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Older adults' participation in occupation in the context of home-based rehabilitation

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ABSTRACT

The overall aim of this thesis was to enhance the occupational therapy knowledge base concerning how older adults with disabilities experience participation in occupation during and after home-based rehabilitation, with a special focus on the perceived influence of the environment. Listening to the subjective experiences of older adults can generate new knowledge about how home-based rehabilitation services can support participation in occupation, which is a stated aim in occupational therapy.

The thesis included four studies. The participants were older adults over 65 years of age who received home-based rehabilitation after an acute illness or accident. **Study I** was a focus group study focusing on how the environment, in terms of physical, social, attitudinal and societal aspects, may influence participation in occupation. **Study II** identified 91 participants' perceived influence of environmental factors on their opportunities for participation by using a questionnaire. **Study III-IV** used a qualitative, in depth-approach to explore how three older adults with disabilities participated and engaged in occupations (study III), and how they perceived, collaborated and made use of the staff's services (IV) during the six months-period they received home-based rehabilitation.

The findings in **study I** showed that the participants perceived environmental pressure to concentrate on performing personal care instead of participating in chosen occupations. However, social environments such as family enabled participation while encounters with the societal environment (e.g. healthcare services) often were perceived as a hindrance. The findings in **study II** supported these results and identified that the participants perceived social environments as mainly facilitating participation. Surprisingly, physical environments in general were perceived as facilitators or not influencing, although societal environments were perceived more positively than in study I. In **study III** the findings revealed that participation was perceived both as being an agent in daily life, and as a strong engagement which occasionally became the agent and governed the participants' participation in daily life. In **study IV** five modes of perceiving and making use of staffs' services were identified, namely as persons to make small talk with, as discussion partners, as advisors or instructors, as teachers and finally as people who carried out tasks efficiently.

In conclusion, the findings showed that in order to support participation in occupation among older adults who receive home-based rehabilitation, it is important to focus on their engagement in social environments. Agency was a strong feature in the participants' perception of participation, and came to fore when the healthcare system was perceived as a hindrance for participation. The findings suggest that it is important to acknowledge the possibility that both staff and the system may be a hindrance for exerting agency. Finally, the fact that the findings showed a variation in how the participants made use of the services from the staff suggests that giving older adults the opportunity to make use of the staff services in different ways during the rehabilitations period may promote agency, and consequently participation in occupation.

Key words; participation, environment, home-based rehabilitation, older adults, agency.

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LIST OF PUBLICATIONS

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

- I Vik, K., Lilja, M. & Nygård, L. (2007) The influence of the environment on participation subsequent to rehabilitation as experienced by elderly people in Norway. *Scandinavian Journal of Occupational therapy*, 14, 86-95.
- II Vik, K., Nygård, L. & Lilja, M. (2007) Perceived environmental influence on participation among older adults after home-based rehabilitation. *Physical & Occupational Therapy in Geriatrics*, 24, 1-20.
- III Vik, K., Nygård, L., Borell, L. & Josephsson, S. (2007) The versatility of participation in everyday life. Experiences of three older adults during home-based rehabilitation. *Submitted*
- IV Vik, K., Nygård, L. & Lilja, M. (2007) Encountering staff in the home; three older adults' experience over six months of home-based rehabilitation. *Submitted*

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THE RATIONALE FOR THE THESIS

The focus of this thesis is older adults who are receiving or have received community-based rehabilitation, and their opportunities for participation in occupation in daily life after rehabilitation. There are several reasons for this choice of focus for the thesis: Firstly, the proportion of older adults in the population is increasing in the West (Schroots, Ballesteros-Fernández-Ballesteros, & Rudinger, 1999; WHO, 2004), which creates a need to better understand how older adults can be given the opportunity to participate actively in daily life. Secondly, since the number of older adults is growing, the proportion of older adults living with illness and disability will increase (Avlund, 2004; Dunlop, Manheim, Sohn, Liu, & Chang, 2002; Romøren, 2001) and one can assume that the need for rehabilitation services will increase. Thirdly, the thesis focuses on rehabilitation services provided by local authorities, as it is in the local environment of each municipality that older adults live their daily lives (Bautz-Holter, Sveen, Sjøberg, & Røe, 2007; Borg, Runge, Tjørnov, Brandt, & Madsen, 2007; Bricout & Gray, 2006). Therefore all the empirical studies were conducted in a municipality and within the rehabilitation context in Norway. Finally, as an occupational therapist (OT), I have a particular interest in exploring participation in occupation in relation to environment, since this is the core of OT (Christiansen & Baum, 2005; Kielhofner, 2002; Townsend, 2002). The overall aim of this thesis is to enhance the knowledge base in OT concerning how older adults with disabilities experience participation in occupation during and after home-based rehabilitation with a special focus on the perceived influence of environment.

BACKGROUND

It is a global phenomenon that the proportion of older adults in the population is increasing (WHO, 2004), and this increase is most rapid in the Western world (Schroots et al., 1999). In Norway, with approximately 4.7 million inhabitants, the proportion of adults over the age of 80 will increase from approximately 190,000 in the year 2000 to 320,000 in 2030 (St. meld 25, 2005-2006). The largest proportion of older adults will be women (St. meld 25, 2005-2006; Romøren, 2001). Even if most older adults live at home and manage their daily lives, the demographic changes will prove quite a challenge to the health services, including rehabilitation and occupational therapy services, in the years to come (Liao, McGee, Cao, & Cooper, 2001; Romøren, 2001; Schroots et al., 1999). A stated aim in health policy is the promotion of health in the ageing population by supporting older adults to participate and be active for as long as possible, both internationally (WHO, 2004) and nationally (St.meld 25, 2005-2006). In order to reach this goal it is thus a need for knowledge about how rehabilitation services provided by the local authority can stimulate increased participation in occupation for older adults with disability.

Community-based rehabilitation and occupational therapy

In the past decades we have seen a change in perspective within occupational therapy and rehabilitation, from treating patients in institutions based on their diagnosis in a medical model, to a community-based model where participation in daily life is the aim of services (Borg et al., 2007; St.meld.21, 1998-99; Law, 2002; United Nations, 2006; Scaffa, 2001; Wade, 2002). United Nations "Standard Rules on the Equalisation of Opportunities for Persons with Disabilities" (United Nations, 1993), and the most recent UN convention, the "Convention on the Rights of Persons with Disabilities" (United Nations, 2006), state that the aim of services for people with disabilities is promoting participation in society. Norwegian legislation is in line with these international documents, and the main responsibility for rehabilitation has been placed with local authorities (Bredland, Linge, & Vik, 2002; St.meld 21, 1998-99; "Lov om helsetjenesten i kommunene," 1984). Rehabilitation in the Norwegian context is defined as "time-limited, planned, processes with well-defined goals and means, in which various actors co-operate to assist users in their own efforts to achieve the greatest

possible functioning and coping capabilities, independence and participation in society” (St.meld 21, 1998-99, p.10). Consequently, individual rehabilitation goals among older adults can be anything from going hunting or spending time at the summer house, to playing bingo or cooking Sunday lunch for the grandchildren. To meet such goals, interventions can utilise a variety of strategies, ranging from remediative approaches (e.g. building up arm strength to be able to hold a gun), to compensatory approaches utilising ergonomic adaptations (e.g. deciding the best working positions in the kitchen), or environmental adaptation (e.g. improving acoustics in the bingo hall to make it easier for older adults with hearing impairments to engage in a bingo game) (Bredland et al., 2002). The Danish “White book on rehabilitation” (Marselisborgcenteret, 2007) also defines social participation as a goal for rehabilitation, unlike in Sweden, where the emphasis is on the improvement of functioning. The Swedish National Board of Health and Welfare (Socialstyrelsen, 2004) defines the aim of rehabilitation as comprehensively promoting the ability of individuals to regain the best possible functioning. These definitions suggest that the formal definitions of rehabilitation vary in the Scandinavian countries. In Norway and Denmark the emphasis appears to be on participation, while this is not explicitly included in the Swedish definition.

However, despite the recent emphasis on participation in rehabilitation and occupational therapy services, several studies show that persons with disabilities have fewer opportunities for participation even after rehabilitation (Law, 2002; Szebehely, Fritzell, & Lundberg, 2001). Research has documented that the physical environment creates obstacles for participation among people with disabilities. (Ayis, Goberman-Hill, & Ebrahim, 2003; NOU, 2001; Shakespeare, 2006). Most studies exploring the relationship between the opportunity for participation and the environment have been carried out mainly among young people with disabilities. (Shakespeare, 2006). Thus, there is a lack of knowledge about how older adults with disabilities in general perceive the influence of the environment on opportunities for participation, and in particular older adults with disabilities who receive home-based rehabilitation.

Before continuing, it is necessary to clarify the concept of rehabilitation provided by local authorities, as international literature uses a variety of different terms for this. For example: community-based rehabilitation (CBR) describes locally based rehabilitation which attempts to reach out to everybody with a disability, particularly those living in rural areas in developing countries (Boyce & Lysack, 2000; Ingstad & Eide, 2007). The concepts

“rehabilitation in the community” and “home-based rehabilitation” are also used in order to distinguish between rehabilitation services given in institutions, and those provided in the home (Boyce & Lysack, 2000; Scaffa, 2001). In this thesis, home-based rehabilitation is used as a collective term for services provided in the clients’ homes and which are organised by the local authorities in a municipality. In the Norwegian municipality where the studies for this thesis took place, the rehabilitation services are organised in multi-disciplinary rehabilitation teams. These teams include OTs, physiotherapists and nurses. One rehabilitation team works in each local district. According to the Norwegian “White Book on rehabilitation” (St.meld 21, 1998-99), all staff, irrespective of their profession, are expected to provide services that relate to the individual client’s unique rehabilitation goals. This means that home-care, provided by home nurses and home helpers outside the rehabilitation team is also expected to provide services in line with the clients’ rehabilitation goals.

Increasingly, occupational therapy services are given as home-based rehabilitation, both internationally (Borg et al., 2007; Lilja, 2000; Scaffa, 2001; Socialstyrelsen, 2007) and nationally (Norwegian Association of Occupational Therapists (NETF). In Norway, 63 % of the members of the NETF are employed in local authority health services, (NETF, personal communication December 2007) where rehabilitation services aimed at older adults constitute a large part of their work (Aas & Grotle, 2006). The purpose of occupational therapy interventions in general is to enable participation in occupation (Borg et al., 2007; Christiansen & Baum, 2005; Townsend, 2002). The NETF describes the task of OTs as motivating and organising training for necessary and wanted daily activities (e.g. personal care, cooking, shopping, reading the papers, surfing the internet and pursuing hobbies) (NETF, 2007). Furthermore, OTs also offers social training to support participation in occupations in the community (e.g. making use of transport and cultural services) (NETF, 2007). However, to my knowledge no empirical research has been conducted in Norway that explores what kind of barriers older adults who have received home-based rehabilitation encounter.

Before continuing it is also necessary to define the concept “occupation”, as it is defined in various ways in the literature. Common to all the definitions is a description of the various aspects of occupation as: “doing” (Miller & Landry, 2004), “engaging in occupations” (Kielhofner, 2002) and “occupying oneself and seizing control” (Christiansen & Townsend, 2004; Clark et al., 1991). Being engaged in occupation is a prerequisite to being able to live,

learn and develop (Christiansen & Baum, 2005; Kielhofner, 2002; Wilcock, 1998). For the purpose of this thesis, the term occupation will be used to refer to “doing” when it implies meaningfulness and purposefulness for the person; while activity is used to describe the performance of concrete tasks, for example dressing and washing the dishes; and task is used to refer to what is done. However, theoretical and empirical literature in OT and gerontology often uses the term “occupation” and “activity” synonymously. Thus, when referring to a specific literature source, these terms will be used in the same way as in the references.

Participation in occupation and older adults

Participation in meaningful occupation and maintaining autonomy and control in daily life are conditions for a good old age (Carlson, Clark, & Young, 1998; Gabriel & Bowling, 2004; Griffin & McKenna, 1998; Rowe & Kahn, 1997). Researchers have argued that participation in occupation prevents illness (Kendig, 2003), prevents functional decline (Clark et al., 1997; Visser, Pluijm, Stel, Bosscher, & Deeg, 2002), improves memory (Stevens, Kaplan, Ponds, Diederiks, & Jolles, 1999), improves physical function (Visser et al., 2002), and influences longevity among older adults (Eriksson, Hessler, Sundh, & Steen, 1999). Empirical research thus documents that participation in occupation is important for older adults in general, and gives arguments for why participation in occupation is an important goal in home-based rehabilitation. In order to gain a better understanding of what participation may imply, the following section reviews participation in relation to occupation, participation as autonomy, and control over daily life.

Participation in relation to occupation

Empirical research shows that participation in occupation exerts a strong influence on successful ageing (Clark et al., 1997; Rowe & Kahn, 1997). Rudman, Cook, & Polatajko, (1997) found, for example, that participation in occupation contributed to well-being as a means of expressing and managing identity, of social interaction with other people, and of organising time. These empirical findings are confirmed in theories of ageing which have looked at different aspects of older adults and activity in relation to successful ageing (Atchey, 1999; Rowe & Kahn, 1998). One of the earliest theories, the “activity theory” (Havinghurst & Albrecht, 1953), claims that being active, and particularly engaged in interpersonal activities, is important for a good old age, the more extensive the activity is the

better. A little later, Cumming & Henry (1961) developed their disengagement theory, which contrasts with activity theory. They claim that it is natural for older adults to withdraw from participation in society. The third of the classical theories of ageing was developed by Atchey (1999), and emphasises the importance of older adults carrying on with their usual activities. Also later theories of ageing, which to a greater extent are based on empirical data, agree that participation in activity is a prerequisite for successful ageing (Baltes & Carstensen, 1996; Gergen & Gergen, 2001-2002; Rowe & Kahn, 1997). As this review of the literature shows, both empirical research and most theories on ageing underline the necessity of participation in occupation for older adults, and thus underscore the need for a rehabilitation policy where participation is the goal. This review states the reasons *why* participation in occupation is necessary. However, participation in occupation always happens in a context. In order to enable participation in occupation during and after rehabilitation, it is also necessary to understand *what* occupation older adults are participating in, and in *which kind of* environment, which will follow.

One study found that 75+ year olds living at home participate in occupation such as gardening, housework, handicraft, going for walks, and social activities (Legarth & Avlund, 2005). Crombie et al. (2004) findings are consistent with the findings from Legarth et al. (2005) in a study in Scotland among older adults between the ages of 65 and 85. In Crombie's study, as many as 94% of the participants engaged in some light housework, and for those who had a garden, 68% did light gardening. They also engaged in a range of social activities, like playing cards, bingo, and attending church or social clubs. The most popular physical activity was walking (Crombie et al., 2004). Research among older adults in the USA describes the same tendency. Horgas, Wilms, & Baltes (1998) found for example that older adults participate widely in occupation in and around the home, but also in leisure activities outside the home. Stevens-Ratchford & Cebulak (2004) report that older adults are likely to be engaged in a wide variety of social occupations similarly to Griffin & McKenna (1998), who conclude that leisure activities are at the core of life and are particularly important in the lives of seniors. These findings are consistent with studies among people over the age of 67 living at home in Norway (Statistikkbanken, 2007). For example, from 1997 to 2004 there was an increase in the number of older adults who visited art exhibitions (from 28% to 41%), went to the cinema (from 13% to 26%) and the theatre (from 23% to 34%). On the other hand, watching TV (86% in both years), reading newspapers (from 86% to 90%), and listening to the radio (from 61% to 64%) have been relatively stable over that period. In Norway, outdoor

life and sporting activities are traditionally culturally valued activities among older adults. In 2004, for example, as many as 60% of people over the age of 67 reported that they had taken day trips in forests or mountains during the past year, while 63% reported that they went for short walks or did some exercise once a week (Statistikbanken, 2007). These empirical data document what the older population generally participates in, and where, and gives an indication of the type of occupations older adults who receive home-based rehabilitation may need or wish to participate in.

To sum up, empirical studies describe domestic occupations such as gardening, social contact with family and the media as occupations older adults occupy themselves with. Many participate in outdoor activities like walking and exercise. The use of cultural facilities is also on the increase. These studies give an indication of the type of occupations and environments that are important in the promotion of participation for older adults in general. At the same time they give an indication of what participation for older adults may imply. Since research has shown that what is experienced as meaningful occupation does not change for older adults even if they become ill (Legarth & Avlund, 2005), one can suppose that also older adults who receive home-based rehabilitation will still wish to participate in the occupations that are described in the literature review.

Participation in relation to autonomy

As initially stated, it is frequently claimed that autonomy and the opportunity to exert control are conditions which influence the opportunity for participation in occupation for older adults (Clark et al., 1996; Rowe & Kahn, 1997). Furthermore, autonomy is an important prerequisite for participation in provision of both home-based rehabilitation and occupational therapy (Cardol, de Jong, & Ward, 2002; Clapton & Kendall, 2002; Townsend, 2002). This chapter will therefore throw light on the connection between autonomy and control, and participation in occupation, for older adults in general.

Empirical research documents that having autonomy implies control over daily life and occupation, and that this is essential for an active old age (Baltes & Carstensen, 1996; Clark et al., 1996; Rowe & Kahn, 1997; Schultz & Heckhausen, 1996). In this thesis, having control is thus regarded as one aspect of having autonomy. Baltes & Carstensen (1996) claims that older adults can largely compensate for functional decline by exercising control in occupation.

Consistent with this view, a number of studies confirm a connection between sense of control and participation among older adults (Krause, 2000; Mirowsky, 1995). For example, Krause (2000) found that to have control over a few activities is more important than participating in several. These findings are consistent with Rudman et al. (1997) who reported that a sense of control seemed to be an important mediator for participation in activities.

The focus on autonomy in health care services is based on the Helsinki Declaration (Frost, 1993) which states that clients have the right to co-determination of the treatment they are given. However, the concept of autonomy is under discussion (Barron, 2001; Cardol, de Jong, & Ward, 2002; Clapton & Kendall, 2002; Frost, 1993). In the context of rehabilitation, autonomy is linked to the right of every individual to be given the opportunity to make decisions and to exert control over themselves and their lives, and as the ability to perform activities (Barron, 2001; Cardol et al., 2002; Clapton & Kendall, 2002). In the light of both the theory of ageing (Baltes & Carstensen, 1996; Rowe & Kahn, 1997; Schultz & Heckhausen, 1996) and empirical studies on older adults in general as previously referred to, it seems that having autonomy, including having control, are necessary prerequisites to being active and to participating as before. This is in line with the ideology of rehabilitation (Bredland et al., 2002) and occupational therapy (Christiansen & Baum, 2005; Townsend, 2002) which stress autonomy and user involvement as necessary in collaboration between the client and professionals. However, there is still a need to gain knowledge of how older adults who receive home-based rehabilitation experience participation, understood as autonomy and control, in daily life while they are receiving rehabilitation. Furthermore, the concept of participation needs to be defined before describing the group of older adults with disability who require rehabilitation

The concept of participation

The introduction may give the impression that the understanding of the concept of participation is unambiguous, and that there is one common understanding. However, the concept is widely discussed both in rehabilitation and occupational therapy literature (Cardol, de Jong, & Ward, 2002; Gustavsson, 2004; Hemmingsson & Jonsson, 2005; Wade & Halligan, 2004). In the following section, some perspectives on the concept of participation will be presented, thus providing a basis for how participation is used in this thesis.

Participation – the perspective in the disability rights movement

The disability movement perspective focuses on equal participation and the demand for equal citizens' rights for people with disabilities. The demand for social participation is promoted by people with disabilities and their organisations, and is called the "social model of disability" (Barnes, Mercer, & Shakespeare, 1999; Knøsen & Krokan, 2003; Oliver, 1996; Scaffa, 2001; Shakespeare, 2006). The emphasis on the right for people with disability to participate in society is highlighted in central international conventions (UN, 1993; and 2006) as well as in Norwegian policy (NOU, 2001; NOU, 2005). The concept of participation is not defined in these documents, but UN Standard Rules state that all people should be able to participate in society on a par with others, with the same rights and obligations as others. This means being able to utilise the same public transport, education, services, cultural offerings etc as everyone else (UN, 1993). The view of participation as a *right* to social participation has influenced both rehabilitation policy and policy for the disabled in many countries (Gustavsson, 2004; NOU, 2005; Van Slyke, 2001). Furthermore, the disability movement perspective has influenced the revision of the WHO International Classification of Functioning, Disability and Health (ICF) (WHO, 2001) and rehabilitation policy in Norway (St.meld, 1998-99). The disability movement perspective has been criticised for having a one-sided view of disability purely created by environment (Shakespeare, 2006). The understanding of participation as a right to social participation is the cornerstone of the ideological framework of this thesis; older adults with disabilities have a right to participation on the same level as younger people with disabilities.

Participation – the perspective in the International Classification of Functioning, Disability and Health (ICF)

The concept of participation is central in the ICF (WHO, 2001). The aim of the ICF is to provide a framework in order to describe and analyse human functioning and disability in interaction with the environment. Function is seen in relation to body, activity and participation (Dahl, 2002; Üstün, Chatterji, Bickenbach, Konstantjsek, & Schneider, 2003). The ICF consists of a model and a classification which have been developed to capture data concerning functioning and disability, where participation is a component of functioning (Dahl, 2002; Üstün et al., 2003). The model in ICF is a biopsychosocial, model integrating the medical model of disability which views disability as a problem of the person, and the social model of disability where disability is created by environment. Participation is described as the individual involvement in a life situation. The definition "involvement" incorporates

taking part, being included or engaged in an area of life, being accepted, or having access to required resources. The concept of involvement should also be distinguished from the subjective experience of involvement (the sense of belonging). There has been a strong and lively debate around the ICF. One criticism concerns classification of disability (Hammel, 2004; Hurst, 2003). Another criticism is that the subjective experience of participation is not sufficiently taken into account in the ICF (Hemmingsson & Jonsson, 2005; Ueda & Okawa, 2003) and that neither the relationship between participation and autonomy (Cardol, de Jong, & Ward, 2002; Grimby, 2002b) nor the distinction between activity and participation components are clarified (Jette, Haley, & Kooyoomjian, 2003; Jette, Tao, & Haley, 2007; Nordendfelt, 2003). This thesis has chosen to use the ICF model because it illustrates how participation is seen both from an individual and a wider social perspective. Furthermore, it serves as background to studying and understanding how environment influences the opportunity for participation in occupation for older adults receiving home-based rehabilitation. This has been particularly important, as this perspective on participation and disability is not frequently seen in research in rehabilitation of older adults.

Participation – the perspective in rehabilitation

As already mentioned, participation as the right to equal participation in society, and the UN Standard Rules (Nations, 1993), constitute the most widely accepted ideological framework and aim for rehabilitation services, including in Norway (St.meld 21, 1998-99). Nevertheless, in clinical work as well as research, it is the ICF which has provided guidance for how participation can be understood (Bredland et al., 2002; Grimby, 2002a; Jette, Keysor, Coster, Pengsheng, & Haley, 2005; Vik, 2004; Wade, 2002; Wade & de Jong, 2000; Wade & Halligan, 2004). The ICF has contributed to a general focus change in rehabilitation. This change is characterised by a shift from “diagnosis and body” to “participation in the environment” (Jette et al., 2005). Autonomy and user involvement are central concepts in all rehabilitation activity (Bredland et al., 2002). Cardol and Ward (2002) claimed that the ultimate goal of rehabilitation is to regain and retain the highest possible level of autonomy, in order to maximise participation. An understanding of participation which includes autonomy has, for example, been shown in the development of recent outcome measures in relation to participation (Cardol, De Haan, Van den Bos, & de Groot, 2001; Gray, Hollingsworth, Stark, & Morgan, 2006; Lund, Nordlund, Nygård, Lexell, & Bernspång, 2005). The two aspects, social participation as an aim for rehabilitation services, and participation as autonomy and user involvement, are in line with Norwegian rehabilitation policy (Bredland et al., 2002;

St.meld 21, 1998-99; Wekre & Vardeberg, 2004). However, these aspects of participation have not been explored in research in relation to older adults receiving home-based rehabilitation. There is therefore a lack of knowledge about how these older adults experience social participation, autonomy, and user involvement.

Participation – the perspective in occupational therapy

A review of the literature shows that the ICF and its predecessor, the International Classification of Impairments, Disability and Handicap – beta version (ICDH-2), have contributed to the focus on participation in occupational therapy (AJOT, 2000; Borg et al., 2007; Christiansen & Baum, 2005; Dahl & Vik, 2000; Gray & Hendershot, 2000; Kielhofner, 2002). Occupational therapy literature describes the aim of occupational therapy intervention as enabling and supporting engagement and participation in occupation, although participation is not clearly defined (Christiansen & Baum, 2005; Christiansen & Townsend, 2004). However, the ICF definition is used, e.g. in Framework for Occupational Therapy (Occupational Therapy, 2002) and in Danish and Norwegian textbook on occupational therapy (Borg et al., 2007; Horghagen, Jakobsen, & Ness, 2005). Generally, OT literature describes an individual perspective on participation, which emphasises the individual's engagement in occupation in his or her immediate environment, and his or her subjective experience of engagement in occupation (Christiansen & Baum, 2005; Kielhofner, 2002). The discussion about the concept of participation has mainly taken place in relation to the ICF, and the main criticism of the ICF has been that participation also must be understood as a subjective experience of participation (Borell, Asaba, Rosenberg, Schult, & Townsend, 2006; Hemmingsson & Jonsson, 2005; Kielhofner, 2002). So far there has not been much focus on the rights perspective and societal environments as a barrier to participation, in the occupational therapy discussion (Borg, 2005; Hemmingsson & Jonsson, 2005). As the purpose of the research in this thesis was to examine participation in occupation and the influence of both immediate environments (e.g. that one encounter face-to-face) and societal environments, an occupational therapy view on participation would not be sufficient for the actual studies. However, the focus of the thesis on older adults' opportunities for participation in occupation is, as described earlier, based on the foundation of occupational therapy: engagement in occupation is a prerequisite for people to live, learn and develop (Christiansen & Baum, 2005; Christiansen & Townsend, 2004; Kielhofner, 2002; Wilcock, 1998).

To summarise, the current theoretical discussion and empirical research show different perspectives on participation, from a strong citizens' rights perspective for equal participation in society for all, to an individual perspective focusing on each individual's experience of a feeling of participation. In order to gain further knowledge about how older adults who are receiving or have received rehabilitation services experience participation in occupation, all the different perspectives have influenced my choices. The disability perspective has provided the ideological framework: older adults with disability have a right to participation. The perspective in the ICF has provided a model for an understanding of participation which is also used in rehabilitation. In addition, the debate in rehabilitation literature has contributed with the perspective on participation which includes autonomy and user involvement. Finally the foundation in occupational therapy has given the focus on participation in occupation.

Older adults with disabilities and the need for rehabilitation

Both international studies (Dunlop et al., 2002; Stuck et al., 1999) and studies carried out in Norway (Romøren, 2001) show that the main reasons for disability in older adults are dementia, depression and co-morbidity. In addition, strokes, fractures and neurological illnesses have a large effect on functional ability (Avlund, 2004; Romøren, 2001). In Norway, for example, approximately 15,000 people have strokes every year, and approximately 60,000 – 70,000 people live with the after-effects of strokes (St.meld.nr.25, 2005-2006). Norway is a “world leader” in femoral neck fracture with approximately 9000 every year, and approximately 2/3 of these patients are over the age of 70. Cancer, asthma, lung disease, diabetes and neurological disease also increase with age (St.meld.25, 2005-2006). However, there are no statistics for how many of older adults with a illness that require home-based rehabilitation, since official statistics on ageing, in Norway and Sweden for example, do not include data about rehabilitation (St.meld.25, 2005-2006; Sosialstyrelsen, 2007; Statistikkbanken, 2007).

There is no clear line between functional decline due to normal ageing, and functional decline due to illness or dysfunction, among older adults (Kauffman, 1994). In general, the older population is independent in primary activities of daily living (ADL) until their mid-70s, however it seems that household activities such as cleaning, transport and cooking can be increasingly difficult to perform (Sonn, Grimby, & Svanborg, 1996). There is still a great variability in changes in older adults, but particularly after the age of 80, many older adults

experience reduced physical functioning (Avlund, 2004). In addition to illnesses Avlund, Vaas and Hendriksen (2003) have shown that tiredness may be a reason why older adults experience reduced functioning in relation to daily tasks. In older adults who have had a stroke, Desrosiers et al., (2005) found that age and co-morbidity predicted the level of participation after rehabilitation. Further, they found that co-morbidity was associated with decreased participation among older adults living in their own homes. A common feature among older adults in the West is that women spend more time in a disabled state than men (Dunlop et al., 2002; Romøren, 2001; Stuck et al., 1999). Data describing the need for home-care for older adults with reduced functioning is available, however these data do not provide information about the need for rehabilitation in this group on a national level (Socialstyrelsen, 2007; St.meld 21, 1996-97; St. meld 25, 2005-06). However, in the municipality where the research in this thesis was carried out, the database showed that strokes and fractures as well as a reduced general condition and co-morbidity were the main reasons for rehabilitation referrals. The majority of users in rehabilitation were aged between 60 and 90, and $\frac{2}{3}$ of these were women (Rådmannens kontor, 2007). Consequently, the data from this municipality are in line with data about the most common reason for illnesses and disability among older adults.

Research relating to older adults and illness often provides a pessimistic picture of a group of weak and ill individuals (Knipscheer, 2000). However, international (Horowitz & Chang, 2004; Liao et al., 2001) and national research (Romøren, 2001) shows that the older population generally has better health, and that more people participate in daily life, than earlier cohorts of older adults. Many have claimed that the disease-centred view on ageing in research related to older adults is neither sufficient to explain why older adults have disability nor why they are unable to participate as before (Ayis et al., 2003; Knipscheer, 2000; Stuck et al., 1999). Also, older adults themselves regard their health as good, as long as they can manage their daily tasks. Indeed, many older adults regard their own health as good or very good (Statistikkbanken, 2007; Stuck et al., 1999).

To summarise, functional decline among older adults because of illness is in general regarded as the main reason why they no longer participate in occupation in a medical model of disability. If the goal of participation is to be reached in home-based rehabilitation, other reasons why older adults do not participate must however be explored. Borell, Lilja, Svidèn, og Sadlo (2001) have demonstrated that many older adults choose to participate despite

reduced functioning, other studies show that environmental factors are barriers to participation in occupation (Iwarsson, 1997; Lilja, 2000). Given the growing numbers of older adults in the population, it is necessary to gain knowledge about conditions other than those internal to the individual which influence the opportunities for participation. Knipscheer (2000) claims that interventions related to the environment have a greater impact on the results of rehabilitation than interventions directed to reduce impairment in older adults. A description of environmental influences on participation with disability follows. First the concept of environment is described, based on the same perspective as the concept of participation; and then, the influence of environment for participation in occupation for older adults.

The concept of environment

Environment – the perspective in the disability rights movement

The disability rights movement perspective emphasises environment as conditions which hinder or facilitate participation, and create disability (Fougeyrollas, 1997; Imrie & Kumar, 1998; NOU, 2001; Oliver, 1996; Shakespeare, 2006). Reducing disabling barriers and increasing accessibility through universal design is essential within this perspective (Iwarsson & Ståhl, 2003; NOU, 2001). The social model also emphasises how societal barriers in the environment (e.g. people's attitudes, legislation and system of services) may create barriers to participation (Knøsen & Krokan, 2003; Oliver, 1996; Shakespeare, 2006). Research which has studied environment from the disability perspective has focused on young people and adults with physical disabilities (Shakespeare, 2006). To my knowledge, no research has been carried out on older adults within this disability movement perspective. More knowledge about whether also older adults who are receiving home-based rehabilitation experience both physical and societal environment as an influence on their opportunity for participation is therefore needed.

Environment – the perspective in the ICF

The biopsychosocial model in the ICF describes both an individual and a societal view on environment (WHO, 2001). Environmental factors are determinants of the individual's functioning positively or negatively, and have an impact on all components in the model (Schneider, Hurst, Miller, & Ustün, 2003; WHO, 2001). The model distinguishes between the individual environment, as the immediate environment of the individual (e.g. settings such as home, workplace, school, and people whom the individual comes face to face with), and the

societal environment which includes both formal and informal structures, services and overarching approaches or systems in the community or society that have an impact on individuals (Schneider et al., 2003; WHO. 2001). The ICF is criticised for the environmental part of the model being insufficiently developed, and for environment being assessed either as a facilitator or a barrier (Hemmingsson & Jonsson, 2005). Because the ICF offers a framework for understanding the influence of environmental factors on participation and separates individual and societal environments, the model was chosen for the thesis. Furthermore, the ICF classification of environmental factors as products and technology, natural and human-made changes to environment, support and relationships, attitudes and services, systems and policies, has been a framework for exploring environmental factors in the studies. The distinction between environmental factors as facilitators and barriers was also considered as a focus for exploring how different environmental factors influenced participation.

Environment – the perspective in rehabilitation

At an early stage, Nagi (1965) and Verbrugge and Jette (1994) described rehabilitation models showing how disability was created in interaction with environment, and stated the necessity of intervention in terms of environment in rehabilitation services. In recent years, the ICF has mostly been used to describe and understand the role of environment in rehabilitation (Bredland et al., 2002; Grimby, 2002a; Wade & de Jong, 2000), and this has consequently also influenced the way environment is described in this thesis.

Environment – the perspective in occupational therapy

Various theoretical models in occupational therapy focus on each individual's opportunity to perform or engage in occupation in environments (Christiansen & Baum, 2005; Kielhofner, 2002; Townsend, 2002). Occupational participation is conceptualised as those activities or tasks which a person is engaged in within his/her environments (Townsend, 2002).

Environments are viewed as enabling or constraining occupational performance (Townsend, 2002), or as press and arousal for occupation (Kielhofner, 2002). In addition, occupational therapy models also show how occupation in itself is a condition external to the individual which makes demands on and influences participation; as occupational form (Kielhofner, 2002; Nelson, 1988). Models in occupational therapy which describe occupational form as an environmental factor external to the individual are different from the models presented within the other perspectives. Even if the models within occupational therapy take a broad view of

environment, the perspective on participation in occupation has been criticised for lacking emphasis on societal environments (Borg, 2005; Townsend & Wilcock, 2004). Additional criticism of the environmental dimensions of occupational therapy models is that they are one-dimensional, and do not capture the complexity of an individual's interaction with environment (Cutchin, 2004; Rowles, 1990, 2000). Since the thesis focuses on exploring how both individual and societal environmental factors influence participation in occupation, the occupational therapy models' perspective on environment has not been sufficient for the purpose of the studies. However, the focus on occupational form as an environmental factor external to clients has provided a perspective which has been included in the thesis (Kielhofner, 2002).

To summarise, in this thesis the disability perspective on environment as facilitator or hindrance for participation forms the overall understanding of the concept of environment. Furthermore, the definition and understanding of environment as described in the ICF is used, since the ICF describes both societal and individual environments specifically in relation to participation. Finally, occupational form as an environmental factor as described by Kielhofner (2002) has been included.

The influence of environment on older adults

Empirical research on older adults living at home and their environment has not particularly focused on participation in occupation. Moreover, the focus has been on how the physical environment in people's homes influences their ability to stay at home and manage personal care and daily life (Gitlin, Mann, Machiko, & Marcus, 2001; Iwarsson & Wilson, 2006; Lilja, 2000). For example in a Swedish longitudinal study, Iwarsson and Wilson (2006) found that in general, older adults living at home are satisfied with their accommodation, and that the prevalence of single environmental barriers was stable between baseline and follow-up six years later. However, in 28 of the 188 environmental barriers, significant changes in environments were identified indicating that older adults may face barriers in their home. A study of a population of older adults in the USA who were living at home, Gitlin et al. (2001) documented that on average the informants had as many as 13 problems in their home environment which could be regarded as deterrents to carrying out daily tasks. Furthermore, assistive devices have proved to be one factor in the physical environment which has a positive effect on the ability of older adults to carry out practical tasks in and around their

homes (Agree & Freedman, 2000; Brandt, Iwarsson, & Ståhl, 2003; Gosman-Hedström, Classon, & Blomstrand, 2002; Sørensen, Lendal, Schultz-Larsen, & Uhrskov, 2003). In this thesis, assistive devices are defined as products and technology for personal use in daily living as in the ICF (WHO, 2001). Findings indicate that assistive devices increase the independence of older adults (Dahlin Ivanoff & Sonn, 2004), and their use has been proven to give older women with disabilities increased control over occupation (Häggblom-Kronlöf, 1999). Consistent with this view, research has suggested that older adults may prefer assistive devices to personal assistance (Dahlin Ivanoff & Sonn, 2004; Lilja, Bergh, Johansson, & Nygård, 2003). It has also been shown that social participation can be increased when older adults are given access to electric wheelchairs (Brandt, Iwarsson, & Ståhle, 2004). However, one disadvantage of using walking aids such as walkers, crutches and wheelchairs is that new barriers may be created by buildings and means of transport no longer being accessible (Brandt et al., 2003; Carlsson, 2002; Zoerink, 2001).

Studies with a particular focus on the physical environment and participation show that a lack of accessibility and access to transport may create problems with participating in a variety of activities (Carlsson, 2004; Sanders, Polgar, Kloseck, & Crilly, 2001). In addition, the distance to facilities and a lack of facilities influence participation in leisure activities (Björklund & Henriksson, 2003; Griffin & McKenna, 1998; Zoerink, 2001). For example, distance to shops may prevent older adults with disabilities from participating in common occupations such as shopping (Ralston et al., 2001; Sanders et al., 2001). Ralston et al. (2001) found that giving up driving was a physical environment factor which greatly influenced the opportunity for social participation.

Studies relating to the social environment describe how family and friends, for example, have a positive effect on successful ageing in general (Rowe & Kahn, 1997). More specifically researchers have argued that social environment influences longevity among older adults (Eriksson et al., 1999), recovery after illness or injury, and reduced risk of ADL-disability (Glass & Maddox, 1992; Palmer & Glass, 2003; Mendes-de Leon, 1999). It is also apparent that the social environment can reduce the risk of functional decline and disability among older adults in general (Lund, Avlund, Modvig, Due, & Holstein, 2004; Mendes de Leon et al., 1999; Mendes de Leon, Glass, & Berkman, 2003). Emotional support from spouse and children and other family has been shown to have a positive influence on participation in older adults (Glass & Maddox, 1992; Levasseur, Desrosiers, & Noreau, 2004a; Palmer &

Glass, 2003). On the other hand, findings indicate that attitudes from people outside the family are a barrier to participation like Liebig and Sheets (1998), who found that neither older adults themselves nor others expect them to participate.

Several researchers have also shown that encounters with healthcare services may be experienced as environmental barriers to participation because service recipients are given less user involvement and control over their own lives and occupation (Haak, Fänge, Iwarsson, & Dahlin Ivanoff, 2007; Johannesen, Petersen, & Avlund, 2004). The organisation of services can also prevent older adults with disabilities from getting access to relevant services. For example, OTs may be a barrier for clients to get access to assistive devices (Jedeloo, de Witte, Linssen, & Schrijvers, 2002). Several studies also show that staff can have a negative attitude to older adults (Liebig & Sheets, 1998; Nemmers, 2004; Rybarczyk, Haut, Lacey, Fogg, & Nicholas, 2001), and this may prevent older adults from getting the same access to services as younger people. However, older adults receiving home-based rehabilitation regard staff both as friends and professionals (Boutin-Lester & Gibson, 2002). A friend was described as a person they enjoyed a positive relationship with, and a professional as someone who encouraged them, had professional competence and was helpful (Boutin-Lester & Gibson, 2002). Some studies also show that older clients can see and acknowledge that staff are tired and stressed, and therefore try not to bother them (McWilliams, 2001). However, no studies have been found that specifically investigated the influence of staff and societal factors on older adults receiving home-based rehabilitation.

To sum up, several studies document how environmental factors influence the opportunities of older adults in general to master task and attain social participation. However, there is little knowledge about how environmental conditions influence the opportunity for participation for older adults who have received or are receiving rehabilitation services. If rehabilitation services, including OT, are to enable older adults to participate in occupation after illness, more knowledge about environmental influence are needed. To my knowledge, there is no research examining physical, social and societal environments in one study, which is essential in order to understand how various environmental conditions together influence participation in occupation. Research shows that illness alone cannot explain why older adults do not have the same opportunity as before for participation in occupation. Therefore two of the studies in this thesis will throw light on how older people who have had, or are having, home-based rehabilitation, experience such environmental conditions influencing the opportunity for

participation. Furthermore, the literature review documented that participation can be understood from different perspectives; consequently the thesis also seeks to examine how participation in occupation is experienced by older adults receiving home-based rehabilitation.

RESEARCH AIM

The main aim of this research was to enhance the occupational therapy knowledge base concerning how older adults with a disability experience participation in occupation during and after home-based rehabilitation with a special focus on the perceived influence of environment.

The specific research aims were:

- to illuminate how the environment, in terms of physical, social and attitudinal aspects, may influence the participation of elderly people with reduced functional ability after an acute illness or accident.
- to identify how older adults with disabilities perceive the influence of environmental factors on their opportunities to participate after receiving home-based rehabilitation services; and to investigate if there are any differences between the perceptions of the respondents in terms of gender, age and ADL function.
- to explore how older adults with a disability participate and engage in occupations subsequent to hospitalisation during the period when they are receiving rehabilitation services.
- to explore and describe how older adults who are receiving home-based rehabilitation perceive the staff during a period of six months when they receive rehabilitation. Specifically the study focuses on how the participants collaborate with and make use of the staff's services.

METHODS

The four studies illustrate various aspects of how older adults experience participation in occupation in their daily lives. The two initial studies explored how older adults, who were, or had been, undergoing rehabilitation, experienced the influence of environmental conditions on their opportunities for participation. This was investigated both through qualitative (study I) and quantitative (study II) methods. Study III explored how participation in occupation was experienced during the period the participants received home-based rehabilitation. Study I and III showed that the staff and the healthcare system were environmental factors which influenced participation in occupation. Consequently, study IV explored how the participants perceived the staff during the period when they received rehabilitation in their homes.

Table 1 Overview of studies I-IV; participants, data collection methods and analysis methods

	Participants	Data collection methods	Data analysis methods
Study I	<i>n</i> = 14 Older adults who had received rehabilitation services 2 years prior to the interview, in one social and welfare district	Focus group interviews (three groups). Four interviews for each group	Constant comparative analysis based on Grounded Theory (GT)
Study II	<i>n</i> = 91 Older adults who were living at home and who had been referred to rehabilitation	Assessments: MQE*, Sunnaas ADL Index, FAI	Descriptive statistical analysis
Study III and IV	<i>n</i> = 3 Older adults in one social and welfare district who were referred to home-based rehabilitation prior to discharge from hospital	Open in-depth interviews. Total of 28 interviews over 6 months	Constant comparative analysis based on Grounded Theory (GT)

* MQE - Measure of the Quality of the Environments (Boschen, Noreau, & Fougeryollas, 1998; Fougeryollas, Noreau, St. Michel, & Boschen, 1998).
Sunnaas ADL Index (Bathen & Vardeberg, 2001).
FAI - Frenchay Activity Index (Holbrook & Skilbeck, 1983).

Selection of participants

In all four studies the participants were older adults over 65 years of age. Usually, rehabilitation studies focus on specific diagnoses or disabilities. However, since the focus in the thesis was on different aspects of participation rather than on specific diagnoses or diseases, the inclusion criterion for all studies were older adults with a disability who had had an acute illness or accident that had led to referral to rehabilitation services from the local authority.

Data collection took place from 2001 to 2005. All studies were conducted in the same municipality in Norway. Study I, III and IV included participants who were referred to rehabilitation from the same social and welfare district. Study II included all older adults in the municipality who were referred to rehabilitation services from the local authority after an acute illness or accident between January 1st. 2001 and September 1st. 2002. The selection of participants was guided by different sampling procedures as presented in the next pages. An overview of the characteristics of the participants is given in table 2.

Study I

In study I the focus group participants were selected through purposeful sampling (Patton, 2002) among older adults who had received rehabilitation services up to two years prior to the start of the study. The study sampling method was designed to yield participants with variety in age, gender and time experienced with a disability. Variability in participants was assumed to give richer data and capture the participants' various experiences in interaction with the environments (Patton, 2002; Strauss & Corbin, 1998). The rehabilitation team in the local social and welfare district identified potential participants, and those who consented to participate were included. Older adults with aphasia and memory deficits that would have had an influence on communication in a focus group were not included. In the literature a group size of 5-12 persons is recommended (Burrows & Kendall, 1997; Dahlin Ivanoff & Hultberg, 2006; Morgan, 1998). However, since small groups are found to be more dynamic (Dahlin Ivanoff & Hultberg, 2006), the group size was planned to be between 4 – 6 participants. The five participants in the first focus group had received rehabilitation services at a day-care centre, and had lived with their disability between one and five years prior to the start of the study. The second focus group consisted of four participants who had received home-based rehabilitation during the two-year period running up to the start of the study. In the third group, five persons who were receiving home-based rehabilitation and who had had an illness or accident two to four months prior to the study start, participated.

Study II

Study II was designed to include all older adults over 65 years of age in the municipality who had been admitted to home-based rehabilitation after an acute illness or accident between January 1st 2001 and September 1st 2002. Two hundred and three persons were identified as the potential study population from the official register in the municipality. Among these, 12

had moved to institutions and were excluded from the study, and 8 were deceased. A letter of invitation was sent to the remaining 183 persons, informing them that a healthcare office representative would call them within a few days to make an appointment for an interview with the researcher (KV) or a research assistant. Of these 183 persons, 17 could not be reached and 75 declined to participate for different reasons (e.g. did not have time, had not read the letter; or most of them declined when the office representative who phoned them was a male). The final study group included 91 persons, which represented a response rate of 50 %. Non-significant differences were found among the respondent and no-respondent groups in terms of age ($p = 0.067$) and gender ($p = 0.053$). However, the reasons for admission to rehabilitation differed between the groups. The group of persons who declined to participate had a higher prevalence of fractures (30.7%) and a lower prevalence of stroke (18.7%) than the respondent group (fractures 22.0%, stroke 51.6%). Data about the rehabilitation needs related to reduced function in activity or participation in the group that declined to participate was not available, consequently the data do not give information about whether the rehabilitation needs differed. However, since most declined to participate when a male telephoned to ask them, we assumed that the difference was random.

Studies III and IV

Three older adults over 65 years of age who had been referred to home-based rehabilitation during their stay in hospital participated in study III and IV. The sampling procedure was guided by the aim of attaining a variety of experiences among the participants (Patton 2002; Strauss and Corbin 1998) with the goal of recruiting 3-6 participants who were diverse in terms of age, gender, living conditions, and the type of illness that had resulted in hospitalisation. Participants with memory deficits or impaired language impacting on their communications skills were not included. Based on these criteria, the rehabilitation team identified potential participants. Eligible individuals who consented to participate were included, one participant at a time.

The first participant to be included was Mr. Hansen, a 72 year old male living in a flat with his wife. He was referred to home-based rehabilitation after a stroke three weeks earlier. He had children and grand-children and his main interest was staying at his summer house with his family. The second participant to be included was Mrs. Jensen, an 82 year old widow who lived alone in a sheltered accommodation complex. She had undergone surgery for spinal stenosis after sustaining a compression fracture, and had been admitted to several

rehabilitation hospitals within a period of eight months before discharge. Her stated main interests were her home and family. She had a number of grandchildren and great-grandchildren. Mr. Nilsson was the last participant to be included. He was 86 years old, divorced and living on his own in a sheltered flat rented from the local authority. Mr. Nilsson had been admitted to hospital for two weeks due to a compression fracture. In addition he had lung cancer, and a medical history of confusion and falls associated with drug side-effects. Mr. Nilsson had family living nearby, and was engaged with them. Since the rehabilitation period lasted for approximately six months for each participant, the data-gathering comprised 28 interviews with each person. This was considered to be rich enough data for the analysis, and no further participants were included.

Table 2. Characteristics of the participants

	Study I	Study II	Study III and IV
Participants	<i>n</i> = 14	<i>n</i> = 91	<i>n</i> = 3
Age, years			
Mean	77.3	78.8	80.6
Range	68-89	65-94	72-86
Gender (<i>n</i>)			
Men	8	38	2
Women	6	53	1
Living with (<i>n</i>)			
Alone	7	47	2
Spouse/family	7	53	1
Housing (<i>n</i>)			
Apartment	7	44	3
Villa/farm	7	47	
Formal help in addition to rehab.			
Home-help	4	13	
Home nurse		21	1
Home-help and nurse	8	28	2
none	2	29	

Data collection methods

In order to achieve the most comprehensive knowledge about older adults' experiences of participation in occupation in their environments, several methods were required.

Triangulation of methods is one way of gaining the widest knowledge of a topic (Patton, 2002). The aims of studies I, III and IV were to explore and illuminate the experience of the participants. As insight into other people's experiences cannot be achieved without access to

their subjective experiences (Dahlberg, Drew, & Nyström, 2001), qualitative interviews methods were required to capture the participants' experiences. In contrast, the aim of study II was to identify environmental factors that were perceived as barriers or facilitators for participation. This aim required a questionnaire for data collection.

Focus group interviews (study I)

Focus group interviews were chosen in study I because this method gives the opportunity to explore the participants' views, how they see the world when they discuss the topic with others in the target group (Dahlin Ivanoff & Hultberg, 2006; Krueger, 1998b). The purpose of focus groups is to encourage discussion among the participants in order for a topic to be explored from several different angles. The purpose is not to arrive at a consensus about a topic in the group, but to encourage participants to develop their reasoning and share their experiences (Burrows & Kendall, 1997; Dahlin Ivanoff & Hultberg, 2006; Krueger, 1998b). Four interviews were conducted with each of the three focus groups in study I. The interview guide was developed in order to cover as many environmental aspects as possible, and was based on the structure of environmental factors as described in the ICF (WHO 2001). The interviews were focused on the physical environment in the first interview, the social environment and attitudes in the second interview, and services from health and social services as well as societal environments in the third interview. The fourth focus group interview, which was held approximately 10 weeks after the third interview, dealt with categories of findings that were not yet saturated (Strauss & Corbin, 1998). A preliminary analysis was carried out after each interview, and preliminary assumptions and hypotheses were brought back to each group for further discussion (Krueger, 1998a; Strauss & Corbin, 1998). Topics which had not been fully illustrated in previous interviews, as well as preliminary findings, were at that time discussed with the participants, and experiences from one group were brought up in discussion with the next group.

The focus group interviews were conducted in local authority venues. The first focus group met at a rehabilitation centre which was familiar to all participants. The second and third focus group met at a community centre. Each focus group interview lasted approximately two hours, including refreshments and was moderated by the author (KV) together with an assistant as recommended (Dahlin Ivanoff & Hultberg, 2006; Krueger, 1998b). The

discussions were tape recorded and lasted approximately one hour. All 12 interviews were transcribed by the author (KV), and contained approximately 150 pages of text.

Qualitative interviews (studies III and IV)

In studies III and IV, the aim was to explore the participants' experiences of participation in occupation and encounters with staff while they were receiving home-based rehabilitation after hospitalisation. The studies thus had a case-oriented design in order to gain rich, detailed and varied information about the participants' experiences in their daily lives (Yin, 2003). This case-oriented design allowed the researcher to be on-site and closely follow each participant throughout the whole period when they received home-based rehabilitation. The interviews were conducted every second or third week during a period of about six months. In qualitative interviews, knowledge is constructed in the meeting between participant and interviewer (Kvale, 1998). The interview is planned as an interaction between two equal partners, and the content is developed during the interview (Kvale, 1998). In order to stimulate the participants to describe their experiences and provide reasoning around their descriptions, it was considered important to let them talk about their current daily lives as freely as possible. The interview guide contained questions like: "Please tell me about your everyday life at this moment", "Could you give me an example of what you do in the course of a normal day?", "In terms of the future, can you please tell me how you view your daily life?", "What happens when the staff arrive?". An interview guide was prepared for each interview. The interview guide was designed to follow up on topics and themes from previous interviews. Since the focus was on participation in occupation in everyday life, the interviews were conducted in the participants' homes. Interviews were conducted at a time that was convenient for the participant. At the same time, an attempt was made to conduct interviews at different times of the day as well as week-ends, in order to capture the participants' experiences as fully as possible as they occurred. Field notes about housing and situations which occurred during each visit were produced after each interview, but only used as contextual information in the analysis. Similarly, medical records and reports from the staff who had provided services to the participants were used in order to obtain information about the reason for referral to rehabilitation services, rehabilitation goals and the services which were provided.

The author (KV) carried out all the interviews. Each interview lasted from 30 - 90 minutes. All the 28 interviews were tape recorded and transcribed, making a total of approximately 300 pages of text.

Assessments

All assessments were conducted as self-report questionnaires.

Measure of the Quality of the Environment (MQE) (Study II)

In study II, facilitators and barriers in the environments were identified by using the standardised Measurement of the Quality of the Environment (MQE) (Boschen et al., 1998; Fougeyrollas et al., 1998). The MQE (version 2.0) was chosen because the measurement was designed to identify facilitators and barriers in the environment in line with the ICF framework (WHO, 2001). The questionnaire consists of six categories: (1) Support and attitudes of family and friends, (2) income, job and income security, (3) governmental and public services, (4) physical environment and accessibility, (5) technology and equal opportunities, and (6) political orientation; all areas that are included within environmental factors in the ICF. In the MQE the respondents are asked to determine on a 7-point scale if each of the 110 items is a “facilitator” (scores from +1 to +3), a “barrier” (-1 to -3) or a non-influence (option 0), they are also provided with “don’t know” and “not applicable” options (Boschen et al., 1998; Fougeyrollas et al., 1998). According to Boschen, et al. (1998), psychometric testing has provided encouraging results in a test-retest study. For study II the English version of the MQE was translated into Norwegian by the first author in collaboration with a bilingual researcher (Norwegian-English) and a researcher who was familiar with both the French and English version of MQE. A third person (bilingual Norwegian-French) compared the Norwegian translation with the French version in order to check if the meaning of the content remained. Two pilot studies were first carried out. The results of the pilot studies showed that the 7-point scale and the original layout of the MQE version 2.0 were too complex for the participants in this study. Additionally some of the items were not applicable for older adults. The scale was therefore reduced to a 5-point scale (ranging from + 2 to -2) and items that were not applicable for older adults, such as kindergartens and schools, were omitted. These changes were discussed with and accepted by the creators of MQE (personal communication, Fougeyrollas and Noreau, winter 2002).

All participants were interviewed in their homes by either the researcher (KV) or a research assistant. At the end of each interview, the questionnaires were checked to avoid internal drop-outs. Each interview lasted approximately one hour. The two interviewers (KV and assistant) met regularly in order to discuss anything that was not clear, e.g. the use of the measurement.

Assessments for all studies

Assessment of performance of ADL

The Sunnaas-ADL Index has been developed to assess the patients' need for assistance in daily life activities in order to be able to live independently (Bathen & Vardeberg, 2001). The Index is made up of 12 hierarchically classified activities, representing three main groups according to how often a person needs help in the given activities. The level of dependence/independence is scored from 0 to 3, with 0 as the lowest possible score (dependence) and 3 as the highest (independence). A total score ranges from 0 to 36, with 36 as the maximum. A test-retest reliability study of the Sunnaas ADL Index confirmed good repeatability for clients in rehabilitation (Bathen & Vardeberg, 2001). Despite the fact that the Sunnaas ADL Index was originally developed to assess the need for assistance based on staff scores, the index was chosen for the studies because it is easy to understand and administer as a self-report questionnaire. The Sunnaas ADL-Index thus provided information of the participants' perceived level of dependence/independence in primary ADL.

Assessment of participation in occupation

The Frenchey Activities Index (FAI) was developed to assess participation in social activities following stroke (Holbrook & Skilbeck, 1983; Piercy, Carter, Mant, & Wade, 2000; Turnbull et al., 2000). It comprises 15 items related to participation in common activities, such as preparing meals, shopping, gardening, social events, car outings etc. Each item is scored on a four-point scale (0 to 3), and the scores are aggregated, giving a value between 0 (inactive) and 45 (active). Ten of the fifteen items refer to everyday activities which the subjects have engaged in during the past three months. The remaining five items refer to more seasonal activities carried out over the previous six months. The instrument has been developed to be administered by an interviewer. For the four studies in this thesis, the FAI was used to obtain information about the participants' own assessment of how active/inactive they had been in recent months.

Socio-demographic data

Socio-demographic data (e.g. age, living conditions, formal help and services) were collected using a questionnaire developed for use in the studies.

Data analyses methods

Constant comparative method – Grounded theory (GT) approach (studies I, III and IV)

Following the recommendations in the GT approach, data analysis is an ongoing process, carried out as a constant comparative analysis from the preliminary analyses during the interviews and continuing until the articles were finished (Charmaz, 2006; Strauss & Corbin, 1998). When all the interviews had been completed, the analysis continued with line-by-line coding of all data. Each line was coded for content by asking questions in relation to the text, e.g. “What does this say?”, “What does it describe?” according to its relevance to the aim of each study. In study I, the codes were described in in-vivo codes as related to environment (e.g. the home, in shops), participation in occupation (e.g. hobbies, social activities) and conditions or consequences (e.g. feeling lazy or tired). Examples of codes in study III were “engaging in daily life”, “to take control again”, “wishes for the future”; and in study IV, “former and present experience with the staff”, “tasks carried out by the staff” and “participants’ view of the staff”. The codes were continually compared with the empirical data (Charmaz, 2006; Strauss & Corbin, 1998). Codes which were related to each other were grouped into categories such as “encountering private and formal help” (study I), “continuing to be an agent in daily life” (study III) and “differences and variation in perception of the staff” (study IV). In order to study the relationship between the categories, the next step was axial coding (Charmaz, 2006; Strauss & Corbin, 1998). Several possible ways to describe the relationships were attempted in each study in order to develop a core-category which embraced all the categories. In study I, the core category “environmental pressure towards withdrawing from participation” emerged as the category that most truly embraced the participants’ experience. In study III the two categories “continuing to be an agent in daily life”, and “leaving the agency to daily life” came to the fore as categories that could shed light upon the participants’ experience of participation. As for study IV, the four categories “differences and variations in perception of the staff”, “experiences and encounters with the

staff”, “expectations for the future daily life” and “participants’ needs and task related to their disability” together created pattern of categories that embraced how the participants perceived and made use of the staff’s services.

Descriptive statistical analysis

As all the assessments (MQE, Sunnaas-ADL and FAI) gave ordinal data, the use of non-parametric tests for data analysis was chosen (Merbitz, Morris, & Grip, 1989; Svensson, 2001) (study II) even though sum scores and parametric tests have been used in other studies with the same assessments (Levasseur, Desrosiers, & Noreau, 2004b; von Koch, 2000). Fisher exact chi-square test (Altman, 1999) was chosen for comparisons between the informants’ demographic data, environmental factors and ADL and FAI scores. However, a T-test was conducted to identify age-related differences between the respondents and non-respondents groups (Altman, 1999). More specifically, each item in MQE was analysed by reducing it to a 4-point scale: facilitators, barriers, no influences and does not apply. Furthermore, a cut-off point was set to each item at 50 % to be considered a facilitator, a barrier, having no influence or did not apply for participation. SPSS.11 was used for all analyses.

ETHICAL CONSIDERATIONS

Studies I and II were approved by the Regional Medical Ethical Committee of Mid-Norway. Studies III and IV were approved both by the Ethical Committee at the Karolinska Institutet and by the Regional Medical Ethical Committee of Mid-Norway. Furthermore all studies were approved by the Norwegian Social Science Data Service (NSD)

All potential participants were asked by staff employed by the municipality whether they wanted to take part in the research. They were given written information about the study. To prevent the participants from being inappropriately persuaded to participate, they were not contacted by the researcher (KV) until they had signed the informed consent form as recommended by NSD.

Data collection in studies II - IV was conducted in the participants' homes, and interviews were individually arranged, at a time that was convenient to participants. In all encounters with the participants it was emphasised that they could withdraw from the study at any time. When data collection is carried out during an extended period as in studies III and IV, there is a danger that participants may experience the contact with the interviewer in their homes as bothersome. In this kind of study, an ethical dilemma may rise from the importance of maintaining the integrity of the participants while also gaining access to their experience. During the 6 months interview period in studies III-IV, the researcher therefore repeatedly stated that the participants had the right to withdraw from the project. Furthermore, the researcher consistently listened to the participants' wishes and needs associated with the interview process (Dahlberg et al., 2001; Patton, 2002). Another dilemma associated with qualitative studies that occur over time, is that participants can become too close to the interviewer. It was therefore considered important to finish the contact between the interviewer and the participants over a period of time, and a follow-up interview was planned approximately six months after the end of the rehabilitation period, when the main part of the data collection had come to an end. The follow-up interview gave the participants the opportunity to reflect and give feedback to the interviewer about their experiences afterwards. One of the participants in studies III and IV wanted to continue the contact with the interviewer after the rehabilitation team had finished their intervention. This coincided with the participant's physical deterioration from cancer. For ethical reasons, and given the wish of

the participant to maintain contact, the researcher decided to keep in touch with this participant for an additional two months. These visits were social in nature and no data were collected during that 2-month period.

When the interviewer is also a healthcare professional, e.g. an OT as in these projects, the interviewer may identify health-related services among participants which have not been adequately addressed by staff in the local authority. Alternatively, the participants may ask the interviewer to establish contact with other staff to address various health-related needs. Both of these situations occurred during that data collecting period in study I and II. In each case, the interviewer asked the participant if he or she wanted the researcher to initiate follow-up by the local authority, and this was done at the participant's request.

FINDINGS

In **study I** the main finding was that the participants perceived an environmental pressure to concentrate their effort and energy on self-care task, rather than participating in occupations of interest. This pressure showed in their encounters with different environments; as encounters with “people and society”, “private and formal help”, and “occupation”. In the encounters with people and society, the participants perceived a pressure to be satisfied when they could manage on their own without being a burden to the family and society. The participants felt they were better off than many other older adults, and experienced meeting nice and helpful people. However, they still felt a pressure because they were under the impression that older adults were viewed as too expensive on society’s resources. Consequently, the participants felt they could not complain, but had to be satisfied. In encounters with private assistance, participants reported experiencing mutual collaboration that facilitated participation. In contrast, participants described encounters with formal assistance as time-consuming and exhausting, with a bureaucracy that imposed additional hurdles to overcome in order to get access to relevant service. Furthermore, the participants had to adapt to regulations set by the healthcare system that relinquished their participation in decision-making. Finally, the encounters with occupation per se could sometimes be experienced as too demanding. Consequently, participation in daily life could be experienced as a series of exhausting, disruptive processes involving a number of hurdles. Taken together, this was perceived as environmental pressure to concentrate on the most necessary daily tasks.

Study II focused on environmental factors which were perceived by the participants as barriers or facilitators for participation. Results showed that support from family was perceived as positive by 83.5% of the informants. In addition, 82.2% saw the healthcare system as a positive environmental factor, while 84.6% felt that assistive devices were a positive factor. The media was regarded as a positive environmental factor by more than ¾ of the informants; 83.5% scored TV, 79.3% the telephone and 69.2% the radio positively for their participation in occupation. Surprising findings showed that environmental factors like accessibility to buses, trains and planes or to cultural arenas like theatres, cinemas and restaurants were not regarded as barriers to participation. Only outdoor accessibility, particularly in winter, was scored as negative by 57.1% of the participants. Lack of time to carry out daily tasks (by 52.7%) and lifting heavy objects (by 63.7%) were regarded as

having a negative influence on the opportunity for participation by more than half of the participants. In general, most of the items listed in the MQE were regarded as having no influence or not being applicable for participation in occupation. Some significant differences with regard to age, gender and ADL-function were found, for example a significant difference in the expectation of social support in the different age groups with the age group 85 - 94 ($p = 0.009$) perceiving social support as the most positive. Managing heavy objects ($p = 0.010$) was seen as a bigger problem for women than for men. Gender differences were also shown in family situation ($p = 0.049$) and support from friends ($p = 0.033$), with these environmental factors being experienced as facilitators by more males than females.

The results from both studies I and II showed that social environment such as support from family and other people, as well as the physical environment like assistive devices and media, were generally perceived as facilitators for participation. Both studies showed that physical access to public buildings, theatres or public transport were not barriers to participation in these samples. Encounters with public services, however, showed contradictory findings. These were assessed as a positive factor in study II, but perceived as barriers in study I.

The main finding in **study III** was that among older adults receiving home-based rehabilitation, participation in occupation was experienced in two ways. On the one hand, participation in occupation was experienced as *agency* (i.e. striving to take control and make decisions on their own); on the other hand, as *engagement* in daily life and letting daily life become the agent (e.g. the participants' engagement in daily life directed their participation in occupation). Consequently, daily life in itself also became an agent.

In order to continue being an agent in daily life, the participants used several strategies, e.g. systematic skills training and requesting help from others to carry out tasks they were unable to manage themselves. Another strategy was to struggle against the healthcare services, and the illness they had contracted. A third strategy was to wait for things to return to normal. The participants alternated their use of the various strategies to maintain agency and engaging in their daily lives in the as usual. Engagement in daily life meant managing the daily rhythm of housework, listening to radio and television, and engaging in family and social arrangements. Engaging in daily life could also be seen as focusing on exercise and interventions from the rehabilitation service, while putting ordinary daily life on standby. Consequently, the findings of this study identified participation as a dynamic engagement ranging from individual agency

including decision-making, choosing and acting in daily life, to letting the on-going daily life be an agent, implying a more social character of participation.

The findings in **study IV** identified five different ways of perceiving staff and making use of their services: as persons to make small talk with, as discussions partners, as advisors or instructors, as teachers and finally as people who carry out tasks efficiently. Each of these sub-categories had several aspects. Small talk, for example, implied the exchange of polite phrases in conversation about the news of the day. Staff were seen as discussion partners in practical situations related e.g. exercises and assistive devices, where the participants made the decisions. The staff's competence as advisors and instructors was used in order to gain knowledge about illness. The staff were perceived as teachers when they created specific educational programmes for training, but also as experts who were responsible for the training. It also emerged that the participants occasionally needed staff to just come in and do an effective job without involving the participants every time. In order for this to be efficient, a precondition was that staff and participants discussed and agreed in advance how the relevant tasks should be performed.

Three conditions influenced how the participants perceived the staff: the participants' experiences and encounters with the staff, their expectations for the future daily life, and their needs and tasks related to their disability. The latter proved to be the condition which had the greatest influence on the participants' perception of the staff and the way they used their services. Requirements for assistance varied throughout the rehabilitation period. As the participants contracted new illnesses there was a constant need for them to ask the staff for advice, or to use them as instructors in order to start, for example, using a new assistive device or learn new skills. On the other hand, the use of staff as teachers declined in the course of the rehabilitation period, as the participants themselves learned over a period of time to perform the tasks, or the tasks were taken on by others.

GENERAL DISCUSSION

The aim of this thesis was to enhance the knowledge base within OT concerning how older adults with a disability experience participation in occupation during and after home-based rehabilitation, with a special focus on the perceived influence of the environment.

The empirical findings in studies I, II, and III showed how the immediate physical environment was experienced as a facilitator for participation, while the physical environment in society was experienced as having little influence on participation in occupation. The findings further showed that the social environment, in particular the family and media, were the environmental factors which facilitated participation. Health services in general were experienced as obstacles to participation (I, III and IV); however encounters with individual staff were perceived as more positive, as the participants could make use of their services and competences in several ways (IV). In study III the findings revealed how participation in occupation was experienced in various ways, both as having agency in occupation and as letting engagement in daily life become an agent. The discussion will elaborate on these findings, including providing suggestions for clinical implications and further research.

The perceived influence of the physical environment

The findings revealed that the physical environment in society was seen by participants as having little influence on participation in occupation (studies I and II), while physical environment in the home and the local environment first and foremost was perceived as a positive environmental factor for participation. These findings were surprising, since researchers have argued that lack of access to public buildings, roads and public transport in society is an obstacle to participation for people with disabilities (Knøsen & Krokan, 2003; NOU, 2001; Shakespeare, 2006). Occupational therapy and environmental gerontology research has also emphasised that the physical environment may be an obstacle to daily life for older adults in general (Gitlin et al., 2001; Lilja, 2000; Wahl & Weisman, 2003). It was, however, quite clear from the findings in studies I and II, that the physical environment in society was not experienced as an obstacle to participation by these older adults with a disability after rehabilitation. The findings in this thesis may coincide with the fact that older adults living at home to a lesser degree participate in cultural activities, as reported by Nilsson et al. (2006). Furthermore, research on time spent outside the home in Norway indicates that

older adults are likely to spend more hours in their homes than on travelling and cultural events (Vaage, 2002). The findings still revealed that participants travelled, went to the theatre and ate in restaurants if they had someone to visit, or to go out with. Thus it was the social environment which was decisive in terms of participation in these occupations (studies I and III). Consequently, if the participants had someone to go out with or to visit, they would participate, despite barriers in the physical environment in society. These findings indicate that an accessible environment alone may not promote participation in occupation for older adults with disabilities, in the way that younger people with disabilities claim it does for them (Knøsen & Krokan, 2003; NOU, 2001; Shakespeare, 2006). Studies I and II further showed that the participants perceived getting practical assistance from people they met, in order to overcome inaccessible environments, as being showed respect as an older person (study I). These findings are in line with Beckley (2006), who reported that social environment and support moderate the effect of functional limitation for participation in society for older adults with disabilities. However, the findings contrast with the views of younger people with disabilities, who want to be independent from personal assistance as a compensation for the lack of physical accessibility (Knøsen & Krokan, 2003; NOU, 2001; Shakespeare, 2006). Consequently, to promote participation for older adults with a disability, both social environments must be taken into consideration in home-based rehabilitation.

However, the immediate environment was experienced as a facilitator for participation, and especially accessible housing and assistive devices were among the single factors that were perceived as positive by the participants in study II. These findings suggest that the participants had received rehabilitation interventions in the form of home modification and assistive devices (I-IV). The findings are in line with Lilja et al. (2003) who found that older adults receiving home-based rehabilitation are well equipped with assistive devices and accept the use of them, as they make daily life easier. In studies I, III and IV the participants felt that assistive devices made them more independent from assistance both from family and formal help (I and III). An association between assistive devices and independence for older adults living at home is also documented by Haak, Iwarsson & Sonn (2007) and Gosman-Hedström and Hägglom-Kronlöf (1999). These findings may be related to the fact that independence is commonly measured in occupational therapy research, and furthermore the findings in the thesis may be interpreted based on the knowledge that independence is an important value in the Western world (Cardol, de Jong, van den Bos, Beelen, & de Haan, 2002; Cott & Gignac, 1999). Older adults receiving home-based rehabilitation have a wish to be independent and

carry out occupations themselves without assistance, as found in study I. However, in the same study the findings showed that the participants perceived being dependent of assistance with overcoming inaccessible environments in public places as partly positive. This difference in the findings may be explained by receiving assistance out door being e.g. a supporting arm, or occasionally being carried into a train; whereas dependence on help at home implies assistance with daily tasks carried out on a daily basis. Furthermore, the findings (studies I and III) showed that independence in daily tasks at home was connected to having control over the tasks. The findings in studies I and III-IV suggested that the participants' wish to be independent and manage personal care, included both carrying out the task oneself and/or having control over how the task should be carried out by others. As shown in the Background section, having control over daily life is a prerequisite for participation (Clapton & Kendall, 2002), consequently immediate physical environmental factors such as assistive devices enabled independence and control over occupations. The participants' wish to be independent of personal assistance with the support of assistive devices can be seen as getting control over their daily lives (studies I and III), and thus promoting participation.

In summary, the findings (I and III) suggest that participation in occupation for older adults who are receiving home-based rehabilitation may be defined as having control over daily tasks in the home, and can be facilitated by the use of assistive devices. Further, the findings suggest that participation in occupation beyond the home and daily tasks, first and foremost is promoted by family and people they encounter giving personal assistance in order to overcome obstacles in the physical environment. Adaptation of the physical environment, both in the wider society (Heggem, 1999; Iwarsson & Ståhl, 2003) and on an individual level (Gitlin et.al 2001; Lilja 2000), forms a part of the work of OTs. Therefore, OTs must map out and put into effect interventions related to both physical and social environment. OTs should also pay more attention to how assistive devices can contribute to independence, both in terms of carrying out the task and maintaining control over occupations in daily life.

The perceived influence of family and media

Family and the media (e.g. television, radio, and newspapers) were among the single factors in the environment which a majority of the participants in study II perceived as facilitating participation in occupation. The significance of family for participation of older adults is in line with several studies, as shown in the Background section (Eriksson et al., 1999;

Levasseur et al., 2004a; Palmer & Glass, 2003). Researchers argue that there is solid evidence that the social environment reduces the risk of disability in older adults (Avlund, 2004; Palmer & Glass, 2003). These studies state the significance of social and emotional support from the family (Mendes de Leon et al., 2003; Palmer & Glass, 2003). The findings in the thesis are also in line with Satariano, Haight and Tager (2002), who show that also after adjustment for health and physical functioning, people with family participate more in leisure activities. However, the findings in studies I-III particularly point out three aspects of how family facilitates participation in occupation. The first aspect relates to participation understood as agency, showing how the families assisted with practical tasks in such a way that the participants felt they were in control themselves even if they were receiving help (study I). According to Bandura (1997; 2001), self-efficacy is an important prerequisite to maintaining agency. Bandura (1997) argues that self-efficacy is created and strengthened in interaction with the social environment by the individual believing in his or her ability to take part in occupation. The findings (studies I –III) reveal how the participants believed they could maintain control over daily life with help from the family, or travel or go to the theatre if they had someone to visit or to go out with.

The next two aspects related to participation as engagement in daily life. The participants' engagement in the family was manifested by e.g. regular visits, telephone calls and numerous birthday parties, which gave routines and structure, and in this way directed their daily life (studies I and III). Rowles (2000) has described daily life for older adults governed by set habits and routines in the environments as "the choreography of being in place". Similarly, for the participants in study III the ongoing daily life was seen as engagement in the family that directed, structured and in that way gave "choreography" as described by Rowles (2000). One last aspect was how contact with the family resulted in engagement in further occupations, like knitting for great grandchildren, cooking Sunday lunch for the family or taking one's daughter to a café (studies I and III). A larger study among older adults in Europe shows continued strong family ties between the generations, as well as a mutual exchange of services (Daatland & Herlofson, 2004). This study indicates that the relationship between generations is characterised by interdependency which may be one of the reasons why the participants in the present studies did not experience receiving assistance from the family as being dependent on help. Other research also reports that it is essential for people with disabilities to do something for or with other people, in order to experience participation (Borell et al., 2006; Nyman & Lund, 2007).

To summarise, the findings in study I-III show that family and family-oriented occupations are important environmental factors which stimulate participation in occupation for older adults receiving home-based rehabilitation. Both the rehabilitation services and OTs have traditionally focused on the individuals' with the disability, even though research has documented the importance of family and social environment. Findings from the thesis suggest the importance of developing interventions that address the clients' social environment, for example by facilitating occupations in the family that are important for the client.

Environmental factors such as newspapers, radio, television, and telephone were also perceived as facilitating participation by older adults who had received home-based rehabilitation (study II). Several studies have described how older adults living at home spend a lot of time watching TV and listening to the radio (Horgas et al., 1998; Statistikkbanken, 2007) and the media has been listed as a leisure activity (Kronlöf & Sonn, 2005; Nilsson et al., 2006). Therefore, it is hardly surprising that media was perceived as an environmental factor which facilitated participation. However, the findings in this thesis expand the understanding of why media may be important for participation for older adults. One aspect in studies I and III revealed how the morning paper, news broadcasts and television series created structures and routines in daily life. Routines are known to give structure to daily life and make it predictable (Christiansen & Baum 2005; Kielhofner 2008). Set routines in familiar surroundings are important for older people in their daily life (Rowles, 2000). Christiansen and Baum (2005) and Kielhofner (2008) claim that structure and routines are important prerequisites for participation, as they free time for other occupations. The empirical findings in the thesis indicate that the media, similarly to contact with the family, create structure and routines in daily life.

The other aspect was how the programmes themselves, whether news, sports programmes or a favourite series, created such strong immediate engagement that the participants forgot both time and place (studies I and III). This engagement was so strong that for example one participant explicitly did not wish to die until a particular television series was finished or a sport broadcast was over (study III). Such engagement may be explained by the fact that the participants in the study were older adults with disabilities who had less opportunity to go out than other older adults, the media thus taking on a more significant role in their lives. Kronlöf

and Sonn (2005) suggest that being at home and using the media to keep up can give a feeling of control over occupation and the environment. However, as shown in the Background section, the media is also an important factor for older adults in general (Horgas et al., 1998; Statistikkbanken 2007). Consequently the finding may just indicate that older adults receiving home-based rehabilitation have the same interest as older adults in keeping abreast of the media.

A third aspect was how the media stimulated the study participants to discuss with others what they had seen, heard or read, for example in a telephone call to a grandchild to discuss a children's TV-programme or conversations with neighbours and friends about the latest sports events (studies I and III). Findings in studies I, III and IV further revealed that older adults who received home-based rehabilitation wished to have the opportunity to discuss daily news with the staff, and use the staff as "small talk persons" in such conversations (study IV). In literature on ageing as well as in occupational therapy, watching television and listening to the radio are characterised as passive activities (Herzog, Franks, Markus, & Holmberg, 1998; Nilsson et al., 2006). However, the studies (I and III-IV) show how using the media to keep abreast has a wider meaning than just spending time watching television or listening to the radio per se. The findings in the thesis show that using the media influences conversation with other people. Moreover, a shared interest in the media can give the experience of participation as belonging; and the wish of the participants to discuss news and current affairs with others may be an indication of continued participation in the public debate and of getting involved, as discussed by Kronlöf and Sonn (2005). It thus follows that the media is an important environmental factor for participation among older adults receiving home-based rehabilitation, and one that goes beyond passively watching or listening.

These empirical findings have some clinical implications that pertain to media use among older adults. Firstly, OTs working with older adults who are receiving home-based rehabilitation should carefully consider clients' utilisation of media (e.g. television, newspapers and radio) as important occupations, and assess the need for physical adaptation to enable their use of the television, radio or telephone. Secondly, OTs should be aware of individual wishes for small talk with staff about the news of the day as reported in the newspapers and on television. As the media is an occupation which older adults spend a lot of time on, it appears necessary to further research its significance in general for older adults.

The perceived influence of services and attitudes

The findings in studies I-IV showed that the participants perceived face-to-face encounters with individuals (e.g. staff and people they met outdoors) and encounters with services and attitudes i.e. societal environments, in different ways. All four studies revealed how encounters with individual staff members in general were perceived as a positive factor for participation in occupation. Study IV particularly explored encounters with staff. The findings showed how the participants throughout the whole rehabilitation period made use of the staff's competence as e.g. teachers, advisors and instructors in order to master or re-learn skills they needed in order to participate in occupation in the way they wanted. Other studies (Boutin-Lester & Gibson, 2001; McKinnon, 2000) show that staff in home-based rehabilitation are often perceived as experts. However, the empirical findings in study IV showed that the participants alternated their use of services provided by the staff. For example they made active use of the staff's specialist knowledge as teachers, instructors, advisors and discussion partners based on their individual ever-changing requirements during the period when they received home-based rehabilitation. Rehabilitation literature emphasises user involvement as a prerequisite for collaboration between staff and client (Bredland et al., 2002; Wade, 2002). The findings in study IV expand on what user involvement may imply; older adults who receive home-based rehabilitation have a need for different forms of collaboration in their encounters with staff. Furthermore, the participants in all four studies experienced the staff's competence and the assistance they were given as important and necessary in order to be able to participate as before.

However, it was apparent that the organisation of services could be perceived as a barrier to participation (studies I and III). This was particularly apparent when participants received formal help, and thereby often lost the opportunity of having agency over daily life. One reason for this finding may be that the services were provided in people's own homes and in their private sphere. Older adults receiving home-based rehabilitation have to relate to a number of staff whose place of work is the participants' homes (Lindquist & Tamm, 1999). Because participants sometimes perceived encounters with the healthcare system as detrimental to their own decision-making about daily life, partly causing them to struggle to maintain agency in daily life (I and III), services were experienced as an obstacle to participation. The findings in studies I and III are consistent with findings in other studies among older adults receiving home-based services (Haak et al., 2007; Johannesen et al.,

2004). In a group of frail older adults living at home, Johansen and Avlund (2004) found that the participants were satisfied with daily life as long as they could manage on their own without formal help. A study by Lilja et al. (2003) shows that some older adults actually did not want home-based rehabilitation because they did not want to be disturbed in their daily life by having staff coming into their homes, and were afraid of losing control. The findings in studies I, III and IV also revealed that receiving formal help might disrupt the possibility of organising daily life according to one's own habits and routines, which has been found important for older adults in general (Rowles 2000), as well as for the participants the study I and III.

The double-edged nature of encounters with individual staff and the system was also perceived in the participants' encounters with occupational therapy interventions for example related to assistive devices. Consistent with several other studies (Gosman-Hedström et al., 2002; McMillen & Söderberg, 2002), the studies (I, II and III) revealed that participants depended on the competence and assistance of OTs in order to get assistive devices (I and III-IV). This was perceived as a dependency on the OTs' organisation of their distribution of assistive devices. The findings revealed how access to assistive devices might imply long periods of waiting. Such periods of waiting can be experienced as an exhausting struggle with bureaucracy and a waste of energy which otherwise might have been spent on engagement in chosen occupations (study I). The goal of OT intervention is enabling participation in occupation (Borg et al., 2007; Law, 2002), nevertheless, the findings indicate that OTs may be an obstacle to participation because they are part of the healthcare service system. One clinical implication of the findings is that it is important for OTs to be aware of how the clients wish to utilise their competence, and to enable individual strategies for clients to keep their own routines and management of daily life. There is a need for additional research to explore how the OTs, as part of the system, can avoid being an obstacle to participation in occupation.

Also, in encounters with attitudes as an environmental factor, a difference in encounters with attitudes from individuals (immediate social environment) and attitudes in society (societal environments) was revealed (studies I–II). As previously described, encounters with individuals, both familiar people and strangers, were perceived as pleasant and helpful. This was experienced as positive attitudes facilitating participation for older adults. However, encounters with individuals contrasted with attitudes in society more generally. The findings

in study I indicate that the participants experienced attitudes among politicians and in the media as older adults being regarded as too expensive for society. This was perceived by the participants as a constraint to participation in occupation, because of a feeling that one ought to be satisfied as long as one could take care of oneself. Similarly, in a study among older adults living at home in Sweden (Nilsson, Ekman, & Sarvimäki, 1998), found that attitudes in society and among politicians were experienced as negative. Other researchers have argued that there may be a negative age bias towards older adults both among older people themselves, among staff, and in society in general (Nemmers, 2004; Rybarczyk et al., 2001). The findings in studies I, III and IV nevertheless did not uncover any negative attitudes to older adults among staff, as reported by Rybarczyk (2001). It is still conceivable that the staff's focus on mastering personal care as perceived by the participants (study I and IV), indirectly may signal a lack of expectation that older adults receiving home-based rehabilitation should participate beyond mastering occupation in the home.

The findings in relation to the concept of environment

As described in the Background section, there are a number of theoretical frameworks that offer different perspectives on the influence of the environment. In this thesis, the ICF was chosen as a framework for the exploration of the relationship between environments and participation. The ICF was selected because it addresses both a medical and a social model for the understanding of functioning and disability (WHO, 2001). Additionally, the ICF provides a framework for the description of barriers and facilitators in the environment. Despite its strengths, the limitations of the ICF must be considered in the context of this thesis. Hemmingsson and Jonsson (2005) raised the issue that people with disabilities may experience the same environmental factor as both a barrier and a facilitator, and thus the ICF may simplify the understanding of the interaction between the individual and environment. The findings in studies I, III and IV are in line with the Hemmingsson & Jonsson argument; for example the staff were perceived as an environmental factor facilitating participation, whereas actually receiving services could be experienced as an obstacle to participation (studies I-IV). There are, however, arguments in favour of using a perspective on environment as barrier/facilitator to explore the relation between functioning and disability. In both empirical and theoretical literature (Knipscheer, 2000; Wade & Halligan, 2004) there is a tendency to regard disability as an individual problem related to reduced bodily function in a medical model. Thus, a perspective on environment which focuses on barriers and facilitators may be

appropriate, both theoretically and clinically, in order to offer alternative explanations of how to understand disability and how to promote participation in occupation.

Bricout & Gray (2004) say that like everyone else, people with disabilities live in a type of dialogue with the environment as an on-going process. It may not be possible to capture reality in one model. Daily life for older adults living at home is complex, and several conditions may influence each individual's opportunity for participation. In order to understand this complexity there is a need for several models. Findings from this thesis suggest that to gain an understanding of environmental influences on participation in occupation, several models may be needed. Along these lines it is interesting to note that neither the ICF nor the disability model (Oliver 1996; Shakespeare 2006) consider occupational form (Kielhofner, 2008) as a condition external to the individual which may be a hindrance for participation. However, findings in study I suggest that occupation in itself is a factor external to the individual which influences the opportunity for participation. When the participants experienced an occupation also creating barriers to participation, it may be understood as "occupational form as conventionalised sequences of action that are at once coherent, oriented to a purpose, sustained in collective knowledge, culturally recognisable, and named" (Kielhofner, 2008, p. 93). The participants in study I wanted to continue with culturally valued occupations in Norway, such as hiking or skiing. However, the occupational form of "hiking" in a Norwegian context is in itself such a challenge that neither measures related to the improvement of impairments nor changes in environment would make it possible to continue to participate in such occupations. A clinical implication may be that in order to fully understand the influences of the environments in home-based rehabilitation, the OTs must make use of several theoretical frameworks to understand the complexity.

The experience of participation as agency

As shown in the Background section of this thesis, several authors have emphasised the importance of autonomy in the understanding of the concept of participation. Furthermore, autonomy and user involvement are important both in rehabilitation and occupational therapy (Bredland et. al 2002; Cardol et. al 2002; Clapton et. al 2002; Townsend 2002). The findings in studies I, III and IV showed however how the participants took control, or tried to take control, over their daily life beyond having user involvement. Agency is described as exerting power through thought, language and actions (Christiansen & Townsend 2004), and intentionally making things happen by one's own actions (Bandura 1997). Consequently,

agency was viewed as a concept which made clear the participants' need for autonomy and control (study III). While autonomy defines every individual's right to co-determination (Frost 1993), the findings in studies I and III showed how older adults receiving home-based rehabilitation both wanted and strove to maintain agency over themselves and their daily life. Studies I, III and IV showed that the participants wanted to govern their daily life by intentionally trying to make things happen, through language and actions (studies I and III) as the definition says (Bandura 1997; Christiansen & Townsend 2004). The findings will be discussed in relation to three aspects of the exertion of agency that came to the fore: agency in relation to environment, agency in relation to occupation and agency in relation to illness and bodily function (studies I, III and IV).

One reason why agency emerged as an important finding in relation to participation in these studies may be that the studies were carried out among older adults receiving home-based rehabilitation services. Home-based rehabilitation is organised in such a way that the interventions often take place in the client's own home, and, as previously discussed, the services was partly experienced as an environmental factor inhibiting control over daily life. Home is usually a place where one has control and the ability to choose whom to allow over the threshold (Angus, Kontos, Dyck, & MCKreever, 2005; Lindquist & Tamm, 1999). With that in mind, it may not be entirely surprising to discover agency-related challenges between the staff and the participants, as shown in our studies (I and III). As discussed previously, the findings in study I-IV showed that the participants associated many benefits with the rehabilitation services; for example they needed the interventions related to exercise or assistance with occupation such as personal hygiene and housework. However, they also experienced agency-related obstacles to participation, specifically when it came to exerting control over daily life. Clapton and Kendall (2002) claim that an encounter between somebody needing assistance and somebody providing it is sensitive, and may entail a power imbalance. Oliver (1996) suggests that the assistance of others to pursue activities, such as dressing and eating in everyday life, means that power and control tend to remain with those who provide assistance. However, some studies show that, compared with institution-based rehabilitation, home-based rehabilitation can imply that the client increasingly becomes host and personally defines the terms for the staff, thus shifting the power balance the other way (Widèn, von Koch, & de Pedro-Cuesta, 2000). In contrast, McWilliam, Ward-Griffin, Sweetland, Sutherland (2001) found that staff tend to keep their power and their role as experts, and that clients still perceive the staff having control and governance. It may not

therefore be entirely surprising that the study participants sought to use several different strategies in order to remain agents in their daily life (study III). This is also documented by Haak et al. (2007), who found that older adults living at home and receiving formal help had several strategies to govern their daily life. One of the strategies used by the participants in study III was precisely the exertion of agency by trying to define the terms for the tasks which the staff should carry out efficiently. According to Bandura (2000), one strategy for exerting agency is to use others to carry out the tasks one cannot personally manage. Bandura calls this “proxy agency”. The findings in study IV show how the participants needed to use the staff as people who performed tasks efficiently, or as discussion partners or advisors. These findings suggest that making use of the staff’s competence and knowledge as the participants personally felt they needed to, based on their ever-changing requirements, and enabled them to experience being in charge and having agency.

Another aspect of agency was related to agency over occupation. Some empirical studies show that older adults with disability tend to participate in fewer leisure activities in order to retain control over a few (Krause 2000; Iso-Ahola, Jackson, & Dunn, 1994). The findings in study I, III-IV however amounted in particular to having control and being independent in personal care and domestic tasks. Earlier in the discussion we saw the participants’ desire to avoid formal assistance through the exertion of agency in daily life. One can however speculate whether the requirement for agency would be as prominent as in studies I and III if older adults were given the opportunity to use the staff as proxy agents in such a way as they felt necessary.

Finally, the third situation where the wish for agency in relation to control became apparent was related to illness and bodily function, as shown in studies I and III. Bodies were experienced as “untrustworthy” (study I), new illnesses were constantly appearing (study III), and some illnesses were new and unfamiliar (studies III-IV). Several empirical studies have shown that people who e.g. have a stroke, experience it as losing control over the body (Eilertsen, 2005; Tham, Borell, & Gustavsson, 2000). The participants in the study also had several illnesses, which is common in older adults (Avlund 2004; Romøren 2001). Taking these three aspects together, it is not surprising that agency was an important finding in the studies (I and III).

A clinical implication of these findings may be the need to assess the individual's opportunities for exerting agency to enable participation in occupation. Furthermore, since older adults often have less possibility to restore body function, it is particularly important to assess how they can make use of environmental factors to facilitate participation. The findings in study I showed that the participants had no problem with using family and significant others as what Bandura (1997) calls "proxy agents" in order to be able to carry out tasks in societal environments. The real challenge was however to have the opportunity to make use of the staff's services as proxy agents. Several authors claim that independence implies having control and agency to exert power through thought and language (Clapton & Kendal, 2002; Cott & Gignac, 1999; Gignac & Cott, 1998). Consequently, it may sometimes be more important to help the clients to use the staff as their proxy agents than training them to be able to carry out the tasks themselves during home-based rehabilitation. Occupational therapy interventions may thus include examining and guiding each individual's opportunity to exert agency.

However, there are problems related to the individualistic view that the individual should be guided to be an agent and seize control. The findings in study I and III show that societal environments, e.g. organisation of services, were barriers to participation. Yeatman (2000) claims that no one can participate in the conduct of their life unless they are invited by relevant others to participate. To have the skills and willingness to respond to the clients to enable him or her to have a say in what happens in their daily life (Yeatman, 2000) is a challenge for both OTs and other staff providing home-based rehabilitation. This is in line with the recent discourse on agency within social science (Wray, 2004) where agency is identified as contextual and relational. In order to create collaboration between the individual clients and staff as well as the service, it is necessary for staff to be able to identify individual wishes and opportunities for exerting agency, but also for the staff to have a willingness to respond to the client's way of exerting agency.

The findings in relation to the concept of participation

One point of departure in this thesis was the different perspectives on the concept of participation. In the following section, the findings in the thesis will be discussed in relation to the different perspectives on participation which are described in the Background section.

Participation as defined in the ICF (WHO, 2001) has influenced the view on participation in this thesis. As already discussed, several authors have emphasised that the definition of participation in the ICF ought to include an understanding of participation as autonomy and user involvement (Clapton & Kendall, 2002, Cardol et., al 2002). The findings in studies I, III and IV add to this by showing that among older adults receiving home-based rehabilitation, agency as exerting control was particularly important, and captured the participant's need to be in charge more than the concepts of autonomy and user involvement did. Whether the findings among older adults who are receiving or have received home-based rehabilitation can be generalised to mean that agency should be included in the definition generally, is still a matter for discussion. One argument in favour of this may be that since home-based rehabilitation services are given by significant others coming into the client's home, it may be necessary for agency to be a central part of the concept, in order to promote participation, since the findings suggest that the need for agency particularly occurred in encounters with the healthcare system. Research confirms that this is also experienced by younger people who receive both rehabilitation and care at home (Lillestø, 1997; Marquis & Jackson, 2000). Consequently, these findings indicate the necessity of the concept of participation also to include agency in order to understand what participation is all about for people with disabilities.

Participation as a right to equal participation in society is a political cause within the disability rights movement's perspective on participation (Oliver 1996; Shakespeare 2006). The findings in studies I and II indicate that the older adults in these studies were not specifically striving for the right to participation in society. One reason for this may be that the older adults in this study had been participating citizens all their lives, and still saw themselves as such. Brigout & Gray (2004) claim that people with disabilities as a group have less opportunity to be agents and to influence their environment, for example in the development of society. Our findings (I and II) indicated that attitudes from politicians and the media influenced the participants to be satisfied and to not make any demands. The findings (I-IV) nevertheless showed that the participants were interested in current affairs and in the public debate, which is another way to participate in society. In the studies (I and III) this was understood as the need to still belong to society, rather than a fight for equal status. Participation, understood as equal participation in society as emphasised in the disability perspective, is still important for older adults with disabilities, because they are under constant pressure to withdraw from participation in occupation, as indicated by the findings in study I.

The discussion in occupational therapy about the concept of participation has focused on the clients' subjective perception of participation (Borell et al., 2006; Hemmingsson & Jonsson, 2005). As mentioned earlier in the Discussion section, the participants' engagement in the public debate may be understood as an experience of being a part of society and giving the participants a feeling of belonging as one aspect of the subjective experience of participation. Another aspect of participation in occupation which emerged from our studies is that participation to a large extent is connected with engagement in social environments, and being part of the family and its activities. Participation as doing something and being something for others has been emphasised also in other empirical studies (Borell et al., 2006; Haak et al., 2007; Nyman & Lund, 2007).

Our findings also suggest that the understanding of participation varies depending on the context. Older adults with disabilities who are receiving home-based rehabilitation may for example perceive participation differently from young persons with disabilities. Furthermore, the findings indicate that participation in occupation for the individual develops in interaction with the environment in the ongoing daily life of each person. As the literature review showed, the discussion about the concept of participation has so far been discussed from the perspective of theoretical models. However, empirical studies (Almquist, Eriksson, & Granlund, 2004; Borell et al., 2006; Bricout et al., 2006, Nyman et al., 2007), as well the present thesis, have started to explore how participation is perceived by each individual in their own context. The findings show some common traits, for example the importance of control both for older adults (study I and III) and pupils with disability in a school setting (Almquist et al. 2004). To further enhance the knowledge of the concept, these studies also confirm the importance of investigating participation from different theoretical perspectives, e.g. that of Borell et al. (2006) which focuses on exploring the feeling of participation, while Bricout et al. (2006) focus on participation in the physical, political and social environment.

One clinical implication might be an acknowledgement that there are different theoretical aspects of participation. Another implication might be joint exploration of the opportunities for participation for individuals who receive home-based rehabilitation in their unique environments as their daily life unfolds both in clinical practice and in research.

METHODOLOGICAL CONSIDERATIONS

The findings in the thesis must be seen in the light of several methodological limitations which may have influenced the conclusions drawn. A selection of these will be commented on in the following paragraphs.

Studies in the fields of rehabilitation and occupational therapy (Eriksson, 2007; Eriksson & Dahlin Ivahoff, 2002; Steultjens et al., 2003; Sveen, 2004) have often focused on clients with specific diagnoses (Desrosiers et al., 2006; Fjærtøft, 2005; von Koch, 2000). The main inclusion criterion for all studies in this thesis was that potential participants should be older adults who had been referred to, or had received, home-based rehabilitation after an acute illness that had led to disability, rather than a specific diagnosis. This was also in line with the criterion for being given home-based rehabilitation in the municipality in question, where disability related to impairment, activity or participation is the criterion for receiving rehabilitation.

There are several reasons for this choice. Firstly, since a diagnosis in itself does not say much about an individual's disability (Wade & Halligan, 2004), people with disability after any acute injury or illness were chosen, as disability was more important in the studies than diagnosis. Secondly, the first two studies explored the participants' experiences of the environment. The assumption was that older adults who had experienced an acute illness might more easily identify environmental conditions which influenced their opportunity for participation than older adults with a gradual loss of function due to a chronic disorder.

In qualitative studies, sampling procedures aim for a heterogeneous sample with for example variability in the time since onset of the illness, living conditions, age and gender to attain a rich base for information (Patton, 2002; Strauss & Corbin, 1998). Furthermore, in qualitative studies the intention is not to search for generalisation on statistical grounds, but rather to use the concept of analytical generalisation, indicating a reflective judgement about the extent to which the findings in one study can be used as a guide to what might occur in other similar situations (Kvale, 1998). Consequently, the findings in studies I, III and IV cannot be generalised to all older adults who receive home-based rehabilitation. However, the findings

suggest a possible understanding of how participation and environmental influences could be understood in similar samples and conditions to these studies (Patton, 2002).

In contrast, study II was a population-based study that aimed for generalisation (Altman, 1999). Approximately 50% of the potential population declined to participate in the study. While no significant differences were found between these groups in relation to age and gender, a difference in diagnosis between the participants who were included in study II and those who declined participation, was seen. This difference could be caused by a lack of information about the diagnosis from 17 persons in the sample of persons who did not participate. It is worth noting that differences in diagnosis do not equal differences in disability and experiences of the influence of the environment between the two groups. The main reason for declining to participate in this sample seemed to be that the invitation to participate in the study was given by a male over the telephone. Based on this information, we assumed that the difference between the groups was random, even though it is possible that there was a difference in disabilities among the two groups. Since the group that declined to participate was 50%, this could limit the possibility for generalising the findings from study II.

At the onset of study II, MQE was the only known assessment developed to measure environmental factors in relation to participation. According to Fougeyrollas et al (1999), psychometric testing of the MQE had provided encouraging results with regard to test-retest reliability among adults with a disability, and the MQE had been used among older adults from the research group that developed the assessment (Levasseur, 20004b). Furthermore, face validity (DePoy & Gitlin, 1998) was found to be satisfactory in our review of the MQE when planning the study. Using an assessment that was not validated for the study group did mean, however, that the cultural context or language brought about a number of limitations. To meet these, an extensive translation procedure was initiated, and the interviews were carried out face-to-face in order to clarify questions and concepts with the respondents (Bowling, 2002). Furthermore, the procedures of using the MQE, was discussed with other professionals. To strengthen the reliability the author (KV) carried out 2/3 of the interviews, and had regular meetings with the other research assistant in order to ensure that the interviews were carried out in a similar manner. Still, since the findings in study II differed from other studies of older adults with a disability, this could be an indication that the measure was not valid. However, the results in study II were in line with the results that Levasseur (2004b) found when using

MQE in a study among older adults with disabilities living in their homes, which is another indication of the validity of the measurement in this particular study.

The FAI was chosen to collect data about participation in occupation, and the Sunnaas ADL-Index to collect data about performance of ADL. Limitations of these assessments were that neither of them was validated for older adults with disabilities living at home. The FAI has been validated for older adults with stroke (Piecy et al. 2000) and the Sunnaas ADL-Index for adults in a rehabilitation clinic (Bathen & Vardeberg, 2001). However, based on its face validity (DePoy & Gitlin, 1998), the FAI was considered to be the most relevant assessment as it showed where and how often a person has participated in an occupation as well as the type of occupation, in a particular period and at study start. Since observation is considered limited when evaluating daily life tasks in the home environment (Fänge & Iwarsson, 2005), and enabling the client to self-report has proved to be more beneficial to outcome (McCreadie & Tinker, 2005), the Sunnaas ADL-Index was chosen to be administered as self-report of ADL ability. As the purpose of all the studies was to explore the views of the participants, the assumption was that the participants could also give their report about ADL-ability.

The aim of focus group interviews (study I) and individual in-depth interviews (studies III and IV) was to explore the experiences of the participants. Focus group interviews are considered to be relevant when the purpose is to gain better understanding of a topic that is explored through a discussion among the participants (Dahlin Ivanoff & Hultberg, 2006; Krueger, 1998). However, one limitation may be the risk that important topics of a private nature are left aside in a group (Burrows & Kendall, 1997). In study I, letting each focus group meet several times gave the participants the opportunity to become confident both with each other and the moderator. This experience from study I influenced the design of studies III and IV when it came to establishing a relationship over time with the participants (Charmaz, 2006; Patton, 2002). In these studies, the participants were interviewed several times over a period, which gave them time to reflect and to expand their thoughts on the relevant topics (I and III-IV) (Charmaz, 2006; Patton, 2002). Participation in occupation, for example, is an abstract concept, and the participants needed time to be able to experience this in their daily life. Study I also showed that the participants needed time before they were able to talk about their experiences with the health and social services system. In addition, according to Gilner (1994), credibility is increased when topics can be followed up during the course of a study, and this design provided the opportunity to reflect on and return to the various topics. All the

interviews, with the exception of the focus group discussions, were held in people's homes. This was based on the assumption that the participants would feel more secure and willing to talk on their own territory, particularly as the aim of the studies was to explore aspects of their daily lives. It is, however, well known that we can only access part of a person's experiences, as many different conditions influence what is shared or left out of a conversation (Kvale, 1998).

Finally, all the studies were carried out in the same municipality and in the context of their system for the organisation of rehabilitation and other local authority services. Consequently, it might be difficult to generalise the findings to other places where older adults receive home-based rehabilitation. However, the findings in the thesis, e.g. concerning health services, concurred with findings from other studies carried out in Scandinavia (Haak et al., 2007; Johannesen et al., 2004; Lillestø, 1997), and the participants' experiences with the social environment have been confirmed in several other, international, studies (Avlund, 2004; Palmer & Glass, 2003; Satariano et al., 2002). This indicates that the findings in this thesis may be relevant for other older adults receiving home-based rehabilitation. However, the findings in study I and II diverge from other studies concerning the influence of the physical environments in society. A reason for this difference could be that the present studies (I and II) focus on the participants' perceptions of environmental influence related to participation, whereas other research has investigated the influence of environments related to performance of tasks, and often from the professionals' point of view (Lilja, 2000). Consequently, the findings in this thesis concerning the influence of the physical environment on perceived participation should be interpreted with caution until further research has been undertaken.

CONCLUSIONS AND CLINICAL IMPLICATIONS

From the findings in the studies included in this thesis, some overall conclusions can be made in relation to participation in occupation for older adults with a disability who receive home-based rehabilitation

- Participation in occupation can be understood in different ways, both exerting agency in daily life and letting everyday life be the agent, thus including contextual and relational factors.
- Letting everyday life become an agent implies an engagement with social environment, especially the family. This participation was seen as: engagement in family-related occupations, maintaining routines through of engagement in the family, and participation in social outings and travelling.
- A wish for maintaining agency and control in daily life arose in encounters with services as an environmental factor. Consequently, receiving home-based rehabilitation was seen as double-edged, since the disability also made older adults dependent on the system that provided home-based rehabilitation services. Assistive devices were therefore seen as especially useful since these devices made the participants more independent of assistance.
- Expectations for the future daily life, and the participants' needs and tasks related to their disability, were seen as conditions that influenced how the staff's were made use of. Participants made use of staff as: small talk persons, as discussions partners, as instructors and advisors, as teachers, and as persons who carry out tasks efficiently.
- The media was seen as an environmental factor which stimulated participation in occupation as a means of engagement in society, maintained routines in daily life and contributed to conversations with social environment.
- Social environments were more important for participation in society than physical environment.

Clinical implications

The findings of this thesis have clinical implications primarily for OTs working with older adults with a disability in home-based rehabilitation. However the findings related to encounters with societal environments might also have implications for other rehabilitation professionals giving services in clients' homes.

- The findings related to the influence of the environment showed that in order to promote participation, supporting the individual's engagement in social environments, e.g. family, is necessary. Engagement with family might enable the individual to participate in family-related occupations, or to maintain his/her own routines related to the family. The importance of including the family also pertains to interventions related to opportunities for social outings and travelling, which may be important aspects of participation.
- Agency may be promoted by staff being aware of variations in their way of encountering older adults during the period they receive home-based rehabilitation. Furthermore, identifying individual wishes and opportunities for exerting agency by enabling individual strategies and keeping up individual routines in daily life is also important. This requires staff, including OTs, to have a willingness to respond to the clients' way of exerting agency. Additional research is required to explore how OTs, as part of the healthcare system can avoid being an obstacle to their clients' participation in occupation
- As media use among the participants was shown to be important for participation, these findings have some clinical implications that pertain to media use among older adults. Firstly, OTs working with older adults who are receiving home-based rehabilitation should carefully consider clients' utilisation of media (e.g. TV, newspapers and radio) as important occupations and, when relevant, assess the need for adaptation. Secondly, OTs should be aware of clients' individual wishes for small talk with staff about, for example, the news of the day as reported in newspapers and on television, as such communication may bring about a sense of participation in the wider society and a sense of belonging. As media is an occupation which older adults

spend a lot of time on, it appears necessary to further research the significance of this in general for older adults.

- To fully understand participation in occupation in relation to environment, OTs need to take several theoretical models into consideration to help them appreciate the complexity of the influence of environment on participation in occupation as it unfolds individually in each client's daily life.

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