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TERAPEUTIC ASPECTS OF ENGAGEMENT IN OCCUPATIONS

Gerd Andersson Svidén

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IN THE CONTEXT OF DAY CARE FOR  
OLDER PEOPLE AND PATIENTS IN  
PALLIATIVE CARE

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# ABSTRACT

The overall aim of this thesis was to identify and describe therapeutic aspects of engagement in occupations in day-care programs designed for older people with chronic conditions or patients in palliative care.

The thesis includes four studies. In **Study I** the aim of the study was to conduct a phenomenological investigation of elderly persons positive experiences of spending time in a community-based activity center and of being engaged in occupations (n=9). This study was based on qualitative interviews analyzed using the Empirical Phenomenological Psychological Method (EPP). **Study II** aimed to identify characteristics of the elderly people living in their own homes and participating in social day centers compared with the participants of a rehabilitative day center, emphasizing on perceived functioning and competence in daily life. Twelve social day center participants and 12 rehabilitative day center participants answered two questionnaires; the sickness impact profile (SIP) and the occupational self-assessment (OSA). In **Study III** the aim was to investigate how people with incurable cancer engage in and undertake activities in their everyday lives. The study was based on qualitative interviews (n=47) with the data analysis conducted concurrently with the data collection according to the techniques of grounded theory. **Study IV** aimed to study the outcomes of palliative day-care, in terms of health-related quality of life, using the European Organization for Research and Treatment of Cancer Quality of Life Questionnaire (EORTC QLQ-30), and emotional well-being, using the Mood Adjective List (MACL), of cancer patients participating in a palliative day-care program (n=23) for 5 weeks, compared with a group of palliative cancer patients (n=12) not participating in day-care.

The findings in **Study I** describe the phenomenon of the experience of being occupied and spending time at a community-based activity centre as a safe and familiar setting to attend on a regular basis; doing was absorbing and gave pleasure; it was a challenge to be able to accomplish something; and the activity center was a meeting-place where doing is shared with others. In **Study II** the results show that the majority of participants from both the social activity centers and the rehabilitative day center were elderly persons living alone who experienced severely restricted physical function. A significant difference between the groups was that those who attended the social day center perceived better psychosocial function than the group attending the rehabilitative center. **Study III** shows how the participants, despite experiencing the threat of progressive loss of functioning, strove to remain involved in everyday life and how a driving force for continued involvement in everyday life was created. The possibility of doing was crucial in this process. In **Study IV** the participants in the day care group and the comparison group reported similar levels of perceived functioning and symptoms, as measured by the EORTC QLQ-30, with no significant differences between the groups. However, the day-care group reported higher levels of emotional well-being as measured by the MACL than the comparison group reported, however these differences were not statistically significant.

In conclusion, the thesis describes what therapeutic engagement in occupations can be and also the conditions for therapeutic engagement in occupations in the context of day-care programs. The studies also indicate that well-being could be influenced through engagement in occupations although no improvements are made with respect to the medical condition.

Key words: day-care, health-related quality of life, grounded theory, occupational therapy, older adults, palliative care, phenomenology

## LIST OF PUBLICATIONS

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

- I. Svidén, G. A., & Borell, L. (1998). Experience of being occupied - some elderly people's positive experiences of occupations at community-based activity centers. *Scandinavian Journal of Occupational Therapy*, 5, 133–139.
- II. Svidén, G. A., Tham, K., & Borell, L. (2004). Elderly participants of social and rehabilitative day centres. *Scandinavian Journal of Caring Sciences*, 18, 402-409.
- III. Svidén, G. A., Tham, K., & Borell, L. (in press). Engagement in everyday life for people with a life threatening illness. *Palliative & Supportive Care*.
- IV. Svidén, G. A., Fürst, C. J., Koch, L., & Borell, L. Palliative day care – a study of well-being and health-related quality of life. Manuscript submitted for publication.

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# INTRODUCTION

This thesis concerns the therapeutic aspects of engagement in occupations. In particular, the perspectives of participants in day-care programs, directed to older people with some kind of chronic condition and patients in palliative care. The interest behind the present thesis stems from the discovery of how little that has been written and documented about occupation as therapy or what the therapeutic components of therapy including occupations could be.

With a long background as a teacher in occupational therapy (I started to teach occupational therapy in the early 1980s), I have struggled over the years, to find theories, models, or even just simply descriptions of the therapeutic aspects of engagement in occupations. Since the knowledge gap that exists is so very large, one solution was to start to make contributions to developments in this area myself. I have therefore over a period of more than ten years back in time conducted research focusing on learning more about the therapeutic aspects of engagement in occupations. Day-care programs were chosen as a natural place and starting point for my studies since one of the characteristics of these settings is occupation-based therapy.

Even though occupation is a taken for granted concept to use in occupational therapy it needs to be further discussed and defined. Occupation is also the core medium of the occupational therapy profession. Yerxa (1998) suggested that in today's world, engagements in occupations are often trivialized, sometimes considered merely as diversions. Yerxa (1998) claims that occupational therapists need to reaffirm that engagement in occupation, rather than being trivial, is an essential mediator of healthy adaptation and a vital source of joy and happiness in one's daily life. However, the commonplaceness of treatment tools in occupational therapy, applying the performance of everyday occupations in therapy as well as ordinary leisure activities is not always understood as valuable when compared to the performance of certain training exercises for better physical and cognitive function.

Supported by Yerxa (1998) I regard it of great importance to further explore occupations "*as a vital source of joy and happiness*" and especially in the context of older people with some kind of chronic condition and patients in palliative care as in the present studies. The concept of occupation has several definitions, in this thesis I have

applied the ideas relating to occupations developed by Law, Polatajko, Baptiste and Townsend (2002): “*Occupation refers to groups of activities and tasks of everyday life, named organized, and given value and meaning by individuals and a culture. Occupations is everything people do to occupy themselves, including looking after themselves (self-care), enjoying life (leisure, and contributing to the social and economic fabric of their communities (productivity))*” (p.34).

## **BACKGROUND**

### **A societal view of the value of an active lifestyle**

The idea of the benefits of being active is accepted in society, and is also supported by commonly encountered reviews of scientific research in the daily press. For example, older individuals are encouraged to be as active as possible, which supposedly should prevent a general deterioration of health (Coyle, 2003; Woods, 1999).

The Swedish National Institute of Public Health (2007) has identified four “cornerstones for aging well” these are: physical activity, good eating habits, social interaction/support and engagement in meaningful activities. Being active rather than passive is considered part of a healthy lifestyle and there are several ways in which engagement in occupations may influence well-being, health and survival. It has been established that older people who increased their participation in leisure activities tended to perceive an improvement in their life conditions (Silverstein & Parker, 2002). Moreover, in preventive occupational therapy day programs for older people reported in the “well elderly study”, evidence is provided of the benefit of participation in occupations and of the provision of opportunities for socialization (Clark et al. 1997; Clark et al. 2001).

However, there are also barriers to be overcome for people who want to be engaged in occupations. For older people, inadequate accessibility can become an overwhelming barrier for engagement in occupations and society. The role of the environment in constructing disability has been increasingly acknowledged in recent years (Christiansen & Townsend, 2004). Environmental factors can both create barriers and support and facilitate participation, and are thus a significant aspect for performing occupations in the everyday lives of older individuals.

### **Older people living with chronic conditions**

In Sweden, as in other countries, many older persons with disability live in their own homes rather than institutions. In 2007, 94% of all Swedish persons 65 and older lived in their regular homes, and 10 % of the population 65 and older, was granted home help services in their regular homes (Socialstyrelsen, 2008). Data from the annual survey of living conditions conducted by Statistics Sweden (Statistiska centralbyrån, 2006) showed that 80% of the population between 65 and 84 years reported long-term illness, problems following an accident, a handicap or other types of weakness.

The policy of enabling people to remain in their homes for as long as possible is a central principle in Swedish welfare policy and the municipalities provide a number of services for example, meals on wheels, home help, and day-care programs to facilitate this (Socialdepartementet, 2001). The participants included in studies I and II in this thesis were all people receiving day-care service through the municipality. Day-care programs for older people run by the municipalities are mostly for people with a dementia disease, but there are also day-care programs targeting older people with restricted physical functioning (described in studies I and II). The types of day-care programs involved in studies I and II in this thesis are both social activity centers without formal requirement of referral and day care with formal requirement of referral. No day-care programs focusing on people with a dementia disease are included in the studies.

A decrease in the day program provision has been seen during recent years. According to the official statistics of Sweden concerning municipal service provided for persons of 65 and older, the number of older persons with decisions on assistance for some kind of daytime occupation has successively been reduced from 15,500 persons in 2000, to 10,600 persons in 2007 (Socialstyrelsen, 2008). The number of day-care programs in term of social activity centers offered by the local municipality with no formal requirements of referral has also decreased, sometimes based on the idea that professionals could be replaced by voluntary organizations.

This decrease in day program provision is consistent with the fact that the public elderly care provision in Sweden has become less extensive in recent decades (Larsson, 2006). Access to elderly care is no longer as widespread, and care provision is directed primarily towards those with more extensive requirements (Szebehely, 2003). Available resources rather than people's needs influence care consumption levels of for example home help (Batljan & Lagergren, 2000).

### **Patients in palliative care**

Palliative care is defined by the World Health Organization (WHO), as the care of patients with life-threatening illness. This definition includes the early palliative phase; rehabilitation and supportive care. The WHO describes palliative care as: *“an approach of care which improves quality of life of patients and their families facing life threatening illness through the prevention and relief of suffering by means of identification and impeccable assessments of pain and other problems, physical, psychosocial and spiritual”* (WHO, 2002). Palliative care is

usually provided through the medical care organization, for example hospital care and home care. Palliative care may also be provided by local authorities in primary care and in nursing home facilities. Patients with incurable cancer comprise the largest group in Sweden that is currently offered palliative care at home.

The participants in studies III and IV were all persons receiving services from palliative hospital-based day care services and/or palliative care at home. The very few specialist palliative day-care programs that exist in Sweden are placed within a medical context. According to the National Board of Health and Welfare, (Socialstyrelsen, 2006) there has also been a decrease in palliative day-care provision in Sweden during recent years, from 11 day-care units 2000, to 7 units 2006

The participants in studies III and IV were all living with a life threatening disease that has an extraordinary influence on the individual's everyday life. Advanced cancer affects life in physical, psychological, social and existential ways (Breitbart, 2002; Tishelman & Emami, 2004; Sand, 2008). The individual is confronted with the fact that cure is no longer expected. Challenges caused by symptoms, loss of control and autonomy, of feeling ignored, lonely and uncertain could constitute a basis for the experience of helplessness and powerlessness (Sand, Strang & Milberg, 2008).

For people living with a life threatening disease, the natural structure and order of daily living, which had always been taken for granted and had, for example, been provided by work before the onset of cancer, disappears in the illness context (Salander, Bergenheim & Henriksson, 2000; Fryback, 1993). Similar consequences of cancer are identified by Vrkljan and Miller-Polgar (2001), who suggest that life-threatening illness challenges the individual's ability to engage in meaningful occupations as a consequence of decreasing choice and control in everyday occupations. Although, the consequences of advanced cancer have profound and widespread effects on the life situation of the individual, including the ability to engage in occupations, little attention has been directed towards ways in which occupation may be useful in the remainder of these people's lives.

### **Therapeutic aspects of engagement in occupations**

It is a founding premise of occupational therapy that health is related to occupation. It follows from this premise that occupation can be used as therapy to promote and support health and well-being (Kielhofner, 2007; Reilly, 1962; Townsend & Polatajko, 2007; Yerxa et al. 1990).

However, the relationship between engagement in occupation and health including also well-being is still a crucial question for more in-depth studies in occupational therapy. Nilsson (2006) claimed that despite the fact that many authors refer to the importance of occupation in promoting and maintaining health, there is limited knowledge about the relationship between occupation and health. Nilsson (2006) also demonstrated in a review of occupational therapy models of practice, that models of practice do not explicitly inform about what kind of or why occupational performance is of importance to human beings. Law, Steinwinder and LeClair (1998) found in a review of research on the relationship between occupation, health and well-being that occupation has an important influence on health and well-being in research including persons without disabilities. However, Law et al. (1998) claims that further research is required to explain the nature of the relationship between occupation and health and well-being for persons who experience a disability which affects their daily occupations. Knowledge about the conditions for therapeutic occupation, when and how occupations become therapeutic will also provide new insights into the relationship between occupation and health.

Rogers (1982) and Cynkin (1995) discussed the concepts of occupation and health, and claimed that health in medicine is defined as order, while health in occupational therapy is defined as function, manifested in the ability to engage in occupation. Conversely ill-health, or disease, is in occupational therapy defined as dysfunction, or the inability to engage in occupations. This means that medical diagnoses or the medical problems are not in focus in occupational therapy, instead the occupational performance problems are in the foreground as well as efforts to find the right occupation that will serve as a therapeutic occupation. In her discussion about how to view and define therapeutic occupation Cynkin (1995) claimed that occupations are therapeutic when they enable change to take place from dysfunction to function.

The focus on occupation and the need to better understand the role of occupation is a focal viewpoint in occupational therapy. Rogers (1982) and Cynkins (1995) ideas build on those of Fidler & Fidler (1978) who argued that when occupational therapy treatment responds to symptom rather than to the development of occupational performance, and thereby is for example is biased toward verbal communication or physical exercise, the therapy will have a limited effect since the occupational therapist is not skilled principally as an expert in these media.

Fidler & Fidler (1978) also claimed that sometimes the motivation for the use of occupations seems to be the avoidance of inactivity rather than providing help and is used in a generalized way. This makes their impact more like random activity and the benefits of occupations tailored to meet individual needs are lost. In a study of a day-care program for persons with a dementia disease Borell, Gustavsson, Sandman & Kielhofner (1994) showed how the activities included in the program only worked as a means of making the patients fall asleep.

A concept that has emerged in the development of an occupation-based language (Pierce, 2001) is the distinction between the uses of occupation as the means of intervention as opposed to the end for intervention. Cynkin (1979) proposed that *“activities are the ends to which occupational therapy directs its energies, activities are also the means to those ends ... there is no better introduction to activities than activities themselves”* (p.34). This highlights how Cynkin views occupations as both means and ends at the same time.

Trombly (1995) further developed the concepts and suggested a distinction between occupation-as-ends and occupation-as-means. With occupation-as-ends the person has a functional goal and tries to accomplish it by using the existing abilities and capacities he or she has. Occupation-as-end is for example brought about by the occupational therapist teaching the activity or task directly or providing adaptations that are necessary. With occupation-as-means Trombly (1995) refers to occupation acting as the therapeutic change agent to remediate impaired abilities or capacities. Various arts, crafts, games, sports, and exercise routines are given as examples of occupations-as-means. Occupation-as-means seems to motivate the person to achieve a therapeutic benefit, which as exemplified by Trombly (1995), can be to require full range of motion in the arm. In adopting this view Trombly reduce the therapeutic potential inherited in occupation, by just applying it to be a tool for an exercise.

However, there are other views of the goals of therapeutic occupation. Gray (1998) argues that instead of being two distinct conditions, occupation-as-ends and occupations-as-means exist simultaneously. Gray (1998) return to the original ideas of Fidler & Fidler (1978) when she propose that occupation-as-means refers to the use of therapeutic occupation as the treatment modality to advance someone toward an occupational outcome and not only to improve impaired capacities or improved body function.

Pierce (2001, 2003) suggests a model for the use of therapeutic occupations in practice, the occupational design approach. According to Pierce (2003) the treatment power of an occupation lies in its appeal, its intactness, and its goal of fit. The appeal of a therapeutic occupation depends on the degree to which the patient perceives it as offering desirable levels of pleasure, productivity, and restoration. Further, Pierce (2003) sees occupational intactness as the degree to which a patient perceives the occupation applied in treatment as occurring in its usual, non treatment context. The final characteristic of the treatment power of occupation is “goal fit”, or the degree to which a therapeutic occupation matches the patient’s goals.

### *Providing the just right challenge*

The concept of “the just right challenge” was introduced by Ayres (1972) as a key principle of occupational therapy with a sensory integration approach designed to guide intervention. Occupational therapists strive to provide their clients with a “just-right-challenge” as a therapeutic occupation to enable occupational performance. Based on a thorough understanding of a person’s capabilities, environment, and the occupation, the occupational therapist facilitates performance by matching the occupation to the person’s capabilities and to the environment in which the person performs (Baum & Christiansen, 2005).

Occupational therapists actually make use of the environment in designing therapeutic occupations. Person-environment theories (CAOT, 2002; Law et al. 1996) focus on the match between the capabilities of the person and the demands of the environment, when the match is poor, performance is poor. The idea of person-environment fit is important for occupational therapy practice. If the environment is set up to be too challenging or too easy for a person’s current capabilities, occupational performance will deteriorate. Also Flow Theory (Csikzentmihaly, 1991) is useful in understanding the aspects of the occupation, the environment and the person that contribute to a “just right challenge”, and to enabling occupational performance through enjoyable, structured and purposeful occupation. Csikzentmihalyi (1991) found that “active experience” (flow) resulted from situations with environmental challenges matching level of competence.

Factors such as stress and perceived control of one’s own life have been shown to influence the relationship between occupation and health. A model of the impact of different working conditions on the individual’s health and well-being is the demand-control model (Theorell &

Karasek, 1996) which deals with the match between the individual's decision latitude and psychological demands in work. Even though this is a model of risk, it could also be applied to better understand the supportive influence of the environment. There is significant evidence in the research that the combination of low control and high demands is a high risk factor for disease (Theorell & Karasek, 1996). The importance of having a sense of control over occupation has also been emphasized in the occupational therapy literature (Polatajko, 1994; Yerxa, 1994). LaLiberte Rudman, Valiant & Polatajko (1997) suggests that control is one condition that differentiates occupation that positively contributes to well-being from occupation that does not.

This review of therapeutic aspects of engagement in occupations, presents a perspective that emphasize engagement in occupations as a resource in everyday life and the importance of occupations matching the client's needs. To further identify the therapeutic mechanisms inherent in the performance of occupations is important, and a greater understanding of therapeutic engagement in occupations will lead to a more trustworthy implementation of occupational therapy.

### **Day care**

The main setting and the context used for the studies included in this thesis are day-care care programs designed for older people receiving social service through the municipality and day care-programs designed for patients in palliative care. Programs of different types are included in the four studies. In this framework for the thesis the term day-care program is chosen as the name for all types of programs included in the studies. This implies a range of services designed to support people in continuing to live in their own homes. The idea is that the participant in a day-care program should get support to enjoy the facilities, maintain their abilities longer, and live as full a life as possible. In addition the participants have opportunities to socialize with others in the day-care context. Attending a day-care program can, in addition, provide a break for a family caregiver.

### *Research based on older persons and patients in palliative care and their experiences and perceptions of day-care programs*

In a review of the literature of geriatric day-care, Bentley, Meyer and Kafetz (2001) point out that qualitative studies do suggest high levels of satisfaction with day-care. In other studies of the perceived benefit of participating in day-care settings it is stressed that clients value the social support and opportunity to engage in occupations provided in the program (Ritchie, 2003).

In addition, all studies describing the participant's experiences of palliative day-care (qualitative studies), report high satisfaction among patients with the day-care they received. Patients valued the social contacts and being able to take part in a range of activities (Davies & Higginson, 2005; Goodwin, Higginson, Myers, Douglas & Normand, 2002; Hopkinson & Hallett 2001; Kennett & Payne, 2005; Kernohan, Hasson, Hutchinson & Cochrane, 2006; Douglas, Higginson, Myers & Normand, 2000; Lyons, Orozovic, Davis & Newman, 2002; Fisher, O'Connor & Abel, 2008). For example the possibility to participate in creative activities taking place in a special environment with a welcoming and relaxed atmosphere was highly valued by the patients (la Cour, Josephsson & Luborsky, 2005). Hopkinson & Hallett, (2001) in a study of what was important for patients in palliative day-care was important for patients, reported that all were satisfied with the care. The main reasons were, a welcoming and relaxed atmosphere where they felt accepted and understood, and the promotion of self-worth by allowing choice and motivating them to take part in valued activities; and reduced feelings of isolation. Kennett (2000) and Kennett and Payne (2005) reports from studies of participants' experiences of palliative day-care that patients included descriptions of enjoyment, enthusiasm, excitement, pride, achievement, sense of purpose, satisfaction and mutual support through involvement. The only negative comments concerned a sense of anticlimax when the project ended. Also Goodwin et al. (2002) reported that most patients made positive comments about day-care. The bulk of this research clearly shows all the benefits and positive participant experiences.

However, there is still no evidence of whether palliative day-care improves symptom control or health-related quality of life. In a systematic review of palliative day-care for adults with cancer (Davies & Higginson, 2005) it was not possible to provide conclusive evidence that symptom control or health-related quality of life was improved for these patients. Also Goodwin, Higginson, Myers, Douglas and Normand (2003) report in a prospective comparative study that palliative day-care was not found to improve health-related quality of life. The authors suggests that the limitations in the quality of life measures in identifying effects indicate the need for further research in this area.

In addition, research measuring the benefit of geriatric day-care in terms of traditional medical outcomes has found less-positive outcomes than expected. For example, a systematic review including 12 controlled trials concluded that geriatric day-care had no clear advantage over

other forms of comprehensive care (Forster, Young & Langhorne, 1999). Studies have not been able to consistently document the effect of day-care programmes on the functional health of participants or the ability of day-care programs to delay nursing home placement (Gaugler & Zarit, 2001). Also Baumgarten, Lebel, Laprise, Leclerc and Quinn (2002) reported that when using standard research instruments, there was no evidence of an effect on the client's anxiety, depression, or functional status; nor on caregiver burden; nor on the cost of health services.

In summarizing previous research intended to provide knowledge on day-care, it is of interest to note how the qualitative studies show how day-care is highly valued in the studies of the participants' experiences. This should be seen in relation to the quantitative studies that have not found evidence of how day-care could improve distinct measurable feature for example, symptom control, functional status, health related quality of life, caregiver burden or lowering the cost of health care services.

Considered together, the contradictory findings provide an intriguing and exciting context for more empirical studies. This knowledge gap can possibly be filled by research of both a quantitative nature as well as a qualitative nature. New more detailed knowledge is needed in order to better understand how day-care programs for people in need of this service should be set up in the future. Of special importance is to learn how occupations become therapeutic in the day-care context since there is still little research on the therapeutic aspects of occupational therapy. As stated in the personal introduction this thesis is founded on the premise that the accumulation of new knowledge from an occupational perspective is of crucial importance in order to better develop the ideas for programs in day-care.

## RESEARCH AIMS

### **General aim of the thesis**

The general aim of the thesis is to identify and describe therapeutic aspects of engagement in occupations in day-care programs designed for older people with chronic conditions or patients in palliative care.

### **Specific aims of the studies**

#### *Study I*

The aim of the study was to conduct a phenomenological investigation of elderly person's positive experiences of spending time in a community-based activity centre and of being engaged in occupations.

#### *Study II*

The aim of the study was to identify characteristics of the elderly people living in their own home and participating in social day centres when compared with the participants of a rehabilitative day centre, with emphasis on perceived functioning and competence in daily life.

#### *Study III*

The aim of the study was to investigate how people with incurable cancer engage in and undertake activities in their everyday lives.

#### *Study IV*

The aim of the study was to study the outcomes of palliative day-care, in terms of health related quality of life and emotional well-being of cancer patients participating in a palliative day-care program during 5 weeks, compared with a group of palliative cancer patients not participating in day-care.

## METHODS

The studies in this thesis concern therapeutic aspects of engagement in occupation in the context of day-care programs. The studied groups, older people receiving day-care service through the municipality and patients in palliative care receiving day-care services or/and receiving palliative home-care, are people living with chronic conditions or illness. This also implies that the participants cannot be expected to recapture full health. The participant's health condition i.e. living with disability and cancer is one of the conditions that influences the choice of the design of the four studies included in the thesis.

The first study describes some older people's experiences of engagement in occupations in day-care programs, while the second study describes and compares the characteristics of the participants in two different types of day-care programs for older people, and the third study describes how people with incurable cancer, engage in and undertake activities in their everyday lives. Finally the fourth study demonstrates what the outcomes of palliative day-care could be. An overview of participants, data collection and analysis methods in the studies is presented in Table. 1.

### **Method study I**

The aim of the first study was to conduct a phenomenological investigation of elderly people's positive experiences of spending time in a community-based activity center and of being engaged in occupations.

Attendees from two activity centers in a local community were interviewed; nine persons in all. Criteria for inclusion in the study were that the participants were over the age of 65, were regular attendees at one of two activity centers and took part in occupations. The activity centers were run by occupational therapists in the community and were open to elderly people receiving some kind of service from the community (e.g. home help). The older adults attended the settings by free, personal choice. Five of the participants lived in their own homes and came by taxi to the activity center. Four persons lived in their

Table 1. Overview of Study I-IV: participants (number, gender, age), research approach, methods of data collection, instruments, and analysis

	<b>Study I</b>	<b>Study II</b>	<b>Study III</b>	<b>Study IV</b>
<b>Participants</b>	9 persons attending activity centers	a)12 persons attending social day centers, b)12 persons attending a rehabilitative day center	47 persons receiving service from palliative home care or/and day-care services	a) 23 persons attending a palliative day-care program, b) 12 persons in the comparison group
<b>Gender M/F</b>	4/5	a)2/10 b) 8/4	8/39	a)4/19 b)2/10
<b>Age, range</b>	67 – 85	a) 69–90 b) 57–94	49–86	a) 49-86 b) 49-85
<b>Research approach</b>	Phenomenological approach	Quantitative descriptive approach	Grounded theory approach	Prospective comparative study with a longitudinal design
<b>Methods of data collection and instruments</b>	Interviews, informal open-ended questions based on an interview guide	The Occupational self-assessment (OSA) and the Sickness Impact Profile (SIP) used as interviews	Interviews, informal open-ended questions based on an interview guide	The Mood Adjective Check List (MACL) and the European Organization for Research and Treatment of Cancer Quality of Life Questionnaire (EORTC QLQ-30)
<b>Analysis</b>	Empirical phenomenological psychological method (EPP-method)	Descriptive statistics, Mann–Whitney nonparametric test, Spearman rank order correlation test	Grounded theory approach with a constant comparative analysis	Descriptive statistics, Mann Whitney U-test, Friedman´s ANOVA

own apartments in a block of service flats and attended an activity center in the same building. The participants had functional impairments related to stroke, orthopaedic diseases, arthritis or heart disease

The interviews took place in a quiet room in the activity centers or in the homes, based on the participants' own choice. The interviews lasted for about an hour. The purpose of the interviews was to gather descriptive data delivered in the person's own words. The interviews were guided by a few, general question areas that covered information about the person's life and interests, the circumstances which led to attendance at the activity center, what they did while at the center, how they experienced the doing, how they experienced the setting, and finally, what the participant regarded as the most important thing about being occupied at the activity center, these general questions were used as a guide.

In analyzing the data, the tape-recorded interviews were transcribed in full and analyzed using a methodological guideline, the empirical, phenomenological, psychological method (EPP method) developed by Karlsson (1993). Transcripts were read repeatedly until a good grasp of the data was obtained. Thereafter, all the data were divided into smaller parts based on what Karlsson refers to as meaning units. A shift of meaning is an indication of a new unit. In this step of the analysis the subject's everyday language was transformed into the researcher's language. In this way, all the relevant meaning units were transformed from their specific facts into their induced meanings. Next, the induced meaning was synthesized into summary formats for each participant. Simultaneously, a process of going back and forth between the creation of situated and the original data occurred continuously. Finally, the situated structures from all participants were compared with each other and an overall structure was obtained, incorporating the themes that ran across all situated structures. This resulted in common constituents for all participants.

## **Method study II**

The aim of study II was to identify characteristics of the older people living in their own homes and participating in social day center compared with the participants of a rehabilitative day center, emphasizing on perceived functioning and competence in daily life.

The participants in study II either attended one of three social day centers or a rehabilitative day center serving the older population in one

urban district of Stockholm, Sweden. All centers were services run by the local community. The social day centers were situated close to service centers for older people that included sheltered housing, and provided a meeting place for older persons living in their own home and offered opportunities to participate in different activities. The staff consisted of one rehabilitation assistant. Clients were invited to the program through the home help service in the community. The rehabilitative day program was also a local social service for older people living in the community, provided for persons who had recently been hospitalized after a disease or an injury. Before admission, assessment was made by a social service officer of the need of rehabilitative support for the individual to enable them to continue living at home. The staff included one occupational therapist and one physiotherapist.

All persons who were registered in the rehabilitative day program during the 3-month long data-collection period were invited to participate in the study. Thirteen people at the rehabilitative day center were invited, 12 of whom accepted. In the three social day centers, users who attended on a regular weekly basis as identified by the staff were invited to participate in the study. In all, 13 people were invited and 12 accepted. All participants were given written information about the study and were asked orally by the staff and the first author if they would accept the invitation to participate in the study. All participants had experienced some kind of disease or injury and had at least one medical diagnosis, for example, stroke, arthritis, heart-disease, a neurological disease or a fall-related injury. Many of the participants had additional diagnosis such as diabetes, eye disease, etc.

Data collection in this study consisted of two questionnaires, the sickness impact profile (SIP), measuring perceived functioning in daily life (Bergner, Bobbit, Carter & Bilson, 1981; Sullivan M. 1988) and the occupational self-assessment (OSA), measuring perceived competence in daily life (Kielhofner, 2007; Kielhofner & Forsyth, 2001). The SIP has been designed to be broadly applicable across different types and severity of illness and across demographic and cultural subgroups. A Swedish version, which has been extensively tested for reliability and validity, was used in this study (Sullivan, Ahlmen, Archenholtz & Svensson, 1986). The OSA is an instrument under development and has only been sparsely evaluated in research but has been shown to work well across cultural and diagnostic differences (Kielhofner & Forsyth, 2001). The fact that the participants were participating in a day center program meant that they experienced some restrictions in their daily lives, so consequently perceived functioning and competence in daily

life were used to characterize the respondents. The concepts of functioning and competence in daily life in these questionnaires included important issues for the study, such as participation in activities and social life.

The OSA and the SIP assessment tools can be self-administered or used in interview form. In this study they were used as an interview to make it possible for participants with low vision to take part. The participants in the study also provided additional information, for example, age and gender, and number of months since their most recent stay in hospital. The interviews lasted about 1 hour each, and were undertaken in a quiet room at the center or in the person's own home, in accordance with the participant's preference.

In the analysis descriptive statistics were used to describe the characteristics of the participants in each group. Differences between the two groups, concerning men and women and living with spouse or alone were analysed by the chi-square test. Differences between the two groups, concerning SIP scores, OSA scores, age and number of months since the most recent hospitalization were tested by the Mann–Whitney nonparametric test. Potential correlations between the SIP and OSA scores were analysed by the Spearman rank order correlation test. A p-value of <0.05 was considered to be significant.

### **Method study III and IV**

The participants in studies III and IV included patients receiving services from a palliative home-care service and a palliative day program delivered by two different day-care centres. The day-care program was a hospital based out-patient service provided for palliative cancer patients. The program aimed to enhance well-being and quality of life. Occupational therapists and nurses managed the programs, and a multi-professional team comprising of a physiotherapist, a physician, a social worker and a chaplain was available for the participants if required.

The aim of study III was to investigate how people with incurable cancer engaged in and undertook activities in their everyday life. The aim of study IV was to study the outcomes of palliative day-care, in terms of health-related quality of life and the emotional well-being of cancer patients participating in a palliative day-care program for 5 weeks, compared with a group of palliative cancer patients not participating in day-care.

### *Participants, study III and IV*

The day-care sample consisted of patients consecutively enrolled into a palliative day-care program, where participants with a variety of primary cancer diagnoses could be included. In order to recruit a group for the comparative study (study IV) that was as similar as possible to the intervention group of palliative cancer-patients living at home and participating in day-care, a comparison group was recruited from a palliative hospital-based home-care service. In order to identify the comparison group, potential participants were matched with the day-care group with respect to gender, age, and level of functioning using Karnofsky performance index (Schag, Heinrich, & Ganz. (1984).

Once the patients had decided to attend the day-care program they were asked if they would like to participate in the study. Forty-eight patients agreed to participate in the study. Forty-seven patients were interviewed (30 from the day-care group and 17 from the comparison group) and 35 filled in questionnaires every week for five weeks (23 from the day-care group and 12 from the comparison group). The reasons for not answering the questionnaires (13 patients) were deterioration of health, hospital admittance, and death.

### *Data collection and analysis, study III*

The participants in the day-care programs were interviewed twice, with 5-6 weeks between the interviews. All interviews were conducted within the day-care settings. The participants who received home-care were interviewed once and the interviews were performed in their homes. The interviews lasted between 30 and 45 minutes and were conducted by the first author. An interview guide comprising open-ended questions was used to explore the topic of how the participants engaged in and dealt with activities in their everyday life. The questions placed an emphasis on learning about the participants' views, experienced events, and actions (Charmaz, 2006). Notes were taken during the interviews (Glaser, 1998) with the most interesting quotations or those that best illustrated particular issues being written down verbatim. Immediately after each interview, completed field notes were written to further expand upon and clarify the views expressed and experiences recounted by the participants. In addition, ideas were written down continually as they emerged in the form of analytical memos (Glaser, 1978). Subsequently the notes were transcribed on a computer.

The data analysis was conducted concurrently with the data collection according to the techniques of grounded theory (Glaser & Strauss, 1967; Glaser, 1978; Glaser, 1998). In the analysis significant phrases and sections in the interview notes were highlighted, and codes were inserted. Coded categories were then labeled and the categories that emerged from the data were, for example, structure, having something to do, having challenges and meeting others. A constant comparison of data with data, data with categories, and categories with categories was ongoing throughout the project to develop the categories and the generation of further concepts. The writings of analytical memos (Glaser, 1978) enabled for the documentation of theoretical ideas, insights, and interpretation during the data collection.

Through analysis in a back and forth process, categories emerged as tentative core categories, for example continuity, competence, and participation in everyday life. These ideas were examined through further empirical inquiry, and through theoretical sampling the participants were asked further questions, concerning experiences that had not been covered in the earlier interviews. Questions constantly changed during the data collection to probe issues relevant to the emergent categories and theoretical sampling. When a category became saturated, new questions of relevance to new emergent issues were asked. The data collection, which was performed at the same time and with the same sample as in study IV, continued with all the same patients as in study IV. Theoretical saturation of the categories was achieved within this sample. To enhance the process of data analysis and constant comparison recurrent discussions were held with the co-authors. The analysis and findings were also discussed in a peer-review research group. In addition to this, the first author received approval pertaining to relevance and workability when presenting the findings to a national group of qualified occupational therapy practitioners experienced in palliative care.

As a result a core category emerged in the analysis, and was named "*Striving for continued involvement in everyday life through the performance of activities*". Through theoretical coding, categories related to the core category were selected and linkages and relationships between the various categories were sought. The categories were identified as phases in a process, i.e. the process of striving for continued involvement in everyday life through the performance of activities. At this stage, a sorting of ideas, analytical memos, rather than of data took place. The categories that emerged were: experiencing progressive loss of ability to do activities in everyday life, revaluing,

being involved and active in everyday life, and experiencing pleasure, feeling competent, and being able to participate.

#### *Data collection and analysis, study IV*

In study IV the participants were invited to fill in two questionnaires once a week for a period of five weeks. For the palliative day-care group their first time to fill in the two questionnaires was one to two weeks after their first visit to the day-care setting. Participants filled in the questionnaires during the stay in the day-care setting. The five-week period of data collection in the comparison group was not related to entering the palliative home-care program. The participants in the comparison group could have received palliative home-care for any length of time as long as they fulfilled the inclusion and matching criteria. The comparison group filled in the questionnaires in their homes at a time of their own choice.

The assessment tools used included the measurement of health-related quality of life, the European Organization for Research and Treatment of Cancer Quality of Life Questionnaire (EORTC QLQ-30) (Aaronson et al. 1993) and the measurement of emotional well-being, the Mood Adjective List (MACL) (Sjöberg, Svensson & Persson, 1979; ). EORTC QLQ-30 was selected because it has been found to be valid and reliable in a variety of palliative care services, and also includes emotional and social functioning which was especially thought to reflect the influence of the day-care. The MACL (Sjöberg, Svensson & Persson, 1979) is designed to give a bipolar comprehensive assessment by self-reports of emotional well-being. A shortened 38-item version that was proven to have good validity and reliability (Lundqvist, Sjösten, Blomstrand, Lind & Sullivan, 1991) was used in the present study.

The data describing the two groups are presented using descriptive statistics, box plots and linear plots. The Mann Whitney U-test was used for cross sectional comparison between the groups and the Friedman's ANOVA for within group changes during the 5 weeks. In the statistical analyses only those participants who had filled in the questionnaires at all points of data collection were included. A p-value of <0.05 was considered to be statistically significant. The statistical analyses were performed in STATISTICA 7.1.

#### **Ethical considerations**

The ethics committees approved all studies in this thesis. The participants in all the studies were given written information about their

study and were invited orally to participate by the staff and the author. Research in palliative care in particular includes people who are in a vulnerable situation due to serious diseases and limited life expectancy. The recruitment of participants was done in a way that showed respect both for the informed consent of the participants and for confidentiality. The participants were approached with information about the study and asked about participating in a way that minimized the risk of putting pressure on them. Furthermore, they were informed about the possibility of terminating their participation at any time without specifying the reason.

The researcher was aware that questions about changes in everyday life may expose problems that the person might not be aware of regarding some aspect of their disease and its consequences. Meetings with participants were therefore conducted with special attention and care, for example, setting aside time to talk if necessary. In the interviews great importance was attached to formulating the questions with dignity and respect.

# OVERVIEW OF STUDY FINDINGS

## **Findings study I**

The aim of the first study was to conduct a phenomenological study of older people's positive experiences of spending time in a community-based activity center and of being engaged in occupations. An important finding was the participant's experiences of the activity center as a safe and familiar place. This finding should be seen in relation to how support from the professionals generated a feeling of security and was of great importance in the creation of a safe environment. A sense of security was also necessary for the older people to become involved in an activity, and it also made it possible for them to concentrate on and enjoy the occupations. Since many of the participants had partly lost functional independence, the regularity of attending the day-care provided them with a more active life.

It was also found in this study that doing and participating in an occupation in the activity center was absorbing and gave pleasure. Overall engagement in an occupation chosen by the person created a feeling of well-being. For some individuals it was more important to become totally absorbed in an interesting occupation than to do an exercise, for example to build up capacity in doing a much more boring occupation. The study gave examples of how participants could be happy to engage in their chosen occupation even if it resulted in pain afterwards, because the pursuit of the occupation disengaged them from the constraints of everyday living and gave them a feeling of well-being.

It was also a challenge for the participants to be able to accomplish something. To have the possibility of challenging one's ability and of developing a new skill gave personal satisfaction. The individual wanted to succeed and prove her or his ability. The feeling of relaxation after achieving something was appreciated and found to be meaningful. The activity center was also regarded by the participants as being a meeting-place where doing was shared with others. Doing things together was experienced as very important and served as a means toward the development of relationships with other people.

## **Findings study II**

The aim of study II was to identify characteristics of the older people living in their own homes and participating in social day centres compared with the participants of a rehabilitative day center, emphasizing on perceived functioning and competence in daily life.

It was found that the social day centre group consisted predominantly of single women, while there were more men than women in the rehabilitative day center group. Almost half of the rehabilitative group lived with a spouse, whilst only one person in the social center group lived with a spouse. All those who lived with a spouse were men. All participants had experienced some kind of disease or injury. Four people in the social day centers and four in the rehabilitative day program had experienced a fall-related injury, and the other eight people in the social day centers and eight in the rehabilitative day program had at least one medical diagnosis, for example, cerebral vascular accident (CVA), arthritis, heart-disease or a neurological disease. Many of the participants had additional diagnoses such as diabetes, eye disease, etc.

A difference was that the time that had passed since the onset of the disease or the time at which the injury had occurred varied considerably between the two different types of settings. The range for most recent hospital stay was between 24 and 96 months prior to the interview with the researcher for the participants in the social centers, but only between 1 and 12 months for 11 of the participants in the rehabilitative program.

The perceived dysfunction was especially high for both groups in the physical dimension, indicating high physical dysfunction, with no significant differences between the groups. In contrast, in the psychosocial dimension there was a significant difference between the groups, with lower perceived dysfunction in the group that attended the social day center, indicating that those in this group had better psychosocial functioning. The items most frequently rated as a problem in daily life for both groups on the OSA were 'physically doing what I need to do', 'getting where I need to go' and 'taking care of the place where I live'. All of these are closely related to physical dysfunction.

The OSA competence scores were significantly negatively correlated to the overall SIP scores for the social group, indicating that the OSA is in keeping with the SIP. The results also display large individual differences from high to low functioning within the social group, with a wide range of scores being measured by both the SIP and the OSA. For the rehabilitation group, the results showed no significant correlation between the OSA competence score and the overall SIP scores. However, the results for the group were restricted within a narrow range of scores measured with both the SIP and the OSA. This indicates accordance with the two questionnaires, since there were only small

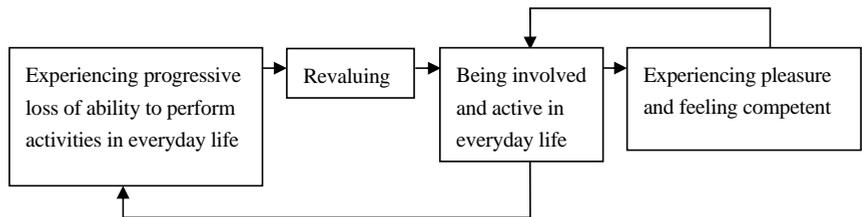
differences between individuals in the rehabilitation group measured by both questionnaires.

### Findings study III

The aim of study III was to investigate how people with incurable cancer engage in and undertake activities in their everyday lives. The findings show how the participants, despite experiencing the threat of progressive loss of functioning, were striving to remain involved in everyday life and how a driving force for continued involvement in everyday life was created. The possibility of doing was crucial in this process.

Experiencing pleasure and feeling competent when doing activities became a driving force for continued involvement in activities and for participation in daily life. The precondition for these experiences to arise was that the participant had revised her/his own expectations of his/her performance so that appropriate goals could be attained.

Thus, there was a process (Fig. 1) that was initiated by a need to revalue how best to perform activities in daily life, and this revaluation led to the creation of new challenges in everyday life as a prerequisite for the participant to experience the pleasure of being engaged in occupation. The motivation to remain involved and to be active in everyday life was developed through the experience of doing.



**Fig. 1.** The phases in the process of *Striving for continued involvement in everyday life through the performance of activities.*

### Findings study IV

The aim of study IV was to study the outcomes of palliative day-care, in terms of the health related quality of life and emotional well-being of cancer patients participating in a palliative day-care program during 5 weeks, compared with a group of palliative cancer patients not participating in day-care.

The results showed that the participants in the day care group and the comparison group reported similar levels of perceived functioning and symptoms, as measured by the EORTC QLQ-30, with no significant differences between the groups.

The day-care group reported higher levels of emotional well-being, as measured by the MACL, than the comparison group reported. The median in the well-being scales was higher in the day-care group than in the control group, although these differences were not statistically significant. These differences between the groups were present from the first week of the study. No statistically significant changes occurred in either group during the five weeks.

## GENERAL DISCUSSION

The participants in the four studies were older people with chronic conditions and patients in palliative care. The participants in the palliative group experienced a life threatening illness, while the older persons lived with some kind of chronic condition. However, the two groups shared at least one condition namely; none of the participants could expect to recapture full health. The discussion will be based on this view of similar and shared conditions and will not further discuss medical differences. In summarising the findings of the four studies the following topics will be further discussed: 1) Conditions in the environment influencing engagement in occupation. 2) Personal conditions for engagement in occupation. 3) Characteristics of being engaged in occupations.

### **1. Conditions in the environment influencing engagement in occupations**

#### *A place with a pleasant and friendly atmosphere*

The findings in study IV indicate that the participants in the palliative day-care program perceived higher emotional well-being than the comparison group, not participating in day-care. This finding indicates that having the possibility to come to the day-care setting was experienced as a source of well-being. Study I also provided additional knowledge on how the day-care setting was experienced by the participants. The participants spoke about a pleasant experience that provided a break in everyday life. Study I also demonstrated how important it was for the participants to have a special place to which they could go instead of being confined to the home setting all the time.

The importance of having the possibility to sometimes leave home and go somewhere else was an important finding both in studies I and III. Lyons et al. (2002) reported that participants in palliative day-care spoke with enthusiasm of attending the day-care program and joining the activities. The participants in Lyons et al. (2002) study saw a day away from home as an escape from boredom and loneliness and that the day-care program offered a place of refuge and comfort. The same aspects of the day-care program seemed to be of great importance also to the participants in the studies included in this thesis.

The participants in study I experienced it as important to simply be at the activity center, and to spend time in a setting where they were free to do something if they liked, or to just spend time in an environment

with a pleasant and friendly atmosphere. Lyons et al. (2002) study of palliative day-care also demonstrates the importance for the participants of having the choice to do or just sit and watch others in action. The atmosphere in the day-care program is of great importance for the outcome of the program. In an atmosphere of tolerance it is easy to become engaged in occupations, a receptive atmosphere forms a good basis for a pleasant milieu. Also la Cour et al. (2005) emphasized the significance of a generous environment in palliative day-care important for the patients to become involved and have the courage to create. The patients in the study by la Cour et al. (2005) felt free to be and do as they liked, and at the same time be supported and “pushed”. An atmosphere that builds on a balance of freedom and demands seem to be a key to the receptive generosity of the environment. In Lyons et al. study (2002) of palliative day-care the presence of the occupations themselves seemed fundamental to the value the participants attached to the day-care program.

The possibility to choose whether to actually perform an occupation or to just “spend time in an occupational setting” corresponds to Wilcock’s (1998) view of occupation as a synthesis of “doing, being and becoming” and her reflections on how a dynamic balance between doing and being is central to healthy living and wellness. Wilcock (1998) also stresses how becoming whatever a person is best fitted to become is dependent on both. Rowles (1991) argued that to provide a place for “just being” should be a component of occupational therapy. The day-care setting at its best could be an environment with the special characteristics of possibilities, of ongoing, but freely chosen occupations. People do not need to produce anything, they can just be there. In summary, the findings in studies I and II describe how the therapeutic aspects are nourished by a pleasant atmosphere with a climate of offering possibilities, without requiring the people to be productive. Participants can also choose to simply be present in the environment.

#### *Professionals providing safety and support*

The wellbeing of the participants in the different types of day-care programs was influenced by the safe and familiar settings that were attended on a regular basis (studies I and III). The presence of professionals provided a sense of security that was of great importance in the creation of a safe environment. Higginson et al. (2003) reported that the staff was of fundamental importance in the creation of an informal warm atmosphere in the day-care setting.

This sense of security was also necessary for the engagement of the individuals in occupations, and it also made it possible for them to concentrate on and enjoy the occupations. Also Lyons et al. (2002) found that the social climate created by staff members, particularly the sense of support, belonging and overall engagement, was a vital ingredient of the palliative day-care program. In addition Lyons et al. (2002) argues that the participant's interest in trying new unfamiliar activities and the ensuing pleasure were intertwined with the milieu which was created by staff members. The importance of the staff was also stressed by Eklund (1996); in a study of a group program in psychiatric outpatient occupational therapy the staff's understanding and helpful attitude was considered to be an important therapeutic factor.

The findings clearly demonstrate the importance of the staff's presence in the day-care setting. The staff should have a professional education in order to understand the individual needs of the participants. This is of special importance considering the findings in study II, demonstrating that the participants who used the social day-care services reported high levels of physical dysfunction. These findings have strong implications for how to set up and organise successful day-care programs. It is also interesting to find how the development of day-care services in Sweden has not taken this aspect into account. Present policies suggest that there is a need for places where people can meet and do things together, but it has not been suggested by the Delegation on Elderly Living (Socialdepartementet, 2007) that staff with occupational knowledge needs to be present.

#### *Doing together with others*

The findings showed how the day-care settings were seen to be a meeting place where doing was shared with others. Doing things together in the day-care context, was experienced as very important and served as a means for the development of relationships with other people (study I). Engaging in an occupation in collaboration with others provided a deeper relationship, another dimension, than just talking to each other. One example of this was when one man said: "*When you are working together with others, it is something more than just sitting and talking. You are more together, I think*" (study I).

A very interesting finding relating to the value of day-care was, according to the participants, the combination of being engaged in an occupation and being together with others. It was experienced as being more valuable than just socializing or just being occupied. Sharing and

doing things together was a good basis for enjoying the day-care programs. La Cour et al. (2005) reports that when the day-care participants engaged in creative occupations alongside others a natural meeting place was formed. This meant that social relations were framed in a process of actual doing, and there were more reasons to be present in the setting other than just sitting and talking.

## **2. Personal conditions for engagement in occupations**

### *Adapted expectations to altered circumstances*

For the participants with a life-threatening illness, it was not taken for granted that they would experience well-being when they were engaged in occupations (study III). With an ongoing deterioration in health it was not possible to continue to do things in the same way as they had been done before their illness, and they were likely to experience a progressive loss of occupation in their everyday life. Fisher et al. (2008) demonstrated in a study of palliative day-care that participants' experiences of losing the ability to undertake their normal every-day activities could sometimes be experienced as more devastating than receiving the diagnosis itself. This can be seen as some kind of occupational disruption or occupational loss (Wilcock, 2006). According to Townsend & Polatajko (2007) "occupational loss" occurs when a person can no longer participate in the normal routines and activities performed within their life context. Experiencing a long term loss may limit or change the choices, scope and number of everyday occupations in which a person engages. This could put the participants at risk of falling into a state of occupational deprivation described as the influence of an external circumstance such as an illness preventing a person from acquiring, using, or enjoying occupation (Whiteford, 2000; Wilcock, 2006).

In study II participants who used the social day-care services reported high levels of physical dysfunction. It is common to expect age-related deterioration of physical functioning according to for example Faber et al (2001). To choose to attend a social day-care program and at the same time experience severe physical dysfunction can be seen as a form of constructive adaptation to the restrictions in daily life. The participants in study II appeared to resolve some of the consequences of their physical restrictions in daily life, such as difficulties with accessibility and participation in the society, by attending a social day-care program. It is also possible that the participants had changed their perception of their own competence in everyday living by adapting their expectations and desires to altered circumstances as they became less

able to perform activities (Schkade & Schultz, 1992). The choice was to try new ways of having social contacts and engaging in occupations.

Based on these findings it is of great importance to better acknowledge that the existence of a day-care program made it possible for the participants in the present studies, to get out of their homes and to do things together with other people, thereby experiencing better well-being despite their physical restrictions (studies I, II, III, IV).

In study III the findings showed that the patients in palliative care had a strong desire to continue to be able to live their everyday life and to keep to the routines they had previously had. But it was not possible for them to continue to do things in the same way as they had done before their illness. In order to enable themselves to continue to engage in occupations, the participants changed their attitudes towards how much they believed themselves to be capable of, and they lowered their own expectations on themselves. They revalued what was important for them in their daily lives to enable themselves to continue to do the most important things. In adjusting their expectations, the participants also began to value and feel satisfaction from just very small benefits. The participants continued to be involved in their daily routines and learned how to continue in their everyday lives with lower expectations concerning their performance.

The process identified in study III suggests that what makes it possible to attach positive meaning to the new expectations is the performance of activities and the pleasure experienced from so doing. According to the cognitive theory of stress and coping (Folkman, 1997), people constantly appraise their interactions with their environment. Interactions that are appraised and considered to be stressful, e.g. receiving a diagnosis of cancer, require the adoption of coping strategies to reduce stress. When coping, an individual must first be able to relinquish unrealistic beliefs about how things are, revise those beliefs, and then substitute with new, downwardly revised expectations that are consistent with the revised expectations. Once this stage has been accomplished, the individual must be able to attach positive value and meaning to his/her new expectations (Folkman, 1997).

It is important to consider when interpreting the results of study III about revaluing that the participants all had a similar level of functioning; Karnofsky 60 or 70 (Schag, et al.1984). This implies that the person being assessed is unable to work, but is still able to live at home, and take care of the majority of his or her personal needs; it also implies that some assistance of varying degrees is needed. The reason

for the similar level of functioning amongst the participants is that in order to join the day-care program the participants had to be able to manage most of their personal care themselves.

This similar level of functioning of all the participants in studies III and VI at the time of the interviews is important to keep in mind when reflecting on the findings. It should therefore be stressed that the studies have not addressed how long the process of revaluing continues in a person's life, nor have they addressed how much functioning a person can lose in everyday life and still be able to revalue activities and at the same time experience pleasure from performing them. Rapkin (2000) argues that changes in goals and priorities have the potential of attenuating threats and people's goals and concern continue to change during the course of serious illness, perhaps to the end of life.

### **3. Characteristics of engagement in occupation in the context of day-care programs**

#### *Challenging one's ability*

It was a challenge for the participants in the day-care programs to be able to accomplish something, and the actual performance of an occupation often seemed to include a challenge. However, the individuals also wanted to challenge their ability, at least a little (study I). The opportunity to challenge one's ability and to develop new skills gave personal satisfaction. Study III showed that the participants created new challenges as a replacement for lost occupations, in order to continue to experience the pleasure of being engaged in an occupation. The participants chose new challenges to compensate for the activities they were not able to do any more, since it was still important to have goals to accomplish in their everyday life. For example they might choose to attend a day-care setting regularly as compensation for not having a job to go to. Based on this one can conclude that it seems important to explore new possibilities for occupational engagement within the constraints of an illness. Lyons et al. (2002) also reported how participants in palliative day-care view the significance of the day-care program as a refuge from boredom and isolation.

In addition, to having the possibility to engage in creative activities, offering the right level of challenge enabled the participants to experience joy and pleasure and competence and made it possible for them to forget their illness for a while. Flow Theory (Csikzentmihaly, 1991) is useful in understanding the aspects of the occupation, the

environment and the person that contribute to a just right challenge, and to enabling occupational performance through enjoyable, structured and purposeful activity.

### *Experiencing competence*

Study III showed that the experience of being engaged in occupation provided a message to patients facing a life-threatening illness that they were still capable and alive, despite the threat of progressive loss of functioning. In a study of women with breast-cancer Vrkljan and Miller-Polgar (2001) described the women's experience of "doing=living" illustrating the connection between occupational engagement and one's self-perception of being a capable and healthy individual.

In study III it is described how lowered expectations concerning performance gave the right kind of possibility to continue by partly doing daily activities as well as performing new and engaging activities that enabled the patients to feel a sense of competence. It has been reported in a study of incurably ill cancer patients (Johansson, Axelsson & Danielsson, 2006) how participants emphasized what activities they could perform in daily life, not their shortcomings, which also illustrates the strive to achieve a sense of being capable. La Cour, Josephsson, Tishelman and Nygård (2007) points out that participants spoke of creations they had made themselves as indications of being active and productive, and how satisfaction could be achieved from both the process and the products of crafting. Also Unruh (2000) in a study of the experiences of women with breast-cancer reported on the sense of satisfaction and accomplishment they experienced through gardening efforts.

Study I showed that the experience of performing occupations was also related to being productive and to gaining recognition for that from others. These findings could be seen as examples of how an individual wants to succeed and prove her or his ability. Learning a craft such as weaving and woodwork required the ability to construct a product, and the product can be proof of the ability of the person, both to self and to others. Also la Cour et al. (2005) reported how patients spoke with pride of having produced something purposeful and worthwhile in the palliative day-care setting. The result achieved was a source of pride and satisfaction, also when giving creations away as presents and making others happy (la Cour et al. 2005). When an occupation provides the right kind of challenge it enables the person to experience

a feeling of competence. This experience of competence is essential when it comes to creating therapeutic occupations.

### *Experiencing pleasure*

Study I demonstrated characteristics of perceived benefits of engagement in occupation and how the well-being of the participants was influenced. For example being engaged in an occupation in the day-care program was experienced as absorbing and gave pleasure. Also study III demonstrated how the well-being of the patients in palliative care was improved by their engagement in occupation which enabled them to experience joy and pleasure and made it possible for them to forget their illness for a while. La Cour et al. (2005) reports in a similar way how engagement in creative occupations contributed to experiences of profound joy. Lyons et al. (2002) stated that more than any other characteristics of the day-care program, a sense of enjoyment was a feature that participants consistently identified as an integral part of the day-care experience.

Engagement in occupations chosen by the person him- or herself was a prerequisite for feelings of well-being. For example, a participant could choose to engage in an occupation even if it perhaps caused them pain afterwards, because they enjoyed doing this and the pursuit of the occupation disengaged them from the constraints of everyday living and also gave them a feeling of well-being (study I). Bundy and Canella (2001) argued that to become totally absorbed seems to be one of the most important factors in choosing to participate in an occupation. To be totally absorbed was also named by Csikzentmihalyi (1991) as the experience of “Flow - the optimal experience”. For some of the individuals in study I it seemed more important to become totally absorbed in an interesting occupation than to build bodily capacity doing a more boring occupation. This relates to Fidler and Fidler’s (1978) early statement that if treatment in occupational therapy is heavily biased toward physical exercise, and if treatment responds to symptom rather than to performance, occupations will have a very limited effect. Based on the findings in study I it can be argued that one condition of a therapeutic occupation is that it should give pleasure in its performance.

### *A feeling of health is experienced*

Being able to engage in everyday activities served as proof to the patients in palliative care that they were still able to be capable individuals and the fact that they were capable provided the grounds for and gave them the experience of being healthy (study III).

The definition of health as the experience of ability to engage in occupations is discussed by many researchers in palliative care. Vrkljan and Miller-Polgar (2001) found that individuals who were able to maintain their habitual pattern in daily life despite the limitations imposed by their life-threatening illness, defined themselves as being 'healthy with cancer'. In addition, Fryback (1993) also noted how individuals with a life-threatening diagnosis defined themselves as being unhealthy; it was not as one would expect, due to their diagnosis, but because they were unable to engage in those occupations they desired to do.

Salander, Bergenheim and Henriksson (2000) identified concepts of the 'time of everyday life' and the 'time of disease'. By the 'time of everyday life', it was meant the time during which life continues as normal. By 'time of disease', it was meant the amount of time when life is primarily occupied by the disease, during which life-continuity is disrupted. Benzein, Norberg and Saveman (2001) described cancer patients' experience of belonging to both life and death, as a dialectic experience of belonging to 'two worlds simultaneously', the world of the sick and the world of the healthy. Also la Cour et al. (2007) discussed the complexity of being both sick and healthy, and argues that the focus on health-associated occupations becomes an active resistance toward the illness itself and toward the way in which participants are seen by other people and society.

#### *Continuity is experienced*

Being a regular attendee in a day-care setting could be particularly important to older people with some kind of chronic conditions (study I). The regularity of the visits to the day-care setting provided a structure for the day or a rhythm in the daily lives of the participants. Since many of the participants had lost much of their functional independence, the day-care visits, becoming a weekly routine, provided them with a more active life pattern and a possibility of maintaining temporal continuity. Jackson (1996) found in a similar way that older people with disabilities who were living successfully in the community developed occupational routines as an adaptive strategy that provided them with a feeling of security.

Findings in study III also showed that the patients in palliative care in spite of the ongoing deterioration in their health were highly engaged in everyday life. The patients in study III had a strong desire to retain daily routines and to continue to be engaged in occupations. The existence of

a day program provided the possibility to be a regular attendee and for continued involvement in occupations. In addition, the studies also provided examples of how doing and being engaged in occupations served as a foundation for the experience of continuity. La Cour (2008) reports that palliative patients emphasized a striving to create ordinary days very much like any other day, giving a sense of repetition and continuity. This was found to be a tool for participants to counteract the threatened loss of occupation they might experience while simultaneously creating satisfaction and value in daily life.

A desire to continue to live a normal life is a phenomenon considered in the continuity theory, developed by Atchley (1989) that states that individuals wish to continue the lifestyle to which they have become accustomed over the years and holds that individuals make adaptive choices that allow them to feel a sense of continuity between past and current events. Gahnström (2003) also found in a study conducted in a psychiatric setting that a working cooperative shaped a life-world that normalized the participant's life, and this was appreciated by the participants.

## **Methodological considerations**

### *Study I*

The study aim was to investigate older people's positive experiences of spending time in an activity center and of being engaged in occupations. The choice to focus only on positive experiences can be an issue for discussion. The researcher's interest that guided this study was to create knowledge about what it means for older people with chronic conditions to be engaged in occupation, in order to gain a greater understanding of the use of occupation as a therapeutic medium. In study I this implied that the benefits of being engaged in occupation were investigated and described in order to explore the therapeutic potential of occupations. Another option for a study would have been to ask people about any kind of experiences from being involved in the day-care program. This would have provided more knowledge about the program as such, however it was not in the focus of interest in study I.

It is also possible to question the validity of the study in the year 2008, since it was conducted over ten years back in time. The organization of day-care programs in the municipalities is under constant change, and since a decrease in the provision of day programs has been ongoing for years, it is possible that some of the investigated programs have closed down. However, the findings build on the experiences of the individuals

participating, and the phenomena under study are not vulnerable to the passage of time; i.e. the older people's positive experiences of spending time in a community-based activity center and of being engaged in occupations. To learn about these topics can still be considered as valid and interesting for research.

Conducting just one interview with each participant could be a limitation in this study, since it could be questioned if it is possible to perform in-depth interviews when only meeting the respondent once. However, since the aim not was to understand the person in the interviews, but to understand the descriptive phenomena of having positive experiences in a day-care context, one interview per person was considered to be satisfactory. Nevertheless, the study suggests that the phenomena under study need to be further explored in other contexts, also including participants with other types of health conditions.

### *Study II*

This study was designed to provide a picture of the individuals participating in two different types of day-care programs, through identifying characteristics of the two groups, described as functioning and competence of the participants.

There are several different forms of day programs for older people in Sweden, but little is known about the persons involved in them. The findings showed that the participants in the social day-care program experienced severely restricted physical function, but on the other hand they perceived better psychosocial function than the group attending the rehabilitative center. This result implies that the centers could serve as an important meeting place for older people who would otherwise be isolated in their homes due to their physical restrictions. In order to fulfil this challenge, the day centers need to improve the quality of the service with regard to the severely restricted function of the persons using this service, not reduce it. The study design makes it possible to demonstrate the needs of the older people using the day programs, in order to consider the level of service required.

The small sample size in the study is a limitation and makes it difficult to generalize about the findings and also increases the risk of a type II error. A larger sample might, for example, have revealed more significant differences between the groups on the SIP and OSA scores. Another limitation is that the validity and reliability of OSA is sparsely evaluated in this population and there is still a lack of normative scores,

whereas the SIP has been well tested for reliability and validity (Sullivan et al. 1986).

However, to use the SIP and the OSA as measures of perceived functioning and competence in daily life to understand the needs of the older people using the day programs appears to have been successful, since these measures revealed interesting characteristics of the participants' health status and problems related to participation in activities and social life. The correlation between the two instruments has not been investigated in any earlier study, although the findings of this investigation indicate that the OSA corresponds with the SIP.

### *Study III*

The aim of this study was to investigate how people with incurable cancer engage in and undertake activities in their everyday lives. Knowledge of how cancer patients engage in occupation will contribute to the understanding of the therapeutic aspects inherent in occupation.

It should be emphasized that activities in everyday life are only one part of an individual's life world, and the process described in the study of continuing to perform activities and of participating in everyday life, is just a small part of the daily living an individual with a life threatening disease is engaged in. Engagement in activities does not represent the individual's entire being. It is of great importance for the study to acknowledge how the participants in this study were patients connected to specialist palliative home-care or day-care units. They received the highest quality of symptom control, as well as the psychosocial counseling required when dealing with fears related to the future and preparation for advancing illness and death. These interventions probably also influenced how they experienced everyday life, and they may have enhanced their ability to handle the strain of living with a life-threatening cancer.

Just taking notes when collecting data during the interviews could be a limitation in the study, since using a tape recorder provides more detailed information. When taking notes it could afterwards be difficult to know exactly what the individuals said, there is also the risk of misinterpretation since it is not possible to go back and check. However, in this study the choice was made to just take written notes. According to Glaser (1998), field notes are preferable to tape recording when using the grounded theory approach because it is possible to code and analyze the data before conducting further data collection, which is an important part of the constant comparative method. In addition to

this, field notes make it easier to conduct brief interviews on particular issues and based on theoretical sampling.

Notes were taken during the interviews and also the most interesting quotations or those that best illustrated particular issues were written down verbatim. A decision was made to not use a tape recorder, since tapes would in this case have generated large quantities of data that were not needed in order to respond to the research question. To make sure that interesting data were not lost, field notes were written immediately after ending the interviews, to further expand upon and clarify the views expressed and experiences recounted by the participants. In addition, ideas were written down continually as they emerged in the form of analytical memos (Glaser, 1978). The notes were subsequently digitally transcribed.

#### *Study IV*

The aim of study IV was to study the outcomes of palliative day-care, in terms of the health related quality of life and emotional well-being of cancer patients participating in a palliative day-care program for 5 weeks, compared with a group of palliative cancer patients not participating in day-care.

It is possible that with a larger sample and a longer period of data collection it may have been possible to identify a difference between the two groups of participants concerning health-related quality of life. As in most clinical studies, there were a limited number of participants available for this study and as in all studies of this type this is a limitation. In addition it is necessary to consider the length of the follow-up period with regard to the participants' health condition. Palliative day-care service in Sweden is provided very sparsely which rendered it unfeasible to perform a study including more participants. A strength was the use of a comparison group matched for characteristics. The comparison sample was controlled for three matching characteristics, age, gender and level of functioning. Moreover, all the participants demonstrated a similar level of functioning.

An additional issue that was raised in the design of the study was the inability to collect data from the day-care patients before they attended the day-care, since this would have provided baseline data before the intervention. There can be problems in evaluating a service already in operation and of recruiting and studying a vulnerable and deteriorating population of patients. It was considered impossible from an ethical point of view to collect baseline data from all patients referred to day-

care. Consequently it cannot be ruled out that the day-care participants might already have been influenced by their experiences from day-care at the first point of data collection and this might have contributed to their perceived better emotional well-being at inclusion.

It is important that outcome measurements used to build evidence regarding interventions reflect variations in variables representing the same construct as the specific goals that the intervention under evaluation is aiming to influence. A health-related quality of life measurement, as the EORTC QLQ-C30 used in this study, includes those aspects of quality of life that are most influenced by health and health-care interventions (Kaasa & Loge, 2002). However the primacy given to health may be questioned in this population (Waldron et al. 1999). The palliative day-care intervention, focused on achieving better well-being in spite of the deteriorating health of the patients, is possibly more appropriately assessed by a an instrument that is not health-related.

The EORTC QLQ-C30 was selected because it was thought to reflect the objectives of day-care, especially emotional and social function, and the instrument has been found to be valid and reliable in a variety of palliative care services. However, the EORTC QLQ-C30 did not seem to contain items that were relevant to the well-being achieved by participating in day-care. Instead the MACL, which measures both positive and negative emotions, seemed to be sensitive to the day-care intervention. This might be explained by the fact that well-being appears to be improved or maintained by palliative day-care intervention despite the fact that functioning and symptoms remain unaffected.

## CONCLUSION AND IMPLICATIONS

The studies indicate that well-being could be influenced through engagement in occupations in the context of the day-care programs. One conclusion from the studies is therefore that a person with a chronic condition or illness can benefit from therapy through engagement in occupation, if for example, the therapeutic characteristics and conditions presented here are present. This finding indicates that emotional well-being can be influenced by occupation-based programs even when no improvements are made in relation to the medical condition.

It is important to reflect on the results in study IV with respect to the design of future studies on these topics. In study IV, the findings indicate that the participants in palliative day-care experienced better emotional well-being than a comparison group who did not participate in day-care. However, the results showed no difference between the groups in terms of experienced body function and symptoms of the disease as indicated by a health-related quality of life measurement. It is therefore also of great interest to consider further how these results can be interpreted.

In an attempt to better understand the lack of coherence in results, Dabelko & Zimmerman (2008) claim that studies of the outcomes of day-care services have neglected the examination of how a program works. Careful consideration of program activities and the examination of meaningful outcomes are necessary in order to demonstrate the effect that programs have on participants. Dabelko & Zimmerman (2008) also point out how previous studies of day-care programs not have linked participant needs and the content of the service to specific outcomes. In this thesis for example, in the case of study IV, it is plausible that the palliative day-care program that aimed at enhancing well-being through engagement in occupation, was also properly measured by an emotional well-being measurement. However, the measurement of health-related quality of life symptoms and functioning was not appropriate, since the participants with a life threatening disease and deteriorating health were not expected to recapture full health.

The present thesis has in a substantial way provided example of how it is possible to in greater detail, describe what therapeutic engagement in occupations can be and also the conditions for therapeutic engagement in occupations. The studies could be seen as examples of how an occupational perspective in research seeks to acknowledge the

occupational nature of humans. Based on the findings presented it is possible to summarize and hypothesize in greater detail as to what has always been a focal viewpoint in occupational therapy (Kielhofner, 2007; Townsend & Polatajko, 2007), that aspects like the conditions in the environment, the nature of the occupation, as well as the conditions for the individual constitute important components for health and well being. Future studies of day-care could base the design of such studies and the choice of outcome measures on the findings presented below (Table 2).

Table 2. Therapeutic aspects of engagement in occupations

<b>Therapeutic aspects of engagement in occupations in the context of day-care programs</b>
<p><b>Conditions in the environment:</b>  <i>A place with a pleasant and friendly atmosphere</i>  <i>Professionals providing safety and support</i>  <i>Doing together with others</i></p>
<p><b>Personal conditions:</b>  <i>Adapted expectations to altered circumstances</i></p>
<p><b>Characteristics of engagement in occupations:</b>  <i>Challenging one's ability</i>  <i>Experiencing competence</i>  <i>Experiencing pleasure</i>  <i>A feeling of health is experienced</i>  <i>Continuity is experienced</i></p>

These findings could also be seen as a foundation for the planning of occupational intervention programs for people with chronic conditions and illnesses. The basic knowledge of occupational engagement acquired in this thesis could be translated into many practical applications. Understanding the specific interventions received by individuals and the resulting outcomes will assist in strengthening individualized service planning and the development of best practices by the providers.

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