>
<td>55</td>
<td>33</td>
</tr>
<tr>
<td>Housekeeping</td>
<td>19</td>
<td>10</td>
</tr>
<tr>
<td>Furnishing and adaptations to homes</td>
<td>52</td>
<td>35</td>
</tr>
<tr>
<td>Handling other objects</td>
<td>16</td>
<td>9</td>
</tr>
<tr>
<td>Others</td>
<td>3</td>
<td>2</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>196</strong></td>
<td><strong>114</strong></td>
</tr>
</tbody>
</table>

The lifeworld studies of assistive devices (Studies I and II)

**Lifeworld perspective**

In Studies I and II, the meaning attached by participants to having assistive devices in their lifeworld have been interpreted and applied in these studies from a hermeneutic phenomenological viewpoint as set forth by van Manen (1997). The lifeworld perspective is described in terms of the meaning of assistive devices in everyday life in relation to four lifeworld existentials or themes: *lived body, lived space, lived time* and *lived human relation* (van Manen, 1997). *Lived body* draws upon Merleau-Ponty’s (2002) theory of the lived body, integrating the physical body and the soul where human beings always are in the world with their bodies. *Lived space* refers to how space is experienced and how space is related to the body. *Lived time* is subjectively felt time and refers to the temporal way of being in the world. Finally, *lived human relation* refers to how persons experience others as human beings and, in different respects, share interpersonal space with them. These existentials together form a unity. They can temporarily be differentiated for descriptive purposes but all are intertwined in our lived world (van Manen, 1997). Van Manen proposes these lifeworld existentials as one way of posing questions and of analysing and organizing the results, and this approach has been applied in Studies I and II.
Interviews
Interviews were carried out in a conversational manner with the persons with stroke (Study I) and the spouses (Study II). An interview guide was used in order to gain knowledge and understanding of the participants’ relationship to assistive devices. This included experiences, meaning, feelings, influences on daily life, possibilities and obstacles associated with the devices in relation to their lifeworld, which comprises the lived body, lived human relation, lived space and lived time. Broad questions about the experiences of living with and using assistive devices as well as more specific questions about the experience of using assistive devices in a particular situation were asked. In the interviews, questions with regard to having assistive devices in their home were adapted to either the participants with stroke or the spouses. The persons with stroke and the spouses were interviewed in their homes, one at a time in private sessions. All interviews except one were audio-recorded, and the interviews lasted from 30 minutes to two and a half hours, with about an hour being the most common. Besides being interviewed, the participants showed the interviewer their assistive devices.

Analysis
The author made every effort to become aware of any pre-understanding with respect to assistive devices when reflecting upon the parts and wholes of the varying material in the different steps of the analytical procedure (Table V). Overall, when analysing the data in Studies I and II, there was an attempt to keep the description and interpretation of the data close to the empirical material. The material was read and reread, written and rewritten several times in order to get as credible and clear a description and interpretation as possible (van Manen, 1997). The analytical procedure was almost the same in both studies. The method include: transcription, listen to and reading the interviews, identifying meaning units, transforming them, formulating core stories, interpretation of core stories and meaning units in relation to four lifeworld existential and, finally, verifying the results. The analysis is inductive but with a deductive element as the four lifeworld existentials were used as a theoretical framework in the analysis and interpretation of the material. Table V gives an overview of the main analytical procedures in these studies. In Study II there was an emphasis on describing and interpreting the core stories according to the lifeworld existentials shown in Table V. In Study I there was more of an emphasis on describing and interpreting the transformed units of meaning in accordance with the existentials.
Excerpts from core stories (Study I) and quotations (Studies I and II) from the interviews are presented to facilitate the understanding of the descriptions and interpretations of the interview texts.

**Table V. The main analytical procedures in Studies I and II.**

<table>
<thead>
<tr>
<th>Strategy</th>
<th>Reason</th>
<th>Analytical focus</th>
</tr>
</thead>
<tbody>
<tr>
<td>Listening to the audio-taped interview</td>
<td>To acquire a general sense of the participant’s experience</td>
<td></td>
</tr>
<tr>
<td>Transcription of the whole interview by a professional secretary, including marks of silence and nuances of emotional expression</td>
<td>To ensure an accurate content to analyse</td>
<td></td>
</tr>
<tr>
<td>Listening to and simultaneously reading the text on the computer. Identification of meaning units in accordance with the “selecting reading approach” with the key question “What phrases seem important in relation to the participant’s lived experiences of assistive devices?” Transformation of these meaning units.</td>
<td>To get a good understanding when listening and simultaneously reading on the computer. To get a more condensed text to work with</td>
<td>Within each case</td>
</tr>
<tr>
<td>Core stories of each participant’s experience of assistive devices were formulated on the basis of the condensed units of meaning</td>
<td>To get a story that gives an overall and holistic understanding of the participant in relation to assistive devices</td>
<td></td>
</tr>
<tr>
<td>Core stories were described and interpreted in accordance with the four lifeworld existentials: lived body, lived space, lived time and lived human relation</td>
<td>To get a deeper understanding of each participant’s lived experience of assistive devices in his or her home environment in relation to the lifeworld concepts</td>
<td></td>
</tr>
<tr>
<td>The descriptions and interpretations of the participants’ respective lifeworld existentials were brought together</td>
<td>To get an overall understanding of each lifeworld existential from the perspective of all participants in relation to assistive devices</td>
<td>Across cases</td>
</tr>
<tr>
<td>Through analysis of core stories and of meaning units, the material was interpreted and described in accordance with themes and aspects of the lifeworld</td>
<td>To get a deep and varied understanding of each lifeworld theme and the emerging aspects in relation to assistive devices</td>
<td></td>
</tr>
<tr>
<td>All of the described and interpreted texts were read and compared with each core story. A co-author examined certain interviews, meaning units, core stories and the results in the case of some of the lifeworld themes and their aspects</td>
<td>A check to verify whether the results were in concordance with the core stories and faithfully described, and to verify the trustworthiness of the described and interpreted text in the case of the existentials and aspects</td>
<td>Within each case and across all cases</td>
</tr>
</tbody>
</table>
The studies concerning the outdoor powered wheelchairs
(Studies III and IV)

Activity/participation and quality of life perspective

The concepts of activity and participation are used in this dissertation with the assumption that a powered wheelchair may decrease or remove the participants' perceived limitations in these areas. The concepts of quality of life and psychosocial impact are used with the assumption that a powered wheelchair may enhance quality of life. In the two studies under consideration here, a powered wheelchair is understood as being either an electrically powered wheelchair for outdoor use or a three-wheeled electric scooter. Both studies proceed from the perspective of the participants. In the case of one of the four measures (IPPA) the participants' stated difficulties concerning activity and participation are measured and scored (Wessels et al., 2000). The other three measures include predetermined questions, and one of them (PIADS) partly originates from focus group interviews with people using assistive devices (Jutai & Day, 2002). ICF is used in Study III as a conceptual framework in the data collection, analysis and presentation of results. ICF describes activity limitations at the personal level in terms of the negative aspect of functioning (difficulty with regard to executing activities), and at the societal level in terms of participation restriction (problems an individual may experience in life situations) (WHO, 2001a).

Data collection

All questionnaires in the two studies were administrated in the form of a face-to-face interview by the author in the participants’ homes at baseline and at follow-up after use of the powered wheelchair for 3–5 months (mean 4 months). At post-test assessment, neither the interviewer nor the participant had any knowledge of the ratings on the items at baseline.

Life-events (Studies III and IV)

A checklist was developed consisting of 17 types of life-events (e.g. sickness or death in the family or of friends, separation, moving to another place) based on a checklist used in previous research (Ahlström, Lindvall, Wenneberg, & Gunnarsson, 2006). This checklist was used to detect possible confounders (e.g. events) that may have influenced activity, participation and quality of life during the relevant period.

Study-specific questions (Study III and IV)

Study-specific questions (13 items) were asked concerning the importance of and satisfaction with the powered wheelchair; how often the wheelchair was used and how far they were driving; mishaps or incidents; and whether
the household had a car. Questions also were raised about the need of help to charge the batteries, the need of someone accompanying them when driving the powered wheelchair, and the need of help to transfer them to the wheelchair. Some of the items were based on items in a previous study of Brandt and co-authors (2004), but also on the PIADS manual (Day & Jutai, 1996b).

**Activity and Participation (Study III)**

*Individually Prioritized Problem Assessment (IPPA)* is a generic measure designed to assess the effectiveness of assistive technology provision (Wessels et al., 2000). It assesses the extent to which everyday activity limitations or participation restrictions are diminished through the provision of assistive technology. It is administered by means of two face-to-face interviews. In the first interview the assistive technology user identifies a maximum of seven concrete activity or participation problems in everyday life that they wish to be eliminated or diminished through the provision of an assistive device. The participants assign scores on a 5-point ordinal scale with respect to both the importance (not important at all – most important) and the associated difficulty (no difficulty at all – too much difficulty) of the identified activity or participation. In the present study (Study III) the participants related the problems to what they expected of an outdoor powered wheelchair. After they had used the device for at least three months, a follow-up interview was performed and the participants assigned new difficulty scores to each activity or participation problem that was mentioned at baseline (Wessels et al., 2000). For each of the participant’s problems the “difficulty score” is multiplied by the “importance score”. The difference between baseline and follow-up represents the effectiveness, the degree to which the problems are solved or diminished by the device provided (Wessels et al., 2000).

IPPA has proved effective in detecting effects of assistive technology interventions (Persson & Hellbom, 2003; Wessels et al., 2000; Wessels, de Witte, Jedeloo, van den Heuvel, & van den Heuvel, 2004). In addition, in this study (Study III) ICF was used to categorise reported activities and participation problems (IPPA) into five of the nine domains included in the activities and participation component of ICF (WHO, 2001a). Two persons, the author and a person well versed in ICF, performed this categorisation independently of each other. A few categorisations were discussed until there was agreement about them. In a few cases, a problem mentioned by the participants could be classified into either of two domains of ICF, e.g. difficulty with regard to going to the food shop as against going to the chemist’s. These problems were categorised as belonging to the domain most frequently occurring, in this example buying food.
The World Health Organization Disability Assessment Schedule II (WHO-DAS II) is a rather new generic instrument (WHO, 2000, 2001b), conceptually compatible with ICF by means of which activity limitations and participation restrictions in the everyday life of adult persons are assessed. WHODAS II is an overall disability assessment tool and the questions were not related to powered wheelchair use. Some different versions exist, but the WHO recommends the 36-item interviewer-administered version as it provides the most complete assessment of activity and participation.

WHODAS II encompasses six domains: Understanding and communicating (6 items), Getting around (5 items), Self-care (4 items), Getting along with people (5 items), Life activities (4 household items, 4 work items) and Participation in society (8 items). It examines how the persons usually do the activities, including the use of any device or personal help. Difficulties over the last 30 days are scored on a five-point ordinal scale (extending from none to extreme/cannot do), and by level of difficulty using the categories increased effort, discomfort or pain, slowness and/or changes in the way the person does the activity. An overall functioning score and subscale scores for the six domains are calculated. All scales range from 0 to 100, higher scores meaning more disability. In this study, 31 items were used – four work items in the Life activities domain were excluded, as well as one item on sexuality in the Getting along with people domain. The calculation of the overall functioning score and the two subscale scores took account of these exclusions. WHODAS II also encompasses an additional item, interference with life (1=none, 2=mild, 3=moderate, 4=severe and 5=extreme/cannot do), which is associated with each of the six domains. Only participants who perceive any problem in these domains will answer this item.

The validity and reliability of WHODAS II have been tested throughout the world (WHO, 2001b). In addition, recent research has again tested the psychometric properties and the validity of the instrument (Chopra, Couper, & Herrman, 2004; Chwastiak & Von Korff, 2003; McKibbin, Patterson, & Jeste, 2004; van Tubergen et al., 2003), showing excellent validity, fair test-retest reliability and a high internal consistency of the items. In this study, analyses revealed a high level of internal consistency (Cronbach’s alpha) in most of the domains at pre- and post-test assessment (Study III).

For this dissertation formal permission to translate WHODAS II, the 36-item interviewer version, into Swedish was obtained from the WHO. The procedure followed the WHO translation agreement guidelines. As WHO-DAS II is an instrument compatible with ICF, the same translator who translated ICF into Swedish was engaged to do this translation in order to obtain a reliable Swedish version (Study III).
Psychosocial impact and quality of life (Study IV)

The Psychosocial Impact of Assistive Devices Scale (PIADS) measures the impact of assistive devices on users’ quality of life. The questionnaire consists of 26 items grouped into three subscales. (1) The Competence subscale reflects feelings such as perceived independence and productivity (12 items), (2) Adaptability reflects feelings of well-being and ability to adapt to activities of daily living (6 items), and (3) Self-esteem comprises questions on emotions such as happiness and sense of security (8 items). The scale is scored from −3 (decrease) to +3 (increase). The midpoint “0” indicates no perceived change in quality of life as a result of using the device (Day & Jutai, 1996a; Day, Jutai, & Campbell, 2002).

PIADS has been shown to possess good psychometric properties (Day & Jutai, 1996a; Day, Jutai, & Campbell, 2002) and to have good clinical utility (Devitt, Chau, & Jutai, 2003; MacPhee et al., 2004). Furthermore, it has been reported to be a sensitive and responsive measure of the impact of various assistive devices among persons with different diagnoses and disabilities (Jutai, 1999). In this study, Cronbach’s alpha values for the total scale and subscales were 0.86–0.95 (Study IV).

The English version of PIADS was translated into Swedish. An initial translation was done by a professional translator with experience of translating questionnaires within health care. Three occupational therapists (two of whom have PhDs) examined this translation. Some items needed to be further discussed with the translator. An authorised translator specialising in psychology and medicine then did a reverse translation. Then the three occupational therapists discussed with the reverse translator certain items that did not accurately reflect the source items. Further, a person with English as native language and fluent in Swedish, and who uses an outdoor powered wheelchair in daily life, completed the questionnaire in both languages. After a minor revision the Swedish version was completed (Study IV).

EuroQol-5D (EQ-5D) is a short generic measure of health-related quality of life (HRQoL). Persons rate their self-perceived problems on five dimensions: mobility, self-care, usual activities, pain/discomfort and anxiety/depression. Each dimension is recorded on three levels: 1 = no problem, 2 = some problem and 3 = extreme problem. The data were presented as a simple descriptive profile across the five dimensions or as a single weighted health state index elicited from general population samples (EQ-5D index). The latter is based on a total of 243 possible health states involving combinations of the three levels and five dimensions. A score of 1 represents maximum good health and 0 the worst imaginable health (Brooks, Rabin, & de Charro, 2003; EuroQol Group, 1990). An HRQoL value of 0.78
matches the reference value of the general population in the 65–74 age-group (Kind in van Exel, Scholte op Reimer, & Koopmanschap, 2004). EQ-5D has demonstrated acceptable concurrent and discriminant validity as a measure of HRQoL after stroke (Dorman, Waddell, Slattery, Dennis, & Sandercock, 1997). Acceptable test-retest reliability has been reported in studies with the general public and a clinical sample of patients with rheumatoid arthritis (Brooks, Rabin, & de Charro, 2003).

**Statistical analysis**

The manuals of the chosen instruments in this project recommend the use of the mean as the measure of the central tendency (Brooks, Rabin, & de Charro, 2003; Day & Jutai, 1996b; Wessels et al., 2000). In addition, previous research using IPPA, WHODAS II, PIADS and EQ-5D has mainly used parametric statistics in hypothesis testing. However, non-parametric statistics were mainly used in this project because of the ordinal data level and the small number of participants. Nonetheless, the mean values of the different scales and subscales are used in conjunction with the median values. As a complement to the non-parametric statistics, the statistical measure of effect size (ES) was used. This is a simple and common method of standardising a comparison of different outcome measures in the same study or across studies (Fayers, 2000; Kazdin, 2003). The within-group effect of activity and participation was analysed by means of the ES (calculation: mean change/mean SD at pre-test) concerning IPPA, WHODAS II and EQ-5D, (Studies III and IV). In the case of IPPA, the ES was calculated both per individual participant and per activity and participation domain in ICF. In WHODAS II the ES was calculated for the total scale (31 items) and the six subscales.

The Wilcoxon Signed Ranks Test (two-tailed) was used to determine significant changes of activity and participation between baseline and follow-up with regard to IPPA and WHODAS II (Study III).

Differences in psychosocial impact and quality of life between independent groups (gender, age, living conditions, stroke onset, side of body paresis, location of housing, type of powered wheelchair, need of company when driving, how far they drive, how often they drive in summer, the availability of a car in the family) were analysed with the Mann-Whitney U-test in the case of PIADS. This test was also used when analysing change scores of the EQ-5D dimensions and index (Study IV). A Kruskal-Wallis test was used to analyse whether the importance of and satisfaction with the wheelchair was significant, with respect to the mentioned groups above.

For all analysis, a value of p<0.05 was chosen as the level of significance. The statistical software SPSS 13.0 was used for all calculations.
Ethical considerations
The participation in the studies was based on informed consent. All persons with stroke (Studies I, III, IV) and the spouses (Study II) received both oral and written information about the study. In the case of all the studies, a first telephone call was made to give brief information about the study, asking at the same time if they would like to receive written information. This information covered the purpose and methods of the study, and it was emphasised that participation was on a voluntary basis. The confidentiality of the data was stressed, as was the possibility of terminating participation at any time. After the written information had been sent, a new telephone call was made asking if they were willing to participate in the study.

When a visit was made to the participants, they again received information and were given the opportunity to ask questions about the study. Participants in Studies III and IV also signed an informed consent. Thus every effort was made to adequately inform the potential participants before they decided whether or not to participate. After consultation with the participants, all interviews were carried out in their own homes. In no case were the participants in a position of dependence in respect of the author. The participants received ordinary intervention with regard to assistive devices, which means that the research project was not an interference in this respect. The project was approved by the Research Ethics Committee at Örebro University Hospital, Sweden – in the case of Studies III and IV, as a multi-center study (00 09 25 and 03 02 17, Dnr 500:16 843/00).
RESULTS
The assistive devices from a lifeworld perspective (Studies I and II)
The results are presented with a focus on similarities and differences within
the different lifeworld existentials, but there is also a focus on the dual
relationship to assistive devices which was found in all the lifeworld exist-
entials (Studies I and II). Further, a summary of possible meanings of as-
sistive devices is presented (Table VI). A synthesis of the two lifeworld
studies, e.g. of persons with stroke (n=22) and their spouses (n=12), is in-
corporated into the presented results.

The results in the case of both study groups showed that the use of diffe-
rent devices is complex and often contradictory at the same time, especially
when it comes to persons with stroke. However, the persons’ experiences of
the advantages of the devices overshadow their experiences of the disadv-
antages in both study groups. The results indicate that the lived experiences
of assistive devices in the different lifeworld themes are closely inter-
connected.

Lived body in relation to assistive devices – issues of habits,
feelings and incorporation
The devices help both the persons with stroke and the spouses to maintain
former habits, e.g. the couples are able to go out for a walk if the husband/
wife with stroke uses a wheeled walker. However, some habits have to be
changed in both groups because of the nature of the assistive devices. The
spouses have to become accustomed to using devices intended for the hus-
band/wife with stroke, for instance, using a raised toilet seat, which may be
seen as inconvenient at first. The participants with stroke say that the devi-
ces may foster bad habits, e.g. becoming less active because there is someo-
ne to push you in a wheelchair. Some of the persons in both study groups
felt that though the devices are intrusive at first, you do adapt to them and
they become a means to organise and structure daily life.

Dual feelings about the devices and their use are present in persons with
stroke as well as in their spouses. An enhanced feeling of safety and security
and enhanced self-esteem as a result of having overcome different challenges
in daily tasks are positive factors. In spite of this, though, the persons with
stroke may still feel insecure and anxious when using the devices. The
spouses are on the one hand glad, grateful and calm when they know that
the husband/wife with stroke manages better with the device. On the other
hand they feel worried, frustrated and anxious when the devices prove in-
sufficient.
Some of the persons with stroke, but also some of the spouses talked about the devices as if they were incorporated with the body. A spouse speaks about the devices as being her right hand, as she cannot do without it, and a person with stroke speaks about the wheeled walker in terms of its being his legs, as he cannot perform daily activities without it. The devices may also have a contrary influence upon the persons with stroke and their spouses. Persons with stroke spoke of the possibility of feeling constrained to use a device. One participant with stroke said that the devices (e.g. reacher, wheelchair) dictate the way he moves his body.

Both persons with stroke and their spouses agree that the devices are a prerequisite for living their life together. However, the persons with stroke put an emphasis on the devices as compensating for the disabled body and giving physical support. But at the same time, the devices are also a reminder of their disability, limiting activity and participation (Studies I and II).

Lived space in relation to assistive devices — new experiences of the indoor and outdoor environment

The assistive devices are essential for both the persons with stroke and the spouses to be able to continue to live in their homes and do things together. The lived experiences of space of the persons with stroke and the spouses, respectively, are sometimes similar and sometimes quite different. The spouses talk about their homes as aesthetically nice places where you can feel secure and at ease. It is important for them that the devices fit into the homes and that their partner with stroke is able to manage on their own for at least some time. Both feel it is important that the devices are stored in special places since it is important for them to know where they are and not litter the place. However, both groups assign the device higher priority than their furniture, which may have to go if the device occupies needed space.

Some persons with stroke and some spouses see the devices as a natural part of their home, others see them as intrusive, especially in the beginning. Nevertheless, the devices are crucial with regard to the daily functioning of the person with stroke.

Both have had new experiences of the outdoor environment. Owing to assistive devices, they now look upon the environment in new ways. What they see are uneven ground and inaccessible shops, not always tailored to the requirements of a person using mobility devices. The assistive devices direct what kind of facilities to visit and how long. Persons with stroke emphasise the need for careful planning before going out with the devices and visiting different places (Studies I and II).
Lived time in relation to assistive device – past, present and future

The participants experience time, incorporating temporal perspectives in the form of the past, present and future, in relation to assistive devices and other people. Concerning the past, both the spouses and the persons with stroke reflect upon the advantage of living in the 21st century where assistive devices are available, comparing with earlier times when people with disabilities had no access to such devices.

Controlling their own time, regardless of other people’s time, seems important in both study groups. Assistive devices are a prerequisite for this to happen. With the use of such devices some of the persons do not need to adjust to the time of home-help staff. This is experienced as a great advantage, to have command and control over their own time, a feeling of doing what they want when they want, regardless of other people’s time. Nevertheless, some spouses often feel that their time is fragmented and that they often have to hurry when they are out shopping and their partners are at home as the partner perceives time as crawling, i.e. they have a different temporal perspective than the partner with stroke. The spouses also feel that they need more time on their own and not always having to be at hand for the persons with stroke. A few spouses are satisfied with their own time, as nothing can compete with the important task of helping their partner with stroke.

Some persons in both study groups urgently want to receive the devices as soon as possible after the prescription has gone through. Delay in the delivery of the devices is perceived as time lost and potentially lessens the improvement of the person with stroke, which also will affect their partner. The lived time in relation to assistive devices gives rise to many thoughts in both spouses and persons with stroke. They long for an improvement in health which will make it possible to return the device or do without a device or at least get a less restrictive one. In addition, the spouses may worry about whether the devices will remain adequate for future needs and if they then will still be able to manage to live in their own home (Studies I and II).

Lived human relationship in relation to assistive devices – participation and stigma

Assistive devices are part of the relations between couples, as well as between users and home-help staff and other people in society. The devices are an interface which will influence the lived relations in situations where the devices are used. When one’s partner has a stroke and needs assistive devices, life is no longer what it used to be. The spouses experience a significant change in family roles and they assume great responsibility for the smooth
functioning of everyday life, including the responsibility for the assistive devices. The spouses make sure their partners use the right device at the right time and prepare the devices for use (e.g. cleaning and putting the wheels in the right direction on a walker) and give different kinds of needed physical and emotional support in conjunction with assistive device use. The persons with stroke, on the other hand, are concerned about the added burden on their spouses, while at the same time reminding themselves that they are no longer able to perform their earlier roles in the family. The devices also contribute to the maintenance of certain roles, e.g. groceries can be transported on the powered wheelchair or wheeled walker.

It is clear that there are stigmatising situations outside the home. The persons with stroke experience another sort of treatment than before the stroke. People can have a condescending attitude towards the device user or they stop socialising with them since they cannot walk unaided. Other people may question their need of the devices or sometimes they are treated as also having an intellectual disability. Feelings of sadness or anger appear. These situations affect the spouses emotionally and it is their role to console and take care of the persons with stroke. Some persons do not experience stigma in connection with such mobility devices as wheeled walkers since these are nowadays so commonly used.

Both study groups have experiences of assistive devices in relation to different prescribers of the devices. Persons in both study groups have experience of being involved in the prescribing process – of having participated – and felt the prescriber to be skilled and sensitive to their needs. On the other hand, some persons with stroke feel that the prescriber doubted their need of a device. Furthermore, the prescriber did not take any notice of some of the spouses’ need of emotional support and information about the available devices or their need to be able to take part in the choice of devices (Studies I and II).

**Dual relations with regard to assistive devices**

A main finding in the lifeworld studies of persons with stroke and their spouses is the existence of dual relations with regard to assistive devices. This was most evident in the case of persons with stroke, but these experiences have been found amongst almost all of the spouses as well. The two parts of the dual relations often contrast with each other, being positive-negative, facilitating-restricting and so on. The majority of these dual relationships are expressed in positive terms, both for the persons with stroke and for their spouses. In the case of spouses these dual relations are more evident at the time when the devices enter the homes. The dual relations exist in the lived world consisting of the four lifeworld existentials.
An individual with stroke or a spouse may experience a dual relationship when using or confronting a special device (e.g. a wheelchair) in a specific situation (e.g. going for a walk). It also may be more general in character in relation to non-specific activities of daily living at home or in the community. Some examples below may serve as illustrations of different dual relations with regard to the four lifeworld themes.

– A woman with stroke discusses the advantages and disadvantages of returning devices. She says that it is great that assistive devices are available and they are very important to her (all assistive devices, situations in general). She has now accepted her devices, but she does not want to use them for the rest of her life. She is worried about what the future holds if she returns the devices (lived time). Returning devices is a sign of improvement (lived body). For instance, if she returns a cane (a specific device) even though she may still have minor problems with her balance, people around will not recognise that something may be wrong with her and may push her, and that makes her worried about falling (lived body, lived human relations). The cane is a sign that she has a disability.

– A man with stroke has a positive attitude to his assistive devices (all assistive devices), they offer security. Without them he could not perform activities of daily life (situations in general). But he considers it to be heavy to walk with the wheeled walker. The slope of a pavement can make it difficult for him to walk straight (lived space, lived body). He used to often go out for a meal but now it is more difficult because he has to be sure that he can get to the toilet with his wheeled walker (a specific situation, a specific device). He has not made a big thing of it but he does not go out so much any more and he says that you feel very tied-down with an assistive device (lived body, lived space).

– A woman says that she is happy about the powered wheelchair (a specific device) her husband has been provided with. The wheelchair makes it possible to maintain roles, such as going out for a walk together (lived human relations). But at the same time her husband has to watch his driving in traffic (a specific situation), which means that the roles have changed and she has to take an added responsibility upon her. Sometimes she also has to console her husband because of stigmatising situations (lived human relations, situations in general) he is exposed to, and she is negatively influenced by that (lived body).
Meanings of assistive devices

The results showed that an assistive device for use in daily life is a complex and multifaceted tool, non-neutral, interwoven with everyday activities in diverse ways. From the perspective of the two qualitative studies, a device can be related to different situations in different ways. Possible meanings attached to assistive devices are presented in Table VI. The knowledge encapsulated in this table may serve as a basis for increased understanding of the meaning of assistive devices used in activities of daily life, offering a possibility of understanding a person’s use of such devices within his or her particular context. There are probably as many combinations of meanings of specific devices or groups of devices as there are people using the devices or health-care staff attempting to understand this use.
### Table VI. Possible meanings of assistive devices in daily life

<table>
<thead>
<tr>
<th><strong>Different meanings of assistive devices</strong></th>
<th><strong>Inherent function of the device</strong></th>
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</thead>
<tbody>
<tr>
<td><strong>Bodily aspects</strong></td>
<td><em>solves problems</em></td>
</tr>
<tr>
<td>• easier performance of activities</td>
<td><em>symbolic significance</em></td>
</tr>
<tr>
<td>• ability or desire to perform activities</td>
<td><em>sometimes dual use, e.g. furniture and mobility</em></td>
</tr>
<tr>
<td>• inability to perform activities</td>
<td><em>free or inexpensive</em></td>
</tr>
<tr>
<td>• doing more</td>
<td><em>need for careful planning</em></td>
</tr>
<tr>
<td>• doing less</td>
<td><em>hierarchy of assistive devices</em></td>
</tr>
<tr>
<td>• compensation for physical dysfunction</td>
<td></td>
</tr>
<tr>
<td>• improved fitness</td>
<td></td>
</tr>
<tr>
<td>• control of movements</td>
<td></td>
</tr>
<tr>
<td>• preparedness of body</td>
<td></td>
</tr>
<tr>
<td>• like part of body</td>
<td></td>
</tr>
<tr>
<td>• like extension of body</td>
<td></td>
</tr>
<tr>
<td>• like friend or pet</td>
<td></td>
</tr>
<tr>
<td>• effect on quality of life</td>
<td></td>
</tr>
<tr>
<td>• life made easier</td>
<td></td>
</tr>
<tr>
<td>• maintenance of habits</td>
<td></td>
</tr>
<tr>
<td>• changed habits</td>
<td></td>
</tr>
<tr>
<td>• use of devices a habit</td>
<td></td>
</tr>
<tr>
<td></td>
<td><em>often indispensable</em></td>
</tr>
<tr>
<td></td>
<td><em>structuring and organising of daily life</em></td>
</tr>
<tr>
<td></td>
<td><em>better functioning</em></td>
</tr>
<tr>
<td></td>
<td><em>greater disability</em></td>
</tr>
<tr>
<td></td>
<td><em>reminder of lost capacity</em></td>
</tr>
<tr>
<td></td>
<td><em>positive emotional affect</em></td>
</tr>
<tr>
<td></td>
<td><em>negative emotional effect</em></td>
</tr>
<tr>
<td></td>
<td><em>sense of freedom</em></td>
</tr>
<tr>
<td></td>
<td><em>means of achieving goals and solving problems</em></td>
</tr>
<tr>
<td></td>
<td><em>greater sense of security</em></td>
</tr>
<tr>
<td></td>
<td><em>less sense of security</em></td>
</tr>
<tr>
<td></td>
<td><em>independence</em></td>
</tr>
<tr>
<td></td>
<td><em>distraction from thoughts of illness</em></td>
</tr>
<tr>
<td></td>
<td><em>something you want to be rid of</em></td>
</tr>
<tr>
<td></td>
<td><em>wish not to need it</em></td>
</tr>
<tr>
<td></td>
<td><em>good that it’s there anyway</em></td>
</tr>
<tr>
<td></td>
<td><em>missed if not at hand</em></td>
</tr>
<tr>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Temporal aspects</strong></td>
<td><em>lost time</em></td>
</tr>
<tr>
<td>• time as rich in content</td>
<td><em>changed perception of time</em></td>
</tr>
<tr>
<td>• time seen as whole</td>
<td><em>possibility of spending more time outdoors</em></td>
</tr>
<tr>
<td>• time short</td>
<td><em>use of devices more natural for old than for young</em></td>
</tr>
<tr>
<td>• control over one’s time</td>
<td><em>devices old-fashioned</em></td>
</tr>
<tr>
<td>• no dependence on others’ time</td>
<td></td>
</tr>
<tr>
<td>• thinking about past, present and future</td>
<td></td>
</tr>
<tr>
<td></td>
<td><em>takes up a lot of space in home</em></td>
</tr>
<tr>
<td></td>
<td><em>damage to furnishings</em></td>
</tr>
<tr>
<td></td>
<td><em>need to rearrange furniture</em></td>
</tr>
<tr>
<td></td>
<td><em>effect on feeling of homeliness</em></td>
</tr>
<tr>
<td></td>
<td><em>home is always home, regardless of number of devices</em></td>
</tr>
<tr>
<td></td>
<td><em>new view of external environment</em></td>
</tr>
<tr>
<td></td>
<td><em>limitation on places to go to</em></td>
</tr>
<tr>
<td></td>
<td><em>dependence on those who prescribe device</em></td>
</tr>
<tr>
<td></td>
<td><em>greater or less participation</em></td>
</tr>
<tr>
<td></td>
<td><em>singling out, stigmatisation</em></td>
</tr>
<tr>
<td></td>
<td><em>device need not have effect of singling out</em></td>
</tr>
<tr>
<td></td>
<td><em>different attitudes of those around</em></td>
</tr>
<tr>
<td></td>
<td><em>less need for home-help</em></td>
</tr>
<tr>
<td></td>
<td><em>device a sign of disability</em></td>
</tr>
</tbody>
</table>

**Spatial aspects**

- natural part of home
- kept in out-of-the-way place
- kept in own special place
- kept in easily accessible place
- prerequisite for living in own home
- not prerequisite for living in own home
- precedence over furniture

**Human-relational aspects**

- dependence on relatives
- sometimes inherent sense of community
- device intermediary between person and activity or person and surroundings
- maintenance of roles
- change in roles

**Inherent function of the device**

- solves problems
- does not solve all problems
- limit to the help it can give
- not for decoration
- not used by many people
The powered wheelchair studies (Studies III and IV)
Results with regard to activity and participation (Study III) and psychosocial impact and quality of life (Study IV) in relation to outdoor powered wheelchair use are reported below. The problems with activity and participation are most evident when measured by IPPA, which investigates the participants’ stated problems in relation to their daily lives. Overall data of all measurements used in Studies III and IV are shown in Table VII. This table shows that the mean and median values are often more or less equivalent in the different measurements.

Three participants reported less use of the powered wheelchair because of a life-event. As there were no interfering life-events for most of the participants, this factor is omitted in the statistical analysis of the studies. Concerning study-specific questions, most of the participants rated their powered wheelchair as extremely important (n=10) and very important (n=10). Half of the participants (n=16) were extremely satisfied with the wheelchair and one fourth were either very satisfied or somewhat satisfied. More data on study-specific questions are presented in Study III and IV.
Table VII. Descriptive statistics and effect sizes in activity and participation (IPPA, WHODAS II), health-related quality of life (EQ5-D) and psychosocial impact (PIADS) in persons with stroke (Studies III and IV)

<table>
<thead>
<tr>
<th>Measurement and subscale</th>
<th>n</th>
<th>Pre test</th>
<th>Post test</th>
<th>Effect size</th>
<th>Wilcoxon p-value</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td>Md</td>
<td>Mean</td>
<td>Sd</td>
<td>Md</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Mean</td>
</tr>
<tr>
<td>IPPA Total mean&lt;sup&gt;1)&lt;/sup&gt;</td>
<td>32</td>
<td>18.1</td>
<td>18.3</td>
<td>(3.6)</td>
<td>8.2</td>
</tr>
<tr>
<td>IPPA divided into ICF&lt;sup&gt;1)&lt;/sup&gt;</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Range 0-25</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Self-care</td>
<td>1</td>
<td>25.0</td>
<td>25.0</td>
<td>(-)</td>
<td>5.0</td>
</tr>
<tr>
<td>Domestic life</td>
<td>34</td>
<td>18.0</td>
<td>18.0</td>
<td>(5.0)</td>
<td>8.0</td>
</tr>
<tr>
<td>Interpersonal interactions and relationships</td>
<td>27</td>
<td>16.0</td>
<td>16.8</td>
<td>(5.3)</td>
<td>8.0</td>
</tr>
<tr>
<td>Major life areas</td>
<td>4</td>
<td>20.0</td>
<td>21.3</td>
<td>(2.5)</td>
<td>6.5</td>
</tr>
<tr>
<td>Community, social and civic life</td>
<td>52</td>
<td>20.0</td>
<td>18.8</td>
<td>(4.4)</td>
<td>8.0</td>
</tr>
<tr>
<td>Total</td>
<td>118</td>
<td>20.0</td>
<td>18.2</td>
<td>(4.8)</td>
<td>8.0</td>
</tr>
<tr>
<td>WHODAS II&lt;sup&gt;1)&lt;/sup&gt;</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Range 0-100</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Understanding and communicating</td>
<td>32</td>
<td>10.0</td>
<td>13.1</td>
<td>(14.4)</td>
<td>10.0</td>
</tr>
<tr>
<td>Getting around</td>
<td>32</td>
<td>65.6</td>
<td>62.1</td>
<td>(18.2)</td>
<td>56.2</td>
</tr>
<tr>
<td>Self-care</td>
<td>32</td>
<td>30.0</td>
<td>35.0</td>
<td>(27.5)</td>
<td>0.0</td>
</tr>
<tr>
<td>Getting along with people</td>
<td>32</td>
<td>10.0</td>
<td>12.5</td>
<td>(16.8)</td>
<td>0.0</td>
</tr>
<tr>
<td>Life activities</td>
<td>32</td>
<td>60.0</td>
<td>55.6</td>
<td>(36.9)</td>
<td>40.0</td>
</tr>
<tr>
<td>Participation in society</td>
<td>32</td>
<td>56.3</td>
<td>52.9</td>
<td>(22.0)</td>
<td>50.0</td>
</tr>
<tr>
<td>Total</td>
<td>32</td>
<td>38.3</td>
<td>39.5</td>
<td>(15.7)</td>
<td>32.2</td>
</tr>
<tr>
<td>EQ-5D&lt;sup&gt;3)&lt;/sup&gt;</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Range 1-3</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mobility</td>
<td>30</td>
<td>2.0</td>
<td>2.0</td>
<td>(0.0)</td>
<td>2.0</td>
</tr>
<tr>
<td>Self-care</td>
<td>32</td>
<td>2.0</td>
<td>1.7</td>
<td>(0.6)</td>
<td>2.0</td>
</tr>
<tr>
<td>Usual activities</td>
<td>32</td>
<td>2.0</td>
<td>1.8</td>
<td>(0.5)</td>
<td>1.5</td>
</tr>
<tr>
<td>Pain/discomfort</td>
<td>32</td>
<td>2.0</td>
<td>1.8</td>
<td>(0.7)</td>
<td>2.0</td>
</tr>
<tr>
<td>Anxiety/depression</td>
<td>32</td>
<td>1.0</td>
<td>1.5</td>
<td>(0.6)</td>
<td>1.0</td>
</tr>
<tr>
<td>EQ-5D index scores&lt;sup&gt;3)&lt;/sup&gt;</td>
<td>32</td>
<td>0.6</td>
<td>0.5</td>
<td>(0.3)</td>
<td>0.6</td>
</tr>
<tr>
<td>Range 0-1</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>PIADS</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Range -3 to +3</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Competence</td>
<td>32</td>
<td>0.5</td>
<td>0.7</td>
<td>(0.6)</td>
<td>0.3</td>
</tr>
<tr>
<td>Adaptability</td>
<td>32</td>
<td>0.6</td>
<td>0.7</td>
<td>(0.6)</td>
<td>0.3</td>
</tr>
<tr>
<td>Self-esteem</td>
<td>32</td>
<td>0.6</td>
<td>0.7</td>
<td>(0.6)</td>
<td>0.3</td>
</tr>
<tr>
<td>Total</td>
<td>32</td>
<td>0.5</td>
<td>0.7</td>
<td>(0.6)</td>
<td>0.3</td>
</tr>
</tbody>
</table>

1) Lower values at post assessment indicate improvement
2) Higher values at post assessment indicate improvement
Activity and participation (Study III)

The participants (n=32) estimated that activity limitations and participation restrictions in daily life as measured by IPPA were to a great extent diminished or eliminated through the provision of an outdoor powered wheelchair. When it came to categorising their activity and participation problems (n=118) into the domains of ICF, the results showed that most of the difficulties (n=52) were related to the domain Community, social and civic life. In Study III this domain mainly includes the participants’ problems in relation to “recreation and leisure”, such as going for a walk in the neighbourhood, going to an ice hockey or football match or going to the library. This domain shows the greatest effect size (ES=2.4, p=<0.001), not counting the Major life areas with few problems (Table VII). In the domain Domestic life, where the participants mainly mentioned problems related to buying foods or other necessities, there is also a large ES (ES=1.6, p=<0.001). The domain Interpersonal interactions and relationships, including socialising with family members, neighbours and friends, shows an ES of 1.4, p=<0.001 (Table VII).

The effect at the group level of a powered wheelchair with regard to solving activity and participation problems (n=32) shows a large and significant ES (ES=2.6, p=<0.001) (Table VII). In addition, the ES at the individual level is also large (ES=>0.8) for almost every participant (n=31) (Study III).

When it comes to the participants’ stated difficulties regarding activity or participation (n=118), 86% of them diminished or disappeared between pre-test and post-test. The greatest change recorded was where in 24 cases “too much difficulty to perform the activity at all” was replaced by “no difficulty at all” after the powered wheelchair provision (Table VIII). Noteworthy is that 14 difficulties (14/118=12%) were unchanged and three difficulties (3/118=3%) were greater after the provision (Table VIII and Table II in Study III). The increased problems were related to barriers having to do with the environment, such as the design of buildings, heavy traffic and a lively dog that is difficult to take for a walk with the powered wheelchair.
Table VIII. Frequency distribution of difficulties with regard to performing activities of daily living (IPPA), before and after provision of an outdoor powered wheelchair (n=118)

<table>
<thead>
<tr>
<th>Difficulties at post test n (%)</th>
<th>1 No difficulty at all</th>
<th>2 Little difficulty</th>
<th>3 Quite a lot of difficulty</th>
<th>4 A lot of difficulty</th>
<th>5 Too much difficulty to perform the activity at all</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>5 Too much difficulty to perform the activity at all</td>
<td>0 (0)</td>
<td>0 (0)</td>
<td>2 (1.7)</td>
<td>1.0 (0.8)</td>
<td>7 (5.9)</td>
<td>10 (8.5)</td>
</tr>
<tr>
<td>4 A lot of difficulty</td>
<td>0 (0)</td>
<td>0 (0)</td>
<td>0 (0)</td>
<td>2 (1.7)</td>
<td>4 (3.4)</td>
<td>6 (5.1)</td>
</tr>
<tr>
<td>3 Quite a lot of difficulty</td>
<td>0 (0)</td>
<td>0 (0)</td>
<td>2 (1.7)</td>
<td>7 (5.9)</td>
<td>9 (7.6)</td>
<td>18 (15.3)</td>
</tr>
<tr>
<td>2 Little difficulty</td>
<td>0 (0)</td>
<td>3 (2.5)</td>
<td>4 (3.4)</td>
<td>19 (16.1)</td>
<td>17 (14.4)</td>
<td>43 (36.4)</td>
</tr>
<tr>
<td>1 No difficulty at all</td>
<td>0 (0)</td>
<td>0 (0)</td>
<td>2 (1.7)</td>
<td>15 (12.7)</td>
<td>24 (20.3)</td>
<td>41 (34.7)</td>
</tr>
<tr>
<td>Total</td>
<td>0 (0)</td>
<td>3 (2.5)</td>
<td>10 (8.5)</td>
<td>44 (37.3)</td>
<td>61 (51.7)</td>
<td>118 (100)</td>
</tr>
</tbody>
</table>

With regard to subscales of WHODAS II measuring difficulties in different activities of daily life, the results show that the effect of a powered wheelchair ranges from none to small (ES=0.13 to 0.20) and non-significant except in the case of Self-care (ES=0.84, p=<0.001) and Getting around (ES=0.41, p=0.021). The total scale (31 items) showed a small but significant (p=0.025) effect size (ES=0.26) (Table VII).

Furthermore, the participants scored Interference with life (additional item in WHODAS II) in the different domains about the same before and after being provided with a powered wheelchair. No significant differences between baseline and follow-up were shown. Getting around and Participation in society are the domains showing the greatest Interference with life at both pre- and post-test assessment, i.e. showing the highest median and mean values (Table IX).

Table IX. Interference with life (1–5) concerning subscales in WHODAS II, pre and post test (n=32)

<table>
<thead>
<tr>
<th>Interference with life concerning</th>
<th>Pre test</th>
<th>Post test</th>
<th>Pre test</th>
<th>Post test</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Number of participants</td>
<td>Number of participants</td>
<td>Md (q1–q3) mean (sd)</td>
<td>Md (q1–q3) mean (sd)</td>
</tr>
<tr>
<td>Understanding and communicating</td>
<td>25</td>
<td>20</td>
<td>2 (1–3)</td>
<td>2.2 (1)</td>
</tr>
<tr>
<td>Getting around</td>
<td>32</td>
<td>32</td>
<td>4 (3–4)</td>
<td>3.6 (0.9)</td>
</tr>
<tr>
<td>Self-care</td>
<td>27</td>
<td>23</td>
<td>3 (2–4)</td>
<td>3.1 (1.3)</td>
</tr>
<tr>
<td>Getting along with people</td>
<td>16</td>
<td>11</td>
<td>2 (1.3–3)</td>
<td>2.1 (0.9)</td>
</tr>
<tr>
<td>Life activities</td>
<td>29</td>
<td>27</td>
<td>3 (1.5–4.5)</td>
<td>3.1 (1.5)</td>
</tr>
<tr>
<td>Participation in society</td>
<td>32</td>
<td>32</td>
<td>4 (3–4)</td>
<td>3.5 (1.1)</td>
</tr>
</tbody>
</table>
**Psychosocial impact and health-related quality of life (Study IV)**

Only a few significant differences between groups were shown concerning the psychosocial impact (PIADS) total scale and subscales. The group who drive the wheelchair at least once a day in the summer show a significantly higher positive impact on the PIADS total scale \( (z=1.98, \ p=0.048) \) and the subscale Competence \( (z=2.099, \ p=0.036) \) than those who drive less. Further, the group with higher rankings of the importance of the powered wheelchair score significantly higher regarding psychosocial impact than the group with lower rankings when it comes to the PIADS total scale \( (\chi^2=9.63, \ df=3, \ p=0.022) \) and the subscale Self-esteem \( (\chi^2=9.57, \ df=3, \ p=0.023) \).

As the PIADS subscales only show very small differences in mean values, it is of importance to study the different items included. After provision of a powered wheelchair, the items Happiness, Independence and Quality of life reached the highest mean values. There are also rather high mean values of the items Competence, Self-esteem, Well-being and Capability (Figure 1).

Between-group comparisons indicate that participants with left body paresis show a higher positive psychosocial impact concerning quality of life than those with right body paresis after the use of a powered wheelchair (Table X). Participants living in locations with more than 8,000 inhabitants show higher self-esteem and well-being than those living in the countryside. In addition, participants who use the wheelchair at least once a day in summer are happier, more independent, more capable and enjoy a better quality of life than those who use it less. Furthermore, participants who drive longer distances score higher for independence than those who drive shorter distances. And finally, the participants who score higher for importance of the wheelchair feel happier, more independent and enjoy a better quality of life than those who score lower on these items (Table X).

In the case of seven participants they gave one to three negative ratings each on PIADS. The powered wheelchair has a negative psychosocial impact on seven items. They feel more embarrassed \( (n=4) \) and frustrated \( (n=2) \) when using the powered wheelchair. Further, five participants record, respectively, lower security, self-esteem, adequacy, efficiency and skilfulness (Table III in Study IV).

The effect size of health-related quality of life measured by EQ-5D shows overall small and non-significant results, except for the dimension activity (Study IV). Effect sizes could not be calculated in the case of PIADS as the data were only measured at post-test.
Figure 1. Mean distribution of each item in PIADS questionnaire and the three subscales and total scale (n=32)
Table X. The psychosocial impact of a powered wheelchair on seven items in PIADS in relation to different study-specific questions and background variables (n=32)

<table>
<thead>
<tr>
<th></th>
<th>Side of body paresis p-value</th>
<th>Location of housing p-value</th>
<th>Used in summer p-value</th>
<th>Driving distance as usual p-value</th>
<th>Importance p-value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Competence</td>
<td>0.28</td>
<td>0.82</td>
<td>0.38</td>
<td>0.48</td>
<td>0.60</td>
</tr>
<tr>
<td>Happiness</td>
<td>0.29</td>
<td>0.13</td>
<td>0.04</td>
<td>0.09</td>
<td>0.04</td>
</tr>
<tr>
<td>Independence</td>
<td>0.34</td>
<td>0.06</td>
<td>0.03</td>
<td>0.02</td>
<td>0.04</td>
</tr>
<tr>
<td>Self-esteem</td>
<td>0.45</td>
<td>0.05</td>
<td>0.58</td>
<td>0.68</td>
<td>0.11</td>
</tr>
<tr>
<td>Well-being</td>
<td>0.71</td>
<td>0.04</td>
<td>0.10</td>
<td>0.18</td>
<td>0.17</td>
</tr>
<tr>
<td>Capability</td>
<td>0.11</td>
<td>0.14</td>
<td>0.03</td>
<td>0.23</td>
<td>0.19</td>
</tr>
<tr>
<td>Quality of life</td>
<td>0.01</td>
<td>0.28</td>
<td>0.01</td>
<td>0.27</td>
<td>0.05</td>
</tr>
</tbody>
</table>

Significant results in bold characters
1) Mann-Whitney U-test
2) Kruskal-Wallis test

The EQ-5D shows only one significant change (p=0.033) between pre- and post-test assessment, this is in the case of the dimension Usual activities, where 14 of the persons respond positively and 5 negatively after the provision of a powered wheelchair. This estimated amount of change (0.58) is considered moderate with regard to effect size (Table VII).

No significant differences are shown regarding background variables and study-specific questions concerning the EQ-5D mean index score or the dimension Usual activities.
**DISCUSSION**

**Methodological considerations**

Two major approaches were chosen for the four studies: the qualitative lifeworld approach and the quantitative approach with different measures. These complementary approaches ensured a comprehensive exploration and description of the experience of assistive device use. Furthermore, ICF was used as a conceptual framework for the dissertation, as was the concept of quality of life. Below, the strengths and weaknesses of these approaches are discussed in detail.

Hermeneutic phenomenology was used as qualitative method. In phenomenological studies it is important to employ a purposeful sampling procedure, which means that all participants must have experienced the phenomena under study (Creswell, 1998). The study group of persons with stroke was in this case all patients participating in a one year follow-up of a stroke study (Appelros, Nydevik, Seiger, & Terent, 2002), prescribed two or more devices and registered at an assistive technology centre. One drawback in Study I, as a consequence of selecting all persons with stroke in the cohort who fulfilled the specific criteria, was that more men than women were included and that consequently more women than men were in the group of spouses. However, it has been reported that women do more often care for their partners with stroke than the opposite (Appelros, Nydevik, & Terent, 2006). It has also been reported that in Sweden the number of men under 80 years of age who have had a stroke is greater than the corresponding number of women. However, two thirds of the persons in Sweden who have suffered a stroke are nevertheless women since they live longer than men (Socialstyrelsen, 2006).

An interview guide was constructed with questions about daily activities in relation to assistive devices use. The guide was constructed in the light of the knowledge that it is not usually easy to speak about the ordinary things of daily life since they tend to be taken for granted. With the help of questions about concrete situations in daily life (van Manen, 1997), a rather extensive interview material was collected in Studies I and II, concerning 22 and 12 participants, respectively. Alternative methods given by van Manen (1997) for the collection of material in order to enter a person’s lifeworld are close observation, diaries and experiential descriptions in literature, but these methods were not used in the present research project.

The interviews were transcribed by a professional secretary and the author then compared the transcripts with the audio-taped originals to ensure accurate transcripts. A few times a word or two was added to the transcripts. The formulation of a core story of each participant’s daily life with assistive devices served a twofold aim: to facilitate comprehension of
the whole interview in relation to the assistive devices and to provide a context in which the analysis of the transformed meaning units in relation to the lifeworld existential could take place. To perform the analyses in this way proved helpful.

The four lifeworld existentials (lived body, lived time, lived space, lived human relations) have been used as a framework in order to interpret and describe the results in relation to assistive devices. However, these lifeworld existentials were not easily distinguishable from each other, which is perhaps best explained by the fact that the lifeworld is indivisible (Bengtsson, 1999; van Manen, 1997). In addition, the performance of activities, with or without assistive devices, permeates all of the four lifeworld existentials. A few authors have presented the concept of lifeworld existentials in a caring science perspective. They have described the same existentials as in this dissertation, with the addition of one or two other lifeworld concepts (Benner, 1994; Berndtsson, 2001; Finley, 1999). Therefore the present way of analysing and presenting the results with respect to the lifeworld concepts was still judged satisfactory. In addition, the studies produced a great variety of meanings of assistive devices in daily life. In order to ensure the trustworthiness of the results (Creswell, 1998; van Manen, 1997), both the collection and analysis of the data and the ensuing results were continually verified and discussed by the authors until agreement was reached on how to understand, interpret and describe the text in relation to the four lifeworld existentials. The application of the lifeworld approach contributed to a deeper understanding of the participants’ lived experience of assistive devices. This knowledge is different from that to be obtained from the quantitative results but the two are complementary.

The choice of using ICF (WHO, 2001) in this dissertation was based on the fact that this framework was recently adopted worldwide and points to the connection between the person, the activity and the environment, including the device. A few conceptual models dealing with assistive technology are described in the literature (Cook & Hussey, 2002; Lenker & Paquet, 2003; Scherer, 2000) but not adopted in the current project since they are more narrow in scope than ICF. Furthermore, occupational therapy models have been found equally insufficient when studying assistive technology outcomes (Brandt, 2005). ICF is of interest in the field of assistive technology when attempting to better understand the complex phenomena appearing when assistive devices interact with the person, the activity and the contextual factors. In this dissertation ICF has proved valuable in the categorisation of the participants’ goals in respect of using a powered wheelchair and in understanding the different interactions associated with device use. But there are still a few shortcomings in relation to assistive
technology outcome. In order for ICF to be a more complete and usable framework, a temporal perspective needs to be added, which also other researchers have called for (Boström & Ahlström, 2004; Lenker & Paquet, 2003; Wade & Halligan, 2003). Temporality is of importance in understanding the individual’s expectations regarding the device in the future, or when analysing his or her past experience of a device with a view to possible prescription of another device. Persons’ own meanings or lived experiences need to be included in the model, as has been stated earlier (Ueda & Okawa, 2003; Wade & Halligan, 2003). A shortcoming of ICF is that subjective concepts such as autonomy and independence, which the participants have mentioned in relation to the evaluation of the powered wheelchair, are not included in it. In addition, the relation of quality of life or health-related quality of life to ICF needs to be clarified (Ueda & Okawa, 2003). WHO is presently discussing the concept of well-being in relation to ICF in an annex (WHO, 2001a).

In the studies using the quantitative approach in this dissertation, several instruments were used to evaluate the effects of the use of a powered wheelchair. They have all been psychometrically tested and mostly showed satisfactory reliability and validity, which contributes to these studies’ reliability and validity. However, WHODAS II and PIADS were used for the first time in the case of a Swedish sample in this dissertation. Accordingly, there is now a need to establish the psychometric properties of the Swedish translation being used in a Swedish context.

In the case of the quantitative analyses, a decision had to be made with respect to whether to use a test of correction (e.g. Bonferroni adjustment) (Kazdin, 2003) or to use a smaller p-value than 0.05 in order to avoid Type I-error due to multiple testing (saying there is a difference when there really is none). Kazdin (2003) discusses, in connection with small sample sizes, whether to choose a p-value of <0.20 or <0.10 with or without adjustments. In the present studies p <0.05 was chosen as level of significance.

ES was shown to be high as measured by IPPA in spite of a rather small study group, which may indicate that IPPA is a reliable measure and sensitive instrument able to detect the effect of the powered wheelchair. This has also previously been indicated in relation to other assistive technology interventions (Persson & Hellbom, 2003; Wessels et al., 2000; Wessels, de Witte, Jedeloo, van den Heuvel, & van den Heuvel, 2004). It is reasonable to expect that a measurement based on the persons’ own defined outcome goals is more sensitive to change, in this case caused by the powered wheelchair.

The results of WHODAS II, with a variety of ES-values, are somewhat more difficult to interpret. The domains of Participation in society and
Getting along with people were expected to show a high ES, which was not the case. Even though WHODAS II showed a moderate to high internal consistency on the total scale and on most of the subscales, the instrument's sensitivity to change in measuring outcome effects caused by powered wheelchairs can be questioned. In previous research concerning WHODAS II there are reports of small to moderate responsiveness (Chwastiak & Von Korff, 2003; van Tubergen et al., 2003) in the evaluation of change in back pain, psychiatric disorders and ankylosing spondylitis. Furthermore, in WHODAS II the participants respond on a five-point rating scale. In the recoding of these items, 19 out of 32 of them are converted from a five-level to a three-level scale. The remaining 13 items keep their five-level scale. This conversion is one possible explanation of the instrument's insensitivity in measuring change with regard to powered wheelchair interventions.

PIADS was found to be useful in measuring the psychosocial impact of a powered wheelchair after a period of use. The separate items showed a range of different values, which in this case are disguised when calculating the mean of the three subscales and the total scale (Figure 1). However, some of the study participants criticised PIADS as having too many items, several with rather similar content. An advantage of PIADS is that it was possible to rate Independence in relation to the use of the wheelchair, which is not possible in ICF. More than 75% of the subjects rated this item positively. In this study group a few participants needed explanation of the three items with a negative connotation, “frustration”, “confusion” and “embarrassment”, otherwise there were no difficulties in responding to the questionnaire.

EQ-5D showed low ES, except in the domain Usual activities. Possible interpretations are either that the sample size of the project was too small or that the measure is not responsive to change because of limited response options. Previous research has indeed criticised EQ-5D for limited response options (Buck, Jacoby, Massey, & Ford, 2000; Paterson, 2004; Salter et al., 2005).

In sum, WHODAS II does not, on the basis of this research, appear to be an adequate instrument in a pre- and post-test design evaluating outdoor powered wheelchairs. The results in the form of a small effect sizes do not seem clinically meaningful. Concerning EQ-5D, the only dimension with a moderate ES was Usual activities. In the light of this study, using index scores and most of the subscales of EQ-5D, a powered wheelchair intervention with a pre- and post-test design may be called into question. In contrast, the PIADS and IPPA were shown to be sensitive and useful instruments in evaluating the effects of powered wheelchair.
In many studies the statistical power to detect significant results is too low. One way to increase statistical power is to include more participants. In this project the study group consisted of every possible person with stroke in the three county council areas, during the study period of almost two years, who was going to be provided with an outdoor powered wheelchair. Therefore it was not possible to increase the number of participants in order to increase statistical power. Another potential problem with regard to the validity of a study is drop-outs. In Studies III and IV five participants dropped out after the first interview, but the drop-outs and the study group did not differ on demographic data. It was not possible to use an experimental or quasi-experimental research design owing to the small population of powered wheelchair users with stroke, consequently it was not possible to control for confounds such as the different prescription routines (Field, 1999; Gelderblom & de Witte, 2002; Smith, 1996; WHO, 2001a); but in an effort to control for some confounds, the participants were asked to answer a check-list of items on recent life-events that may have influenced the effects of the intervention in relation to activity, participation and quality of life.

Concerning the transferability or external validity of the results there are certain considerations. The results of the lifeworld study of persons with stroke, taking into account moderate to severe disablement, are judged to be applicable not only to other persons with disabilities after stroke, but also to other persons with similar disabilities and living conditions. The proper application of the results is conditional on their being set in relation to the new context (Dahlberg, Drew, & Nyström, 2001). The view of van Manen (1997) is that the phenomenological results have a universal intersubjective character in that they concern possible human experience.

The participants in Study I had moderate to severe disability on the Modified Ranking Scale (van Swieten, Koudstaal, Visser, Schouten, & Van Gijn, 1988). Those in Studies III and IV they probably had about the same degree of disability or somewhat more as they have been provided with a powered wheelchair. Obviously their mobility needs were not fulfilled with just manual wheelchairs or wheeled walkers. A point to be noted in relation to the transferability of the results of this project is the predominance of men with stroke in Studies I, III and IV. A further point is that the use of the devices differed in length, one year in Study I and about four months in Studies III and IV. Furthermore, on the basis of this dissertation the instruments IPPA (Study III) and PIADS (Study IV) are recommended for studies concerning assistive technology outcome. The results deriving from these measures, addressing activity, participation and psychosocial impact, ought to be transferable to persons in Sweden with similar disabilities and similar living conditions.
In sum, the use of phenomenological concepts such as the lifeworld (including the existentials) in order to understand the use of assistive devices and the experience of the devices as tools, has been fruitful and is recommended for future studies. Furthermore, IPPA and PIADS seem adequate in research and clinical practice when it comes to evaluating assistive devices. However, PIADS is here used for the first time in a Swedish context, so there is a need for studies evaluating its psychometric properties.

The lifeworld studies (Studies I and II)

The lived experience of assistive devices

The results show that the devices influenced the lived body in relation to lived time, lived space and lived human relations in the case both of persons with stroke and their spouses. The results revealed a broad and variegated range of meaning attached to the use of assistive devices. The spouses were as involved with the assistive devices as the persons for whom the devices had been prescribed. To use assistive devices is complex and the meaning of the use is individual in the case of both user and spouse. Persons using assistive devices have more tools to be mediated between the body and the task, than people in general, which modifies the common way of performing the task (Ihde, 1990). The devices contributed to a change in bodily habits or these were given up. Sometimes there was also a description of an incorporation of the device with the body (Ihde, 1990; Merleau-Ponty, 2002). Often there are different twofold relations to the devices. The devices were found to either expand or restrict the performance of activities in daily life, sometimes indeed both at the same time. This finding is in accordance with that of Csikszentmihalyi and Rochberg-Halton (1981), who investigated ordinary things and objects. Similarly, in a study of the use of ventilators, the technology was experienced both as a burden and as a relief to the body (Lindahl, Sandman, & Rasmussen, 2003). The devices have in this dissertation been found to be tools that mediate a relation between the person with stroke and the spouse, as well as with other persons in the community, sometimes including stigmatising situations (Davis, 1997; Goffman, 1990). The lived space is influenced when using assistive devices, as also other researchers have to some extent discussed (O’Brien, Dyck, Caron, & Mortenson, 2002; Toombs, 1992). The use of assistive devices, as well as of ordinary tools (Csikszentmihalyi & Rochberg-Halton, 1981), is linked to past feelings and hope for the future.

The results of employing the lifeworld approach in this research can be compared with those of three previous studies also using this kind of approach in relation to assistive technology (Berndtsson, 2001; Erikson,
Karlsson, Soderstrom, & Tham, 2004; Lampinen & Tham, 2003). However, in these studies the results are not presented in relation to the four lifeworld existentials as is done in this study.

**The twofold meaning**

In both study groups, a duality of meaning of the devices or the device use was shown, but it was most evident in the case of persons with stroke. This twofold meaning was found in situations of the personal lifeworld of persons with stroke and their spouses, in relation to a specific device or group of devices and in relation to a specific or general situation in daily life. Devices are tools that affect many aspects of the lives of persons with stroke and their families. These devices may be facilitative or restrictive with regard to situations in daily life, depending on personal or situational characteristics. Other researchers have, to some extent, also shown that duality is present in different ways in disabled persons using assistive devices. These persons experienced a dual meaning of the devices in relation to engaging in activities, in relation to dependence/independence vis-à-vis other people, in relation to thoughts about the future and in relation to socio-cultural values (Aminzadeh & Edwards, 1998; Berndtsson, 2001; Gitlin, Luborsky, & Schemm, 1998; Haggblom Kronlof & Sonn, 1999; Lund & Nygard, 2003; Lupton & Seymour, 2000; Mc Millen & Söderberg, 2002). In a study by Gitlin and co-authors (1998) the meaning attributed to assistive device use by persons with stroke was examined in an early phase. The results showed that devices may be reminders of the loss and disruption caused by stroke and yet provide a mechanism for continuing valued roles and activities.

Now that the experience of different assistive devices has been investigated by different qualitative research methods, it may be regarded as an established fact that low-tech assistive devices intended for use in daily life are not neutral in their value. Often there exists a twofold meaning for the disabled persons who are using the devices.

The results of this dissertation are in line with those of previous studies involving groups of persons with different disabilities including persons with stroke (Gitlin, Luborsky, & Schemm, 1998). The present studies and four of the others were performed in Sweden, which may enhance the transferability of the result in this geographical context. The fact that the spouses also sometimes experienced a twofold relationship to the devices has to be further investigated.
Incorporation of the devices

The results have shown different relations between the participants and the devices. One relation was that the device was incorporated into the person (e.g. a wheeled walker equalled legs or a reacher equalled an extension of the body) and felt transparent with regard to certain activities. People want the transformation allowed by technology, says Ihde (1990), but do not want to be aware of its presence. At the same time there is a wish to engage in activities without the mediation of technology. Ihde (1998) discusses embodiment relations from the perspective of technology in general, and he presents the following diagram illustrating the incorporation of technologies into perceptually-bodily actions: [ (I-technology) – World ]. A situation is transformed when technology is used, and the activities performed are now mediated through the technology. Ihde speaks of a phenomenological-hermeneutical approach to philosophy. An example from the present dissertation will illustrate this point: [(I-wheeled walker) – World]. In this example the wheeled walker is incorporated into the person’s body and does not feel like an extra thing in the performance of different activities. Once the person has learned to use the device properly, it (as Ihde [1990] puts it) “withdraws”.

In another example from the dissertation there was the following relation to technology: [(I – reacher – keys)]. According to Ihde (1998) the reacher is not embodied but feels like an extra piece of material when picking up the keys. The reacher mediates between the person and the keys. Something has been lost, the tactile sense of the keys. But on the positive side, this is the only way in which the person can pick up the keys. Use of the device changes the way in which the keys are experienced. All technologies change and transform situations, but the extent differs (Ihde, 1998). The use of assistive devices in conjunction with disablement does not simply replicate the situations existing before disablement where there was no need of any device. All technologies have different assignments and they are all culturally embedded (Ihde, 1998), and how we relate to a technological object has to do with its use for us (Ihde, 1990). Ihde’s conclusions are comparable to the results of Studies I and II.

The discussion above is mainly from the point of view of Ihde, but other philosophers, such as Heidegger and Merleau-Ponty, also have discussed technology in relation to the human being, though not to the same extent. Ihde himself draws upon the knowledge of these philosophers in his conclusions regarding the effects of technology on the body (Ihde, 1998). Furthermore, he explains that technologies extend bodily capacities and are non-neutral as they change the basic situation. Sometimes this is subtle change and sometimes more noticeable (Ihde, 1990). It is obvious from
Studies I and II that assistive devices were not neutral in their value since they have changed the basic situation in daily life for the participants.

**Different meanings of assistive devices**

As shown in Table VI and in Studies I and II, assistive devices may give rise to many thoughts and associations with regard to different situations in life. The major differences between “ordinary tools” used at home and assistive devices can be discussed. Many of the examples in Table VI may be transferred to the meaning or association of a bicycle or a chair. A bicycle may contribute a feeling of freedom and may be associated with improved fitness. For another person it may represent a means to fulfil certain goals. A chair may facilitate performance of activities or be seen as a natural part of the home. However, all of the examples in Table VI are specifically associated with assistive devices in a Swedish context, in addition to being associated with ordinary tools, but to a lesser degree. Participants in our study conveyed strong feelings about their relation to assistive devices – they really would like to get rid of them and manage without. If they do not have to use them they often relate this to signs of becoming healthier. This kind of reasoning is in contrast to the mindset of a person buying an ordinary tool and wanting to use it in one way or another. Another difference is that most disabled persons in Sweden have been prescribed assistive devices through the health-care system, which also provides the device. Ordinary tools can be chosen individually. Assistive devices are presented in the literature as being a special kind of tool as not everyone wants to have them. Additionally, they are rarely a tool demonstrating personal choice, taste or social fashion (Brooks, 1991).

Assistive devices may give rise to stigmatising situations (Davis, 1997; Goffman, 1990), especially in public places, and most often other tools will not. Toombs (2001) states that people will not use devices if they feel ashamed of using them. In this dissertation the people use the devices in spite of the feeling of stigma, since the wish to manage on their own and be able to be outdoors is stronger. When new technology is introduced, for instance the mobile phone, people tend to stare at the person using it, in this example wondering why the person is talking to himself/herself. When many people are using the new technology it seems to lose its stigmatising effect. Wheeled walkers are now so common in Sweden that they will probably be less connected with the experience of stigma in the future. The same sort of thing has been discussed with regard to canes (Mann, Granger, Hurren, Tomita, & Charvat, 1995). If social attitudes are changing because more persons use canes, there is likely to be a decline in the number of persons who feel stigmatised by cane use. As the devices are visible to others and
constantly remind the user that a disability is present, this will influence self-perception (Brooks, 1991; Hocking & Wilcock, 1997). However, if persons see the device as an extension of bodily space instead of a sign of disability, this may give a better self-image and increase the possibility of being more active (Toombs, 1992). Another way to diminish stigmatisation is to enhance the aesthetics of the device (Aminzadeh & Edwards, 1998; Mann, Granger, Hurren, Tomita, & Charvat, 1995).

Finally, Kvigne and Kirkevold (2003) maintain that persons with a disability in relation to stroke have an unpredictable body. The findings presented in this dissertation have shown that some of the devices, for some of the persons in some situations, are indeed unpredictable, specifically in conjunction with an unpredictable environment in the form of buildings, weather, support and attitudes of others. If providers of assistive technology can contribute to lessening the burden of having to use assistive technology it will be a valuable improvement.

The powered wheelchair studies (Studies III and IV)

The main results of the powered wheelchair studies indicate a variegated, positive impact of an outdoor powered wheelchair on activity, participation and quality of life in the case of persons with a disability after stroke after some months’ use.

The results concerning activity and participation measured with IPPA showed a large effect size (2.6) of powered wheelchair use (n=32), as did the results concerning categorisation of own perceived problems (n=118) with ICF (ES=1.9). Especially in the domain Community, social and civic life including engagement in recreation and leisure was there a large effect size. The contribution of the powered wheelchair to a richer leisure engagement in persons with stroke may also facilitate the daily life of next of kin. This result was encouraging since previous studies reported restrictions in leisure activities (Cardol et al., 2002; D’Alisa, Baudo, Mauro, & Miscio, 2005; Young, Murray, & Forster, 2003) including difficulties with regard to going out unsupervised in the community (Lord, McPherson, McNaughton, Rochester, & Weatherall, 2004). In a study investigating powered wheelchairs (indoor and outdoor), using the instrument IPPA in an elderly population, the presented effect sizes were comparable to those of our study (Wessels, de Witte, Jedeloo, van den Heuvel, & van den Heuvel, 2004). Furthermore, a study of powered wheelchairs in Denmark showed that going for a ride and shopping were the most frequent activities, and this result is in line with what was found in our studies (Brandt, Iwarsson, & Stahle, 2004).
As WHODAS II showed divergent results and the effect was highest in the domain of Self-care, the results are somewhat difficult to interpret. This result is probably not an intervention effect. The expected effects concerning the domains Participation in society and Getting along with people did not occur. There was no or only small effect (ES=0.18, 0.20). The measurement of activity and participation difficulties with WHODAS II showed that 44% (n=14) of the study group at the post-test assessment had severe or extreme difficulties with regard to taking part in community activities (domain Participation in society). This is comparable to results in respect of persons with stroke in Ireland (Gallagher & Mulvany, 2004). As WHODAS II is of recent construction, there are no comparable studies within the field of assistive technology.

Concerning psychosocial impact, an outdoor powered wheelchair influenced the participants positively on the total scale and subscales of PIADS. The three items with the highest means were happiness, independence and quality of life. Concerning independence, 78% (n=25) of the participants in our study rated a positive impact of the powered wheelchair, as compared with 85% (n=26) in another Swedish study (Wressle & Samuelsson, 2004). The items concerning independence in this previous study were included as a supplement to the QUEST instrument used for measuring satisfaction with mobility devices. Additionally, independence was found to be a key factor in a qualitative study in relation to other main factors influencing users of powered wheelchairs (Evans, 2000). Further, the item quality of life was rated positively by 81% (n=26) in our study, as compared with 95% (n=18) in a qualitative study investigating safety of powered wheelchairs (Mortenson et al., 2005). Furthermore, a pilot study investigating transitions to powered mobility found high ratings in independence, quality of life and happiness (Buning, Angelo, & Schmeler, 2001). Another item in PIADS is self-esteem, which 56% in the present study (n=18) rated positive, as compared with 84% (n=25) in the study by Wressle and Samuelsson (2004). In sum, the PIADS subscale scores in this dissertation showed on average a lower positive impact than has been found in other studies (Demers, Monette, Descent, Jutai, & Wolfson, 2002; Devitt, Chau, & Jutai, 2003; MacPhee et al., 2004). Such differences are of course worth further study.

Health-related quality of life measured with EQ-5D showed low effect (ES=0.17) on the index score in this study. Comparable low effects were shown in previous research concerning powered wheelchairs (Davies, De Souza, & Frank, 2003) and in a study evaluating assistive devices in four countries, including Sweden, using EQ-5D for validation purposes (Wessels et al., 2000).
To conclude, the results of this dissertation concerning the outdoor powered wheelchair showed a positive impact on leisure activities, shopping and social activities such as meeting relatives and friends (IPPA). The powered wheelchair enhanced the psychosocial aspects, which may be summarised in the form of competence, adaptability and self-esteem (PIADS). The results concerning activity, participation and health-related quality of life measured with WHODAS II and EQ-5D mostly showed no or only small effects. The value of these instruments is therefore in doubt when it comes to evaluating the use of outdoor powered wheelchairs in a pre- and post-test research design.

Relationships between the lifeworld and powered wheelchair studies

The results in the lifeworld study of spouses of persons with stroke (Study II) showed that they are highly involved in assisting the partner with stroke to use assistive devices. They assume great responsibility regarding the devices and give support when the partner needs it, which requires a great amount of physical and psychosocial effort. In WHODAS II the persons with stroke (Study III) rated how much of a problem the family had because of the health problem. The results showed that 78% (n=25) at pre-test assessment and 69% (n=22) at post-test assessment rated the problems of the families as “moderate”, “severe” or “extreme”, which is an indication that there was a substantial influence on the spouse (from the point of view of the partner with stroke). Previous research has shown that caring for husbands/wives with stroke is experienced as highly stressful (Han & Haley, 1999). Especially women experience great difficulties, and the lack of social involvement due to caring for their husbands is particularly acute (Hartke & King, 2002); women also tend to accept a heavier burden than men (Appelros, Nydevik, & Terënt, 2006).

Certain negative influences in the form of increased problems after the powered wheelchair use in relation to activity and participation measured with IPPA were found in the case of three participants. It was mainly a question of problems with regard to the environment. Problems related to the environment were also a common finding in the qualitative studies. In several qualitative studies, a dual outcome of assistive devices has been reported, including the studies of persons with stroke and the spouses in this dissertation.

A main finding in the qualitative studies was the phenomenon of duality when using assistive devices. In the quantitative study using PIADS, all participants rated the use of a powered wheelchair as positive, but there were also seven participants that rated the use as both positive and negative. Four of the seven persons felt more stigmatised after using the powered
wheelchair than before. In the qualitative study of persons with stroke it emerged that every participant gave expression to both enabling and constraining influences of the devices. Stigmatising situations were more often in focus in the results of the qualitative studies. The difference between the studies with regard to the pattern of results may be attributable to the different research methods used, the PIADS with predefined items versus conversational interview. It may also be attributable to the difference in the devices discussed. The powered wheelchair is a high-tech device, in contrast with the low-tech devices mainly included in the qualitative study.

In the light of the results of this dissertation, it is highly important to discuss the consequences of both the qualitative and the quantitative results, especially in those cases where the participants experience a negative impact of the device.
CONCLUSIONS

Both quantitative and qualitative methods were used when investigating different aspects of low-tech assistive devices and outdoor powered wheelchairs. These research approaches complemented each other with respect to the broad range of new information and knowledge gained in this dissertation.

The research project employed the lifeworld existentials *lived body*, *lived space*, *lived time* and *lived human relation*. These existentials proved to be useful when it came to acquiring a deeper understanding of the essential aspects of assistive device use from the perspectives of persons with stroke and their spouses. The lived experience of assistive devices in both study groups goes beyond the biomedical view of the body and the device. When the devices enter the homes of these persons they give rise to existential questions that can be understood and interpreted in terms of an individual’s own or shared lifeworld. Concerning *lived body*, the devices elicit different kinds of feelings depending upon the situational context, bodily habits are maintained or changed with use of the devices, and the devices are sometimes, figuratively speaking, incorporated into the users’ own bodies. Since assistive devices are a prerequisite for being able to continue living at home, they contribute to a new view of the environment, which belongs to the lifeworld existential of *lived space*. Regarding *lived time* the devices are experienced in relation to the different temporal perspectives of past, present and future. In addition, assistive devices are a prerequisite for taking control of one’s own time, which gives a sense of freedom. Finally, these devices are mediators in the *lived human relation* between the couples in the study groups, as well as between the disabled persons/spouses and other people, including the health-care professionals. The maintenance or change of social roles can be attributed in part to the devices, and they sometimes also give rise to stigmatising experiences. Thus the influence of assistive devices is complex and often contradictory, especially when it comes to persons with stroke. As a result, these devices cannot be considered to be just value-neutral tools since they are imbued with meaning and significance. Still the overall experience of assistive devices is positive as the advantages of the devices outweigh the disadvantages in both study groups.

With regard to the quantitative results of the project, assistive devices such as an outdoor powered wheelchair proved important for persons with disabilities after stroke with regard to overcoming activity limitation and participation restrictions in everyday life (IPPA). This is particularly the case with respect to activities related to “recreation and leisure”, different kinds of shopping related to “domestic life” and also “interpersonal interactions” such as socialising with family and friends (ICF). Furthermore,
the outdoor powered wheelchair improves quality of life for its user in the form of increased competence, independence, well-being, happiness and self-esteem (PIADS). Concerning health-related quality of life, the only measurable positive impact is found in the Usual activity domain (EQ-5D). It is also important to highlight the negative impact of powered wheelchairs in the case of seven participants: there were such reactions as embarrassment and frustration. Both the IPPA, PIADS and ICF have proved valuable when studying the outcome of the use of outdoor powered wheelchairs.
IMPLICATIONS

The present dissertation provides knowledge and insight into the meaning and complexity of assistive devices from the perspective of persons in need of such devices and their spouses. It is important that the prescriber should be sensitive to the user’s and his/her family’s thoughts, feelings and experiences in order to be able to provide the necessary support and encouragement. The person in need of devices may well have a dual or contradictory attitude towards them, and it is important that the prescriber should give the person ample opportunity to talk about this.

The results from this research could be implemented in prescribers’ formal education and clinical practice, and other health professionals as well could take advantage of them. This newly acquired knowledge highlights the concrete problems encountered with respect to assistive devices in activity, participation and quality of life. In addition, it is important to understand and interpret the subjective meaning these devices have for the particular user and his/her family, with particular reference to stigmatising situations. Therefore an emphasis on how to support the participation of the family in the prescription process should also be part of the prescribers’ education. One objective of the Swedish Handicap Institute is to provide knowledge about the possibility of using different technologies to enhance participation in society. These findings of the dissertation can contribute towards the fulfilment of that objective – different disability organisations, for instance, could be invited to arrange special seminars where the role of assistive devices is to be discussed.

ICF proved useful for categorising the participants’ stated problems before and after the provision of a powered wheelchair in this project. If ICF is expanded to include a temporal dimension as well as a subjective dimension of the persons’ experiences, it ought to be possible to better fathom and understand the complex situation brought about by the use of assistive devices and employ this knowledge in the prescription process. However, until this expanded model has been presented and accepted, the recommendation arising from this research is that both the lived experience from the lifeworld perspective and ICF are useful when prescribing assistive devices in rehabilitation and occupational therapy. How useful ICF is in clinical practice and in conjunction with other types of assistive devices needs to be tested of prescribes and other health staff. However, ICF may serve as a framework for documenting the prescription process in patient records.

Further studies should focus on the meaning of assistive devices from the perspective of the next of kin and also investigate possible gender differences. Knowledge of the spouses’ experiences early in the prescription process is
important, as well as including spouses of other patient groups than stroke. In addition, the lived experience of using these devices, including powered wheelchairs, should be investigated in longitudinal studies covering at least 12 months. With this added knowledge, the devices will hopefully not contribute to stigmatising situations in the future. Finally, as WHODAS II and PIADS are here used in a Swedish context for the first time, there is also a need of psychometric studies of the Swedish versions of these instruments.
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REFERENCES


McKibbin, C., Patterson, T. L., & Jeste, D. V. (2004). Assessing disability in older patients with schizophrenia, results from the WHODAS-II. *Journal of Nervous and Mental Disease, 192*(6), 405-413.


"For sure it’s good that they (assistive devices) are there, the best would be that one wouldn’t need to use them. But if you do, it’s good that they are there.”

(A man with stroke, Study I)
Lifeworld Perspectives utilizing assistive devices: Individual’s lived experience following a stroke
doi:10.2182/cjot.06.005

Ingvor Pettersson • Peter Appelros • Gerd Ahlström

Key words
- assistive devices
- lifeworld perspectives
- hermeneutic phenomenology

Abstract

Background. In lifeworld research, the individual’s experience of meaning is of primary importance. Purpose. This paper explores how individuals post stroke who have a disability described their personal meaning and lived experiences associated with the use of assistive devices. Methods. A hermeneutic-phenomenological research approach was used. A conversational interview was conducted with 22 post-stroke individuals regarding their daily experiences utilizing assistive devices. Results. The results showed a dual experience regarding the use of assistive devices, which is often complex and contradictory. The devices were viewed as a prerequisite for well-being and independence but at the same time, the devices gave rise to negative feelings because of the restrictions implied by their use. These dual experiences were explored in relation to the lived body, space, relations to others, and time. Practice Implications. The results of this study will facilitate occupational therapists understanding of an individual’s experiences utilizing assistive devices and their need for support with this process.

Assistive devices are tools for living (Wolf, 1980 in Gitlin & Levine, 1992) that can improve quality of life (Gitlin & Levine, 1992; Scherer, 1996) and allow independence in daily living for people with disabilities (Wielandt & Strong, 2000). Assistive devices are designed to improve the function of an individual with a disability (World Health Organization, 2001) or prevent, compensate, monitor, relieve or neutralize the disability (International Organization for Standardization, 2002).

Occupational therapists often prescribe assistive devices to encourage and facilitate daily activities of people with disabilities. Gitlin & Levine (1992) present four basic principles to guide in the device selection and instruction from the perspective of the individual with a disability and their next of kin. These principles are goal identification, psychosocial factors, caregiver involvement, and collaborative-based treatment approaches. Furthermore, Smith (1995) proposed a client-centred model for prescription, in order to take account of individual values, roles, interests and goals. Understanding how individuals with disabilities experience their lived world in relation to assistive devices is a prerequisite for enhancing their participation and quality of life. The purpose of this study was to explore how people with a disability following a stroke described their personal meaning and lived experiences associated with the use of assistive devices.

Literature Review

Extensive research in the assistive technology field has been conducted during the last 10 years, but still there is only a small though growing, body of knowledge about the personal meanings assigned to assistive devices in daily life.

In lifeworld research, the meaning of different...
phenomena is crucial. One phenomenon in daily life is an individual's experience of using assistive devices. The lifeworld, then, is the lived or existential world as experienced in everyday life. This life is most often taken for granted and hard to describe (Van Manen, 1997). Van Manen (1997) describes four fundamental lifeworld themes referring to the existentials that contribute to the understanding of lived experiences. They are lived body or corporeality, lived space or spatiality, lived relation to others or relationality, and lived time or temporality. These existentials form a unity, they can be differentiated but not separated. In the experience of a disability, the lived body may change. Merleau-Ponty (2002) gives an example where a blind individual experiences a cane as an extension of the body. Concerning lived space, the relation between the lived body and space is changed. For example, the bathroom can be experienced as being far away after earlier being close (Toombs, 1992). The lived relation with others is the interpersonal space that people share with others and having a disability may project a negative body image (Toombs, 1992; Van Manen, 1997). Finally, lived time is subjectively felt time, which constitutes dimensions of past, present and future, and the sense of time may be altered depending on disability and what we are doing (Benner, 1994; Van Manen, 1997). Other researchers have presented similar foci for lifeworld experiences. Benner (1994) presented five sources of commonalities related to the lifeworld: situation, embodiment, temporality, concerns and common meanings. Further, Finley (1999) described the same lifeworld concepts as Van Manen with the addition of identity.

People relate to things in their immediate environment, and Van Manen (1997, preface, p. xiv) states that "we know things through our bodies, through our relations with others, and through interaction with the things of our world." More specific objects, such as assistive devices, are used at the interface between people and environment, and there is little evidence of the influence of devices on the lived experience or self-identity of people who use them (Hocking, 1994; Hocking & Wilcock, 1997). When assistive devices are necessary to perform daily activities they have a considerable impact on the daily life of an individual with a disability (Häggblom Kronlöf & Sonn, 1999; Luborsky, 1993; Lupton & Seymour, 2000; McLennan & Soderberg, 2002). Assigning of personal meanings to assistive devices has been studied from the perspective of elderly women (Häggblom Kronlöf & Sonn, 1999), people with disabilities (Lupton & Seymour, 2000; Lund & Nygard, 2003; McLennan & Soderberg, 2002) and users of mobility devices (Aminzadeh & Edwards, 1998; Copolillo, 2001; Pippin & Fernie, 1997) and of spouses of persons with stroke (Pettersson, Berndtsson, Appelros, & Ahlström, 2005). These studies have, in some respects, showed a two-fold meaning of assistive device use that comprises positive and negative qualities.

Stroke is a major health problem in all industrialized countries and the most important cause of physical disability in people over 60 years of age (Kaste, Fogelholm, & Rissanen, 1998). About a third of the people with stroke who are alive after 6 and 12 month are dependent on others in their daily life (Appelros, Nydevik, & Viitanen, 2003; Warlow, 1998). When an individual recovers from stroke there is a personal experience of rebuilding and restructuring their lifeworld including social, emotional and physical aspects (Burton, 2000). Previous research has shown that the use of assistive devices is common in people with a residual disability after stroke (Mann, Hurren, Tomita, & Charvat, 1995). Most devices are used to compensate for hygiene-related activities, mobility and transfers (Gosman-Hedström, Claesson, Blomstrand, Fagerberg, & Lundgren-Lindquist, 2002; Hass, Freden-Karlsson, & Persson, 1996; Löfgren, Nyberg, Mattsson, & Gustafsson, 1999). In a recent study, people with visuospatial agnosia provided their experiences of striving to master the physical world (Lampinen & Tham, 2003). They found devices, such as wheelchairs, unruly, especially in early rehabilitation. Further, Gitlin, Luborsky, & Schemm (1998) showed that personal, physical and psychosocial implications of assistive device use are complex when it comes to people with stroke in early rehabilitation. Topics dealt with included adaptation between the device and the body, and dilemmas of social identity and of cultural values derived from socio-cultural and psychological processes.

Only one study (Gitlin et al., 1998) has been found that examines the perspective of individuals with a stroke using assistive devices in early rehabilitation. Further research is also needed concerning the later stages when the people are living in their home environment. The present study deals with the personal meaning for people and their particular experiences of living with and using assistive devices 1-year post-stroke.

**Method**

A hermeneutic-phenomenological method guided primarily by the works of Van Manen (1997) and Benner (1994) was used in both the data collection and analysis, thereby seeking to capture the personal meaning of using assistive devices as expressed by the participants. Phenomenology seeks to describe the individual in the situation and the meaning of his or her lived experience of everyday life. Hermeneutics relates to the interpretation of "the expressions and objectifications (texts) of lived experience in the attempt to determine the meaning embodied in them" (Van Manen, 1997, p. 38). The lifeworld, which refers to the meaning of lived experiences in everyday life in relation to lived body, lived space, lived relations to others and lived time, as described by Van Manen (1997) has been applied in this study.

It is important for the researcher to have the ability to be reflective about the impact of his or her own assumptions,
background and earlier experiences (Benner, 1994; Van Manen, 1997). The first author’s pre-understanding derived from many years’ work as an occupational therapist and lecturer. Such experience should be made explicit, held deliberately at bay and allowed to be challenged, altered or extended (Benner, 1994; Van Manen, 1997).

Participants
All the people with a first-time stroke (n=388) were registered during a 12-month period in the municipality of Örebro, Sweden (123,506 inhabitants). The search for these individuals occurred within and outside the hospital. Details of the recruitment have been previously published (Appelros, Nydevik, Seiger, & Terent, 2002). Adult survivors at 1 year (n=253) from that cohort were eligible for inclusion in the present study. The inclusion criteria for the participants were as follows:

1. Score of 22 to 30 on a Mini-Mental State Examination (MMSE) (Folstein & Folstein, 1975).
2. Moderate to severe disability including assistance with Personal or Instrumental Activities of Daily Living (P-ADL, I-ADL), which represents a score of 3 to 5 on the Modified Rankin Scale (MRS) (Van Swieten, Koudstaal, Visser, Schouten, & Van Gijn, 1988).
3. None or slight communication problems (i.e. able to participate in an interview).
4. Own two or more assistive devices for daily life and registered at a centre for assistive technology. Orthopaedic, vision and hearing aids were not included.

Of the 26 possible participants who fulfilled the inclusion criteria, 22 agreed to participate. The group consisted of 6 women and 16 men with an average age of 75 years (range 35-86). The mean scores of the MMSE were 26.3 and of the MRS were 3.6. Seven participants received help with ADL from spouses only, 5 received help from both spouses and home-help staff/personal assistant, and finally 10 participants were living alone and received help only from the home-help service. None of the participants was working at home-help service. Each interview lasted from 1 to 2 hours. A broad question about the experience of living with and using assistive devices in daily life was asked. This question was followed by direct questions about an ordinary day and specific situations involving assistive devices. Conversation was about their identity, lived time, lived space and relationship to different people in society in relation to device use. Past time and present perspective were also discussed. Probing questions were asked, such as: “Can you give an example?” or “What was it like?” in order to obtain a level of concreteness. All questions which were asked were guided by the participant’s own lifeworld experiences with the devices. The participants also showed their devices and were asked to rate the device: “What is, in your opinion the importance of this device in daily life?” according to VAS (Visual Analogue Scale) (see Table 1). The VAS was a 100 mm line with the ends “not at all important” and “very important”. In summary, all the devices were very highly rated with regard to importance but there was a slightly lower median in the case of devices for housekeeping.

### Table 1. Number of Assistive Devices and Participants’ Rating of Their Importance in Daily Life According to VAS (n=22)

<table>
<thead>
<tr>
<th>Category of Device</th>
<th>Number</th>
<th>VAS* (Md)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Personal care</td>
<td>51</td>
<td>9</td>
</tr>
<tr>
<td>Mobility</td>
<td>55</td>
<td>9</td>
</tr>
<tr>
<td>Housekeeping</td>
<td>19</td>
<td>7.5</td>
</tr>
<tr>
<td>Furnishing and adaptations to homes</td>
<td>52</td>
<td>8</td>
</tr>
<tr>
<td>Handling other products</td>
<td>16</td>
<td>9</td>
</tr>
<tr>
<td>Others</td>
<td>3</td>
<td>-</td>
</tr>
<tr>
<td>Total</td>
<td>196</td>
<td></td>
</tr>
</tbody>
</table>

*Note: Three people dropped out. The median was calculated on all devices (n = 170) for daily living.

Data collection
The Research Ethics Committee of Örebro University Hospital in Sweden approved the study. The participation was based on informed consent after receiving both oral and written information. The first author visited the 22 participants in their homes. The purpose of this visit was to gain understanding of participants’ uses of assistive devices in their familiar surroundings. Conversational interviews with guiding questions were conducted and each audio-recorded interview lasted from 1 to 2 hours. A broad question about the experience of living with and using assistive devices in daily life was asked. This question was followed by direct questions about an ordinary day and specific situations involving assistive devices. Conversation was about their identity, lived time, lived space and relationship to different people in society in relation to device use. Past time and present perspective were also discussed. Probing questions were asked, such as: “Can you give an example?” or “What was it like?” in order to obtain a level of concreteness. All questions which were asked were guided by the participant’s own lifeworld experiences with the devices. The participants also showed their devices and were asked to rate the device: “What is, in your opinion the importance of this device in daily life?” according to VAS (Visual Analogue Scale) (see Table 1). The VAS was a 100 mm line with the ends “not at all important” and “very important”. In summary, all the devices were very highly rated with regard to importance but there was a slightly lower median in the case of devices for housekeeping.

Analysis
The analysis procedure was guided by an attempt to reflect on the inherent meaning, balancing the research context by considering parts and whole. There was reflection on the lifeworld themes in relation to the data and the phenomenon was described with increasing precision through writing and rewriting. This methodical structure was employed in the analytical procedure in order to obtain a credible description and interpretation of what constitutes the lived experience of using assistive devices (Van Manen, 1997).

The analytical procedure involved the following steps:
1. The researcher listened to each audio-taped interview to acquire a general sense of each participant’s lived experiences.
2. The interviews were transcribed verbatim, including
nuances of expression such as periods of silence, crying and laughing.

3. The selective reading approach was used (Van Manen, 1997) and involved simultaneously listening to the tape and reading the text on the computer. A key question was posed at this stage: What phrases seem important in relation to the lived experience of using assistive devices? As a result of the question, in each interview text, meaning units (a coherent expression of content) of assistive device use were identified. Furthermore, the meaning units were transformed in the sense that they were expressed in a more coherent and condensed language (Kvale, 1996). Consequently conversations about other topics were excluded.

4. The method of capturing the whole main content in the interview about each participant’s personal meanings and experiences of assistive device use was to reconstruct a personal core story. These core stories configured the transformed meaning units into a whole, a story that gives meaning to each participant’s lived experiences.

5. The transformed meaning units of each interview were first tentatively grouped, then categorized into the four fundamental structures of the lifeworld: lived body, lived time, lived human relations and lived space (Van Manen, 1997).

6. Analysis across the cases began with bringing together transformed meaning units from all the participants according to the four lifeworld structures.

7. Analyses were completed across all core stories and transformed meaning units according to the four lifeworld existentials. Similarities, as well as differences and variations were investigated. A preliminary result emerged, organized within themes of lifeworld existentials and aspects.

8. Finally, each core story was read again and compared with the results to find out if the personal meaning of using assistive devices in the core stories was in accordance with these results. To verify trustworthiness of the results one of the authors (GA), experienced in qualitative analysis, listened to and read transcripts of five of the interviews, verifying the themes and aspects.

Results

The specific lifeworld concepts of the lived body, relations to others, space and time were evident as themes in the interviews, closely interconnected with one another and with the assistive devices (see Table 2). Within each lifeworld theme there emerged a two-fold experience of assistive device use, the two sides being in contrast with each other for example, positive-negative, advantage-disadvantage, and pleasure-displeasure. This was the case with regard to all the participants, though it differed in extent within the lifeworld themes and the aspects of the themes.

Theme one: Lived body and assistive devices

Functioning and disability:

People experienced the assistive devices in relation to their bodies in different ways. Sometimes these devices were felt to be positive. They compensated for a physical dysfunction or facilitated the performance of activities and they were seen as a prerequisite for becoming healthier. They were felt to be energy-saving, and they were sometimes used for preventive purposes. A mobility device was experienced as a means for being prepared, such as preventing a fall, getting to a bathroom quickly or to improve fitness. There were people to whom the devices which offer physical support and a sense of security meant all the world to them. At the same time the devices reminded the people that they were disabled, limiting their activity and participation. People could no longer do what they used to do, and they had to be extra careful in situations where assistive devices are involved. Despite being glad to have their devices, some of the people said that they still got aches and pains in their arms and hands from a walker, constipation from sitting in a wheelchair, and continued to suffer from a lack of exercise if they had to depend on a powered wheelchair.

<table>
<thead>
<tr>
<th>Themes and aspects</th>
<th>Themes and aspects</th>
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<tbody>
<tr>
<td>Lived body and assistive devices</td>
<td>Lived relations to others and assistive devices</td>
</tr>
<tr>
<td>- Functioning and disability</td>
<td>- Lived relations to the device</td>
</tr>
<tr>
<td>- Habits</td>
<td>- Lived relations to persons in society</td>
</tr>
<tr>
<td>- Feelings</td>
<td>- Lived relations to family, friends and neighbours</td>
</tr>
<tr>
<td></td>
<td>- Lived relations to professionals</td>
</tr>
<tr>
<td>Dual relations to assistive devices</td>
<td>Dual relations to assistive devices</td>
</tr>
<tr>
<td>Lived space and assistive devices</td>
<td>Lived time and assistive devices</td>
</tr>
<tr>
<td>- Change in lived space</td>
<td>- Temporal perspective</td>
</tr>
<tr>
<td></td>
<td>- Use of time, and habits</td>
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<td></td>
<td>Dual relations to assistive devices</td>
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<tr>
<td>Dual relations to assistive devices</td>
<td>Dual relations to assistive devices</td>
</tr>
<tr>
<td>- Assistive devices as objects in lived space</td>
<td>Dual relations to assistive devices</td>
</tr>
<tr>
<td>- Choice of environments for performing activities</td>
<td>Dual relations to assistive devices</td>
</tr>
<tr>
<td>Dual relations to assistive devices</td>
<td>Dual relations to assistive devices</td>
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</table>

Four individual excerpts from the core stories, each representing one lifeworld concept, were chosen to illustrate the results.
Habits:
The devices helped people to organize and structure their daily lives, enabling them to maintain, modify or abandon earlier habits. Most of the people became accustomed to the assistive devices which they used on a daily basis.

Having to change established routines and habits because of assistive devices required thought and planning. Several people said that a further assistive device, like a powered wheelchair, could foster bad habits by decreasing their activity level. Sometimes the changes in habits were felt forced upon the individual because of requirements by the staff, which they had to learn and adhere to. Others were content to let the staff establish new habits for them or in collaboration with them. Others said that they would like to have retained earlier habits but have had to modify or abandon them because of disability, assistive devices and rapid turnover of staff.

Feelings:
Feelings in relation to the use of assistive devices were directed not only towards the devices themselves and one’s own person but also towards the social environment and people within it. The majority of the people were happy, positive and grateful regarding the devices as they improve safety and ability to do activities. People became more independent, felt more satisfied and respected. There was a strengthening of self-esteem, and they felt proud at having met the challenge of working out for themselves how to simplify different procedures in accordance with the body’s new conditions. These feelings enabled them to go on performing various tasks. Some of the people felt anxious and insecure at the thought that their mobility devices might be stolen or that children might use them for play. Others were anxious about the possibility of needing a further assistive device, which validated a deterioration of their health. Individuals were afraid of hurting themselves if they do not use the assistive devices, but they were also afraid when they do use them. They were afraid when they moved about in the community where there were high pavements and drains, where the walker or wheelchair could get stuck, or when they went by bus and received no help getting on or off. Several were afraid when there were a lot of people and a risk of being jostled and falling. They got irritated when they had to use a device but could not handle it, not knowing whether the fault lied with the device, the environment or themselves. Furthermore, an assistive device could be felt to be a thing you are forced to have, but at the same time is demeaning and unpleasant.

The use of assistive devices could be simultaneously experienced both positively and negatively by individuals. These experiences could involve a specific device, a category of devices or all of the devices that have been utilized. As one person said, the process can be a "love-hate relationship." People with a stroke were dependant on their devices in order to function, but they also preferred to not have to use them and welcomed the opportunity to return them if this was a viable option. One person spoke of his ambivalent feelings whereby he was depressed when he got an assistive device while acknowledging that it helped him to get recover. Feelings were generally expressed relative to the individual’s present situation, but also in relation to when the device was obtained, or also to the past when the device may not have been available.

Case Example:
K is a woman who has recently moved into an apartment. As a result of the move, K has had to change how she completes some of her daily activities, either by limiting them, changing the approach, etc. She depends on the use of assistive devices to complete many tasks and is appreciative of their availability. "I suppose I’ve accepted them,” she said. At the same time she is afraid to go out of her suite with her walker when it is a crowded place; also the devices are constant reminders of her disability. "I can’t be without the devices but I’m still tired of them and I’d like to be able to get about under my own steam now. I’ve got to have them but I can’t do anything when I’ve got them. Life has changed. You’re glad the devices are available but you can’t help wondering about your needing them.” She says that the devices have given her a better quality of life than she would have had without them.

Theme two: Lived space and assistive devices

Change in lived space:
Assistive devices affected the perception of individuals in relation to their home, as well as the social and physical environment. Their lived space changed and became restricted. Several participants indicated that they would like to be able to go to other places in order to extend this space. One person said it was like going from the free world to a more restricted world. Others looked with satisfaction upon the fact that they could go on living at home because they used assistive devices, whilst there were those who were aware that they may not be able to go on living at home if they got worse, there being limits to what the devices could accomplish.

People who used mobility devices attached great importance to the weather. During the cold, rainy and snowy part of the year they had less chance of going out. When they were dependent on staff with regard to going out, the people often did not ask for that help because it was humiliating. They would rather stay in than run the risk of a refusal from the staff. Their lived space became more restricted to home than they preferred.

Assistive devices as objects in lived space:
Assistive devices need to have a place within lived space if
they were to be used for the performance of necessary and desired activities. Some people think the devices took up a lot of room in the home. Others saw the devices as a natural part of the home and in nobody’s way. The devices were given priority, even if it meant rearranging the furniture or getting rid of a piece of furniture. Certain people mentioned that the devices could scrape against furniture or doorframes and this was a nuisance.

The devices had been assigned special storage spaces where they would not be in the way but sometimes they had to be stored in a stair-well or cellar or in the car. Being regarded as indispensable, they had to be easily accessible. In the case, particularly, of small assistive devices such as reachers, the individual had to remember where they were. Certain people worried about having to watch out that staff did not put a device in the wrong place.

**Choice of environments for performing activities:**
The assistive devices played a role in determining what places a person could go to and how much time was spent outside the home. People had to plan their outings and they could be limited regarding where they could go. Reported barriers included uneven surfaces, with differing heights, which is evident on curbs, steps and entrances to stores. Several people with wheeled walkers were afraid of falling over if the walker got caught in an object such as a drain. This was a particular problem for people with improperly fitted walkers, for example with wheels that were too small.

**Case Example:**
E lives in a small flat of his own in an apartment where staff is available 24 hours a day. His health has improved and E can now manage to take a few steps with his wheeled walker, though he remains largely dependent on a wheelchair. His goal is to manage without these assistive devices. He is glad that with the aid of the wheelchair he can get to the common dining-room and TV room on his own. E has arranged the furniture in such a way that there is a special corner at the foot of the bed where the walker and the wheelchair conveniently stand. However, members of staff keep moving them. He had to shift the TV because it almost got broken by the devices. He is so tired of finding them put here, there, and everywhere, but now he has given up: “I haven’t got the energy to keep making a fuss and going on about it,” he said.

**Theme three: Lived relations to others and assistive devices**

**Lived relations to the device:**
For some of the people the assistive device was incorporated and became a part of their own body. This applied chiefly to mobility devices. Other people looked upon the devices as friends or faithful pets. Still others looked upon them in terms of “relatives that you’ve got to stay in touch with.” Devices having to do with hygiene, however, were not looked upon as friends but as mere necessities. A device could also be used as a means of exerting pressure when it came to having services performed (e.g. one person using a walker needed help immediately and threatened the attendant to fetch him on the walker). Assistive devices meant a great deal to the people who needed to use them.

**Lived relations to people in society:**
Half of the people experienced a changed relation to society by feeling stigmatized or singled out. Certain individuals felt that other people did not talk to them because it was assumed that they had an intellectual disability. Some individuals found that people initiated more contact than before, others found that this was less. At times, there were questions regarding the use of assistive devices, but this was not consistent. There is a stronger reaction to manual wheelchairs but less to a motorized scooter or a cane. Certain individuals felt exposed the first time they used mobility devices out of doors, when people stared, but they became acclimatized.

The feeling of being exposed is related to the fact that the equipment indicates to people that they have a disability. Individuals reported that people are not that considerate to accommodate their needs when they are outdoors, but this is not always the case. Furthermore, people who do not feel exposed are of the opinion that walking devices are so common that no one reacts. In addition, the use of assistive devices has become legitimized through the use of them by royal families.

**Lived relations to family, friends and neighbours:**
People found that the introduction of a new assistive device into the home had an effect on family roles and tasks. The people were dependent on spouses and were sometimes anxious lest their spouses should hurt themselves on the device or should, in the long run, find themselves overburdened and be unable to offer the requisite help. It was the spouses who were the best “device”, and without them the people with disabilities often found it impossible to go on living at home. The spouses acquired new roles and tasks where assistive devices were involved. It could be, for example, cleaning, lifting or fetching a device, or pushing the wheelchair on a trip outdoors. This reminded people with a stroke that they could not do such things themselves. At the same time the assistive devices could help the person to maintain roles to some extent; he or she can, for example, transport groceries on a powered wheelchair or wheeled walker.

The people with a stroke related that family could help too much and give them no chance to use a device. For instance, they may have prepared a piece of bread and butter for them, and not been given a chance to use their adapted cutting board. Spouses were also afraid that the people would fall if they tried to get about with their walking devices and without their spouses’ help.
The people found that friends and neighbours could be both supportive and sceptical when it came to their need for assistive devices. For example, these people could have a condescending attitude to the user of such devices, stop associating with the person because they do not want to go out with someone who cannot walk unaided, speak ill of the devices or feel sorry for the person. The latter’s reaction to this may be one of sadness, anger or indifference. But other friends and neighbours could be supportive, thinking it is a good thing that the person has acquired the devices and thinking the person should be glad about it.

Lived relations to professionals:
Feelings differed when it came to the relationship with home-help staff and personal assistants, on the one hand, and with prescribers on the other hand. Those who were dependent on staff for their personal care wanted to be able to manage on their own or at least with less help. Without the assistive devices, they would be even more dependent on staff. It meant a lot to be able to do things oneself, for example, to be able to get out of bed without having to ring and bother staff. Sometimes members of staff would do more than the person really wanted, and it was difficult to say no to such help. On occasion, people would have to be particularly attentive when home-help staff had been there. They had to readjust assistive devices or put them in their right place. Sometimes different members of the home-help staff had different attitudes towards the person. One of them may think it important, for example, that the person should train using the walking-frame. Another may not agree. Staff was viewed as providing security in that they offer help, and they support the person in the use of assistive devices.

Some of the people would have liked more chance to participate in the prescription process, for example, choosing which devices to have. Sometimes they had to convince the prescriber that a particular device was what they needed, sometimes, to their disappointment, they felt that the prescriber doubted whether they needed a device at all. Others felt that they were involved in the process and they were glad to find that the prescriber could see what their needs were.

Case Example:
L lives with his wife in a flat. He needs help both from her and from the home-help service. He has a positive attitude to assistive devices and regards them as a means of self-help, though at the same time they are a sort of constraint. He feels greatly tied by them, yet at the same time there are things he would not be able to do without them. When he was prescribed a wheeled walker, he would like to have tried out different types of wheeled walkers and see which was best for him, but he was not allowed to do this. He automatically takes it with him wherever he goes, and at night it stands ready beside his bed so that he can get to the toilet if necessary. "It's like a dog lying by my side," he says. And when he goes to the bathroom he parks it outside the door just like a car.

He himself feels no embarrassment about going out with a wheeled walker, but he knows others who do. His attitude is that they should be glad that they have a device to help them. L does find it troublesome going around town in the middle of the day, because people stand talking everywhere. In his irritation at their not moving when he comes along, he bumps his walker into their legs. "It doesn't cost a healthy person anything to step aside," he says. "It doesn't bother me to bump into their legs, it's the only way to get them out the way. I ought to have a loud horn, make them jump." When he goes out to town (which is more or less every day) he needs the support of his wife. Reminiscing, he says: "In the past people from the social services came and helped you go out if you were old - now they send a walker instead, saving money."

Theme Four: Lived time and assistive devices

Temporal perspective:
People experienced time in different ways. Present, past and future were perceived from the perspective of assistive devices. There were people who looked to the future with hope, envisioning the day when they would be able to hand back their devices and thus have a sort of proof that they have gotten better. Others looked to the future hoping that they would be able to receive a less restrictive device than what they had now, for example, replace their wheelchair by a wheeled walker. Some compared their own situation with that of their parents or other elderly relatives. They wished that these people could have had the same access to assistive devices as they themselves now have. One man saw his present need of assistive devices in relation to other "devices" he had used, first bicycle, then car, then cane, then walker. He thought that things had first gone forwards, then backwards.

Certain people compared their present circumstances to when they were healthy, noting that things took longer when using an assistive device. They had accepted that, though in some cases grudgingly. Others adopted a different temporal perspective; they could do things better and faster now than before they acquired such devices. They felt that the main thing was being able to perform the activities and the extra time required because of having to use assistive devices is of less importance. Others, however, said that they never thought about things taking more time or even say that things do not take more time. They said they had all day or “all the time in the world”. Time was not a problem.

Another aspect of the relationship to time was that the person could be out considerably longer, and go considerably further, with the use of an assistive device. Going out helped...
the person to stop thinking about their illness and disability. Those who needed the help of next of kin or staff were dependent on these people’s time and opportunity. Having to wait, having to adjust to other people’s time, affected their own experience of time. Having the power of determination regarding your own time meant having a measure of control over what you did during the day. There was a sense of freedom in being able to perform activities just when you wanted, regardless of other people’s time. Assistive devices are a prerequisite for this.

Use of time and habits:
The people changed their habits, both indoors and outdoors. For some of them, it did not take long, from a few days to a couple of weeks, to fully incorporate an assistive device into their lives and adopt its use as a new habit.

They had to check the devices and see that they were in the right place, so they could use them quickly when required. They were so important they needed to be readily accessible, otherwise there would be tasks that are difficult or even impossible to perform.

Some of the people needed to structure their daily activities because of the assistive devices. One woman, for example, used a cutting-board with clamps. She cut up bread, vegetable and cheese for several days at a time, because it was difficult to set up the board. Another person saw to it that he always had his reacher easily accessible from his wheelchair, so as to be able quickly to pick up dropped door-keys. Had he not had the device, someone might have been able to get into his flat before he had the chance to pick up the keys.

Several people also planned their day and activities so that they were home when they need to go to the toilet or were in some secure place where the people knew that they could manage this on their own. At home there was an adapted toilet, but not always elsewhere. The uncertainty about getting to the toilet in time imposed a severe restriction on their daily lives. There was also a feeling of uncertainty when it came to a lift with automatic doors: Will they make it with their mobility device before the doors shut?

Case Example:
S is a single woman living in a flat where she receives daily help with personal care. She uses her assistive devices often and would not be without them. She says that, in general, things take longer with the devices, but the opposite is the case when it comes to walking. It takes time and energy to see that the devices are standing right, or in the right place, so that she does not hurt herself or fall. She says that she would know where they were "even if you blindfolded me". She thinks about how she used to regularly go out for a walk with a friend. Now this woman does not come round any more, and S assumes that it is because the woman is ashamed to go out with her because of her wheeled walker. S does go out on her own sometimes, but she has difficulty coping with the various obstacles along the way. One trouble is when snow gets under the mudguards, she has to sit on the walker and use a stick to get the snow off. Every time that she has been out she thinks the wheeled walker is unpleasant, because it has got dirty. She cleans it with a cloth wound around the reacher, but it irritates her having to spend time on this. For her bed S has a back-rest, a hoist, lifting-blocks and handles, which means that she herself can decide when to get up in the morning. Getting up may be a slow process but she persists, because then she does not have to wait for staff.

Discussion
From the perspective of people with a disability following 1-year post-stroke, the study revealed a broad, deep and variegated meaning attaching to the use of assistive devices. To use such devices influences how people with a stroke experienced their lived body, lived relations with others and lived space and time. Assistive device use seemed to be two-edged: while the devices are a prerequisite for well-being, independence and the performance of daily activities and are highly esteemed, they also give rise to negative feelings. Similar results were found in a previous study (Gitlin et al., 1998). Although people with stroke in early rehabilitation using assistive devices are able to engage in daily activities that have a personal meaning, use of the devices also contributed to emotional, physical and social disruption. Studies with groups other than people with a stroke (Brooks, 1991; Hägglom Kronlof & Sonn, 1999; Lund & Nygard, 2003; McMullen & Soderberg, 2002) showed similar results. Assistive device users felt that they had achieved a better life but that there were difficulties in accepting the devices emotionally. Furthermore, similar results were found in a study examining mainly computerized technologies; the devices allowed the people to transcend some aspects of their disability but had negative aspects (Lupton & Seymour, 2000).

These results can be compared with studies of the usage of technologies, revealing a kind of essential ambiguity. There are contradictions: "The user both wants and does not want the technology. The user wants what the technology gives but does not want the limits, the transformations that a technologically extended body implies" (Ihde, 1990, p. 76). Were it possible, people wanted a total embodiment of the technology, wanted it to "become me", equivalent to there being no technology (Ihde, 1990). For some people in this study, the results indicate that the device has indeed "become me", for instance a walker is experienced as equal to legs, but for others the devices are not embodied in the same way.

Csikszentmihalyi & Rochberg-Halton (1981) stated that each new object in our homes changes the way we organize and experience our lives. They also stated that:
"Objects affect what a person can do, either by expanding or restricting the scope of that person’s actions and
thoughts … objects have a determining effect on the development of the self, which is why understanding the type of relationship that exists between people and things is so crucial” (Csikszentmihalyi & Rochberg-Halton, 1981, p. 53).

Their findings are in line with the findings in this study: people with stroke feel that the devices contribute to giving up or modifying their habits to a great extent. People who need assistive devices have more things to be mediated between the body and the task than people in general, which changes their way of performing activities. Nevertheless their new habits seem to be incorporated; they have no other choice if they want to perform daily tasks.

Through the entire interview the participants constantly come back to an important question, that of visiting the toilet, both in their homes and in other places. These visits include the self, the relation to others, and lived space and time. They are greatly concerned about whether there is a toilet at all; getting to the toilet in time; whether the toilet is high enough, or whether there are grab bars to facilitate getting up or whether they can reach the toilet; and also about whether they have their devices, such as wheelchair, wheeled walker, or cane, ready prepared, as this is a prerequisite for visiting the toilet. Often they come to the conclusion that it is safest to stay in their home environment. But even if they stay home, they are not sure that they will get to the toilet in time. Thus, visiting the toilet largely determines what they do during the days.

The people in this study experienced changed spatiality in relation to the places they visit or would like to visit depending on their disability, their devices, the climate, other people, and the design of the surroundings. The same aspects are discussed in the literature (Toombs, 2001). Often they must restrict places to visit and also make a careful plan regarding which places are safe to visit. Assistive devices both restrict and extend their lived space, depending on ways of relating to the devices. Certain places may contribute to inclusion or exclusion, and people tend to choose places where their lived space is encouraging (O’Brien, Dyck, Caron, & Mortenson, 2002). Further, the meaning of space changes over time, and home may be a place of isolation owing to stigmatization in society (O’Brien et al., 2002). This finding is consistent with the results in this study.

The participants experience a two-fold lived relation to the device, to people in general, to professionals, and to next of kin. They need the devices, but they prefer to be independent and do without assistive devices or help from the home help service. If they need personal help, it may remind them that they are not capable of managing by themselves. Staff or next of kin can also reinforce that by taking over tasks which the users would be able to manage by themselves. Verbrugge, Rennert, & Madans (1997) show a hierarchy of preferences whereby people first try devices and then turn to human assistance when the equipment fails to help them.

Toombs (2001) stated that people will not use devices if they feel ashamed of using them. In this study some of the people felt stigmatized (Davis, 1997; Goffman, 1990), a feeling associated with the appearance of the device, when meeting friends, professionals and people in general. But they used the devices in spite of that, because managing to get out was a stronger drive.

The temporal perspective concerns past, present and future and is something inside us as well as around us (Csikszentmihalyi & Rochberg-Halton, 1981; Westergren, 1990). In this study some people see the future as a time when they can abandon the device, while other people are worried about what the future has in store, especially if their spouses do not have the strength to help them with daily activities including handling the devices. To decide about your own time by yourself, so you can carry out daily activities as and when you want, irrespective of others’ time, is of great importance. These results can be compared with previous results that show that the past, present and future of each person are inextricably linked to the objects in his or her environment (Csikszentmihalyi & Rochberg-Halton, 1981).

This study group was limited to people with stroke who were able to communicate about the use of assistive devices. Their most frequent devices were canes, wheeled walkers, wheelchairs, shower chairs or stools, and reachers. Only 3 people were in the possession of a powered wheelchair. In a study by Mann et al. (1995), people with a stroke used 9 "physical" assistive devices during year one, which agrees with the present study. In this study the mobility devices, which were used in society, yielded a majority of experiences. Personal meaning ascribed to device use included an influence on the people’s identity and individually perceived roles. Assistive devices were not a value-neutral tool, especially when used in society.

Each person’s life is always too complex for any description and interpretation by a group of people to do it justice (Van Manen, 1998), and assistive devices and their use are only a part of a larger whole. The major themes lived body, lived others, lived space and time (Van Manen, 1997) have been used in the analysis in this study. The description and interpretation of the text within these themes is only a simplification of the whole lifeworld. Constantly, a decision has to be made about into which theme and aspect the particular lived experiences should be placed. Here an interpretation was carried out. As these themes are closely interconnected, the intention is not to break up the participants’ experiences. Using the existentials described by Van Manen (1997) produced a deeper knowledge about the lived experiences of using assistive devices.

The people with a stroke in this study were interviewed
onc e, and this might be regarded as a limitation of the trustworthiness of the results. Furthermore, there was an overrepresentation of male participants, which may contribute to other results than if there were a more equal distribution of men and women.

**Implications for practice and research**

All professionals prescribing assistive devices should be aware of the broad range of meaning and experiences that are possible to the users. All things that we use are expressions of ourselves and change the content of what we think about ourselves (Csikszentmihalyi & Rochberg-Halton, 1981; Hocking, 2000). Assistive devices are no exception.

Assistive devices, in this study, seem to be an object that the people need but really do not want to have. The devices are products that normally are not common in the homes before the people get a disability, and other people in society do not want to use or own them either as they bear a symbolic meaning (Brooks, 1991). This raises the question whether there are any other products in society that can be compared with assistive devices regarding usability, appearance and symbolic meaning. Occupational therapists can contribute to a change of attitudes in society and empower the people using devices not to feel stigmatized when using devices.

People in need of devices ought to be asked to participate in the prescribing process, so they can choose devices according to personal preferences and to the attractiveness of each device (Smith, Quine, Anderson, & Black, 2002). Probably their lived experience of using devices would then be more satisfying. In this study, a few people wanted to participate in that process but were not allowed to do so. According to Louise-Bender, Kim, & Weiner (2002) successful integration in the community depends on the meaning the people assign to devices, expectations of devices, anticipated social costs, and ways to come to terms with the disability. From the point of view of this study, it seems appropriate, when prescribing assistive devices, to ask probing questions concerning both psychological and adaptation issues. This recommendation is endorsed in previous research (Copolillo, 2001; Häggblom Kronlöf & Sonn, 1999; Louise-Bender et al., 2002; Luborsky, 1993).

Investigating how people experience the differences and similarities between using assistive devices and ordinary tools is important. The studies cited were performed in Western societies. Useful knowledge would be obtained from studying cultural aspects both within countries and within one country as compared with others.

**Conclusion**

This qualitative study explores not only the specifics of the use of devices, but also the universalities with regard to assistive device use by people with stroke in relation to lifeworld concepts. All people with a stroke were frequent users of assistive devices for daily living, and the devices influenced their experience of the lifeworld in different ways. The lifeworld existentials, lived body, lived space, lived others and lived time, proved useful for acquiring a deeper understanding of the essential aspects of assistive device use. Within all lifeworld themes there emerged two-fold experiences, which can be seen as contradictory: whilst the devices are a prerequisite for well-being, independence and the performance of daily activities, and are highly esteemed, they also evoke negative feelings and restrictions in daily life.

Concerning lived body, the devices elicit feelings of gratefulness and satisfaction because of the assistance they offer when it comes to mastering situations in daily life, being independent in daily life, preventing further disabilities and maintaining earlier habits. On the other hand, a device may be a reminder of the person’s disability, or of his or her getting worse. The people need to have the devices but they do not really want to need them. Regarding lived space the people with stroke are positive towards the devices as a prerequisite for going on living in one’s own home and surroundings. At the same time the devices contribute to negative feelings, restricting places to go owing to inaccessible environments. Further, lived others and assistive device use contribute to both facilitating and hindrance aspects. The people with stroke are treated with respect by people in society, and next of kin support them in the use of the devices. On the other hand there can be a changed relation to people in society and friends who question their use of the devices. Feelings of stigmatization occur. Some occupational therapists, as well, question the person’s desire to participate in the prescription process. Finally, lived time is experienced in relation to past, present and future. Assistive devices are a prerequisite for taking control of your own time, which gives a sense of freedom. On the other hand people may relate time to when they were healthy, not in need of assistive devices.

The implications of the results of this study, the lifeworld perspectives in relation to assistive device use and the dual outcome, can enable the occupational therapist to better understand the complexity of a person’s experiences when using assistive devices and the person’s need for support in connection with the prescribing of such devices.

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**References**


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“The devices are my right hand. That’s the way it is when you’ve got to have them. They’ve got to be there like another part of me all the time. They’ve just got to be there. Otherwise it’s no good”

(Spouse of a person with stroke, Study II)
Lifeworld perspectives on assistive devices: Lived experiences of spouses of persons with stroke

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Abstract
The purpose of this study was to explore how spouses of persons with a disability following stroke describe their lived experiences regarding assistive devices in everyday life. A phenomenological lifeworld approach was used and conversational interviews were conducted with 12 spouses. Their lived experiences of assistive devices were explored in relation to four lifeworld existentials intertwined in everyday life. The results showed that lived body concerns aspects of feelings, habits, and incorporation of the devices with one’s own body. The devices are, from the spouses’ perspective, a prerequisite for their partner with stroke living at home. Successively the devices are incorporated into the couples’ homes, and they provide a new view of the environment, aspects related to lived space. The devices bring about a changed relation to lived time, related to past, present, and future. Further, lived human relation concerns changed relationships to husbands/wives with stroke, including a great responsibility due to the devices and their usage. The results also included stigmatizing aspects and a twofold relationship to health professionals regarding participation in decisions about prescribing assistive devices. Understanding the unique meaning of assistive devices from the spouses’ perspective is vital for occupational therapists prescribing such devices.

Key words: Assistive technology, carer, hermeneutic phenomenology, home environment, occupational therapy, qualitative research

Introduction
The use in the home of equipment such as assistive devices concerns not only the person with a disability but also his/her next of kin. This study focuses on assistive devices from the perspective of spouses who have a partner with stroke. Assistive devices are aimed at “improving the functioning for a disabled person” as stated in the ICF (1). In another definition the concepts “prevent”, “compensate”, “monitor”, “relieve”, and “neutralize” are used to designate the aims of assistive technology in relation to disability (2). In Sweden, county councils and municipalities are obliged to provide people with disabilities with assistive devices for day-to-day life. Devices for daily living are essentially free of charge for the users (3). Assistive devices are one of two common means for reducing task demands of persons with a disability; the other is personal assistance (4–6). The devices may support the person both directly and through supporting his/her family (7). Assistive devices, then, may be seen as a potential means to reduce the care need for persons with a disability and also to reduce the burden of the primary carer (4,8). Persons with a disability try devices first if possible and then turn to human assistance only when devices fail (9). The use of assistive devices has a considerable impact on the person with a disability (10,11) and their spouse, as the devices become part of the life of the whole family (7).

The spouses as primary carers encourage, teach, and assist their partner with a disability to use...
assistive devices (4,12). When assistive devices are to be prescribed, the involvement of carers is therefore important (13). Factors affecting the carer’s implementation of assistive devices include the characteristics of the carer and the member of the family with a disability, the relationship between the two, the carer’s resources, attributes of the devices, and situational characteristics (14).

Persons with disabilities after stroke are a group in which the use of assistive devices for daily living is common. In a study of 27 persons with stroke, it was found that 1 year after stroke a mean of 9 physical assistive devices was used and that 2 years after stroke the number had increased to 10 (15). In another study, a group of 155 patients with stroke constituted 20% of the total population of stroke patients in the area. In this sample the results showed that 81% were provided with assistive devices or environmental modifications within 6 months after discharge from hospital (16). In another research project it was found that 12 months after discharge from hospital (16). In this sample the results showed that 81% were provided with assistive devices or environmental modifications within 6 months after discharge from hospital (16). In another research project it was found that 12 months after discharge, about 80% (n = 139) of the persons under study possessed one or more assistive devices. The most common devices were those for bath/shower, walking, toileting, and grip/reach (17).

Spouses have an important role in supporting their member of the family with stroke in the course of rehabilitation (18), including support with the assistive devices. Experiences of relating to, or personal meanings assigned to, assistive devices have been studied from the perspective of persons with disabilities after stroke who use assistive devices (19,20). Thus it seems important to understand the unique meaning of assistive devices from the perspectives of spouses, as the devices exist in a shared environment. Research has not previously addressed these kinds of questions. Therefore the purpose of this study is to explore how spouses of persons with a disability following stroke describe their lived experiences regarding assistive devices in everyday life. In this study focusing on the spouses’ perspective, the spouse is the person cohabiting with a partner with stroke. The spouses’ partners with stroke are not termed “patients” in this study because they are living in the community in their own homes.

Material and methods

A lifeworld approach

The theoretical framework for this study is based on the concept of the lifeworld, which has its foundation within phenomenology (21,22). The lifeworld is the world in which persons live their daily lives. It is related to a person perceiving the world, but is also the world in which persons live together with others. Generally the lifeworld is taken for granted and in everyday life it is most often not questioned. In the epistemological sense the lifeworld is pre-scientific and pre-reflective. Within a lifeworld approach the question of meaning, as it is lived by a person, is of primary importance (22). However, in everyday life meanings are often implicit or “tacit”, for example the meaning of a person’s experience of different things in the home environment.

Within a lifeworld approach, assistive devices, like all other things, are not simply objects, but are closely integrated in the man–world relationship (21,23). Merleau-Ponty (24) emphasizes that things can be an extension of the body, and to embody things means to acquire a habit. Csikszentmihalyi and Rochberg-Halton (25) state that each new object in the home changes the way people organize and experience their lives. They also state that “objects affect what a person can do, either by expanding or restricting the scope of that person’s actions and thoughts . . . objects have a determining effect on the development of the self, which is why understanding the type of relationship that exists between people and things is so crucial” (p. 53). Further, van Manen (22) states that people know things through their bodies and through relations with other people as well as through interaction with things in the world.

The ground for the study is four fundamental lifeworld existentials, described by van Manen (22). These are lived body, lived space, lived time, and lived human relation. Lived body or corporeality draws upon Merleau-Ponty’s (24) theory of the lived body, integrating the physical body and the soul, where human beings are always in the world with their bodies. Lived space or spatiality refers to how space is experienced, and how space is related to the body. Lived time or temporality is subjectively felt time and refers to the temporal way of being in the world. Finally, lived human relation or relationality refers to how persons experience others as human beings and in different respects share interpersonal space with them. These existentials form a unity; they can be differentiated but not separated; instead, they are intertwined in the lived world.

In this study, the participants’ personal meanings regarding assistive devices and how they interact in their lifeworld have been interpreted and described from a hermeneutical phenomenological standpoint described by van Manen (22). Phenomenology emphasizes description, seeking to describe the person in the situation, and mediates between concreteness, differences, what is unique, and what is essential. Hermeneutics is a matter of interpretation of “texts” of life while declaring faithfulness to
the person’s lived experiences (22). Of importance is the researchers’ ability to be reflective about the influence of earlier experiences and assumptions in their own background (22). The main author’s (IP) pre-understanding derives from many years of work as an occupational therapist visiting persons with physical disabilities and their families in their homes. This experience is not “bracketed” but treated tentatively, and is seen as the basis for understanding (22).

Participants

All spouses (n = 12) of a study group of persons with stroke included in a previous study (n = 22 (20) were asked whether they would participate in this study, and all consented. The group consisted of 10 women and 2 men with a median age of 75 years (range 36–80). Two of them were working and 10 were retired. All spouses were cohabiting with the persons with stroke. Ten of the families were living in urban and two in rural areas in a municipality in Sweden.

The spouses’ partners had had a stroke a year before the spouses were included in the study. The partners had a moderate to severe disability, which represents a score of 3–5 on the Modified Rankin Scale (MRS) (26). They required personal or instrumental care every day either from spouses only (7 persons) or from spouses and home help staff/personal assistant (5 persons). The persons with stroke possessed on average 9 assistive devices (range 5–16) and most of the devices had been prescribed in connection with discharge from hospital a year earlier. Their devices included ones for personal care (e.g. shower chairs, raised toilet seats), mobility (e.g. walkers, wheelchairs—manual and electrically powered), housekeeping (e.g. cutlery), and adaptations for housing (e.g. beds, bed back-rests, cushions) as well as ones for handling other products (e.g. reachers) (Table I). The most common device was a shower chair/stool, which had been prescribed for all persons with stroke except one. All persons with stroke had mobility aids such as a walker, cane, or wheelchair, and three of them had a powered wheelchair.

Data collection

A regional research ethics committee at a university hospital in Sweden approved the study. The first author visited the spouses in their homes a year after their partners had had a stroke and conversational interviews of about an hour long were carried out. The interviews were audio-recorded, except in the case of one spouse where notes were taken because of this person’s refusal to be recorded. The interviewer (IP) was familiar with the homes and families through having earlier interviewed the persons with stroke, as presented in a previous study (20). The interviews were carried out with openness to the spouses’ lived experiences and the meanings attached to assistive devices in their homes. A broad question about the participants’ experiences of living with assistive devices in their home environment started the interview. More specific follow-up questions were asked about an ordinary day and particular situations where assistive devices were involved. The spouses’ own relations to the devices, associated with the concepts lived body, lived human relation, lived space, and lived time, underlay the conversations.

Data analysis

In order to grasp the meaning of the spouses’ lived experiences of assistive devices the analysis was carried out with openness to the material while reflecting on the inherent meaning. The procedure was guided by considering parts and whole both within and across the interview transcriptions, with the persons’ lifeworld situations in mind, both as they appear in the texts and with reference to the encounters in the interview situations (22). The procedure was essentially performed in the following way:

- The researcher listened to each audiotaped interview to acquire a general sense of each spouse’s lived experiences. The whole interview, including the interviewer’s questions and conversations, was transcribed verbatim, including nuances of expression such as laughing and periods of silence.

<table>
<thead>
<tr>
<th>Category of device</th>
<th>Spouses (nos) of partners with prescribed assistive devices</th>
</tr>
</thead>
<tbody>
<tr>
<td>Personal care</td>
<td>2  3  2  2  4  1  2  3  2  2  2  2</td>
</tr>
<tr>
<td>Mobility</td>
<td>2  2  4  4  2  4  2  3  2  2  5  1</td>
</tr>
<tr>
<td>Housekeeping</td>
<td>3  3  1  1  2  2  2  1</td>
</tr>
<tr>
<td>Furnishing and adaptations to homes</td>
<td>6  3  5  3  2  3  3  5  2  2  1</td>
</tr>
<tr>
<td>Handling other products</td>
<td>1  1  1  2  2  1  1</td>
</tr>
<tr>
<td>Others</td>
<td>1  1</td>
</tr>
<tr>
<td>Total</td>
<td>10  6  16  10  6  12  5  11  12  9  12  5</td>
</tr>
</tbody>
</table>

Table I. Category and number of assistive devices in each spouse’s home (prescribed for their partner with stroke).
A selective reading approach was used involving simultaneously listening to the tape and reading the text on the computer. A key question was posed: What phrases seem important in relation to the participants’ lived experiences, associated with living in a home where assistive devices are a part of everyday life? As a result of the question, meaning units were identified within each interview text and then transformed in the sense that they were put into a more coherent and condensed linguistic form. Consideration was given to how different themes were elaborated in a dialogue between the researcher and each participant in the interviews.

One way of capturing a whole was through transforming the main content of the meaning units related to each participant into a personal “core story”. In each case it was a condensed coherent story of each participant that gave meaning to his/her lived experiences of assistive devices in the home environment.

In an attempt to capture the meaning of each core story, significant parts of the story were described and interpreted in relation to the chosen lifeworld existentials: lived body, lived space, lived time, and lived human relation.

Analysis across cases was performed by bringing together descriptions and interpretations regarding each lifeworld existential. Aspects of the existentials were identified and interpreted with reference to their context.

Finally, the described and interpreted texts were read again and compared with each core story. A coauthor (IB) experienced in studies within a lifeworld approach examined some interviews, and the transforming of meaning units and core stories in some interviews, to verify the trustworthiness of the descriptions and interpretations regarding the lifeworld existentials and the aspects that emerged.

Results: Spouses’ lived experiences of assistive devices

The meaning assigned to living with assistive devices from the spouses’ perspective has proved complex, as the devices are an integral part of the spouses’ own lifeworld as well as of the lifeworld shared with their husbands/wives with stroke. The devices are of significance for the spouse’s lived body. The lived body and the devices exist in relation to lived time and lived space, and in lived relationships with other people. The devices are seen as non-neutral things, experienced as both possibilities and restrictions in the situations where they are used. However, the advantages overshadow the disadvantages.

Lived body in relation to assistive devices

When the partner with stroke has become disabled and needs both assistive devices and daily help, this represents a challenge to the lived body of the spouse. Life is not what it was. This affects the spouse’s habits, routines, and feelings, both positively and negatively. Daily life now involves assistive devices, and gradually these become incorporated with the spouse’s body. The following quotation represents the lived body integrating assistive devices such as wheeled walker, raised toilet seat, and shower chair:

“The devices are my right hand. That’s the way it is when you’ve got to have them. They’ve got to be there like another part of me all the time. They’ve just got to be there. Otherwise it’s no good.” (Spouse no. 4)

Feelings in situations where assistive devices are involved

Assistive devices in the home give rise to both positive and negative feelings in the spouse. These feelings are directed towards the devices themselves, the person with stroke, future life together, and society in general. Often there are both positive and negative feelings regarding the same situation where assistive devices are involved. There are positive feelings when the couple can continue to share their lifeworld as before, albeit with certain modifications. Several spouses speak of being glad and grateful that assistive devices are made available, this being a prerequisite for the couple’s continuing to live together at home. But there are ambivalent feelings, as expressed in a remark such as: “I like the device, I’ve got to” (spouse no. 2). That the person with stroke uses assistive devices means that the spouse can feel calm and secure. But there are also more negative feelings such as anxiety, frustration, and exhaustion when the spouse has to bear the main responsibility for the proper functioning of everyday life. The spouse’s anxiety, for instance, can be about what the future holds: will her/his partner with stroke be able to cope, mentally and physically, or will things go downhill and the devices be insufficient for the continuance of a life worth living? There is also anxiety about possible injury, arising from the partner’s not using adequate devices; and anxiety about possible injury to others, arising from the difficulty of handling certain devices, such as a powered wheelchair in traffic.
On other occasions the spouses’ feelings derive from the assistive devices as such, in relation to the spouses themselves. One woman speaks of “laziness” with reference to her using her husband’s shower stool despite being capable of showering while standing. The device affects her self-image by bringing home to her that she is not as active as she might be.

Habits and becoming accustomed to assistive devices

Assistive devices enable many couples to retain their former habits. A wheelchair or a wheeled walker, for instance, makes it possible to go out together every day as before. The spouses can relax if they can go out. Some have become more tied to the home, which they find difficult. The spouses have themselves to become accustomed to using devices primarily intended for the husband/wife with stroke: a raised toilet seat, for instance. Though at first some of the spouses felt the new devices in the home to be intrusive, they gradually became accustomed to them.

Assistive devices are incorporated with the body

Most spouses regard the assistive devices prescribed for their husband/wife as independent of themselves, though some feel them to be incorporated with their own bodies. One spouse names the wheeled walker “a car”, and in her case the car has been replaced by the walker, and this she has learned to accept. The walker enables them to go out together. Another spouse says that her husband’s assistive devices are like a right hand to her, a second self. What she cannot do on her own, the devices help her to do. Without them, she and her husband would not be able to go on living at home together. A third spouse regards the assistive devices as intruding upon her “self”, though she adds that this is a bagatelle considering their importance to her husband.

Lived space in relation to assistive devices

Assistive devices are not valued as other things in the home are; nevertheless they are crucial with regard to the ability of the person with stroke to do things either independently or together with the spouse. The assistive devices become part of the home according to the spouses. There are often stationary ones in bathroom and bedroom. Mobile ones are moved by the person with stroke, the spouse or both together in every room. Sometimes they are in special spaces, sometimes “parked” here, there, and everywhere. Sometimes they are attached to furniture, sometimes moved from one piece of furniture to another. They are not always easily incorporated into the home, because they have played no part in the couple’s earlier life there. The following quotation from a female spouse whose husband has a severe disability after stroke illustrates the lived space:

“You don’t think about them every day, I’d say. They’ve become so much a part of your everyday life you don’t see them as separate. In the end they’re just there, and that’s it. It’s when they’re not there you notice it, and miss them.” (Spouse no. 1)

Assistive devices—a prerequisite for living at home

From the spouses’ perspective the home should be aesthetically appealing and a place where you can feel secure and at ease. Several spouses are preoccupied, both emotionally and physically, with getting everyday life to run smoothly so that the home is a nice place to be. By the time the devices have been in the home for a year they have become part of the home and are essential to the couple’s continuing to live there. Characteristic comments are “They’re worth their weight in gold” (spouse no. 5) and “Without them, things would’ve gone off the rails long ago” (spouse no. 4). Certain spouses speak of sleeping securely because they know that the walker is there beside their partner’s bed. Mobility devices are seen by some as offering an escape from being shut in at home; others feel shut in anyway. Some wonder about the situation when the limit has been reached and the devices are insufficient to permit the continuance of life together at home. Perceiving this limit to be impending is a painful experience. The thought of moving to different accommodation is not easy to handle.

Assistive devices are gradually incorporated into lived space

For most spouses the devices have been incorporated into the home and have their natural place there. They have become one with everyday life. “At the start they were just sort of in the way, there was something there that shouldn’t have been there. But as time went on – well, you don’t think about it so much, do you?” (spouse no. 6). One woman states that in the beginning she knew nothing about the disease or assistive devices. “First you manage on your own in life, then comes disease and then come assistive devices, creeping up on you, and then they’re there and that’s that” (spouse no. 1). When assistive devices are introduced into the home they
are given priority over furniture. When the husband/wife with stroke has to use assistive devices it is necessary to modify the home, refurnish it, get rid of mats. It seems difficult at first, but the spouses become accustomed to it. The devices make life easier, and if they are not there or not functioning they are missed.

People feel differently about assistive devices in the home. The devices should be in their place, “not just anywhere, littering the place”. Mobility devices not in use should be out of sight. The spouses often have to see to this. One spouse says that her home is not at present as she would like it to be because the furniture has had to be rearranged, and she is not pleased with the result. The devices arrived in the home as alien objects but she had to get used to them. Another spouse says that there is a limit when it comes to assistive devices: one device too many and the home will look like a nursing home. None of the spouses feels now that the devices take up so much room that it does not feel like a home. Spouses would like their partners who are confined to wheelchairs to use ordinary furniture, ordinary armchairs, but this would mean that the husband/wife was “bound” to this furniture and would need help getting into and out of the armchair. Therefore the wheelchair is both a mobility device and a piece of furniture.

The outdoor environment—assistive devices give new perspective

The outdoor environment is now seen differently, not always being tailored to the requirements of the person with a wheeled walker or wheelchair. Pavements are uneven, kerbs are high, slopes are difficult, aisles in shops are narrow, and the goods hard to reach. Solving such problems is often up to the spouse. Spouses who push their partners in wheelchairs find it hard work, whilst spouses whose partners use a wheeled walker find it necessary to “watch over” this use.

Lived time in relation to assistive devices

Having assistive devices in the home, being responsible for them, and helping the husband/wife with stroke to handle them affects how the spouse experiences time. The spouse’s experiences and thoughts concerning the devices are set in relation to past, present, and future. Sometimes the spouse’s experience of time is straightforward: there is a superfluity of time, where nothing competes with the urgent task of helping the husband/wife. Not always, however. It may be that the rhythm of family life changes, the spouse’s own time diminishes and becomes fragmented, and the spouse feels too tied to the home. There may also be uncertainty as to whether the devices will remain adequate in the future. One of the spouses illustrates how important rapid delivery of the devices is in relation to the lived time of her and her husband with stroke:

“I mean, it can be months before everything’s sort of in place, and in this case it’s important months—yes, it is, vital months.” (Spouse no. 6)

Assistive devices in relation to past, present, and future

Usually within a few weeks the spouse will have got used to the devices and stopped thinking about them, seeing them as a natural part of the home. With the devices the couple can cope better on their own and more easily dispose of their own time. Sometimes, to their satisfaction, persons dependent on home help find that they become less so because of the devices. Further, they experience time more as a whole, not interrupted when home help staff arrive.

The devices can give rise to reflection on living with a disability in the past. Spouses can see the improvement and feel glad that they are living at a time when such devices are available. It is of importance what a device looks like. It may be perceived as unappealingly old-fashioned. Some spouses assign importance also to the age of the user: an old person will find the use of an assistive device more natural than a younger person.

Spouses’ worries about the future is a heavy burden for them. They worry about their partner’s becoming worse and thereby more dependent on assistive devices, and about their own capacity to help, mentally and physically. However, some feel confident that they will be able to cope. Spouses hope that it will continue to be possible to go out together, and that the partner may even be well enough to do tasks without assistive devices.

Changed experiences of lived time

Several of the spouses perceive a change in their lived time due to their husband’s/wife’s having had a stroke. When they are out they feel under stress and must keep an eye on the clock so as not to be late getting back. They experience that time goes fast as they have so much to do in so little time. They know that their husband/wife perceives time as crawling along and is wishing for their return. The spouses are in a hurry to return, concerned about whether there has perhaps already been an accident. Before going out, the spouse has arranged things as best possible.
at home, seeing to such things as wheeled walker at hand and video to watch. Spouses try to ensure that their partners will not hurt themselves during the spouses’ time away, but frustrating uncertainty remains. Some spouses felt that the time spent waiting for delivery of the assistive devices was time lost, and they “had to wait ages”. During this time, the couple could not do certain things together and the husband/wife with stroke did not improve much because the absence of assistive devices made him/her more passive.

“So there we were, just shut in. And it was like that for three and a half months, didn’t go outside the door… We just couldn’t go out, because there was no way I could leave him on his own at all.” (Spouse no. 4)

Dreams of time of one’s own
Finding it burdensome to constantly have to share their time with their husband/wife, spouses dream of having more time to themselves. When they have to both plan the shared daily life and give help, one day becomes like another and their freedom diminishes. One spouse considers it unrealistic to expect more time to oneself; others have hopes of obtaining such time through their partner’s becoming more independent. To this end, several spouses get their partners to use the devices whenever possible, even if it takes more time.

Very few spouses feel that the help they give their husband/wife encroaches on their time, indeed it is not something they think about in such terms, because as retired people they have plenty of time, sometimes too much. They are glad to fill their day with urgent tasks.

Lived human relationship in relation to assistive devices
The dependence on assistive devices in daily life affects not only the lived relationship between husband and wife but also the relationship to prescribers and people in the community. In one situation this relationship will be facilitated and maintained, in another impeded. Roles change, and often the spouse assumes greater responsibility for both his/her partner and the devices. In the shared lifeworld the devices bring husband and wife together in certain activities. The words of a female spouse exemplify the lived relationship:

“This mug [beaker with a spout on the lid] means I don’t have to get up in the night if he wants to take a painkiller or something. Before, I was always having to get up for that, but now he can take a tablet on his own and doesn’t need me to help him at all. It may not seem much, but it’s a big thing to me.” (Spouse no. 3)

Changed lived relation to husband/wife
The assistive devices are experienced as a “built-in” community factor that brings husband and wife together in various ways. The devices are sometimes intrusive; sometimes they come as a relief in the relation between husband and wife. Often a device constitutes an intrusion and a relief at the same time. But after a while the devices become very much a natural part of the husband–wife relationship. Both persons must become accustomed to the presence of the devices in their relationship. The spouse helps the husband/wife with stroke in different situations and solves problems. Husband and wife are no longer equal regarding activities. When the couple go out, the wheeled walker or wheelchair plays a role in the relationship between them. The spouse helps guide the walker, pushes the wheelchair or, in the case of a powered wheelchair, sees that the way ahead is clear. At home the spouse will for instance help manoeuvre the bed back-rest or help in the shower when a shower stool is used. The assistive device links husband and wife and links the couple and the world around.

Increased assumption of responsibility
Most spouses assume great responsibility concerning the smooth functioning of the home so that life may be as good as possible for the couple. They take responsibility for the lifeworld of both, but the starting-point is the needs of their partner. The spouse assumes responsibility for seeing to it that the husband/wife is as active as possible, which in the long run can make the spouse’s life easier.

The spouses assume responsibility for seeing that the persons with stroke receive the assistive devices they need at the right time. They also assume responsibility for seeing that the devices are where they should be, for instance that the wheeled walker is in the car or in the cellar. Some spouses keep an eye on their partner’s health and decide which devices are going to be needed on the particular day and to what extent. Several spouses see that the devices are ready for use, making sure that the wheels of the walker are facing in the right direction or that it is in the right place beside the bed in case the husband/wife needs it during the night. They do this without their partner’s knowing it. Thus the
spouses are prepared and have taken responsibility upon themselves regarding situations involving the assistive devices. With correct use of the devices, the person with stroke can expect to be able to participate more in everyday life.

**Twofold relation to health professionals**

Most spouses regard the relation to the person prescribing the assistive devices as satisfactory: the prescriber is seen as being skilled and sensitive to the couple’s needs. However, some spouses feel powerless or insulted in the encounter with the prescriber and feel that the process requires too much energy and time. They feel that the couple’s need for emotional support in this situation is disregarded. Or they feel that they have not been granted enough, say, in the choice of devices. One spouse says she was not told which devices were available but had to find out for herself.

**Stigmatizing situations outside the home**

Outside the home some spouses protect their husband/wife from stigmatizing experiences. One spouse, whose partner is in a wheelchair, stays in the background so that others will speak directly to the person. Another spouse is influenced by people’s attitudes, and she has had to console her husband when someone has spoken to him condescendingly. A third spouse regards the distance from the ground as crucial: the person in a wheelchair is more vulnerable than the person using a walker. Others say that assistive devices are so common these days as if they were sufficient, which people interact are not simply tools for survival, or for making survival easier and more comfortable. Things embody goals, make skills manifest, and shape the identities of their users” (25, p. 1). This seems to be in accordance with the results of our study. The spouse’s identity is influenced by the use of assistive devices by the husband/wife, and the goals often concern managing daily life. Ihde (29) describes embodiment relations through technology in daily life as constituting an existential relation with the world. The person takes the technology into experience by perceiving through the devices as having both advantages and disadvantages in everyday life.

**Discussion**

The focus in this study is on spouses of persons with stroke and on the assistive devices which have come into their homes in connection with their partner having a stroke about a year earlier. The results show that the spouse’s own lifeworld is influenced by the devices as well as the lifeworld shared with their partner. The assistive devices mediate between the lifeworlds of the couples. When the devices enter the homes they give rise to existential questions concerning lived body, lived time, lived space, and lived human relations.

Concerning *lived body* some of the spouses in this study experienced the devices as an extension of their own body. An example is the woman who points to the devices as her extra hands by means of which she helps her husband. This extension of the body can be understood from Merleau-Ponty’s (24) theory about the lived body. Things are in this theory inseparable from persons perceiving them. Similarly, in this study, Merleau-Ponty tells of a blind man whose cane, which he perceives with, has become an extension of his body. To become accustomed to a cane is to be transplanted into it or incorporate it into one’s own body. This incorporation is, according to Merleau-Ponty (24), both a motor and a perceptual habit. The world begins not at the outer skin of the hand but at the end of the cane. Previous research concerning persons with severe visual impairment or blindness showed similar results (28). The spouses in this study seem to integrate the devices in quite a short time so that using them becomes a bodily habit. But though the devices have become incorporated into a habit-body, there are nevertheless diverse feelings, both positive and negative, about the use of them. Further, Csikszentmihalyi and Rochberg-Halton (25) state that things in the homes are non-neutral objects and inseparable from who we are. They state: “The things with which people interact are not simply tools for survival, or for making survival easier and more comfortable. Things embody goals, make skills manifest, and shape the identities of their users” [25, p. 1]. This seems to be in accordance with the results of our study. The spouse’s identity is influenced by the use of assistive devices by the husband/wife, and the goals often concern managing daily life.
goals is likely to be encouraged. In the present study the spouses experienced the devices as a prerequisite for the everyday life of themselves and their husbands/wives with stroke. But at the same time the devices make demands on the spouses and are most often an intrusion into family life. Tamm (30) also calls attention to furniture as a part of one’s identity, and when assistive devices enter the home there has to be a rearrangement of furniture. This may be experienced as a significant intrusion. In this study the spouses prioritize the devices before furniture.

In the present study the aesthetic look of the home is important to the spouses and some of them want to participate more actively in the prescription process to get devices to suit the person with stroke, themselves, and the home setting. In a previous ethnographic framework, the focus was on understanding the personal meaning of caring for an elderly family member when providing occupational therapy in the home (31). In a case example the occupational therapist found that the devices were kept out of sight until they were required. A similar finding was noted in the present study. Tamm (30) discusses what a home is and when it ceases to be a home in relation to rehabilitation and care. The home may not be the same private place as before, and assistive devices may be seen as an intrusion in daily life at the same time as the home is a workplace of health professionals.

Concerning lived time, in the current study the devices prompted thoughts about earlier generations, the current situation, and the future. Csikszentmihalyi and Rochberg-Halton (25) draw attention to lived time as past memories, present experiences, and future dreams of each person, all inextricably linked to the objects in the environment. Further, Tamm [30, p. 51] states: “It is through everyday things and the symbolic value attached to them that the past is intertwined with the present.” Time is, according to Heidegger (32), nothing in itself; it is personal, which means there are many times. Further he states that time “persistence merely as a consequence of the events taking place in it” [32, p. 3], and Bluedorn [33, p. 31] defines epochal time by events: “the time is in the events”. The events in the present study comprise lived experiences in different situations in daily life, e.g. when the wifes are out shopping or when the married couple are out for a walk. The time perspectives of the spouses in relation to going shopping are different from those of their husbands/wives who are at home. This finding is supported by Toombs (34): a person with a disability may see minutes like hours and hours like days.

The devices in this study exist within a lived human relation to others; they mediate between the activity and the persons who use them. From the spouses’ perspective the devices also mediate between themselves and their husbands/wives with stroke and people in society. According to Heidegger (23) tools exist in relation to a totality of useful things belonging to the person who uses them. These tools are also a symbol of integration or separation of the user in relation to the social context (25). Persons with disabilities may feel a kind of social stigma when assistive devices are introduced into their homes (30,35,36). In the present study too, the spouses were concerned about their husband/wife and the social stigma that is attached to the use of a device in the community. The device is no thing in itself (23,29). It exists between a person with a disability, the family, and a context including the physical, social, and attitudinal environment (1). As shown in this study and other research (13), these factors either promote or constrain the use of assistive devices by persons with a disability and their spouses. The spouses in this study mostly take great responsibility and have an important role in assisting and encouraging the device use of their husbands/ wives. This finding is similar to that of the research on carer involvement from the perspective of elderly people with a disability (4). Research has also addressed carers’ need for support with regard to how to care both for their next of kin with stroke and for themselves. On the basis of these findings a checklist of needs and strategies has been developed (37). Furthermore, spouses of persons with cognitive or astheno-emotional impairment showed low life satisfaction and it would seem that there is a need to focus on the spouses’ activity situation (38). The present research has shown that some of the spouses feel that they would like more attention to their emotional needs and their need for information on assistive devices.

As can be seen from the results regarding the four presented lifeworld existentials, the spouses take great responsibility and are often prepared to assist with the devices in many situations. The spouses carry, lift, move, place, and take the devices out and away. They act, plan, arrange, prioritize, initiate, and discuss the devices. Further, they give support when their husbands/wives with stroke use assistive devices either on their own or together with them. The spouses supervise the daily condition of the persons with stroke as well as correct and prioritize the assistive devices to fit this condition. They also take responsibility for their husbands/wives using devices in public, protecting them from other people’s stigmatizing behaviour. The spouses on their own acquire different feelings, change their habits and routines, and incorporate the devices into their own bodies. The spouses also reflect on and dream about
different situations involving assistive devices to find the best solutions for their husbands/wives with stroke, the family together, or themselves. All these situations involve the spouse's lived body in space and time, and relations to others. Prior research has shown that caring for husbands/wives with stroke is experienced as highly stressful (39). Women in particular experience great difficulties, and lack of social involvement is particularly acute (40).

The devices are important to the families in their embodied being but it should be stressed that they are not value-neutral things. The symbolic value attached to them is intertwined with the lived body, lived time (including past, present, and future), lived space, and lived other. From the spouses’ perspective the device is a tool raising many questions. One question concerns whether the device indicates the user as being worse or being healthier. In fact the same device may indicate improvement to one person and decline to someone else, or a device may at the same time be both positive and negative. Depending on situational and personal characteristics the devices may facilitate or restrict activity and participation in daily life. They may be seen either as ordinary tools or as tools that give rise to stigmatizing behaviour on the part of other people (35). The devices may also be seen as problem-solvers or as the cause of extra problems. Further, the devices raise questions about family existence. Without the devices everyday life at home is impossible, but there is an upper limit to what they can assist with. The devices can be seen as an indispensable asset with a certain negative effect on daily life. They can have different meanings for the spouses and their husbands/wives respectively, as well as for other people. Previously, research from the perspective of persons with stroke has shown similar twofold results (19,20).

When interpreting the results of this study there is a need to take into account the small study group in which 10 of the 12 participants are female and one of the male spouses did not want the interview to be audio-recorded. Accordingly, the lifeworlds of men in relation to assistive devices may have additional, unexplored facets. The strength of the study is in the use of a hermeneutical-phenomenological method and the lifeworld existentials. The four lifeworld existentials were not easily distinguishable from each other, which is perhaps to be explained by the fact that the lifeworld is indivisible (22). In spite of this it was a way in this study of gaining a deeper understanding of the great variety of meanings that objects such as assistive devices can have in daily life. Another merit of the study is the co-authors’ verification of the trustworthiness of the descriptions and interpretations, more particularly by the co-author with previous experience of studies with a lifeworld approach. “Member-check” is sometimes used in search of rigour in qualitative studies, but it was not the case in this study. However, this technique is controversial and involves theoretical, moral, and representational problems (41).

In this study, the meaning of assistive devices when the spouses are accustomed to them has been described. Further research, from the spouses’ perspective, should be considered in connection with the prescription of the devices for their partners in the early stage of rehabilitation. The results of this study further suggest research comparing the meaning of assistive devices with the meaning of other objects in the home. Hocking’s (42) study of how Western people explored objects to reflect self and identity could be the basis for further exploration in the field. Furthermore, since this study mainly included female spouses it is of great importance to perform a similar study where men are in the same proportion as women. Such a research design allows for gender comparison.

In sum, this research from the spouses’ perspective has shown that they experienced assistive devices as being of great importance in their daily lives shared with their husband/wife with stroke. The devices mediate between the couples and influence the spouses’ experience of their lived body in space and time. This knowledge can increase the occupational therapist’s sensitivity, humility, and understanding of family lives when assistive devices are a part of the home. It is of the utmost importance that when prescribing assistive devices occupational therapists take into consideration the needs of the spouses, which also are very important. Follow-up of the prescribed devices should also integrate the perspective of the spouses regarding both indoor and outdoor use. An understanding of the unique meaning of assistive devices from the perspective of the spouses, explored in relation to lifeworld existentials, is vital when occupational therapists and other health professionals are to assist persons with stroke living at home with their spouse.

Acknowledgements

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References

Lifeworld perspectives on assistive devices


“Now I can pick dandelions in the garden. It is fun and a rather important pastime”

(Elderly man who has been provided with a powered wheelchair, Study III)
THE EFFECT OF AN OUTDOOR POWERED WHEELCHAIR ON ACTIVITY AND PARTICIPATION IN USERS WITH STROKE

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THE EFFECT OF AN OUTDOOR POWERED WHEELCHAIR ON ACTIVITY AND PARTICIPATION IN USERS WITH STROKE

ABSTRACT

Purpose: Persons with disabilities after stroke are often restricted in activity and participation in society because of mobility limitations. An outdoor powered wheelchair may be one among other interventions in a rehabilitation programme. The aim of this study was to describe and compare activity limitations and participation restrictions in persons with stroke from their own perspective, before and after using an outdoor powered wheelchair.

Method: At baseline and follow-up two instruments were used: Individually Prioritized Problem Assessment (IPPA) and World Health Organization Disability Assessment Schedule II (WHODAS II).

Results: The results indicated that the powered wheelchair has a great positive effect on activity and participation assessed with IPPA. The results also showed that most of the participants’ problems could be categorised as belonging to the domain of ‘Community, social and civic life’ according to the International Classification of Functioning, Disability and Health (ICF), and the effect size in this domain was large (2.4) after the participants had used the wheelchair.

Conclusion: An outdoor powered wheelchair is an essential device for persons with disability after stroke with regard to overcoming activity limitations and participation restrictions in everyday life.

Keywords: assistive technology devices, powered wheelchair, stroke, evaluation, ICF, IPPA, WHODAS II
INTRODUCTION

To be mobile is often a prerequisite for participating in activities of daily living. Mobility devices, such as powered wheelchairs, are one approach of rehabilitation intervention1 when activity and participation is restricted.2 Provision of powered wheelchairs is increasing3 and the use of such devices can according to the International Classification of Functioning, Disability and Health (ICF)4 interact with body functions, activities and participation in daily life, environmental factors and personal factors. The aim of assistive technology is in the ICF described as improving the functioning of the disabled.4 The ICF has been proposed as a useful conceptual framework for describing clinical practice and outcomes in rehabilitation research5-7 including assistive technology.8-10

There are few instruments specially designed to measure assistive technology outcome.11 Individually Prioritized Problems Assessment (IPPA), developed in a European research project, is one instrument including concepts compatible with the activity and participation component of the ICF.12 IPPA has been used in previous studies of mobility devices.10-13 The World Health Organization Disability Assessment Schedule II (WHODAS II), with its theoretical foundation in the ICF, has recently been developed in a world-wide project.14 So far this outcome measure of activity and participation has not been used to measure assistive technology outcome.

Previous research on the use of, and experience of, powered wheelchairs showed enhanced activity and participation,15-17, satisfaction18 and quality of life.19 The wheelchair also gave the user independence16,18. However, a previous study has also shown that powered wheelchairs also was experienced with ambivalence as negative feelings of discrimination and frustration arise.19

Persons with stroke are a group of individuals where remaining disabilities are frequent and they often need to use different assistive devices.20-22 Further, they are often restricted in participation in leisure activities including going out or going to different places by car or public transport.23,24 In a study of persons with stroke using different types of wheelchairs (including powered ones), the results showed that the persons perceived the wheelchair as either a necessity, a great asset or a part of themselves.25

Though some attention has been given to the issue of activity and participation in persons using powered wheelchairs, we have found no study addressing this issue in respect of a group consisting entirely of persons with disability after stroke using outdoor powered wheelchairs. Therefore the purpose here is to describe and compare activity limitations and participation restrictions in persons with stroke from their own perspective,
before and after using an outdoor powered wheelchair. A powered wheelchair in this study is understood as either an electrically powered wheelchair for outdoor use or a three-wheeled electric scooter.

**MATERIAL AND METHODS**

**Design**
A pre- and post-assessment design was used to evaluate the outcome of using an outdoor powered wheelchair. The study was a multicentre one approved by the Research Ethics Committee, Örebro University Hospital, Sweden, and all of the participants gave their written informed consent. The data collection was in the form of questionnaires in connection with a face-to-face interview by the first author (IP) in the participants’ homes at baseline and at follow-up after 3–5 months (mean 4 months) of using the powered wheelchair. At post-assessment neither the interviewer nor the participant had any knowledge of the ratings on the items given at baseline. The ICF is used in this study as a conceptual framework in data collection, analysis and presentation of results. It describes the negative aspect of functioning at the personal level as activity limitation (difficulties with regard to executing activities) and at the societal level as participation restriction (problems an individual may experience in life situations). These concepts are used in this study with an assumption that a powered wheelchair may decrease or resolve the participants’ perceived limitations.

**Participant selection**
The participants were recruited consecutively from three centres for assistive technology, each situated in a county council area in Sweden. Inclusion criteria were that participants a) had had a stroke, b) were going to be prescribed an outdoor powered wheelchair, c) were able to take part independently in an interview (e.g. prescribers of the powered wheelchairs judged that the participants had no or only slight communication and cognitive problems) and d) had not previously possessed an outdoor powered wheelchair. The technical aids consultants informed the investigator (IP) about persons eligible for the study. Forty consecutive persons were invited to participate and three of them declined. Of the remaining 37, five dropped out after the first interview (four because of illness and one because of not having received his wheelchair in time). The remaining 32 persons (80%, 32/40) participated in baseline and follow-up assessments.

The five persons who dropped out after the first interview were somewhat older (mean 72 years) than our study group. No other marked differences emerged regarding demographic data at baseline.
Instruments

Study-specific questions (13 items) were collected concerning the importance of and satisfaction with the powered wheelchair; how often the wheelchair was used and how far they were driving; mishaps or incidents; and whether the household had a car. Questions were also raised about the need of help to charge the batteries, the need of someone accompanying you when driving the powered wheelchair, and the need of help to transfer to the wheelchair. Some of the items were based on items in a previous study of Brandt and co-authors 16, but also on the instrument Psychosocial Impact of Assistive Devices Scale (PIADS) manual 16.

A check-list comprised of 17 life-events, events that could influence the use of the powered wheelchair (e.g. sickness or death in the family or of friends, separation, moving) and one open item was applied. These items were based on a check-list used in previous research.27 The check-list was applied at follow-up, the intention being to discover confounders affecting the results.

Individually Prioritized Problem Assessment (IPPA) is a generic measure which has been used to assess the effectiveness of assistive technology interventions.10,12,18 It assesses the extent to which everyday activity limitations or participation restrictions are diminished through the provision of assistive technology. It is administered by means of two face-to-face interviews. In the first interview the assistive technology user identifies a maximum of seven concrete activity or participation problems in everyday life which they wish to be eliminated or diminished through an assistive device. The participants assign scores on a 5-point ordinal scale with respect to both the importance (not important at all, not so important, somewhat important, quite important and most important) and the associated difficulty (no difficulty at all, little difficulty, quite some difficulty, a lot of difficulty and too much difficulty) of the identified activity or participation. In the present study the participants related the problems to what they expected of an outdoor powered wheelchair. After they had used the device for at least three months, a follow-up interview was performed and the participants assigned new difficulty scores. The differences between baseline and follow-up form the basis of the calculation of the effectiveness.28

In addition, in this study the ICF was used to categorise reported activities and participation problems (IPPA) into five of the nine domains included in the activities and participation component of the ICF.4 This was performed independently by the first author and a person well-versed in the ICF. A few categorizations led to discussion until the examiners agreed about the appropriate categorization.
Four problems given in IPPA at baseline were not appropriate at follow-up and therefore excluded in the calculations. There were difficulties with regard to taking the dog for a walk (pre-assessment) but now the dog had died (post-assessment) and there had been difficulties with regard to taking out money at a cash point (pre) but now the children took out the money (post).

At follow-up, the participants were also asked to mention activities that they performed with the wheelchair but which they at baseline had not expected to be able to perform. This question was complementary to IPPA.

The World Health Organization Disability Assessment Schedule II (WHODAS II) is a rather new generic instrument, conceptually compatible with the ICF, by means of which activity limitations and participation restrictions in the everyday life of adult persons are assessed. The instrument is recommended for use in health care to study outcome and effectiveness. WHODAS II is an overall disability assessment tool and the questions were in the present study not related to powered wheelchair use. Some different versions exist, but the WHO recommends the 36-item interviewer-administered version as it provides the most complete assessment of activity and participation. Formal permission to translate this version into Swedish was obtained from WHO.

WHODAS II encompasses six domains or subscales: Understanding and communicating (6 items), Getting around (5 items), Self-care (4 items), Getting along with people (5 items), Life activities (4 household items, 4 work items) and Participation in society (8 items). It examines how the persons usually do the activities, including the use of any device or personal help. Difficulties over the last 30 days are scored on a five-point ordinal scale (none, mild, moderate, severe, extreme/cannot do). An overall functioning score and the six subscale scores are recoded in accordance with an algorithm available from the WHO. All scales range from 0 to 100, with higher scores meaning more disability. In this study, 31 items were used — excluded were the four work items in the Life activities domain and one item on sexuality in the Getting along with people domain. The calculation of the overall functioning score and the two subscale scores was based on these corrections. WHODAS II also encompasses an additional item, interference with life, associated with each of the six domains with the same response options as above.

WHODAS II has been validity and reliability tested in centres throughout the world. In this study, analyses revealed a high level of internal consistency (Cronbach’s alpha) at both pre- and post-assessment. All subscales showed a moderate to high consistency (alpha coefficients ranged 0.6 – 0.9, the mode is 0.8) except Getting along with people, whose Cronbach’s alpha value was low (0.4 and 0.5).
Analysis
The within-group effect in IPPA and WHODAS II was calculated as Effect Size (ES). In the case of IPPA the ES was calculated both per individual participant (mean change/weighted mean SD of 32 participants at pre-assessment) (Table I) and per activity and participation domain in the ICF (mean change/mean SD at pre-assessment – of the overall scale and subscales respectively) (Table III). In WHODAS II the ES was calculated with regard to the total scale (31 items) and the six subscales (mean change/mean SD at pre-assessment). The ES is considered large (>0.8), moderate (0.5–0.8) or small (0.2–0.5). The Wilcoxon Signed Ranks test was used to determine significant changes between baseline and follow-up. For all analysis, a p-value of 0.05 was considered significant.

RESULTS
The mean age of the 32 participants was 67 years, with a range of 43–85 years. Twenty-two (69%) were male and ten were female. The majority of the men (86%) and half of the women (50%) were living with a partner. At the time of the study the median time since stroke onset was 24 months (mean 56, range 6–300 months). Most of the participants (n=31, 97%) were retired or on sick-leave and half of the participants (n=16) were affected with paresis in the right side of the body. Nearly half of the participants (n=15) had a powered wheelchair with a joy-stick, the remainder (n=17) a three-wheeled scooter. A majority of the participants (n=23) were able to drive their wheelchair on their own, the others needed a companion on some or all occasions. In the summer, half of the participants (n=16) use their wheelchair every day and nearly half of them (n=12) use it at least once a week. They usually drive a kilometre (n=14) or two (n=8) and on average they drive 3 kilometres (range 1–20 km) at most on one and the same day. About half of the participants (n=17) have a car available in the family.

About half of the participants reported life-events. Three of them reported that they used the powered wheelchair less than expected: one because of a lack of care staff to help with the transfer to the wheelchair, one because of an operation, and one because of having become healthier. The other life-events did not influence the wheelchair use and are therefore not considered in the following calculations.

The scores in IPPA showed that all participants (n=32) experienced a total positive outcome through provision of a powered wheelchair as assessed by IPPA. The effect size was large (ES =2.6) at the group level (n=32). The ES was also large for almost every individual participant (n=31) (range 0.62 to 4.42) and moderate for one participant (Table I).
Table I. Magnitude of effect size (ES) per participant (n=32) assessed by IPPA

<table>
<thead>
<tr>
<th>Effect size/IPPA</th>
<th>n (%)</th>
<th>Mean change score</th>
</tr>
</thead>
<tbody>
<tr>
<td>&gt; 0.8 large effect</td>
<td>31 (97)</td>
<td>9.7</td>
</tr>
<tr>
<td>0.5 – 0.8 moderate effect</td>
<td>1 (3)</td>
<td>2.3</td>
</tr>
<tr>
<td>0.2 – 0.5 small effect</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>&lt; 0.2 no effect</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Total</td>
<td>32 (100)</td>
<td>9.4</td>
</tr>
</tbody>
</table>

The 32 participants rated a total of 118 activity limitations and participation restrictions (range 1–7 problems, median = 4, mean 3.7, SD 1.5) at baseline and follow-up. Most of the problems were related to shopping, leisure activities and visiting family and friends. Examples of the problems classified in accordance with the activity and participation domains of the ICF are visiting a rehabilitation centre (Self-care), buying food (Domestic life), visiting family or friends (Interpersonal interactions and relationships), look after the farm (Major life areas) and recreation, such as looking around in the neighbourhood or going to the library (Community, social and civic life). The latter was the domain into which the majority of the problems (n=52) were categorised, and 50 of these problems were solved or diminished (Table II). Most of the 118 problems were solved or diminished at post-test (n=101, 86%): 41%, (41/101) were solved (“no difficulty at all”), 40% (40/101) were diminished (“little difficulty”). However, it is also noteworthy that some problems were unchanged (n=14, 12%) or even increased (n=3, 2%) after the provision of a powered wheelchair (Table II). The increased problems were related to barriers having to do with the environment, such as the design of buildings, heavy traffic and a lively dog that is difficult to take for a walk with the powered wheelchair.

Table II. Activity and participation problems at pre and post test assessed by IPPA in 32 persons, categorized according to ICF domains (n=118)

<table>
<thead>
<tr>
<th>Domains in ICF</th>
<th>Activity and participation problems</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Decreased or Solved</td>
</tr>
<tr>
<td>Self-care</td>
<td>1</td>
</tr>
<tr>
<td>Domestic life</td>
<td>28</td>
</tr>
<tr>
<td>Interpersonal interactions and relationships</td>
<td>18</td>
</tr>
<tr>
<td>Major life areas</td>
<td>4</td>
</tr>
<tr>
<td>Community, social and civic life</td>
<td>50</td>
</tr>
<tr>
<td>Total</td>
<td>101</td>
</tr>
</tbody>
</table>
The effectiveness (ES) within the different ICF domains was large (Table III) and significant, especially the domain Community, social and civic life, which had an ES of 2.4. This domain mainly included problems related to going for a walk in the neighbourhood, going to the library, a football match, etc. However, the Major life areas with only four problems showed no significant changes.

Furthermore, at follow-up ten participants mentioned 16 new activities that they had performed with the powered wheelchair which they had not brought up at pre-assessment. Of these activities, the majority could be classified within the Community, social and civic life domain of the ICF.

Table III. Activity and participation problems at pre- and post-test assessed by IPPA, categorized according to ICF activity and participation domains (n=118)

<table>
<thead>
<tr>
<th>Domains in ICF</th>
<th>Number (%) problems</th>
<th>Pre-test Mean (SD)</th>
<th>Post-test Mean (SD)</th>
<th>Effect size (ES)</th>
<th>Wilcoxon test p-value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Self-care</td>
<td>1 (1)</td>
<td>25 (-)</td>
<td>5 (-)</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Domestic life</td>
<td>34 (29)</td>
<td>18 (4.9)</td>
<td>10.1 (5.8)</td>
<td>1.6</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>Interpersonal interactions and relationships</td>
<td>27 (23)</td>
<td>16.8 (5.3)</td>
<td>9.2 (6.1)</td>
<td>1.4</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>Major life areas</td>
<td>4 (3)</td>
<td>21.3 (2.5)</td>
<td>6.5 (1.7)</td>
<td>5.9</td>
<td>0.066</td>
</tr>
<tr>
<td>Community, social and civic life</td>
<td>52 (44)</td>
<td>18.8 (4.4)</td>
<td>8.3 (4.1)</td>
<td>2.4</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>Total</td>
<td>118 (100)</td>
<td>18.2 (4.8)</td>
<td>8.9 (5.1)</td>
<td>1.9</td>
<td>&lt;0.001</td>
</tr>
</tbody>
</table>

Finally, with regard to WHODAS II, all participants (n=32) experienced difficulties (mild to extreme/cannot do) in the domains Getting around and Participation in society at baseline and follow-up, and almost everyone’s life was interfered with (Table IV). More than half of the participants experienced severe or extreme problems in these domains at baseline or follow-up regarding four items: “standing for long periods” 72% (n=23) – 72% (n=23), “walking a long distance” 88% (n=28) – 84% (n=27), “joining in community activities” 56% (n=18) – 44% (n=14), and “time spent on the health condition or its consequences” 56% (n=18) – 56% (n=18). The difficulties in the domains Getting around and Participation in society interfered severely with the lives of 63% (n=20) of the participants at both baseline and follow-up, and interfered extremely with the lives of 56% (n=18) at baseline and 50% (n=16) at follow-up.
Table IV. Number of participants with difficulties, whose lives were interfered with according to WHODAS II domains at pre- and post-test (n=32)

<table>
<thead>
<tr>
<th>WHODAS II- Domain of disability</th>
<th>Participants that have any difficulty, pre and (post) n</th>
<th>Participants whose lives were interfered with, pre and (post) n</th>
</tr>
</thead>
<tbody>
<tr>
<td>Understanding and communicating</td>
<td>25 (20)</td>
<td>18 (16)</td>
</tr>
<tr>
<td>Getting around</td>
<td>32 (32)</td>
<td>31 (32)</td>
</tr>
<tr>
<td>Self-care</td>
<td>27 (23)</td>
<td>22 (20)</td>
</tr>
<tr>
<td>Getting along with people</td>
<td>16 (11)</td>
<td>12 (10)</td>
</tr>
<tr>
<td>Life activities</td>
<td>29 (27)</td>
<td>22 (20)</td>
</tr>
<tr>
<td>Participation in society</td>
<td>32 (32)</td>
<td>31 (32)</td>
</tr>
</tbody>
</table>

Overall, the effect size in the case of WHODAS II ranged from none to small, except in the domain Self-care where it was large. Significant changes were shown on the overall scale and the subscales Getting around and Self-care (Table V).

Table V. Descriptive statistics and effect sizes of WHODAS II total scale and subscales at pre- and post-test (n=32)

<table>
<thead>
<tr>
<th>WHODAS II</th>
<th>Pre-test Mean (SD)</th>
<th>Post-test Mean (SD)</th>
<th>Effect size (ES)</th>
<th>Wilcoxon test p-value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Overall functioning, 31 items</td>
<td>39.5 (15.7)</td>
<td>35.4 (15.3)</td>
<td>0.26</td>
<td>0.025</td>
</tr>
<tr>
<td>Understanding and communicating</td>
<td>13.1 (14.4)</td>
<td>10.8 (13.6)</td>
<td>0.16</td>
<td>0.091</td>
</tr>
<tr>
<td>Getting around</td>
<td>62.1 (18.2)</td>
<td>54.7 (20.1)</td>
<td>0.41</td>
<td>0.021</td>
</tr>
<tr>
<td>Self-care</td>
<td>35.0 (27.5)</td>
<td>11.9 (21.6)</td>
<td>0.84</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>Getting along with people</td>
<td>12.5 (16.8)</td>
<td>9.1 (20.5)</td>
<td>0.20</td>
<td>0.287</td>
</tr>
<tr>
<td>Life activities</td>
<td>55.6 (36.9)</td>
<td>50.9 (36.4)</td>
<td>0.13</td>
<td>0.443</td>
</tr>
<tr>
<td>Participation in society</td>
<td>52.9 (22.0)</td>
<td>48.8 (19.9)</td>
<td>0.18</td>
<td>0.095</td>
</tr>
</tbody>
</table>

DISCUSSION

The main finding was that the participants regarded their activity and participation problems as having been to a great extent decreased or solved at follow-up as compared with baseline when assessed with IPPA. The results showed a large effect (ES) of the powered wheelchair in the ICF activity and participation domain Community, social and civic life. This domain is about engagement in recreation and leisure (informal or organized), religion and spirituality, and community life. In the case of the WHODAS II overall functioning score, there was a small but significant ES. An unexpected result was a large and significant ES in the case of Self care.
This study demonstrates the value of an outdoor powered wheelchair as a means to increase participation in different leisure activities. This is encouraging as prior research has shown that persons with stroke perceive severe problems in leisure activities.24,35 In our study the results showed that effect sizes of powered wheelchair use were high, with an ES of 2.6 on the group level (n=32) and an average of 1.9 in the case of the 118 problems. In recent years, a few studies have examined the effect of mobility devices using IPPA.10,13,28,36 Wessels et al.10 investigated powered wheelchairs (indoor and outdoor) in an elderly population and presented an ES of 2.5, which is comparable to our result. Our study also showed a large effect size in the domain Major life areas (ES=5.9). A comparable result in this domain (ES=7.4) was also presented in Wessels et al.10 However, there were few problems in this domain in both studies, and this must be taken into consideration when interpreting the results.

In previous studies, a version of IPPA with a 7-point scale has been used, which may make the comparisons somewhat inexact. The ES is nevertheless a means to compare the outcome of different measures.34,37 However, effect sizes are dependent on several factors, e.g. the variability within the group of participants, the prescription procedure regarding the devices and the sample size.

The ICF was used in this study as a conceptual framework in collecting, analysing and interpreting the data. In this way the model has been proved valuable. Prior research has addressed the ICF as a useful framework in relation to assistive technology intervention and outcome.9,10 However, the ICF has also been criticized as lacking the temporal and causal components which are needed when developing a predictive model of rehabilitation outcome.8,38

All participants reported that the wheelchair was a facilitator with regard to the problems they experienced in the ICF domains Domestic life, Interpersonal interactions and relationships, Major life areas, Community, social and civic life. However, some participants mentioned barriers beyond their control, e.g. shops that were not adapted. There were also barriers related to the wheelchair users themselves in relation to the technology. They do not trust that a charging of the batteries will be sufficient for them to dare to drive to places far away. These different barriers may have contributed to a lower effect in the case of IPPA in this study. Research has shown that a wheelchair is both a facilitating and a limiting factor when participating in the life of society.19,39 When it comes to the present study, it is possible that if the participants had used the wheelchair for a longer period and become more skilled in using it, some of the barriers might have been overcome. This aspect should be a subject for further research with
longitudinal design. The provider has a vital role to play in supporting and encouraging the user to fulfil his/her wishes regarding use of the wheelchair.

Some participants said at the interview that the wheelchair would be, or is of great importance with regard to freedom, independence and autonomy concerning activities. These issues are important, but not addressed in the ICF and could consequently not be classified\(^3\). Further, a few participants who had been disabled for a long time did not dare to bring up problems of the sort a powered wheelchair might solve. They would wait and see what became possible when they had the wheelchair, otherwise they might be disappointed. A previous study\(^2\) showed that for some persons problem identification is difficult because they get used to their disabilities and no longer perceive problems.

WHODAS II reaches statistical significance in the overall functioning score and the subscales Getting around and Self-care. The results seem somewhat difficult to evaluate since the largest effect was shown in the domain Self-care and this cannot be explained by the outdoor powered wheelchair and is therefore not clinically meaningful. The domains Getting along with people and Participation in society are probably the ones where an effect of powered wheelchair intervention ought to be most likely. Items included in these domains reflect barriers in the environment, attitudes of others and maintaining a friendship.

Up to now WHODAS II has mainly been used in cross-sectional studies, for epidemiological purposes\(^4\) and to determine disability frequency.\(^4\) Before and after studies have been performed with 31 subjects with treatment of ankylosing spondylitis,\(^3\) and in depression (n=73) and back pain (n=76).\(^3\) The ES of the total scale in our study was somewhat lower (0.26) than it was in the case of persons with ankylosing spondylitis who had been on a three-week spa course (0.39) and markedly lower in the case of persons with back pain who had received primary care (0.60).

In a previous study,\(^4\) one aim was to explore the levels of disability in an Irish sample. Among others, 64 persons with stroke younger than 66 years (mean age 51 years) participated, and they had mean WHODAS II levels that were somewhat comparable to those in our study in the domains as Getting around, Life activities and Participation in society, though our study group were older (mean age 67 years). In the present study 44% of the participants had severe or extreme difficulties with regard to “join[ing] in community activities the same way everyone else does”, as compared to Gallagher & Mulvany’s result of 41%. A difference between the studies is that a lower proportion of severe or extreme “barriers in the world around” is to be found in our study: 16% as compared with 44%. The powered wheelchair, as was the intervention in this study, probably does not
constitute an explanation of this difference. To our knowledge there are no great differences in the built-up and attitudinal environments in relation to powered wheelchair use as between Sweden and Ireland. However, the conclusion is that persons with disability after stroke, as well as an elderly Turkish population are greatly restricted with regard to participation in society.

Regarding the present study, an item concerning sexual activity was omitted because of the risk of a lower response rate in the second interview when this item might be judged inappropriate by the participants in the context of the evaluation of powered wheelchair use. To omit this item makes it more difficult, though, to compare our results with those of other studies using WHODAS II. However, previous studies have reported that this item was consistently unanswered, or had a fairly large percentage (23%) of missing values.

The instruments used in this study (IPPA, WHODAS II) are in concordance with the ICF, particularly in the case of the activity and participation domains. In the ICF, one way of coding is not to denote activity and participation as separate, and this was adopted in the present study. Two studies have been performed where the items in WHODAS II have been linked to the components body functions, environmental factors and activity and participation in the ICF. Perenbom & Chorus differentiated between participation and activity, which was not done by Cieza & Stucki. Further, a few items in WHODAS II were assigned as non-definable with regard to the ICF in both studies. The ICF is useful for selecting measures but there is a need to distinguish between activity items and participation ones. Furthermore, Cieza et al. found that WHODAS II obtained the highest level of agreement between two health professionals when linking a series of health-status measurements to the ICF.

WHODAS II seeks to determine the level of difficulties encountered in activities that a person actually does as opposed to activities that he/she can do but does not. The ICF domains in the Activity and Participation component may be coded as “capacity” or “performance”. To perform an activity is also in accordance with IPPA. In the present study the aim is to evaluate the performance of the different activities before and after the provision of a powered wheelchair.

The two instruments used in this study are of different structure. When studying the outcome of assistive technology, the IPPA is outstanding as it has been shown to be highly sensitive to changes and is based on the subjects’ own preferences. The likelihood that the powered wheelchair accounts for the change is great according to IPPA. It is reasonable to expect that a measure which is based on the persons’ own defined outcome goals with
regard to using a wheelchair will be particularly useful. WHODAS II has predetermined domains and items, and was not as sensitive in this study. However, this study is the first using WHODAS II in a Swedish sample. Accordingly, there is now a need to establish the psychometric properties in a Swedish context, including sensitivity to change according to different rehabilitation interventions.

A threat to the internal validity is the fact that the participants are not randomly selected. Nevertheless, the study group consists of every possible person with stroke in the area who was going to be provided with an outdoor powered wheelchair. A limitation of the study is the small study group, which may result in weak statistical power – the ability to detect differences between pre- and post-assessment concerning WHODAS II. A further threat to the validity is that we were unable to design an experimental study in which it would be possible to control for prescription, instructions and training periods, which undoubtedly differ in this study in relation to the participants, depending on their individual needs. It would not have been ethically acceptable for the participants to have been provided with a powered wheelchair all at the same time. Consequently we could not control for differences in the wheelchair use, e.g. depending on the weather.

It was possible to conclude that the use of an outdoor powered wheelchair had a positive effect on activity and participation in daily life in the case of persons with stroke. It could also be concluded that the instrument IPPA, based on the persons’ own assessments of their activity and participation problems, is highly sensitive to changes resulting from the provision of the wheelchair.

Acknowledgements: The authors wish to thank the technical aids consultants for screening the referrals, and the participants for their time and cooperation. The study was supported by grants from the Johanniter Order and the Department of Health Sciences, Örebro University, Sweden.
REFERENCES


32. McKibbin C, Patterson TL, Jeste DV. Assessing disability in older patients with schizophrenia, results from the WHODAS-II. Journal of Nervous and Mental Disease 2004;192(6):405-413.


45. Perenboom RJM, Chorus AMJ. Measuring participation according to the International Classification of Functioning, Disability and Health (ICF). Disability and Rehabilitation 2003;25(11/12):577-87.

“My world of ideas has been narrow before; suddenly there is an opening for something new. The city isn’t just a quarter of a city anymore, but a whole city. Another way of thinking is there.”

(Women who has been provided with a powered wheelchair, Study IV)
THE VALUE OF AN OUTDOOR POWERED WHEELCHAIR WITH REGARD TO THE QUALITY OF LIFE OF PERSONS WITH STROKE: A FOLLOW-UP STUDY

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THE VALUE OF AN OUTDOOR POWERED WHEELCHAIR WITH REGARD TO THE QUALITY OF LIFE OF PERSONS WITH STROKE: A FOLLOW-UP STUDY

Abstract:
To evaluate the use of a powered wheelchair is of importance because of the increasing number of people with disabilities who are provided with one. The aim of this study was to describe characteristics of persons with stroke using an outdoor powered wheelchair and to evaluate the impact of the wheelchair on quality of life. A further aim was to compare the impact on quality of life in respect of age, gender, different disability characteristics, and living conditions. The 32 participants with stroke were recruited consecutively from three county council areas in Sweden. A follow-up design was applied including the EuroQol-5D questionnaires at baseline before the persons were prescribed an outdoor powered wheelchair and data after 3-5 months of using it was collected by means of the EuroQol-5D and the Psychosocial Impact of Assistive Devices Scale (PIADS). The results indicated an improved quality of life in respect of the items: competence, independence, capability, quality of life, well-being, happiness, and self-esteem on Psychosocial Impact of Assistive Devices Scale. The Usual activity dimension in EuroQol-5D showed a significant improvement after wheelchair use. The group who drive the powered wheelchair at least once a day in the summer showed a more positive impact on the total Psychosocial Impact of Assistive Devices Scale and its subscale Competence than persons who drive less. Further, the group with higher rankings of the importance of the powered wheelchair scored higher on psychosocial impact than did the group with lower rankings. The conclusion is that the powered wheelchair mostly has a positive impact on the quality of life of users with stroke. Service providers should be alert, however, to the possible negative impact of a powered wheelchair on quality of life and support the user.

Keywords: PIADS, EQ-5D, powered wheelchair, evaluation, stroke, quality of life
INTRODUCTION

Quality of life is described as a multidimensional concept (Bowling, 2005; Fayers, 2000) which emphasizes the person’s perception of different aspects of life. Most people define quality of life as including emotional well-being, physical and mental health, the physical ability to do things you want to do, relationships with friends and family, participation in social activities and recreation and living in a safe neighbourhood, good services, having enough money, and being independent (Bowling, 2005). Quality of life is a broad concept while health-related quality of life (HRQoL) is a dimension which mainly refers to disease-related functioning and well-being (Bowling, 2005; Fayers, 2000).

Stroke affects approximately 30,000 individuals in Sweden each year and the estimated incidence rate is 300 out of 100,000 inhabitants (Riksstroke, 2005). Studies regarding Sweden are moderately comparable to those regarding Western Europe (Appelros, Nydevik, Seiger, & Terent, 2002; Di Carlo et al., 2000; Thorvaldsen, Asplund, Kuulasmaa, Rajakangas, & Schroll, 1995). Stroke is reported as the most common cause of disability in all industrialized countries (Kaste, Fogelholm, & Rissanen, 1998) and it is known that many stroke survivors experience deterioration in quality of life in terms of several aspects of health (Bays, 2001; Kim, Warren, Madill, & Hadley, 1999; Pilkington, 1999; Young, Murray, & Forster, 2003).

The literature indicates that there is agreement in the field of rehabilitation that quality of life is an important concept in evaluative studies, and it is often given as the ultimate objective of rehabilitation (Pain, Dunn, Anderson, Darrah, & Kratochvil, 1998). Quality of life is a concept also included in definitions of assistive technology (Jedeloo, De Witte, Linssen, & Schrijvers, 2002; Jutai, 1999) and it has been proposed as one dimension to be studied in relation to the outcome of assistive technology (DeRuyter, Scher, 1997; Scherer, 1996).

Persons with stroke sometimes need mobility devices, such as a powered wheelchair, to perform daily activities and maintain and enhance valued habits and roles. A few studies (Barker, Reid, & Cott, 2004; Dawson & Thornton, 2003; Evans, 2000) concerning persons with stroke and powered wheelchairs have been performed. One study evaluated the use of an indoor powered wheelchair in the case of two persons with unilateral neglect (Dawson & Thornton, 2003). The results revealed that the participants learned to drive the wheelchair regardless of the training intervention and despite persisting neglect. In a qualitative study of ten participants with stroke the lived experience of using a wheelchair was explored (Barker et al., 2004). Two of them used a powered wheelchair. Acceptance of the wheelchair (manual and powered) was categorized as Reluctant acceptance.
or Grateful acceptance. In a third study the effect of indoor and outdoor powered wheelchairs on occupation was investigated. Three of the eight participants had had a stroke. The author found that participation and controlling occupation were enhanced by the powered wheelchair (Evans, 2000).

The mentioned studies are all of a qualitative design and though some attention has been given to the quality of life of persons using powered wheelchairs, no study has addressed this issue in relation to a study group of only persons with stroke using outdoor powered wheelchairs. Therefore, the aim of this study was to describe characteristics of persons with stroke using an outdoor powered wheelchair and to evaluate the impact of the wheelchair on quality of life. Furthermore, the aim was to compare the impact on quality of life in respect of age, gender, different disability characteristics, and living conditions. A powered wheelchair in this study is understood as either an electrically powered wheelchair for outdoor use or a three-wheeled electric scooter.

Studying quality of life calls for a decision as to whether the study should rely on objective measures of external conditions or on subjective evaluation by the individuals themselves. The term objective refers to factual conditions of life and overt behaviour whereas the term subjective refers to attitudes, expectations, and life experiences (Bowling, 2005; Meeberg, 1993). In the current study both perspectives have been applied.

**METHODS**

**Study design**

A follow-up design was used with structured questionnaires at baseline before the persons obtained a powered wheelchair for outdoor use and after 3–5 months of using it. Subjective quality of life data from pre- and post-assessment was collected by means of EuroQol-5D (EQ-5D). Data from Psychosocial Impact of Assistive Devices Scale (PIADS), life-events and study-specific questions was collected at post measurement. The data was collected by means of two personal visits (IP) to each participant’s home.

The study was a multicenter study approved by the Research Ethics Committee at Örebro University Hospital, Sweden. The participants obtained oral and written information about the study and all participants signed an informed consent.
Participant selection
The participants with stroke were recruited consecutively from three county council areas in Sweden. They were selected from three centers for assistive technology where they were going to be prescribed a powered wheelchair for outdoor use. A criterion for inclusion was that participants should be able to take part independently in an interview, e.g. have no or only slight communication and cognitive problems. Further it should be the first time ever the participants possessed a powered wheelchair for outdoor use. The technical aids consultant responsible for the provision of the powered wheelchair informed the investigator (IP) about persons eligible for the study. Forty consecutive persons in the three county council areas were invited to participate in the study, and 37 accepted. Five persons dropped out after the first occasion of data collection, four of them because of sickness and one because he had not received his wheelchair within the appropriate time of the data collection. The remaining 32 persons participated throughout the study.

Participants
The mean age of the 32 participants was 67 years, with a range of 43–85 years. Most of the participants, 31 (97 %), were retired or on sick-leave. Descriptive data is presented in Table I. The study group showed most problems with mobility, such as standing for a long period or walking a long distance (Table II), according to the screening items in the World Health Organization Disability Assessment Schedule II (WHODAS II) (World Health Organization, 2001).
Table I. Descriptive data of the participants (n = 32)

<table>
<thead>
<tr>
<th>Variables</th>
<th>n</th>
<th>(%)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Age (year)</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>“Younger” range 43–67</td>
<td>15</td>
<td>(4)</td>
</tr>
<tr>
<td>“Older” range 69–85</td>
<td>17</td>
<td>(53)</td>
</tr>
<tr>
<td><strong>Gender</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>22</td>
<td>(69)</td>
</tr>
<tr>
<td>Female</td>
<td>10</td>
<td>(31)</td>
</tr>
<tr>
<td><strong>Months post-stroke</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>6–24</td>
<td>16</td>
<td>(53)</td>
</tr>
<tr>
<td>36–300</td>
<td>14</td>
<td>(47)</td>
</tr>
<tr>
<td><strong>Side of paresis</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Left</td>
<td>15</td>
<td>(47)</td>
</tr>
<tr>
<td>Right</td>
<td>16</td>
<td>(50)</td>
</tr>
<tr>
<td>Bilateral</td>
<td>1</td>
<td>(3 )</td>
</tr>
<tr>
<td><strong>Living conditions</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Cohabitng</td>
<td>24</td>
<td>(75)</td>
</tr>
<tr>
<td>Living alone</td>
<td>8</td>
<td>(25)</td>
</tr>
<tr>
<td><strong>Location of housing</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Living in countryside or small villages</td>
<td>14</td>
<td>(44)</td>
</tr>
<tr>
<td>Living in places with &gt;8000 inhabitants</td>
<td>18</td>
<td>(56)</td>
</tr>
<tr>
<td><strong>Powered wheelchair</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Four wheels with joystick</td>
<td>15</td>
<td>(47)</td>
</tr>
<tr>
<td>Three-wheeled scooter</td>
<td>17</td>
<td>(53)</td>
</tr>
</tbody>
</table>

* two drop-outs

Table II. Severe and extreme problems reported by participants according to WHODAS II screening items (n=32)

<table>
<thead>
<tr>
<th>Severe and extreme problems with</th>
<th>n</th>
<th>(%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Standing for long periods</td>
<td>23</td>
<td>(72)</td>
</tr>
<tr>
<td>Taking care of household</td>
<td>13</td>
<td>(41)</td>
</tr>
<tr>
<td>Learning new tasks</td>
<td>1</td>
<td>(3 )</td>
</tr>
<tr>
<td>Joining in community activities</td>
<td>14</td>
<td>(44)</td>
</tr>
<tr>
<td>Emotionally affected</td>
<td>14</td>
<td>(44)</td>
</tr>
<tr>
<td>Concentrating doing something</td>
<td>1</td>
<td>(3 )</td>
</tr>
<tr>
<td>Walking a long distance</td>
<td>27</td>
<td>(84)</td>
</tr>
<tr>
<td>Washing the whole body</td>
<td>6</td>
<td>(19)</td>
</tr>
<tr>
<td>Getting dressed</td>
<td>7</td>
<td>(22)</td>
</tr>
<tr>
<td>Dealing with people you don’t know</td>
<td>2</td>
<td>(6 )</td>
</tr>
<tr>
<td>Maintaining a friendship</td>
<td>1</td>
<td>(3 )</td>
</tr>
<tr>
<td>Day-to-day work</td>
<td>–</td>
<td></td>
</tr>
</tbody>
</table>
Measurements

*Study-specific questions* were collected concerning the importance of and satisfaction with the powered wheelchair; how often the wheelchair was used and how far they were driving; mishaps or incidents; and whether the household had a car. Questions were also raised about the need of help to charge the batteries, the need of someone accompanying you when driving the powered wheelchair, and the need of help to transfer to the wheelchair.

*Life-events.* A checklist was developed of 17 types of life-events (e.g. sickness or death in the family or of friends, separation, moving to another place) based on a checklist used in previous research (Ahlström, Lindvall, Wenneberg, & Gunnarsson, 2006), applied in this study for events which could influence quality of life in relation to the use of a powered wheelchair. These items were evaluated at post measurement in order to discover any confounders affecting the results.

*PIADS* measures the impact of assistive devices on users’ quality of life. The questionnaire consists of 26 items grouped into three subscales. 1) The *Competence* subscale (12 items) reflects feelings such as perceived independence and productivity, 2) *Adaptability* (6 items) reflects feelings of well-being and ability to adapt to activities of daily living, and 3) *Self-esteem* (8 items) comprises questions on emotions such as happiness and security. The scale is scored from –3 (decreases) to +3 (increases). The midpoint “0” indicates no perceived change in quality of life as a result of using the device (Day & Jutai, 1996; Day, Jutai, & Campbell, 2002).

PIADS has been shown to possess good psychometric properties (Day & Jutai, 1996; Day et al., 2002) and to have good clinical utility (Devitt, Chau, & Jutai, 2003; MacPhee et al., 2004). Furthermore, it has been reported to be a sensitive and responsive measure of the impact of various assistive devices among persons with different diagnoses and disabilities (Jutai, 1999). In this study Chronbach’s alpha values for the total scale and for the Competence, Adaptability, and Self-esteem subscales were 0.95, 0.92, 0.87, and 0.86 respectively.

For this study, the English version of PIADS was translated into Swedish. A forward and backward translation was made by two professional translators. Three occupational therapists (two of whom have a PhD) examined the forward translation. Some items needed to be further discussed with the translators. The same procedures were made for the backward translation of the English version. Further, the questionnaire was completed in both languages by a person using a powered wheelchair in daily life and whose native language is English but who is fluent in Swedish. After a small revision a Swedish version was finalized.
EQ-5D is a short generic measure of health-related quality of life (HRQoL). It is developed and supported by an international research group and is suitable for use in postal surveys or face-to-face interviews. Persons rate their self-perceived problems on five dimensions: mobility, self-care, usual activities, pain/discomfort, and anxiety/depression. Each dimension is recorded on three levels: 1 = no problem, 2 = some problem and 3 = extreme problem. The data can be presented as a simple descriptive profile across the five dimensions or as a single weighted health state index elicited from general population samples (EQ-5D index). The latter is based on a total of 243 possible health states involving combinations of the three levels and five dimensions. A score of 1 represents maximum good health and 0 the worst imaginable health (Brooks, Rabin, & de Charro, 2003; EuroQol Group, 1990). A HRQoL value of 0.78 matches the reference value of the general population in the 65–74 age-group (Kind in van Exel, Scholte op Reimer, & Koopmanschap, 2004). EQ-5D has demonstrated acceptable concurrent and discriminant validity as a measurement of health-related quality of life after stroke (Dorman, Waddell, Slattery, Dennis, & Sandercock, 1997). Acceptable test-retest reliability has been reported in studies with the general public and a clinical sample of patients with rheumatoid arthritis (Brooks et al., 2003).

In this study two questions were added as a complement to EQ-5D, as earlier suggested by Persson (Persson et al., 2002) as being relevant when it comes to evaluating assistive devices. One mobility question about “moving about” was added as the original mobility item is restricted to “walking about” and is thus inappropriate for detecting benefits of certain mobility devices. A second question about Social relationship was added as a complement to the Usual activity dimension of the EQ-5D descriptive system. The response options on both questions followed the pattern with three levels from EQ-5D (Persson et al., 2002).

Analysis
As the data was mainly on the ordinal level, the Wilcoxon Signed Ranks test (two-tailed) was used to determine significant changes in the study group between pre- and post-measurement concerning EQ-5D index, the mean of specific dimensions, and complementary questions. The within-group effect of the EQ-5D index score was calculated by the effect size (ES) (calculation: mean change divided by the mean SD at pre-test). The ES is considered large (>0.8), moderate (0.5–0.8) or small (0.2–0.5) (Fayers, 2000). A Mann-Whitney U test (two-tailed) was performed for change scores on the EQ-5D index, the mean of specific dimensions of EQ-5D, and the mean of the PIADS total scale and subscales when comparing independent groups.
In these cases the ordered categorical and continuous data was dichotomized as near the median as possible. A Kruskal-Wallis test was performed regarding two ordinal 5-point scaled variables: importance of, and satisfaction with, the wheelchair. For all analysis, a p-value of 0.05 was considered significant. The statistical software SPSS 13.0 for Windows was used for all calculations.

RESULTS

After four months using the powered wheelchair approximately one third of the participants rated their wheelchair as extremely important (value 5), very important (value 4) or somewhat important (value 3) in daily life. However, one of the participants rated the wheelchair as not very important (value 2). In addition, half of the participants (n=16) were extremely satisfied with the powered wheelchair. About half of the participants (n=17) charged the batteries themselves with no problem, and 14 participants needed help from other people. A majority (n=21) were able to transfer themselves to the wheelchair on their own. About the same proportion of the participants (n=23) were also able to drive their wheelchair on their own, the others needed a companion on some or all occasions. Ten mishaps (e.g. got stuck on the edge of the pavement or in a railway line, bumped into a bicycle) were reported by ten participants. In the summer half of the participants (n=16) use their wheelchair every day and nearly half of them (n=12) use it at least once a week. They usually drive a kilometer (0.6 miles) (n=14) or two (1.2 miles) (n=8). On average they drive 3 kilometers (1.9 miles) (range 1–20 km) (0.6–12.4 miles) at most on one and the same day. About half of the participants (n=17) have a car available in the family.

About half of the participants reported significant life-events. Three of them reported that they used the powered wheelchair less than expected: one because of a lack of care staff to help with the transfer to the wheelchair, one because of an operation, and one because of having become healthier. The other life-events did not influence the wheelchair use.

Psychosocial impact of a powered wheelchair

Concerning PIADS, the results show that the items independence (md=2), quality of life (md=1), and happiness (md=1) received the highest numbers of positive ratings (1–3) as a result of the impact of the powered wheelchair on everyday life (Table III). The items competence (md=1), capability (md=1), well-being (md=1), and self-esteem (md=1) also received relatively high ratings. Notably, a few users indicate that there was a negative impact on their quality of life on seven items in relation to the powered wheelchair use. Four persons feel embarrassed when using the wheelchair (Table III).
The median and mean values on the total scale (md=0.46, q1=0.25, and q3=1.11; mean 0.67) and the Competence (md=0.50, q1=0.27, and q3=0.98; mean=0.70), Adaptability (md=0.33, q1= 0.00, and q3=0.79; mean=0.59), and Self-esteem subscales (md=0.56, q1=0.13, and q3=1.13; mean=0.67) were similar. Only a few significant differences between groups were shown on PIADS. The group who drive the wheelchair at least once a day in the summer showed a significantly higher positive impact on the PIADS total scale (z=1.98, p=0.048) and the subscale Competence (z=2.099, p=0.036) than did those who drive less. Further, the group with higher rankings of the importance of the powered wheelchair scored significantly higher regarding psychosocial impact than did the group with lower rankings when it came to the PIADS total scale (chi2=9.63, df=3, p=0.022) and the subscale Self-esteem (chi2=9.57, df=3, p=0.023). Other comparisons showed no significant differences.
**Table III. Frequencies of participants’ ratings of PIADS item distributed on three subscales (n=32)**

<table>
<thead>
<tr>
<th>Subscales</th>
<th>Rating score</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>–3</td>
</tr>
<tr>
<td><strong>Competence subscale</strong></td>
<td></td>
</tr>
<tr>
<td>Competence</td>
<td>13</td>
</tr>
<tr>
<td>Independence</td>
<td>7</td>
</tr>
<tr>
<td>Adequacy</td>
<td>1</td>
</tr>
<tr>
<td>Confusion</td>
<td>27</td>
</tr>
<tr>
<td>Efficiency</td>
<td>1</td>
</tr>
<tr>
<td>Productivity</td>
<td>22</td>
</tr>
<tr>
<td>Usefulness</td>
<td>29</td>
</tr>
<tr>
<td>Expertise</td>
<td>26</td>
</tr>
<tr>
<td>Skillfulness</td>
<td>1</td>
</tr>
<tr>
<td>Capability</td>
<td>13</td>
</tr>
<tr>
<td>Quality of life</td>
<td>6</td>
</tr>
<tr>
<td>Performance</td>
<td>20</td>
</tr>
<tr>
<td><strong>Adaptability subscale</strong></td>
<td></td>
</tr>
<tr>
<td>Well-being</td>
<td>14</td>
</tr>
<tr>
<td>Willingness to take chances</td>
<td>24</td>
</tr>
<tr>
<td>Ability to participate</td>
<td>19</td>
</tr>
<tr>
<td>Eagerness to try new things</td>
<td>23</td>
</tr>
<tr>
<td>Ability to adapt to the activities of daily living</td>
<td>19</td>
</tr>
<tr>
<td>Ability to take advantage of opportunities</td>
<td>22</td>
</tr>
<tr>
<td><strong>Self-esteem subscale</strong></td>
<td></td>
</tr>
<tr>
<td>Happiness</td>
<td>7</td>
</tr>
<tr>
<td>Self-esteem</td>
<td>1</td>
</tr>
<tr>
<td>Security</td>
<td>1</td>
</tr>
<tr>
<td>Frustration</td>
<td>1</td>
</tr>
<tr>
<td>Self-confidence</td>
<td>16</td>
</tr>
<tr>
<td>Sense of power</td>
<td>16</td>
</tr>
<tr>
<td>Sense of control</td>
<td>20</td>
</tr>
<tr>
<td>Embarrassment</td>
<td>1</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td>2</td>
</tr>
</tbody>
</table>

**Health-related quality of life**

The EQ-5D frequencies (Table IV) showed that the greatest change between pre- and post-assessment concerned Usual activities, where 14 of the persons changed their response positively and 5 negatively. It was only on this dimension that a comparison of the data before (md=2, mean=1.81, SD=0.53) and after (md=1.50, mean=1.50, SD=0.51) indicated significant
change ($z=2.13$, $p=0.03$). This estimated amount of change (0.58) was considered moderate in respect of effect size (ES). No significant differences were shown regarding background variables and study-specific questions and Usual activities. The before and after mean index scores were 0.5 (SD=0.32) and 0.55 (SD=0.29) respectively. The ES of the mean change of index score was small, 0.17.

Table IV. Frequencies of unchanged, positive and negative changes of health-related quality of life at follow-up compared with baseline ($n=32$)

<table>
<thead>
<tr>
<th>EQ-5D</th>
<th>Unchanged</th>
<th>Positive change</th>
<th>Negativ change</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mobility*</td>
<td>30</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Self-Care</td>
<td>24</td>
<td>4</td>
<td>4</td>
</tr>
<tr>
<td>Usual activities</td>
<td>13</td>
<td>14</td>
<td>5</td>
</tr>
<tr>
<td>Pain/discomfort</td>
<td>21</td>
<td>7</td>
<td>4</td>
</tr>
<tr>
<td>Anxiety/depression</td>
<td>21</td>
<td>5</td>
<td>6</td>
</tr>
</tbody>
</table>

Complementary questions

| Mobility             | 28        | 4               | 0              |
| Social activities    | 17        | 10              | 5              |

* two drop-outs

**DISCUSSION**

The main results of the study indicate that the quality of life of persons with stroke was positively influenced by an outdoor powered wheelchair concerning items such as competence, independence, capability, quality of life, well-being, happiness, self-esteem (PIADS), and Usual activities (EQ-5D). Between-group comparisons regarding age, gender, different disability characteristics, and living conditions show only a few significant differences on the PIADS total scale and the subscales. The group who used the wheelchair more often in summer and the group who scored their wheelchair as the most valuable indicated a significantly greater positive impact than did the others on the PIADS total scale. Before starting the study, one assumption was that the scooter type of wheelchair would have a greater influence on quality of life than the powered wheelchair with joystick, but this was not confirmed in the study. This may be a result of type II error – a poor ability to detect an existent significant difference because of a small sample size.

The PIADS subscale scores showed on average a somewhat lower positive impact of powered wheelchair use in our study (mean=0.59–0.70) as
compared with studies on wheelchair use (mean=1.06-1.64) (Devitt et al., 2003), the use of mobility devices (mean=1.11-1.55) (Demers, Monette, Lapierre, Arnold, & Wolfson, 2002) a wheelchair skills training program (post training, mean=1.55-1.96) (MacPhee et al., 2004), and using hearing aids (mean=1.13-1.18) (Saunders & Jutai, 2004). Further, the psychosocial impact of the subscale Adaptability was rated lower (mean=0.59) in this study than in previous studies involving manual or powered wheelchairs (mean=1.64 and 1.96) (Devitt et al., 2003; MacPhee et al., 2004), where Adaptability was the subscale with the highest scores. The items independence and happiness in PIADS were rated positively (score 2 or 3) by about half of the participants in our study. In a pilot study examining the transition to a powered wheelchair of 8 participants, all 8 gave the highest scores (2 or 3) to the items independence, quality of life, adequacy, ability to adapt to activities of daily living, and ability to take advantage of opportunities (Buning, Angelo, & Schmeler, 2001). The mentioned results suggest the need for further research with larger samples to find out if significant differences between countries exist. There are several possible explanations of the lack of agreement between our own and previous results: differences in culture, diagnoses, disability or the prescription of the devices; also the fact that the longer use of a device may encourage a more positive attitude toward it (Day & Jutai, 1996). In this study the powered wheelchair was used rather a short time. A follow-up when the persons have used the wheelchairs for a longer period will produce deeper knowledge and is a subject for future research.

The participants in this study have all used the powered wheelchair for about the same length of time, 4 months, and this may increase the internal validity of the study. In other studies using PIADS, the reported time since receiving or using the wheelchair varied from 2 weeks to 10 years (Devitt et al., 2003) and 6 months to 24 months (Buning et al., 2001).

In this study seven persons gave one to three negative ratings each on PIADS. Four persons tell of feeling stigmatized because people stare at them and at the wheelchair. Two persons feel frustrated because of the difficulty of maneuvering the wheelchair in narrow passages. Further, one person feels more disabled when using the wheelchair and it lowers his self-esteem. It is important to help the user to feel safe, secure, and satisfied in relation to wheelchair. Earlier studies with a study group of persons with stroke (Gitlin, Luborsky, & Schemm, 1998; Pettersson, Appelros, & Ahlström, 2006) have shown that assistive devices may have a dual outcome, they may be both enabling and constraining in relation to the performance of different activities. The powered wheelchair was found to be a means to maintain roles but also a means to be less active (Pettersson et al., 2006).
Some of the participants felt that there were too many items in the PIADS questionnaire and that various questions were similar. However, only a few of the participants needed further explanation to understand the scoring. It was particularly the negative items “frustration”, “confusion” and “embarrassment” that caused a certain amount of trouble. Validation studies of the Swedish version of PIADS are an important task for future research (Fayers, 2000).

Measures of HRQoL have been considered important in stroke rehabilitation (Golomb, Vickrey, & Hays). In this study the EQ-5D dimension Usual activities showed a significant result in within-group comparisons. Activity is a dimension likely to be favorably affected by powered wheelchair use, as indeed a previous qualitative study has shown (Evans, 2000). Previous studies have shown that activity, socialization, and leisure activities are poor among persons with stroke (Bays, 2001; Buning et al., 2001). It is reasonable to suppose that a powered wheelchair can serve to improve this situation. The Mobility dimension in the EQ-5D about “walking about” was not suited to detecting changes due to powered wheelchair use in this study. The complementary Mobility item only showed a minor change with regard to “moving about”. However, when mobility devices such as wheelchairs are prescribed the addition of the new mobility item seems appropriate. The EQ-5D has been described as not responsive to change because of its limited response options (Buck, Jacoby, Massey, & Ford, 2000; Paterson, 2004; Salter et al., 2005). A few previous studies have been found where the EQ-5D has been applied in respect of the outcome of the use of assistive devices (Davies, De Souza, & Frank, 2003; Joore, Potjewijd, Timmerman, & Anteunis, 2002; Persson & Hellbom, 2003; Wessels et al., 2000). In the study by Davies et al. (2003) the EQ-5D was used pre- and post-measurement to determine the perceived changes in the quality of life of persons (irrespective of diagnosis) provided with an indoor or outdoor powered wheelchair (Davies et al., 2003). The results showed no significant differences concerning before and after mean scores of the total index scores of EQ-5D or subdimension scores. The ES of index scores shows an effect even lower than is the case in our study (0.08 as against 0.17).

To evaluate the use of powered wheelchair seems to be an important task as the number of people with disabilities who are provided with powered wheelchairs is increasing. In the 1990’s the number of powered wheelchairs (indoor and outdoor) almost trebled in Sweden. Two hundred and twenty-six out of every 100,000 Swedes possessed a powered wheelchair in 2002, and the same year 59 new powered wheelchairs were prescribed per 100,000 inhabitants (The Swedish Handicap Institute, 2004). Assistive devices in
Sweden, including powered wheelchairs, are essentially free of charge when they are required on the basis on needs assessment by prescribers (Nordic Cooperation on Disability, 2004). Further, statistics of wheelchair incidents are of particular importance when evaluating device use including the safety of the user. In our study the reported mishaps were noteworthy but of no statistical significance in respect of the impact of the powered wheelchair on quality of life. Other studies have reported considerable wheelchair incidents (Frank, Ward, Orwell, McCullagh, & Belcher, 2000; Gaal, Rebholtz, Hotchkiss, & Pfaelzer, 1997) and we agree with the authors who highlight the importance not only of follow-up but also of the design of the wheelchairs.

A problem in evaluating assistive technology, including powered wheelchairs, is that there are interaction effects (Field, 1999; Gelderblom & de Witte, 2002; Smith, 1996; World Health Organization, 2001) between e.g. the person using the powered wheelchair, the wheelchair itself, services provided, temporal aspects, the performance of daily activities, and the physical and attitudinal environment. To some extent the questions concerning life-events included in this study were designed to control for certain interaction effects. As there were only a few persons who reported a few life-events that have had an impact on wheelchair use, this was not considered in the statistical analysis. In this study only four persons were prescribed wheelchairs during the autumn and they were interviewed for the second period in spring or early summer. They did not have the opportunity to use the wheelchair in summer. The time of year when the wheelchair was prescribed could not be taken into consideration in this consecutive small sample. These factors may constitute a threat to the internal validity (Kazdin, 2003).

In contrast to the result in this study that showed no problem with non-use of assistive devices, this was a reported problem in a literature review (Wessels, Dijcks, Soede, Gelderblom, & De Witte, 2003). All the prescribed wheelchairs in this study were used, but a few of the participants used the wheelchair to a lesser extent than expected, this because of improved health, because of being being stigmatized or because of cold weather. Different definitions of non-use have been reported – not used at all, not used for a substantial part of the day, not used for all the activities it was prescribed for (Wessels et al., 2003). Accordingly non-use depends on definition and in our study the weather was a factor that contributed greatly to how often the wheelchair was used.

EQ-5D and PIADS have been recommended as standardized measures to evaluate assistive devices (Fuhrer, 2001; Gelderblom & de Witte, 2002). PIADS is especially constructed to evaluate the psychosocial impact of
assistive devices and EQ-5D is a generic measure which has to be performed twice (or more) to have the possibility of showing differences in HRQoL between before and after using a device. On the basis of this study, PIADS may serve as both an outcome measure in research and a measure in clinical practice. PIADS adds knowledge about psychosocial factors on a detailed level such as may serve as a tool of discussion with the user to improve the use of and satisfaction with the powered wheelchair or other devices. Future studies should focus on comparing the use of different kinds of devices. The research on assistive devices needs to be embedded in the daily work of provision of assistive technology. EQ-5D seems to be appropriate in larger samples in a cross-sectional design when between-group comparisons of the use of different devices are needed. In a review of outcome measures after stroke, the methodological rigor of EQ-5D is discussed (Salter et al., 2005).

To summarize, the findings in this study indicate that persons with stroke using an outdoor powered wheelchair experienced an improvement in their overall quality of life in respect of different psychosocial areas such as competence, independence, capability, quality of life, well-being, happiness, and self-esteem. In the HRQoL dimension Usual Activities there was a significant change after using a powered wheelchair. Other within-group comparisons showed no significant results in EQ-5D. Between-group comparisons in PIADS showed only a few significant results. Providers of assistive technology services have to incorporate follow-up studies in rehabilitation to have the possibility of supporting the users in the best way. It is vital to also pay attention to persons who experience a certain negative impact of powered wheelchair use.

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REFERENCES


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