General Motor Function Assessment and Perceptions of Life Satisfaction during and after Geriatric Rehabilitation

BY

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Abstract
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Two main goals of geriatric rehabilitation are to re-establish ability for physical function in
order to facilitate independence in activities of daily living (ADL), and to promote an optimal
degree of well-being, i.e. life satisfaction, in the individual. In this research a new scale, the
General Motor Function assessment scale (GMF), was developed and evaluated.
Subsequently, factors perceived as important for the life satisfaction of people undergoing
geriatric rehabilitation were investigated.

The GMF includes both mobility and upper limb functions and comprises three subscales
covering different aspects of functioning, namely performance-related Dependence, Pain and
Insecurity. The clinical practicality of the GMF was evaluated by a field test. Its psychometric
properties were analysed in both hospital and community-based settings of geriatric
rehabilitation, using non-parametric statistical methods. The results indicated that the GMF is
clinically adequate, possesses good reliability and is sensitive enough to demonstrate changes
from pre- to post-intervention in different forms of geriatric rehabilitation.

For investigation of perceptions of life satisfaction, individual qualitative interviews were
conducted with old (80+) care recipients and with their significant others, who had a helping
relationship with them. The results revealed that habitual activity, independence and
adaptation were generally considered to be important for the life satisfaction of the care
recipients. Recalling of pleasant past memories in an effort to achieve current life satisfaction
was a commonly used adaptive strategy among the care recipients. This strategy created a
temporary sense of life satisfaction, with a potential for concealing dissatisfaction with
conditions that might otherwise be correctable. From the perspective of the significant others,
protection of the continuity of the care recipients’ self was seen as vital for the latter's life
satisfaction, and was thus an underlying general purpose of the informal caregiving.

Keywords: geriatric rehabilitation, motor function, assessment, qualitative interviews, life
satisfaction, self-expression, informal care

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List of Papers

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


Reprints were made with the permission of the publisher
Att åldras är ungefär som bergsbestigning.
Man blir lätt andfädd, men man får också mycket bättre utsikt.

Ingmar Bergman
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# Abbreviations

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<tr>
<td>ADL</td>
<td>Activities of daily living</td>
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<td>GMF</td>
<td>General Motor Function assessment scale</td>
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<tr>
<td>IADL</td>
<td>Instrumental activities of daily living</td>
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<td>ICF</td>
<td>The World Health Organization’s International Classification of Functioning, Disability and Health</td>
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<tr>
<td>ICIDH</td>
<td>The World Health Organization’s International Classification of Impairment, Disability and Handicap</td>
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<tr>
<td>KW</td>
<td>Kruskal-Wallis one-way analysis of variance test</td>
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<td>Md</td>
<td>Median</td>
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<tr>
<td>PA</td>
<td>Percentage agreement</td>
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<td>PADL</td>
<td>Personal activities of daily living</td>
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<td>QOL</td>
<td>Quality of life</td>
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<td>ra</td>
<td>Augmented rank-order agreement coefficient</td>
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<tr>
<td>RC</td>
<td>Relative concentration</td>
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<tr>
<td>RP</td>
<td>Relative position</td>
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<td>RV</td>
<td>Relative rank variance</td>
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<tr>
<td>rs</td>
<td>Spearman’s rank correlation coefficient</td>
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<td>WHO</td>
<td>World Health Organization</td>
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One of the main goals of geriatric rehabilitation is to re-establish and maintain the ability of physical functioning, in order to facilitate independence in activities of daily living (ADL). This is based on the assumption that the ability of older people to maintain daily activities determines their level of independence and influences their overall quality of life (QOL), including life satisfaction, which constitutes the subjective or perceived QOL (Heady, 1992; Meeberg, 1993). Several studies have pointed to a positive correlation between physical functioning, level of activity and QOL at higher ages (Bowling, 1990; Grimby, Grimby, Frändin, & Wiklund, 1992; Hilleras, Jorm, Herlitz, & Winblad, 2001). Moreover, both physical and social activity has been assigned a relation to a positive sense of self and life satisfaction in old age (Atchley, 1999; Fernandez-Ballesteros, 2001). Despite this, a valid instrument feasible in geriatric care for the general assessment of functional limitations, such as limitations of motor function, has been lacking (Sletvold et al., 1996).

The overall goal of rehabilitation is that the individual shall achieve an optimal degree of social well-being and an optimal ability to be active and fulfil vital life goals (WHO, 1980). However, rehabilitation goals from the older patient’s perspective are not well described, and studies of the extent to which the researchers’ definitions of QOL correspond to the elderly patients’ conceptions are sparse (McWilliam, Brown, Carmichael, & Lehman, 1994; O’Boyle, 1997; Sarvimäki & Stenbock-Hult, 2000). It has been shown, further, that older patients do not generally participate in the goal-setting of their own rehabilitation (Baker, Marshak, Rice, & Zimmerman, 2001; Wressle, 1999). Moreover, patients, their informal caregivers and clinicians are all able to describe goals of elderly care, but may bring differing perspectives to the goal-setting process (Bogardus, Bradley, & Tinetti, 1998). Since significant others, in the long term, commonly are the most important source of care and support for many people (Pickard, Wittenberg, Comas-Herrera, Davies, & Darton, 2000), their influence on the care provided is of vital importance.

Hence, to approach these goals of geriatric rehabilitation and to evaluate the results of interventions, assessment instruments useful for indicating the need for treatment of motor function and for evaluating the effects of that
treatment are needed. In addition, it is necessary to improve the understanding of what factors are important for the patients’ life satisfaction from their own viewpoint, as well as from that of their significant others.

Geriatric rehabilitation

The concept of geriatrics involves the understanding of consequences of the interactions between disease, psychosocial and environmental factors, and old age. Rehabilitation has been defined as all activities aimed at reducing the effects of functional limitations and handicapping conditions, as well as at social integration of the individual (WHO, 1980). Rehabilitation is commonly referred to as a process, which in turn is defined as a ‘series of operations, events or steps leading to the achievement of a specific result’ (Dorland, 1985). Geriatric rehabilitation can be regarded as a multidimensional process, which is based on problem-oriented – in contrast to diagnosis-directed – multidisciplinary teamwork, involving functional, medical, caring, psychological and social factors (Styborn, Larsson, & Drettner, 1994). Age definitions of patients in geriatric care vary between countries and depend upon the structure of the health care systems. The official retirement age, which in Sweden commonly is 65 years for both men and women, is often used as a lower limit. In this thesis the terms ‘older’ and ‘elderly’ are generally applied to the age of approximately 65 years and above. The older patient’s bodily and psychosocial conditions, problems and resources, as well as the perceptions of that person and of the person’s significant others should ideally be appreciated and allowed to influence the planning of the geriatric goal setting and care.

The geriatric team usually consists of a physician, nursing personnel, a clinical social worker, an occupational therapist and a physiotherapist. Sometimes the team is complemented with a speech therapist or nutritionist. According to the Swedish Board of Health and Welfare (Socialstyrelsen, 1999), the specific role of the physiotherapist in the geriatric team involves interventions to promote movement functions, movement ability and movement behaviour, and to provide adequate pain relief. Co-operation with other staff and significant others, and reporting to other care providers in an unbroken care path, are also emphasised as a vital part of the work.

Geriatric rehabilitation services include several forms of care, both in hospital and in community settings, including institutional care, day-care and home rehabilitation. Since a combination of old age and disease extends the need of care, older people have a greater need of rehabilitation than younger ones (Felsenthal, Garrison, & Steinberg, 1994). Therefore, the entire process of rehabilitation of the elderly commonly engages several formal as well as
informal caregivers in a care path, which for some continues for the rest of their lives.

To evaluate the results of geriatric rehabilitation interventions, the traditional measures of health care outcome in terms of mortality, morbidity, cost-benefit and measures of medical signs or symptoms, are not always sufficient or even relevant. One reason is the increasing incidence of chronic disease and disability accompanying ageing. Hence, researchers in this field are now increasingly concerned with evaluation of the patients’ functioning and preferences, including QOL (Svensson, 2001a).

The disablement process in the elderly

Although there are reports on trends of declining disability rates among older people, studies still show a higher rate of chronic disabling diseases among older than among younger people (Guralnik, Branch, Cummings, & Curb, 1989; Khaw, 1997; Manton, Corder, & Stallard, 1997; McMurdo, 2000; Melzer, McWilliams, Brayne, Johnson, & Bond, 2000; Tonks, 1999). Elderly individuals with chronic diseases or disability, and the oldest old (80+) are characterised by multiple pathology, non–specific presentations of symptoms, a high incidence of secondary complications, and a high need of intensive rehabilitation (Felsenthal et al., 1994; Tonks, 1999). Living with the functional limitations and the disablements that these conditions bring about emphasises the importance of rehabilitation to increase the ability to function and live in a home environment.

Investigation of disablement is, hence, a major concern in geriatric research (Jette, 1997; Simonsick et al., 2001; Verbrugge & Jette, 1994). Several conceptual schemes for defining and classifying key factors involved in the process of disablement and relating them in meaningful systems have been developed. One of the most best-known is the WHO model, the International Classification of Impairment, Disability and Handicap (ICIDH) (WHO, 1980), which recently was followed by a further developed version, the International Classification of Functioning, Disability and Health, known as ICF (WHO, 2001).

In contrast to both these classifications, the socio-medical model, the Disablement Process, conceptualised by Verbrugge and Jette (1994), represents a more obviously process-oriented perspective of disablement. This model is an extension and elaboration of the Nagi scheme (Nagi, 1969). It includes the potential for recovery from disability and/or transition back to a less disabled or healthier state and takes into account the risk of secondary conditions and dysfunctions as a consequence of negative feedback effects, a
risk which is particularly applicable to people with chronic conditions and of higher ages.

The Disablement Process links Pathology and Impairment with Functional Limitations and Disability in a multidimensional process - rather than a static state. In contrast to the WHO classifications, the Disablement Process emphasises the stage between Impairment and Disability. This stage is labelled Functional Limitations (Verbrugge & Jette, 1994).

Functional Limitations are identified as limitations in the task-oriented action executed by an individual, for example in the performance of motor function. This concept has been shown to be a key component and a main driving force in the disabling process and therefore needs to be elucidated in rehabilitation and assessed separated from disability, such as difficulty in performance of ADL (Femia, Zarit, & Johansson, 2001; Gill, Williams, Mendes de Leon, & Tinetti, 1997; Verbrugge & Jette, 1994). The treatment of Functional Limitations is a fundamental part of geriatric rehabilitation, since physical functioning is an essential prerequisite for independence in ADL and for good health among older adults (Cress et al., 1995; Guralnik et al., 1989; Judge, Schechtman, & Cress, 1996). Furthermore, the capability of older persons in ADL depends on their ability to manoeuvre safely and effectively (Fleming, Evans, Weber, & Chutka, 1995). Ability in ADL has, in turn, been considered to be positively related to measured subjective well-being (Noro & Aro, 1996; Sonn, 1996). One recent study on patients in geriatric care, however, unexpectedly showed no statistically significant covariance between ADL dependence and measured subjective well-being (Nygren, Iwarsson, & Dehlin, 2000).

As mentioned above, the Disablement Process (Verbrugge & Jette, 1994) takes into account the risk of secondary conditions and dysfunctions as a consequence of negative feedback effects. Reduction of an activity level caused by negative emotions, such as situation-specific pain, and insecurity due to fear of failure, may, in a specific disablement process, entail secondary effects on other bodily functions and thereby impair, for example, cardiopulmonary function and muscle strength. This risk is particularly pronounced among frail and elderly people with chronic disorders (Verbrugge & Jette, 1994). Furthermore, previous studies have confirmed that both pain (Brattberg, Parker, & Thorslund, 1996) and fear of falling (Kressig et al., 2001) are prevalent among older persons with frail health. Research has confirmed that in the elderly, pain is associated with difficulties in performing ADL (Scudds & Robertson, 1998; Won et al., 1999) and that fear of falling is associated with functional limitations (Kressig et al., 2001) and with decreased QOL (Salkeld et al., 2000; Suzuki, Ohyama, Yamada, & Kanamori, 2002). One recent study, further, showed that musculoskeletal pain is common and persistent among older women
with disability and appears to predict the progression of disability (Leveille et al., 2001). Thus, several factors closely connected with motor functioning, such as performance-triggered pain and insecurity, have the potential to have a negative influence on the disablement process in older persons and reduce their QOL.

Since the Disablement Process concept was first introduced, the perspectives of the conceptual models of disability have been shifted from exclusively focusing on consequences of disease to additionally including components of health. Jette (1997) presented a further developed version of the Disablement Process, in which the main pathway of the process has a slightly reversed terminology, including a mix of relating negative and positive terms (Fig. 1).

![Figure 1](image1.png)

Figure 1. The main pathway of the Disablement Process as conceptualised by Verbrugge and Jette (1994) and further developed by Jette (1997).

With the recent development of the health-oriented classification ICF (WHO 2001) from the previous classification ICIDH, with its negative terms, WHO provided the option of expressing some main concepts in two ways: both in negative terms to indicate problems, and in positive terms, as non-problematic aspects of health. According to the ICF the main pathway of disability and health, comparable to the Disablement Process, includes only three main components (Fig. 2).

![Figure 2](image2.png)

Figure 2. The main pathway of the ICF, including positive health terms and corresponding negative terms.
Within the framework of ICF the term Activity is used in its broadest sense to capture everything that an individual does, at any level from simple activities to complex skills and behaviours. The domains for Activity cover the full range of life areas, from communication, self-care, mobility and interpersonal interactions to social and civic life and are regarded as a positive health aspect. Participating covers the same domains but is defined as involvement in a life situation. These domains are qualified by the two qualifiers performance and capacity. The Capacity of an individual describes her or his ability to execute a task or an action in a ‘standardised environment’, whereas Performance describes what an individual does in her or his current environment including the social context (WHO, 2001). Additionally the ICF includes personal and environmental factors, comparable to the intra-and extra-individual factors of the Disablement Process, which can modify the main pathway by facilitating or hindering the process of disability and/or health. The ICF does not, however, model the process of functioning and disability, although it can be used ‘to describe the process by providing the means to map the different constructs and domains’ (WHO, 2001, p 18).

Recently, Ueda and Okawa (2003) have claimed that the ICF lacks an important dimension of human life, namely the subjective dimensions of functioning and disability. They consider that the understanding of the subjective experience of disability, which is defined as ‘a set of cognitive, emotional and motivational states of mind’ (Ueda & Okawa, 2003, p599), provides a vital benefit in clinical rehabilitation. It should be noted that the subjective dimension includes both positive and negative aspects, of which the experience of satisfaction in relation to each of the ICF terms - Body Structure and Functions, Activities and Participation – is central. The authors conclude that subjective dimensions of functioning and disability should be actively discussed among professionals and people with disability, to facilitate its future inclusion into the ICF.

Assessment of motor functioning in geriatric rehabilitation

Assessment of an individual’s level of functioning is the starting point for and a cornerstone in geriatric rehabilitation (Branch & Meyers, 1987; Guralnik & Winograd, 1994; Kane & Kane, 1981; Sletvold et al., 1996). The assessment of functional limitations regarding body movements, i.e. motor functions, is the key that directs physiotherapy intervention in geriatric rehabilitation. However, the absence of and demand for a satisfactory scale for general assessment of motor functioning, that is valid, reliable,
acceptable to the patient, responsive to change and easy to administer, have
been stressed (Sletvold et al., 1996).

Although several scales for assessment of motor functioning have been
developed, few of them, if any, are suited for overall use in a clinical setting
of geriatric rehabilitation. The Elderly Mobility Scale (EMS) (Smith, 1994)
and the Physical Performance and Mobility Examination (PPME) (Winograd
et al., 1994) include only mobility functions, despite the fact that upper limb
functions are necessary for independence in ADL. Older persons with poor
hand function tend to need more care resources and run a risk of
institutionalisation (Fleming et al., 1995). The Physical Performance Test
(PPT) (Reuben & Siu, 1990), however, assesses multiple domains of motor
function. The PPT is focused on measurement of fairly advanced and
complex functions and activities, including mobility and hand functions. The
items of the PPT are scored by measuring the time required to perform the
tasks. However, all these three assessment scales lack a multidimensional
approach, by not taking interactive factors, such as pain and insecurity, into
account in the assessments. In contrast, the Fast Evaluation of Mobility,
Balance and Fear (FEMBAF) (Di Fabio & Seay, 1997) includes mobility,
fear of falling and pain, but not functions referring to the upper limbs. The
FEMBAF is a mainly performance-based tool for screening the risk of falls
in ambulatory older community dwellers. Consequently, all the tasks of the
FEMBAF are designed to challenge balance, most of them require
performance in a standing position, and advanced tests such as jumping and
standing up from the kneeling position are parts of the assessment, making it
less suitable for the majority of patients undergoing rehabilitation in a
geriatric clinic (Di Fabio & Seay, 1997).

Hence, none of the above measurements - the EMS, PPME, PPT or
FEMBAF - combine on the one hand physical performance of a diversity of
motor functions (such as mobility and upper limb functions) with the related
subjective aspects of that performance (such as pain and insecurity). However,
with references to the Disablement Process (Verbrugge & Jette,
1994) and to the importance of the subjective dimensions of disability
expressed by Ueda and Okawa (2003), such integration should be an
advantage since it would make it possible to serve the clinical need for
treatment in specific problem areas and the need for evaluating the effects of
that treatment. When the treatment is successful, it will also prevent
secondary conditions and dysfunctions, which are a common consequence of
negative feedback effects in the Disablement Process, and hence the
patient’s satisfaction will be more likely to be preserved or enhanced.
Quality of life or life satisfaction as a rehabilitation outcome

Geriatric rehabilitation has a long tradition of aiming to improve the functions of the patients it serves. However, the recognition of the importance of maintaining and improving quality as well as quantity of life has increased during the past five decades (Jacobsen, Davis, & Cella, 2002; Lau & McKenna, 2002; Musschenga, 1997; O'Boyle, 1997). Assessment of QOL has been pointed out as particularly relevant to ageing populations, including those who develop chronic diseases, in whom the maintenance of QOL, rather than cure, may be the primary goal of treatment (O'Boyle, 1997). Furthermore, it has been suggested that rehabilitation research should consider not only activity outcomes, but also QOL and the connection between the two (Johnston & Miklos, 2002).

On the other hand, several authors have indicated that problems may arise in attempts to measure QOL. One major disadvantage is the lack of a clear conceptual basis for QOL measurement (Hunt, 1997; Lau & McKenna, 2002; Leplege & Hunt, 1997; Musschenga, 1997; O'Boyle, 1997; Sarvimaki & Stenbock-Hult, 2000). It has been pointed out that QOL commonly has been conceptualised and measured on the basis of the researcher’s own definitions, which may not reflect the values and perspectives of the people assessed (Hunt, 1997; Lau & McKenna, 2002). A need has been expressed for further research that improves assessments of QOL and their interpretation (Johnston & Miklos, 2002; Lau & McKenna, 2002).

Nevertheless, there is a broad consensus that QOL is a multidimensional concept with both objective and subjective components. The subjective or perceived QOL has been defined as life satisfaction (Heady, 1992; Meeberg, 1993), which in turn has been described as the ‘global evaluation by the person of his or her life’ (Pavot, Diener, Colvin, & Sandvik, 1991). According to Veenhoven (1996) the concept of satisfaction is probably universal and there seems to be a word for satisfaction in all languages. Naess (1989) has described life satisfaction as a dynamic concept that is related to the way in which an individual experiences and evaluates her or his own circumstances. This evaluation is made in relation to a specific standard or frame of reference. The degree of life satisfaction is directly correlated to the difference between, on the one-hand, a person’s expectations and ambitions and on the other hand, the realities in that person’s life. People try to minimise this difference, or the degree of dissatisfaction, both by improving their circumstances and by decreasing their ambitions and/or expectations.

The process-oriented equilibrium approach to life satisfaction suggested by Naess has close points of similarity to Pörn’s definition of health (Pörn,
According to Pörn, health is related to a balance between a person’s capacity and her or his vital goals in life. In this perspective, the equilibrium between a person’s abilities and knowledge, and her or his environmental circumstances and goal profile, further balanced (when necessary) through adaptedness, is vital for good health. Hence, health and life satisfaction might be regarded as conceptually related.

Although a large body of literature on life satisfaction has emerged during the last twenty years (Melin, 2003), studies aiming to conceptualise QOL and life satisfaction among older people are still rare. Studies including interviews with older people with disability or frail health are almost completely lacking in the literature. One singular exception found was an investigation of the conceptualisation of QOL for Chinese elderly people with stroke (Lau & McKenna, 2002). Although some similarities in components of QOL between participants with stroke and healthy elderly persons were identified, differences due to socio-cultural factors, explained by the effects and experiences of having a stroke, were apparent. The authors therefore concluded that the subjective QOL of a population needs to be investigated within a local context.

Thus, needs have been expressed for research that conceptualises the subjective components QOL, i.e. life satisfaction (Johnston & Miklos, 2002; Lau & McKenna, 2002; Meeberg, 1993; Musschenga, 1997; O'Boyle, 1997; Sarvimaki & Stenbock-Hult, 2000; Wetzler & Ellwood 1991). Such research should include the use of qualitative methods to make the research more ethnographically accurate and to improve the understanding of processes that influence the individual’s own concepts of what factors are important for that person’s satisfaction (Aharony & Strasser, 1993).

**Informal caregiving**

Informal caregiving is an important source of care and support for elderly people (Pickard et al., 2000). As a result of the changes in care organisation in the past few decades, with strong emphasis on the prevention of institutionalisation, the demand for informal care by the older age groups in the population is likely to increase further (Pickard et al., 2000; Sundstrom, Johansson, & Hassing, 2002). This implies a shift from institutionalised care, delivered by staff in formal environments, towards care provided by significant others in the home of the care recipients.

Informal care is always based on a relationship. It is provided on an unpaid basis, typically by a female family member. The main responsibility for the caregiving is often assumed by one person, i.e. primarily the spouse if there is one, and secondly a daughter, a daughter-in-law or other relatives,
whereas it is more unusual for friends to act as primary carers (Johansson, 1991). The caregiving often includes many different forms of support (Twigg, 1992). Distinctions can be made between emotional support, which mainly implies maintaining contact, and instrumental care, which involves meeting the needs of daily personal care and homemaking. The formal care system tends to focus on instrumental care, with emotional support left to the informal carers (Habib, Sundstrom, & Windmiller, 1993). Formal care has been described as most suited for standard procedures, which demand greater professional skills, whereas informal caregiving is better for managing tasks that are less easy to standardise and that need more time and a higher degree of empathy and personal knowledge of the care recipient (Litwak, 1985; Litwak, Messeri, & Silverstein, 1990).

Several factors, such as the focus of the support, sense of obligation and pressure to care, as well as affection and attachment, explain differences in the role manifestations of informal caregiving (Dupuis, 2001). Informal care given within a spouse relationship is often seen as an extension of the love and support that is a mutual expectation. There is more of an element of choice in the case of an adult child caring for a parent and there is also a greater tradition of independence between a daughter or a son and a disabled parent (Atkin, 1992; Johansson, 1991). The role of friends and neighbours as informal carers can also be important in caregiving to older people (Nocon, 2000). However, non-kin carers feel less obligation to care and find it easy to give up the role if too much is expected from them. Non-kin carers usually offer emotional and practical support, and are rarely involved in intimate or physical care (Atkin, 1992).

Both informal and formal caregiving can be regarded as a largely communicative act, created through interaction (Giles, Coupland, & Wimann, 1990; Twigg, 2000). Bowers (1987) conceptualised informal caregiving interactions by meaning or purpose, rather than by task. According to this approach any process that people are engaged in for the purpose of caring is included in the typology of caregiving. This includes five overlapping categories of care: preservative or protective care, implying preservation of the care recipient’s concept of self and the caregiving relationship; preventive care, to prevent physical harm; anticipatory care, with anticipation or preparation for what may happen; supervisory care, in which the care provided by others is co-ordinated and supervised; and instrumental care, with performance of direct physical care tasks. It is to be noted that only one of these categories, namely instrumental care, includes the hands-on care behaviour or tasks that are commonly regarded as caregiving. The other four are not observable behaviours but are processes crucial to informal caregiving.
Bowers’ conceptualisation of informal caregiving (1987), which was adopted in this thesis, implies that there is no need for consensus or shared understanding about the meaning of an activity in order to define it as care. Since identification of caregiving in this perspective is an interpretation of a situation rather than an observable event, any situation is open to multiple understandings. This definition is hence dependent on the person from whose point of view the situation is interpreted. Further, it is to be noted that caregiving behaviours may serve more than one purpose simultaneously; for example preparing a meal may serve either social-emotional or instrumental household purposes, or both at once.
The two principal aims of this investigation were:

to develop and test a new instrument for assessment of motor function among older people undergoing rehabilitation, and

to improve the understanding of what is important for life satisfaction of older people during and after geriatric rehabilitation.

More specific aims were:

to examine the clinical practicality and reliability of the General Motor Function assessment scale (GMF), a newly developed instrument (Paper I),

to evaluate the psychometric properties of the GMF when used in a setting of geriatric rehabilitation (Paper II),

to investigate old peoples’ perceptions concerning factors of importance for their life satisfaction (Paper III),

to investigate informal caregivers’ perceptions of the caregiving situation and its purpose, including what factors they consider important for the life satisfaction of the old person they care for (Paper IV), and

to determine whether and how these perceptions, investigated in studies III and IV, are related to the care recipients’ motor function as assessed by the GMF (Papers III and IV).
Methods and results

Theoretical perspectives and frameworks

This thesis includes two perspectives relating to the goals of geriatric rehabilitation, namely assessments of motor function and subjective views of the patient’s life satisfaction, during and after geriatric rehabilitation. The investigations thus required various research strategies focusing on general and personal perspectives, including perspectives based on different research paradigms, i.e. positivism and naturalism.

The ontological assumption from a positivistic perspective is that a real world exists. This world is driven by natural causes and can be studied and known. Measurements of quantitative information, which can be statistically analysed, are commonly used as research methods in such studies (Polit & Hungler, 1999). In studies I and II (Papers I and II) a new assessment instrument was developed and tested within a positivistic framework.

The main ontological assumption of naturalists is that reality is multiple and subjective, constructed mentally by individuals. Research methods commonly used in this framework consists of collection of narrative information which is qualitatively analysed (Polit & Hungler, 1999). In studies III and IV (Papers III and IV), perceptions of care recipients and their significant others were explored within a mainly naturalistic framework.

Two main theoretical bases were utilised. Firstly, the Disablement Process (Verbrugge & Jette, 1994), which is described in the introduction, provides a common feature of studies I-IV. This process-oriented framework constituted the underlying socio-medical perspective from which disability was consistently viewed in this work. Accordingly, the Disablement Process was used as a conceptual basis for the construction of the new assessment instrument, the GMF.

Secondly, symbolic interactionism (Blumer, 1998) was applied as the basic theoretical framework for investigations of perceptions of life satisfaction in studies I and II. This theory is a foundational perspective well known in qualitative research, but is compatible with quantitative methods.
and can be integrated with other theoretical frameworks (Benzies & Allen, 2001).

In addition, in the processes of qualitative analysis the concept of adaptation and the continuity theory of ageing (Atchley, 1999) provided important contributory foundations for the exploratory part of the theoretical interpretation of the data. These theories are described below. All the theoretical frameworks mentioned in this section of the thesis are, further, linked to the results in the discussion.

Symbolic interactionism
The three major assumptions underlying Symbolic interactionism are: that individuals act on the basis of the meaning that events have for them; that the meaning of these events is derived from interaction with others, and within oneself, through thinking; and that these meanings are handled in, and modified in an interpretive process (Blumer, 1998). In the light of this theory, a caregiving situation involves active and creative construction and reconstruction of roles over time in a dynamic and fluid role-taking and role-making process. This process includes definition and redefinition of the situation, interpretation and reinterpretation of the behavioural and verbal gestures and expectations of others, and ongoing negotiation processes (Blumer, 1998; Dupuis, 2001). The definition of the situation, which can be formulated according to the Thomas theorem, is a cornerstone in this process, since ‘If men define situations as real, they are real in their consequences’ (Thomas & Thomas, 1928, p.572). This implies that the way people perceive and make their definitions of specific situations also rules their behaviour, including their social interactions with others. For example, when a person defines or assesses a situation or attitude (of another person) as important and as very good or bad, this will affect the behaviour of that person differently from when the same situation or attitude is perceived as unimportant and negligible.

The social anthropologist Lisbeth Sachs (1992) has shown that communication between people in daily care situations often involves undiscovered misinterpretations, due to discrepancies concerning definitions of the situation. There is a dilemma here in that as long as the discrepancies are not obvious, we are not aware of the problem. Not until we realise that we are not accurately grasping the other party’s true messages and needs do we feel responsibility to view this as something we should consider. Communications that are built on hidden misinterpretations can therefore give a false impression of being satisfactory. Since the definitions that rule people’s behaviour are ongoing processes, it is possible, however, to re-define a situation and adjust the attitudes and behaviours in accordance with that reinterpretation (Trost & Levin, 1999).
As in all interaction, the basis for constructive and co-operative interaction in a caring situation is, communication, which is accomplished through the use of complex patterns of symbols represented by words, such as daughter, son, mother, father, friend, youth, middle-age, old age, care, support, satisfaction, life and so on. By use of an inherited cultural repertoire of such shared symbols, symbolic interaction with others and within oneself, through thoughts, is possible. Social interaction is achieved through communication with symbols, which have to be meaningful and vital for the involved parties. In other words the symbols, which most often are words but also can be represented by body-language as well as attributes and artefacts, have to contain shared meanings for the persons involved in the interaction. Otherwise, understanding of the other party’s views and needs is not possible (Hepworth, 2000).

According to Cooley (1964), humans use sympathy (Cooley uses this word in the sense that we today generally apply to the word empathy) in an effort to understand the world of other people. We try to put our selves into the other person’s situation, into her or his definition of the situation and into the interpretations the person makes of a specific incident in a specific situation, i.e. into what significance or meaning an incident or an object has for that person. Such sympathetic introspection facilitates our possibility of imagining the life of others who are not totally unfamiliar to us. The ability of people for sympathetic introspection is a prerequisite for interaction; otherwise it would be impossible for us to interpret and understand each other’s actions. This ability is also a decisive requirement in caregiving, in which the care recipients’ values and perceptions are considered.

This introspection also makes it possible to understand others’ perceptions and judgements of us, which form and change our selves. In this perspective, primary groups are of vital importance. Firstly because they have provided the primary basis for the development of our selves, and secondly because they continue to socialise and re-socialise our selves. A primary group is characterised by face-to-face contact and co-operation, and it gives a sense of social belongingness and emotional security. The most important primary groups are the family and friends and neighbours (Cooley, 1964), which are the same groups that provide most care for older people.

The concept of adaptation
Adaptation is a characteristic of all living beings, including humans, who build up and develop adaptive resources through evolution and learning. Adaptation has been defined as a master concept that includes defence mechanisms, mastery and coping (White, 1974). Defence mechanisms are commonly referred to in psychoanalytical terminology, describing unconscious processes aimed at protection against anxiety. Mastery is
successful performance, and coping is defined as adaptation under relatively
difficult conditions. Adaptation also includes habits which give basic
structure and order to daily activities (Thorén-Jönsson, 2000). Further,
adaptation is closely linked to Pörn’s concept of ‘generalised adaptedness’
(Pörn, 1993, p298). According to Pörn, however, adaptedness should be
distinguished from adaptation, since the latter is a process or action of
becoming adapted. Generalised adaptedness is achieved when people
become adapted over a period of time. This adaptedness can be described as
an equilibrium between a person’s act repertoire (of abilities and
knowledge), the environment and the goal profile of that person. From this
perspective, good health is obtained if, and only if, the individual has the
repertoire which her or his generalised adaptedness requires.

**Continuity theory of ageing**

Although ageing undeniably brings changes into people’s lives, within the
continuity theory of ageing continuity is emphasised as a key concept in old
age. Atchley (1999), who developed this theory, found that a large
proportion of older adults show considerable consistency over time in their
patterns of activity profiles, social relationships, living arrangements and
patterns of thinking, despite vital changes in health, physical independence
and social circumstances. A recent study has pointed in the same direction,
by showing continuity in physical activity through the life span (Hirvensalo,
Lintunen, & Rantanen, 2000).

Atchley concludes, however, that continuity in feelings of personal
effectiveness, of being able to accomplish what one sets out to do, is much
less prevalent among the elderly, especially among those who develop
disability as they age. This implies that in the framework of the continuity
theory of ageing, continuity and change are not necessarily mutually
exclusive, but can occur simultaneously within an individual’s self and life-
style and are matters of degree. Continuity is identified as the maintenance
of general, internal and external patterns of thinking and acting, which are
balanced against change when people strive to adapt to life changes. The
continuity theory of ageing is thus concerned with the way in which people
attempt to adapt to changes in life in old age and with the mental
frameworks used by people when doing so.

According to Atchley (1989), adults accept their inner self to an
increasing extent as they grow old. This supports the inner continuity of the
self. Moreover, people try to establish continuity in their external life
situation to support their internal framework. This is compatible with the
activity theory of ageing (Lemon, Bengtson, & Peterson, 1972), the essence
of which is that there is a positive relationship between activity and the role
support, which is necessary for maintaining a positive self-image and life satisfaction.

However, physical decline and the ageing of the body may hinder habitual ADL activities and intrude in the process of communicating a continuous self to others. This might be problematic, since according to the continuity theory of ageing the exercise of habitual skills is seen as reinforcing the continuity of self, providing a sense of competence and self-worth. Consequently, individuals strive to maintain familiar activities in order to maintain continuity in sense of self and a positive self image.

Subjects

The studies described in this thesis can be divided into two main sections. The first section, comprising studies I and II, concerns the development of an instrument for assessment of motor function. The patients participating in these two studies were mainly recruited from two Swedish geriatric clinics. Additionally, two units for home-based rehabilitation in two Swedish municipalities were involved in the test of reliability of the instrument. Participants in the tests of reliability and validity were all included consecutively. Analyses of distribution of data and sensitivity were based on data collected by retrospective scrutiny of the medical records of patients who had undergone geriatric rehabilitation, comprising: 1) institutional rehabilitation, for patients with the most extensive care needs, 2) home rehabilitation, for those who were independent enough to assimilate it in their own homes and 3) rehabilitation for a limited period in day-care for patients who are in a more stable state of illness. These GMF assessments were conducted before and after intervention, as part of the physiotherapists’ routine examinations of all patients referred to them for rehabilitation during a period of 3 months (Table 1).

The second section, comprising studies III and IV, concerns perceptions of life satisfaction. The patients participating in study III were recruited from one of the two above-mentioned geriatric clinics, by a combination of a convenient and purposive procedure. With the co-operation of the care staff 15 persons of both sexes, from a range of household formations and with various diagnoses, were identified as being appropriate for the present study, on the basis of criteria of age (≥80), a diagnosed need of rehabilitation, and unimpaired cognition. One significant other of each of those persons was also invited to participate. However, one of them declined to participate when the interview was about to be held. This resulted in participation of 14 significant others in study IV (Table 1).
In each patient, the primary diagnosis necessitating rehabilitation was assigned to one of three groups: neurological, orthopaedic and other diagnosis. In the neurological group stroke was the most common diagnosis and in the orthopaedic group femoral fracture predominated; the other diagnoses were mainly heart, vascular or lung diseases (Table 1).

Hereafter, the participants undergoing formal rehabilitation will be referred to as patients, and after discharge those patients will be referred to as care recipients.

**Table 1.** Overview of the participants of studies I-IV and the study focus.

<table>
<thead>
<tr>
<th>Study focus</th>
<th>n (women)</th>
<th>Age (mean) years</th>
<th>Form of geriatric rehab.</th>
<th>Diagnosis Ort Neu Oth</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Study I</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Inter-rater reliability 1</td>
<td>20 (9)</td>
<td>57-91 (80)</td>
<td>Institutional</td>
<td>9 3 8</td>
</tr>
<tr>
<td>Inter-rater reliability 2</td>
<td>25 (18)</td>
<td>69-90 (81)</td>
<td>Home *</td>
<td>9 7 9</td>
</tr>
<tr>
<td>Test-retest reliability</td>
<td>20 (13)</td>
<td>62-86 (76)</td>
<td>Day-care</td>
<td>5 15 —</td>
</tr>
<tr>
<td><strong>Study II</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Validity</td>
<td>20 (14)</td>
<td>73-93 (82)</td>
<td>Institutional</td>
<td>7 7 6</td>
</tr>
<tr>
<td>Distribution &amp; Sensitivity</td>
<td>154 (110) †</td>
<td>56-98 (80)</td>
<td>See below †</td>
<td>65 54 35</td>
</tr>
<tr>
<td></td>
<td>101 (73)</td>
<td>56-98 (81)</td>
<td>Institutional</td>
<td>40 33 28</td>
</tr>
<tr>
<td></td>
<td>30 (22)</td>
<td>65-95 (80)</td>
<td>Home</td>
<td>22 5 3</td>
</tr>
<tr>
<td></td>
<td>23 (15)</td>
<td>69-93 (77)</td>
<td>Day-care</td>
<td>3 16 4</td>
</tr>
<tr>
<td><strong>Study III</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Care recipients’ perceptions</td>
<td>15 (11)</td>
<td>80-94 (85)</td>
<td>Institutional‡</td>
<td>6 5 4</td>
</tr>
<tr>
<td><strong>Study IV</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Significant others’ perceptions</td>
<td>14 (12)</td>
<td>42-86 (63)</td>
<td>——</td>
<td>——</td>
</tr>
</tbody>
</table>

Ort = Orthopaedic; Neu = Neurological; Oth = Other diagnosis. These groups refer to the patient’s main diagnosis

* Community-based rehabilitation

† This group was divided into subgroups for the instrument sensitivity test

‡ Interviews were carried out in hospital and at two follow-ups after discharge

Additionally 14 physiotherapists, experienced in geriatric rehabilitation, took part in a field test of the clinical feasibility of the GMF.
Ethical considerations

Consent to participate in the studies described in this thesis was obtained only after the patients had acquainted themselves with the aims of the study in question. The assessments for the testing of the new instrument, GMF, were carried out during ordinary clinical practice. Thus they were part of a clinical routine, but some assessments were repeated more frequently than was required solely for clinical purposes.

Participants in the qualitative interviews were recruited through cooperation of the staff at the hospital ward where they were receiving care. This was done to ensure that the inclusion criteria were met and to exclude individuals with severe cognitive problems, which might have caused ethical as well as validity problems.

Consent to participation in the studies was obtained from all participating patients/care recipients and from the participating significant others. The participants were informed that they could withdraw from participation whenever they liked. One care recipient did so in an early stage of the study and one significant other who had agreed to participate did not finally enter the study.

All studies included in this thesis were approved by the Ethics Committee of the Medical Faculty, Uppsala University. The data were treated confidentially, and the integrity of the participants was protected both during the research process and in the presentation of the results.

Studies I and II - General motor function assessment

Procedures for instrument development and evaluation

The purposes of studies I and II were to develop and evaluate a performance-based instrument for multiple use, namely for routine examinations by physiotherapists, development work and research. This instrument should be practically useful and possess satisfactory psychometric properties. The process of development was initiated by a series of group discussions with physiotherapists with several years of experience in geriatric rehabilitation, followed by clinical testing and retesting of drafts of preliminary scales. This formed the basis of the construction of the GMF. The clinical and psychometric properties were subsequently tested, as illustrated in Table 2 and described below.
**Table 2.** Overview of the procedures for development and evaluation of the General Motor Function assessment scale (GMF)

<table>
<thead>
<tr>
<th>Instrument properties</th>
<th>Operational bases</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Clinical practicality</strong></td>
<td></td>
</tr>
<tr>
<td>Time-efficiency</td>
<td>Questionnaire to PTs</td>
</tr>
<tr>
<td>Clinical feasibility</td>
<td>Subjective evaluation and questionnaire to PTs, regarding:</td>
</tr>
<tr>
<td></td>
<td>– ease of administration</td>
</tr>
<tr>
<td></td>
<td>– degree of simplicity of the scoring</td>
</tr>
<tr>
<td>Clinical validity</td>
<td>– meaningfulness from a patient’s and a professional point of view</td>
</tr>
<tr>
<td><strong>Reliability</strong></td>
<td></td>
</tr>
<tr>
<td>Inter-rater agreement</td>
<td>Agreement between simultaneous assessments of in-patients and patients in home rehabilitation.</td>
</tr>
<tr>
<td>Test-retest agreement</td>
<td>Agreement between repeated assessments of patients in day-care</td>
</tr>
<tr>
<td><strong>Content validity</strong></td>
<td></td>
</tr>
<tr>
<td>Conceptual basis</td>
<td>Disablement Process (Verbrugge &amp; Jette, 1994)</td>
</tr>
<tr>
<td>Face validity</td>
<td>Subjective evaluation</td>
</tr>
<tr>
<td></td>
<td>Questionnaire to physiotherapists regarding relevance of the items</td>
</tr>
<tr>
<td><strong>Criterion validity</strong></td>
<td></td>
</tr>
<tr>
<td>Concurrent validity</td>
<td>Correlation between GMF and the Katz index of ADL</td>
</tr>
<tr>
<td><strong>Distribution</strong></td>
<td></td>
</tr>
<tr>
<td>Floor and ceiling effects</td>
<td>Clusters of &gt;20% at the minimum or maximum score</td>
</tr>
<tr>
<td><strong>Sensitivity</strong></td>
<td></td>
</tr>
<tr>
<td>(Discriminant validity)</td>
<td>Capacity to distinguish between:</td>
</tr>
<tr>
<td></td>
<td>– assessments pre- and post-intervention</td>
</tr>
<tr>
<td></td>
<td>– groups of patients in different care levels, using known-groups technique</td>
</tr>
</tbody>
</table>

PT=physiotherapist

**The development and conceptualisation** of the instrument were based on the prerequisite that the items should be relevant both from a professional and a patient’s point of view. The GMF was thus constructed to cover both mobility and upper limb functions. Another intention was to integrate physical performance with the patient’s response to that performance, i.e. function-related pain or insecurity. This was done by incorporating three subscales, one for each of the three components of functioning - Dependence, Pain and Insecurity. Dependence was defined as dependence...
on help from another person. Both pain and insecurity were defined as the negative and situation-specific emotional responses related to the performance of specific motoric tasks.

The items included in the measurement were conceptualised according to the level described as Functional limitations in the Disablement Process, since this was experienced as the appropriate level for physiotherapists’ assessment and intervention. Another reason was the awareness that this concept has been shown to be a key component in the disablement process.

**The clinical practicality** of the instrument was tested according to the physiotherapists’ perceptions of this aspect. For this test a semi-structured questionnaire was distributed to 14 physiotherapists who had applied the GMF in daily practice in geriatric rehabilitation. The questionnaire included questions about the estimated time needed to carry out the assessment in clinical work, and the clinical feasibility, including its clinical relevance and usefulness for documentation and communication with other care staff.

**Reliability** tests were performed on three different groups of patients undergoing geriatric rehabilitation (Table 2). Since a test of inter-rater reliability (achieved by two physiotherapists by simultaneous assessments of the same patient) is relevant only for the subscale of the GMF comprising observer-assessed Dependence, this subscale was tested for both inter-rater and test-retest reliability. To evaluate the stability of all three subscales of the GMF, tests of test-retest reliability were carried out by repeated assessments carried out by the same rater, on patients in day-care. The day-care setting was chosen for this purpose since the patients receiving this care are in a later and more stable phase of disability.

**Validity** was tested in several ways (Table 2). Content validity was ensured as it corresponded with the concept of Functional Limitations as classified by the Disablement Process (Verbrugge & Jette, 1994). Face validity, which is the subjective judgement by the investigator and other experts in the field regarding the relevance of the items, was additionally evaluated by the author, by the physiotherapists involved in the initial construction of the instrument and by the physiotherapists who took part in the field test.

Criterion validity testing was focused on concurrent validity, which is criterion-related and measured by comparing the tested instrument with a concurrently administered established (criterion) instrument (Johnston, Keith, & Hinderer, 1992). Since no assessment scale analogous to the GMF was available and as motor functioning has been considered a prerequisite for ability in ADL, we hypothesised that the GMF should exhibit correlations to the Katz Index of ADL (Katz, Downs, Cash, & Grotz, 1970),
and this was therefore chosen for comparison in the investigation of concurrent validity.

The Katz Index of ADL (Dowd & Davidhizar, 1999; Katz et al., 1970) is one of the most well established general tests of ADL aimed at evaluating functional change in the chronically ill and elderly. The index includes six activities: bathing, dressing, toileting, transfers indoors, continence (bowel and bladder) and eating. Although originally reported as a scale based on dichotomous items, the concept of the Katz Index of ADL has been adapted differently; the level of independence being assessed on a three-point scale (0= independent, 1=partly dependent, 2=totally dependent) for each of the six activities (Kane & Kane, 1981). The score setting is based strictly on the patient’s independence of help when carrying out the activities included in the assessment.

The distribution of data was examined on the basis of the central tendency, range and possible presence of ceiling or floor effects (Mao, Hsueh, Tang, Sheu, & Hsieh, 2002; Polit & Hungler, 1999). The distributions of scores of the three GMF subscales were examined on data from assessments of 154 patients pre- and post-intervention (Table 1).

The sensitivity of the GMF was examined in two ways, i.e. by evaluating its ability to discriminate between patients in three different forms of care (institutional, home and day-care rehabilitation) representing three different care levels, and by analysing its sensitivity to discriminate between assessments of these patients, pre- and post-intervention (Table 1). The 'known-groups technique' (Polit & Hungler, 1999) was used, which implies a procedure where groups that are expected to differ in critical attributes because of some known characteristics are assessed with the instrument. The results are then logically analysed. This procedure can also be regarded as a test of discriminant validity (Polit & Hungler, 1999; Streiner & Norman, 1995)

Statistical analysis
Since the GMF can be regarded as an ordinal measurement, non-parametric statistics were used. A relatively new non-parametric rank-invariant method (Svensson, 1998a, 1998b) was used in studies I and II. This method, which is valid for all types of ordered data, without assumptions regarding the distribution, was applied for two purposes: first for analysis of reliability and secondly for analysis of sensitivity between pre- and post-intervention assessments. This approach allows the systematic component of observed
differences between paired ordered categorical assessments to be separated from the random variability and measured.

**Reliability** was analysed by calculations of percentage agreement (PA) between the paired data sets in each study group for all items of the GMF one by one. Additionally, Svensson’s method (Svensson, 1997) was used to measure the random disagreement separately from the systematic part of the disagreement. The presence of systematic disagreement, implying lack of stability of the scale, is summarised by two statistics, relative position (RP) and relative concentration (RC). The values of RP and RC lie in the interval −1 to 1. Values of RP and RC close to zero mean negligible systematic disagreement.

The empirical measure of the random part of the disagreement is the relative rank variance (RV). RV expresses the random component of disagreement, which is adjusted for systematic disagreement. This method also allows the definition of an agreement coefficient related to RV. This is the augmented rank-order agreement coefficient $r_a$, which was calculated in the analysis of reliability. A high value of $r_a$, which ranges from 0 to 1, implies a high level of agreement between the paired assessments, which is an expression of good reliability (Svensson, 1997). The 95% confidence intervals for the measures RP, RC, RV and $r_a$ were obtained by bootstrap calculations (Bradely & Tibshirani, 1993).

**Concurrent validity** was analysed by calculations of Spearman’s rank correlation coefficients ($r_s$). The correlation between scores of each of the GMF subscales and scores of the Katz Index of ADL (Katz et al., 1970) was examined.

**The distributions** of GMF data were examined by calculations of descriptive statistics, including median, minimum and maximum values and range for each subscale. Floor and ceiling effects, i.e. the extent to which the scores cluster at the bottom or top of the scale range, were also examined. A cluster of $>20\%$ at the top or bottom values was considered to be statistically significant (Holmes & Shea, 1997).

**Sensitivity** for discriminating between patients in three different forms of care (institutional, home and day-care rehabilitation) was analysed using the Kruskal-Wallis one-way analysis of variance test (KW) (Siegel & Castellan, 1989). If statistically significant differences ($p<0.05$) were indicated by the statistics of KW, in a subsequent step multiple comparisons (Siegel & Castellan, 1989) were made in the items for which the difference had been shown.
Sensitivity for discriminating between pre- and post-intervention assessments was calculated by the method developed by Svensson (Svensson, 1998b), mentioned above. This allowed measurement of the observable individual changes that were unexplained by the group change, separately from the order-perceived systematic group change in categories between pre- and post-intervention assessments. The level of ordered-preserved change in the group is defined by the parameters of systematic shift in position (RP) and concentration (RC), indicating change in response according to the GMF assessments, between pre- and post-intervention. Values of RP and RC close to zero imply negligible changes over time (Svensson, 1998b). A negative RP implies decreasing GMF scores, i.e. systematically decreased levels of help-dependence, pain and insecurity at the post-intervention compared to the pre-intervention assessments.

The empirical measure of individual changes is the RV (Svensson, 1998b). RV expresses the degree to which an individual has changed her/his categorical level from a pre- to post-intervention assessment, to a greater or lesser extent that is expected from the change in pattern of the group. Possible values of RV are between 0 and 1. The smaller the RV, the more homogeneous is the measured change in the group from pre- to post-intervention. The 95% confidence intervals for the measures RP, RC and RV were obtained by bootstrap calculations (Bradely & Tibshirani, 1993).

Results of studies I and II

The scale construction resulted in development of the final version of the GMF, including 21 motor functions, of which 11 are mobility functions (from turning over in bed to climbing stairs and transferring outdoors) and 10 are upper limb functions including both arm movements and grip functions (Table 3). Three aspects of mobility functions - Dependence, Pain and Insecurity - are assessed, and upper limb functions are evaluated regarding Dependence and Pain.

These assessments are carried out by asking the subjects to perform the 21 motor functions, one by one. During each task the assessor observes the degree of dependence and asks the patients a ‘yes-or-no’ question about pain and, in the case of the mobility functions, also about insecurity caused by the execution of the task in question. Pain and insecurity are thus always assessed on a two-point (dichotomised) scale, whereas degrees of Dependence are assessed on two- or three-point scales, which can be dichotomised.

The scoring of the scale is constructed as sum-scores of the three subscales measuring Dependence, Pain and Insecurity. The scores for each subscale are summarised separately. Attainment of the maximum score for
Dependence, i.e. 34, Pain, i.e. 21 and Insecurity, i.e. 11, implies that the patient is dependent in all 21 assessed motor functions and that she/he experiences pain when executing all these functions and insecurity when executing all mobility functions. The Dependence scores can be dichotomised (dependent/independent) when the results are analysed on a group level. The sum of dichotomous Dependence scores has a maximum of 21.

Through its task-oriented measures of motor functioning and related aspects that can affect motor functioning, the GMF thus targets the stage between Impairment and Disability, namely Functional Limitations as defined within the Disablement Process (Verbrugge & Jette, 1994).

Table 3. The GMF items and scoring

<table>
<thead>
<tr>
<th>Function</th>
<th>Dependence</th>
<th>Pain</th>
<th>Insecurity</th>
</tr>
</thead>
<tbody>
<tr>
<td>A Turn around when lying in bed</td>
<td>0-2</td>
<td>0-1</td>
<td>0-1</td>
</tr>
<tr>
<td>B Sit up from recumbent position</td>
<td>0-2</td>
<td>0-1</td>
<td>0-1</td>
</tr>
<tr>
<td>C Lie down from a sitting position</td>
<td>0-2</td>
<td>0-1</td>
<td>0-1</td>
</tr>
<tr>
<td>D Transfer from bed to chair</td>
<td>0-2</td>
<td>0-1</td>
<td>0-1</td>
</tr>
<tr>
<td>E Touch left big toe</td>
<td>0-1</td>
<td>0-1</td>
<td>0-1</td>
</tr>
<tr>
<td>F Touch right big toe</td>
<td>0-1</td>
<td>0-1</td>
<td>0-1</td>
</tr>
<tr>
<td>G Stand up from a sitting position</td>
<td>0-2</td>
<td>0-1</td>
<td>0-1</td>
</tr>
<tr>
<td>H Stand more than 10 sec</td>
<td>0-2</td>
<td>0-1</td>
<td>0-1</td>
</tr>
<tr>
<td>I Transfer indoors 10 m</td>
<td>0-2</td>
<td>0-1</td>
<td>0-1</td>
</tr>
<tr>
<td>J Climb stairs up/down 7 steps</td>
<td>0-2</td>
<td>0-1</td>
<td>0-1</td>
</tr>
<tr>
<td>K Transfer outdoors 25 m</td>
<td>0-2</td>
<td>0-1</td>
<td>0-1</td>
</tr>
<tr>
<td>L Move left hand to mouth</td>
<td>0-1</td>
<td>0-1</td>
<td>-</td>
</tr>
<tr>
<td>M Move right hand to mouth</td>
<td>0-1</td>
<td>0-1</td>
<td>-</td>
</tr>
<tr>
<td>N Move left hand to head</td>
<td>0-1</td>
<td>0-1</td>
<td>-</td>
</tr>
<tr>
<td>O Move right hand to head</td>
<td>0-1</td>
<td>0-1</td>
<td>-</td>
</tr>
<tr>
<td>P Move left hand on back</td>
<td>0-1</td>
<td>0-1</td>
<td>-</td>
</tr>
<tr>
<td>Q Move right hand on back</td>
<td>0-1</td>
<td>0-1</td>
<td>-</td>
</tr>
<tr>
<td>R Greeting grip with left hand</td>
<td>0-2</td>
<td>0-1</td>
<td>-</td>
</tr>
<tr>
<td>S Greeting grip with right hand</td>
<td>0-2</td>
<td>0-1</td>
<td>-</td>
</tr>
<tr>
<td>T Pinch grip with left hand</td>
<td>0-2</td>
<td>0-1</td>
<td>-</td>
</tr>
<tr>
<td>U Pinch grip with right hand</td>
<td>0-2</td>
<td>0-1</td>
<td>-</td>
</tr>
</tbody>
</table>

Range 0-34 0-21 0-11

Analysis of reliability showed that PA for Dependence ranged from 90% to 100% concerning both the tests of inter-rater and test-retest reliability. The test-retest PA for Pain had a range of 85% to 100% and for Insecurity 70% to 100%.

No disagreement was observed in tests of inter-rater reliability on the GMF subscale Dependence. The calculations of RP and RC showed no
The test of test-retest reliability revealed negligible random disagreement for the Dependence and Pain subscales, by RV values close to zero. In contrast, Insecurity showed random disagreement between assessments, with RV = 0.16, and a 95% confidence interval of 0.03 – 0.46.

In an agreement context the results showed that all values of the agreement coefficient \( r_a \) exceeded 0.8. In conformity with the results for random disagreement, the agreement coefficient for the Insecurity subscale showed the lowest value of agreement with \( r_a \), i.e. 0.83, with a 95% confidence interval of 0.48 – 0.96 (Table 4).

**Table 4.** The augmented rank-order agreement coefficients, \( r_a \), of paired GMF assessments, with 95% confidence intervals (CI) calculated by bootstrap statistics.

<table>
<thead>
<tr>
<th>Test</th>
<th>Dependence</th>
<th>Pain</th>
<th>Insecurity</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Inter-rater</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Institutional</td>
<td>20</td>
<td>1.00</td>
<td>95% CI</td>
</tr>
<tr>
<td>Home rehab.</td>
<td>25</td>
<td>0.99</td>
<td>95% CI</td>
</tr>
<tr>
<td><strong>Test-retest</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Day-care</td>
<td>20</td>
<td>1.00</td>
<td>95% CI</td>
</tr>
</tbody>
</table>

The test of concurrent validity showed a high correlation, with \( r_s = 0.80 \) (p<0.001), between the subscale Dependence and the Katz Index of ADL, This confirmed the hypothesis that dependence in the tasks included in the GMF are related to ADL capacity. In contrast, no statistically significant correlations were found for Pain (\( r_s = 0.28 \), p=0.23) or Insecurity (\( r_s = -0.07 \), p=0.76).

The distribution of the GMF scores of 154 patients assessed before and after intervention is shown in Table 5 and illustrated in Figure 3.

**Table 5.** Distributions of GMF scores among patients in geriatric rehabilitation (n=154).

<table>
<thead>
<tr>
<th></th>
<th>Dependence</th>
<th>Dichotomous Dependence</th>
<th>Pain</th>
<th>Insecurity</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pre-intervention</td>
<td>154</td>
<td>5.2 (0-26)</td>
<td>4.6 (0-18)</td>
<td>2.9 (0-21)</td>
</tr>
<tr>
<td>Post-intervention</td>
<td>154</td>
<td>1.9 (0-23)</td>
<td>1.9 (0-16)</td>
<td>0.5 (0-17)</td>
</tr>
</tbody>
</table>

Md = interpolated median
Calculations showed no floor effects. This means that the measurement is able to discriminate between individuals with most functional limitations covered by the GMF, concerning all three subscales, both pre- and post-intervention. Statistically significant ceiling effects, implying inability to discriminate between individuals with the best functioning according to the GMF, were shown for the subscales Pain (37%) and Insecurity (39%) before intervention and for all three subscales in post-intervention assessments. The ceiling effect after intervention was 29% for both non-dichotomous and dichotomous Dependence scores, 53% for Pain and 67% for Insecurity.

Figure 3. Box plots of Dependence (non-dichotomous and dichotomous scores), Pain and Insecurity, assessed by the GMF, before (pre) and after (post) geriatric rehabilitation (n=154).
Sensitivity tests on patients in three different forms of geriatric care, institutional, home and day-care rehabilitation, revealed statistically significant (p<0.05) differences between patients in these forms of care in Dependence pre-intervention, whereas Pain and Insecurity did not differ between the groups. No differences between the care forms in any of the subscales were found after intervention. The subsequent multiple comparisons showed that in-patients had higher Dependence scores before intervention than both home rehabilitation (p<0.05) and day-care rehabilitation (p<0.05), whereas no differences were found between patients undergoing home and day-care rehabilitation.

**Figure 4.** GMF scores (dichotomous subscales) before (pre) and after (post) institutional (n=101), home (n=30) and day-care (n=23) rehabilitation, showing the line of equality. One marking may indicate more than one patient.
Reductions of GMF scores from admission to discharge were indicated by data plots with a line of equality, where the marks above the line show a reduction in GMF scores from admission to discharge (Fig. 4).

These indications were subsequently verified by the use of Svensson’s method (Svensson, 1998b) (Table 6). A systematic shift in GMF scores (p<0.05) from pre- to post-intervention, expressed by RP, showed changes in all three groups of patients in all three subscales - Dependence, Pain and Insecurity, with one exception. No statistically significant difference in Dependence scores was found among patients in day-care. In contrast, this group showed the most obvious change in Insecurity as identified by RP=0.49 (p<0.05). A systematic shift in concentration between the two assessment occasions was only observed in one of the subscales in one of the groups: Pain scores in in-patients showed a significant (p<0.05) RC value of 0.18. The measure of individual changes (RV) varied from 0.05 to 0.19 (Table 6).

Table 6. The measures of group and individual changes in Dependence (Dep), Pain and Insecurity (Ins) assessed by the GMF, among patients in institutional (Inst.), home (Home), and day-care (Day) rehabilitation.

<table>
<thead>
<tr>
<th>Group/ Sub-scale</th>
<th>n</th>
<th>Systematic change in the group</th>
<th>Individual changes</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td>RP</td>
<td>95% CI</td>
</tr>
<tr>
<td>Inst. Dep</td>
<td>96</td>
<td>-0.46</td>
<td>-0.56—-0.36</td>
</tr>
<tr>
<td>Pain</td>
<td>100</td>
<td>-0.29</td>
<td>-0.40—-0.20</td>
</tr>
<tr>
<td>Ins</td>
<td>100</td>
<td>-0.32</td>
<td>-0.44—-0.22</td>
</tr>
<tr>
<td>Home Dep</td>
<td>29</td>
<td>-0.42</td>
<td>-0.60—-0.23</td>
</tr>
<tr>
<td>Pain</td>
<td>29</td>
<td>-0.20</td>
<td>-0.35—-0.06</td>
</tr>
<tr>
<td>Ins</td>
<td>29</td>
<td>-0.25</td>
<td>-0.44—-0.08</td>
</tr>
<tr>
<td>Day Dep</td>
<td>22</td>
<td>-0.03</td>
<td>-0.23—-0.20</td>
</tr>
<tr>
<td>Pain</td>
<td>23</td>
<td>-0.22</td>
<td>-0.44—-0.09</td>
</tr>
<tr>
<td>Ins</td>
<td>23</td>
<td>-0.49</td>
<td>-0.74—-0.30</td>
</tr>
</tbody>
</table>

RV=relative rank variance, RC=relative concentration, RP= relative position, CI= confidence interval calculated by bootstrap statistics. Statistically significant values in bold type
Methodological considerations, studies I and II

The clinical relevance of the methodology used in the construction of the GMF was ensured by the initiating close collaboration with physiotherapists in the field and the evaluation of the clinical practicality of the scale through a field test (Paper I). Additionally, assessments of its psychometric properties were carried out in different care settings, including both formal institutional settings in hospital and in the patient’s home.

The studies, however, are attended with several methodological limitations that need to be considered in the interpretation of the findings. To begin with, the sum-scores of the dependence subscale may be criticised, as the lack of equidistance between the scores for each item may entail deceptive sum-scores (Paper I). One way to reduce this problem is to use a dichotomised scale. The summed-up results of the dichotomous scores of the GMF can be interpreted as the number of functions in which the performance entails problems, expressed as Dependence, Pain and Insecurity. These dichotomous scores can thus be regarded as discrete numerical data (Altman, 1991, p 12). However, since the numbers only contain information on ordering, a statistically correct way to regard and manage these data is to view the scores as a set of labels. In other words, the GMF scores should be regarded as data on an ordinal level with rank-invariant properties, which require appropriate statistical methods that take into account the non-metric properties (Svensson, 2001b). Nevertheless, the procedure of summing up the scores of each item of multi-item scales providing ordinal data, such as the GMF, may still be criticised, for giving a false impression of better precision than the result can allow (Svensson, 2001a). On the other hand, summary measures can provide meaningful information on complex phenomena such as physical disability. These are commonly utilised, as alternative use of multiple evaluations is not always feasible, satisfactory or desirable (Coste, Fermanian, & Venot, 1995).

To ensure credibility of the results of the GMF evaluation, the statistical methods used were selected to take into account the non-metric properties of the data (Papers I and II). Additionally, these methods allowed the measurement of the systematic part of disagreement separately from the random part, as well as measurement of the observable individual changes (that were unexplained by the group change) separately from the systematic group change in GMF scores, from pre- to post-intervention (Svensson, 1998a, 1998b). It is to be noted that there are still only few reliability studies that pay consideration to the properties of data from rating scales. On the contrary there is a widespread misuse of correlation, which does not measure the level of agreement (Svensson, 2001b). Statistical methods that are based on parametric correlation and assumptions of a normal distribution, which is not achievable in data of this kind, are also frequently used. Thus,
comparison of reliability between established rating scales can be problematical. For example, all four performance-based assessment scales referred to in the introduction - the EMS (Smith, 1994), the PPME (Winograd et al., 1994), the PPT (Reuben & Siu, 1990) and the FEMBAF (Di Fabio & Seay, 1997) - have been tested for reliability, but with a variety of methods, methods which commonly do not measure the level of agreement.

The test of reliability, in study I, can be criticised on the ground that the test-retest interval of one week might appear too long to expect stability over time. Since the participants do not generally tolerate repeated assessments on the same day, a two- or three-day interval, or use of video-recorded material, might have been preferable. Another limitation is that the material in the analysis of clinical sensitivity was collected through a retrospective survey of medical records (Paper II). It is therefore impossible to determine whether there is a hidden number of missing values due to failed assessments. A further conceivable limitation is that the assessments were made only with use of the GMF scale, and another instrument was used only in the test of concurrent validity. Since there is no golden standard that is quite sufficient for validating the GMF, the ‘known-groups technique’ (Polit & Hungler, 1999, p356) was used as an alternative to test construct validity and clinical sensitivity.

On the bases of the judged representativeness of the sample, it should be possible to generalise the findings, the conclusions and the indicated clinical implications referring to the development and testing of the GMF to settings with contextual similarities to the researched area (Polit & Hungler, 1999).

Studies III and IV - Perceptions of life satisfaction

Studies III and IV were undertaken to examine different perspectives of factors perceived as important for life satisfaction among old care recipients who were undergoing geriatric rehabilitation. A multiple case study design with methodology inspired by ethnographic considerations (Hammersley & Atkinson, 1995) was employed. This implies that the studies were carried out in everyday settings, combining methods, and allowing the design to evolve through the studies and focusing on the meanings of perceptions of different individuals (Savage, 2000).

The studies were centred around 15 persons (80+) undergoing institutional rehabilitation in hospital. Perceptions both of these persons themselves and of 14 of their significant others, who had a helping relationship with them, were investigated. Individual interviews were conducted with each of the participants. In addition the level of motor
function, assessed by the use of the GMF, was utilised for descriptive purposes and for providing background data, which were related to the qualitative results from the interviews.

These studies focused mainly on factors of importance for life satisfaction in older people undergoing rehabilitation, with emphasis on factors upon which the rehabilitative interventions were expected to have influence. These factors were defined as functions and abilities in their broadest sense, covering all possible life areas from body functions to social behaviour. Further, in line with symbolic interactionism and with propositions by Sarvimaki and Stenbock-Hulth (2000), we presumed that there are several aspects of life satisfaction that include, for example, a sense of well-being, of meaning in life and of self-worth. Above all we aimed at openness to the possibility that other perspectives than were initially presumed could have relevance for people in the life situation studied here.

Data collection procedures

Qualitative interviews were conducted with the care recipients on three occasions to cover different phases in the rehabilitation: 1) during the stay in hospital, usually within one week from admission, 2) at a first follow-up one month after discharge, and 3) at a second follow-up six months after discharge. The motor function of the patients/care recipients were assessed on admission, at discharge and at each follow-up, one and six months later, using the dichotomised Dependence subscale of the GMF. Interviews with significant others were primarily held in their homes, always without the care recipient being present. These interviews were carried out one month after the care recipient had been discharged from hospital (Table 7).

Table 7. Overview of the data collection sequences of study III and IV.

<table>
<thead>
<tr>
<th>Occasion</th>
<th>Interview with:</th>
<th>GMF assessment</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>care recipient</td>
<td></td>
</tr>
<tr>
<td>On admission*</td>
<td>x</td>
<td></td>
</tr>
<tr>
<td>At discharge</td>
<td></td>
<td>x</td>
</tr>
<tr>
<td>One month after discharge</td>
<td>x</td>
<td>x</td>
</tr>
<tr>
<td>Six months after discharge</td>
<td>x</td>
<td></td>
</tr>
<tr>
<td></td>
<td>significant other</td>
<td></td>
</tr>
<tr>
<td>On admission*</td>
<td>x</td>
<td></td>
</tr>
<tr>
<td>At discharge</td>
<td></td>
<td></td>
</tr>
<tr>
<td>One month after discharge</td>
<td>x</td>
<td>x</td>
</tr>
<tr>
<td>Six months after discharge</td>
<td>x</td>
<td></td>
</tr>
</tbody>
</table>

*within 10 days from admission
† Two participants failed to take part

In total, 57 interviews were conducted. These lasted from 30 to 100 minutes each, a majority of them at least one hour. All interviews were tape-
recorded and transcribed verbatim. Initially, before the qualitative interviews began, a specific form was used for the collection of descriptive data, such as age, sex, and living conditions, of all participants. This form also included estimations of care and support received and provided. The author of this thesis collected most of the data, and two co-workers, physiotherapists experienced in geriatric rehabilitation, collected data for three and four cases, respectively.

Qualitative interviews and analyses

The qualitative interviews were focused on the main query: ‘What is important for you/the person you care for to be able to do in order to be satisfied with life?’ The participants were encouraged to talk around this question and related issues specified in an interview guide. This guide was constructed as a checklist covering as broad as possible a collection of life areas, from personal care to social and leisure activities. The guide was used as a reminder for the interviewer and allowed modifications of questions posed to individual respondents (Appendix).

This made it possible to collect data regarding 1) how the care recipients themselves perceived factors of importance for their life satisfaction, and 2) how their significant others reasoned about the same topic. Each interview was concluded with a short summary to check whether the content had been correctly understood.

In the early stage of the data collection all three interviewers individually carried out preliminary analyses of a selected part of the data, namely the initial interview with four of the care recipients and the interview with their significant others. A team triangulation (Hammersley & Atkinson, 1995; Mays & Pope, 2000) was made by comparisons and discussions of themes between the interviewers. Thus the interview process iteratively shed light on important questions and generated strategies to be applied at subsequent interviews. For example, to encourage the participants to talk about factors of importance for, rather than factors that hindered, life satisfaction, we asked them to tell us about a day to wish for – ‘What would you/the person you care for do on such a day?’ This question was added to the interview guide in an early stage of the interview process.

A participant validation (Hammersley & Atkinson, 1995; Mays & Pope, 2000) was performed at the follow-up interviews, by checking data from earlier interviews with the participant, and exploring contradictions by probing for more information. This allowed refinement of the data.

Analyses of the transcribed interview material were carried out in line with the ‘thematic framework’ approach (Ritchie & Lewis, 2003). These systematic analyses were first performed concerning all the care recipients,
and subsequently analyses of interviews with significant others were completed. Initially data concerning interviews with one individual were analysed as a separate case. Underlying themes and categories relating to the focus of the research were identified and coded in the transcripts. This analysis yielded preliminary interpretations of each participant’s perceptions, which were re-analysed and again checked in the transcribed material. The results from each case were then cumulatively compared with those of all other cases in order to find differences and similarities. This analytical procedure, aimed at testing theoretical ideas, was thus carried out in a circular process of modifications and redefinitions in line with the process of analytical induction (Hammersley & Atkinson, 1995). The author of this thesis analysed all the material, whereas one of the co-authors of Papers III and IV (B. Sidenvall) individually analysed data from a selected part of the material, i.e. all interviews concerning three cases. This allowed comparisons of themes and interpretations, to determine what inferences were valid.

The analysis additionally involved a progressive process, which implied a gradual shift from descriptive purposes towards development and testing of explanations (Hammersley & Atkinson, 1995). In a later stage of the analysis this implied exploration of the data from a theoretical perspective, using symbolic interactionism (Blumer, 1998), the concept of adaptation (White, 1974) and the continuity theory of ageing (Atchley, 1999) as main theoretical frameworks.

**Results of studies III and IV**

**Descriptive data** obtained by the use the GMF Dependence subscale showed a wide range in levels of Dependence. The range was 0-14 (Md=8.5) on admission, 0-14 (Md=4) at discharge, 0-16 (Md=3) at the one-month follow-up and 0-13 (Md=3) at the six-month follow-up. The GMF results allowed comparisons of the care recipients’ limitations of motor function with findings at the interviews.

**From the care recipients’ perceptions** described at the interviews, three main themes could be identified as being important for life satisfaction, namely activity, independence and adaptation. These themes were defined according to how they were expressed in the interviews. Hence, the term ‘activity’ was used in the broadest sense to capture everything that an individual does, at any level from simple activities to complex skills and behaviours. Activity thus covered the full range of life areas, from self-care, mobility and interpersonal interactions to social life. ‘Independence’ was used to imply the ability to be active and participate in a life situation
without the need of assistance from another person. ‘Adaptation’, on the other hand, was the means by which the negative consequences for life satisfaction caused by activity limitations and decreasing independence could be coped with. In this context adaptation was regarded as a process which people resorted to in order to maintain satisfaction in life when the conditions of life had changed.

Activity limitations challenged life satisfaction, in some of the participants to a degree that loss of functioning meant both loss of meaning in life and loss of a positive self-image. Further, a strong wish for continuity in daily activities was evident. Familiar activity performed in a habitual way, as before the hospitalisation, was expressed as a desirable ideal. This involved maintaining traditional gender-related spheres of activity.

Activity and independence appeared to be associated with each other, as ability to be active was frequently considered a prerequisite for independence. Those who were used to being independent in their daily life had a great fear of becoming chronically disabled with a high degree of dependence. On the other hand, the most help-dependent, who needed considerable help with daily activities, including personal care, accepted their situation. Control and influence over help and services, freedom of choice in daily life and avoidance of being a burden to others were aspects of independence which were regarded as important for life satisfaction. The importance of avoiding being a burden was expressed most frequently concerning adult children, but also regarding other informal carers and staff. Professional care was commonly preferred to informal care. The difficulty in confronting dependence was most obvious among the women, who stressed the importance of being of use to others, instead of being dependent on help.

A majority of the participants referred to the onset of illness as a turning point in life, when feeling old became an experienced reality and reassessments of activity preferences became a necessity. Factors perceived as important for life satisfaction did not change considerably between different interview occasions, but functional decline over time, both as experienced by the participants and according to the GMF assessments, entailed restrictions of activity preferences.

Activity related to the care of one’s own body and to social contacts with significant others was perceived as most important for life satisfaction, irrespective of the levels of physical function of the care recipients. Key issues judged as important by all care recipients were ability to care for one’s own body, ability to walk alone and ability to keep in touch with significant others. Participants with few activity limitations also frequently referred to activities carried out at home as being important for their own life satisfaction. Those with even less disability often mentioned the importance of hobbies and other activities related to personal interests, emphasising
participation in a socially wider sphere. Keeping in touch with significant others was one of the most important activities for a majority of the participants. Concerning socialising, also those with less disability frequently mentioned activities related to personal interests and participation in a geographically wider sphere.

Adaptation consisted of a series of strategies that were employed to cope with declining levels of activity and independence. These strategies were physical reorganisation, interaction with caregivers, mental adaptation and mental activities (as pastimes or escape). The level of motor function and independence – both judged by the GMF assessments and as expressed by the patients/care recipients - influenced the kind of adaptation strategy that was most frequently used.

Reorganisation was most often employed by subjects with a low degree of help dependence, whereas the mental strategies were frequently used by those with the highest degree of dependence. The participants who became dependent on help from others realised that they needed help and were grateful for it. But they were also aware of the lack of control over their own lives that their dependence entailed. Some of them, however, found ways to influence the caregiving, so that they were more self-sufficient, even though dependent on help.

Mental adaptation implied changes in perceptions and values, i.e. not expecting much but ‘taking it as it comes’ and also, by thinking that what is difficult or impossible is not too important. Mental activity was used as a pastime and escape from current difficulties. Thinking and reading served these purposes. The participants frequently attempted this strategy by thinking of pleasant memories from their earlier life. A typical phenomenon noted during the interviews was that when asked about perceptions of the present, the participants described happiness experienced in the past. Many participants found that thinking about good experiences in earlier life made it possible to find life satisfying even if they were greatly dependent and the realities were considered far from optimal. In answer to questions about how life was being experienced, almost all of the participants first said that they were satisfied, but often answered with references to their earlier life. For some it was very hard to express any opinions at all about the present, and for others, when questions were rephrased the answer could change completely from ‘all right’ to ‘deadly boring’.

From the perceptions of the informal caregiving expressed by significant others at the interviews, one underlying concept was found to run through all the material. This was the continuity of the care recipient’s self, which was seen as important both for the care recipient’s life satisfaction and for meaningful communication and interaction with others. This was thus
important for both parties involved in the helping relationship. Several significant others referred to what they judged to be negative changes in the care recipients’ communicated external self. This was expressed as difficulties in recognising the person as her or his old self within the joint interaction. In an attempt to facilitate the preservation of the self, the significant others brought up the life story of the care recipient, including earlier self-expressions, interactions and relationships. In addition, they strove to arrange for good formal caregiving including continuity and dependability, for those who had such needs. Consequently, the general purpose of the care given by the significant others was the protection of the continuity of the care recipient’s self. This protection was an important aspect of the three identified caregiving categories: social-emotional, proxy and instrumental care.

Social-emotional caregiving was provided in all cases by maintaining contact, which ranged from daily face-to-face contacts to telephone contact every second week and occasional visits. Proxy caregiving included checking up, arranging, planning and managing things on behalf of the care recipients, which was done with or without the care recipients’ awareness and/or approval, but always with the same motive, namely for the good of the care recipient. Instrumental caregiving, included assisting with and/or carrying out household tasks, such as cleaning, shopping and washing. It is to be noted that no significant other reported assistance with personal activities of daily living (PADL), such as personal care. In the case of social-emotional caregiving, the protective purpose meant support of a (positive) self-image, whereas proxy caregiving involved efforts to prevent and protect the care recipient from experiences of physical and emotional harm by facilitating safety and the provision of good formal care. In relation to instrumental caregiving the protective purpose was evident in that by providing and doing things for the care recipient the significant others aimed at protecting that person’s health status and integrity.

According to their own descriptions, the significant others strove for reciprocity and empathic understanding in their caregiving. They prioritised social-emotional and proxy care, and expected formal services to provide instrumental hands-on care when needed. Reliable information, continuity in contacts and responsive every-day socialising were, further, stressed as essential components of the formal care. Whereas continuity was emphasised in connection with physical activity, change and adaptation were encouraged, and sometimes forced on the care recipients. The latter was evident in connection with increasing social contacts, accepting help dependence, spending money on formal support, moving to sheltered accommodation and reorganising activities and the home environment.
Hence, although protection of the self was the main purpose of the informal caregiving, changes (such as those mentioned above) were sometimes forced on the care recipients for their ‘own good’. This led to obvious dilemmas and raised the question whether changes that are strongly encouraged and/or forced on a care recipient can be expected to be consistent with that person’s own valuations concerning satisfaction in life.

**Significant others’ perceptions of what is important for the care recipient’s life satisfaction** comprised four types of factors. These emerged from the interviews in terms of four overlapping themes: activity-related factors, independence-related factors, environmental factors and adaptive factors. Physical and social activity was frequently seen as connected to self-expression, which was judged as fundamental for life satisfaction. Independence was viewed as important for two main reasons: to maintain control of daily life and to avoid becoming a burden to others. The environmental factors concerned household economy, the home environment and the social and attitudinal environment, in which formal carers played a vital role. When the ability to be active and independent declined, different means of adaptation were seen as a necessity for the care recipients to keep their degree of life satisfaction as high as possible. This involved adaptive strategies in order to accept and master changes related to disease or illness, to reorganise and adapt the physical environment, and to develop a working interaction with the carers.

In addition, the results disclosed a hierarchical pattern that matched the perceived importance of activity with the care recipients’ level of dependence. For example, ability to manage housework or use the subsidised transportation service to visit friends was only mentioned as important for those who had a low degree of dependence on help. For those who were more help-dependent, activities out of the home were rarely mentioned as valuable. On the other hand, activities that were taken for granted in the previous group, such as walking and managing personal care independently, were frequently stressed as important. Personal care and other activities that could be related to the care recipient’s own body was the lowest common denominator, which was stressed as important for all, including the most disabled who were confined to bed most of the day.

According to the significant others, a decline in physical functioning of the care recipient led to increased adaptive demands both on the environment and on care recipient strategies to achieve as high a degree of life satisfaction as possible. It was difficult, however, for those who cared for someone who was seriously dependent to imagine that any such adaptation could develop and increase the life satisfaction towards an acceptable level. Conversely, an extensive lack of ability to be physically and socially active was considered
to jeopardise the meaning of life. Thus, an ability to maintain daily activities was generally perceived by significant others as important for a meaningful and satisfying life.

Methodological considerations, studies III and IV

A clear strength of the qualitative approach used in the studies aimed at improving the understanding of important factors for life satisfaction (Papers III and IV) is its potential to detect, present and explain the meaning of phenomena such as actions, decisions, beliefs and values from the viewpoint of the involved people (Gubrium & Sankar, 1994; Ritchie & Lewis, 2003). As mentioned in the introduction, previous research has highlighted the need for studies of this type.

The sample size was small, which is usual in qualitative studies. There are several reasons for this. For example frequency is not a concern of this methodology, which is in sharp contrast to quantitative studies requiring statistically significant discriminatory variables. In qualitative studies phenomena need appear only once to be part of the analysis and there is a point at which further data collection generates an increasingly smaller amount of new information. Moreover, to justify the richness in detail contained by data of this kind the sample needs to be restricted (Ritchie & Lewis, 2003).

Several procedures were conducted to ensure the quality of the data collection and analysis. To ensure satisfactory data variation and depth in the interviews, care recipients of both sexes, from a range of household formations and with various diagnoses, were included. They were interviewed on three occasions, which meant that each of them was interviewed for a total of two to four and a half hours. Additionally, the interviews with significant others were focused on the same care recipients and their life satisfaction, which should further broaden the perspective.

To ensure the quality of the data collection, interviewers of both sexes and of different ages participated. This should provide more breadth and depth to the data and possibilities of validating the data collection, and should reduce the potential bias connected with the use of only one person. Further, the data collection included conclusions drawn by interviewers at the end of the interview, comparisons of data between repeated interviews with the same person, and a team triangulation (Hammersley & Atkinson, 1995) between the interviewers. Finally, the interviews were transcribed verbatim.

To ensure the quality of the data analysis, this process involved cumulative comparisons of cases and constant checking of the interpretations within and between the cases to ensure the internal validity of the findings.
The analysis was validated by parallel analysis carried out by two researchers (Hammersley & Atkinson, 1995; Mays & Pope, 2000). Finally, the findings and interpretations were compared with and related to previous research results and different theoretical perspectives to constitute a theoretical triangulation (Ritchie & Lewis, 2003).

The representativeness in qualitative research refers to the data rather than to the sample (Sandelowski, 1986). The findings and conclusions regarding the qualitative parts of the present studies may, on that ground, well be relevant for theoretical generalisation and for empirical transfers (Hammersley & Atkinson, 1995). Based on the trustworthiness of the descriptions of the research process and of the findings and conclusions, the indicated clinical implications should be transferable to settings which have contextual similarities to the researched area (Polit & Hungler, 1999; Ritchie & Lewis, 2003).
Discussion

The General Motor Function assessment scale (GMF)

The conceptualisation of the GMF (Paper I) had two main sources of inspiration; first it was based on clinical experiences of physiotherapists working in geriatric rehabilitation, and secondly it was inspired by the Disablement Process (Verbrugge & Jette, 1994). This resulted in the inclusion of a unique combination of both mobility and upper limb functions and related aspects of functioning (Dependence, Pain and Insecurity) within the GMF assessment.

Initially the GMF was conceptualised in consistence with the Disablement Process and its concept Functional Limitation, which later was labelled Functional Incapacity. The GMF might, further, with the use of the terminology of the ICF (WHO, 2001), be regarded as evaluating Activity Limitations concerning Capacity. However, according to the ICF pain and insecurity are seen as impairment of emotional Body Functions, and are not related to the activity domains. For conceptualising these aspects of Functional/Activity Limitations in a meaningful way, the intra-individual factors of the Disablement Process, which correspond with the personal factors of the ICF, might be useful. These factors spring from or operate within a person and can modify the main pathway by facilitating or hindering the process of disability and/or health.

Moreover, Ueda and Okawa (2003) who have suggested a complementary category of ICF classification, i.e. Subjective Experience of disability, argue that it is important to recognise such experience as an independent dimension of functioning and disability. They state that this could help professionals working with rehabilitation to obtain a greater and deeper understanding of the disability of the people they serve. It may also help the people with disabilities to achieve empowerment, autonomy and self-determination through self-recognition and higher motivation. In this framework, Pain and Insecurity as measured by the GMF could be regarded as negative Subjective Experiences of disability. However, the classification
of the subjective dimensions of functioning and disability is so far tentative and needs to be discussed and developed.

The performance-triggered pain and insecurity, assessed by the GMF, can thus be regarded as intra-individual/personal factors. Alternatively it might be even more relevant to label these as negative Subjective Experiences of disability (Ueda & Okawa, 2003), that imply a possible risk of decreased physical activity, resulting in further disability and negative influence on life satisfaction.

The GMF seems, further, to comprise functions of vital importance for the life satisfaction of its target population. This was indicated by the interview findings in studies III and IV, which showed that physical functioning was regarded as a prerequisite for continuity of habitual daily activities. These daily activities were, in turn, commonly appreciated as of basic importance for the self-expression and the life satisfaction of the participating older care recipients, both according to their own statements and according to those of their significant others.

Additionally, the use of all three subscales of the GMF encourages the patient to verbally express emotional factors associated with the performance of a task. This verbalisation has been suggested as important for the motivation to be physically active (Resnick, 1991). It has been proposed that factors which reduce the incentive for activity, for example pain and insecurity, are among the most important to consider when evaluating motivation for activity among older people with frail health (Resnick, 1999; Resnick, 1991). Moreover, previous research has indicated that older patients might be less willing to report pain (Scudds & Robertson, 1998; Sherman & Reuben, 1998; Yates, Dewar, & Fentiman, 1995) and that, among patients who are afraid of falling, lack of communication regarding falls is associated with activity limitation (Howland et al., 1998). Hence the assessment procedure of the GMF may serve as a facilitator in the rehabilitation process for older people, since it may identify problem areas that need to be observed, expressed, noticed and treated.

The test of the clinical and psychometric properties of the GMF showed overall satisfactory results (Papers I and II). The field test of the GMF (Paper I) strengthened the evidence of its clinical feasibility and clinical validity by indicating clinical practicality, relevance and usefulness. It was frequently stated in the questionnaires answered by physiotherapists that the GMF allowed a quick overview of relevant variables concerning the patient’s motor function. This is important, since the feasibility determines whether instruments are actually used or not in clinical practice (Jette, 1993; Sletvold et al., 1996; Streiner & Norman, 1995; von Faber et al.).
The results of the reliability tests (Paper I) showed overall high values of PA (≥70) and of $r_a$ (>0.82), and low degrees of systematic disagreement. This implied high levels of both inter-rater and test-retest reliability for the Dependence subscale. Comparable test-retest results for the Pain subscale indicated good agreement. In the interpretation of this result it is important to distinguish instability due to unreliability of the measurement from instability in the phenomenon being measured (Johnston et al., 1992). If a day-to-day variation in emotional experiences such as insecurity is present, good test-retest reliability of this kind of item might be hard to establish. Since the random part of disagreement is not related to the assessment instrument, the weaker stability of results of the Insecurity subscale has to be explained by other factors. One explanation for the random disagreement could be that this reflects a true clinical difference between assessments. Hence these results can be interpreted as indicating a high degree of reliability of the GMF when applied in geriatric rehabilitation, concerning both institutional settings and rehabilitation in the patients’ home environment.

On analysis of the concurrent validity of the GMF (Paper II), it was found that the Dependence subscale was highly correlated with disability in ADL as indicated by the Katz Index of ADL (Katz et al., 1970), which confirmed the hypothesis that dependence in the tasks included in the GMF are related to ADL capacity. Pain and Insecurity, on the other hand, instead of being correlated to capacity in ADL, might play a vital role in the performance in real ADL situations, where issues such as motivation and other intra-individual factors influence the behaviour (Cohen & Marino, 2000).

The distribution of GMF scores was examined in study II. This is rarely analysed in clinical studies regarding performance-based functional measures, although it can provide information that determines whether the scale measures a restricted proportion of the target population or not (Mao et al., 2002; Polit & Hungler, 1999). The distribution of the GMF scores showed no floor effects. This is an important indicator of an ability to discriminate between subjects with severe functional limitations. As the aim in using the GMF was to identify a need for treatment in specific problem areas, namely Dependence, Pain and Insecurity, individuals without such problems should have low scores. Hence the statistically significant ceiling effects after intervention were expected and could hardly be avoided in this type of assessment. The pre-intervention ceiling effects indicating a prevalence of pain and insecurity of around 60% correspond to previous reports of a prevalence of pain of 70-75% (Ferrell, Ferrell, & Osterweil, 1990; Scudds & Robertson, 1998; Sherman & Reuben, 1998) and of fear of falling of 50-55% (Howland et al., 1998; Kressig et al., 2001) among old people in frail health.
Comparisons between different forms of geriatric care i.e. institutional, home and day-care rehabilitation, with the use of the GMF (Paper II) showed that before intervention the Dependence subscale discriminated between patients in institutional care and those receiving day-care and home rehabilitation in that in-patients had higher dependence scores than both day-care and home rehabilitation patients. This finding is consistent with the care level classification, where all patients who are judged as able to manage rehabilitation in non-institutional care are offered such an alternative. No differences between the care forms were observed after intervention, which might imply that the intervention outcomes in the compared forms of care were equivalent, according to the functions assessed by the GMF.

The analyses of systematic changes in GMF scores after intervention, compared to the pre-intervention scores, expressed by RP (Paper II), indicated that the GMF is sensitive enough to detect changes in functional limitations from pre- to post-intervention in all the three forms of geriatric care mentioned above. This was evident by a decrease in all three subscales in these three forms of care, with only one exception: the Dependence subscale in day-care showed no change from pre- to post-intervention. This unexpected finding in the day-care group may illustrate the fact that the patients in the day-care programme had more chronic conditions, in that dependence was difficult to reduce, whereas both pain and insecurity related to motor functioning were treatable. It is to be noted that the day-care group, compared to the patients in the other forms of care, showed the most obvious reduction of Insecurity.

Functional limitations and activity preferences

Repeated GMF assessments that were co-ordinated in time with interviews of 15 elderly care recipients (80+) during and after rehabilitation (Paper III) and (though only once) with their significant others (Paper IV) revealed a common pattern of hierarchy of activity preferences associated with both assessed and expressed levels of functional limitations. This hierarchy of preferences was evident both among the care recipients and their significant others. It indicated that activity preferences diminished in parallel with declining ability to be active, in a pattern corresponding with the 'life-space diameter' (Tinetti & Ginter, 1990).

The life-space diameter concept implies that the level of physical functioning is associated with the diameter of the area throughout which an individual moves during a set period of time. With the home as the central location, where for most people basic and crucial activities are established and reproduced, the life-space area can be divided into concentric zones,
such as the bedroom, the rest of the home, the ground surrounding the home, and so on. The further and more often an individual can move around, the greater the extent to which she or he is likely to engage in habitual physical and/or social activities.

The hierarchical pattern of diminishing activity preferences that was found in studies III and IV also included one further distinct vital and narrow life-space diameter which may be labelled: ‘close to one’s own body’. Key issues that all participants in these studies appreciated as important prerequisites for life satisfaction were ability to carry out activities connected with personal care or other needs (e.g. washing, toileting, dressing, eating), which was stressed as fundamentally important even by participants in whom such ability was very limited. In addition, participants with some, but few activity limitations frequently referred to activities carried out at home, such as cooking. Those with even less disability and even fewer symptoms often mentioned the importance of hobbies and other activities related to personal interests, emphasising participation in a socially wider sphere.

Further, in conformity with Tinetti and Ginter (1990), we found extensive individual differences in preferences for higher levels of physical and social activities, especially among participants with higher levels of motor functioning.

This hierarchical pattern can be interpreted as an attempt at adaptation to the circumstances, which in simple words can be expressed as a basic endeavour towards the attitude: What is not (likely to be) possible is not either the most important. However, even among participants with a very limited ability to be active, activities not related to personal needs and their own body, for example going out of doors, were appreciated. With references to the equilibrium theories of Næss (1989) and Pörn (1993), this adaptation can be regarded as part of a process crucial for rehabilitation targeting life satisfaction and health, a process by which people interact with the environment to achieve and maintain satisfaction in life when the conditions of life change.

Activity, continuity and self-expression

The interviews with care recipients during and after geriatric rehabilitation disclosed a strong wish for continuity in daily habitual activities, which was considered important for life satisfaction (Paper III). The ability to perform familiar activity in a habitual way, as before the hospitalisation, was expressed as a desirable ideal. These findings correspond with the continuity theory of ageing (Atchley, 1999) and the activity theory of ageing (Lemon et
al., 1972), according to both of which activity provides various role supports, which are necessary for maintaining a positive self-image, which in turn is associated with a high degree of life satisfaction. A comparable observation has also been reported concerning the rehabilitation process of geriatric care in patients with stroke. These patients talked more about attaining their previous stroke status than about their future rehabilitation goals (Wressle, 1999).

Daily activities can thus be regarded as part of an ongoing process of self-expression, which through interaction with the environment maintains continuity of the self and creates satisfaction and meaning in older people’s lives. An analogous interpretation was made by Leidy & Haase (Leidy & Haase, 1999) who investigated the meaning of functional performance from the perspective of elderly patients. They considered that, patients viewed performance of ADL within the context of the purpose and meaning of life and as representing an important part of who they were as individuals. Analogously with the highly valued activities in the current study (Paper III), this self-meaning expressed through daily tasks was considered to be regarded as challenged through limitations in physical functioning.

The significant others who participated in study IV shared the opinion with the care recipients that an ability to maintain daily activities was important for the latter’s life satisfaction. Continuity of the care recipient’s self-expression through activity was commonly seen as important for life satisfaction, including maintenance of a positive self-image. This was also considered by the significant others as vital for the interrelationship, as they felt that maintenance of habitual activities strengthened the recognition of the care recipient as her or his old familiar self. Accordingly, the results of study IV showed that ‘continuity of the self’ was a key concept relating to the significant others’ views on factors of importance for the care recipients’ life satisfaction. Protection of the social and physical self of the care recipient was thus shown to be a general underlying purpose of the informal caregiving.

Since informal caregiving always occurs in a relationship in which the parties concerned have established good everyday knowledge about each other, this interaction provides good opportunities for reciprocal reflection of the selves of the involved persons. The protection of the continuity of the self can thus probably best be supported by informal carers who have knowledge enough to reflect the individual’s authentic self, despite changes concerning the body. This authenticity has been defined as the experience of commitment to one’s own self-values, emerging from a biographically unique set of relationships. Authenticity, from this viewpoint, is a question of being true to the ‘self-in-context’ and the ‘self-in-relationship’ and an experience of more or less authenticity rather than all or none (Erickson,
All significant others in study IV used their knowledge to support the continuity of the care recipient’s self. They frequently referred to how the care recipient used to be, to the life story of the person in question and to the former nature of the interrelationship. This approach generated caregiving actions aimed at protection of “the old self”, for example: by encouraging and supporting continuity of self-expressions, use of references to the life story in the caregiving interaction, supporting the integrity of the self in interaction with the environment (such as formal carers), facilitating safety and providing for a good home environment.

The results of study IV thus made it clear that the significant others prioritised those tasks for which Litwak et al. (1985, 1999) suggested that informal care would optimally be most suited, namely non-uniform tasks and tasks that cannot be changed from non-routine to routine and that risk being completely lost if no informal caregiver is available. In the light of the continuity theory (Atchley, 1999), this caregiving can also be regarded as facilitating continuity strategies that are essential in adaptation to life changes due to ageing with disability.

According to their own statements the significant others in study IV strove for reciprocity and empathic understanding in their caregiving. These are interactive qualities that have been referred to as prerequisites for constructive support and caregiving (Kunyk & Olson, 2001; Lewinter, 2003; Mercer & Reynolds, 2002; Reynolds & Scott, 1999; Tanner, 2001). Hence, caregiving interactions with significant others can make contributions to life satisfaction, when there is (at least some degree of) reciprocity. On the other hand, caregiving that obscures the multiplicity and reciprocity may fail to support the authenticity and positive sense of self of the person cared for (Tanner, 2001).

**Dependence and reciprocity**

We found that ability to be active was seen by the elderly care recipients as a prerequisite for independence, which further was judged as important for satisfaction in life. This finding is in accordance with previous research, suggesting that independence is related to efforts to sustain a positive sense of self in old age (Coleman, Ivani-Chalian, & Robinson, 1998; Tanner, 2001). Subsequently, in the qualitative studies described in this thesis, dependence was judged to be a threat against life satisfaction. This standpoint was common among both the care recipients themselves and their significant others (Papers III and IV). The care recipients, especially those with extensive help needs, experienced dependency as a disadvantage entailing constrains of autonomy and control in daily life. In agreement with
Ellefsen (2002) we found, further, that dependency has an aspect of burden among elderly persons, which in the current study was most obviously expressed in relation to relatives. Moreover, a fear of becoming disabled and dependent on help was common among those care recipients who before hospitalisation had been used to managing their ADL independently (Paper III). Since fear of physical decline and dependence is a common phenomenon in the western culture (Hepworth, 1995; Tornstam, 1992), an attempt to live up to cultural ideals to maintain a positive sense of self may well contribute to the perceived importance of both activity and independence that was clear from our findings (Papers III and IV). Previous findings have similarly indicated that diseases that are believed to entail disability and loss of control over the body or the environment are the most feared among elderly patients (Brorsson, Lindbladh, & Rastam, 1998). This fear was related to the estimated stigmatisation potential of the disease and the infirmity was regarded as a failure and a sign of inferiority.

Although the significant others participating in study IV associated independence with the care recipient’s feelings of pride, vanity and protection against shame, in this issue their approach was more ambiguous than that of care recipients themselves. On the one hand they relied on the care recipient’s own judgement of the significance of independence, and on the other hand they encouraged acceptance of a need for help. Whereas the importance of continuity was emphasised in connection with physical activity to protect the continuity of the self, change and adaptation were encouraged and sometimes forced on the care recipients in relation to, acceptance of help dependence, spending money on formal support, reorganisation of activities and the home environment, and moving to sheltered accommodation.

With the use of Bower’s (1987) conceptualisation of caregiving, implying that any process in which people are engaged in for the purpose of caring can be regarded as caregiving, both the encouragement and the force can be seen from the significant others’ point of view as part of a caregiving interaction. The quality of this caregiving can in turn be interpreted from at least two perspectives. From an outsider’s point of view the question may be raised as to whether such force can be regarded as constructive caregiving, based on respect for the care recipient’s authentic self. Empathy, which has been emphasised as a prerequisite for achieving constructive caregiving interaction (Kunyk & Olson, 2001; Mercer & Reynolds, 2002; Reynolds & Scott, 1999; Tanner, 2001), might seem to be lacking.

Another possible interpretation of this double-edged caregiving interaction disclosed in study IV can be linked to the ideas of Finch and Mason’s (1993) of the negotiating of responsibilities in informal family caregiving. Those authors suggest that the people involved try to achieve a
proper balance in their relations, by negotiating the form that their specific roles are to take. The main rule for achieving such balance, where neither party controls the other, is to avoid giving more to someone than they are able to return, which in helping relationships can be problematic. In line with this, Lewinter (2003) has shown that reciprocity is an important factor in informal caregiving to elderly people, by mediating the stability, continuity and quality of the relationship. Reciprocity can also be crucial for the care recipient’s sense of independence, by ensuring some sense of control and a positive self-image (Tanner, 2001).

The strong and sometimes forceful encouragement, found in study IV, that was given to care recipients in an attempt to get them to accept formal care and move to sheltered accommodation, and the absence of informal support with PADL, might thus, alternatively, be understood as an effort to maintain a balance, reciprocity and interdependence in the relationship rather than one party being dependent on the other.

Adaptation and life satisfaction

Both the care recipients and their informal caregivers who participated in studies III and IV considered that adaptation was important for improving life satisfaction when the ability to be active and independent was declining. In many respects, the perceptions of the significant others concerning what they thought to be important for the life satisfaction of the person cared for were in agreement with the care recipients’ own views. Physical reorganisation and the interaction with carers were appreciated by both groups. However, the significant others expressed more frank demands on formal care. Further, they were not aware of the frequent use of mental adaptations strategies and activities by the persons they cared for.

From the care recipients’ point of view, the use of physical reorganisation, interaction with caregivers, mental adaptation and mental activity as adaptation strategies made it possible to maintain life satisfaction, despite disabilities, although sometimes with a very low level of what they prioritised as important (Paper III). By using a combination of these strategies, capacity and realities on the one hand could be balanced against expectations and ambitions on the other. If and when an equilibrium was thus achieved, life satisfaction and health, as conceptualised by Næss (1989) and Pörn (1993) respectively, were improved. In agreement with this, von Faber et al. (von Faber et al., 2001) has suggested that successful ageing is a process of adaptation, rather than a state of being.

The results of the interviews with the care recipients (Paper III) indicated, however, the importance of being aware that the adaptation strategy of
recalling pleasant past memories provides only a temporary escape and obviously does not affect external realities. The use of this strategy for adaptation to declining physical functioning in old age has not, to our knowledge, been described before. Although previous research (Roberto, 1992; Ågren, 1998) has revealed strategies among old people comparable to those demonstrated here, mental activity as a conscious and important strategy has not been highlighted. Nevertheless, this strategy can be associated with the ideas proposed by Cohen and Taylor (1992) concerning ‘escape attempts’, i.e., that different ways of thinking and fantasising provide a temporary means for average people to escape from unpleasant realities, and allow the development of a special sense of identity. To cope with routine, boredom and frustration, people look elsewhere in an attempt to find an escape to an area in which they can absent themselves from such realities.

The care recipients in study III obviously used the extensive biographical material available through their long life experience for supporting continuity of their own self. From the viewpoint of symbolic interactionism (Blumer, 1998), this strategy can be interpreted as efforts to construct a positive meaning in life even if the circumstances are far from optimal. Even when the individual considers her or his life situation to be unsatisfactory, the strategy of recalling pleasant past memories in order to achieve current life satisfaction will give a perspective that does not denigrate the self and that makes the situation occasionally satisfying. Additionally this strategy may add a new aspect to the continuity theory of ageing (Atchley, 1999), this is, use of mental compensation of lost physical ability to carry out familiar activities in order to support the continuity of the self.

The use of the mental adaptation strategies, (i.e. mental adaptation and mental activity) demonstrated in study III may constitute an alternative explanation for previous research results that have been difficult to understand. It may, for instance, partly explain the so called disability paradox (Albrecht & Devlieger, 1999), according to which people with serious disability report that they experience a high degree of QOL, even though they may seem to live under undesirable circumstances. This may further explain why greater life satisfaction has been found at higher ages, which is a phenomenon that previously has been interpreted within the framework of the disengagement theory (Cumming, 1963). This theory assumes that ageing entails a tendency to disengage and withdraw from social roles and activities. According to the disengagement theory inactive living may be natural for old people and therefore some older people are satisfied with life even though they do not perform according to the norms of the activity theory (Lemon et al., 1972). Our results, in contrast, indicate that this ‘naturalness’ could be a form of adaptation when few other options are
available and that the effect of this adaptation may to some extent be fluctuating. Moreover, a recent study on patients in geriatric care unexpectedly showed no statistically significant covariance between dependence in ADL and measured subjective well-being (Nygren et al., 2000). In line with the indications from our findings, the authors speculated that health may have a different meaning for elderly people in a process of geriatric rehabilitation than for an elderly population maintaining their everyday life. The findings in the qualitative studies described in this thesis further indicate that appreciation of adaptive strategies is vital for the understanding of the life satisfaction and health of old people undergoing geriatric rehabilitation.
Conclusions and clinical implications

Conclusions

**Paper I.** A new instrument for assessment of general motor function by physiotherapists, the GMF, was developed. In contrast to other instruments, the GMF includes assessment of both mobility and upper limb functions and three aspects of functional related Dependence, Pain and Insecurity. The GMF was shown to possess good reliability and good clinical practicality, including time-efficiency, clinical feasibility and clinical validity.

**Paper II.** The GMF was found to have satisfactory psychometric properties when applied and evaluated in different settings of geriatric rehabilitation, by showing: no floor effects; a high correlation between the Dependence subscale and ADL; and sufficient sensitivity to reveal differences between pre- and post-intervention assessments in geriatric institutional, home and day-care rehabilitation.

**Paper III.** People in the oldest age groups (80+) who are undergoing geriatric rehabilitation consider ability to be active, independence and adaptation as important for their life satisfaction. Habitual daily activities are appreciated as of basic importance for self-expression. A common adaptation strategy is to actively recall pleasant past memories, in an effort to achieve current life satisfaction. This adaptation strategy creates a temporary sense of life satisfaction, with a potential for concealing dissatisfaction with conditions that might otherwise be correctable. On the other hand, this adaptation can give a perspective of a continuous self and meaning in life.

**Paper IV.** Protection of the continuity of the self of the care recipient is a common purpose of informal care provided by significant others to older (80+) relatives and friends. Continuity is commonly encouraged in connection with self-expression of the care recipient through habitual activities, whereas the need for change and adaptation is encouraged, and sometimes forced on the care recipient, concerning acceptance of formal care and a change in home environment. This ambiguous approach might constitute an attempt to preserve a balanced reciprocity in the interaction between the care provider and the care recipient.

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Clinical implications

The GMF is an instrument with satisfactory psychometric properties, which is time-efficient and practically useful for general assessment of motor function in geriatric rehabilitation. The GMF seems to comprise parameters of importance for the life satisfaction of its target population.

The GMF should be a useful screening instrument for standardised individual assessments by physiotherapists in geriatric practice and for drawing general conclusions at a group level. This includes assessments in geriatric institutional, home and day-care rehabilitation.

Caregivers should be aware that continuity of the self is important for the life satisfaction of old care recipients. Manifestations of such continuity can be achieved through the execution of habitual activities and through recalling pleasant past memories.

Promotion of the ability of old patients undergoing rehabilitation to be active and independent, and in addition support of their strategies to achieve physical and mental adaptation should help to improve their life satisfaction.

When evaluating life satisfaction among old patients in clinical practice, it should be important to be aware that use of mental adaptation strategies and mental activities may influence the results. Possible constructive approaches are use of open-ended questions, rephrasing of questions and sympathetic listening.

Caregiving by significant others’ should be respected and valued, because their established interrelationship with the care recipient give them unique incentives and possibilities to support a continuous and positive self-image of the person cared for.

It should be noted, however, that significant others sometimes have an ambiguous role in the caregiving interaction, since their perceptions about what is important for the care recipient do not always and necessarily agree with those of the person her- or himself.
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References


Appendix

INTERVIEW GUIDE

It should be the aim of the interviewer to enable and encourage the respondent to freely narrate around the main query and related issues.

Main query addressed to the care recipient/caregiver:
*What is important for you/the person you care for to be able to do in order to be satisfied with life?*

Key issues:
What is important for you/the person you care for in order to achieve satisfaction in daily life?
Examples of areas to ask about, if appropriate and relevant are: mobility, personal care, meals, housing, social contacts, interests and hobbies, commissions.

*Do the circumstances matter concerning the issues of importance for life satisfaction? In that case, what circumstances and in what way?*
Examples of circumstances: environment, independence (from equipment or helpers), security, freedom from pain or other symptoms.

*Tell me about a day to wish for – What would you/the person you care for do on such a day?*

Concluding question:
*Among all the things we have talked about, what would you say is the most important to you/the person you care for?*

The interview is concluded with a summary by the interviewer, to check whether the content has been correctly understood.
A doctoral dissertation from the Faculty of Medicine, Uppsala University, is usually a summary of a number of papers. A few copies of the complete dissertation are kept at major Swedish research libraries, while the summary alone is distributed internationally through the series Comprehensive Summaries of Uppsala Dissertations from the Faculty of Medicine. (Prior to October, 1985, the series was published under the title “Abstracts of Uppsala Dissertations from the Faculty of Medicine”.)