

Participation in everyday life

Very old persons' experiences of daily occupation, occupation of interest and use of assistive devices

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Göteborg 2007

ISBN 978-91-628-7181-9
Printed by FRAM Boktryckeri, Vasa, Finland 2007

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Abstract

The overall aim of the present thesis was to examine, extend and deepen the understanding of very old persons' experience of participation in everyday life from an occupational perspective.

The thesis consists of four empirical studies. The participants are mainly very old persons (80+) living at home and were derived from the gerontological and geriatric population studies in Göteborg (H70), Sweden. *Study I* (n=11) and *study IV* (n=10) are qualitative studies in which a phenomenographical approach was adopted. *Study II* is a cross-sectional study (n=205), and *study III* is a cross-sectional and longitudinal study (n=201), which were subjected to qualitative content- and statistical analysis.

The findings in *study I* and *II* showed that very old persons used assistive devices to a high degree, and that the use of devices increased with age. Most common were devices used in hygiene- and mobility related occupations. The experiences of being a user of assistive devices varied greatly and various contradictions were found. On the one hand, the assistive devices were seen as natural or normal for the age, the devices gave support, made the person feel safe and facilitated their daily occupation. On the other hand, the assistive devices were experienced as cumbersome, gave a feeling of incapability, were a mark of old age, and made the person concerned avoid participation in everyday life.

The findings in *III study* showed that the participants had a broad range of occupations of interest, media and individual leisure interests being the most common. Personal and environmental factors were reasons for giving up interests. Persons who regarded their health as good, or had no problems in daily activities or in mobility outdoors, had more interests than those with poor health, limited abilities in mobility and in managing daily occupations.

The findings in *study IV* showed how 99-year old persons regarded themselves as competent and proud of their ability to participate in everyday life. Many signs of involvement in daily occupations were found; how they challenged; how occupational patterns preserve occupational abilities, and how incapability and restrictions as a result of personal, environmental and social hindrances were experienced.

In conclusion these studies revealed that very old persons live a creative and varied life and appear to have a variety of management/coping ability for handling the balance between abilities, limitations and environmental demands in everyday life. Daily occupations are mainly performed with the support of assistive devices, though these may be sometimes seen in a negative light. What very old persons experience and how they experience their participation in everyday life greatly affect their self-images, and this is a challenge to everyone who works with elderly persons.

Key words: very old, participation in everyday life, daily occupation, activities of daily living, assistive devices, occupation of interest, leisure, experiences, dependence, independence, living at home, occupational therapy, qualitative research, phenomenography, qualitative content analyses, community living,

ISBN 978-91-628-7181-9

LIST OF PUBLICATIONS

This thesis is based on the following papers, which will be referred to in the text by their Roman numerals:

- I. Hägglom Kronlöf, G. & Sonn, U. (1999). Elderly women's way of relating to assistive devices. *Technology and Disability*, 10, 161-168.
- II. Hägglom Kronlöf, G. & Sonn, U. Use of assistive devices - a reality full of contradictions in elderly person's everyday life. *(Submitted)*
- III. Hägglom Kronlöf, G. & Sonn, U. (2005). Interests that occupy 86-old persons living at home – associations with functional ability, self-rated health and socio-demographic characteristics. *Australian Occupational Therapy Journal*, 53, 196-204.
- IV. Hägglom Kronlöf, G., Hultberg, J., Eriksson, B.G. & Sonn, U. (2007). Experiences of daily occupations at 99 years of age. *Scandinavian Journal of Occupational Therapy*, 1-9, iFirst article, DOI: 10.1080/11038120601124448

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INTRODUCTION

Very old persons' everyday life

Everyday life is generally taken for granted and any problems connected with daily occupation have often escaped attention and not been questioned on the part of professional carers (Ellegård, 2001). Occupation is a concept used in occupational therapy, referring to groups of activities and tasks of everyday life, named, organised and given value and meaning by individuals and a culture. It is everything people do to occupy themselves, including looking after themselves (self-care), enjoying life (leisure) and contributing to the social and economic fabric of their communities (productivity) (Townsend, 1997). For many, especially among the very old¹, daily occupation is not so obvious any longer and participation in everyday life means trying to keep a balance between limitations and abilities in the living context. Participation [sv delaktighet] is defined as a person's involvement in a life situation (WHO, 2001), and can also be described from a political perspective as disability rights (Gustavsson, 2004). Many elderly² persons, even the very old, have developed different strategies to keep this balance. Common strategies are, for example, to ask for help from someone else, to use assistive technology (Dahlin Ivanoff, Gosman-Hedström & Sonn, 2006; Dahlin Ivanoff & Sonn, 2001), or to apply strategies based on earlier experiences in life (Haak, Fänge, Iwarsson & Dahlin Ivanoff, 2007; Hinck, 2004; Jackson, 1996).

It is difficult to describe everyday life in the elderly population because the elderly are not a homogeneous group, and each individual focuses on finding a meaning in what they do (Gubrium & Holstein, 2000). Becoming old is a very individual process. According to Laslett (1996), four different life course levels or perspectives can be identified. The third level is that time when a person retires, has few duties, is free from work and is able to choose what he/she wants to do. There is no or little functional decline at this time of life that would have an impact on participation in everyday life. The fourth level or stage is the period when functional decline and illness appear and have a marked impact on participation in everyday life, leading in many cases to a need for personal and/or artificial assistance. At the fourth level of the life course, elderly persons spend most of their time in their home environment, which becomes more important than before (Hillerås, Jorm, Herlitz & Winblad, 1999). Elderly persons at the fourth level could also be described as frail because of declining health with co-morbidity, disability and vulnerability (Fried, Ferrucci, Darer, Williamson & Anderson, 2004).

¹ 80+ (WHO, 2006)

² The retirement age of 65 (in Sweden) is often adopted as that point in a life course for defining people as elderly

Health can be defined in different ways emphasising both objective indications of health and self-perceived health. Health can also be viewed in a holistic way, including achievement of vital goals in everyday life through engagement in daily occupations, and not seen merely as freedom from pathology (Pörn, 1993). This view is similar to that found in occupational therapy, which states that it is through the process of engagement in occupation people develop and maintain health (Wilcock, 1998; Wilcock, 2005; Yerxa, 1998). Health is defined from an occupational perspective as the absence of illness but not necessarily of disability; a balance of physical, mental and social well-being attained through socially valued and individually meaningful occupation; enhancement of capacities and opportunity to strive for individual as well as community potential; social integration, support and justice (Wilcock, 1998, p.110). That means that health-related factors can be found at both a personal and a social level and can be promoted by enabling very old persons to gain mastery over daily occupations to reach participation in everyday life, and thereby improve their health (Bracht, 1998; Carlsson, Clark & Young, 1998; Dahlin Ivanoff, 2000; Jackson, 1996).

Today the average length of life among women in Sweden is 82.8 and is expected to rise to 86.3 years by 2050, while that of men will increase from 78.4 to 83.6 years. The proportion of the very old in the population is also expected to increase. Out of the total population of almost 9 million, 487 000 persons belonged to the very old category in the year of 2005, and this number is expected to reach 900 000 by the year 2050 (Statistiska centralbyrån [SCB], 2006a). This clearly indicates an increasing need of support and interventions to enable the very old to engage in daily occupation and participate in everyday life.

Old age can sometimes be characterised in a negative way, a time without participation in daily occupation. This is, to some extent, a social construction or image of old age as a time of steady decline and withdrawal from ordinary life, which is often incorrect (Hazan, 2000; Hugman, 1999). Very old persons can live an active life as well as younger persons do and participate in everyday life in a creative way (Haak, 2006; Hinck, 2004; Jackson, 1996). This means that they are capable of adapting to possibilities and hindrances that appear in daily occupations. However, the presence of impairment or disability might lead to restricted or less diverse participation in everyday life, and activities may be located more in the home and involve fewer social relationships (Law, 2002). Under these circumstances, elderly persons preserve their identity by conveying to their home environment (Helin, 2000). Such persons can still engage and participate in everyday life by modifying their occupational performance with the help of compensatory/adaptive strategies and changing the meaning of the occupation (Jackson, 1996). Occupational performance refers to the

ability to choose, organise and satisfactorily perform meaningful occupations that are culturally defined and age-appropriate and concerned with looking after one's self, enjoying life, and contributing to the social and economic fabric of a community (Townsend, 1997, p. 30). Everyone ages differently, and it is important for any caregiver to have a broad perspective to understand the complexity of becoming old and how various factors interact and have an impact on everyday life.

Participation in everyday life

Participation in everyday life, i.e. having functional ability and being able to engage in daily occupation, is essential for all human existence (Wilcock, 1998) and for a positive influence on wellbeing (WHO, 2001; WHO, 2002). For elderly persons to be able to live an active everyday life, attention must be paid as much to their mental health and social connections as to their physical health (WHO, 2002). In the International Classification of Functioning, Disability and Health (ICF) (WHO, 2001) the concepts are integrated and described as functional health or ability. In ICF functional ability together with activity and participation are core concepts and seen as important in determining health. The concept of participation includes involvement³, which can be described in different ways such as “taking part”, “being included”, “engaged in an area of life”, “being accepted” and “having access to needed resources” in everyday life (Molin, 2004 p. 66; WHO, 2001). Involvement and engagement in everyday life are treated almost synonymously in the ICF framework (Molin, 2004; WHO, 2001) and in occupational therapy (Desrosiers, 2005). A basic assumption in the profession of occupational therapy is that health can be achieved by engagement in occupation (Meyer, 1977; Reilly, 1962; Wilcock, 1998). Engagement in occupation is seen to have an overall impact on people's health and wellbeing (Christiansen & Townsend, 2004; Hasselkus, 2002) and people's engagement in goal-directed and meaningful occupation is seen as a vital part of human development and lived experience (Hasselkus, 2002; Law, 2002; Rioux, 2005). Engagement in occupation is self-initiated and has a motive for doing (Yerxa, 1998) and means taking control, being given the opportunity to express ourselves, structure our existence, find meaning in our life and adapt to life's challenges (Christiansen & Townsend, 2004). This means that participation; involvement or engagement in daily occupation is not only essential but also constitutes a great part of a person's everyday life. Each day we perform countless tasks⁴ that require different skills that enable us to carry out activities⁵. We sleep, wash, cook, eat, play, talk, socialize, read, make reflections, watch TV, listen to the radio, create and engage in a wide

³ Involvement [sv. engagemang] (Molin, 2004)

⁴ Task is a set of purposeful activities in which a person engages (Law, Cooper, Strong, Stewart, Rigby & Letts, 1996)

⁵ Activity is the execution of a task or action by a person (WHO, 2001). In this theses the term activity is used interchangeably with occupation

range of activities that are included in our daily occupation and give meaning to our lives (Christiansen & Townsend, 2004).

Accordingly, participation in everyday life and engagement in daily occupation among the very old is a complex issue and influenced by many different factors. Three factors were found to influence engagement in daily occupations in a randomised controlled study (n=361, age 60+). The factors were having a sense of control over one's life, healthy habits and achieving continuity with one's past, and the result showed that daily occupation might mitigate the health risks of elderly persons (Carlson et al. 1998; Clark et al. 1997). In a retrospective study in a Swedish population (n=150, born 1902/1903) Iwarsson et al. (1998) found, that daily occupation promotes health, as there were significant differences in survival rates (as an objective measure of health) between the "more active" and "less active" females. This was not shown among men. However, one must interpret the result with cautions as the study had a very small sample. A qualitative study with a randomly selected sample (n=22, age 75+) looked for discriminating factors between more or less healthy old persons. To these elderly persons health was experienced as having something meaningful to do; a balance between abilities and challenges; appropriate external resources and personal attitudes. Positive attitudes emerged as important contributors to positively perceived health, while the opposite "a poor me" attitude was found to be a negative contributor to perceived health (Bryant, Corbett & Kutner, 2001). Studies have found that people with a less positive belief in and attitude to occupation described their physical functioning more negatively than persons with a more positive belief in occupation (Borell, Lilja, Svidén & Sadlo, 2001; Helin, 2000). Similar results about engagement in meaningful occupation and its importance for health and wellbeing have also been obtained in other studies (Bonder & Martin, 2000; Lysack & Seipke, 2002). Together these studies show that an active life with engagement in meaningful occupations and with a balance between ability and challenges promotes health and participation in everyday life. Needless to say, a high level of capabilities or activities does not necessarily lead to a high level of engagement and participation (Desrosiers, 2005). That is, functional and mental capacity only indicates the potential for activity. It tells us what a person can do but not what he or she actually does or experiences in everyday life.

Everyday life occurs in time and space and has been studied according to different kinds of patterns. A study of the activity patterns in everyday life among the very old (90+) showed that intellectual activities were more common than physical and social activities. Intellectual activities were performed in the evenings, physical activities in the mornings and afternoon, and social

activities had a peak at lunch time and in the evenings. Perception of health was related more to intellectual activities than to physical and social activities. Men performed the latter more frequently than women (Hillerås et al. 1999). Carlsson, Berg and Wenestam (1991) found a pattern of daily occupations among 85-year-olds called 'ritualisation'. They performed certain occupations at certain time. This pattern was shown to be important for maintaining control, increasing their self-esteem and retaining autonomy.

The place and space of home

Ninety-five per cent of the citizens in Sweden between 65 and 89 years of age live in ordinary housing (SCB, 2003). Home is the place where especially the very old spend much of their time and where most daily occupations are performed (Haak, 2006; Hillerås et al. 1999; Östlund, 1995). This applies particularly to women, who view home as a place for family members and domestic activities, while men tend to focus more on outdoor activities (Vilkko, 1997). Home is also a space filled with personal interests, and it illustrates a person's experience and expectations; it is like a portrait of self-identity (Kontos, 2000). The objects of meaning in their home provide very old persons with a sense of continuity in life (Jackson, 1996).

It is well known that, for elderly persons living in their own homes in the community, there is a risk of becoming dependent because of illness or disease. This also means a risk of not being able to continue living at home (Albert, 2000). Studies about everyday life commonly focus on independence or dependence in instrumental activities of daily living⁶ (IADL) as well as basic or personal activities of daily living⁷ (PADL). Dependence/independence in ADL is a common measure or assessment of health and disability in general (WHO, 2001) and is used to describe the elderly populations (Sonn, 1996; Spillman, 2004; Verbrügge & Jette, 1994) as well as for assessments in clinical work (Law, Baum & Dunn, 2001). A study in a general population of elderly persons showed that dependence on personal help increases with age (Sonn, Grimby & Svanborg, 1996; Spillman, 2004), and that dependence on personal help in both PADL and IADL predict mortality as well as institutionalisation to a higher degree than among those dependent only in IADL (Sonn, Grimby et al. 1996). Another study concerning health and functional ability among centenarians showed that the persons had been healthy and independent for most of their lives (Hitt, Young-Xu, Silver & Perls, 1999). However, a cross-sectional study (75+, including 276

⁶ Instrumental activities of daily living – IADL include activities such as cleaning, shopping, transportation and cooking (Sonn & Hulter Åsberg, 1991)

⁷ Personal activities of daily living –PADL include bathing, dressing, going to toilet, transfer and feeding (Sonn & Hulter Åsberg, 1991)

centenarians) living both in their own homes and in nursing homes has shown that significantly more centenarians had difficulty in personal activities in daily living and mobility outdoors than in the younger age groups. Physical ability has shown to diminish gradually among both women and men from the age of 80 years compared to persons aged 75-79 years (Andersen-Ranberg et al. 1999). Thus, with advancing age there is a progressively decreasing ability in performing daily occupation. These progressive changes and their impact on participation in everyday life need to be further understood. At the same time, it is essential to study and understand the very old persons and the centenarians who keep up their ability and participate in everyday life. Their experiences might teach us and increase our knowledge about how to be able to continue participation in everyday life even at very high ages.

The home and neighbourhood environment affect participation in everyday life and independence since daily occupation is controlled by the person him/herself. It has been shown that elderly persons experienced that their home was the locus and origin of performance-oriented and togetherness-oriented participation in everyday life (Haak, 2006). In the neighbourhood, the most important public facilities they usually visited were department stores, pharmacies, post offices, manufacturers and banks. They perceived problems along walking routes in the public outdoor environments more often than in public facilities (Valdemarsson, Jernryd & Iwarsson, 2005). Demands in the physical environment cause disability in daily activities to emerge among elderly persons (Haak, 2006; Iwarsson & Wilson, 2006). Östlund (1995) studied elderly person's preferences for technology in everyday life. The use of technology was an important part of the elderly persons' everyday life; the telephone and television were especially well integrated into their everyday life and important for connecting the home with the world outside. New technology was of no interest or no longer held any fascination; they were positive to technical development in general but had a pragmatic attitude towards modernity and new technology. There had to be a real need of new technology among the users for them to start using it and the technology needed to be familiar and could not constitute a contradiction of the persons' basic values.

A relatively high degree of independence and autonomy is valued among the very old living at home despite different diseases and disabilities, but we also know that many persons who live in their own homes have extensive needs (Jeune, 2002; Romoren & Blekeseaune, 2003). One way of defining independence means being able to live at home without personal help, and this is, according to Rioux (2005), the best way to retain one's autonomy. Independence in daily occupation can also be seen as an ideology in our social culture that is reproduced as goals for the

persons in rehabilitation (Becker & Kaufman, 1995). Hasselkus (2002) argues that there is a tension between rehabilitation goals for independence and social relations. Having social relations means “being with others, feeling connected with one’s world, independence is acting without others, functioning separately from others, using personal initiative” (Hasselkus, 2002, p. 94). According to Chan (2002), autonomy can be defined as deciding not only what one wants to do, but also when, how, where and with whom (decisional autonomy), and doing what one decides to do (executorial autonomy). Persons have individual needs and their own ideas about how to stay independent and/or retain control in everyday life, and it is essential to take their experiences into account when planning an intervention, in designing health-promoting interventions and in further research (Agahi, Lagergren, Thorslund & Wånell, 2005; Clark et al. 1997; Dahlin Ivanoff, 2000; Eklund, 2005). Society might benefit economically if the elderly can remain living in their own homes (Agree & Freedman, 2000; Mann, Ottenbacher, Fraas, Tomita & Granger, 1999), but this has to be done by meeting an increasing need of formal or informal personal support and technical support to enable them to handle everyday life (Fänge & Iwarsson, 2003; Gosman-Hedström, Sonn & Aniansson, 1995; Sonn, Grimby et al. 1996).

Studies about participation in everyday life among very old persons living in the community are relatively rare and vary in their focus. However, together they portray not only the complexity of everyday life but also the importance of understanding the impact of different factors. It is now imperative that further knowledge and understanding of elderly persons’ engagement in daily occupation and participation in everyday life is obtained to cope with the growing demands of an aging population (Gubrium & Holstein, 2000; Polatajako, 2004; Stanley & Cheek, 2003).

Experience of daily occupations

Engagement in daily occupation means different things for each one of us and provides unique experiences (Yerxa et al. 1990). To experience something can be depicted in terms of the structure of awareness at a particular moment, which can be characterised in terms of a generalised figure-ground structure. Some aspects of a moment come to the fore when other aspects must recede into the background or margins. Although a person is aware of numerous things at the same time, one is certainly not aware of everything in the same way (Pang, 2003, p.150). Runesson and Marton (2002) argue that being able to experience an aspect of a phenomenon or object at a particular moment means first being able to discern critical features and then being able to focus upon them simultaneously. Only that which varies can be discerned in the simultaneous focus (Pang, 2003). Experiencing something in daily occupations is a question of discerning critical aspects of daily

occupation and comparing them with others that make us aware of individual or collective experience.

How we experience daily occupations varies from situation to situation, based on our present goals, values and past experiences (Kaufman, 1986). We create meaning and significance in the spaces and places in which we live (Zemke, 2004), and experiences can only be assessed or described by the person him/herself (Perenboom & Chorus, 2003; Yerxa et al. 1990). The unique experience gained from participation and engagement in daily occupations calls for an understanding of different aspects of everyday life (Gubrium & Holstein, 2000; Ueda & Okawa, 2003). Larsson (2004) proposes that experience of occupation contains three elements: subjective engagement in occupations, assessment of our personal performance affected by occupational complexity, and how well we achieved the purpose or function. Furthermore, in our society, the feeling about how well we are using our time in a particular occupation may also become an important part of our occupational experiences (Larsson, 2004).

In the literature we can find different aspects of experiences that have an impact on the ability of very old persons to engage in daily occupation. Feeling secure in performing daily occupation is one such aspect that exerts a positive effect. Feeling insecure is, however, common among persons with disability, for example, among elderly persons with age-related macular degeneration who have problems in several daily occupations as a result of their impairment (Dahlin Ivanoff, Sjöstrand, Klepp, Axelsson Lind & Lundgren-Lindqvist, 1996). Self-reported tiredness in daily occupations may reflect early signs of disability. In one longitudinal study, it was shown that sustained self-reported tiredness in daily occupations from age 75 to 80 was an early sign of functional decline from age 80 to 85 (Avlund, Pedersen & Schroll, 2003). In contrast, the very old (age 85) experienced satisfaction in everyday life when they were occupied as usual; had friends; felt able to manage their own lives; did not live alone and had not recently lost close friends. Lack of satisfaction in everyday life, were experienced when the subjects were dependent on personal help and were living in an institution (Johannesen, Petersen & Avlund, 2004). Very old persons' (n=22, age 80+) experiences of everyday occupation outside their home were studied by Hovbrandt, Fridlund and Carlsson (2006). Three different aspects of experiences were found. The first describe how participants preferred to keep on doing occupations as before but decline in functional capacity made it more difficult to overcome barriers in the environment. The second experience of importance was that they preferred using their own resources such as body capacity, assistive devices, family members and the car in daily occupation. And the third was described as

sometimes having to use their utmost capacity to reach their goals and overcome environmental barriers. Environmental barriers like uneven pavements and high entrance steps on buses were difficult to overcome and limited their participation in everyday life.

As discussed above, being aware of very old persons' own experiences is now seen by many professionals as important from a theoretical perspective, in clinical practice and for health promotions in the society. This kind of knowledge can also advance our understanding of engagement in daily occupation and participation in everyday life. In an attempt to conclude the literature review, it can be stated that although there were some studies describing *what* is experienced, very few studies focus on *how* daily occupations are experienced, and few studies concern very old persons' own experiences. "How experiences" enable us to reach personal goals and reinvigorate everyday practices, focusing towards personal meaning and context relevancy (Gubrium & Holstein, 2000; Wicks & Whiteford, 2006; Yerxa et al. 1990). These must be made more explicit in different intervention programmes in rehabilitation settings and in geriatric care. This can also be seen not only as an ethical question that needs to be taken into account (Hammell, 2002) but also as a question of occupational justice in our society (Townsend & Wilcock, 2004).

Occupation of interest

Occupation of interest is the concept that is used in this thesis to describe an occupation in everyday life that very old persons engage in with joy and pleasure, as a result of internal motivation and perceived freedom (Csikszentmihalyi & Graef, 1980; Iso-Ahola, 1979). The motivation and meaningfulness in performing different occupations of interest can occur both in the doing process and in the result or product of the occupation (Fortmeier, 2003). The enjoyment of doing things ranges from the simple satisfaction derived from daily rituals to the intense pleasure a person can feel in pursuing their driving passions (Kielhofner, 2002). Enjoyment is often more connected with the people one shares the occupation with than with the kind of occupation itself (Rioux, 2005). Leisure or leisure activities are concepts commonly used to describe this kind of occupation as distinct from work and productivity occupations (Thibodaux & Bundy, 1998), but occupations of interest are sometimes also described as instrumental activities (Fricke & Unsworth, 2001).

Occupations of interest are generally seen as contributing to health, quality of life and motivating people to engage in occupations despite functional limitations. Stebbins (2005a, 2005b) makes a distinction, however, between casual leisure and serious and project-based leisure. Casual leisure

can be defined as occupations that are pleasurable, of short duration, intrinsically rewarding and require no special training for enjoyment, and serious, project-based leisure includes amateurism, volunteering, hobbyist pursuits, and self-development. The first is seen as “unhealthy” because it is largely sedentary and fails to challenge the mind while the second is “healthy” because it includes fitness and challenges.

For many very old persons, the relative freedom from obligation provides the person with an opportunity to choose their own life style and pursue a variety of interests more seriously or fully than before. This has been shown to have an impact on quality of life among community-living and resident-living elderly persons (mean age 84 years) (Duncan-Myers & Huebner, 2000). Studies have also shown that social activities and productive activities (light housework with gardening being the most common) were related to greater happiness, reduced functional decline and reduced mortality, whereas more solitary activities (reading, handwork and hobbies) were related only to psychological wellbeing such as happiness (Menec, 2003). Cognitive leisure activities such as playing board games and reading (Verghese et al. 2006) and an overall engagement in cognitively stimulating activities, apart from watching television, may lower the risk of cognitive impairment in old age (Rundek & Bennett, 2006). Lennartsson and Silverstein (2001) found that healthier individuals tend to be more involved in activities in general, especially in solitary-active ones like reading, and that this had a positive effect on the survival of very old persons. Glass, Mendes de Leon, Marottoli and Berkman (1999) found that social and productive activities lower the risk of all-cause mortality as much as fitness activities do. This indicates that both solitary, social and productive activities and even activities involving less physical exertion might improve health and can be an alternative intervention for frail elderly people.

A longitudinal study among persons followed from 1968 to 2002 from the ages of 43-62 to 77-96 years showed stability over time with respect to participation in leisure activities. Individuals who had participated in one kind of occupation in middle age tended to maintain a similar interest late in life, even if some of them participated less frequently. Starting new kinds of leisure activities in old age is rare, although it might occur (Agahi & Parker, 2004). The levels in productive and leisure activities (Klumb & Baltes, 1999) and in social participation (Bukova, Maas & Lampert, 2002) decrease in the very old age groups. Women with a commitment to housework were associated with having less time for leisure (Klumb & Baltes, 1999), but studies also show that very old women prefer cooking and housework as a leisure activity more than men (Nilsson, Löfgren, Fisher & Bernspång, 2006). Men (85+) in the north part of Sweden preferred activities

like bathing, boating, sailing, attending sport events, fishing, hunting and shooting more than women. Differences were also found between urban citizens, who preferred more cultural activities and hobbies than rural-living persons who preferred pets, music and fishing/ hunting/ shooting (Nilsson et al. 2006).

Nilsson (2006) measured seven life domains among very old persons and found that they were least likely to be satisfied with engagement in “leisure”, followed by “economy”, “activities in daily life”, “life as whole”, “contacts”, “partner relationship” and most likely to be satisfied with “family life”. Among elderly persons with disability, Mann (2001) found that they missed occupations of interest that involve an active doing role, such as gardening, dancing and playing games, compared with passive activities such as watching TV. Active doing also requires functional ability that is not always possible to reach in old age. Adapting the performance of occupation of interest and/or providing an appropriate assistive technology enables elderly persons to resume occupations of interest they once enjoyed but had abandoned (Schweitzer, Mann, Nochajski & Tomita, 1999).

The review of the literature showed that there are few studies of the very old population that focus on occupations of interest or leisure activities except for a recent thesis by Nilsson (2006). Although it is recognised that being able to engage in occupations of interest in everyday life benefits elderly persons in different ways, there is a further need for studies about very old persons living in the community, what they prefer to do, how their interest repertoire changes and reasons for this change. This information is essential for health promotion both at the societal level and the individual level. In occupational therapy, occupations of interest could be used even more fully in interventions among those still living at home to promote participation in everyday life.

Assistive technology in everyday life

Assistive technology and assistive devices have proved essential to maintaining and facilitating daily occupation among the very old (Agree & Freedman, 2000; Janlöv, Hallberg & Petersson, 2005; Spillman, 2004), enabling them to feel safe and secure and to overcome environmental demands (Sonn & Grimby, 1994; Cook & Hussay, 2002; Roelands, Van Oost, Buysse & Depoorter, 2002). People with disability in Sweden receive assistive devices free of charge or for a small fee regardless of age, sex or income. It is the person’s needs that are paramount. About 10% of the total population, primarily elderly persons, use some kind of assistive technology (SOU, 2004). According to Swedish Handicap Institute (SHI) statistics, 70% of all assistive devices are

prescribed to persons over 65 years of age (SHI, 2006).

Assistive technology has also been called health technology, because the use of devices has been seen as an important contributor to public health (Agahi et al. 2005). Gerontechnology is another concept used that describes the whole gamut of assistive technologies for elderly persons and is defined as “the study of technology and aging for the improvement of the daily functioning of the elderly” (Graafmans & Taipale, 1998, p.3). Gerontechnology originates from the human-technology-perspective and aims to compensate for a shortage and prevent age-related changes (Östlund, 2002). Assistive technology can also be defined as devices, services, strategies and practices that are conceived and applied to ameliorate the problems faced by individuals with disabilities and assistive devices is any item, pieces of equipment or product system (acquired commercially, modified or customised) that is used to increase or improve the activity and participation of individuals with disability (Cook & Hussay, 2002, p.5). In this thesis both the terms assistive devices and assistive technologies are used and used interchangeably with a focus on how they enable participation in everyday life.

Use of assistive devices

It is difficult to compare the number of users of assistive devices in different studies, not only due to cultural differences but also to different sampling methods, type of devices and definitions of assistive technology. However, some longitudinal studies have proved useful. It has been shown in a representative sample of elderly persons living in ordinary housing in Sweden, that 21% were users of assistive devices at the age of 70 compared to 47% at the age of 76 (Sonn & Grimby, 1994). In a retrospective longitudinal population study, 74% of 85-year-olds were users of assistive devices compared to 92% at the age of 90 (Dahlin Ivanhoff & Sonn, 2005). The numbers of users, of assistive technology increases with age, but fewer new users appear in the oldest groups. Women use assistive devices more than men (Parker, Thorslund & Lundberg, 1994; Edwards & Jones, 1998; Agahi et al. 2005). This is seen especially in the younger (Sonn & Grimby, 1994) rather than the older age groups (Dahlin Ivanoff & Sonn, 2005).

Studies of elderly Americans (including very old persons) with difficulty in one or more daily activities found that nearly two thirds (Agree & Freedman, 2000), compared with 93% in another population (n=2368) age 65 and older (30% were 85+) (Hoenig, Taylor & Sloan, 2003), used one or more assistive devices to meet their needs. In a systematic review study of national surveys on assistive devices in USA, it was shown that prevalence rates for use of one or more assistive

devices differed between surveys, from 39-44% in a group of persons 85+ to 14-18% in a group aged 65 and older (Cornman, Freedman, & Agree, 2005). A cross-national project among the very old (75-89 year-olds) in five European countries⁸ revealed that 65% were using assistive devices. The proportion of participants using assistive devices was higher in Sweden and in the UK than in the other countries (Löfqvist, Nygren, Széman & Iwarsson, 2005).

Activity limitations and/or physical disability are the strongest predictors of the use of assistive technology, and their use increases with increasing levels of disability (Hartke, Prohaska & Furner, 1998; Tomita, Mann, Fraas & Stanton, 2004). Assistive technology has been shown to have a positive effect on independence among the very old as it enables them to continue to participate in everyday life and perform activities of daily living (Parker, Ahacic & Thorslund, 2005). In a study among 85-year-olds (n=617) living at home, the proportion of users of assistive devices was 77%, and the majority of them were independent (Dahlin Ivanoff & Sonn, 2004). A randomised controlled trial of (n=104) home-based frail elderly persons showed that, after an intervention period of 18 months, assistive technology together with environmental intervention had a positive effect on maintaining independence as well as reducing costs for home care (Mann et al. 1999). Even if users of assistive technology in the higher age groups also receive personal help to a high degree (Roelands et al. 2002), it is acknowledged that assistive technology enables daily occupations, reduces the need for personal help, makes living more effective and reduces the costs to society.

Even if spectacles and hearing aids are assistive devices commonly used among elderly persons (Edwards & Jones, 1998; Hartke et al. 1998), this thesis focuses on the assistive technology used in everyday life such as personal hygiene, chair and bed transfer, dressing and grip and reach activities and mobility. It has been shown that the most commonly used devices in everyday life are the ones for mobility, such as walking canes and walking frames, and for hygiene-related activities (Dahlin Ivanoff & Sonn, 2005; Hasting Kraskowsky & Finlayson, 2001; Löfqvist et al. 2005; Sonn, 2000; Sonn & Grimby, 1994).

The literature review showed that most studies focus on the use of assistive devices among the younger age groups and that few concentrate on their use among the very old persons. Some studies include the very old within a wide range of elderly persons or do not discriminate between

⁸ Sweden, Germany, Latvia, Hungary and United Kingdom

age groups. This makes it hard to observe any special pattern concerning the use of assistive devices in higher age groups. Furthermore, most descriptions of the use of assistive technology among elderly persons living in the community are cross-sectional (Agree & Freedman, 2000; Cornman et al. 2005; Dahlin Ivanoff & Sonn, 2004), while longitudinal studies are few in number (Dahlin Ivanoff & Sonn, 2005; Sonn & Grimby, 1994; Taylor & Hoenig, 2004). This means that information on changes in the use of assistive technology with age is limited. Such knowledge is of special value as the proportion of very old persons in the general population is expected to increase (SCB, 2006a). More studies with a longitudinal design are required to provide material for planning preventive and health-promoting interventions. Knowledge of the process and the pattern of change over time, together with results from cross-sectional studies would be invaluable if we wish to have a more comprehensive and dynamic approach to the use and users of assistive technology.

Users' experience of assistive devices in daily occupations

Studies of elderly persons living in the community show that high proportion of persons are satisfied with their use of assistive technology in everyday life, while the specific types of devices used vary (Brooks, 1991; Löfqvist et al. 2005; Mann & Tomita, 1998; Roelands et al. 2002; Sonn & Grimby, 1994). The effectiveness of use of assistive devices in daily activities in a 76-year-old population was described by the users in terms of increased safety, less effort, increased independence and promotion of activity in everyday life (Sonn & Grimby, 1994). Similar results have been reported from other studies (Hastings Kraskowsky & Finlayson, 2001; Roelands et al. 2002). Studies with a focus on a special kind of device, such as mobility devices, have also shown many different experiences of advantages (Bateni & Maki, 2005; Brandt, Iwarsson & Ståhl, 2003).

Elderly persons might prefer using assistive technology in everyday life to relying on personal help to be able to continue living at home and stay independent (Dahlin Ivanoff, et al. 2006). Agree (1999) suggested that the reason for preferring assistive technology might be that devices do not require ongoing cooperation or coordination with other people and therefore increase the user's sense of independence.

Roelands and co-authors (2002) have studied attitudes regarding assistive devices in a sample of persons aged 75+ receiving home nursing (n=117). The opinions of the use of assistive devices were mainly positive, but some users thought that personal help should not be admitted if they used assistive devices. Many responders agreed that the use of assistive devices would make

someone less dependent on personal assistance, and that they could remain independent longer at home if they used assistive devices. Opinions concerning the impact of the use of assistive devices on feelings of loneliness differed. People who lived alone did not have a more positive attitude towards the use of assistive devices, although they were in a more vulnerable position. The authors state that psychological variables might be a stronger predictor of the use of assistive devices than the actual possession of assistive devices (Roelands et al. 2002). Psychosocial and cultural issues have been found to determine both assistive technology use and the abandonment of certain devices (Hastings Kraskowsky & Finlayson, 2001; Pape, Kim & Weiner, 2002). Both these and others authors call for further research into the use of assistive devices in everyday life (Gitlin, 1995; Roelands et al. 2002; Scherer, 1996).

Scherer (1996) stated that it is often assumed that the physical freedom to perform occupations provided by assistive technology results in improved quality of life. Looking behind the traditional perspective, illustrated in the literature that use of assistive technology compensates for physical impairment, we can find that the impact of the use of assistive technology can be both positive and negative. Studies point out that assistive technology in everyday life can be too complicated for elderly persons, or that the use of assistive devices did not make any difference in the activities where they were used (Sonn & Grimby, 1994). In a study of younger users (mean age 50, range 25-73) with physical disability, assistive technology was experienced as leading to less activity, and resignation occurred in daily occupations for various reasons (Larsson Lund & Nygård, 2003). Becoming resigned to a situation has an impact on the user's identity and occupational self-image (Gitlin, Luborsky & Schemm, 1998; Larsson Lund & Nygård, 2003). Opinions about the symbolic value of assistive technology diverge, i.e. one loses ability, one gains ability to participate in everyday life. The use of a certain device might either generate respect or lead to an inadequate reception in the environment (Brandt et al. 2003; Copolillo, 2001; McMillen & Söderberg, 2002; Pape et al. 2002). As an object in the environment, assistive technology also has personal and social values in everyday life and can be described both at the individual, social and cultural level (Csikszentmihalyi & Rochberg-Halton, 1981; Hocking, 1994; Kielhofner, 2002). For a person to accept and become a user of assistive technology in everyday life, he or she must feel a personal need for artificial assistance (Mann, Goodall, Justiss & Tomita, 2002; Sonn, Davegårdh, Lindskog & Steen, 1996).

Though the use of assistive technology is known to increase with age, user experiences have been rarely explored among very old persons. It is important for occupational therapists and other

professionals to realise that the use of assistive technology among the very old can result in quite different experiences. It can be seen either as a means of enabling them to participate in everyday life or as a hindrance to participation. Further research into how this age group experiences the use of assistive technology is therefore urgently needed.

Rationale for the study

The rationale for this thesis is based on the assumption that it is of vital importance to understand how very old persons still living at home experience participation in daily occupation in everyday life. Participation is seen as a prerequisite for health and wellbeing (WHO, 2001). For many elderly persons and especially for the very old, participation in everyday life means a balance between abilities and limitations in occupational performance, and further knowledge is required about how everyday life is experienced from the perspective of the elderly themselves. Using assistive devices is a common strategy for enabling participation in everyday life, but very few studies have focused on the users' own experiences of assistive devices and of being a user of assistive devices. In everyday life occupations of interest are the kind of activities that engage persons and bring joy and pleasure, as a result of internal motivation and perceived freedom. However, we do not know what type of occupation of interest is preferred and what has been given up in this age group, and this needs to be further studied in order to be able to support them in joyful occupations.

In summary, the need for more research into the experiences of daily occupation among the very old, as indicated above, has been put forward previously (Gubrium & Holstein, 2000; Polatajako, 2004; Stanley & Cheek, 2003) and the results could be of great value when attempting to cope with the growing demands of an ageing population.

RESEARCH AIMS

The overall aim of the study was to examine, extend and deepen the understanding of very old persons' experiences of participation in everyday occupation from an occupational perspective.

The following research aims were formulated:

- to describe how elderly persons experience the use of assistive devices in occupational performance in everyday life and how they think about and express thoughts about the experiences of assistive devices. (*Study I*)
- to study the overall use of assistive devices cross-sectional and longitudinally between 76 and 86 years of age, and to study the type, frequency, usage rate and overall use of assistive devices and reason for use, advantages and experiences of being a user of assistive devices in daily occupation. (*Study II*)
- to explore self-reported interests in a general population of 86-year-old women and men living at home and to analyse the repertoire of interests in relation to different socio-demographic characteristics, self-rated health and functional ability. (*Study III*)
- to investigate and explore various ways 99-year-old persons experience daily occupations. (*Study IV*)

METHODS

This thesis comprises two empirical qualitative studies, *study I* and *study IV*, in which a phenomenographical approach was adopted (Marton, 1994; Marton & Booth, 1997), and two studies of a general population, *studies II and III*, in which both qualitative and quantitative data were analysed. *Study III* is a cross-sectional population study, while *study II* is both a cross-sectional and retrospective longitudinal population study. Descriptive statistics were used in these studies, and both statistical analysis (Altman, 1991) and qualitative content analysis were carried out (Graneheim & Lundman, 2004; Malterud, 1998) (Table I). This multimethod approach is a strategy for overcoming the weaknesses and limitations of individual methods by combining them within the same investigations (Brewer & Hunter, 1989).

Table I. Overview of the studies

Study	Participants	Age	Design of the study
I	n=11	72-95	Qualitative study with a phenomenographical approach
II	n=199 ^a /201 ^b)	76/86	Descriptive cross-sectional ^b) and retrospective longitudinal ^a) population study, with qualitative and quantitative analysis
III	n=205	86	Descriptive cross-sectional population study, with qualitative and Quantitative analysis
IV	n=10	99	Qualitative study with a phenomenographical approach

Participants

The participants in *study I* were primarily selected from a socio-medical follow-up study, called the Johanneberg study, conducted in a district of Göteborg in 1996. The first examination had been made in 1991 when all persons aged 70+ years in this district were invited to participate (n=217) (Augustsson et al. 1994). The same population was followed up at the age of 76+ (n=125). Seven

women were strategically selected for participation in *study I*, in connection with a home visit by an occupational therapist. Noticing that very few of these used only one assistive device and aiming to describe the variation of experiences in the use of assistive devices, we wanted to include women with a more extensive use of assistive devices than those we could find in the population from the Johanneberg follow-up study. Following suggestions by the local occupational therapist, we called up four other women who were not included in the Johanneberg study, told them about the aim of the study and asked if they were interested in participating. They all consented, and thus a total of 11 women aged between 72 and 95 years were included. They had been users of assistive devices in daily activities for between one to 36 years. The inclusion criteria for participation in *study I* were: age 70+ years, living in one's own home, user of assistive devices and being able to communicate verbally.

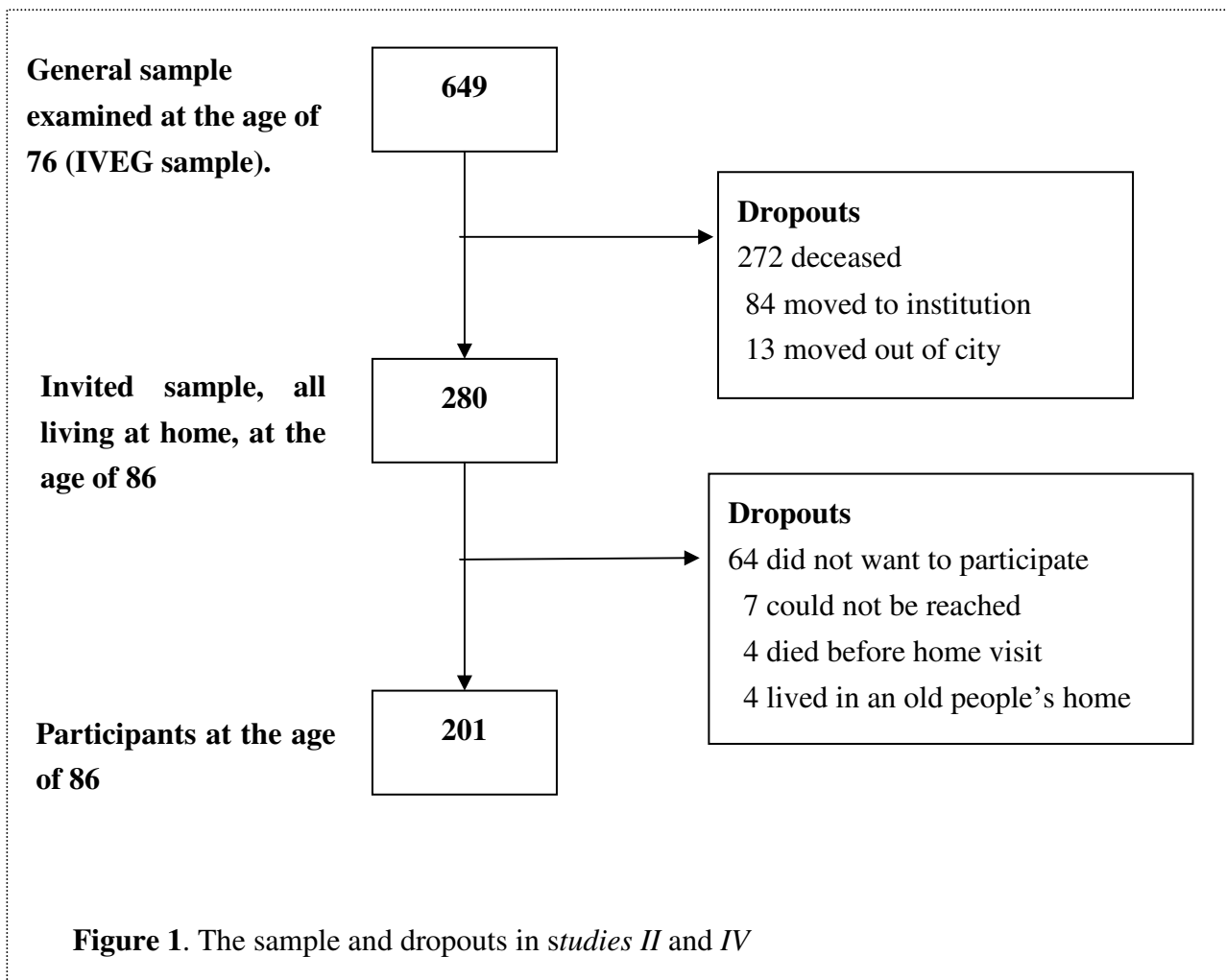
The participants in *studies II, III* and *IV* were all very old persons living in the community and were derived from the gerontological and geriatric population studies in Göteborg (H70) in Sweden, where five cohorts of 70-year-olds have been studied and followed longitudinally (Rinder, Roupe, Steen & Svanborg, 1975; Steen, 2004; Steen & Djurfeldt, 1993).

The participants in *studies II* and *III* were all born in 1911-12 and were derived from the third cohort of 70-year-olds in the Intervention Study of Elderly in Göteborg (IVEG). At the age of 76, 649 persons were examined (Eriksson, Mellström & Svanborg, 1987; Sonn, 1996). Those still alive and living at home were invited to participate ten years later. Between 76 and 86 years of age, 272 persons had died, 84 persons had moved to institutions, and 13 persons had left Göteborg. Thus, 280 persons were invited to participate in the follow-up examination at the age of 86. Of these, 201 persons (127 women and 74 men) (72%) were included in *study II* and 205 persons (131 women and 74 men) were included in *study III* (73.2%). The dropouts comprised 64 persons who did not want to participate, 7 persons who could not be reached, 4 persons who had died before the home visit, and 4 persons were excluded in *study II* because they had moved to an old people's home (Figure 1).

There were also secondary dropouts in the longitudinal part of *study II* (n=201, see above) where two participants failed to answer the questions about assistive devices. In the cross-sectional part of *study II* secondary dropouts included two persons who failed to answer the questions

concerning activities of daily living and 10 persons that had not answered the open-ended questions about experiences of the use of assistive devices. There were also secondary dropouts in study III; two persons who failed to fill in the questionnaire on interests. In *study III*, four women who were living in an old people’s home were included, by mistake, which was acknowledged later.

All persons in the sample (n=201) in *studies II* and *III* were living in their own homes, and 87% in both women and men rated their health as good. Nineteen per cent among both women and men used no medications at all, while 20% (women 24%, men 12%) used six or more. Twenty-two per cent (women 25%, men 18%) received home help service and 25 % received transport services (women 28%, men 20%). Nearly half of the population took walks outside regularly (women 39%, men 62%). Forty per cent reported tiredness (women, 44%, men 23%) and half of the sample (women 51%, men 51%) felt dizzy and had balance problems.



The participants in *study IV* are a consecutive sample derived from the first cohort of 70-year-olds born 1901/02 included in the gerontological and geriatric population studies in Göteborg (H70) in Sweden. The target group for this follow-up study comprised 99-year-old survivors in the years 2001 and 2002. Fifty-six persons were invited to take part in the follow-up examination of 99 year-olds. Twenty-two persons, 20 women and 2 men, declined to participate, leaving 34 persons, 30 women and 4 men, to participate in the general examination (60.7%).

All were visited by a nurse, who asked them if they would accept a home visit from an occupational therapist, which included an interview about daily occupations. Furthermore, one of the inclusion criteria for participation in the interview was being able to communicate verbally. Of the total sample, 10 persons (9 women and 1 man) were included in the present study. All but one of the participants lived in the city of Göteborg. Three of the participants lived in sheltered accommodations and seven were living in their own homes (apartments or houses). All received home help or support from relatives from once a week up to several times daily. The sample in the present study had a better functional ability compared to the other persons (n=24) included in the follow up study, as they were less dependent on personal assistance in walking indoors, dressing, using the toilet, in transfer and eating.

Data collection methods

The data collection method in *studies I* and *IV* was the in-depth interview and in *studies II* and *III* the structured interview (Table II).

In-depth interview

The data collection method that was used in *study I* and *IV* was an in-depth interview, also called a focus interview (Troost, 2005). The interviews were carried out in the participants' home environment and took the form of a dialogue focusing upon an ordinary day. The participants were informed about the aim of the study, that participation was voluntary, and that the collected data would be handled confidentially so that their identity would not be revealed.

Study I focused on experiences of managing daily occupation with and without assistive devices. The interviews began with an open question like *Can you tell me about your everyday life?* It then focused on the phenomena concerned, i.e. elderly person's experiences of use of assistive devices in daily occupation. The focus of the interview was how they managed with and without their

assistive devices and what they felt and thought about being a user of assistive devices in daily occupations. The interviews lasted between 20 and 90 minutes and were transcribed verbatim, resulting in a total of 104 pages.

Table II. Data collection methods

Study	Data collection methods
I	<u>In-depth interview</u> <i>Can you tell me about your everyday life?</i> , with focus on how elderly persons experience the use of assistive devices
II	<u>Structured interview</u> Questionnaire: ADL staircase. Independence/dependence in activities of daily living Questions with predefined answers: Type of assistive devices and usage rate Reason for not using assistive devices Self-reported advantages of assistive devices Open-ended questions: Experiences of being a user of assistive devices in daily occupation Reason for using assistive devices
III	<u>Structured interview</u> Questions with predefined answers: Kind of interest, with possibility of adding new interests to the list Living and housing conditions Mobility outdoors Self-estimated health Open-ended questions: Self-estimate of daily activity management Changes in interests during the last 5 years
IV	<u>In-depth interview</u> <i>Tell me what an ordinary day looks like. or Can you tell me about what you do on an ordinary day?</i> , with continuing focus on what and how they do and think about their daily occupation.

Study IV focused on experiences of daily occupations. All interviews started with an open question *Can you tell me what an ordinary day looks like?* The follow-up questions were based on what the subjects said in order to be able to catch the phenomenon as experienced and to explore its different aspects jointly and as fully as possible (Marton, 1994). One participant did not allow the

use of a tape-recorder, so notes were taken instead. A summary was made of the interview directly afterwards. One participant was visited twice because of technical problems with the tape-recorder. The interviews lasted between 30 minutes to two hours and were transcribed verbatim, resulting in a total of 191 pages.

Structured interview

In *studies II* and *III* the structured interview was used as a data collection method. The interview was carried out during a home visit according to a structured questionnaire with both predefined questions, about e.g. social conditions, education level, self-reported interests, mobility, self-rated health, ability in daily activities, type and overall use of assistive devices and open-ended questions.

In *study III*, interests were recorded by asking the participants the open-ended question *What kind of interests do you have /occupy you?* and *What kind of interest have you dropped during the last five years?*. The questionnaire contained a list of 19 types of interests including the following items: listening to the radio; watching TV; reading the newspaper; reading books; visiting concert halls or theatres; taking part in courses, society or club activities; company with relatives; company with friends; exercise/take walks; animals/pets; flowers/gardening; crafts, art of crafts; making food, baking, giving a party; church activities; travel; doing the pools, the lottery; dancing; crosswords and being at home, idling. In order to capture the variety of self-reported interests, there were several open response alternatives.

Open-ended questions were used to record the reasons for changes in the interest repertoire during the last five years. The participants were asked *Why have you dropped the interest /interests?*. Activities of daily living were recorded by using an open-ended question *How do you manage your daily life activities?* The answers were written down verbatim, sometimes in a shortened version.

Questions were also asked about: living arrangements, type of housing and education level. Mobility outdoors was recorded by posing the question: *Are you able to walk/move outside?* Self-rated health was measured by posing a predefined question *How do you estimate your health at the moment?*.

In *study II*, the level of independence and dependence in activities of daily life were assessed according to the ADL Staircase, which has been tested for reliability and validity in earlier studies with satisfactory results (Sonn, 1996; Sonn & Hulter Åsberg, 1991), including instrumental activities (IADLs); cleaning, shopping, transportation and cooking, and personal activities of daily living (PADL); bathing, dressing, going to the toilet, transfer and feeding. In this study only two levels were used: those independent in all activities and those dependent on personal help in one or more activity/ies.

Questions about assistive devices were asked in connection with questions about how they managed different activities in daily life: personal hygiene; chair and bed transfer; dressing activities; activities within grip and reach and mobility. The types of assistive devices were recorded in a pre-defined list. Overall use of assistive devices was also documented, that is how many participants used one or more assistive devices in any of the activity domains that were studied. The usage rate of each assistive device was recorded (used regularly, used sometimes or not used at all). When an assistive device was not used, the reason for this was asked and recorded according to predefined answers. The advantage of assistive devices in different activities was assessed by the question *In what way are the assistive devices useful to you?* and recorded according to predefined answers: makes no difference, less pain, less effort, increased activity, increased independence, increased safety/security, absolute necessary, other reason. Reasons for non-use were: do not need anymore because of recovery or got worse, do not need for other reasons e.g. broken, uncertain how it should be used, hard to use, prefer personal help and other reasons.

Information on the reason for use of assistive devices and experiences of being a user of assistive devices was obtained with the help of open-ended questions. The answers were written down verbatim and, if the answer took the form of a long narrative, it was assessed and summarised. Information on reason/s for use was obtained in the following way. *There might be different reasons for using an assistive device/assistive devices. Mention the main reasons why you use an assistive device/assistive devices?* Experiences of being a user of assistive devices were assessed by means of an open-ended question, *How do you experience being a user of assistive devices?*

Methods of analysing data

Qualitative data analyses were used in all studies. *Study I* and *IV* are entirely qualitative studies with a phenomenographical approach, while *studies II* and *III* include data that were subjected to qualitative content analysis. The data in *studies II* and *III* were also analysed and described by both descriptive and analytical statistics (Table III).

Table III. Data analysis methods

Study	Data analysis methods
I	Phenomenographical approach
II	Qualitative content analysis and descriptive and analytical statistics
III	Qualitative content analysis and descriptive and analytical statistics
IV	Phenomenographical approach

Phenomenography

Phenomenography was used in *studies I* and *IV*. It is an empirical, qualitative research approach that was developed within the framework of educational research at the University of Göteborg, Sweden in the early 1970s. The purpose is to describe people's different perceptions or experiences of phenomena in the world as they see them. The main focus of interest is not the reasons for variations in the experiences but the content of the thinking as it is expressed by the person who is interviewed, what he/she has perceived about a phenomenon, and how it is perceived. It is an explorative way of doing research, and the approach has gained ontological significance thanks to the 'theory of variation'. The theory of variation describes the way of experiencing something in terms of discerning critical aspects of the phenomena that have been focused upon by the *experiencer* at the same time (Pang, 2003; Runesson, 2005). The result is the description of what the phenomena are, and how or in what ways they are expressed by the study subjects. In phenomenography private experiences are interesting only in relation to other experiences, own or other persons, in order to be able to cover a diversity of experiences

(Alexandersson, 1994; Marton, 1994; Marton & Booth, 1997; Marton & Morris, 2002). The analytical process can be described in steps, but in reality it is a dynamic working process involving repetition (Alexandersson, 1994; Marton, 1994). In *study I*, the analysis was carried out in two analytical steps and in *study IV* in five steps. In principle, the working process was the same in both studies but was described in different ways. It was carried out as follows: To become familiar with the content of the interviews they were carefully read through several times by the researcher. Relevant passages, i.e. the places where the phenomenon in question was experienced, were marked. Then similar statements were grouped together for further processing.

When the groups of similar statements had been rewritten a couple of times, the comparison of the excerpts started. The working process consisted in looking for differences and similarities between the excerpts, which were grouped together by cutting them out and gluing them to the same piece of paper. In this phase of the analysis the co-examiners were included to check if the categories corresponded with the excerpts in order to strengthen empirical validity, the credibility and internal consistency (Alexandersson, 1994; Larsson, 2005).

Similar excerpts were read through several times in order to explore *What are the excerpts telling me?* Then the groups of excerpts were labelled with a suitable linguistic expression and again compared with each other to be able to find a distinct pattern of thinking that represented different ways in which the participants related to the phenomena. The categories needed to have a logical connection and describe one or more dimensions of experiences of the phenomena concerned. The analytical steps described above had to be repeated frequently before the different experiences of the phenomena could be fully clarified.

Qualitative content analysis

Qualitative content analysis involves organising, interpreting and reaching conclusions about human experiences relevant to the purpose of the study question (Malterud, 1998). Manifest and latent content analysis according to Graneheim and Lundman (2004) was used. Manifest content analysis deals with what the text says and describes data obtainable from the visible and obvious text content. Latent content analysis deals with what the text talks about, the relationship aspects and involves an interpretation of the underlying meaning of the text.

In *study II*, qualitative content analysis (Graneheim & Lundman, 2004; Malterud, 1998) was used to analyse the answers to the open-ended questions about *reason for use of assistive devices* in different activity domains and *experiences of being a user of assistive devices* in daily occupation. The first and second analytical steps were initially similar to those described above. In the third step, the groups were interpreted, described in own words and labelled with a heading. All groups were compared with each other, and some were included in another group and others were split into new groups. The question about reason for use of assistive device ended up with four categories, and the question about experiences of being a user of assistive devices ended up with 18 different experiences. A fourth analytical step was taken concerning experiences of assistive devices by asking: *What kind of experiences did the users of assistive devices have?* This resulted in seven categories being redefined, and the categories were dichotomised into personal, practical and social aspects of being a user of assistive devices.

Qualitative content analysis was used in *study III* when handling the answers to the open-ended questions about reasons for changes in the interest repertoire during the last 5 years and to the open-ended question about subjective experiences of how the informants manage daily life activities. The first analytical step was to become familiar with the data by reading through the answers several times and reflecting on the manifest content. The following step was to look for similar and different content and description aspects in the text, which was done by cutting out statements, comparing them with each other, looking for similarities and differences in statements, and putting them into groups. The different groups and the content of the groups were compared and resulted in categories. The question about reasons for changes in the interest repertoire ended up with seven categories, and subjective experiences of how to manage daily life activities ended up with four categories. Concerning changes in the interest repertoire, a further step in the process was to emphasise description and interpretation on a higher logical level by asking *What do the meaning-bearing units tell us?* This meant that the meaning-bearing units could now be categorised under a code name and described in words. For the categories about changes in the interest repertoire, the analytical process involved continuing to look for the latent content, what the text was talking about. Two themes or aspects were found; personal and environmental factors. Seven different categories that describe the themes and personal and environmental factors that changed the interest repertoire during the latest five years were established.

The description of a content analysis suggests a linear process, but is in reality an analytical process that involves a back and forth movement between the part of the text and the whole interpretation until a result is reached.

Statistical analysis

When preparing data in *study III*, the open response alternatives to the question on interests were arranged according to existing alternatives or new ones added to the list. The interest list was classified into five domains inspired by the occupational form perspective (Nelson, 1988): media interest; individual leisure interest; collective leisure interest; social interest and relaxing interest.

Living arrangements were dichotomised into those living alone and cohabitants. Type of housing was dichotomised into persons living in a block of flats and one-family houses. Education level was operationalised as persons with elementary schooling (6 years) versus above that level. Mobility outdoors was dichotomised into those with no mobility difficulties versus those with difficulties that only could be met with personal support and/or assistive devices. Self-rated health was dichotomised into those with good versus poor self-rated health.

Descriptive statistics were used in *studies II* and *III* to describe frequencies and the proportions of different variables. Median values were used to present assistive devices that each participant used over all (*study II*), and the interquartile range (IQR) was used when calculating the number of interests (*study III*).

Fisher's two-tailed exact test was used in *study II* when testing differences in the proportions between two groups, e.g. when testing differences between women versus men, independence versus dependence, and use versus non-use of assistive devices. Fisher's exact test was also used when testing differences between participants and non-responders in the study concerning "admitted to hospital", "5-year mortality". In *study III* the same test was used when testing differences between living arrangements, type of housing, education, self-rated health and mobility outdoors among women and men.

Changes over time of paired proportions of use and non-use of assistive devices, between 76 and 86 years of age were tested with McNemar's test in *study II*. The result was presented with confidence intervals (CI) for pair-wise change in proportions was calculated by bootstrapping (Altman, 1991).

The non-parametric test of linear trend was used when testing the association between two factors with more than two levels in at least one of them (Cox & Hinkley, 1974). This test was used when analysing the number of interests according to four categories of self-estimates of ability in daily life activities. When the results were reported for the total group, the test was adjusted for gender (*study III*).

The Bonferoni method was applied in *study III*, to correct the effect caused by risk of mass significance. The correction was made in all interest items in *study III*, and a p-value of less than $p < 0.01$ and all results in *study II* with a p-value less than $p < 0.05$ were considered statistically significant (Altman, 1991).

ETHICAL CONSIDERATIONS

All studies were approved by The Research Ethical Committee of Göteborg University.

Different ethical aspects of the studies have been frequently discussed throughout the research process. Before the interviews were performed it was pointed out that participation in all studies was voluntary and the importance of confidentiality was also considered throughout the research process. All participants in *studies I, II and IV* had been approached by an occupational therapist and in *study III* by a nurse, during their home visits. If they agreed to another interview with an occupational therapist, oral and written information was given about the interview, and they were informed that an occupational therapist would soon contact them by phone to ask if they were interested in participating and if so, she would book an appointment. They were also told that all data would only be used for the research and handled confidentially. The importance of anonymity and confidentiality was also considered throughout the research process. This has applied in particular to *study IV* because of the special group that could easily be identified.

MAIN FINDINGS

Users' experience of assistive devices in everyday life

The first study describes how elderly women (72-95 years of age, n=11) experience the use of assistive devices in occupational performance in everyday life and how they think and express thoughts about their experiences of assistive devices.

Three dimensions were found, each with two or three categories describing variations in how the women experienced and actually used assistive devices. The dimensions 'user attitude' and 'accommodation' focus on the user of assistive devices, and the dimension 'support' describes experiences of the use of assistive devices in everyday life (Table IV).

Table IV. Dimensions and categories of different ways of experiencing how elderly women relate to assistive devices and their actual use of the devices in occupational performance

Dimensions	Categories
User attitude	Incorporation Forced to accept Inadequacy
Accommodation	Modification Resignation
Support	External safety Internal security Respect

The dimension "user attitude" describes how the assistive devices were either well incorporated into the elderly women's everyday life or simply an object that they were forced to accept. The negative impact the assistive devices sometimes had on their participation in everyday life was both experienced in a practical way and caused by the symbolic meaning of the assistive device. The dimension "accommodation" describes how the users needed to be creative in modifying their

performance of daily occupation with standard devices. The women also challenged situations in order to be able to cope with everyday life independently. However, some became resigned to their situation and did not try to find alternative ways of performing daily occupations. This could also be seen as a way of mastering daily occupations at the cost of a reduced occupational repertoire and less participation in everyday life. The dimension “support” reveals that the use of assistive devices can be experienced as external, internal or as social support. Social support took the form of respect from people around them. External safety describes how the devices facilitate and make the performance less strenuous, and internal security means that the devices provide a feeling of security that helps the women rely on their own capacity.

Study II also dealt with experiences of assistive devices in daily occupation among 86-years-olds (n=128) who were living at home. The result showed great variation, with contradictory experiences of personal, practical and social aspects (Table V).

Table V. Experiences of being a user (n=128) of assistive devices.

<u>Personal aspects</u>		
Normal	_____	Mark of old age
Pleasant	_____	Unpleasant
Safe	_____	Unsafe
<u>Practical aspects</u>		
Usable	_____	Inappropriate
Essential	_____	Cumbersome
<u>Social aspects</u>		
Feel respected	_____	Afraid
Do not mind	_____	Embarrassing

The dimension “Personal aspects” of being a user of assistive devices refers to the user’s inner feelings or attitude. This seems to vary from positive experiences such as assistive devices being pleasant, safe and normal to use at this age to more negative aspects such as assistive devices being a mark of old age, unpleasant and unsafe to use. There were also “practical aspects” of being a user of assistive devices. Again experiences varied – the users found them to be either useful and essential or inappropriate and cumbersome. “Social aspects” refer to how the elderly subjects experienced the attitudes of the people around them. On the one hand, some users seemed to

experience respect from others and did not mind using the devices in the community, on the other hand, some were afraid and embarrassed to use the devices in a social context outside home.

Advantages of assistive devices were explored in *study II*. The most common answers given were that the users' *felt more secure* when using assistive devices in hygiene-related (56%) and outdoor mobility activities (55%). *Less effort* was mentioned as an advantage by 45 % when performing hygiene-related activities and 65% for transfer from/to/in chair and bed. Assistive devices were regarded as *absolutely necessary* in mobility activities outdoors by 36%, mobility indoors by 19%, in hygiene-related activities by 30% and for transfer from/to/in chair and bed by 29%.

The users reasons for using assistive devices in daily occupation were: *functional limitation, activity problems, others identified the need and proprietor of a device*. Functional limitation was the most common reason given for use of assistive devices, because of restrictions and difficulty in performing daily occupation after accidents and surgical interventions. Activity problems and difficulties in performing daily activities were other reasons for using assistive devices. In some cases, it was the doctor, the nurse, "the hospital" or relatives that saw and decided there was a need of assistive devices. Simply being a *proprietor of assistive devices* was sometimes a reason for using one without there being any special need.

Changes of use and use of assistive devices

The changes in the use of assistive devices in everyday life (*study II*) showed that the proportion of users (n=199) at 86-years of age was 69% compared with 43% at the age of 76 ($p<0.0001$). 23% did not use any assistive devices either at 76 or 86 years of age (n=45). Thirty-five percent were permanent users (n=70) , which means they had used assistive devices both at 76 and 86 years, and 34% were new users (n=68) at 86 years of age. In contrast, 7% were temporary users (n=14), that is, they used devices at 76 but no longer at 86 years of age. In the total population 42% were independent in daily activities while 58% were dependent on personal assistance in one or more daily activities. Among those persons who were independent (n=82) 55% were users of assistive devices, while of those persons being dependent on personal assistance (n=115) a significant higher proportion were users of assistive devices 81% ($p=0.00013$) (Table VI).

Table VI. Longitudinal perspective of assistive device use between 76 and 86 years of age, in relation to persons' independent (n=82) and dependent (n=115) in daily activities at 86 years of age (n=197, 2 missing).

	Independent in ADL	Dependent in ADL
	n (%)	n (%)
Non-users	28 (34%)	17 (15%)
Temporary users ^{a)}	9 (11%)	5 (4%)
New users ^{b)}	23 (28%)	45 (39%)
Permanent users ^{c)}	22 (27%)	48 (42%)
Total	82 (100%)	115 (100%)

a) Users of AD at 76 years of age but not at age 86. b) Users of AD at age 86 but not at age 76. c) User of AD at both 76 and 86 years of age.

Most users of assistive devices were found in the following activity domains: mobility activities (61%), hygiene activities (53%), followed by transfer from/to/in chair and bed (17%) and grip and reach (16%) in different daily activities.

The most common type of all assistive devices identified (n=477) was the walking cane (19%), followed by tub boards (12%), raised toilet seats (10%) and rollators for outdoor use (10%). The highest usage rate was 96% among the hygiene-related devices followed by mobility devices (82%) (Table VII). Of those devices not used, mobility devices dominated i.e. cane and rollator for outdoor use, which were not used mainly because *lack of need caused by recovery or change for worse*. Another reason for not using mobility and hygiene devices was *lack of need caused by other than recovery, or personal help was preferred*. Stocking aids were not used because they were *difficult to use*, and grip and reach devices were not used because they were *broken*.

Table VII. Type, frequencies and usage rate of assistive devices (n=477)

Type of assistive devices in different activity domains	n	Usage rate		
		Regular n (%)	Sometimes n (%)	Not used n (%)
Hygiene	195	182 (93)	5 (3)	8 (4)
Tub board	58			
Bathtub seat	12			
Grab rails bath/shower	27			
Bathtub stool	1			
Shower stool	27			
Raised toilet seat	48			
Grab rails toilet	18			
Toilet arm support	4			
Mobility	186	113 (61)	40 (21)	33 (18)
Walking cane/s	92			
Crutch/es	17			
Walking frame	8			
Rollator for inside use	16			
Rollator for outside use	47			
Manual wheelchair	5			
Other mobility devices	1			
Chair/bed	53	52 (98)	-	1 (2)
Raising cushions	24			
Raising blocks for the chair	6			
Office chair	5			
Other chair devices	4			
Raising blocks for the bed	8			
Bedraiser	2			
Bed gate	1			
Electrical manoeuvred bed	2			
Other bed devices	1			
Grip/reach	43	23 (53)	9 (20)	11(26)
Grip tong/reacher	19			
Tap turner	1			
Tap opener	2			
Grip devices in household	2			
Scissors	3			
RA-knife	3			
Pick-up tong/reacher	4			
Universal grip	1			
Stocking aids	8			
Total Assistive Devices	477	370 (78)	54 (11)	53 (11)

Occupation of interest

Concerning occupation of interest (*study III*) among 86-year-olds living at home, the result showed a wide interest repertoire (Table IX). The most common interest domain was the media, including watching television (14%) and reading the newspaper (11%), followed by the domains individual leisure interests, social interests, collective leisure interests and relaxing interests.

Table IX. Number (n) and type of present interests among 86-year old women (n=131) and men (n=72), categorised into interest domains, and the proportion (%) of women and men with each interest

Interests	Women		Men		p
	n	%	n	%	
Media interests					
Listening to radio	71	54.2	38	52.8	
Watching TV	113	86.2	59	81.9	
Reading newspaper	83	63.4	52	72.2	
Reading books	47	35.9	29	40.3	
Crosswords	38	29.0	16	22.2	
Writing	7	5.3	2	2.8	
Total	359		196		
Individual leisure interests					
Physical exercise	28	21.4	24	33.3	
Gardening and flowers	32	24.4	19	26.4	
Crafts and art activities	32	24.4	4	5.6	0.005
Cooking, baking	32	24.4	2	2.8	0.000
Pools, lottery	25	19.1	18	25.0	
Collecting activities	6	4.6	7	9.7	
Fishing, sailing, golf	-	-	3	4.2	
Take care of cottage	2	1.5	6	8.3	
Music - listening and playing	3	2.3	7	9.7	
Driving and working on car	-	-	3	4.2	
Total	160		93		
Collective leisure interest					
Concerts etc	9	6.9	5	6.9	
Courses, society	35	26.7	20	27.8	
Singing in choir	3	2.3	-	-	
Bridge, chess, cards	4	3.1	3	4.2	
Attending sports	1	0.8	4	5.6	
Dance	1	0.8	1	1.4	
Church activities	17	13.0	7	9.7	
Total	70		40		
Social interests					
Company with friends	50	38.2	20	27.8	
Company with relatives	73	55.7	33	45.8	
Travel	11	8.4	5	6.9	
Outings	3	2.3	6	8.3	
Political involvement	2	1.5	-	-	
Total	139		64		
Relaxing interests					
Pets/animals	3	2.3	4	5.6	
Being at home, idling	61	46.6	35	48.6	
Puzzles, patience	4	3.1	1	1.4	
Total	68		40		

The distribution of the number of interests in relation to experiences of how to manage daily life activities showed that women with a higher number of interests were associated with an higher level in ability in daily life activities ($p < 0.001$) especially concerning the domain individual leisure interests ($p < 0.001$). Among men no such trend was found. In the total group with gender as background factor, the trend test showed that a greater number of interests was associated with higher level of ability in daily life activities ($p = 0.001$), especially concerning the domain the media ($p < 0.001$) and individual leisure interests ($p < 0.001$).

Concerning the total number of occupations of interest in relation to social and living conditions and functional ability, few significant differences were found between women and men. However, women with difficulties in *mobility outdoors* had fewer interests (md 5) compared to those with no difficulties (md 7) ($p = 0.002$). In the total group, with gender as a background factor, persons that estimated their health as poor had fewer interests (md 4) compared to those persons that estimated their health as good (md 7) ($p = 0.008$).

Almost all participants (women 88% and men 83%) reported *changes in their interest repertoire* during the last 5 years. *Travelling* was the most common interest that both women (41%) and men (33%) had had to give up. The reason for not performing occupations of interest anymore was related to *personal* or *environmental factors*. Personal factors that explain reasons for changes in interest repertoire were functional capacity, lack of motivation, lack of time/doing took much longer and insecurity. The environmental factors that had an impact on the interest repertoire were physical environment, social circumstances and economic considerations.

Engagement in daily occupation

Experiences of daily occupations at 99 years of age were investigated and explored in *study IV*. Here it was shown that daily occupation have an impact on the sense of self, build identities, and described engagement and creative processes in everyday life. The very old persons' experiences of daily occupations were described in five different dimensions: *being involved*, *being challenged*, *having a pattern*, *being incapable* and *being restricted*, each with variations of experiences of daily occupations (Table VIII).

Table VIII. Dimensions and categories of different ways of experiencing daily occupations among 99-year-olds

Dimensions	Categories
Being involved	Amusement Recalling Participation
Being challenged	Testing and trying Considerations Learning
Having a pattern	Rhythm Predictability Interruption
Being incapable	Obstruction Insufficiency Feebleness
Being restricted	Estrangement Lack of control Generalisation

“Being involved” in daily occupation in an active way improved the participants’ sense of self. Daily occupation could be *amusing* and stimulate involvement, while *recalling* experiences from their earlier life was a way of getting involved in the past as much as in the present. Actively performing and *participating* in daily occupation was a way of experiencing involvement.

“Being challenged” was experienced as a way to retain skills and get confirmation that they were capable and still able to do and learn new things. Different ways of meeting challenges were to find out and *test and try* occupational abilities, to *consider* and make plans how to be able to perform occupations that seemed to be out of limits. When problems arose, they *learned* a new way of performing daily occupations in order to be able to master the occupation in question.

A personal pattern in daily occupation was formed by the person’s own abilities and environmental factors. The pattern was like a reference point that framed day-to-day experiences out of temporal and spatial arrangements. Everyday life was experienced in patterns, often in a circadian *rhythm*

scheduled by time and formed by earlier experiences in life that were *predictable*, and served to contribute a sense of continuity and unity. *Interruptions* in the pattern easily upset and disordered their daily occupational arrangements.

“Being incapable” and being restricted describe experiences of personal, environmental and social hindrances in daily occupation. *Obstruction* refers to environmental factors that prevented them from doing something, while *insufficient* refers to incapability caused by bodily functions and *febleness* describes an overall feeling of being tired and weak. “Being restricted” is caused by a feeling of *estrangement* when their everyday life was confronted by the world outside, or when they experienced *lack of control* over daily occupation because of dependence on others. The persons also met expectations from people around them that older persons should appear in a special way, while their own will and wishes were ignored. This kind of *generalisation* restricts a person’s freedom to participate in everyday life.

DISCUSSION

Experiences of participation in daily occupation

The elderly persons who participated in the studies were engaged in everyday occupations in different ways. Their engagement was seen in *how* they did and experienced their occupation rather than in *what* was actually done. Some lived their everyday life in a *creative way*, finding their own solutions to occupational problems. They were aware of their limitations and environmental demands but challenged their own resources/ability (*studies I, IV*). Creativity can be seen as a mental activity that can lead to new and valuable actions (Csikszentmihalyi, 1996). In *study I* this was illustrated by women who used assistive devices in a creative way to modify their occupational performance so as to be able to continue an active life. Modifying occupational performance with the assistive devices is a creative process of problem solving, which generates new ways of mastering daily occupations when a person grows older and maybe faces functional limitations. This was rewarding and confirmed their picture of themselves as capable persons. According to Kaufman (1986), the creative process that people experience in different ways in everyday life is a lifelong process. As far as elderly persons are concerned, they not only cope with their losses, they reformulate and build viable selves or identities.

Three different ways of *challenging* problems in daily occupations in a creative way were evident in *study IV*; testing and trying new occupational limits, making plans considering different factors, and learning or relearning skills. These are all ways of testing the balance between own abilities, limitations and occupational demands in the context where the occupation is performed (*study IV*). According to several theoretical models, it is importance to keep a balance between environmental demands and both age-related and individual competence (Lawton & Nahemow, 1973), and another important factor is the occupations that are preferred to be performed (Townsend, 1997). The balance can be achieved by changes in any parts of the person-environment-occupation interaction and will affect occupational performance.

When considering the *manageability* of occupations in everyday life, the findings pointed to a number of factors that need to been taken into consideration in contact with elderly persons. According to Antonovsky (2005), manageability means problem solving and the capacity to use available resources to meet the demands in everyday life. Available resources are not only one's own resources but also those that are controlled by qualified others, that is, persons that one can trust (Antonovsky, 2005). This is where the use of assistive devices comes in. Both studies *I and II*

showed that the use of assistive devices leads to manageability in everyday life because they were integrated into the persons' lives, habits, roles and routines. However, *study II* also showed the opposite, that some users of assistive devices were not able to master their daily occupations with their help, which led to feelings of inadequacy. According to Silverstone, Hirsch and Morley (1991) this means that the assistive devices were not integrated into the routines of the household. Other signs of this lack of integration were that the devices were experienced as unpleasant, unsafe and cumbersome. The device could have a negative symbolic value as a "mark of old age" or be experienced as an embarrassment in some social contexts. However, the findings also showed how persons achieved manageability in daily occupations. As already mentioned above, their creativity took different forms. By testing and trying new or old occupational limits, by making plans and take under consideration different aspects in order to be able to carry out a certain occupation, and by learning or relearning skills to be able to master certain occupations in everyday life (*study IV*). Limited manageability was also evident in *study IV*, when the occupational pattern was interrupted by qualified others, e.g. because of late delivery of food service, unknown persons visiting from the home help services or just unexpected visitors. Such external factors limiting manageability could also be evidence for signs of occupational deprivation (Whiteford, 2004; Wilcock, 1998).

Occupational deprivation occurs when "someone or something external to the individual is creating conditions that lead to deprivation" and can be social, economic, environmental, geographic, historic, cultural or political in nature (Whiteford, 2004, p.222). Findings in *study I* showed how assistive devices were not able to support persons' occupational repertoire, which resulted in feelings of resignation. Obstructions in daily occupations such as limited accessibility in the environment prevented them from performing occupations with or without assistive devices (*studies II, III, IV*). Obstacles in everyday life that hindered the elderly persons from being active and from engaging in daily occupations have an impact on both their self-image and their well being. Occupational deprivation in this case can be seen as a consequence of attitudes and policies that have failed to make environment accessible for the diversity of physical, mental and cognitive abilities that exist within a population (Whiteford, 2004).

The *symbolic value* described to assistive devices in our society was reflected in the way users of such devices are treated by people around them both in a positive and a more negative way (*study I*). For the same reason, social occupations were avoided because of being afraid of becoming a victim and feeling embarrassed in company as a user of assistive devices (*study II*). Earlier studies have shown that the symbolic value of and attitudes towards assistive devices in society have an

impact on the users as well as the use and non use of assistive devices (Gitlin, 1995; Hastings et al. 2001; Roelands et al. 2002). The result is occupational deprivation.

In the present studies, all persons at the age of 99 and 58% of them at 86 years of age were *dependent* on personal help in everyday life. For many persons, the helper might be perceived as the closest person. The attitudes of those persons are therefore of ultimate importance for autonomy and participation (Grimby, 2002). Autonomy is central to client-centred rehabilitation since it is a prerequisite for effective participation (Clapton & Kendall, 2002). Autonomy and independence are different but related concepts (Haak et al. 2007). We are all dependent to varying degrees or in some way at some time. Independence is a central concept in occupational therapy and can be defined as “self-direction and participation in day-to-day decision-making about when and how things will be done to one’s body, to one’s environment, and with one’s time become the crucial distinctions between dependence and independence and ultimately lead to a sense of personal and social worth” (Jackson, 1996, p.353). Jackson’s (1996) definition of independence is similar to Chan’s (2002) definition of autonomy; deciding what one wants to do and doing what one decides to do. Independence is often measured as independence of or dependence on personal help in daily occupations and a wide range of instruments has been developed and used (Law et al. 2001). Both internal and external factors influence independence, autonomy and participation (Chan, 2002; Molin, 2004; WHO, 2001). In *study IV* the persons were restricted by internal factors such as limited capacity and lack of motivation, factors that influenced participation in everyday life. Persons experienced insufficiency and a feeling of feebleness because of being incapable of performing the daily occupations they preferred to do. The external factors were also evident as interruptions in the occupational pattern, occasions or permission, limited accessibility in both the physical environment and the social environment (*study IV*).

Occupational justice is a perspective focused on in occupational therapy as a complement to social justice in order to be able to recognize and provide for personal occupational needs as personal rights in the society. Occupational justice focuses on rights, responsibilities, and liberties of enablement related to the persons occupational need, strength and potential (Wilcock, 1998; Townsend & Wilcock, 2004). In *study IV* some occupational justice was evident. The very old persons experienced estrangement from and generalisation by the social environment in their daily occupation. Persons who were dependent on personal help experienced a lack of control in daily occupation, personal help become more of a hindrance because the staff did not have the time, knowledge, or ability to listen to what the persons wished to have help with and how. People

around them expected the very old persons to appear in a special way, while their own will and wishes were ignored. These aspects can be seen as external factors that hindered participation in everyday life. The findings showed that the social environment caused the persons to experience exclusion from everyday life because of their age, frailty or dependence. This had a negative impact on participation in everyday life, on the persons' picture of self and probably also on their wellbeing, and thereby, their health (Hazan, 2000; WHO, 2001; WHO 2002).

Engagement in daily occupation change along a person's life course, into new patterns and are also described as the aging process, with a change from a more active to a more passive occupational performance. The role changes from "actor to spectator" (Haak, Dahlin Ivanoff, Fänge, Sixsmith & Iwarsson, in press), and this was also evident in *study IV*. The findings showed that the persons perceived involvement and engagement in different ways by following the changes in nature by watching out of the window, following the television programmes and taking part in daily occupations in a more distant way. It was also shown how recalling their earlier lives were another way of getting involved with the past as much as in daily occupations (*study IV*). In a recent study by Santamäki Fischer (2007), this reflective activity is explained as a way one can come in contact with oneself. The unchanged part of one's identity is balanced with the part of the person that has been changed. According to Tornstam (1999) this describes a change and reconstruction of identity and the personal frames of references, a way of human development towards maturity and wisdom.

Participation in occupation of interest

Occupations of interest engage persons because of the pleasure, comfort and enjoyment they give, and they can be threatened or altered by disability (Kielhofner, 2002). However, a large number of occupations of interest do not necessarily mean a high level of engagement and participation (Desrosiers, 2005). *Study III* showed, however, that those with a larger number of occupations of interest also tended to rate their health as good ($p=0.008$), had fewer or no problems in performing daily occupation ($p=0.001$) or had no or less difficulties in mobility outdoors ($p=0.001$) than those with a smaller number of occupations of interest. It is difficult to tell something about a person's engagement in these occupations of interest, but one might assume that an occupation of interest by its definition (Kielhofner, 2002) engages a person because it is meaningful and has a purpose. In a recent study on occupational engagement among older persons (85+), a twenty-item leisure interest checklist was used together with four subscales indicating: interested in; do perform; motivated for and perceived wellbeing. The result showed that the most common interests the persons had had, they also performed, were motivated for and had an impact on wellbeing (Nilsson

et al. 2006). Thus it can be assumed that the most common interests persons had in the present study were also performed with engagement and might have an effect on wellbeing.

Home assumes more and more importance with age because of functional decline (Haak et al. in press; Hillerås et al. 1999; Hovbrandt et al. 2006). The most common occupation of interest found among both women and men was the media, e.g. watching TV, listening to the radio, reading books. This was followed by individual leisure interest e.g. crafts and art activities; pools and lottery; gardening and taking care of flowers. The interest in both these domains was mainly performed in their home environment and alone. Some interests that had occupied the elderly persons outside their homes could have changed in its occupational form to being performed at home, which might explain why so many performed their interests in their home environment and mainly alone (*study III*). It is evident that home is the place where very old persons spend much of their time and where most daily occupations, including occupations of interest, are performed, which is in accordance to earlier studies (Haak, 2006; Hillerås et al. 1999; Östlund, 1995). The importance of home for elderly persons' engagement in daily occupation has several aspects. Home symbolised a place perceived as a prerequisite for maintained independence (Haak et al. 2007), means security and freedom (Dahlin-Ivanoff, Haak, Fänge & Iwarsson, 2007) but also a space filled with personal interests that provide identity (Kontos, 2000) and give a sense of continuity in life (Jackson, 1996). This requires that anyone involved in their care has to begin by entering into their meaning of home. Reasons for given up occupations of interests outside their home was for example given up driving the car, fear of performing occupations outside home and mobility limitation (*study III*). Environmental barriers have an impact on persons' participation in interests outside home, and especially on frailer elderly persons' interest repertoire. This indicates the importance of accessibility to occupational arenas, and how the transaction between the person, the occupation and environment influences participation in everyday life, in this case occupation of interests (Lawton & Nahemow, 1973; Townsend, 1997).

Almost all the elderly (95%), both women and men, that participated in *study III* had one or more *media interests* (md 3), with watching TV (86% women and 82% men) as the most common type of occupation of interest. Comparing this finding with the Swedish "mediabarometer" shows similar results, as 93% of persons in the age group between 65-79 years watch television daily (Nordricom, 2005). Stebbins (2005a,b) distinguishes between two different kinds of leisure activities; casual leisure activity such as watching TV, which is seen as unhealthy for the person because it fails to challenge the mind, in contrast to serious, project-based leisure, which includes

fitness and challenges. This is according to Rundek and Bennett (2006), who found that watching television increases the risk of cognitive impairment in old age, that is, the activity has a negative influence on functional capacity. However, *study IV* showed that watching television programmes such as the news and weather forecast provided an occupational pattern that helped the persons to continue with their everyday life. Television together with the radio kept them informed about what was happening outside home and enabled them to compare their own life situation with the world outside, and according to Östlund (1995), a way of building a frame of reference. Sometimes a feeling of estrangement arose because of difficulties in identifying oneself with the life of today, but also a feeling of being able to keep in touch with life and being a part of society (*study IV*). Watching television and listening to the radio were also experienced as amusing, a source of company which is in accordance with findings from earlier study (Östlund, 1995). Östlund also found that watching television gave the old persons a chance to generate a space of time free for having thoughts and reflections. According to earlier studies and findings in *study III*, watching television needs to be seen as an occupation that does not primarily engage person mentally but which actually benefits in daily occupation, persons socially and emotionally. Rundek & Bennett (2006) recommend us to turn off the television but we also need to see watching television from an occupational perspective and listen to and respect elderly persons' choices and experiences.

Participation in everyday life with an assistive device

The findings showed that elderly persons who lived in their own home *used assistive devices* to a high degree and for different reasons (*study II*). *Study II* confirmed the findings of other longitudinal studies of general populations in Sweden that the proportion of users of assistive devices increases within age (Dahlin Ivanoff & Sonn, 2005; Sonn & Grimby, 1994). The proportion of new users of assistive devices between 70 and 76 years was found to be 31% (Sonn & Grimby, 1994), compared with 34% recorded in the present study for the age group 76-86 years, and 19% for the age group 85-90 years of age (Dahlin Ivanoff & Sonn, 2005). This means that there were a higher proportion of new users in the younger age groups, while there were more permanent users in the older age groups. Two thirds of new users of assistive devices between 76 and 86 years of age in *study II* might represent a group that are more frail as they already had personal assistance in daily occupation compared to the group of persons that did not have personal assistance. This means that more attention need to be paid to these persons needs, concerns and opinions regarding assistive devices before prescribing new devices and during the evaluation process. In that way it will be more obvious how the assistive devices should be

integrated into their daily occupations and to identify adaptive approaches that may be used to achieve a readiness for use of assistive devices (Scherer, 2002) and desirable occupational self-images (Larsson Lund & Nygård, 2003). The majority (81%) of elderly persons who were dependent on personal help in ADL were also users of assistive devices. This implies that assistive device use and personal help are complementary to each other, and that the use of assistive devices should not be regarded as a means of compensating for lack of personal assistance or vice versa.

Hygiene- and mobility-related activities were the most common occupations where assistive devices were used, 53% and 61%, respectively (*study II*). This confirms other reports that show the predominance of hygiene-related activities and that mobility devices such as walking canes and walking frames are the most commonly used types in the elderly populations (Cornman et al. 2005; Dahlin Ivanoff & Sonn, 2005; Hasting Kraskowsky & Finlayson, 2001; Löfqvist et al. 2005). The type of hygiene and mobility device found in *study II* was mainly simple, uncomplicated and low-tech. Neither devices related to cognitive disabilities nor computer-based devices were found, and only a few devices with a more advanced technology were identified. As the interviews were carried out in the study participants' own homes, there was less risk of omitting any of the devices in use. It should be born in mind that these persons were a well-functioning group, and that any with cognitive impairment were probably not represented as persons living in sheltered housing were not included in the study. This group would probably use cognitive devices as well as more complicated devices than the participants in *study II*. The same types of assistive devices were found at the age of 86 in *study II* as among 76-years-olds in an earlier study (Sonn & Grimby, 1994) as however, at the age of 76 the proportion of mobility devices was 7% while it was 38% in the present study. This indicates that the mobility problem increased during the 10-year interval. *Study II* showed that the proportion with difficulties in mobility was 70% in women and 62% in men, which indicates that nearly all persons with difficulties in mobility also used assistive devices as 61% used assistive devices for mobility. The total device usage rate was high, 89% (*study II*), and ten years earlier it was 90% (Sonn & Grimby, 1994). This indicates that the devices are used in everyday life but not how effective they are or how they are experienced. That is why it is not enough to report only usage rates as a sign of effectiveness of assistive devices.

The widespread use of hygiene and mobility devices among elderly persons (Dahlin & Sonn, 2005; Edwards & Jones, 1998; Hastings Kraskowsky & Finlayson, 2001; Löfqvist et al. 2005) calls for innovative designs not only for the assistive devices themselves but also for hygiene rooms. It has

been shown in a study of attitudes to assistive devices in persons aged 74 years and over, that 25% agreed that designers of assistive devices were not familiar with the problems elderly persons might have (Koski, Luukinen & Kivelä, 1998). Thus it is imperative to include elderly persons in the different stages of developing a user-orientated approach to assistive devices and technical products. Elderly persons have experienced tremendous changes in technology in everyday life during their life time. There is no reason to assume that elderly persons are more resistant to new technology than younger persons are, though there might be a risk that the changes in the environment and in the social structures that determine environment occur more rapidly than people's ability to keep up with them, which will result in an individual lag (Lawton, 1998). Elderly persons have a pragmatic perspective on technology because they want it to meet their needs in everyday life (Östlund, 1995). They also have a sense of perspective and their experience could be valuable for user involvement in developing new technology.

The many advantages of using assistive devices to facilitate or enable participation in everyday life, particularly with reference to personal safety and security, have been brought out (*study II*) and confirm earlier studies (Bateni & Maki, 2005; Brandt et al. 2003; Sonn & Grimby, 1994). However, *studies I and II* also pointed to contradictory experiences of being a user of assistive devices. On the one hand, the elderly persons regarded device use as normal for their age, and it was pleasant and safe to use an assistive device. On the other hand, assistive devices were also experienced as a mark of old age, and unpleasant and unsafe to use. Looking at the practical aspects showed that assistive devices were usable and essential but could also be inappropriate and cumbersome to use. The social aspects of device use were also contradictory. Some experienced receiving respect from others in the environment and did not mind using assistive devices; others thought it was embarrassing for the company around them. It is imperative to recognise these contradictions as they show both the positive picture when the devices are integrated into the daily occupations and the risk of hindering a person from participation in everyday life (*study IV*). Similar results have been reported from a study of physically disabled persons (age 25-73), which showed that assistive devices had a double-edged meaning (Larsson Lund & Nygård, 2003). Thus, using and accepting to be a user of assistive devices can be complicated; it involves personal-, physical-, social- and cultural environmental factors as well as demands from the occupation that is performed. The present findings showed that it is important to understand the users' value of and perspectives on assistive devices, which is also emphasized by Gitlin et al. (1998) and Larsson Lund and Nygård (2003), in order to improve the quality of the interventions (Hedberg-Kristensson, 2006). Every use of an assistive device needs to be seen as a unique measure and

should be evaluated with these aspects in mind. The symbolic value of, and attitudes towards, assistive devices – one's own as well as those of others in the community have been shown in earlier studies to have an impact on the use or the users of assistive devices as well as on non-use of assistive devices (Gitlin, 1995; Hastings et al. 2001; McMillen & Söderberg, 2002; Roelands et al. 2002). The findings confirm that the living context, the physical environment and the social environment can all lead to occupational deprivation and thus have an impact on participation in everyday life.

Methodological considerations

The central aim of this thesis is to describe experiences of different aspects concerning participation in everyday life with the help of both qualitative and quantitative research methods. According to Yerxa et al. (1990), the only way to understand experiences is to get the persons concerned to describe them. However, there are several aspects concerning methodological issues that need to be considered because they may have an impact on the results and conclusions drawn from the studies.

The decision to use *interviews* for data collection was based on the need to reach and obtain the meaning aspects as experienced by the study subjects themselves. All interviews were carried out during a home visit (*studies I, II, III, IV*), keeping as open-minded as possible to the person's own experiences. In *studies I* and *IV* an in-depth interview, also called a focus interview (Troost, 2005), was performed to gain a deeper understanding. In-depth interviews have a focus but also a freedom in the way to reach the focus. As far as the quality of the data is concerned, doing all interviews in the elderly persons' home environment was a great advantage. It enabled the interviewer to ask questions about something that was observed in the home environment which could supplement other information, and it was especially relevant in connection with in-depth interviews. It was also very useful in *study II* when obtaining answers to the structured questions about occurrence of assistive devices and other questions concerning the use of assistive devices. The decision to perform interviews in their home environment was also based on the assumption that the persons would feel safer and freer to talk about their everyday life in their own environment. This resulted in richer material, giving a more nuanced picture of the phenomena studied than if the interview had been done in a more unfamiliar place or over the telephone.

The interviews in *studies I* and *IV* began with a short introduction which was the same for all participants. The introduction included the aim of the study, focus of the interview and ethical

aspects about anonymity and confidentiality. This was followed by an open-ended question, to invite the persons to start the interview with what was of importance to them. The following questions were formulated during the interview depending on what the person concerned started to talk about and how she/he talked. A “mind-map” worked as an interview guide and was very useful, especially during interviews when the person talked “too much” or had difficulty in expressing her/himself. However, persons who found it difficult to talk about the phenomena of concern got more leading questions, while in other interviews the introduction and the first question were enough to start the discussion and the interview was a success. If more pre-defined questions had been asked, a deeper understanding might have been achieved, but then it might not have been possible to capture the variation of experiences that was actually found. The interviews in *studies I* and *IV* were deliberately performed in this way because of their explorative nature and the need to keep an open mind about the phenomena concerned, and the results can be considered to be rewarding.

The interviews with both structured and open-ended questions (*studies II, III*) followed the same order as in the questionnaire and were carried out mainly by the authors. There is a risk that can be discussed concerning the structured questions with predefined answers, as the researcher has decided the focus in forehand (Burns & Grove, 2005). However, the questionnaire was based on structured questions used in earlier examinations of the persons (Eriksson et al. 1987; Sonn & Grimby, 1994). To be able to follow longitudinal changes and produce reliable data, it is very important to use the same questions. This is especially essential in general population studies as guidelines and policies in society are often based on this kind of data (Agahi et al. 2005; SOU, 2002). Accordingly, it is a strength that it was possible to follow changes in the proportion of users of assistive devices both at 76 and 86 years of age (*study II*) and to compare these with data collected in the same way between 70 and 76 years of age (Sonn & Grimby, 1994) as well as between 85 to 90 years of age (Dahlin Ivanoff & Sonn, 2005). Nevertheless, it is also important to add new research questions, as in this case on experiences of being users of assistive devices.

The answers to the open-ended questions about experiences were written down verbatim or as a short summary during, or in some cases immediately after, the interviews. Using open-ended questions could be both risky and weaken the results since one might ask whether it is possible to reproduce the content in appropriate terms. Some answers such as in “It is good”, “I don’t know” did not reveal any content. However, when all the answers were read together several times, they

could also be organised, interpreted and finally assigned to the categories (Malterud, 1998). The open-ended and structured questions gave another kind of results than that obtained from in-depth interviews but is still valuable and informative knowledge complementing the quantitative data in the studies (*studies II, III*).

In *study I* a selective *sample* was included to reach a variation in the use of assistive devices. The intention of this sampling procedure was not to generalise the results to a population, rather to form a heterogeneous group with as wide a range of experiences as possible. The sample varied considerably in the age, the number of assistive devices and in their need them. In *study IV* the sample was selected consecutively from the first cohort, born 1901-1902, in the H70 studies. The size of the study group in phenomenographical studies (*studies I, IV*) has no significance as far as the outcome of the study is concerned and as long as the outcome reveals different experiences (Alexandersson, 1994). However, a second interview, especially with the 99-year old persons and including more men might have produced a more nuanced picture of experiences of the phenomena concerned.

In *studies II and III* subjects were derived from a representative sample of elderly persons from the third cohort in the series of longitudinal gerontological and geriatric population studies (H70) in Göteborg, Sweden. The response rate was 72%, which can be regarded as acceptable, when comparing with similar studies in this age group (Hillerås, 2000; von Heideken Wågert, 2006). However, the results can not be generalised to a general population in the same age group, because persons with sheltered living were not included in the studies and the participants were shown to have a lower 5-year mortality rate than those who did not participate. Thus, the number of users of assistive devices in a general population in this age group would certainly be higher than in the present study population. In recent decades, the non-response rate in studies has tended to decrease. For instance, in the gerontological and geriatric population studies in Gothenburg, the response rate 1971 was 85%, in 1981 77% and in 2000 65% (SCB, 2006b; Sund, 2002).

A phenomenographical approach was chosen for *studies I and IV* in order to be able to gain an insider perspective, *what and how* a person experiences the phenomena in different ways. Qualitative content analysis with a latent and in some questions a manifest content analysis was used in *studies II and III*. The manifest content analysis was used in questions concerning reason for use of assistive devices and experiences of being a user in *study II*. Both approaches are

explorative and strive to interpret and describe personal perspectives.

The researcher's preconceptions can both facilitate and bias the quality of the findings, and it is important to take this into consideration (Kvale, 2005). Interpretation of data is influenced by professional as well as personal experiences. During the interview process, the data-collection phase and the analyses, and in the presentation of the result there has been an awareness of these perspectives and an attempt was made to be as open-minded as possible to the person's experiences to reach a new understanding. During the *interpretation* process, the object was to stay close to how the old persons expressed their own experiences in their living context and not to regard them as single experiences separated from the phenomena concerned. The interviews were read several times back and forth, in order to become aware of the experiences being told and to be able to discern the critical features, which then could be compared with other experiences (Pang, 2003; Runesson & Marton, 2002). In *studies II* and *III*, the results were not analysed close to the context but close to the text, an approach known as manifest content analysis. In some cases, the underlying meaning of the answers had to be interpreted with the help of latent content analysis (Graneheim & Lundman, 2004). It is especially here that weaknesses might have occurred because of the risk of misunderstanding the content of the answers or of labelling the categories in an unsuitable way. In all studies the categories are labelled with one or two words only. Doing so could have created fragmentation (Graneheim & Lundman, 2004) or misinterpretation of the result. To remedy this, the words that label the categories have been carefully selected so that the results can be seen to be credible and dependable.

In all studies, but particularly in *studies I* and *IV*, several persons were involved in the interpretation and discussion of the results. To ensure the reliability of the interpretation process and the result, the researcher started from the excerpts from the interviews to identify the categories, while the co-examiners started from the categories and checked if the categories corresponded with the excerpts (Alexandersson, 1994). The co-examiners were all experienced researchers from different disciplines, which was of great value especially in the interpretation of the data. During the working process, the results were also presented and discussed in seminars and conferences, by peer reviews (*studies I, III, IV*), and member checking (Conneeley, 2002) was used in *study II*. In this way, the risk of any preconceptions influencing the findings was reduced (Larsson, 2005).

Concerning the *validity of the result*, it is important that the descriptions of experiences are grounded in empirical data and make sense in relation to the elderly persons' everyday life (Larsson, 2005; Lepp & Ringsberg, 2002). In phenomenographical studies, it is important to distinguish qualitatively differentiated categories of descriptions of the phenomena in question to describe a valid internal logic (Marton, 1997; Marton & Morris, 2002). The results and the structure of the results have been presented both in text and in tables, and excerpts have been used to elucidate the meaning of the categories described, allowing the reader to assess their validity (Larsson, 2005; Lepp & Ringsberg, 2002). A table is sometimes better at showing the internal logic that is vital to the validity, especially in the phenomenographical studies (*studies I, IV*) but also in the qualitative content analyses (*studies II, III*). In *study I* the excerpts were marked with the interview number to show that all the persons in the study had contributed to the result.

There is a risk that *credibility* might suffer if the text is condensed too much even when the aim is to preserve the core of the statement (Graneheim & Lundman, 2004). This refers especially to the process of shortening the text as in *studies II and III*. Another possible risk occurs when the authors have to capture and express; nuances in the descriptions, feelings and attitudes in a foreign language. The text has been treated with caution, sometimes together with a professional translator, to ensure that the results are grounded in elderly persons' everyday life. We thus found a heuristic value in the studies.

The *multimethod approach*, applying both qualitative and quantitative methods to complement each other (Brewer & Hunter, 1989; Morgan, 1998) was a strategy to obtain as comprehensive picture as possible of the elderly persons' situation and ensure the credibility of the result (Morgan, 1998). In *study II* this turned out well and gave a valid picture of both the proportions of users, the type of assistive devices that were used, as well as how being a user was experienced. This was also the case in *study III*, the interests the elderly persons had had to give up in the past five years together with information on the frequency and type of interests that occupied them. It seems reasonable to claim that this approach improved the trustworthiness of the findings.

Implications for practice

In gerontology and geriatric medicine, ageing is described from manifold angles and the interdisciplinary approach is evident (Steen, 2004). The findings in this thesis contribute with valuable knowledge based on empirical data for application in clinical practice, research and health promotion both in occupational therapy and geriatric medicine and gerontology. The results from

this thesis are of value for different professionals working with elderly people and for further research. Elderly persons' experiences can be used to further understand the aging process and help professionals and policy makers to enhance persons' participation in everyday life and reduce occupational deprivation in society. All persons have a fundamental human need and rights to live meaningful and active lives, to create and recreate themselves through what they do, with or without support and regardless of age and status (Hasselkus, 2002; Jackson, 1996; Townsend & Wilcock, 2004).

It is important for all professionals working with elderly persons to recognise, consider and support the personal challenges met and the creative solutions for managing daily occupations found in *studies I, III and IV*. Professionals are often perceived as being close to elderly persons. They are therefore important facilitators of the elderly persons' participation in everyday life. The elderly persons' have thoughts, ideas, wishes and goals for their everyday life. It is their rights that the facilitators, based on trusting and relationship, assist them in making autonomous decisions and acting independently in everyday life (SFS 1982:763 / 2006:631). A *client-centred practice* is grounded on these assumptions, and a model can guide professions to achieve both consideration of the ethical aspect and an optimal quality in the intervention (Hammell, 2002; Rosin & van Dijk, 2005; Townsend, 1997). To operate this model, professionals need to discuss values and clarifications with clients. This starts with treating the clients with respect, sharing information, not merely giving it - a two-way process. This is also a basic prerequisite for involvement, engagement and participation (Desrosiers, 2005; Molin, 2004; WHO, 2001). One aspect of quality in clinical practice is being aware of and having respect for the great variation of experiences in everyday life among elderly persons (Akner, 2006; SFS, 1982:763/ 2006:639) - that is ethical considerations.

Many studies recommend a client-centred approach to enable meaningful occupations and to get an active user of assistive devisers rather than a passive recipient. For the majority of elderly persons, the use of assistive devices is not only a strategy for functional independence, but one that enables engagement in daily occupations in various ways to keep up their ability to have control of, or take control in, everyday life. Again, it should be remembered that assistive devices can become a 'disabler', because of its negative symbolic value and the practical experience of the user in daily occupation, especially in a social context outside home. Prescribers of assistive devices should be aware of both the positive and negative impact that the symbolic value of the assistive devices can have on the use and users. Positive experiences of being users can be seen as indicating that the assistive devices are integrated into their everyday life, while the negative

experiences can be seen as risk factors. These can be valuable indicators when evaluating the effect of assistive devices.

The variation of experiences that appeared highlighted the study participants' own views of participation in everyday life and of being a user of assistive devices and tells us something about *what* the very old experience and *how* they experience participation in everyday life. Once again it was confirmed that elderly persons are not a homogeneous group. Their own perspective on participation in everyday life needs to be made clear and explicit both in research, intervention or plans for health promotion.

Occupations of interest are seen as essential motivators and as having rich therapeutic potential for encouraging participation and engagement in everyday life (Kielhofner, 2002). Thus, before interventions for enabling occupations of interest are initiated, each client's history must be carefully assessed to find what he/she is curious about and feels motivated to do, and to find individual solutions and appropriate assistive technology. The home environment is the best place and space to become engaged or continue being engaged in daily occupation and especially in occupations of interest.

The persons in the studies gave many examples of how they managed/coped with their everyday life, and these examples need to be taken into consideration and supported. The results confirm the importance of individual creative reflections and solutions to the challenges the elderly have to meet to be able to master daily occupation that needs to be seen as part of everyday life. These personal resources must be respected and supported regardless of the person's age.

CONCLUSIONS

Participation in everyday life was experienced in different ways from being physical engaged to being engaged in a more distance way as a spectator, and even being involved in memories about their earlier lives. Both internal aspects, such as capacity and motivation, and external aspects, such as accessibility, occasions and permission, affected their participation in everyday life. The utmost limit of participation is being able to master everyday life, and this thesis showed that very old persons have resources to do so. Generally speaking, though, the ability to perform daily occupation gradually decreases with age. Some persons reach a state of resignation concerning their decline, while others live a creative life and strive to maintain their autonomy with own capacity, with support from personal help and or assistive devices. This thesis gave very old persons a voice about *what* they experienced and *how* they experienced participation in everyday life. Their experiences teach us about different aspects of abilities and limitations to being able to continue participation in everyday life even at a very advanced age. To be able to reach the optimal type of approach in clinical practice, we must recognize the variety of experiences of everyday occupations persons have, respect them and let them guide interventions. Hence, occupational therapists as well as other professions in geriatric medicine must create opportunities, based on trusting and relationship for people to assume autonomous decision-making and action in everyday life, where these professionals can act as facilitators. In agreement with Akner (2006), the importance of ethical considerations must be emphasized in all work with and for elderly persons, not only in clinical practice but also in national goals and visions.

ACKNOWLEDGEMENTS - TACK TILL

Ulla Sonn, min huvudhandledare, för att du under alla år alltid har funnits där och generöst delat med dig av din tid, kunskap och erfarenhet. Att du med din vetenskapliga skicklighet guidat mig in i en ny kunskaps värld, gett mig konstruktiv kritik, väckt tankar och visat på nya möjligheter. Det är ovärderligt att ha en så engagerad handledare som du har varit.

John Hultberg, bihandledare, för att du med din kunskap och konstruktiv kritik engagerat dig och uppmuntrat mig i arbetet

Sten Landahl, för att du under det senaste året, fungerat som bihandledare och gett mig ditt stöd

Bertil Steen, för att du antog mig som doktorand och det stöd som du gav mig inledningsvis i doktorandstudierna

Torgny Ottoson, för att du hjälpte mig att förstå hur ”kompassen och den fenomenografiska kartan” kan användas för att finna oupptrampade stigar i erfarenhetens värld bland de äldre

Valter Sund, för att du från din ”guldgruva” har tagit fram variabler till mina arbeten

Harriet och Lena som hjälpt till med det administrativa på sektionen för geriatrik

Gillan, för ditt arbete med engelskan och texten, din flexibilitet och alltid lika trevliga bemötande

Alla personer som jag har fått besöka och intervju i era hem - utan er ingen avhandling

För ekonomiska understöd från: Stiftelsen Hjalmar Svenssons forskningsfond; Anna Ahrenberg stiftelse; Greta & Einar Askers stiftelse; Axel Lennart Larssons donation; Svenska Kulturfonden i Finland; Svensk-Österbottniska samfundet i Finland; Professor Jan-Magnus Janssons Stiftelse för geriatrik och forskning kring äldreomsorg; Oskar Öflunds Stiftelse.

Fredrika, Gunilla, Ingeborg, Johanna, Camilla = min ”doktorandgrupp” utspridd i Finland och Sverige och som på olika sätt uppmuntrat, sympatiserat och haft tid med ”smal talk” över en lunch, telefon eller e-post

Birgitta Lundgren Pierre, kollega, mentor och vän, för att du en gång för länge sedan inspirerade mig att fortsätta studera, hjälpte mig att tänka vidare och att utvecklas i mitt yrke som arbetsterapeut och senare som lärare

Anette Klippe, kollega och mentor som tyvärr lämnat oss här på jorden, men dina spår finns kvar hos mig

Carita, väninna och kollega för att du plötsligt fanns där med alla dina intressanta frågor, diskussioner och trevliga stunder som vi har delat. Du väckte lusten hos mig att fortsätta och slutföra mitt arbete

Monica, för din vänskap och ditt varma och generösa bemötande jag har mött när jag besökt Göteborg

Maria och Susanne, för er vänskap, uppmuntran och stöd under arbetets gång

Stina för att du finns!

Tanja, för att du skickligt illustrerat mina ord i dina bilder, ätit lunch med mig ibland och skött om och motionerat Bisin när jag suttit vid datorn eller varit borta på resa

Ulrika, för ditt genuina intresse för ergoterapi och i mitt arbete

Gudrun med familj, för att ni finns i mitt och min familjs liv. Ni är ovärderliga

Olga med familj, er omtänksamhet och generositet som ni bjudit på när jag kommit som en flyttfågel med kappsäck från nordost

Pappa Fride, och *mamma Gunvor* som tyvärr inte finns bland oss längre, för att ni fostrade in mig i livets skola och lärde mig att se på livet med en ödmjukhet och nyfikenhet. För att ni visade på glädjen i att undersöka och upptäcka vardagen redan som barn tillsammans med mina syskon.

Tom, min man, för att du aldrig har ifrågasatt mina vägval och projekt i yrkeslivet, utan alltid uppmuntrat och gett mig ditt stöd på olika sätt. Jag är lycklig över att ha dig som livskamrat.

Jacob, vår älskade son, för att du anmälde din ankomst till livet samtidigt som jag klev in i doktorandrollen och för att du tidigt markerade med din lilla hand mitt på tangentbordet, behovet av balans mellan arbete och familj i vardagen. Inga ord kan säga vad jag känner för dig - Kram.

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