

Significance of Assistive Devices in the Daily Life
of Persons with Stroke and Their Spouses

Örebro Studies in Caring Sciences 8



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ABSTRACT

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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

Pettersson I, Appelros P, Ahlström G. Lifeworld perspectives on using assistive devices: Individual's lived experience following a stroke. *Canadian Journal of Occupational Therapy*. 2006; In press.

STUDY II

Pettersson I, Berndtsson I, Appelros P, Ahlström G. Lifeworld perspectives on assistive devices: Lived experiences of spouses of persons with stroke. *Scandinavian Journal of Occupational Therapy* 2005; 12 159–169.

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.

The studies I, II and III have been printed with the permission of the publishers.

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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

Att använda olika hjälpmedel är ofta en förutsättning för personer med funktionshinder att klara av sitt dagliga liv i hemmet och ute i samhället. Hjälpmedel definieras i många sammanhang som produkter som bidrar till att minska eller helt kompensera för ett funktionshinder. De beskrivs också som att de underlättar i genomförandet av olika aktiviteter och bidrar till en ökad livskvalitet. Allt fler personer idag lever med funktionshinder och är i behov av hjälpmedel. Denna utveckling förväntas att fortsätta då befolkningen i Sverige blir allt äldre. Stroke som är vanligt hos äldre leder ofta till begränsningar av aktivitet och delaktighet i samhället. Tidigare studier har visat att personer med stroke har svårigheter med förflyttning och därmed minskad möjlighet att vara aktiva på olika sätt. Olika hjälpmedel, däribland eldrivna rullstolar, utgör en av flera möjliga interventioner i ett rehabiliteringsprogram för dessa personer. Eftersom hjälpmedel också spelar en roll i interaktionen mellan människor så berör hjälpmedlen även närstående till personer med funktionshinder. Ingen studie har påträffats där betydelsen av hjälpmedel ur närståendes perspektiv har undersökts och ingen tidigare studie har heller påträffats med fokus på personer med stroke som använder en elrullstol för utomhusbruk. Således finns ett behov av att få ökad kunskap om upplevd mening, betydelse och erfarenhet av hjälpmedel både ur individens och närståendes perspektiv, men även betydelsen av en elrullstol för aktivitet, delaktighet och livskvalitet. Huvudsyftet med denna avhandling är att undersöka betydelsen och användningen av olika hjälpmedel i vardagslivet. Projektet innefattar fyra studier, tre utifrån personer med stroke och en från deras närståendes perspektiv.

I **Studie I** studerades hur personer med funktionshinder pga. stroke beskrev sina levda erfarenheter i relation till användningen av hjälpmedel. En hermeneutisk-fenomenologisk livsvärldsansats användes och intervjuer genomfördes med 22 personer ett år efter att de fått stroke. Vid intervjuerna fick personerna berätta hur de upplevde att använda sina hjälpmedel i hemmet och i omgivningen. Materialet analyserades i relation till fyra livsvärldsexistentialer (den levda kroppen, det levda rummet, den levda tiden och levda relationer). Ett huvudresultat var upplevelser av en dubbelhet som fanns i beskrivningar relaterade till alla livsvärldsexistentialer. Personerna upplevde både positiva eller underlättande faktorer samtidigt som negativa eller hindrande faktorer vid användningen av sina hjälpmedel. När det gäller

den levda kroppen framkallar hjälpmedlen känslor av tacksamhet och tillfredsställelse, eftersom de gör det lättare att klara av olika dagliga aktiviteter, att förbli oberoende, att undvika ytterligare funktionshinder och att bibehålla tidigare vanor. Å andra sidan kan ett hjälpmedel vara en ständig påminnelse om att personen har ett funktionshinder som begränsar deras förmåga. Ibland upplevs hjälpmedlen som införlivade med den egna kroppen. Hjälpmedlen framstår som produkter som man behöver ha och är tacksam för att de finns, men som man egentligen inte vill behöva använda. När det gäller *det levda rummet* är personer med stroke positiva till hjälpmedlen som är en förutsättning för att kunna fortsätta bo i sitt eget hem och i sin invanda miljö. Samtidigt ger hjälpmedlen upphov till negativa känslor på så sätt att de begränsar vart man kan komma pga. olika hinder i miljön, t.ex. trottoarer som lutar eller att det inte finns tillgång till anpassade toaletter. *Den levda tiden* upplevs i relation till det förflutna, nuet och framtiden. Hjälpmedel är en förutsättning för att kunna ta kontroll över sin tid och på så sätt uppleva en känsla av frihet att kunna utföra olika dagliga aktiviteter oberoende av andras tid. Slutligen, när det gäller *levda relationer* både underlättas och hindras dessa av att använda hjälpmedel. Människor med stroke behandlas med respekt av andra människor ute i samhället och de får stöd av närstående i användningen av hjälpmedlen. Å andra sidan uppstår känslor av stigmatisering då andra personer ifrågasätter deras behov av hjälpmedel eller behandlar dem nedlåtande. Vid förskrivning av hjälpmedel upplever vissa personer en stor delaktighet medan andra önskade att få bli mer delaktiga i den processen.

I **Studie II** studerades hur närstående till personer med stroke beskrev sina levda erfarenheter i relation till de hjälpmedel som finns i deras hem och vardagsliv. En hermeneutisk-fenomenologisk livsvärldsansats användes och intervjuer genomfördes med tolv närstående personer, vars partner fått stroke ett år tidigare. Deras levda erfarenheter av hjälpmedlen beskrevs utgående från fyra livsvärldsexistentialer, vilka ses som sammanflätade med varandra. Resultatet visade att *den levda kroppen* relaterar till olika aspekter av känslor och vanor som upplevs både positivt och negativt. Ofta beskrivs positiva och negativa känslor samtidigt för samma situation där hjälpmedel är involverade. De närstående upplever oro och frustration i samband med hjälpmedlen men även positiva känslor såsom tacksamhet och glädje över att hjälpmedlen finns som en möjlighet att lösa problem. I flera fall måste närstående själva vänja sig vid att använda hjälpmedel, t.ex. en toalettstolsförhöjning, som primärt är avsett för deras make/maka med stroke. Några närstående beskrev också att hjälpmedlen kan upplevas som införlivade med den egna kroppen. Undan för undan inkorporeras hjälpmedlen i ma-

karnas hem och hjälpmedlen medför att de närstående får en ny syn på sitt hem och sin omgivning, aspekter som härrör till det *levda rummet*. Hjälpmedlen är ur de närståendes perspektiv en förutsättning för att personerna med stroke ska kunna bo kvar hemma, men de ger också uttryck för funderingar kring om hjälpmedlen är tillräckliga för att makarna fortsättningsvis ska kunna bo kvar i sitt hem. Det oroar dem om gränsen är nådd då ytterligare hjälpmedel inte finns som kan förbättra situationen om deras partner blir sämre. Hjälpmedlen medför också att de närstående relaterar till den *levda tiden* på ett nytt sätt, avseende dimensioner av dåtid, nutid och framtid. Att de närstående med hjälp av hjälpmedlen kan ta kontroll över sin och familjens tid upplevs som en stor fördel. Tiden upplevs på så sätt mer som en helhet som inte avbryts av personal. Vidare kan de närstående uppleva att tiden går fortare än tidigare då de är borta från hemmet, samtidigt som de undrar om det hänt deras make/maka med stroke någonting medan de är borta. Ytterligare en tidsaspekt är då familjerna måste vänta på att få hjälpmedel levererade, vilket kan upplevas som förlorad tid. *Levda relationer* omfattar förändrade relationer och roller i förhållande till maken/makan med stroke och innefattar att de närstående tar ett stort ansvar för hjälpmedlen och användningen av dem. Resultatet innefattar också stigmatiserande aspekter och en dubbelhet i relationer till hälso- och sjukvårdspersonal när det gäller att delta i olika beslut som rör förskrivning av hjälpmedel.

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 mättillfället 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 "Samhällsgemenskap, socialt och medborgerligt liv". Denna domän inkluderar i huvudsak deltagarnas problem i relation till

rekreation och fritid, t.ex. när det gäller att gå på en fotbollsmatch eller besöka biblioteket. Det är i denna domän den största positiva effekten uppvisades. En stor effekt uppvisades dock också i domänerna ”Hemliv”, där deltagarna i huvudsak nämnde problem i samband med att handla mat eller andra förnödenheter, och ”Mellanmänniska interaktioner och relationer”, som innefattar umgänge med familjemedlemmar, grannar och vänner. När det gäller aktivitet och delaktighet mätt med WHODAS II, totala skalan, visade resultatet en liten men signifikant förbättring. Ett oväntat resultat var en stor och signifikant förbättring när det gäller ”Personlig vård”.

Slutligen var syftet i **Studie IV** att beskriva egenskaper hos personer med stroke som använder elrullstol för utomhusbruk samt att utvärdera effekten av elrullstolen avseende livskvalitet. Ytterligare ett syfte var att jämföra elrullstolens påverkan på livskvalitet i relation till olika variabler såsom ålder, kön, typ av funktionshinder och levnadsförhållanden. De 32 deltagarna med stroke rekryterades konsekutivt från tre landsting i Sverige. I studien användes ett hälsorelaterat livskvalitetsinstrument, EuroQol-5D, före förskrivningen respektive efter fyra månaders användning av elrullstolen, och ”Psychosocial Impact of Assistive Devices Scale” (Skala för mätning av den psykosociala effekten av hjälpmedel) (PIADS) efter fyra månaders användning. Resultatet i PIADS visade förbättrad livskvalitet efter elrullstolsanvändning främst avseende frågorna; lycka, oberoende, livskvalitet, kompetens, självkänsla, välbefinnande och känslan av att vara kapabel. De som kör elrullstolen minst en gång om dagen på sommaren jämfört med de som kör mindre, uppvisade en signifikant högre positiv effekt på totala skalan och på delskalan Kompetens i PIADS. De som skattar elrullstolens betydelse högt skattar också dess psykosociala påverkan signifikant högre än vad övriga gör, både på den totala skalan och på delskalan Självkänsla. Det är också viktigt att notera att för sju deltagare hade elrullstolen en negativ psykosocial effekt. Fyra personer upplevde en ökad känsla av pinsamhet och två kände sig mer frustrerade efter att ha använt elrullstolen. Fem personer uppgav också minskad trygghet, självkänsla, effektivitet, skicklighet respektive sämre förmåga att räkna till enligt PIADS. Slutligen, visade dimensionen ”Huvudsakliga aktiviteter” mätt med EuroQol-5D en signifikant förbättring efter användning av elrullstol för utomhusbruk.

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-neutrale produkter. De livsvärldsexistentialer 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 delaktighetsbegränsningar i vardagslivet (Studie III). Vidare har den för det mesta 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 samband med förskrivningen av hjälpmedel, däribland elrullstolar för utomhusbruk. Fortsatta studier med longitudinell design rekommenderas av användning av elrullstol för utomhusbruk, 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; Hultér-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 tactilely 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 & Henriks-son, 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 (Wiert, 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; Haggbloom 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

| Study | Design | Participants | Methods of data collection | Methods of data analysis |
|-------|---|--|---|--|
| I | Qualitative Explorative | 22 persons with stroke using assistive devices | Personal visit Conversational interview grounded in a lifeworld approach | Hermeneutic phenomenological (van Manen) |
| II | Qualitative Explorative | 12 spouses of persons with stroke included in Study I | Personal visit Conversational interview grounded in a lifeworld approach | Hermeneutic phenomenological (van Manen) |
| III | Quantitative Descriptive Prospective Before and after | 32 persons with stroke (referred to an assistive technology centre for provision of an outdoor powered wheelchair) | 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) | Descriptive statistics Non-parametric statistics: -Wilcoxon signed ranks test; Parametric statistics: -Effect size; Deductive analysis: ICF |
| IV | Quantitative Descriptive Comparative | 32 persons with stroke (the same study group as in Study III) | 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) | Descriptive statistics Non-parametric statistics: -Wilcoxon signed ranks test; -Mann Whitney U-test; Parametric statistics: -Effect size |

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).

Table II. Participant selection in the studies I–IV

| | Study I | Study II | Study III, Study IV |
|--------------------------|---|---|--|
| Eligible subjects | 26 fulfilled the inclusion criteria of the cohort of patients with stroke at one-year follow-up (Appelros, Nydevik, Seiger, & Terent, 2002) | All 12 spouses of persons with stroke who participated in Study I | 40 consecutive persons with stroke who were going to be provided with an outdoor powered wheelchair |
| Withdrawn | 4 (1 declined, 3 could not be contacted) | - | 8 (3 declined at start and 4 dropped out because of illness, and 1 did not receive his wheelchair in time) |
| Participants | 22 persons with stroke using assistive devices | 12 spouses of persons with stroke | 32 persons with stroke |

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)

| | Study I | Study II | Study III, IV |
|---|------------|------------|---------------|
| Participants (n) | 22 | 12 | 32 |
| Mean age (range) | 75 (35–86) | 75 (36–80) | 67 (43–85) |
| Gender (n) | | | |
| female | 6 | 10 | 10 |
| male | 16 | 2 | 22 |
| Marital status (n) | | | |
| – Married or cohabitant | 12 | 12 | 24 |
| – Single | 10 | 0 | 8 |
| Location of housing (n) | | | |
| Living in countryside or small villages | 2 | 2 | 14 |
| Living in places with >8000 inhabitants | 20 | 10 | 18 |
| Work status (n) | | | |
| Working full- or part-time | 0 | 2 | 1 |
| Retired or on sick-leave | 22 | 10 | 31 |

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)

| Category of device | Study I (Assistive devices included) n | Study II (Assistive devices included) n |
|-------------------------------------|--|---|
| Personal care | 51 | 25 |
| Mobility | 55 | 33 |
| Housekeeping | 19 | 10 |
| Furnishing and adaptations to homes | 52 | 35 |
| Handling other objects | 16 | 9 |
| Others | 3 | 2 |
| Total | 196 | 114 |

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.

| Strategy | Reason | Analytical focus |
|---|---|--|
| Listening to the audio-taped interview | To acquire a general sense of the participant's experience | Within each case |
| Transcription of the whole interview by a professional secretary, including marks of silence and nuances of emotional expression | To ensure an accurate content to analyse | |
| 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. | To get a good understanding when listening and simultaneously reading on the computer. To get a more condensed text to work with | |
| Core stories of each participant's experience of assistive devices were formulated on the basis of the condensed units of meaning | To get a story that gives an overall and holistic understanding of the participant in relation to assistive devices | |
| Core stories were described and interpreted in accordance with the four lifeworld existentials: lived body, lived space, lived time and lived human relation | 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 | |
| The descriptions and interpretations of the participants' respective lifeworld existentials were brought together | To get an overall understanding of each lifeworld existential from the perspective of all participants in relation to assistive devices | Across cases |
| Through analysis of core stories and of meaning units, the material was interpreted and described in accordance with themes and aspects of the lifeworld | To get a deep and varied understanding of each lifeworld theme and the emerging aspects in relation to assistive devices | |
| 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 | 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 | Within each case and across all cases |

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* (WHODAS 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 WHODAS 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 existentials (Studies I and II). Further, a summary of possible meanings of assistive 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 incorporated into the presented results.

The results in the case of both study groups showed that the use of different 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 disadvantages in both study groups. The results indicate that the lived experiences of assistive devices in the different lifeworld themes are closely interconnected.

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 husband/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 devices may foster bad habits, e.g. becoming less active because there is someone 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 insufficient.

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

| <i>Different meanings of assistive devices</i> | |
|--|--|
| Bodily aspects | |
| <ul style="list-style-type: none"> • easier performance of activities • ability or desire to perform activities • inability to perform activities • doing more • doing less • compensation for physical dysfunction • improved fitness • control of movements • preparedness of body • like part of body • like extension of body • like friend or pet • effect on quality of life • life made easier • maintenance of habits • changed habits • use of devices a habit | <ul style="list-style-type: none"> • often indispensable • structuring and organising of daily life • better functioning • greater disability • reminder of lost capacity • positive emotional affect • negative emotional effect • sense of freedom • means of achieving goals and solving problems • greater sense of security • less sense of security • independence • distraction from thoughts of illness • something you want to be rid of • wish not to need it • good that it's there anyway • missed if not at hand |
| Temporal aspects | |
| <ul style="list-style-type: none"> • time as rich in content • time seen as whole • time short • control over one's time • no dependence on others' time • thinking about past, present and future | <ul style="list-style-type: none"> • lost time • changed perception of time • possibility of spending more time outdoors • use of devices more natural for old than for young • devices old-fashioned |
| Spatial aspects | |
| <ul style="list-style-type: none"> • 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 | <ul style="list-style-type: none"> • takes up a lot of space in home • damage to furnishings • need to rearrange furniture • effect on feeling of homeliness • home is always home, regardless of number of devices • new view of external environment • limitation on places to go to |
| Human-relational aspects | |
| <ul style="list-style-type: none"> • dependence on relatives • sometimes inherent sense of community • device intermediary between person and activity or person and surroundings • maintenance of roles • change in roles | <ul style="list-style-type: none"> • dependence on those who prescribe device • greater or less participation • singling out, stigmatisation • device need not have effect of singling out • different attitudes of those around • less need for home-help • device a sign of disability |
| Inherent function of the device | |
| <ul style="list-style-type: none"> • solves problems • does not solve all problems • limit to the help it can give • not for decoration • not used by many people | <ul style="list-style-type: none"> • symbolic significance • sometimes dual use, e.g. furniture and mobility • free or inexpensive • need for careful planning • hierarchy of assistive devices |

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)

| Measurement and subscale | n | Pre test | | | Post test | | | Effect size | Wilcoxon p-value |
|--|-----|----------|------|--------|-----------|------|--------|-------------|------------------|
| | | Md | Mean | Sd | Md | Mean | Sd | | |
| IPPA Total mean¹⁾ <i>Range 0-25</i> | 32 | 18.1 | 18.3 | (3.6) | 8.2 | 8.9 | (3.5) | 2.6 | <0.001 |
| IPPA divided into ICF¹⁾ <i>Range 0-25</i> | | | | | | | | | |
| Self-care | 1 | 25.0 | 25.0 | (-) | 5.0 | 5.0 | (-) | - | - |
| Domestic life | 34 | 18.0 | 18.0 | (5.0) | 8.0 | 10.1 | (5.8) | 1.6 | <0.001 |
| Interpersonal interactions and relationships | 27 | 16.0 | 16.8 | (5.3) | 8.0 | 9.2 | (6.1) | 1.4 | <0.001 |
| Major life areas | 4 | 20.0 | 21.3 | (2.5) | 6.5 | 6.5 | (1.7) | 5.9 | 0.066 |
| Community, social and civic life | 52 | 20.0 | 18.8 | (4.4) | 8.0 | 8.3 | (4.1) | 2.4 | <0.001 |
| Total | 118 | 20.0 | 18.2 | (4.8) | 8.0 | 8.9 | (5.1) | 1.9 | <0.001 |
| WHODAS II¹⁾ <i>Range 0-100</i> | | | | | | | | | |
| Understanding and communicating | 32 | 10.0 | 13.1 | (14.4) | 10.0 | 10.8 | (13.6) | 0.16 | 0.091 |
| Getting around | 32 | 65.6 | 62.1 | (18.2) | 56.2 | 54.7 | (20.1) | 0.41 | 0.021 |
| Self-care | 32 | 30.0 | 35.0 | (27.5) | 0.0 | 11.9 | (21.6) | 0.84 | <0.001 |
| Getting along with people | 32 | 10.0 | 12.5 | (16.8) | 0.0 | 9.1 | (20.5) | 0.20 | 0.287 |
| Life activities | 32 | 60.0 | 55.6 | (36.9) | 40.0 | 50.9 | (36.4) | 0.13 | 0.443 |
| Participation in society | 32 | 56.3 | 52.9 | (22.0) | 50.0 | 48.8 | (19.9) | 0.18 | 0.095 |
| Total | 32 | 38.3 | 39.5 | (15.7) | 32.2 | 35.4 | (15.3) | 0.26 | 0.025 |
| EQ-5D¹⁾ <i>Range 1-3</i> | | | | | | | | | |
| Mobility | 30 | 2.0 | 2.0 | (0.0) | 2.0 | 2.0 | (0.0) | 0 | 1.000 |
| Self-care | 32 | 2.0 | 1.7 | (0.6) | 2.0 | 1.7 | (0.7) | 0 | 1.000 |
| Usual activities | 32 | 2.0 | 1.8 | (0.5) | 1.5 | 1.5 | (0.5) | 0.58 | 0.033 |
| Pain/discomfort | 32 | 2.0 | 1.8 | (0.7) | 2.0 | 1.8 | (0.7) | 0.12 | 0.366 |
| Anxiety/depression | 32 | 1.0 | 1.5 | (0.6) | 1.0 | 1.6 | (0.7) | 0.10 | 0.593 |
| EQ-5D index scores²⁾ <i>Range 0-1</i> | | | | | | | | | |
| | 32 | 0.6 | 0.5 | (0.3) | 0.6 | 0.6 | (0.3) | 0.17 | 0.195 |
| PIADS <i>Range -3 to +3</i> | | | | | | | | | |
| Competence | 32 | | | | 0.5 | 0.7 | (0.6) | | |
| Adaptability | 32 | | | | 0.3 | 0.6 | (0.7) | | |
| Self-esteem | 32 | | | | 0.6 | 0.7 | (0.6) | | |
| Total | 32 | | | | 0.5 | 0.7 | (0.6) | | |

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)

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

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)

| Interference with life concerning | Pre test | Post test | Pre test | | Post test | |
|-----------------------------------|------------------------|------------------------|----------------------|-----------|----------------------|-----------|
| | Number of participants | Number of participants | Md (q1–q3) mean (sd) | | Md (q1–q3) mean (sd) | |
| Understanding and communicating | 25 | 20 | 2 (1–3) | 2.2 (1) | 2 (2–3) | 2.2 (0.9) |
| Getting around | 32 | 32 | 4 (3–4) | 3.6 (0.9) | 4 (3–4) | 3.6 (0.9) |
| Self-care | 27 | 23 | 3 (2–4) | 3.1 (1.3) | 4 (2–4) | 3.2 (1.2) |
| Getting along with people | 16 | 11 | 2 (1.3–3) | 2.1 (0.9) | 2 (2–3) | 2.5 (1.1) |
| Life activities | 29 | 27 | 3 (1.5–4.5) | 3.1 (1.5) | 3 (1–4) | 3.0 (1.5) |
| Participation in society | 32 | 32 | 4 (3–4) | 3.5 (1.1) | 3.5 (3–4) | 3.4 (0.9) |

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.

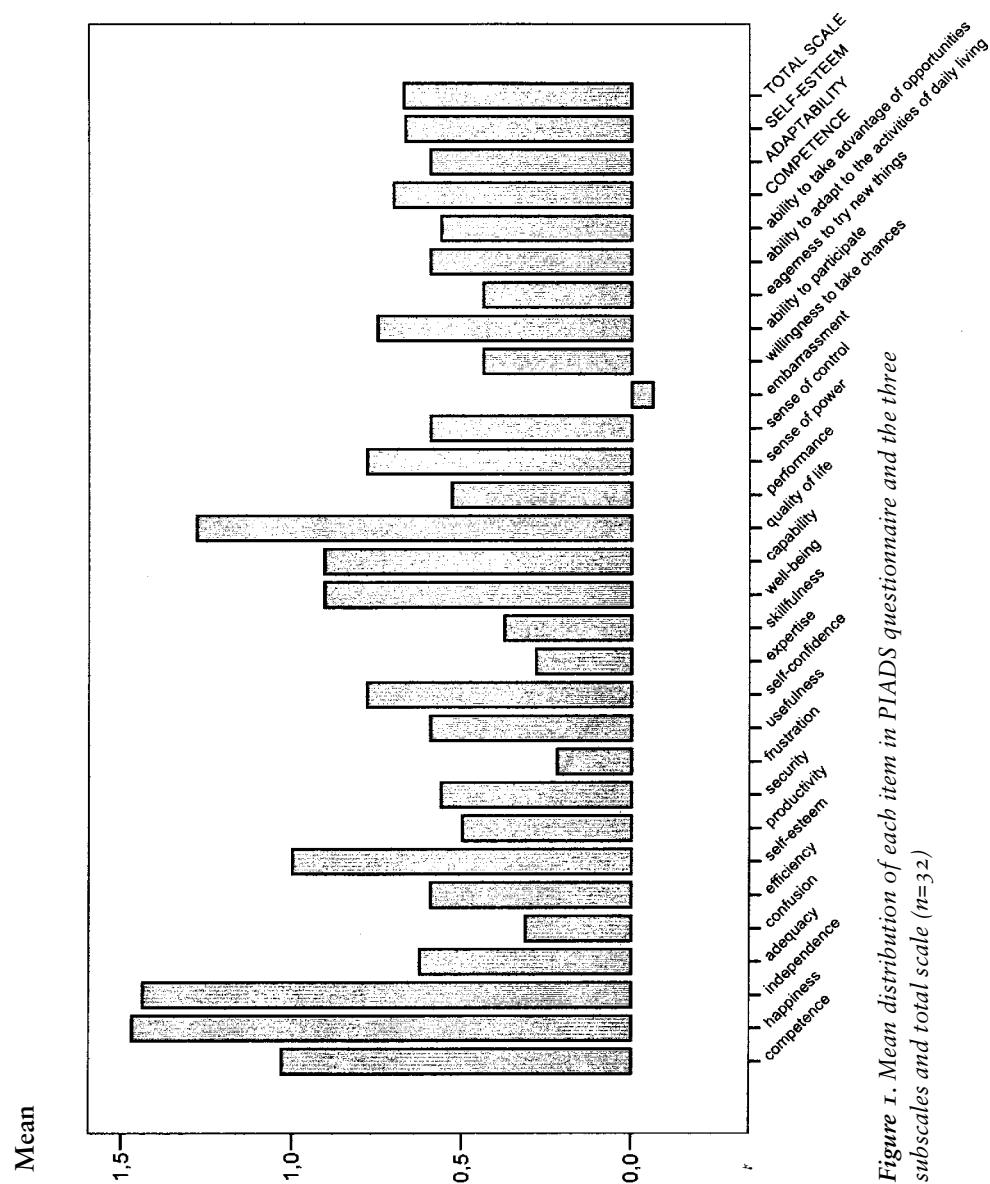


Figure 1. Mean distribution of each item in PIADS questionnaire and the three subscales and total scale (n=32)

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)

| | Side of body paresis ¹⁾ | Location of housing ¹⁾ | Used in summer ¹⁾ | Driving distance as usual ¹⁾ | Importance ²⁾ |
|------------------------|--|--------------------------------------|---------------------------------|---|--------------------------|
| | p-value | p-value | p-value | p-value | p-value |
| Competence | 0.28 | 0.82 | 0.38 | 0.48 | 0.60 |
| Happiness | 0.29 | 0.13 | 0.04 | 0.09 | 0.04 |
| Independence | 0.34 | 0.06 | 0.03 | 0.02 | 0.04 |
| Self-esteem | 0.45 | 0.05 | 0.58 | 0.68 | 0.11 |
| Well-being | 0.71 | 0.04 | 0.10 | 0.18 | 0.17 |
| Capability | 0.11 | 0.14 | 0.03 | 0.23 | 0.19 |
| Quality of life | 0.01 | 0.28 | 0.01 | 0.27 | 0.05 |

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, 2001a) 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; Haggbloom 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, & Terént, 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 prescribers 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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