LUND UNIVERSITY

Urinary and faecal incontinence among older women and men in relation to other health complaints, quality of life and dependency

Stenzelius, Karin

2005

Citation for published version (APA):
Stenzelius, K. (2005). *Urinary and faecal incontinence among older women and men in relation to other health complaints, quality of life and dependency*. [Doctoral Thesis (compilation), Sustainable occupations and health in a life course perspective]. Department of Health Sciences, Lund University.

Total number of authors:
1

URINARY AND FAECAL INCONTINENCE AMONG OLDER WOMEN AND MEN

in relation to other health complaints, quality of life and dependency

Karin Stenzelius

LUND

UNIVERSITY

To my lovely family, David, Elin,
Helena and Viktor,
and my fantastic parents
Maja and Anders

CONTENTS

PAPERS I–IV

ABSTRACT

Aim: The aim of this thesis was to investigate type, degree and patterns of health complaints, need for help and health-related quality of life across gender among persons aged 75–105 as well as to identify how patterns of health complaints, gender, age and socio-economic factors related to need for help with daily activities and quality of life (Paper I). The aim was also to investigate the prevalence of self-reported symptoms of urinary, faecal and double incontinence among men and women aged 75 and above, and to identify how other health complaints and quality of life relate to incontinence symptoms (Paper II). Furthermore urinary symptoms and their influence on daily life among elderly (75+) women and men were compared in a sample that previously reported having incontinence and/or other urinary symptoms. A further aim was to find underlying structures of urinary symptoms and to identify symptoms which had an impact on seeking medical help and need for help in daily activities (Paper III). The aim of the fourth study was to compare faecal incontinence and related bowel symptoms in relation to gender and being dependent or not (aged 75 and above) and to identify which bowel symptoms predicted help seeking, dependency and low quality of life (Paper IV).

Design: A cross-sectional design in a randomly selected sample of 8500 persons 75 years and above in four age groups of five-year intervals. They received a postal questionnaire including questions about health, socio-economy, quality of life and need for help in daily activities. In the follow-up persons received another postal questionnaire with focused questions depending on previous reported health complaints. Those needing help in daily activities once a week or more were visited in their own homes and interviewed face to face. The first sample (Papers I, II) included 4277 persons, mean age for women 84.3 and for men 82.7 years. The second sample (Paper III) included 771 persons who had reported difficulties controlling urine or other urinary problems. The sample in Paper IV included 248 persons who had reported difficulties controlling stool.

Result: Coexisting health complaints, i.e. multi-complaints, had impact on QoL as well as on dependency. The patterns of health complaints could be understood from a functional perspective. Problems in communication, mobility and psychosocial functions were those most common and with the highest severity. Women were especially affected as they had more health complaints in functions that were related to help in ADL and to low QoL. Furthermore the prevalence of urinary, faecal and double incontinence was high in all age groups and higher with more advanced age. Incontinence had a negative impact on quality of life and increased need for help in daily activities, and those with double incontinence were the most affected. Among those with urinary problems the character of symptoms differed in storage or voiding symptoms among men and women. However, the influence on social life, avoidance of places and situations and the impact on the whole life seemed equal. Less than 50% had sought medical help for their symptoms and few wore protective aids, especially men. Diarrhoea, constipation, incomplete emptying and laxative use were common among those who reported faecal incontinence, and few had sought medical help or wore protection.

Conclusion: Patterns of health complaints indicated problems on a functional level of importance for need for help in daily activities as well as quality of life. Mobility, psychosocial, communication and elimination problems were strongly related to dependency and low health-related QoL. Women seem to be more at risk as they were more often affected in three of these functions and thus more often dependent and had lower QoL. Women also seemed to have more additional negative socio-economic factors. Dysfunctions that were most common should be focused on and interventions aiming to reduce such complaints are of high priority. Overall urinary and bowel functions seem to be equally as important as incontinence per se and therefore a wider perspective when investigating these symptoms would benefit decisions about investigations and help. Men and women have different needs and none of them should be overlooked. There is a risk that men are neglected as incontinence is regarded as a female problem. Urinary, faecal and double incontinence were common conditions but also other urinary and bowel problems, and few had sought help although they reported considerable problems. All urinary problems as well as bowel-related problems seemingly interacted and had equal effect on daily life and quality of life. Therefore those areas should preferably be seen together and not separately.

ABBREVIATIONS AND DEFINITIONS

Abbreviations

ADL	Activities of daily living
CI	Confidence interval
DI	Double incontinence
EMG	Electromyography
FI	Faecal incontinence
IADL	Instrumental activities of daily living
ICF	International Classification of Functions
ICS	International Continence Society
LGC	Lund Gerontological Centre questionnaire
LUTS	Lower urinary tract symptoms
MCS	Mental Component Summary
MS	Mixed urinary symptoms
OU	Other urinary symptoms
PADL	Personal activities of daily living
PCS	Physical Component Summary
QoL	Quality of life
SD	Standard deviation
SF-12	Short-Form Health Survey, SF-12
UI	Urinary incontinence
WHO	World Health Organization

Definitions

Disease	Diagnosed or undiagnosed description of an illness.
Diagnosis	Disease which has been objectively detected.
Symptoms	Subjective or objective indicators of a disease or change in condition as perceived by the patient, carer or partner, which may lead him/her to seek help from health care professionals (Abrams et al., 2002).
Health complaints	Health problems and other functional declines subjectively described that may or may not relate to any disease.
Dependency	Need for help in daily activities once a week or more, personal or instrumental
Incontinence	Any leakage of bodily waste products as urine and faeces
Urinary incontinence	The complaint of any leakage of urine
Faecal incontinence	The complaint of any accidental and unintentional loss of faeces
Anal incontinence	The complaint of any accidental and unintentional loss of gas and or faeces
Double incontinence	The complaint of both urinary and faecal incontinence

ORIGINAL PAPERS

I   Stenzelius. K., Westergren, A., Thorneman, G., Hallberg, IR. Patterns of health complaints among people 75+ in relation to quality of life and need of help. *Archives of Gerontology and Geriatrics* 2005. **40**, 85–102

II   Stenzelius, K., Mattiasson, A., Hallberg, IR., Westergren, A. Symptoms of urinary and faecal incontinence among men and women 75+ in relation to health complaints and quality of life. *Neurourology and Urodynamics* 2004. **23**, 211–222

III   Stenzelius, K., Westergren, A., Mattiasson, A., Hallberg, IR. Older women and men with urinary symptoms, seeking medical help, dependency and influence on daily life. Submitted.

IV   Stenzelius, K., Westergren, A., Hallberg, IR. Bowel symptoms among persons 75+ reporting faecal incontinence in relation to help seeking, dependency and quality of life
Accepted for publication in *Journal of Clinical Nursing* 2005.

The papers have been published with the kind permission of the respective journals.

INTRODUCTION

It is common that older people suffer from several health complaints, such as difficulties walking, seeing, hearing, pain and incontinence, both urinary and faecal. Certain health complaints may also coexist with other health complaints in different patterns although this coexistence is not very well known. When one health complaint is added to another it may be that it comes to a point where help from another person is needed to deal with everyday matters. Health care is by tradition often focused on isolated problems rather than the coexistence of health complaints, but older people with health complaints may benefit from a comprehensive assessment and interventions to increase the chances of improving the situation. Therefore knowledge about health complaints and their interrelationship and consequences for the individual is of great importance.

Incontinence, urinary and faecal, is a common health complaint among older persons although the prevalence among the oldest old, 85 years and above, has been sparsely investigated. It is known that a health complaint like incontinence negatively influences daily life for an older person and it also plays an important role in the need for help in daily activities or institutional care (Hellström et al., 1990, Ekelund et al., 1993) but what may influence this "turning point" is not clear. Some studies indicate that incontinence is not life-threatening, but affects quality of life rather than length of life (Ouslander and Abelson, 1990, Grimby et al., 1993, DuBeau et al., 1998, Dugan et al., 1998, DuBeau et al., 1999, Dugan et al., 2000) while others claim it is not a strong risk factor for nursing home admission, functional decline or death (Nakanishi et al., 1999, Holroyd-Leduc et al., 2004). However, as incontinence seems to have an impact on quality of life and need for help, it may be of interest to show which of the incontinence-related symptoms are most important for need for help and quality of life.

BACKGROUND

Although many older people stay healthy even in high age, some develop several diseases and health complaints, and incontinence is one of these. The presence of comorbidity has been focused on in research but the presence of health complaints has been sparsely investigated. However, it has been reported that older women had more health complaints than men, such as sleeping problems, memory decline, dizziness, mobility impairment, fatigue and being nervous (Borglin et al., 2005). It may be also that several health complaints occur in special patterns and influence each other in certain ways. For instance, the ability to be continent is dependent on a person's ability to reach the toilet in time, i.e. to walk, and when such an important function declines this ability may be diminished. Single health complaints have been reported to be negative for quality of life, as for instance pain

(Jakobsson et al., 2003, Jakobsson et al., 2004) and decreased mobility (Noro and Aro, 1996, Grimby and Svanborg, 1997), but how quality of life changes when several health complaints occur at the same time or in special patterns is not known.

As the term "incontinence" is often used synonymously with urinary incontinence, faecal incontinence may be overlooked and has been less investigated. Thus, the term *incontinence* is used hereafter as a concept covering both urinary and faecal incontinence (Crowther, 1995). As incontinence among younger persons is often regarded as a female problem, this perception has also influenced research among older persons and incontinence among older men is sparsely investigated. Different reports have however indicated that both men and women in higher ages have incontinence (Molander, 2001, Molander et al., 2002 a, Molander et al., 2002 b) and that it has relations to other health complaints such as mobility (Jirovec, 1991, McDowell et al., 1996, Chassagne et al., 1999), diarrhoea (Goode et al., 2005) and comorbidity (Grimby and Svanborg, 1997, Aggazzotti et al., 2000, Quander et al., 2005). The hidden incontinence, i.e. faecal incontinence, needs to be focused on as well as urinary incontinence in men.

It is problematic, also, that few seem to seek medical help (Johanson and Lafferty, 1996, Steeman and Defever, 1998, Edwards and Jones, 2001, Shaw et al., 2001). It may have to do with bodily wasting products being viewed as dirt and something to hide from others as much as possible. That has been found to be the case with snoring, perspiration, vomiting, expectorations, urine and faeces (Ross et al., 1968, Hirt et al., 1969). It has been reported that patients have difficulties talking openly about it with their family or health care staff, and doctors have difficulties asking about it (Cohen et al., 1999). In addition psychosocial consequences such as fear of bad smell, feeling of dirt, decreased self-esteem, feeling of being alone with such problems, shame and despair have been reported among elderly persons with urinary incontinence (Hunskaar and Sandvik, 1993, Sandvik et al., 1993) as well as diminished social contacts (Ouslander et al., 1987) and thus detrimental effects on quality of life. Although the problem seems to be big, the actual size of the problem in the higher ages among both sexes, relation to other health complaints, help seeking, quality of life and/or need for help requires investigation.

Old age and ageing

The number of older persons is increasing as a result of the success of public health together with social and economic development in most of the developed countries (WHO, 2002a). Another important reason for the increasing number of older people is the higher birth rates in these cohorts. In 2025 one third of the populations in Japan, Germany and Italy and in other European countries will be

60 years and above compared with 8–12% in the year 2000 (WHO, 2002a). Even more important is that the number of those over 80 years old, the age when health declines most, will grow fastest. Those aged 100 and more have doubled from 1980 to 1990 as in most European countries (Evans et al., 2001). The increasing number of elderly means an increasing number of persons with age-related diseases and symptoms, which raises demands on the health care systems. "The challenge to society consists in the search for structures and rules that allow people at all stages of life to have fair chances of further development and a good life" (Baltes and Mayer, 1999).

In the last part of 17th century there was only half a year's difference in remaining mean age at the age of 65 between men and women, but in 2004 the difference was almost three years (SCB, 2004). The mean age is 78.35 years for men and 82.68 years for women (SCB, 2004). The changes in the population over 65 years old, which have happened only during the past fifty years, makes demand on the health care sector, and women are those who statistically will live longer and will live alone (Evans et al., 2001, SCB, 2004). There have also been changes between genders in social and economic respects as women have part-time work rather than full-time, lower income, more economic hardship, lower subjective rewards and higher level of distress (Ross and Bird, 1994). However, as the social pattern may change in the future, older persons may show another pattern than the old in this decade. The effect of socioeconomic differences needs to be understood and health care designed to meet the special needs of men and women.

Chronological age is a state or a description but may be a rather unspecific measure of ageing. The age of retirement (in Sweden 65 years) is commonly used to express a borderline for being old. As expected lifetime becomes higher, the length of old age has increased to 20–30 years or even more. Furthermore, the individual differences of the ageing experience may be bigger as some live in extreme economic deprivation whilst others are fit and wealthy and can live a good life (Denny and Earle, 2005). The division of older people into young old (65–74 years), mid-old (75–84 years) and oldest old (85+) (Given and Given, 1989) is useful in research, but the growing amount of very old people may require a further description of those over 85 years. Thus, a person's age should be considered relative and unspecific and not as an unquestionable truth, whilst the functional "age" should be estimated individually.

Ageing includes biological and psychological dimensions, a process starting at birth and finishing at the end of life. Ageing has been defined as "a chain of changes or transitions where every such occurrence means an accumulation of earlier circumstances" (Schroots, 1988). Although it is a general experience it is difficult to describe the process. It is not only a biological process but also a psychological and social process, and these processes may not follow each other in time (Thornstam,

1994). Ageing is by tradition regarded as a decline in all functions, although "ageing" is supposed to be neutral as the definition does not include the direction of the changes or transitions (ibid.). Biological ageing is mainly about changes in cells that are impossible to restore, psychological ageing means experiences and impressions accumulated to understand life. Social ageing is about how earlier experiences and roles influence older life and also the ability to adapt to new roles and the changing circumstances in which the person is living (ibid.).

Biological changes in the ageing body are supposed to be genetically coded, and the ability of the cells to divide themselves seems to be essential (Viidik, 2002). This genetic code could be an active guiding process, a passive decline of functions or an increasing amount of defects in information transportation from the genes (ibid.). Additionally, ageing is to a high extent dependent on environmental factors, physical activity, diet and socio-economy. The respiratory system is always in contact with air and is thus most sensitive to environmental contamination. Vital capacities diminish, and the surface where gas exchange occurs, leading to decreased oxygen saturation. Blood vessels become thicker which makes the heart work against increased resistance, with higher blood pressure as a result. Additionally, decreased function in the liver and kidneys makes an older person more sensitive to drugs. However, even though the cellular changes may be considerable with advanced age, it seems that it is the decreased reserve capacity that makes the big difference compared with younger ages (Dehlin and Rundgren, 1995, Viidik, 2002).

Baltes and Baltes (1993, p. 1) described ageing from a *psychological perspective* as inter-individual variability and plasticity i.e. adaptivity. There are major individual differences as ageing is not similar to becoming sick. These individual differences depend on how a person influences his or her life course but are also caused by genetic factors and environmental conditions. Furthermore, interventions among older people have shown that there are sizeable reserves, cognitive and physical, which could be activated through learning, exercise and or training. However this capacity is limited, which means that although reserves can be obtained there is also a limit to what can be achieved by each individual. The gap between gains and losses becomes smaller and smaller in high age, added to a decreased margin of adaptation, which is an important issue in understanding ageing (ibid). However the authors also described strategies for successful ageing, for instance, a healthy lifestyle, individual flexibility, strengthening reserve capacities, environmental compensatory technology. According to these theories there is potential to find compensatory support to adjust to losses (ibid.).

The sociological view of ageing has been described in two major perspectives. One is the theory of activity, which suggests that an older person has similar needs and wishes to younger persons. This theory emphasizes the importance of keeping

active, being needed and worthy, thus compensating for losses (Havighurst and Albrecht, 1953). An opposite perspective is presented in the theory of disengagement, which suggest that older people do not have the same needs as younger people but on the other hand successively try to cut the bands to life, a process which is natural and accompanied with harmony and satisfaction (Cumming et al., 1960). Lawton (1983, Nordbeck et al., 1993) described ageing in an ecological theory as interplay between individuals and their environments, where adaptation has a key role. Individuals tend to adapt to external stimuli in such a way that after a time they are barely perceived at all (Nahemow, 2000). Older persons need more time to reach adaptation and sometimes a reduced function accompanies ageing and becomes a hinder to reaching adaptation (ibid.). Lawton et al. (1983) also described adaptation as a range between comfort and challenge zones. Environmental changes can be without challenge and may cause reduced competence or functional level. Furthermore, the environment is not static either and the environmental pressure decreases with the time spent within it (ibid.).

Ageing by tradition is often viewed from a medical perspective (Fries, 1993) or in terms of the WHO personal tragedy model (WHO, 2002a), which means that dysfunction is a strictly personal problem and a medical issue. The medical model has the ideal, healthy person as a norm and no justifications are necessary, no aids need to be used to handle daily life. This could be altered to a minimum morbidity model (Fries, 1993) or social model. "This model stresses the necessity to move the onset of chronic decrease upward and gain healthy years. The social model moves the perspective from the individual to a social and political issue. Physical and social environment, the barriers to participation in society should be minimized" (WHO, 2002a). In recent work by WHO and supported by disability organizations a new classification of disability, the International Classification of Function (ICF) was developed, focusing on functioning in a perspective that involves the environment as well as personal health (Figure 1).
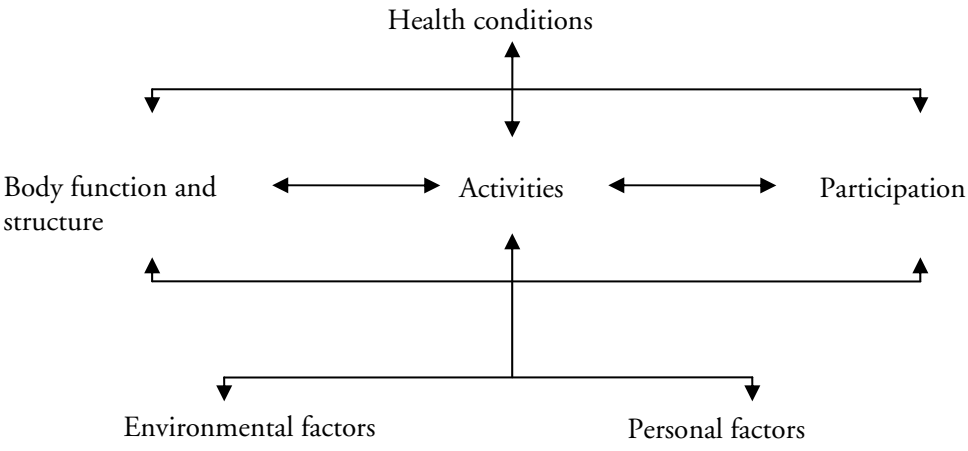

Figure 1. Interactions between the components in the ICF model

17

The earlier classification system rather focused on the consequences of diseases or people as disabled, while the new focus is on their level of health or functioning (WHO, 2001). Use of classification system that focus on persons' functioning could be helpful in the selection of suitable interventions aiming to ascertain participation in society (Dahl, 2002). The ICF comprises two parts, each with two components: first functioning, which include body function (with or without health complaints) and structure (medical perspective), then and disability, which include activity and participation. Additionally there are contextual factors, which include environmental and personal factors (WHO, 2001).

For instance, stoke can cause mobility limitations that in turn cause problems reaching the toilet in time (activity) that have an impact on incontinence (body function). Due to feelings of shame (personal factors) caused by bad smell and feelings of fear the person might avoid being with other people (participation). By adapting environment factors such as help provided, adjustments in the apartment, assistive devices, clothing and so on it might be possible to facilitate activities and participation. The personal factors involve the motivation to seek medical help and knowledge about available treatment options, which could also be influenced by efforts from medical care. Thus, this model could be useful in order to show how different health complaints are influenced by surrounding factors and how adapting, for example, environmental factors and affecting personal factors can improve activities and participation. It may be a way of implementing theories of ageing in practice. Such a multi-perspective including in-personal and outlying factors have proved to be of value in rehabilitative work among disabled people. This could also be of value in the work with older people as many of those have dysfunctions of some kind and would benefit from an approach that stimulates activity and participation.

Comorbidity and health complaints

Although many older people stay healthy even in high age, a considerable number of older people have several diagnoses and health complaints. Comorbidity is a common expression, which means two or more diseases or diagnoses present at the same time, and comorbidity is reported to be higher in higher ages (John et al., 2003, van Dijk et al., 2005). However, it was reported that the presence of two or more diseases was similar among those age 77–84 compared with those aged 90 and over (Äldrecentrum, 2001). It is also common that older people report several health complaints, for example, difficulties in seeing, hearing, pain, disturbed bowel function and so on. As the term symptom covers only problems related to a disease (Abrams et al., 2002) health complaints such as difficulty walking and others do not fit that term. Tibblin et al. (1990b) reported the prevalence of different symptoms in different cohorts, including men and women aged 66–67. Eye problems,

impaired hearing, pain in the legs, depression, sleep disturbance and fatigue were most common. In an older population (n=448, mean age 84.1 years) where 30 health complaints were investigated it was reported that approximately 80% had musculoskeletal pain, 70% impaired mobility, 60% impaired sight and hearing during the previous three months (Hellstrom and Hallberg, 2001). Another study (n= 133, mean age 79 years) reported that 53% had pain in the legs, 51% difficulty hearing, 48% difficulty seeing, 38% general fatigue and 36% backache (Nygren, 2003). Furthermore, the number of health complaints varied from none to 26 per person, median 10, while the number of diseases varied from none to 14, median three (Hellstrom and Hallberg, 2001). Thus it seems as if health complaints are very common and likely to coexist, and they should be taken into consideration when health and quality of life are investigated.

Women seem to have a disadvantage as they are reported to have more health complaints and higher morbidity than men, although men have higher mortality rates. Verbrugge (1985) did a literature review and drew some interesting conclusions about similarities and differences in men's and women's health. According to Verbrugge there is a gap between the genders over the lifetime, but this gap tends to be smaller at high age. Women had more frequent illness and disability, but the problems were not life-threatening. In contrast, men suffered more from life-threatening diseases, which caused them permanent disability and earlier death. In higher age men seemingly catch up with women in health service use because their problems are more severe and threaten life (ibid.). This could, however, be an effect of "fitness of survivors" and the view may therefore be questioned. Some authors claim that there are gender differences in attitude, the way symptoms are perceived, evaluated and treated. They suggested that women may be more alert about reporting illness and seeking help, have greater flexibility to accommodate to illness than men (Macintyre et al., 1999). There are also other explanations put forward, such as that women in these ages were less educated, had lower income and worse economy, which are known factors for reduced health (Ross and Bird, 1994). In searching for any health differences between men and women it seems important to identify those areas which seem to be most problematic, especially for women but also for men.

The diseases that are common in older ages, or their treatment, may also add to the problems in the urinary tract and the bowel and influence a health complaint such as incontinence. Cardiovascular diseases are most common, such as angina, arrhythmia, arteriosclerosis, cardiac insufficiency, hypertension and stroke (Äldrecentrum, 2001). For example, persons with cardiac insufficiency are treated with digitalis and diuretics, which sometimes cause extensive urine production and may force a person to drink less fluid, which is not good for stool consistency. Musculoskeletal diseases such as fractures, rheumatoid arthritis, arthrosis and osteoporosis make up the second most common group of diseases and cancer the next

(Äldrecentrum, 2001). In men the high prevalence of prostatic cancer causes micturition disturbances and in women cancer in the genital region may require operations that additionally influence pelvic floor muscles and contractily of the urethral sphincter. Furthermore, musculoskeletal disorders may influence walking ability and the time it takes to reach a toilet. These examples demonstrate that morbidity in old age may influence other health complaints, and as there are many gender differences in how different diseases occur, both men and women should be in focus.

Old age and quality of life

Quality of life has been used during the last 30 years as an outcome measure in health care research, but few studies have investigated quality of life among the oldest old and in relation to several other health complaints at the same time or compared quality of life among the frailest, i.e. those needing help in daily activities compared with those not in need of help. Quality of life (QoL) is a multidimensional concept, and there are several definitions. Quality of life is defined by WHO as "*Individuals' perceptions of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns*" (WHO, 1998, p. 551). Another definition is that by Lawton, which is also called a good life: QoL is the multidimensional evaluation, by both intra-personal and social-normative criteria, of the person-environment system of an individual in time past, current and anticipated (Lawton, 1983). In this definition four major dimensions were described: *behavioural competence* (health, functional health, cognition, time use and social behaviour), *objective environment*, *psychological well-being* and *perceived quality of life*. Behavioural competence, which can be objectively measured, is complemented with perceived QoL, which is the subjective part. These are the two central dimensions while the other two are more seen as causal components (Lawton, 1991). The same author insisted on the importance of QoL as a mixture of both objective and subjective measures, with the objective part serving as a reference (ibid.). Others have also viewed QoL as both a subjective and objective phenomenon, including the conditions as well as experience of life (George and Bearon, 1980). Furthermore, special consideration may be taken when assessing older persons living in constricted circumstances, i.e. nursing homes or special accommodations (Kane and Kane, 2000), and factors such as time use, meaningful activity, autonomy/choice, privacy, dignity could be added to other QoL domains (ibid.). It is very difficult to estimate QoL objectively, thus most research focuses on the subjective aspects of QoL. In addition, it can be argued that it is the personal view that should value what quality life brings in this phase of life, and therefore it may be particularly important to capture the subjective aspect, especially in groups which seems to be difficult to reach, i.e. the frail and the oldest old.

Quality of life has been measured and investigated along with several health complaints such as pain (Jakobsson and Hallberg, 2002, Jakobsson et al., 2004), fatigue (Jensen et al., 1998, Liao and Ferrell, 2000), incontinence (Grimby et al., 1993) and mobility (Borglin et al., 2005), but whether special patterns of health complaints may have more influence on QoL than other patterns has not been investigated to my knowledge. Studies have demonstrated areas of special importance for QoL among older persons, for instance social relations, help and support, access to local facilities, mobility, having enough money for basic needs and retaining independence (Gabriel and Bowling, 2004). Another study has recognized that older people, like younger people, are vulnerable to losses, bereavements and serious illness (Wiggins et al., 2004). As older people are more often exposed to such events, psychological emotional complaints should also be taken into consideration when measuring quality of life.

Old age and dependency

Need for help in daily activities, i.e. dependency, has been described as an important factor for declined QoL (Hellstrom et al., 2004a, Hellstrom et al., 2004b) and is therefore an important outcome factor. Dependency means a loss in physical and mental function, a product of decline, as an inevitable consequence of ageing (Baltes, 1996). Many chronic illnesses have consequences for the ability to perform activities in daily life, which is sometimes referred to as disability (Verbrugge, 1990) or activity limitations according to the ICF (WHO, 2001). Dependency cannot be associated merely with biological status but also with social and environmental conditions (Baltes, 1996), i.e. a gap between the person's capacity and the environment's demand (Verbrugge, 1990). There are two ways to manage such a situation, either restoring the capacity or reducing the demand, which could be described as buffering strategies. One such strategy is to use help from others or become dependent, which is the indirect measure of whether or not a person is in need of personal assistance to perform a particular activity (ibid.). The second strategy is to increase the capacity, i.e buffers in the person himself or exterior like in the immediate periphery (ibid). Need for help is difficult to measure because it includes both met and unmet needs. Furthermore, if external supports from aids are used, a need will be hidden and the consequence of the illness can be diminished or minimized (ibid.). Buffers can reduce the environmental demands, which probably is commonly used by older persons as they change the activities, reduce social contacts, time spent outdoors and so on (Verbrugge, 1990).

Physical dependency is usually caused by disease or health complaints, and scales are in wide clinical use to measure how it affects activities of daily living (ADL) (Katz and Akbom, 1976). These activities are divided into two major categories, personal and instrumental. ADL scales give an indication of how much help is

needed to support daily activities. However, this should not be mixed up with such activities as may be wanted by the person him/herself, i.e. an inside perspective. Measuring dependency has pitfalls, as the most common classification systems measure what help actually is needed not how hindered the person is in daily life (Thomas et al., 1998, Fagerström et al., in manus). A person may be able to take care of personal hygiene by himself but it takes so much energy that there is no strength left for other activities. There may be hidden and unmet needs or a minimized demand, as dependency could be seen as incompetence, an undesirable situation. Therefore those who feel hindered are not represented in those already receiving help, and measures of the prevalence of dependent persons may not give the full answer to how much help is needed. Furthermore, preventive work may be more strategic among these groups.

Dependency or need for help from others in personal and intimate care influences a person's autonomy, which is defined as "the perceived ability to control, cope with and make decisions about how one lives on a day-to-day basis, according to one's own rules and preferences" (WHO, 2002a, p. 13). Sometimes independency and autonomy are used synonymously (Kane, 1991). Dependency is also described as incompetence, as if the individual does not have the skills required for a particular task (Nahemow, 2000). However, to connect independency with competence may be a negative way of describing dependency and may be used to justify the paternalistic way of taking over people's decision making (Baltes, 1996). Depending on another person may influence a person's sense of control, which have proved to be important for self-perception (Thornstam, 1994). Retaining independence or delaying or at least compressing the time of dependency therefore seems crucial for perceiving autonomy and control. However, no one has fully described what factors are related to dependency more than others.

The lower urinary tract and effects of ageing

The normal micturition cycle involves several anatomical, physiological and neurological structures and functions. The bladder and lower urinary tract have two main functions: storage and periodic elimination of urine (Wein, 2002). The anatomic structures involved in these functions are: the bladder and the bladder neck, the urethra with the urethral sphincter and the pelvic floor. The bladder is located outside the peritoneal cavity and extends upwards during filling. Urine passes from the kidneys to the bladder with peristaltic contractions in the ureters and enters the bladder in the trigone area, a triangle in the lower part of the bladder (ibid.). The passage of the ureters through the bladder wall is about 1.5 cm long. The oblique course functions like a valve and prevents reflux. The bladder wall consists of several layers, the most important of which is the smooth muscle layer called the detrusor muscle, whose contraction makes the bladder muscle fibres

decrease in both length and diameter, rendering complete emptying possible (Chancellor and Yoshimura, 2002). The bladder neck differs anatomically in women and men. In men this inner sphincter has a sexual function and prevents retrograde ejaculation, while women have mainly longitudinal smooth muscle which extends into the urethra (Mattiasson, 2005). A weakness of the supporting structures will cause a descendence of the bladder neck. The external sphincter is separated from the pelvic floor in both the male and the female. This important sphincter is under voluntary control and consists of circular striated muscle fibres (Blaivas and Groutz, 2002). Normal frequency of micturition in adults is up to eight times or 200–300 ml/micturition in the daytime and no times during the night and the total excreted volume is approximately 1500 ml. The neuromuscular regulation of switching between storage and elimination of urine is complex. The most important area is the pontine micturition centres. Other structures of importance are the spinal cord (S2–S4) and cerebral cortex (Mattiasson, 2005). An interaction between the pons and the sacral cord coordinates the voluntary control of the lower urinary tract by motor impulses via parasympathetic fibres in the pelvic nerves and somatic fibres in the pubendal nerves (Chancellor and Yoshimura, 2002). Emptying of the bladder is initiated voluntarily and is maintained by contraction of the detrusor muscle, which depends on sensory impulses from nerve endings in the bladder wall and trigone area, i.e. a positive feedback mechanism for emptying (ibid.).

There is still debate as to whether ageing *per se* has effects on the urinary tract or not (Fonda et al., 1999). The ageing process may influence anatomic structures as well as physiological functions. The most important change in the kidney is a decreasing glomerular filtration rate by 50% at the age of 80 years compared to the young person and a decreased ability to concentrate urine and to reabsorb water in the tubules. This means that elderly need 20–30% larger volumes of urine to excrete the same amount of waste products (Dehlin and Rundgren, 1995). Parallel changes in the vascular system result in a reduced blood flow through the kidneys (ibid.). The disappearance of antidiuretic hormone (ADH) production in older persons will also significantly contribute to a changed micturition pattern (Brockel-hurst, 1994).

Changes in the bladder wall may lead to reduced bladder capacity and decreased contractivity (Fonda et al., 1999). There may also be an increased collagen content leading to decreased compliance (Doughty, 2000). This could explain why many elderly have some residual urine, which is a risk factor for lower urinary tract infec-tion. Afferent sensors of the bladder become less sensitive with age, which delays the desire to void until the bladder is almost full and then there is less time to find or reach a toilet (DuBeau and Resnick, 1991). Urethral compliance also decreases with age but the underlying factors are still unclear. Reduced vascularization may be one component as well as imbalance in the circadian rhythm of oestrogen, which

can lead to atrophy of muscles, ligaments and fascia. All these factors are involved in the bladder outlet control (Getliffe and Dolman, 1997). However, it is known that in older men the prostatic gland increases in size and may cause obstruction with reduced urinary flow rate. In women, childbirth and ageing often cause descent and atrophy of the pelvic floor muscles. In addition, lubrication decreases and may contribute to infections and increased vulnerability of mucous membranes (Hunskaar et al., 1999). The prevalence and character of urinary symptoms and their relation to age in older people has been sparsely investigated and especially so in men and women at the same time.

Effects of ageing on the bowel

Like the function of micturition, normal defecation is partly an involuntary reflex and partly voluntary controlled (Podock and Richards, 1999). The colon consists of eight sections: appendix, caecum, ascending colon, transverse colon, descending colon, sigmoid colon, rectum and anal canal. When there is sufficient stool in the left colon peristaltic contractions begin and normally defecation is initiated. Colon content is then processed into the rectum, which otherwise is empty (Podock and Richards, 1999). Feeling of rectal distension starts at the level of approximately 50 cc (ml) and can reach a maximum of 250–500 cc (ml). This ability to stretch and store stool is also called rectal "compliance" (Doughty, 2000). Awareness of rectal distension and identification of rectal content is crucial in attempting continence. This is a sensory function, located distally to the anorectal junction (Podock and Richards, 1999). These receptors are able to distinguish solid stool from gas or fluid. The two sphincters – the internal anal sphincter and the external sphincter – control the faecal outlet but are completely different. The external sphincter consists of both smooth and striated muscle and is thus under partly voluntary control, while the internal sphincter consists of smooth muscle only and is under involuntary control (ibid.). Relaxation of the internal sphincter occurs in response to rectal distension. The pelvic floor also plays an important role in defecation and perceiving continence as it is striated and together with the external sphincter plays an important part in perceiving continence (Podock and Richards, 1999). The motility in the colon plays also an important role in forwarding colonic content into the distal colon with two types of muscle contractions, haustral and peristaltic movements (ibid.). The haustrum includes both longitudinal and circular muscle bands and serves to increase exposure of the content to the intestinal surface and to slowly move content distally, which can take from 8 to 15 hours (ibid.). The peristaltic waves are present in the left colon and persist for about 10 to 15 minutes, two to three times a day, usually after meals, and move content towards the rectum (ibid.).

As in other parts of the body, bowel function may also change later in life, but little research has actually examined these changes. Atrophy of the intestinal wall and reduction in blood supply may lead to delayed bowel movements, delayed transit and decreased stool-water content (Herbst et al., 1997). However, the gastro-intestinal tract does not show much changes with ageing; for instance, secretion and absorption are much the same as in younger ages (Doughty, 2000). Anal function declines with age, especially among women where it has been connected with previous childbirth or injuries. Atrophy of the pelvic floor musculature is described in women but it maybe also be present among men, although to a smaller extent (ibid).

Behavioural and environmental factors seem to be more important for bowel function in old age than changes in the intestinal canal. Immobility has been reported to cause constipation (Doughty, 2000). Low fibre and too small fluid intake play an important role for stool consistency. In addition, a lot of medicines common in old age have side effects that affect the intestinal function (ibid.). Drugs such as antihistamines, antispasmodics, antidepressants, antipsychotics, diuretics, antiarrhythmics, calcium-channel blockers, opiates, barbiturates, antacids, acetyl-salicylic acids and others may all cause constipation in the elderly (Doughty, 2000). Various drugs can cause diarrhoea, for example antacids, antibiotics, anti-depressants, diuretics (some cause diarrhoea and some constipation), antineoplastic agents, beta-adrenoceptor blocking agents, oral hypoglycaemic agents, theophyllin, aminophyllin, caffeine and lipid-regulating drugs (Getliffe and Dolman, 1997). Different diseases may influence bowel function, such as Parkinson's disease, multiple sclerosis, depression, stroke, diabetes, hypothyroidism, hypercalcaemia and hypokalaemia (Doughty, 2000). Constipation is very common among the elderly and has different causes, of which immobility and diet are the most important. Diarrhoea is also common among elderly and can contribute to faecal incontinence (Norton, 1996). Thus, as so many factors common among older people seems to influence bowel function, it is difficult to draw conclusions about bowel symptoms without taking several factors into consideration at the same time. Also, its relation to urinary incontinence is mostly unknown.

Incontinence among older people

Leakage of urine and faeces in older people may have different causes compared to younger persons, as not only the urinary tract or bowel dysfunctions play a role. The time it takes to reach a toilet is one important factor. A person with walking and mobility problems could be incontinent just because it takes him or her too long to get to the bathroom, to remove the necessary clothes and to sit down on the toilet. Other contributing factors could be the ability to use hands, to remember and to see clearly where the toilet is located. As research often excludes the frailest

elderly, i.e. those with many contributing factors in terms of incontinence, knowledge about incontinence among older persons may be skewed. Therefore it is necessary to include the oldest old who are dependent and have several dysfunctions. Thus, incontinence could be a leakage due to urinary tract dysfunction but also due to other dysfunctions or both; incontinence is therefore a vague concept.

The condition of incontinence is not easily defined as most persons experience some combination of controlled and uncontrolled elimination, i.e. have a single episode of urine or faecal leakage. The definitions used include the frequency of uncontrolled elimination as well as the volume and consistency of the leakage (in the case of faeces) (Doughty, 2000). The definition of continence could be simplified as an ability to retain urine or faeces until a socially appropriate time and place for elimination. Standardization work has been focused on urinary incontinence. The ICS (International Continence Society) has made efforts to arrive at a standardized vocabulary for urinary problems including urinary incontinence. They define urinary incontinence as "*the complaint of any involuntary leakage of urine*" (Abrams et al., 2002, p. 168). There is unfortunately no standardized definition of faecal incontinence, and in the literature there are expressions like faecal, anal, complete or partial, depending on whether leakage of gas is included or not in the definition. The most common definition is perhaps "*any accidental and unintentional loss of faeces*" (De Lillo and Rose, 2000, p. 903). Thus, there is a need for a common vocabulary for different types of faecal incontinence and for consensus in using "incontinence" as a term for both types of incontinence.

Living with incontinence

Behind shame and the anxiety about other people's disgust is an idea that a fundamental aspect of human dignity is about control of body functions (Widding Isaksen, 2001). A person feels ashamed of him/herself in relation to other people. This means there needs to be an interpersonal relation for a feeling of shame. The fear of losing control over urinary or bowel function is grounded in the fear of reactions from others as they may look at, touch or smell the waste products that adult people usually keep in secret. Additionally, in western culture nakedness is strongly associated with sexual intimacy, old bodies associated with bodily decay and death. Descriptions of older bodies as open mouths, gaping throats, faded vaginas and shrunken penises were common in a Swedish study (Hyltén-Cavallius, 1998). Skårderud (2001) described incontinence and incontinence care as a social and cultural phenomenon in three dimensions: questions of life and death, to be and not to be, and order–disorder. In the same way these three dimensions may reflect people's associations and reactions to dirt. Dirt is cultural, actually only existing in the eyes of the beholder and can also be defined as "matter out of place" (Douglas, 1997). In our culture the denial of death is general but has different

meanings. It is natural to expect a long life and to have a fear of dying too early. Modern medical developments have also given the impression that it is possible to have a long life and a good quality of life without any major diseases. The need for care in the elderly is dominated by women as a consequence of women's longer life and the carers are also mostly women. Honour and prestige among health care staff are ranked after the status of the organs they are working with. Chronic diseases as a result of the ageing process are ranked among the lowest and incontinence very low compared to diseases of the heart, brain or blood (Album, 1991).

Incontinence may be associated with loss of identity and dignity. As bodies all persons are very much like each other, but it is our social and cultural interaction with others that makes a person an individual. The bad smell is often overlooked but is likely to be very important in the relation to others for an incontinent person. In a psychological study 105 relations between elderly incontinent people and their adult children were studied and showed that the disturbing presence of odours, sights and textures seemed to have a disruptive effect on their relation (Widding Isaksen, 2002). As a cultural person bodily waste products should be private as the western mode of individualism is strongly related to bodily control (Elias, 1989) and it may be that a loss of control means decreased self-esteem. Incontinence has aspects which could be related to social order or disorder. That means a social integration and feeling of belonging in a family or in society. Family members could experience distance, loss of friends and destruction of formerly good relations. Therefore incontinence could be a threat to the social order of which families are part. In another aspect theories of civilization have stated that in the civilization process bodily fluids have become increasingly personal matters (Elias, 1989). For instance, in the 17th century it was common to pass urine and even faeces in the street, to spit in front of someone, to eat from the same plate with the same spoon etc. However, in that century different guidelines on how to behave were produced, and this was a starting point in the civilization process (Elias, 1989). It was a matter of constructing order in social life and this meant that all bodily waste products had to be kept in secret (Elias, 1989).

The way different kinds of dirt are ranked differ according to culture, history and context, and also between men and women. Kubie (1937) seems to be the first author to have reflected on attitudes of dirt and how these differ from time to time. He pointed out that dirt could not merely be a question of the wrong thing in the wrong place, but also that it was related to bad smell and whether people ranked different kinds of dirt consciously or not (ibid.). In an American study blackheads/-acne was regarded as the dirtiest thing and pus, nose pickings and vomit as next. A total of 22 different body excrements were classified from the least dirty to the most dirty. Urine was in eighth to ninth place from the top and faeces sixth from the bottom (Ross et al., 1968, Hirt et al., 1969). In 1999 in Norway faeces was regarded as the dirtiest thing followed by vomit (Widding Isaksen, 2001). Thus, it

seems as if there are cultural barriers that need to be considered in the understanding of incontinence and why it is often hedged with taboos.

Quality of life has been studied mostly among middle-aged women, while studies among men, older persons, and those with faecal or double incontinence have been scarce. In a qualitative study from 1993 among middle-aged women, urinary incontinence was described as vague and difficult to grasp, for example as a forbidden subject, a taboo, an isolated illegitimate problem and something which had no clear plan of action and as an inevitable thing connected with childbirth (Ashworth and Hagan, 1993). Furthermore, it was described as to have effects on their self-image, as it was their fault, they felt ashamed of themselves and some even hated their bodies. Urinary incontinence was also reported to have an impact on daily life, such as anticipating carefully and taking special precautions such as obsessive bladder emptying, toilet routine planning, selecting safe activities, avoiding dangerous movements and strictly regulating fluid intake (ibid.). Other practicalities such as choosing suitable clothes of easy washable materials, protecting soft furniture, carrying spare underwear, constantly checking for smell, readiness to clean up immediately and throw underwear away were examples that were part of daily life (Ashworth and Hagan, 1993). Other quantitative studies have focused on various aspects of QoL being lower among those with urinary incontinence compared with those without, for example psychological distress (Bogner et al., 2002), depression (Valvanne et al., 1996), social isolation and emotional disturbances (Grimby et al., 1993). Furthermore, compared with other diseases urinary incontinence seems to have a negative impact on QoL, as found by a Swedish study among 76-year-old community-dwelling elderly which compared 16 different diagnoses common among elderly and their impact on health-related QoL as measured by the Nottingham Health Profile (Grimby and Svanborg, 1997). The result showed that after anginal pain, urinary incontinence had most impact on health-related QoL. Another study compared chronic disorders in different population studies which measured QoL with SF-36 (Ware and Sherbourne, 1992) i.e. incontinence (mean age 77 years, severe incontinence), prostate cancer, chronic obstructive pulmonary disease (COPD), AIDS, fibromyalgia and hyperlipaemia (Schlenk et al., 1998). However, studies have shown that interventions with conservative treatment gave improvements in QoL. For instance, Fonda et al. (1995) followed a group of person >60 years for one year. The intervention consisted of a comprehensive uro-gynaecological and geriatric assessment followed by conservative management such as bladder retraining, pelvic floor exercise, general advice about fluid intake and bowel habits. After 12 months there was a significant improvement in depression, isolation, embarrassment, which in this study were seen as measures of quality of life, but also other everyday items such as smell and less laundry were seen (ibid). Thus, this examples show that incontinence, exemplified as urinary incontinence, has a large negative impact on quality of life but also that quality of

life could be improved with interventions that reduce the effects that incontinence has on daily life and the life situation.

Few studies are available about faecal incontinence and its impact on quality of life, although it may be quite similar or even more distressing. A study among elderly aged 65 years and over with bowel disorders showed that persons with diarrhoea and faecal incontinence had lower overall QoL scores, measured with SF-36, and those with faecal incontinence differed significantly from the asymptomatic group in pain and health perception scores (O'Keefe et al., 1995). However, the oldest old, those dependent or living in special accommodations, persons with faecal and double incontinence have been little investigated with regard to QoL and incontinence, even though it is one of the most common symptoms in these groups.

As the relation to relatives and the close family may be influenced or changed due to incontinence, the relational aspects need to be taken into account in the care of incontinent persons. A qualitative study among married couples (n=8) aged 65 and above showed changed roles, decreased intimacy, poor sleep and social isolation (Cassells and Watt, 2003). For example, couples who had slept in a double bed all their lives had to sleep in separate beds due to nightly urinary incontinence. The close relative had to take over decision making and control, which he/she was not used to doing, for example having to control the frequency of micturition and defecation, helping with toileting, leakage and fittings of pads (ibid.). Changing pads on a close relative seems to be surrounded with taboos. For instance, women found it uncomfortable to change a pad and make it fit on a man (Cassells and Watt, 2003). In another study among 105 incontinent persons and their adult children, men felt it worse to have their pad changed by an adult daughter than by their wives (Widding Isaksen, 2002). Men were also at risk of decreased sense of authority, masculinity and fatherhood, self-respect and dignity when intimate parts of the body had to be cleaned by a daughter (ibid.). Urinary symptoms also affect other dimensions such as sexual life because of feelings of shame over the body (Elliott et al., 2004, Salonia et al., 2004). For women it is mostly decreased desire, not being able to relax when touched, lack of orgasm (Salonia et al., 2004) and for men impotence and disturbed ejaculation (Elliott et al., 2004). Older people may still want to keep up an active sexual life and it is therefore important for health professionals to be aware of this aspect. Thus, incontinence affects the person experiencing it in several ways and also those nearby. In addition, it is a problem that seems to be difficult to talk about. Thus, all efforts made to reach a better understanding of how to minimize the negative consequences seem worthwhile.

Urinary incontinence

Although urinary incontinence (UI) is a common condition among older people the prevalence varies depending on the definitions used and the groups selected in terms of age, living conditions, and gender. Therefore it is difficult to know the prevalence, especially among those over 85 as few studies have actually included these ages and those living in special accommodations as well as in the community. UI is regarded as being more common in higher ages and more common among women than men, lower among community-dwelling elderly than among those living in sheltered accommodations, but few studies have included a whole population without any exclusions. The prevalence of UI among women aged 75 and above living in the community varied between 22% and 62% (Hellström et al., 1990, Kok et al., 1992, Wetle et al., 1995, Damian et al., 1998, Simeonova et al., 1999, Gavira Iglesias et al., 2000, Temml et al., 2000, Maggi et al., 2001, Stoddart et al., 2001) and among men from 9 to 56% (Hellström et al., 1990, Wetle et al., 1995, Malmsten et al., 1997, Damian et al., 1998, Gavira Iglesias et al., 2000, Maggi et al., 2001, Stoddart et al., 2001). Among those in special accommodations (nursing homes) it ranged from 38 to 76% (Sgadari et al., 1997, Aggazzotti et al., 2000). Thus, due to the variations previously reported there is still a need for studies with special focus on the prevalence within different age groups of older people.

Urinary incontinence is usually divided into stress, urge and mixed incontinence, with *stress incontinence* defined as "a complaint of involuntary leakage on effort or exertion, or on sneezing or coughing" (Abrams et al., 2002). The standardization committee considers the term unsatisfactory in English because of its mental connection and would rather prefer a wording as used in Swedish like "effort incontinence". However "effort" does not cover all dimensions either, so it is still "stress incontinence" (ibid.). *Urge incontinence* is defined as "the complaint of involuntary leakage accompanied by or immediately preceded by urgency". *Mixed incontinence* is defined as the complaint of "involuntary leakage associated with urgency and also with exertion, effort, sneezing or coughing" (Abrams et al., 2002). These are the traditional types of incontinence but there are also terms such as functional incontinence (Doughty, 2000), transient incontinence (Fonda et al., 1999) or *uncategorized incontinence* (Abrams et al., 2002). All these descriptions stand for incontinence whose cause is unknown or lies outside the urinary tract or, as in the latest definition, "the observation of urinary leakage that cannot be classified into one of the above categories on the basis of signs and symptoms" (Abrams et al., 2002, p. 171). Stress incontinence is more common among women but rare among men, although it can occur after prostatic surgery. Urge incontinence due to detrusor overactivity is the leading cause of incontinence among the elderly (Evans et al., 2000). Another common cause of incontinence among men is outlet obstruction due to prostatic hyperplasia.

Urinary incontinence in the elderly is more complex than only an affection of the urinary tract. Resnick (1984, p. 281-290) described this complexity using the mnemonic DIAPPERS, which refers to the initial letters of transient causes of incontinence among the elderly:

Delirium, an acute or fluctuating confusional state.

Infection, as urinary tract infection may cause temporary UI.

Atrophic vaginitis and urethritis, because of post-menopausal hypo-oestrogen.

Pharmaceutics are one important factor especially as many elderly are on multiple medications, which have more or less known effects on the urinary tract.

Psychological causes such as depression are believed to be related to UI.

Excessive urinary output, which may arise from cardiac failure, treatment of diuretics and also increased fluid intake.

Restricted mobility such as the ability to walk, rise and sit down, use the arms, hands and fingers.

Stool impaction.

There are also other factors which have been shown to be related to UI, such as diabetes mellitus, overweight, prostatic hyperplasia and disorders of the central nervous system such as stroke or Parkinson's disease. Different drugs commonly used among the elderly also cause disturbances in the bladder function or the urinary tract. As examples, sedatives or hypnotic drugs impair alertness, diuretics cause polyuria, antidepressants, anticholinergic or antispasmodic agents, anti-parkinsonian drugs and calcium-channel blockers can predispose elderly to urinary retention (Doughty, 2000).

There are several strategies to treat or improve urinary incontinence also in old ages. First of all a proper diagnosis must be reach in order to exclude other contributory factors. There are behavioural strategies such as toilet training, bladder training, biofeedback, electric stimulation therapy, pelvic muscle exercise programmes and training with vaginal weights. There are several medications which may help depending on the type of UI, as anticholinerics, alpha-adrenergics and anti-depressants have also proved to be effective. Different surgical treatment such as retropubic suspension, bladder neck suspension, anterior vaginal repair, bulking injections, sling procedures and even artificial urinary sphincters are available (Doughty, 2000). Unfortunately, many older people do not seem to get access to available investigations and may rely on protective aids only.

Faecal incontinence

There is no common definition of faecal incontinence (FI) as there is in the case of urinary incontinence (Abrams et al., 1988, Abrams et al., 2002). However, faecal continence has been defined as "the ability to retain faeces until a socially appro-

priate time and place for elimination" (Doughty, 2000, p.345). FI has also been described as accidental and unintentional loss of stool (De Lillo and Rose, 2000). There are also other definitions, for example excluding or including leakage of gas, duration, frequency and amount. Most used are definitions that specify *anal* or *complete incontinence* when gas leakage is included and *faecal* or *partial incontinence* when leakage of stool is considered (Faltin et al., 2001, Macmillan et al., 2004). FI is defined in this study as any leakage of stool. Faecal continence is maintained as long as anal canal pressure is greater than rectal pressure. It is achieved by a combination of different mechanisms such as adequate rectal capacity and compliance, conscious control, closed anal sphincter, anal sensibility and stool consistency. There are also those who argue that the ano-rectal angle, which measures 90 degrees at rest and 135 degrees when straining, has an influence on continence (Bentsen and Braun, 1996a, Sagar and Pemberton, 1996). According to that theory, this angle is like a flap which prevents stool from the upper colon proceeding to the rectum during defecation.

There are relatively few studies describing the prevalence of faecal incontinence among older people; the variations are wide and in many cases not defined. The literature review of FI among elderly (75+) presented in Paper II showed a prevalence from 3.7% to 17.8% among women and 3.7% to 11.6% among men living in the community (Kok et al., 1992, Talley et al., 1992, Edwards and Jones, 2001, Perry et al., 2002, Teunissen et al., 2004) and 46% among nursing home residents (Johanson et al., 1997, Nelson et al., 1998). Later studies among community-living people > 65 years have reported a prevalence of 9.6% (Quander et al., 2005) and 12% (Goode et al., 2005).

Factors correlating with FI (age >65) and other type of conditions included diarrhoea, which was the strongest, but also UI, poor perceived health status, swelling in the feet and legs, previous hysterectomy (women), prostate disease (men), and ischaemic attack (Goode et al., 2005). Another study (age 75, SD 6) showed that FI correlated with haemorrhoids, constipation and taking stool softener (Bliss et al., 2004). There are also other factors that could be related to or even the cause of FI: for example out of 55 women (age 75–93) with faecal incontinence 52 had a treatable abnormality such as rectocele or enterocele (Savoye-Collet et al., 2003). Among women the most likely cause of FI is anal sphincter damage by perineal tear or trauma associated with childbirth (Kamm, 1998).

Although there is a belief that nothing can be done to treat FI among older persons, nothing could be more wrong. There are several options to treat or improve this symptom. Most important for the treatment is a proper patient history, including complaints and both specific and general health information. Furthermore, a bowel diary, physical examination, visual inspection of the perineal skin and anus and digital examination of the anal canal and rectum are essential in assessing FI. Other

32

investigations that could be performed in order to establish a proper diagnosis are various physiological and radiological investigations such as electromyography (EMG), anal EMG, anorectal manometry, ultrasound, proctography etc. (Doughty, 2000). Treatments of FI vary depending on the cause of FI, but behavioural therapy, such as bowel training programmes and stimulated defecation programmes, have shown positive effects (Benton et al., 1997, Chassagne et al., 2000, Harari et al., 2004). Other types of treatments are different kinds of biofeedback in order to train the anal sphincter (Heymen et al., 2003) and finally surgical therapies such as sphincter repair or replacement with an artificial sphincter (Doughty, 2000). Different kinds of aids are also available which may reduce leakage, and these should not be overlooked; they include plugs, perineal pouches and diapers (ibid.). Nor should we forget the lifestyle factors that contribute to improved stool consistency and thus improve FI. Increased fluid and higher fibre intake are examples of lifestyle changes, and many older persons may not have a proper diet. As faecal incontinence is hardly recognized as a common problem among older persons, the available treatment and intervention options that could improve FI are not known either.

Double incontinence

Double incontinence, i.e. both urinary and faecal incontinence, is the subject of little comment and investigation. It should not be confused with combined incontinence (urinary stress and urge incontinence). In fact there is no common expression for the situation where both urinary and faecal incontinence occur: terms used are *combined* (Roberts et al., 1999, Lacima et al., 2002, Lacima and Pera, 2003, Eguare et al., 2004, Kapoor et al., 2005), *dual* (Chiang et al., 2000, Shiwach and Peris, 2000) or *double* incontinence (Shiwach and Peris, 2000, Soligo et al., 2003, Ostbye et al., 2004, Teunissen et al., 2004). As *combined incontinence* has also been used for different combinations of urinary incontinence (Hjalmas, 1992, Liu and Andrews, 2002), the expression double incontinence seem to be more adequate. The prevalence of double incontinence has been reported among community-living persons over 65 years to be between 1% and 16.1% (Nakanishi et al., 1999, Roberts et al., 1999, Chiang et al., 2000, Edwards and Jones, 2001) and among nursing home residents between 17.7% and 54% (Peet et al., 1995, Chiang et al., 2000). As both urinary and faecal incontinence have been reported to influence quality of life as well as need for help in daily life, the combinations of problems should add to the burden even more. As double incontinence appears to be common among the oldest old and the frailest, it is important to focus on it and also the factors that contribute to this condition.

Help seeking

Although incontinence is common, few seem to seek medical help. Few studies have investigated help seeking in older ages, but studies among younger persons showed help seeking rates from 38 to 57% (Steeman and Defever, 1998). It is more rare to find studies of why and when they do seek help for their problems. Reasons why people do not seek help have been reported, for instance lack of knowledge of treatment available (Burgio et al., 1994) a belief that incontinence is part of normal ageing and nothing can be done about it (Shaw et al., 2001) or that lay people have a vague understanding of normal functioning and available treatment (Cunningham-Burley et al., 1996, Roe et al., 1999, Gannon et al., 2004). A study among older persons found that they minimized the problem, and if the symptoms were severe they also had other major diseases and then incontinence was not the main reason for seeking help (Horrocks et al., 2004). Kinchen et al. (2003). compared help seekers with non-seekers in a sample of 1840 women with UI (mean age 53 years). The characteristics of the help seekers were that they were not embarrassed to speak about their problems with the physician, had their symptoms for longer time, worse disease-specific quality of life scores and had regular appointments for health checkups (ibid.). Help seeking has to our knowledge not been studied in relation to faecal incontinence among older people.

Help seeking behaviour has been discussed mostly on a personal level, although there seem to be barriers that hinder people from seeking help which are on other levels. Palmer (2004) suggests more comprehensive strategies in constructing interventions in research on incontinence, applying theories of behaviour change. Such interventions focus on reaching targeted populations. As it is reported that women do not discuss incontinence with their health care provider (Palmer and Fitzgerald, 2003), social marketing theories may be applicable in order to increase help seeking (Palmer, 2004). There seem to be certain norms in incontinence care that are difficult to overcome, as it may be a socially accepted behaviour in nursing homes, for example a custom for all patient to use pads (ibid.). Lack of knowledge among health care staff is also a contributory factor in not seeking help, which is on another level than personal. As incontinence is a major complaint in an older population, it must be focused on in all health care education in a better way. Additionally, the wording is of great importance, as there are common words to express that something is wrong, words that are neutral. Here the work of WHO could serve as a good example: "wherever possible, domains names should be worded in neutral language so that the classification can express both positive and negative aspects of each aspect" (WHO, 2002b). For example, it may be easier to talk about difficulties controlling urine than of urinary incontinence. Thus, a better expression may reduce some barriers to seeking help.

Although several studies have pointed out the high direct and indirect costs for incontinence, these estimates do not seem to cover all the costs, as many incontinent persons do not seek medical help or do not get access to treatment or investigations. Health care costs for incontinence consist of three main categories: treatment, care and aids. A study in the USA estimated in 1995 the costs for all persons over 65 years at 26.3 billion US dollars, or 3565 US dollars per person (Wagner and Hu, 1998). Hu et al. (1990) estimated direct costs in 1987 in USA for urinary incontinence to be 10 billion US dollars compared with 15.1 billion US dollars for senile dementia and 1.8 for AIDS. In institutions urinary and or faecal incontinence are common conditions and take up a great part of nursing care. A study in an institution in London estimated that the staff spent 52 minutes a day dealing with incontinence, which was estimated at a annual cost of 9771 US dollars per patient (Borrie and Davidson, 1992). In an Australian geriatric sub-acute setting the time spent caring for urinary and faecal incontinence accounted for two hours per day, which was about 12% to 20% of total cost (Morris et al., 2005). Furthermore, less money seems to be spent on treatment, as studies from the USA and Sweden showed that only 5% to 7% could be derived from treatment of urinary incontinence (Milsom et al., 1992, Wagner and Hu, 1998). In another study 60% of direct costs were related to diagnosis and treatment among the community-dwelling persons but only 0.8% among those in nursing homes (Hu, 1990). There are also indirect costs, as persons with urinary incontinence are more likely to have accidental falls (Brown et al., 2000), lower urinary tract infections (Bortolotti et al., 2000) and wounds (Nelson et al., 1998). Thus, as incontinence accounts for a great part of health care costs and work load recourses, official and voluntary, there need to be more efforts to prevent, reduce and treat this health condition.

In conclusion, there are several problems among an increasing older population as, the persons in need of help will increase. Older people are often regarded as one homogeneous group, although there are differences of 25–30 years, and a majority of those in oldest ages are women. However, the time in need of help could be reduced if more was known about the different health complaints that are common in higher ages, how they occur, coexist and relate to need for help and quality of life. Furthermore, if the time with common complaints such incontinence, which is often one important factor for needing help in daily activities, is to be reduced, then knowledge about important relations must be accumulated in order to develop interventions. It is crucial, however, that a person with, say, incontinence seeks medical care in order to receive such help.

AIMS

The overall aim was to investigate health complaints and incontinence among women and men aged 75 years and above regarding prevalence. A further aim was to investigate urinary and faecal symptoms in relation to other health complaints, quality of life, daily life, help seeking and dependency.

The specific aims were:

To investigate the type, degree and patterns of health complaints, need for help and health-related quality of life across gender among persons aged 75–105 years. A further aim was to identify how patterns of health complaints, gender, age and socio-economic factors related to need for help with daily activities and quality of life (Paper I).

To investigate the prevalence of self-reported symptoms of urinary, faecal and double incontinence among men and women aged 75 and above, and to identify how other health complaints and quality of life relate to incontinence symptoms (Paper II).

To compare urinary symptoms and their influence on daily life among elderly (75+) women and men in a sample that previously reported having incontinence and/or other urinary symptoms. A further aim was to find underlying structures of urinary symptoms and to identify symptoms which had an impact on seeking medical help and need for help in daily activities (Paper III).

To compare faecal incontinence and related bowel symptoms in relation to gender and being dependent or not (aged 75 years and above) and furthermore to identify which bowel symptoms predicted help seeking, dependency and low quality of life (Paper IV).

METHOD

The studies in this thesis have their origin in a collaborative undertaking on a research project about "Quality of life, care for older people in the community and special accommodation". The results of this extensive data collection served as a starting point for several research projects. The data were collected in two steps starting in the autumn of 1999 and completed in September 2000. During this time the group had regular meetings to ensure similarity in registration, assessment interviewing, instruments and so on. The study was carried out in the south of Sweden, "Skåne Region", as this part of the country includes big cities, villages and remote areas and the selected population could thus be in a sense representative of the Swedish population.

A cross-sectional design has been used in this thesis (Papers I–IV), together with a comparative design. This design was chosen in order to describe prevalences and compare independent variables between genders as well as age groups. Furthermore, a correlational design was used in order to describe the relation between variables, not to draw conclusions about causality, which is not possible in such a design (Brink and Wood, 1998, Kazdin, 1998). The Swedish National Population Register, based on personal identification numbers, was used with a random selection in age groups, i.e. 75–79 years, 80–84 years, 85–89 years and 90 years and over. As all citizens are registered, this register has a good potential to give access to names and addresses of everybody without any limitations.

Sample

The samples for studies I and II derive from 8500 persons age 75 and above, stratified for age into the four age groups. The stratification was done in order to give enough of those who reported being dependent on help from others in daily activities. Therefore the sample consisted of more persons in the youngest age group and fewer in the oldest age group. The sample and the respondents in relation to the Swedish population are shown in Table 1.

Table 1. The initial sample, respondents and non-respondents, in relation to the Swedish population.

	Population % (n=793 356)	Target sample % (n=8500)	Respondents % (n=4337)	Non-respondents % (n=3883)
Women	61.0 (486 844)		61.7 (2677)	69.5 (2867)
Men	39.0 (306 512)		38.3 (1660)	30.5 (1256)
p-value			<.0005[a]	
Age group				
75–79	41.5 (329 145)	2 500	34.0 (1474)	25.0 (1029)
80–84	32.3 (256 484)	2 500	31.5 (1368)	25.6 (1054)
85–89	17.8 (140 736)	2 000	21.1 (913)	26.8 (1104)
90+	8.4 (66 991)	1 500	13.4 (582)	22.7 (936)
p-value			<.0005[a]	

[a]Comparisons between respondents and non-respondents measured with Chi-square test.

The questionnaire was distributed at the beginning of December 1999, with two reminders at one-month intervals. A new questionnaire was enclosed with the last reminder. During this time a telephone line was open every day in order to make it possible to ask questions. Reasons for not participating were given by 483 persons, mainly by phone. Relatives reported, for instance, persons having cognitive diseases (n= 114), being too weak (n=93) or being too sick (n= 15). The enclosed letter also offered help in completing the questionnaire. The response rate varied in the different age groups from 52.8% in the oldest group to 59.7% in the youngest group. A total of 280 persons were not reached, of whom 199 had died (Table 2 and Figure 2).

Table 2. Description of the target population, sample and response rate.

Age groups	75–79	80–84	85–89	90+	Total
Original sample	2 500	2 500	2 000	1 500	8 500
Deceased (%)	24 (1.0)	31 (1.2)	50 (2.5)	94 (6.3)	199 (2.3)
Address unknown (%)	6 (0.2)	15 (0.6)	18 (0.9)	17 (1.1)	56 (0.7)
Answers by another person (%)	3 (0.1)	9 (0.4)	4 (0.2)	9 (0.6)	25 (0.3)
Final sample (%)	2 467 (98.7)	2 445 (97.8)	1 928 (96.5)	1 380 (92.0)	8 220 (96.7)
Response rate (%)	1 474 (59.7)	1 368 (56.0)	913 (47.4)	582 (42.2)	4 337 (52.8)
Dropout (%)	993 (40.3)	1 077 (44.0)	1 015 (52.6)	798 (57.8)	3 883 (47.2)
Internal missing	8	17	16	19	60
Final sample	1 466	1 351	897	563	4 277
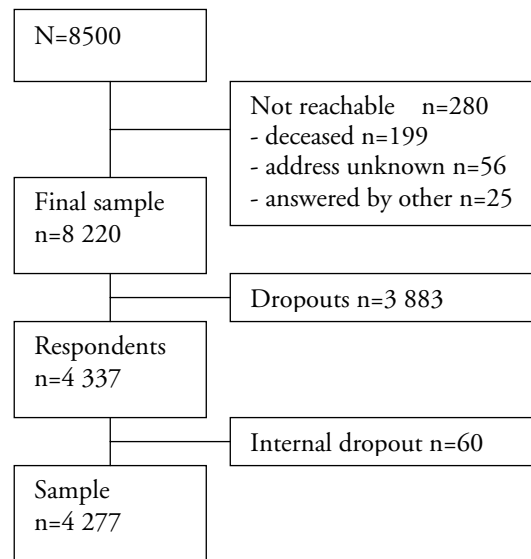
Figure 2. Description of the sample in studies I and II.

An analysis of the non-respondents was performed from the available data combined with a telephone interview with a random sample of 54 persons. They were asked questions about help from others, living in special accommodation and their view of life and life satisfaction. The non-respondents were less worried about their health (p=0.025) and viewed their lives as rather bad or bad to a greater extent than the respondents (p=0.021) (Table 3).

Table 3. Description of the phone interview compared with the respondents and the total Swedish population.

	Phone interview non-respondents n=54	Respondents n=4 337	Population n=793 356
Women % (n)	64.8 (35)	61.7 (2 677)	61.0 (486 844)
Men	35.2 (19)	38.3 (1 660)	39.0 (306 512)
Age group % (n)			
75–79 years	22.2 (12)	34.0 (1 474)	41.5 (329 145)
80–84	18.5 (10)	31.5 (1 368)	32.3 (256 484)
85–89	24.1 (13)	21.1 (913)	17.8 (140 736)
90+	35.2 (19)	13.4 (582)	8.4 (66 991)
Domicile % (n)			
countryside	29.6 (16)	5.2 (224)	
small village/village	51.9 (28)	52.1 (2 258)	
city	18.5 (10)	42.7 (1 853)	
Living in special accommodation % (n)	19.5 (8)	12.3 (523)	
Helping another person % (n)	5.6 (2)	22.2 (783)	
Worries about one's health % (n)			
never/seldom	89.2 (33)	72.2 (3 007)	
often/very often	10.8 (4)	27.8 (1 156)	
p-value	.025		
View of life % (n)			
very good/good	81.1 (30)	85.4 (3 572)	
neither good nor bad	10.8 (4)	13.1 (549)	
rather bad/bad	8.1 (3)	1.5 (64)	
p-value	.021		

About six months later a follow-up questionnaire was distributed to those who had reported having urinary incontinence, other urinary symptoms (Paper III) and faecal incontinence (Paper IV). Those who were independent of help in daily activities (personal activities of daily living, PADL, or instrumental activities of daily living, IADL) received a postal questionnaire. Two reminders were sent and with the second one a new questionnaire was enclosed. Both postal questionnaires were followed by an explanation of the aim of the survey, instructions for completing the questionnaires, telephone numbers and names of persons in the department if they wanted to get in contact. Those dependent were personally contacted by phone and a suitable time for interview was booked and took place in the respondent's own home. The interview lasted for one to two hours and was formed in a structural way and tape-recorded if permitted. All interviews were performed by the research team together with five trained helpers, who had regular meetings to ensure inter-rater reliability (Paper III, figure 3, and Paper IV figure 4).

Figure 3. Description of the sample of Paper III.
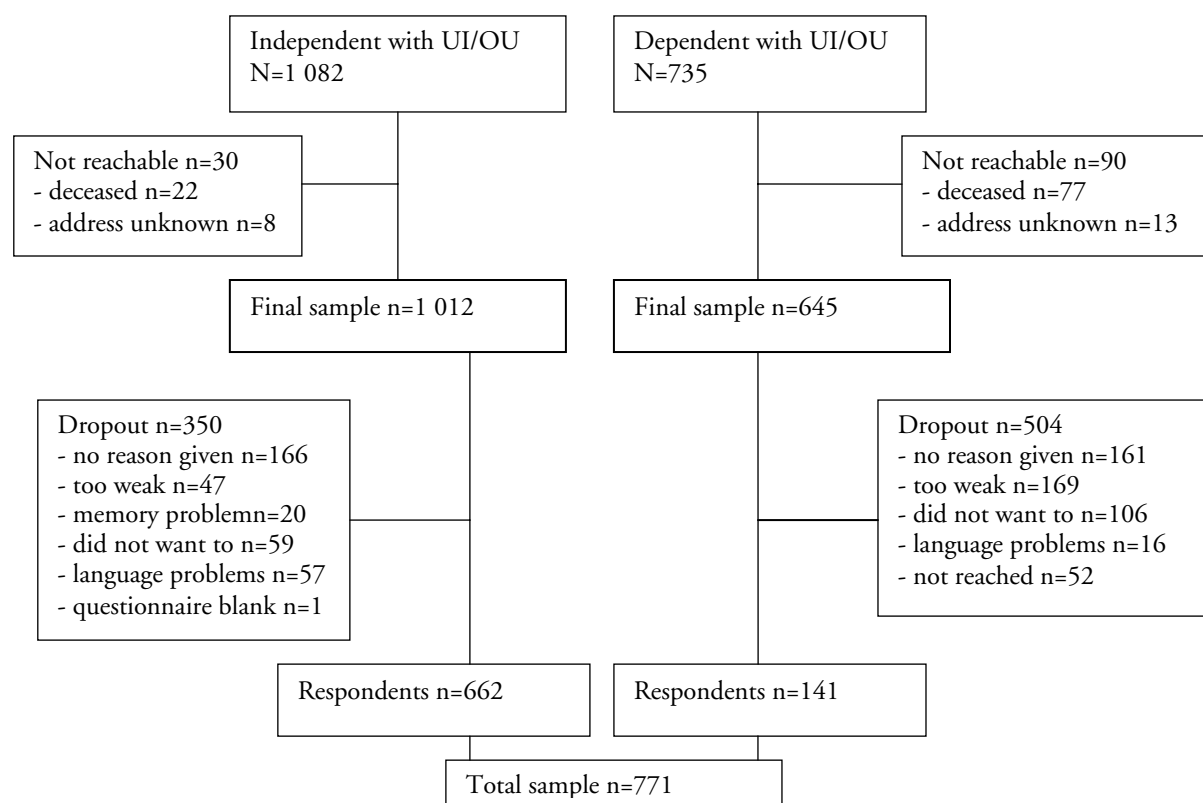
Analysis of those not contacted/non-respondents (Paper III) in the group of independent persons showed that the respondents were younger, had reported fewer memory problems, fatigue, difficulties controlling urine and walking, compared to non-respondents. Similarly analysis of non-respondents in the dependent group showed that the respondents were younger, more often men, married,

lived together with someone more often, had less memory problems, less dependent in PADL and IADL than the non-respondents. Thus, respondents in both groups were likely to be those with fewer problems (Paper III).

The non-respondents in the independent group (Paper IV), did not differ significantly from the respondents in age, gender, marital status, living conditions, domicile, economy, view of life, or MCS, but reported lower PCS (p=.011) more often had difficulties walking (p=.045) and worried more about their health (p=.032). The non-respondents in the group of dependent persons were older (p=.017), lived alone more often (p=0.04), in special accommodation (p=.02) and had more memory problems (p<.001). Thus, respondents in both groups were likely to be those with fewer problems (Paper IV).

```
┌──────────────────────┐          ┌──────────────────────┐
│ Independent with FI  │          │ Dependent with FI    │
│ N=357                │          │ N=321                │
└──────────────────────┘          └──────────────────────┘

┌──────────────────────┐          ┌──────────────────────┐
│ Not reachable n=52   │          │ Not reachable n=45   │
│ - deceased n=9       │          │ - deceased n=38      │
│ - address unknown n=43│         │ - address/tel. unknown n=7│
└──────────────────────┘          └──────────────────────┘

    ┌──────────────────────┐      ┌──────────────────────┐
    │ Final sample n=305   │      │ Final sample n=276   │
    └──────────────────────┘      └──────────────────────┘

┌──────────────────────┐          ┌──────────────────────┐
│ Dropout n=141        │          │ Dropout n=192        │
│ - no reason given n=97│         │ - too weak n=87      │
│ - too weak n=15      │          │ - did not want to n=48│
│ - memory problem n=4 │          │ - language problems n=6│
│ - did not want to n=17│         │ - no reason n=22     │
│ - language problems n=8│        │ - not contacted n=29 │
└──────────────────────┘          └──────────────────────┘

    ┌──────────────────────┐      ┌──────────────────────┐
    │ Respondents n=164    │      │ Respondents n=84     │
    └──────────────────────┘      └──────────────────────┘

            ┌──────────────────────┐
            │ Total sample n=248   │
            └──────────────────────┘
```

Figure 4. Description of the sample of study IV.

Questionnaires

The survey questionnaire consisted of 77 items altogether, including living conditions, previous work, economy, relatives, safety and fear, loneliness, activities, health and quality of life and needing or given help and support. The questionnaire was tested in a pilot study (n=1000) (c.f. Borglin et al., 2005) and was corrected as a result of this. For example, questions about economy and sexual problems were

regarded as too inquisitive. Most of the questions served as a primary selection base for several other studies as well and have previously been used in another population study among elderly people (Hellstrom and Hallberg, 2001, Hellstrom and Hallberg, 2004, Hellstrom et al., 2004b) (Papers I, II).

The questions about health complaints (Papers I, II) were initially used by Bengtsson et al. 1987 and Tibblin et al. 1990 as a part of the Göteborg Quality of Life instrument (GQL). They investigated 30 symptoms common among elderly with *yes* or *no* questions (Bengtsson et al., 1987, Tibblin et al., 1990a, Tibblin et al., 1990b). In this study some of these complaints were changed to others, for instance feeling cold or warm and urinary symptoms. The response alternatives were also changed from *yes* or *no* alternatives into a four-graded scale: *no, yes a little, yes rather much* and *yes very much*. The questions about diseases were chosen from the classification register of main diseases (Socialstyrelsen, 1997), in total 26, followed by one open alternative for additional diseases.

Short Form Health Survey, SF-12
To measure health-related quality of life, SF-12 was used (Ware et al., 1996). This instrument is a short form of SF-36, the MOS 36-item short-form health survey (Ware and Sherbourne, 1992), preferable for use among the elderly because it is short and it does not include questions that concern working situations (Resnick and Nahm, 2001). The 12 questions were selected through a regression analysis and describe the same eight areas as SF-36. These are physical function, role physical, role emotional, bodily pain, social function, vitality and perception of general and mental health. The items are calculated into a mental component summary (MCS) and a physical component summary (PCS), where the score ranges from zero, which is the lowest, to 100, which is the highest QoL. Norm values for a Swedish population have been described, although the low sample size (n=127, 56 men and 71 women) in the older age, i.e. over 75 years, could be discussed. For MCS it was 48.4 (SD 12) for women and 55.3 (SD 8) for men and for PCS 39.2 (SD 11.2) for women and 41.7 (SD 12) for men (Sullivan, 1997). Internal consistency was tested in samples in Papers I and II with Cronbach's alpha and was found to be 0.85 for PCS and 0.83 for MCS.

Lund Gerontological Centre questionnaire, LGC
The quality of life instrument LGC, Lund Gerontological Centre questionnaire, which was used in Paper II, was developed to suit an elderly population and was inspired by several other instruments (Neugarten et al., 1961, Rubenowitz, 1980, Lawton, 1983), supplemented with questions about life span quality and present quality of life. The instrument consists of 51 questions in its original version and was divided into ten dimensions: present QoL, psychological well-being, life span

quality, satisfaction with living conditions, economy, relations to neighbours, social relations, close relations, activities and view of life (Nordbeck, 1989, Nordbeck, 1992, Nordbeck et al., 1993). Each question had four to five response alternatives. The scoring system gives mean values where *zero* is the worst possible and *one* the best value. The instruments were tested in a group of stroke patients and the total internal consistency was 0.91, varying from 0.80 to 0.90 in the different dimensions. In this thesis (Paper II) only two dimensions were used: present quality of life (11 items) and life span quality (four items). Internal consistency for this sample was 0.89 for present quality of life and 0.71 for life span quality (Paper II).

International Continence Society – male questionnaire (ICS-male)

The choice of the two instruments describing urinary symptoms, International Continence Society – male questionnaire (ICS-male) and BF-LUTS, was based on their fulfilling the criteria of being able to compare urinary symptoms between men and women (Paper III). Those instruments had been used in older populations; they were psychometrically tested and internationally well known. After contact with the constructors of the instruments they gave their permission for usage. Both instruments were developed by a research team in Bristol, UK, and started with the construction of the ICS-male questionnaire (Donovan et al., 1996, Jackson et al., 1996). Through a literature review of instruments covering prostate enlargement symptoms they found six instruments (Bovarosky et al., 1977, Madsen and Iversen, 1983, Fowler et al., 1988, Hald et al., 1991, Barry et al., 1992, Bolognese et al., 1992, Cockett et al., 1993), but these in fact covered only limited symptoms. With the aim of covering most of the symptoms related to the urinary tract, a new questionnaire was constructed for use in clinical settings as well as in research. The questions, 22 in all, were based on the previous questionnaires, interviews with men suffering from BPH and symptoms identified by urologists. It contained questions about urine storage, voiding and incontinence. The response alternatives were *never, occasionally, sometimes, most of the time* and *all the time*. The constructors aimed to capture a subjective expression and thus the "*bother*" of each special symptom was added to the questionnaire, an idea from a Danish instrument (Hald et al., 1991). The response alternatives for these were: *not a problem, a bit of a problem, quite a problem* and *a serious problem*. Questions about daily life aimed to cover general as well as disease-specific questions and consisted of seven items. Additionally the instrument consisted of four items concerning sexual life, but those were not analysed in this study.

Psychometric test of the ICS-male questionnaire

The testing of the symptoms and quality of life items was performed in a multi-centre study in a total of 12 countries in patients (n=1271, age >45 years) with benign prostatic hyperplasia (Abrams et al., 1997). Additional testing was done

with a control group of 423 healthy men. The questions about quality of life were not included in all psychometric testing and the questions about sexual life were not tested.

Content validity determines whether an instrument really measures what it is supposed to measure. This can be assured through theory, research, previous instruments, experts and clinical observations (Streiner and Norman, 1998). The conclusion was that the content validity was good, as it corresponded to theories of prostate enlargement and its effect on urinary problems, systematic literature review, discussions with professionals and patients were performed and the internal dropout was low (2–5%) (Donovan et al., 1996). *Construct validity* shows whether an instrument after an intervention can identify the causal concept behind the change (Kazdin, 1998). This cannot be measured once but has to be evaluated every time an instrument is used (Streiner and Norman, 1998). A new study can confirm construct validity but a single negative result would reject the theory (Chronbach and Meehl, 1955). The comparison between the healthy group and the patient group showed significant differences in all items. Furthermore, the theory that symptoms increase with increasing age was confirmed in both the patient group and the control group (Donovan et al., 1996). These results could be referred to as good construct validity, but should be tested in further studies. *Criterion validity* shows how the instrument correlates to what is called the "gold standard" (Streiner and Norman, 1998). In this case comparisons were made with the items in the instrument with common clinical investigations such as flow rate and volume voided charts. The correlation between objective flow rate and patient subjective estimation was low, but between volume voided charts and three items about voiding it was high (Donovan et al., 1996).

Internal consistency shows to what extent items relate to a particular dimension in a scale but not to another; it is often measured with Cronbach's alpha (Bowling, 2002). It is based on the average correlation among the items and number of items (ibid.). A value above 0.7 is regarded as good and could be interpreted as indicating that 70% of the variance is reliable and 30% is due to random error (ibid.). A low coefficient indicates that the item belongs to another category in the questionnaire. On the other hand, many items give higher alpha values. The ICS-male questionnaire was tested for internal consistency as a whole, *multiple form*, for symptom items (0.84) and for bother items (0.91) (Donovan et al., 1996). The high values could be explained by the relatively large number of questions. Measures of the storage and voiding symptoms, *split half*, were 0.69 and of the bother items 0.82 and 0.85., which were regarded as acceptable. The values for the quality of life items were lower, 0.59 (Donovan et al., 1996).

The instrument's *stability* was measured by test-retest on 40 patients, who responded to the questionnaires again after two weeks. This method is used to

determine whether the instrument gives the same result after a retest, where no difference is expected. It is calculated as agreement by using Cohen's kappa coefficient for nominal data, weighted kappa for ordinal data and Pearson's correlation or intraclass correlation coefficient for interval data, where a value of 1 is regarded as perfect (Bowling, 2002). Sometimes confidence intervals are recommended to assess the size of difference between the scores (Bland and Altman, 1986). ICS-male questionnaire was tested with Spearman's rank correlation and showed for symptom items 0.78 (CI 0.62–0.88) and for bother items 0.83 (CI 0.70–0.91) (Donovan et al., 1996).

The instrument was later tested regarding *sensitivity*, which shows whether an instrument can detect changes after interventions (Donovan et al., 1999). The patient's symptoms scores were tested before and after different treatments and, as before, there were low correlations between flow rate (objective measure) and patients' descriptions of urine stream, but in all other items there were significant differences. The authors concluded that this instrument is suitable for treatment evaluations (Donovan et al., 1999).

Bristol Female-Lower Urinary Tract Symptom questionnaire (BF-LUTS)
The development of the female version used in Paper III was also based on the previous testing of ICS-male questionnaire and therefore the female version was constructed in a similar way and is therefore less tested. A literature review of previous questionnaires (Bo, 1994, Resnick et al., 1994, Schumaker et al., 1994, Uebersax et al., 1995) found that the questionnaires available did not cover all symptoms or the grading was incomplete (Jackson et al., 1996). The female version consists of similar questions to the male version and is constructed in a similar way. An additional ten items were added concerning daily life, and four items concerning sexual life; the latter were not analysed in this study.

As the construction of the instrument was similar to ICS-male questionnaire, the *content validity* seemed to be good judging by the interview with patients, the experts, previous research and instruments. Furthermore, the internal dropout was about 2% (Jackson et al., 1996). The *construct validity* was ensured through comparison between those with symptoms and those without and showed significant differences on a p-level of 0.05, and more than one third of the items had a significance level of less than 0.001. Also, the bother items showed significant differences. Criterion validity was tested by comparing the clinical investigation through volume voided chart with questions about daytime voiding, which showed a low value kappa coefficient (0.29) and Spearman's rank-order correlation 0.5 (CI 0.22–0.70) and night-time voiding, kappa=0.70 and Spearman's rank-order correlation 0.85 (CI 0.73–0.92). The question about incontinence episodes, however, showed a higher value, kappa 0.62 and Spearman's rank-order correlation

0.95 (CI 0.90–97) and number of pads used, kappa 0.79 and Spearman's rank-order correlation 0.97 (CI 0.94–0.98) (Jackson et al., 1996).

Internal consistency for all symptom items (*multiple form*) showed a Cronbach's alpha of 0.78 and for the bother items 0.85, which were regarded as good levels in spite of the number of items. The values were lower, though, when analysing the different dimensions of symptoms, *split half*, into voiding, storage and incontinence (0.48, 0.72 and 0.82 respectively) and for bother items (0.69, 0.89 and 0.81 respectively) (Jackson et al., 1996). Stability was tested with test-retest reliability and showed good values as 78% of the items were answered equally and 97% within one category. The authors concluded that the instrument had good validity and reliability (ibid.).

Faecal symptoms questionnaire
A literature review showed that few instruments had been constructed at the time when this project was planned, and none for an elderly population. Either they focused on post-partum problems or on stool consistency and food habits. Therefore the instrument used in Paper IV was constructed from two questionnaires from two clinical settings, one developed at St. Mark's Hospital, UK (with permission from C. Norton), which was professionally translated into Swedish by an official translation office. The other questionnaire was from a Swedish hospital (Malmö University Hospital). The questions used were those which occurred in both questionnaires and/or were most suitable for this study's aim, in total 21 questions. Most questions were on a Likert scale with four response alternatives, *never, sometimes, often* and *always*, and questions with any frequency, size or time were exemplified as *seldom*: once during the last four weeks; *sometimes*: more than once during the past four weeks but not once a week; or *weekly* and *daily*. Due to inconsistent answers, one question about the number of bowel movements per week and faecal leakage consistency was discarded (Paper IV). One question about stool consistency was transformed in the further analysis into two questions, hard stool, *yes* or *no*, and loose stool, varying from *normal* to *fluid*. A total of 14 questions addressed FI-related symptoms and the other questions addressed how to handle the symptoms. Questions about help seeking and use of laxatives were constructed especially for this study.

Data analysis

All analyses were performed using the computer software SPSS for Windows 10.1 and 11.0.

Group comparisons
Differences between two independent groups were analysed with Mann-Whitney U-test for ordinal data, t-test for normally distributed numeric data and chi-square test for nominal data. Differences between three or more groups were analysed with Kruskal-Wallis one-way ANOVA for ordinal data, chi-square test for nominal data and parametric one-way ANOVA for normally distributed numeric data (Polit, 1996, Altman, 1999). When making multiple comparisons a reduction of p-value with p-value divided by the number of comparisons was used according to the Bonferroni method (Bland and Altman, 1995) or with the Bonferroni test as post-hoc analysis in the computer program (Papers I, II, III).

Factor analysis
Principal component analysis (PCA) was used in Papers I, III, IV because of the need to identify the underlying structure and interrelationship of variables, but also to reduce items into a more manageable number by defining a set of dimensions or factors (Hair, 1998). This method was also used in order to replace the original set of variables in the further analyses, i.e. logistic regressions. Furthermore, this method was used for reducing data and calculating new scores for each factor to use in the further analyses. Each factor was then interpreted and understood in a smaller number of concepts. The correlation between variables to be used in the PCA was tested and correlations above 0.3 were used as a limit (Hair, 1998). Correlations could also be tested by Bartlett test of sphericity and measure of sampling adequacy (MSA), which was used in Paper IV. MSA values range from zero to one and 0.8 or more is assumed as meritorious, >0.7 as middling, >0.6 as mediocre, >0.5 miserable and below 0.5 as unacceptable (Hair, 1998). Another assumption is that the sample size must be big enough for the amount of independent variables in the analyse. The recommended sample size is at least five but preferably ten times as many as there are variables to be analysed (ibid.). In Paper I, 29 variables were used in a sample of 4377 (one did not fit into the factor solution), in Paper III, 21 variables in a sample of 771 and in Paper IV, 14 variables were used in a sample of 248 persons.

An orthogonal Varimax rotation method was chosen because of the assumption that the factors were not correlated. Furthermore, it is assumed to be easier to interpret, and the aims were not to construct a theoretical model but rather to simplify and summarize data. However, in the analysis process of the first paper an

oblique method was also used with a result similar to that presented in the paper. Factor loadings above 0.3 are considered in the literature as a *minimal* level (Hair, 1998), but it depends on the sample size on which level factor loadings are significant. Factor loadings above 0.4 are considered *important* and above 0.5 considered *practically significant* (ibid.). The choice of number of factors to be extracted was grounded on the latent root criteria, which is the most common method used. Most authors state latent roots or Eigen values >1 as a limit for the number of factors to include (Hair, 1998), although some have stated 1.5 as a limit (Bowling, 2002). The Eigen value method is most reliable if the variables included are between 20 and 50. If the number is smaller, there is a tendency to extract too few factors. In this work Eigen values above one were used as a limit (Papers I, III, IV). Scree-test criterion was also used in Papers III and IV; this is the point where the Eigen values begin to straighten out, which indicates the maximum number of factors to be extracted (Hair, 1998). These two methods gave similar results in Papers III and IV. Labelling of the factors is a subjective and non-statistical method whereby an interpretation was made and labelled with the focus on a functional perspective; this was performed in discussions between the first author and the co-authors (Polit, 1996, Hair, 1998).

In Paper I the principal component analysis was used for the 30 questions about complaints with an orthogonal rotation method. The sample size was big enough (n=4277), as for 30 questions ideally at least 300 are needed (Hair, 1998). Internal dropout was low (n=185) and was therefore considered without any action. The goal of rotating factors is to obtain factors that have high loadings in only one factor. Loadings close to one are interpreted as aligning with a factor and loadings close to zero are not. Factor loadings over 0.4 were chosen as a limit for variables to fit into a factor (Kim, 1982). One item did not fulfil this criterion. Six factors were chosen, based on Eigen values above one and clinical face validity. Internal consistency was checked for the items in each factor with Cronbach's alpha. In Paper III the same method was used for urinary symptoms that were equal in the male and female versions, in total 21 items. In Paper IV the bowel symptoms related to FI were used in PCA, in all 14 items, which resulted in four factors.

Logistic regression analysis
Logistic regression analysis is the statistical method recommended when the dependent variable is binary (Hair, 1998). The independent variables which were nominal or categorical could be changed into dummy variables where the lowest risk group is assumed to be the reference value. In this thesis, for instance, age group was transformed into dummy variables with the 75–79 group as reference. Sample size should exceed 20 observations per independent variable used in the analysis or at least exceed five (Hair, 1998). This criteria was fulfilled in studies I, II, III and IV. Another caution is that even though the sample size is as

recommended, subgroups within the sample may vary in size. The larger group has a disproportionately higher chance to influence the result in a certain direction (Hair, 1998). Model fit of the logistic regression models was tested with Hosmer-Lemeshow goodness-of-fit test. This test measures differences in predicted and actual values of the dependent variables with chi-square test. Small value and non-significant test give indications of a good model fit (Hair, 1998). This criterion was fulfilled in studies I, II, III and IV.

A multiple logistic regression, backward conditional, with dependency in PADL and IADL (0=independent, 1=dependent) as dependent variables and factors of health complaints (0=having no complaints within the factor, 1=having one or more) as independent variables was performed together with age group (dummy coded with 75–79 years as reference), sex (0=male, 1=female), marital status (dummy coded with married as reference), living conditions (dummy coded with living in own house as reference) and previous work (dummy coded with white-collar work as reference). Similarly, backward logistic regression was performed with PCS and MCS (0=higher value of PCS or MCS than the 25th percentile, 1=lower than the 25th percentile) as dependent variables and the same as mentioned above as independent variable (Paper I).

Backward multiple logistic regressions were also performed with urinary incontinence (0=no difficulties controlling urine, 1=little, rather much or very much difficulty controlling urine), faecal incontinence and double incontinence as dependent variables (Paper II). Other health complaints, in total 28 (0=no problem, 1=little, rather many or very many problems), and age group (dummy coded with 75–79 years as reference) and gender (0=male, 1=female) were used as independent variables (Paper II).

In the same way, backward multiple logistic regressions were performed with dependency (1=needing help in PADL and/or IADL once a week or more, 0=not needing help that much) as the dependent variable and urinary symptoms (6 voiding and 7 storage symptoms) as independent variables. Most of the symptoms were dichotomized as having the symptom never or occasionally (=0) and having the symptom sometimes, most of the time or always (=1). Night-time voiding frequency was dichotomized as none or one time (=0), 2 or more times (=1) and daytime frequency as 1–8 times a day (=0) and 9 times or more (=1) (Paper III).

In Paper IV four logistic regression models were performed. Dependent variables were help seeking (have sought help =1, have not= 0), dependency (dependent= 1, non-dependent =0) and low PCS (below or equal to the 25th percentile =1, over the 25th percentile =0) and MCS used below or equal to the 25th percentile =1, over the 25th percentile =0). Age group was used as an independent variable, while dummy variables were gender and the four factor scores (Paper IV).

Reliability tests

Reliability describes the degree of accuracy with which an instrument measures what it is supposed to measure (Polit, 1996). One way of measuring reliability is to measure internal consistency, and in this thesis items in different instruments were measured by Cronbach's alpha. Normal values for alpha should be above 0.70 but not higher than 0.90 (Streiner and Norman, 1998). As reliability decreases, the items become less consistent, which means that the item or items do not belong to the same conceptual domain. Cronbach's alpha value is however sensitive to the number of items included in the factor or dimension, as more items give a higher value.

ETHICAL CONSIDERATIONS

Ethical considerations must be taken into account when doing research on a group, especially if the people are extra vulnerable. In this project the four major ethical principles have been followed, i.e., the principles of *autonomy, non-maleficence, beneficence* and *justice* (Beauchamp and Childress, 1994). First the *respect of autonomy*, which includes informed consent, informed refusal, truth-telling and confidentiality. To respect autonomy is to make sure that the persons involved are respected for their individual integrity and fully understand that they are able to make choices and decisions of their own without the influence of any person, authority or institution. To ensure the respect for autonomy it was explained that participation in this study was voluntary and could be interrupted whenever anyone wanted to. There could be problems with autonomy in research focused on the elderly, frail persons who are dependent on, for instance, the municipality for help in various matters. There is a risk that they feel forced to participate. This was considered by giving information in the letter stating that the decision not to participate in this study did not have any connection with the provision of health care or other services. The respondents were assured that no one would be able to trace data on an individual basis. All questionnaires, printouts of interviews or tapes were kept in safe place and separate from code lists.

The principle of beneficence and non-maleficence, i.e. doing good and no harm, was assured by establishing confidence in the research team. The letter enclosed with the questionnaire clearly described the purpose of this study and how the results would give knowledge which would benefit older people as a group. Furthermore, the research team was available for any questions eight hours a day during the data collection in order to answer phone calls. To perform interviews the respondents were asked to decide a suitable time so that the interview could take place when they were alert. The time schedule was not too tight that other things could not be discussed, and it was possible to make friends before the interview started. The principle of doing good can also be applied to the study's design in that over- or under-sampling should be avoided, i.e. not investigating too many or too few.

It could be questioned whether it was ethically correct to phone those who did not answer the questionnaire. However, they had not actively said no but only omitted to answer the questionnaire. Getting an explanation for the dropout was important, and with that result we were able to draw conclusions about generalization that would not otherwise have been possible, and they had still a chance to say no. Thus, interviewing the non-respondents by phone could be regarded as being balanced by the benefit of obtaining results that could enable conclusions as to the representativeness of the respondents reached. Furthermore, it was emphasised

again that the person could refuse to answer the questions, and only one person did so.

The principle of justice was applied as everyone in the population was selected without any restrictions, regardless of social status, race, gender, religion, native language or political views. However, those who did not know the Swedish language were disfavoured, as the initial questionnaire was in Swedish. Even if translation was promised, few used that opportunity.

Special attention was paid to not mixing roles as nursing professionals and researchers. Therefore it was decided that questions about treatment and care should be assigned to the persons responsible. However, if negligence or other unsatisfactory conditions were detected, a strategy of action was established, although it never happened during this data collection. The study was approved by the Ethics Committee of the Medical Faculty of Lund University (LU 478-99).

RESULTS

Sample characteristics

The background data for the sample in Paper I and II was the same and presented in Table 4 and for the sample in Papers III and IV in Table 5.

Table 4. Characteristics of the respondents per age group (%) with comparison between women and men.

	75–79 year		80–84 year		85–89 year		90 +	
	women n=811	men n=655	women n=797	men n=554	women n=597	men n=300	women n=431	men n=132
Gender	55.3	44.7	59.0	41.0	66.6	33.4	76.4	23.6
Marital status								
married	41.2	70.5	22.3	65.7	10.4	52.3	3.0	30.1
widowed	44.7	14.7	63.4	21.5	75.2	37.3	81.9	61.7
unmarried, divorced	14.0	14.8	14.3	12.9	14.4	10.3	15.1	8.4
p-value women/men	*<.0001*[a]		*<.0001*[a]		*<.0001*[a]		*<.0001*[a]	
Domicile								
village or rural area	19.0	26.2	18.8	24.2	18.1	24.0	19.2	27.8
densely built-up area	35.4	36.3	34.8	37.0	35.5	37.0	39.7	33.1
big city	45.6	37.4	46.4	38.8	46.4	41.0	41.1	39.1
p-value women/men	*<.0001*[a]		*<.0001*[a]		*.277*[a]		*.003*[a]	
Living conditions								
own house	31.9	47.1	24.1	43.0	18.1	33.2	12.6	28.2
flat or similar	64.1	51.3	66.2	52.7	61.4	54.9	44.0	42.7
special accommodation	4.0	1.7	9.7	4.2	20.5	11.9	43.4	29.0
p-value women/men	*<.0001*[a]		*<.0001*[a]		*<.0001*[a]		*<.0001*[a]	
Living status								
together with someone	45.6	75.4	26.1	69.7	12.7	57.0	8.1	36.1
alone	54.4	24.6	73.6	30.3	87.3	43.0	91.9	63.9
p-value women/men	*<.0001*[a]		*<.0001*[a]		*<.0001*[a]		*<.0001*[a]	
Occupation before retirement								
white-collar	13.9	28.2	12.1	22.5	9.3	18.2	7.2	18.8
blue-collar	52.2	55.2	45.1	57.6	43.6	56.4	37.5	44.1
farmer/own company	8.7	16.4	8.9	19.7	12.9	25.3	13.0	37.8
housewife/man	25.1	0.0	33.9	0.0	34.1	0.0	42.3	0.0
p-value women/men	*<.0001*[a]		*<.0001*[a]		*<.0001*[a]		*<.0001*[a]	
Sufficient money for expenses								
very good	13.6	23.0	13.0	18.8	12.2	18.6	12.6	19.2
good	44.8	48.3	42.3	53.7	44.9	53.6	42.9	44.6
neither good nor poor	32.0	25.8	34.7	22.7	30.7	22.4	32.6	26.2
poor or very poor	10.1	5.8	10.0	4.7	12.2	5.4	11.9	10.0
p-value women/men	*<.0001*[b]		*<.0001*[b]		*<.0001*[b]		*.052*[b]	
Can obtain 8000 SEK if needed*	80.8	92.0	77.7	89.9	80.8	90.5	79.6	89.3
p-value women/men	*<.0001*[a]		*<.0001*[a]		*<.0001*[a]		*.011*[a]	
Economic situation								
better than others	14.8	20.6	15.4	22.6	12.8	24.5	15.9	20.2
same as others	75.1	72.4	75.3	72.3	77.6	69.2	72.9	71.3
worse than others	10.2	7.0	9.4	5.1	9.6	6.3	11.1	8.5
p-value women/men	*<.001*[b]		*<.0001*[b]		*<.0001*[b]		*.194*[b]	

[a] Chi-square test, [b] Mann-Whitney U-test. * 8000 SEK is equivalent to about 800 EUR

53

Of the total sample of 4 277 persons the proportion of men was smaller in the higher age groups. The mean age was 83.6 (median 83, SD 5.69). Their domiciles were bigger cities (42.8%), villages or densely built-up areas (52.8%) and rural areas (5.2%), with no differences between the age groups. More women lived alone, were widows and lived in special accommodations. Women in all age groups had more often had a low-income job or been a housewife and felt that their economic situation was poorer than that of the men in the sense of having a reserve of money, sufficient money for expenses and in comparison with others (Table 4) (Papers I and II).

The sample in Paper III was 771 persons, who in the previous questionnaire reported to have urinary incontinence and/or other urinary problems. The mean age was 81.44 years (SD 5.11, range 75–101 years). There were significantly more men in the youngest age group (75–79) and more women in the oldest age group (90+), p<0.0001. Men were more often married (p<0.001) compared to women whilst more women lived in sheltered housing compared to men. The sample was divided in three groups with urinary incontinence (UI) and/or other urinary symptoms (OU). The mean age was in the UI-group 81.7 (SD 5.1) years and in the OU-group 80.8 (SD 4.9) years. (Paper III).

Table 5. Sample description of respondents in follow-up studies reported in Paper III and IV.

	Sample Paper III			Sample Paper IV		
	women n=419	men n=352	*p-value*	women n=142	men n=106	*p-value*
Mean age (SD)	82.1(5.4)	80.6 (4.6)		82.6(5.5)	81.3(4.6)	
Age group			*<.0001*			*.075*
75–79	37.5	47.7		32.4	38.7	
80–84	30.5	29.8		31.7	35.8	
85–89	20.5	21.7		24.6	21.7	
90+	10.3	3.4		11.3	3.8	
Civil status			*<.0001*			*<.0001*
married	28.5	65.9		29.6	61.3	
Living conditions			*<.0001*			*.03*
community	93.0	96.8				
sheltered housing	7.0	3.2		14.3	2.9	

Significances tested with Chi-square test

The sample in study IV consisted of 248 persons with mean age 82.04 years (SD 5.19, range 75–96 years). A total of 90.6% were living in ordinary housing and 9.4% in special accommodations, women more often than men. There were more women in the oldest age group (90+). More men than women were married (Table 5) (Paper IV). A total 66.5% were independent of help in ADL, men more often than women (p=0.004). Furthermore, 12.8% viewed their economy as worse than others, women more often than men (p=0.006) (Paper IV).

Health complaints and their patterns

Several different health complaints and diseases were reported, with higher prevalence in higher ages. There were significant differences between men and women as men reported more communication problems and women more mobility and psychosocial problems. The three most common problems were difficulties in hearing (62.9%), memory problems (62.8%) and difficulties in walking (50.8%). Men reported significantly more difficulties in hearing and memory problems and women reported significantly more difficulties in walking (Table 6). The most common self-reported diseases were eye diseases (31.7%) and hypertension (25.8%), which were more common among women, and myocardial infarction (16.4%), which was more common among men (Table 6) (Paper I).

Table 6. The most common health complaints and self-reported diseases among women and men (Paper I).

	Women n=2636	Men n=1641	Total N=4277	*P-value* diff. between sexes
Health complaints				
difficulty hearing	58.9	69.3	62.9	*<.0001*
memory problem	59.8	67.4	62.7	*<.0001*
difficulty walking	55.8	48.0	50.8	*.0001*
dizziness	48.5	44.7	47.0	*.020*
difficulty reading	45.6	48.5	46.7	*.062*
difficulty sleeping	46.1	35.1	41.9	*<.0001*
difficulty controlling urine	41.6	34.8	39.0	*<.0001*
fatigue	40.2	32.8	37.4	*<.0001*
difficulty talking	34.9	40.8	37.2	*<.0001*
breathlessness	35.1	32.3	34	*.220*
mobility limitation	35.0	31.8	33.7	*<.0001*
nervous and anxious	34.5	25.4	31	*<.0001*
pain from extremities	32.3	28.3	30.7	*<.0001*
Self-reported diseases				
eye disease	36.0	24.7	31.7	*<.0001*
hypertension	27.4	23.3	25.8	*.005*
myocardial infarction/heart disease	13.8	20.6	16.4	*.001*
ear/hearing disease	12.8	14.3	13.4	*.189*
disease in abdominal tract	10.1	8.4	9.5	*.087*
diabetes	8.0	10.0	8.8	*.034*
osteoporosis	12.6	1.2	8.3	*<.0001*
skin disease	7.0	10.4	8.3	*<.0001*
rheumatic diseases	9.5	4.7	7.6	*<.0001*
status post-stroke	6.6	8.5	7.3	*.029*

Health complaints with prevalence over 30% and self-reported diseases with prevalence over 8% are presented. Significances tested with Chi-square test.

The factor analysis resulted in six main categories of the thirty health complaints investigated. The categories were labelled communication, mobility and psycho-social problems, elimination, digestion-related and respiratory-circulatory problems,

of which the first three were most common (Table 7). Internal consistency was measured and all dimensions had a Cronbach's alpha >.72.

Table 7. Patterns of health complaints presented with Cronbach's alpha values(Paper I).

	Communication	Mobility	Psychosocial
	Difficulty hearing	Difficulty walking	Nervous
	Difficulty reading	Mobility limitation	Low mood
	Difficulty talking	Pain from extremities	Difficulty sleeping
	Memory problem	Oedema in legs	Fatigue
Cronbach's alpha	.73	.74	.78
	Elimination	**Digestion-related**	**Respiratory-circulatory**
	Difficulty controlling faeces	Abdominal pain	Breathlessness
	Difficulty controlling urine	Nausea	Dyspnoea
	Diarrhoea	Headache	Palpitations
	Other urinary symptoms	Loss of appetite	Chest pain
	Slow healing wounds	Difficulty swallowing	Protracted coughing
		Constipation	
		Dizziness	
Cronbach's alpha	.72	.83	.79

A total of 80.9% reported one or more of the communication problems, 66.6% the mobility problems, 63.7% the digestion-related problems. Additionally, 61% reported one or more of the psychosocial problems, 53.1% the elimination problems and 47.7% the respiratory-circulatory problems. The degree of health complaints was significantly higher among women in mobility and psychosocial problems. However men and women reported similarly about communication, elimination, digestion-related and respiratory-circulatory problems (Paper I).

Quality of life in relation to health complaints, age, gender and dependency

Women reported lower values in all age groups in PCS and MCS, and in both PCS and MCS the values were lower at higher ages (Figure 5). Those dependent on help in PADL and IADL reported significantly lower values ($p<0.001$) in both dimensions compared to the independent people. Women reported lower values in both PCS and MCS among those independent of help in PADL and IADL (PADL $p<0.0001$, IADL $p<0.001$) but among those dependent on help no significant gender differences were seen ($p=0.7$, and 0.5) (Paper I).
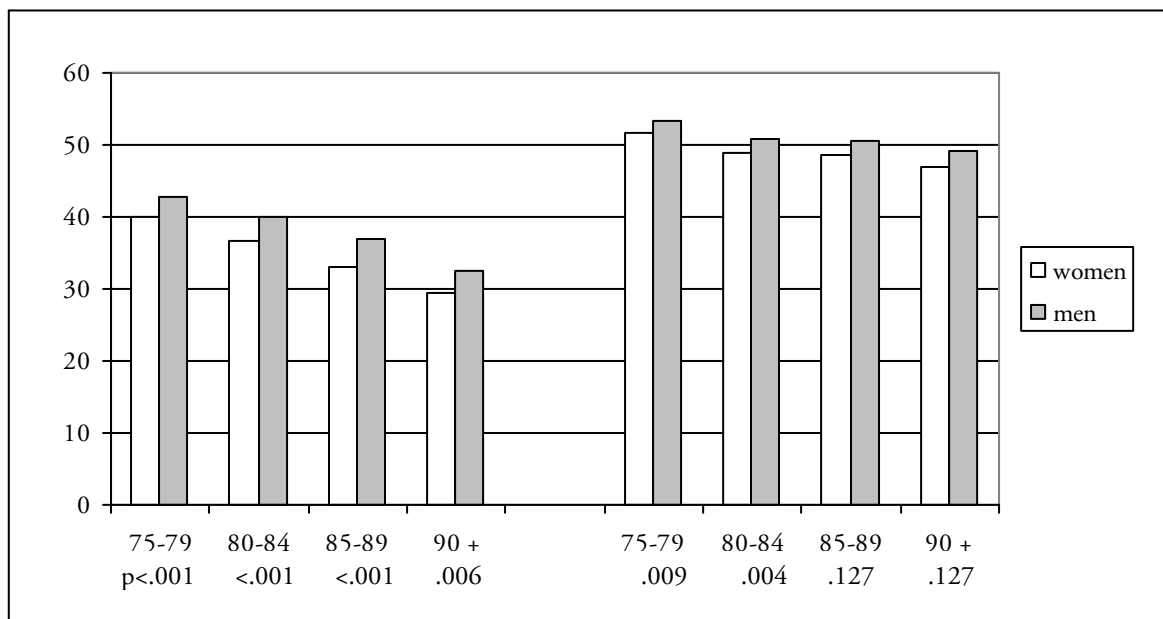
Figure 5. Mean values of PCS and MCS among women and men in different age groups. Significances were measured with Mann-Whitney U-test (Paper I).

Female gender and high age predicted low PCS but not low MCS. Having previous blue-collar or household work predicted both PCS and MCS (OR 1.33 and 1.56 respectively for low PCS and OR 1.4 and 1.51 respectively for low MCS). Of the groups of health complaints mobility (OR 7.47), digestion-related (OR 1.89) and psychosocial problems (OR 1.49) predicted low PCS. Psychosocial (OR 3.6), digestion-related (OR 2.02), mobility (OR 1.78) and elimination problems (OR 1.24) predicted low MCS (Paper I).

Dependency in relation to health complaints, age and gender

Need for help in PADL once a week or more varied from 6.9% among women (75–79 years) to and 58.8% (90 years and above) and from 3.9 to 40.6% among men in the same age groups. Need for help in IADL varied from 12.1 to 69.1% among women and from 6.6 to 58.5% among men. Women in all age groups were more dependent on help from others in both PADL and IADL (p=.003) except for PADL in the group of those aged 75–79 (Figure 6).
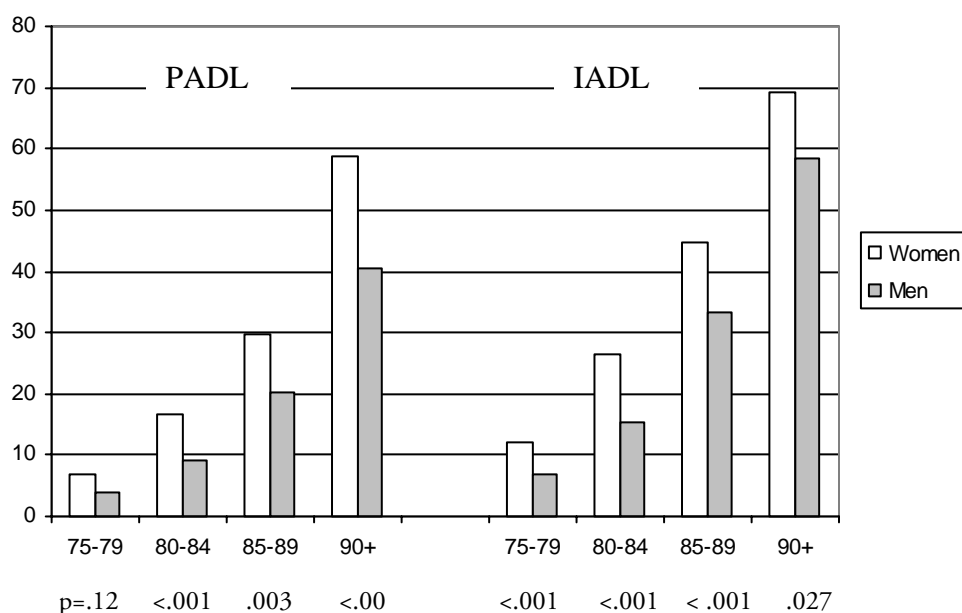
Figure 6. Those dependent on help in activities of daily living, PADL and IADL once a week or more (%).

Female gender and high age, single living or widowed predicted help in PADL and IADL. Of the groups of health complaints mobility (OR 3.97) and elimination (OR 1.78) but also communication (OR 1.39) and psychosocial problems (OR 1.30) predicted need for help in PADL. Mobility (OR 3.67), communication (OR 1.36), digestion-related (OR 1.31), psychosocial (OR 1.29) and elimination problems (OR 1.21) predicted help in IADL (Paper I).

Urinary, faecal and double incontinence

There were significantly fewer of those with previous white-collar work in the group with double incontinence (DI) than in those without incontinence (11.0% compared to 17.4%). In the same way significantly more lived alone or in special accommodations of those with urinary, faecal or double incontinence, and those with DI were less able to afford a sudden need for 8000 SEK compared with those without incontinence (Paper II).

The prevalence of UI varied from 33.3% among those age 75–79 and 55.8% among those aged 90 and above. In the same way, the prevalence varied from 31.2% to 41.9% among men. Women had higher prevalence rates in the ages below 85 years and in the oldest age group (90+), whilst in the 85–89 age group the prevalence was similar among men and women. The prevalence of FI was 11.7 (75–79 years) to 27.6 (90 years and above) among women and from 12.9% to 25.6% among men, with no difference between men and women compared in each age group (p>0.3). The prevalence of DI was 9.8% to 24% among women and 11.3% (75–79 years) to 22.5% (90 years and above) among men, with no differences

among men and women when compared within each age group (p=0.3) (Figure 7). Other urinary problems were significantly more common among men (p=0.003) in all age groups except those 90+ and varied from 23.6% (75–79 years) to 30.2% (90 years and above) compared to 13.6% (75–79 years) to 25.9% (90 years and above) among women (Paper II).
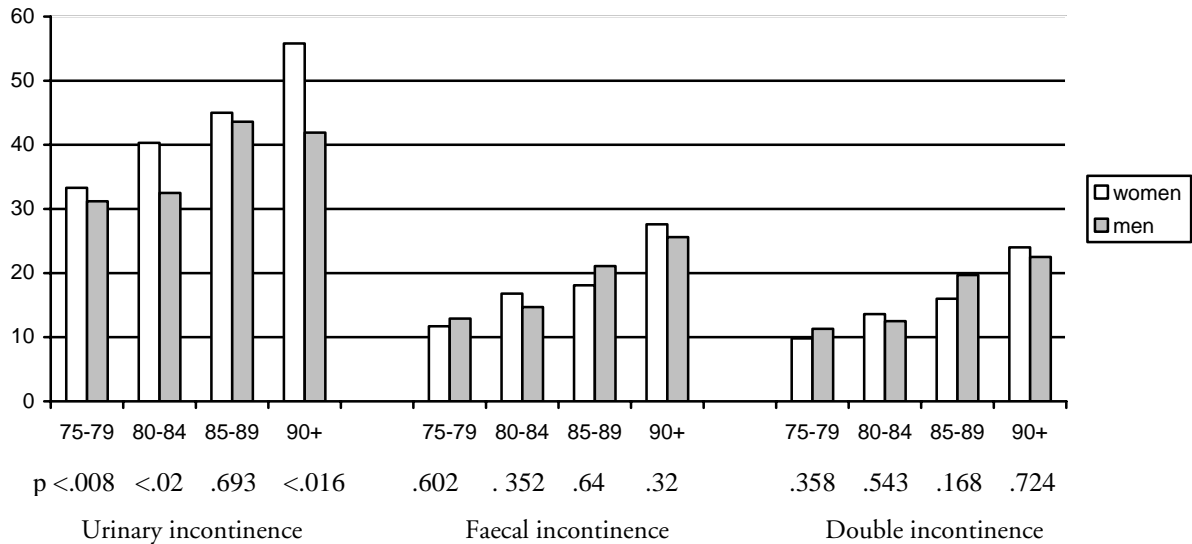

Figure 7. Prevalence of urinary, faecal and double incontinence among women and men in different age groups (Paper II).

Prevalence of diarrhoea and constipation was higher in the advanced ages, with no differences between men and women. The prevalence of diarrhoea was 13.3% (75–79 years) to 28.3% (90 years and above) among women and 16.2% (75–79 years) to 24.0% (90 years and above) among men. The prevalence of constipation was 20.8% (75–79 years) to 39% (90 years and above) among women and 17.4% (75–79 years) to 39.5% (90 years and above) among men (Paper II).

All incontinence groups reported a higher number of health complaints with mean values of 9 (UI), 11.4 (FI) and 21.3 (DI) compared with those without incontinence, who had a mean 6.1 health complaints (p<0.0001). In the same way mean values of self-reported diseases were higher among the incontinence groups 2.14 (UI), 2.63 (FI) and 2.82 (DI) compared with 1.7 diseases among those without incontinence (p<0.0001). Furthermore, the incontinence groups reported more previous falls, 28.8% (UI), 24.7% (FI) and 37.8% (DI) compared to 16.3% among those without incontinence (p<0.0001) and used more medications, 88% (UI), 94.8% (FI) and 89.8% (DI) compared to 84.1% among those without incontinence (p<0.0001) (Paper II).

Risk factors for UI were mainly within the areas of mobility (walking OR 1.63, mobility limitation OR 1.23, oedema in the legs OR 1.32), communication (memory problem OR 1.7, difficulty talking OR 1.25) and elimination complaints

(other urinary symptoms OR 1.37). Risk factors for FI were diarrhoea (OR 6.77), abdominal pain (OR 1.86) and fatigue (OR 1.77) and other types of pain than skeletal pain (OR 1.77). Risk factors for DI were in the areas of communication, mobility, elimination problems as well as digestion-related problems and breathing and circulation problems. The strongest single health complaints were diarrhoea (OR 7.72), other urinary symptoms (OR 2.29), memory problems (OR 2.26) and difficulty talking (OR 2.26) (Paper II).

Incontinence prevalence in relation to dependency and quality of life

Incontinence groups differed significantly as they were dependent on help in PADL and IADL to a higher extent than those without incontinence (p<0.0001). Among those without incontinence 12.4% were dependent in PADL compared with 24.2% (UI), 24.7% (FI) and 36.9% (DI) (p<0.0001). Among those without incontinence 21.3% were dependent in IADL compared to 34% (UI), 28% (FI) and 45.2% (DI) (p<0.0001) (Paper II).

Groups with incontinence (UI, FI and DI) reported significantly lower values in PCS and MCS (p<0.0001) and also concerning present QoL and life span QoL compared with those without incontinence (p<0.0001). Those with double incontinence had significantly lower values in MCS and present QoL than those with UI (Paper II).

Urinary symptoms

Of the sample who previously reported difficulties controlling urine and/or other urinary problems, a total of 43.3% had sought medical help, the same among women and men (p=0.266), although about 70% had had their symptoms for more than two years and up to more than 10 years (Paper III). Men took medications for their symptoms to a higher extent than women (30.4% compared to 22.9%, p=0.029). 13.4% reported having red skin or wounds in the genital region due to urinary problems, significantly more women than men (18.4% compared to 7.3%, p<0.0001). Women also had more problems related to defecation than men (41.9% compared to 25.5%, p<0.001).

Factor analyses of urinary symptoms gave five categories of symptoms labelled *storage, voiding, frequency, pain/burning* and *influence on daily life* (Table 8) (Paper III). The internal consistency was >0.74 for all except for frequency, which was 0.44.

Table 8. Patterns of urinary symptoms presented with Cronbach's alpha values(Paper III).

Storage	Voiding	Frequency	Pain/burning	Influence on daily life
Leakage before reaching toilet	Hesitance	Frequency day	Bladder pain	Reduce fluid intake
Frequency of incontinence	Strain to start	Frequency night	Burning sensation	Influence on daily activities
Stress incontinence	Strength of stream			Avoid places and situations
Leakage without reason	Incomplete emptying			Influence physical activities
Size of leakage				Social life
Leakage during sleep				Whole life
Reach toilet in time				
Cronbach's alpha				
.86	.77	.44	.74	.83

Women reported more storage symptoms (p<0.001) and men more voiding symptoms and daytime frequency (p<0.001). However, they reported similar night-time frequency, 62.6% got up 1–2 times per night and 28.3% got up three times or more (p=0.128).

Symptoms related to storage were more common in the UI group (p<0.001, Table 9), whilst voiding symptoms were more common in the group with other urinary symptoms than incontinence (p<0.001, Table 10). However, nocturia, daytime voiding frequency, feeling of incomplete emptying of the bladder and bother of these symptoms were similar in the both groups (p=0.2). Limitations in social life due to urinary symptoms, avoiding places and situations as well as feeling that one had to spend the rest of life with these kind of problems were similarly reported in the groups with UI symptoms and those with other urinary symptoms (p=0.5) (Paper III).

Table 9. Differences in urinary **storage symptoms** among those reporting having difficulty controlling urine (UI) and those reporting having other type of urinary symptoms (OU) and compared between genders (Paper III).

	Urinary incontinence UI				Other urinary symptoms OU				Diff. UI/OU
	All n=423	Women n=276	Men n=147	P-value	All n=140	Women n=45	Men n=95	P-value	P-value
Hurry to get to toilet in time				<.001				.538	<.001
occasionally	26.7	20.3	38.6		34.1	27.9	37.1		
sometimes	36.1	38.0	32.4		28.8	27.9	29.2		
most of the time/all the time	27.0	31.8	17.9		10.6	16.3	6.7		
Leakage before reaching the toilet				<.001				.105	<.001
occasionally	35.2	33.2	39.0		31.8	39.5	28.1		
sometimes	38.8	44.5	28.1		14.4	18.6	12.4		
most of the time/all the time	10.2	12.0	6.9		3.1	2.3	2.2		
Frequency of incontinence				<.001				.007	<.001
once a week or less	27.1	24.1	32.9		20.9	29.3	17.0		
2–3 times a week	16.1	18.0	12.6		11.6	9.8	12.5		
daily/several times a day	36.2	44.0	21.7		7.0	17.0	2.3		
Stress incontinence				<.001				<.001	<.001
occasionally	25.5	26.5	23.2		22.0	31.3	16.0		
sometimes	32.3	39.1	16.2		14.6	28.1	6.0		
most of the time/all the time	16.3	21.9	3.0		2.4	6.3	–		
Incontinence without reason				.158				.571	<.001
occasionally	23.4	21.7	27.1		16.9	15.6	17.6		
sometimes	17.5	20.0	12.1		7.2	12.5	3.9		
most of the time/all the time	6.5	5.5	3.7		1.2	–	2.0		
Night-time incontinence				<.001				.026	<.001
occasionally	12.9	13.5	11.7		3.9	9.5	1.1		
sometimes	6.8	9.0	2.8		3.9	7.1	2.3		
most of the time/all the time	4.6	6.3	1.2		0.8	–	1.1		
Size of leakage				<.001				.704	<.001
soaked or wet underwear	77.9	83.0	67.0		42.5	45.2	40.8		
flowing, soaking other clothes	4.5	5.1	3.0		–	-	-		

Significance measured with Mann-Whitney U-test.

Table 10. Differences in **voiding symptoms** among those reporting having difficulty controlling urine (UI) and those reporting having other type of urinary symptoms (OU) and compared between genders (Paper III).

	Urinary incontinence UI				Other urinary symptoms OU				Diff. UI/OU
	All n=423	Women n=276	Men n=147	P-value	All n=140	Women n=45	Men n=95	P-value	P-value
Daytime voiding				.035				.110	.902
1–6	60.2	63.4	54.1		56.8	65.1	52.8		
7–8	23.0	22.5	24.0		31.8	30.2	32.6		
9–12	13.7	12.3	16.4		8.3	4.6	10.1		
13 or more	3.1	1.8	5.5		3.0	–	4.5		
Night-time voiding				.190				.187	.644
1–2	63.5	63.5	63.3		59.4	65.1	56.6		
3	20.1	20.0	20.4		24.1	20.9	25.6		
4 or more	8.3	7.6	9.5		4.5	2.3	5.6		
Hesitance				<.001				<.001	<.001
occasionally	24.8	19.8	34.0		33.1	26.2	36.4		
sometimes	14.5	11.9	19.0		25.4	11.9	31.8		
most of the time/always	4.8	3.4	7.5		8.4	4.8	9.1		
Strain to start				.005				.028	<.001
occasionally	17.3	11.8	27.4		31.5	14.3	39.8		
sometimes	9.4	9.0	8.9		11.5	7.1	13.6		
most of the time/always	1.9	1.8	2.1		3.1(4)	7.2	1.1		
Strength of stream				<.001				<.001	<.001
occasionally/-sometimes weak	38.0	29.5	52.5		57.0	41.8	63.6		
often/always weak	12.7	7.7	21.6		16.1	7.1	20.4		
Feeling of incomplete emptying				.002				<.053	.329
occasionally	28.8	24.7	36.4		32.8	27.5	35.2		
sometimes	17.7	15.2	22.4		19.5	15.0	21.6		
most of the time/always	7.6	7.6	7.7		7.	5.0	9.1		

Significance measured with Mann-Whitney U-test.

The highest mean scores of the symptoms were frequency of leakage (2.02 for women), hurrying to reach the toilet (1.97 among women) and night-time voiding (1.97 among men). All symptom scores were higher among women than men (p=0.04). Distress scores were also significantly higher among women than men in all storage and voiding symptoms (p=0.003) whilst there were no differences in the frequency symptoms (p=0.2) (Table 11) (Paper III).

Table 11. Mean scores for urinary symptoms and distress and their influence on daily life among women and men (Paper III).

	Symptom score[a]			Distress score[b]		
	Women n=419	Men n=352	P-value	Women n=419	Men n=352	P-value
Storage						
hurry to reach toilet in time	1.97	1.44	<.0001	1.00	.80	.003
leakage before reaching toilet	1.53	.93	<.0001	1.02	.68	<.0001
frequency of leakage	2.02	1.01	<.0001	1.04	.63	<.0001
stress incontinence	1.73	.60	<.0001	1.02	.44	<.0001
leakage without reason	.87	.54	<.0001	.70	.47	.002
size of leakage*	1.02	.67	<.0001	–	–	
leakage during sleep	.51	.19	<.0001	.33	.13	<.0001
Voiding						
hesitance	.57	1.08	<.0001	.34	.50	.002
strain to start	.38	.61	<.0001	.19	.33	.001
strength of stream	.72	1.63	<.0001	.25	.56	<.0001
incomplete emptying	.83	1.07	.001	.37	.57	<.0001
Frequency						
daytime voiding (7 times/day or more)	.55	.78	.01	.74	.81	.277
night-time voiding (1 time/night or more)	1.77	1.97	.014	.67	.74	.251
Pain						
bladder pain	.39	.29	.049	.33	.24	.036
burning sensation	.39	.27	.016	.25	.18	.090
Daily life						
reduce fluid intake	.53	.46	.237	.24	.23	.737
avoid places and situations	.99	1.01	.760	.63	.63	.915
influence on daily activities (1–3)	.40	.24	<.0001	.39	.23	.001
influence on physical activities (1–3)	.46	.34	.018	.46	.32	.012
influence on social life (1–3)	.32	.36	.362	.37	.36	.860
influence on whole life (1–3)*	.69	.68	.779	–	–	

Significance measured with One-way ANOVA. aScoring from 1–4 in all variables except influence on daily, physical activities and social and whole life, which had 1–3. bScoring 1–3. *Were not included as questions in the distress questions.

High age was a strong predictor of dependency (OR 1.57 to 4.23). Frequency symptoms (day- and night-time voidings) were the only predicting factor of the urinary symptoms (OR 3.24) when gender was controlled for. Predicting factors for seeking help were influence of urinary symptoms on daily life (OR 2.52), storage (OR 2.21) and pain symptoms (OR 2.10), whilst gender was not predictive (Paper III).

Bowel-related symptoms among those with faecal incontinence

The sample in Paper IV consisted of 142 women and 106 men, 35.1% aged 75–79 years, 33.5% 80–84, 23.4% 85–89 and 8.1% 90 and over. Men were to a greater

extent married and women more often widowed (p<.001). More men were independent (76.4% compared to 59.2% of the women) while more women were dependent on help in ADL (40.8% compared to 23.6% of the men). Women also reported lower PCS than men (p=0.007) while there was no difference in MCS between men and women (p=0.284). However, this sample reported lower physical and mental QoL than others in these ages compared with norm values for the Swedish population (Figure 8) (Sullivan, 1997) (Paper IV).

Figure 8. Comparison of values of PCS and MCS in the sample in Paper IV with the population sample in Paper I and the Swedish norm values among people aged 75 years and over (Sullivan, 1997).

A total of 41.2% reported limitations in daily life due to bowel symptoms, 79% had had their symptoms for more than one year and 28.4% for more than 10 years. Altogether 17% had red skin or wounds in the genital area due to FI. Only 40.8% had sought medical help for their problems and only 43.2% of the women and 12.6% of the men used protective aids (p<.0001). Laxatives were used often or daily by 20.7% and another 13% used laxatives sometimes, similarly among women and men (p=0.056). Women reported a significantly larger amount of leakage, 18.2% compared to 6% of the men (p=.01) and more often did not reach the toilet in time, 18.6% compared to 4.9% of the men (p=0.01). Additionally, women could more seldom withstand urgency than men did (p=0.006) (Paper IV).

There were no differences between those independent and dependent in the amount of leakage, not reaching the toilet in time, ability and time to withstand urgency, feeling of incomplete emptying and difficulties controlling gas. Those dependent more often had hard stool (46.3% compared to 18.8%, p<0.0001), often or always abdominal pain (14.4% compared to 5.5%, p=0.02) and bad bowel function (34.7% compared to 16.6%, p<0.001) and used protection day and night (24.2% compared to none, p<.0001) compared with those who were independent. Additionally, 42% of the dependent people used laxatives often or always compared

with 9.1% of the independent ones (p<0.0001). The dependent people had however sought help to a higher extent than the independent (54.4% compared to 33.1%, p=0.002) (Paper IV).

Factor analyses of symptoms related to faecal incontinence gave four categories labelled *leakage, discomfort, consistency* and *contractility* (Table 12). The internal consistency was in two categories above 0.83 and considered as acceptable, one factor 0.62 and one 0.31; the latter is too low (Paper IV).

Table 12. Patterns of faecal symptoms related to FI presented with Cronbach's alpha values (Paper IV).

Leakage	Discomfort	Consistency	Contractility
Size of leakage	Bowel function	Loose stool	Time to withstand urgency
Leakage whenever	Feeling of incomplete emptying	Constipation	Control of gas
Not reaching toilet in time	Frequency of bowel movements		
Bother with moisture from anus	Bowel pain		
Ability to withstand urgency >30 minutes			
Cronbach's alpha			
.83	.62	.88	.31

Discomfort symptoms (OR 1.53) were the strongest predictors of dependency after controlling for age and gender. Of the bowel-related symptoms, discomfort (OR 3.01) and leakage (OR 1.96) predicted help seeking. Discomfort predicted low PCS (OR 1.73) (Paper IV).

DISCUSSION

Methodological considerations

Internal validity
The result of these studies have to be valued with respect to *internal validity*, which refers to the extent to which the result can be explained by other factors than the independent variables in a study. Threats to internal validity include *history, maturation, testing, instrumentation, statistical regression, selection bias* and *attrition* (Kazdin, 1998). Postal questionnaires, as used in these studies, need straightforward questions, the respondents must be literate and use the same language. If any of these options are not fulfilled this method is not useful. In this study those not understanding Swedish were offered help to respond and interpret the questions. Postal questionnaire methods also depend on the person's willingness to take the time to complete the questionnaire and return it. It is not possible to state whether all persons were positive, but the research team received many positive comments from the participants throughout the survey. The risk of postal questionnaires is that they are supposed to have lower response rates, the researcher cannot be sure who answered the questionnaire, the order in which questions are answered cannot be controlled and may influence the way of responding (Bowling, 2002). Some authors suggest that health problems may be underestimated in postal question-naires compared to personal interviews (Doll et al., 1991). In the follow-up studies face to face interviews was performed to those being dependent on others on help in ADL. The positive side of a face-to-face interview is that the interviewer can clarify, and explain more complicated questions. The disadvantage is the risk of bias due to the interviewers, and also a risk of answers that the respondent thought were expected by the interviewer. As the face-to-face interview was used with the frailest persons, the combination of these two methods made it possible to reach a large number of people in these ages, who may not have been able to complete a postal questionnaire. On the other hand, the initial survey was performed with postal questionnaires alone and thus more of the frailest people may not have been able to respond.

History and maturation are threats to internal validity if there are events or circumstances which could influence the results of the follow-up studies. During the three to six months between the initial questionnaire (Papers I and II) and the follow-up (Papers III and IV), events may have taken place with regard to health, need for help and so forth. To check for that, questions about health complaints and need for help in daily activities were asked again in the interviews. Those who were sent a postal questionnaire as a follow-up received a letter explaining why and on what basis they had received the questionnaire. If they did not have, for instance, any urinary or faecal symptoms any longer they had the choice not to answer that questionnaire.

Another threat to internal validity concerns *testing*, as the same persons received two or more questionnaires; there may be a threat to internal validity as one can get used to the questions asked. Studies have shown improvements without any interventions at the second time of responding to a questionnaire (Kazdin, 1998). In this study new questionnaires were introduced in the follow-up and thus there may be no threat to internal validity in that respect. However, the construction of the questionnaires was influenced by the first one, and response alternatives in the bowel questionnaire may have been influenced the alternatives in the BF-LUTS and ICS-male questionnaires. It is impossible to say whether another approach would have been more valid, but the way of answering does not seem to be similar in the two studies, which may show that the strategy chosen was adequate.

Loss of subjects, *attrition*, is a threat to internal validity, as a group that scored in a certain direction could be missed (Kazdin, 1998). Varying response rates in the age groups, with lowest rates among those aged 90 years and more, are a threat. Groups that were not literate in the Swedish language may have dropped out to a larger extent. Although help with translation was offered, few asked for it. Those who were most frail, too weak, living in special accommodations or cognitively impaired are other groups that may have been less represented in this study. However, as a thorough analysis of the non-respondents was performed (Paper I) it was possible to identify which groups were less represented not only in socio-economic terms but also in terms of attitudes. This analysis is a strength of the study. The result of the analysis of the dropouts in the first studies showed that those not responding were older, more often women, living in special accommodations, viewing their lives as bad or very bad and less worried about their health compared to those who responded. The results must be interpreted with this in mind.

As all studies in this thesis are based on quantitative methods, the *statistical conclusion validity* is crucial. There are always risks of stating a difference between groups that actually is false, type I error, which is best avoided with a restrictive level of significance. In these studies a p-value less than 0.05 were chosen as the limit for significance. Multiple comparisons were frequently used, with consciousness of the risk of mass significance. A restrictive p-value was used to compensate for this risk according to the Bonferroni method, i.e. reducing the p-value limit (0.05) divided by the number of comparisons made (Paper II) (Bland and Altman, 1995). Thus, the statistical significances could be regarded as conservative. There is also a risk of state that there is no difference when there actually is one, type II error. The sample size is one important factor for reducing the risk of type II error, and in all the present studies the sample sizes were quite large. In study I and II the sample size was big enough for comparisons between four groups (age group). In studies III and IV two group comparisons were made as the sample size was smaller. However, there were more than 100 in each group, which is considered as rather big. A power analysis was performed, aimed to get a sufficient number of people

dependent on help in daily activities in each age group, which justified the decision to have an initial sample of 8500 persons.

The *clinical significance* has to be considered even though the result shows statistical significance. Most of the results represent frequencies expressed in percentages or actual numbers, and as these variations were quite great it could regarded as reflecting a difference which could have clinical relevance. In big samples significances are easier to find than in smaller samples, which must be considered. Therefore, the actual values must be regarded together with significance tests. In Papers I and II the sample sizes are considerable big and the risk that small differrences are statistically significant has to be observed. In Papers III and IV that risk is minor because the sample sizes are smaller. In the discussions in all the papers the actual values have been considered together with the significance tests. However, there is always a risk of overestimating the result of a study, and thus results have to be compared with other studies and valued in relation to these findings.

Convergent validity refers to the extent to which two measures give similar results (Kazdin, 1998). In study III two questions from the initial questionnaire (Papers I and II) were tested. Those with urinary incontinence and/or other urinary symptoms were targeted for the follow-up. BF-LUTS and ICS-male questionnaire measure urinary symptoms whether, for instance, the dominant factor is storage or voiding symptoms, i.e. incontinence-like or lower urinary tract symptoms. The result showed that the initial two questions did differentiate those two groups. Thus, the use of these two questions proved to be valuable and may be useful in health surveys as they are simple, i.e. only two questions, and thus easy to use.

Construct validity of the study reflects whether the measurements used assess the underlying constructs (Streiner and Norman, 1998). Most questions in the initial questionnaire have been used in other studies (Hellstrom and Hallberg, 2001) and this questionnaire was also tested in a pilot study (Borglin et al., 2005). The questions about health complaints were tested in the factor analysis (Paper I) and have thus contributed to the construct validity. The questionnaire included SF-12, which is well known and widely used (Sullivan, 1997, Gandek et al., 1998, Lim and Fisher, 1999), also in samples of older people (Pettit et al., 2001) to measure health-related quality of life.

The instruments used to measure urinary symptoms were psychometrically tested with acceptable construct validity (Donovan et al., 1996, Jackson et al., 1996). However, the translated version has not been tested although used in other contexts (Teleman, 2003). The initial questions (Papers I and II) about difficulties controlling urine and other urinary problems proved good at differentiating those with leakage problems from those with storage problems (Paper III), which strengthens the construct validity in the initial questions as well as in the instruments used

about urinary symptoms. Additionally, those who answered positively to the question about difficulties controlling faeces (Papers I and II) turned out to have faecal incontinence related problems, which thus strengthens the construct validity (Paper IV). The factor analyses of the questions about urinary symptoms (Paper III) and bowel symptoms (Paper IV) served also to contribute to the construct validity.

Reliability

New samples and circumstances could make instrument reliability change, as reliability is related to the circumstances in which it is used (Kazdin, 1998). It is recommended to test even standardized instruments when used in new samples and contexts, which was done in this thesis. One way of testing reliability is to check the *internal consistency*. New reliability tests of SF-12 were performed with satisfactory values (Paper I). Furthermore, the items that were similar in BF-LUTS and ICS-male were analysed and all the factors except one (frequency) had satisfactory internal consistency (Paper III). Thus, SF-12 proved to be reliable and so also did BF-LUTS and ICS-male questionnaire. The questionnaire about bowel symptoms was also tested and showed good internal consistency in two factors, moderate in one and low consistency in one factor. This instrument was used for the first time and has potential to be developed with inspiration from other questionnaires in this field. The 30 items about health complaints were tested for the first time and showed satisfactory internal consistency, although they need to be tested further in another sample. Tests of internal consistency in subgroups within these samples have not been done, as instrument testing was not a primary aim of these studies. In this thesis reliability has been measured with Cronbach's alpha, which should be at least above 0.7(Polit, 1996). This criteria was fulfilled for SF-12 in dimensions of PCS and MCS, the factors of health complaints, all factors of the urinary symptoms except frequency and two of the factors of bowel symptoms. *Internal dropout* was also investigated and questions with high internal dropout were omitted from the analysis.

Inter-rater reliability was not tested in these studies, which may be a disadvantage especially with regard to the face-to-face interviews. The interviews were carried out by seven of the project participants together with persons recruited for this purpose. They were nurses, experienced in visiting older persons and talking to them. The interview manual was thoroughly discussed in the group of interviewers and during the time of the interviews regular meetings were held in order to control the method and to discuss any problems. This was done to ensure that interviews were performed in the same way as much as it was possible. Ideally one person should have done all interviews, but that would have consumed too much time as the purpose was to do the follow-up as close as possible to the initial questionnaire.

External validity
With respect to *external validity* the sample was randomly selected in groups of older persons without any exception, which would therefore reflect the population of southern Sweden. The relatively low response rate in the older ages skewed the sample in relation to the target population. In order to obtain knowledge about the dropout, careful analysis was performed. Conclusions can be drawn from the results bearing in mind that those reached are healthier, younger, more often men, married, independent and more worried about their health. The intention here was to reach all people in the target sample, and those who were too sick, in hospital, disabled, in psychiatric wards were not excluded, which is usually the case in most population studies in these age groups. Thus, the low response rate was expected. Therefore the low response rate cannot be compared to other population studies without reflecting the inclusion criteria. Furthermore, the dropout systematically resulted in the loss of the frailest individuals.

General discussion of the findings

Coexisting health complaints had impact on QoL as well as on dependency. The patterns of health complaints could be understood from a functional perspective. Problems within communication, mobility and psychosocial functions were the most common and those with highest severity. Women were especially affected as they had more health complaints in functions that were related to help in ADL and to low QoL. Furthermore, the prevalence of urinary, faecal and double incontinence was high in all age groups and higher with more advanced age. Incontinence had a negative impact on quality of life and increased the need for help in daily activities, and those with double incontinence were the most affected. Among those with urinary problems the character of symptoms differed in storage or voiding symptoms among men and women. However, the influence on social life, avoiding places and situations and the impact on life as a whole seemed equal. Only about half of them had sought medical help for their symptoms and few wore protective aids, especially men. Diarrhoea, constipation, incomplete bowel emptying and laxative use were common among those who reported faecal incontinence, and also among these people, few had sought medical help or wore protecttion.

The patterns of health complaints
The presence of many health complaints among older people and their coexistence may indicate "frailty" and there may be a need for a concept which could be called "multi-complaints", rather like comorbidity, drawing the attention to their possible interaction. The complaints coexisted in certain patterns, which were identified as functions, for example mobility and elimination functions. These clusters of health

complaints had a relationship to dependency and QoL. Other researchers have also tried to develop measures that would be of interest to identify "frailty" (Mitnitski et al., 2002, Rockwood et al., 2004). Similar functions were included in their measurements, such as mobility, psychosocial, communicational, elimination and nutritional problems and could thus confirm our results (ibid.). Others have constructed a comorbidity symptom scale combining diseases, symptoms and activities, some of which are similar to those in this thesis (Tibblin et al., 1990b, Jylha et al., 1992, Crabtree et al., 2000, Mitnitski et al., 2004). The need for such measures is supported also by "The Intervention on Frailty Working Group", who concluded that research that refines criteria for screening, subjectively and objectively, is needed. Furthermore, the need to construct interventions that can prevent or delay disability in older persons was emphasized (Ferrucci et al., 2004), which requires identifying patterns of problems rather than looking at each problem in isolation. Mitnitski et al (2001) proposed that such a measure may also provide knowledge of ageing at organism level. Thus, measuring multi-complaints may give important information complementing that about comorbidity. A systematic way of assessing health complaints as patterns and not separately may contribute to an overall view of the health status of older people on individual as well as on group level.

The questionnaire with health complaints proved to be useful, reliable and also possible to use in further analyses such as logistic regression analyses. It could however be discussed whether the different items fit into each factor in a proper way, as protracted coughing and diarrhoea loaded in two factors. A clinical inter-pretation was however that coughing fitted best into respiratory-circulatory problems and diarrhoea into elimination problems. Another question is whether the health complaints asked about really were those most common among older people. However, Tibblin et al. (1990) and also others have used a majority of those health complaints (Jylha et al., 1992, Hellstrom and Hallberg, 2001). As many health complaints were prevalent in older ages they probably should be included. Comparing the list of health complaints used in this study with others measuring health complaints or frailty (Tibblin et al., 1990b, Jylha et al., 1992, Crabtree et al., 2000, Mitnitski et al., 2002, Mitnitski et al., 2004, Rockwood et al., 2004, Stenzelius et al., 2005) showed a wide range of different symptoms (Appendix 1). There are several commonalities, for instance mobility, skeletal pro-blems, psychosocial, communicational, elimination and nutritional problems. There are also differences as some include diseases like diabetes, epilepsy (Crabtree et al., 2000) or hypertension (Mitnitski et al., 2002) and others include ADL activities such as difficulty in toileting or bathing (Mitnitski et al., 2002) and more behaviour such as crying easily, irritability and exhaustion (Tibblin et al., 1990b). Another problem is how to phrase the question about a health complaint, which could be differently understood although it is the same health complaint. For instance, *difficulty hearing*, *impaired hearing* and *hearing loss* all express some degree

of hearing disability. As another example, *urinary problems*, *difficulties passing urine* or *difficulties controlling urine* are questions about the same area but with different meanings. Therefore, the phrasing also makes the results difficult to compare and thus there is a need for an instrument which could be used in research as well as in clinical practice.

It seemed as if those patterns that are important for interaction with other people, taking part in daily life and society were most prevalent and had most influence on quality of life, daily life and dependency, such as mobility, psychosocial, communication and elimination problems. Their importance for quality of life has been supported by other studies. Quality of life was related to health complaints such as impaired mobility (Grimby and Wiklund, 1994), elimination (Grimby et al., 1993, Fonda et al., 1995, Dugan et al., 1998, Simeonova et al., 1999, Temml et al., 2000), psychosocial (Grimby and Svanborg, 1997) or communication problems (Cacciatore et al., 1999, Scott et al., 1999, Brunnstrom et al., 2004). Furthermore, dependency or need for help in daily activities was related to mobility, elimination, psychosocial (Stuck et al., 1999) and communication problems (Cacciatore et al., 1999, Scott et al., 1999, Brunnstrom et al., 2004). A Finnish study showed that those with higher numbers of symptoms had an increased risk of institutional care than those with fewer (Laukkanen et al., 2000). Even if the reported health complaints were numerous there may be hidden problems that are not reported. In 1963 it was reported that the symptoms and diagnoses seen in clinical practice were only a small part of the health problems experienced in a population, "the iceberg of morbidity" (Last, 1963). In that sense many of the health complaints reported in this thesis have indicated areas that have been little described before, for instance elimination. Verbrugge (1990), introduced another iceberg: the iceberg of disability which covers the unseen strategies to reduce the effect of any dysfunction or disability. Surely that must be considered when looking at the results in this thesis. Time spent with a health complaint makes the person adjust to the complaint and perhaps view it as part of "normal" life. Also, the person may reduce the demands on activities that cannot be performed any longer, and such activities will then be "out of mind" (ibid.). Therefore the true amount of health complaints must be valued with this in mind. The dysfunctions identified as common among older people may be relevant and therefore need to be focused on. In clinical practice this means that improving functions related to mobility, elimination, psychosocial and communication problems may be effective in improving quality of life as well as delaying dependency.

Problems in mobility, psychosocial and elimination functions were more prevalent in women, whilst communication problems were more common among men. Additional negative factors for women such as economic situation, more often being widowed and left alone, poorer health and health-related quality of life and more often being dependent on others in ADL (Papers I–IV) emphasize the need

for special attention to women's needs. For example, difficulties in walking, depression, low mood, fatigue and incontinence seems to be "female threats". These findings are also reported in other studies (Grimby and Svanborg, 1997, Hellstrom and Hallberg, 2001, Hellstrom et al., 2004b). On the other hand, men seem to be more troubled by cardiovascular and environmentally influenced troubles such as communication problems like hearing impairment, difficulties talking and memory problems. In addition, men also had more elimination problems in relation to other urinary problems. However, men seem to have additional positive factors such as better economy, more often being married and having higher quality of life. Thus, being aware of the positive and negative factors that contribute to men's and women's health seems to be useful, as women and men need attention in different functions. Thus, as behaviour and lifestyle may change in the next generation of older people, the pattern identified among men and women could change.

The patterns identified in Paper I as functions of six areas seems logical and resemble the WHO classifications of function or disability, ICF (WHO, 2001), as this also focuses on functioning. Mobility and elimination problems could serve as examples. Health complaints such as difficulty walking, moving extremities, oedema in the legs and mobility limitations fitted into mobility problems, which are symptoms with different anatomical and pathophysiological causes. However, the cause and function are completely different things they are easily mixed up. Similarly, health complaints such as difficulties controlling urine, other urinary problems, constipation, diarrhoea and slow-healing wounds fitted into the elimination problems. These also have a different origin, but their commonalities in a functional perspective may easily be understood. In the ICF model any dysfunction or health problem has an external and an internal character, which could be diseases and health complaints but also environmental barriers to participation in daily life (ibid.). Diseases could express the internal or medical view whilst functioning, i.e. pattern of health complaints, has an external view. For instance, walking ability is not related to any specific disease. Difficulties could be due to a fracture but also to general weakness in the legs. In the pattern identified, a health complaint like oedema in legs, which is normally a cardiac-related symptom, would not automatically suggest walking assistance and training as treatment but rather with diuretics isolated. Thus, the ICF model integrates biological/medical and social models (ibid.). As any dysfunction or disability is an interaction of features of the person and features of the environment a dysfunction may best be compensated by environmental or personal factors aiming to improve participation in daily life and in society (see Figure 1, page 17). This model may stimulate a greater focus on reducing barriers together with the medical-technical care in the planning and practical care of older people. Or, as Kearny and Pryor (2004, p.167) suggested "It is time for health care personal to translate the ICF ambition into practice as a complement to medical perspective. For example by maintaining and restoring integrity and function of body structure, prevent and minimize impairment, enable

74

activities and participation, prevent and minimize activity limitations". The result of this study may contribute to a functional, activity-centred view of older persons' health complaints. The results in Paper I indicate the usefulness of multi-complaints as a tool to arrive at a comprehensive view of functions in an older population. Focusing on the pattern of health complaints may be more effective for improving functions that are important for participation, interaction and social life.

Incontinence among older persons
The high prevalence of urinary, faecal and double incontinence among both women and men (Paper II) and the troubles related to them, their impact on daily life and quality of life as well as on need for help in ADL (Papers III and IV) demonstrates that this must be regarded as a major public health problem. There are studies that report higher prevalence rates which have investigated these age groups (Gavira Iglesias et al., 2000) using a wider definition of, for instance, urinary incontinence – "any difficulty in controlling urine" – and studies with lower prevalence, among women (Kok et al., 1992) and among men (Malmsten et al., 1997) using a stricter definition – "leakage twice a week" – or objectively tested with a pad test. Similar comparisons can be made with the prevalence of faecal incontinence, indicating higher prevalence rates with wider definitions (Paper I). Thus, prevalence rates very much depend on definitions used and questions asked. According to the latest definition of the ICS (international Continence Society), "any leakage" (Abrams et al., 2002), which was changed from the earlier definition also including amount of urine leakage (Abrams et al., 1988), would therefore support the use of a wide definition and may thus corroborate the findings in this study. It may however be doubted whether the question asked about "*difficulties controlling urine or faeces*" is an expression of urinary or faecal incontinence. How and when leakage occurs depends very much on external factors such as distance to the toilet, time needed to reach the toilet, ability to unbutton and undress, ability to see the contours of the toilet and so forth. If the external obstacles are reduced, then continence may be the result. Asking about difficulties controlling urine or faeces may include such circumstances and thus give a wider and neutral expression. Other studies have also used the expression, for instance "*difficulties in holding*" (Wetle et al., 1995). Thus, incontinence among older people is a matter of the urinary tract as well as bowel function but also concerns environmental factors, and when investigating incontinence in this population such factors may play a role in the results. Therefore, the term *incontinence* does not express the actual problem; *difficulties controlling urine* or *faeces* should rather lead to follow-up questions such as when, where, in what situations, and thus give more details about the actual problem.

The prevalence rates presented in Paper II are unusual in the sense that both men and women and the oldest old are seldom included. The literature review (Paper II)

showed a gap in research on incontinence in population studies in people aged 75 and above, among both women and men, using similar definitions and including urinary, faecal and double incontinence at the same time. Although incontinence is defined as loss of urine or faeces, faecal incontinence seems to be less often investigated or is not even mentioned in studies. Additionally, the high prevalence of double incontinence and the few studies that have reported it demonstrates that this may be a forgotten area. Those with incontinence, urinary, faecal or double, seem to be a more vulnerable group as they had more other health complaints and diseases, less good economic situation, more often a low-income job, accidental falls, medications and lower health-related and general QoL than those who were continent. To my knowledge no studies have previously presented such results or compared types of incontinence. There are studies which suggest that mortality rates are higher among the incontinent (Herzog et al., 1994, Thom et al., 1997, Nakanishi et al., 1999, Johnson et al., 2000, Holroyd-Leduc et al., 2004) and it is assumed to be a marker of frailty (Holroyd-Leduc et al., 2004). Thus, there are indications that risk factors for incontinence may be found within the anatomic structures and functional level but also among socio-economic factors. Causal conclusions can not be drawn from this thesis, although the need for extra attention to the elderly with advanced incontinence seems to be important in that several factors may contribute to incontinence. Also, it seems important to observe the negative factors that seem to coexist with incontinence, such as accidental falls.

As expected, those with more impaired health had lower health-related quality of life, such as women, those with incontinence and those dependent on help in daily activities (Papers I, II, IV). This result may be criticized as it could be questioned what the measurement used (SF-12) really measures. Moons (2004) suggested that health-related instruments naturally show similar results as measures of a person's perceived health. On the other hand, general aspects of QoL were measured (Paper II), i.e. present QoL and life span quality, which showed similar patterns to PCS and MCS when groups with incontinence were compared with those not having any symptoms of incontinence. That finding could thus strengthen the use of SF-12 as measuring an aspect of health-related QoL. However, health problems seem to be central for older persons and may therefore also influence quality of life to a great extent.

Measuring any aspect of QoL proved to be useful in identifying the groups most vulnerable; for example, those with any type incontinence had lower QoL and those with double incontinence were most affected (Paper II). Women seem to be more affected as they were more often incontinent, were more often dependent and reported more of health complaints that had most impact on QoL, such as mobility, psychosocial and elimination problems. These vulnerable groups need extra attention if we are to develop and implement interventions that could improve their general as well as health-related quality of life.

Urinary incontinence and other urinary problems
The findings indicate that urinary incontinence should not be addressed as an isolated problem but rather as a complex of urinary problems, since other urinary problems were also quite common. Urinary incontinence was a female as well as a male problem and symptoms often regarded as male symptoms, such as hesitancy and strain to start, were common among women too (Paper III). As men and women most of the times are investigated separately in research it may not be possible to detect similarities and difficulties between them. In the traditional way of dividing urinary symptoms into storage and emptying phases as the phases just before and after the actual phase starts, i.e. the transition parts, are not included (Mattiasson, 2001). These phases may be crucial as they involve the neurological and muscular activities in the micturition cycle and are of special importance in an older person when neurological dysfunctions are common. The importance of investigating bladder function as a whole was emphasized in another study (Araki et al., 2003) which reported that urinary symptoms were equally common among both sexes. Similar reports were found in a cross-sectional study in four countries (Boyle et al., 2003). Thus, the findings in Paper III are supported and the importance of any dysfunction in the micturition cycle is therefore important for understanding the origin. As urinary problems independent of leakage or storage problems had similar influence on daily life, equally among men and women, it seems important in clinical practice to reduce symptoms that influence daily life, regardless of whether it is leakage or other urinary problems such as frequent micturition during night and day, or a feeling of incomplete emptying of the bladder.

The mixture of questions from BF-LUTS and ICS-male questionnaires was useful in study III as it enabled comparisons between genders. The result of the factor analyses indicated areas important to focus on. For instance, frequency problems and distress proved to be important in predicting the need for help in daily activities and low quality of life. The low Cronbach's alpha in the area of frequency must be considered and may be due to few items within the factor, and that factor thus needs more methodological development. Both BF-LUTS and ICS-male questionnaires have been widely used and were developed from a theoretical framework. However, no factor analysis has to our knowledge previously been performed to confirm the theory. The result of the factor analysis in this thesis (Paper III) confirmed the theory for voiding, storage and daily life factors whilst some questions did not fit into the same category. Therefore a further development of the questionnaire for use among older people may be of value. The use of similar questions for men and women at the same time has pitfalls, as some questions of interest may be lost. The advantages in this study were obvious, however. Similarities and differences in the urinary symptoms would not otherwise be detected, and therefore instruments which measure health complaints that occur in both sexes should sometimes be used in both sexes.

Faecal incontinence and other bowel problems

Overall bowel function seems to be greatly disturbed among older people in the population as well as among persons with faecal incontinence, as diarrhoea and constipation were common (Papers I, II) and also among persons complaining of faecal incontinence. Furthermore, laxatives seemed to be used quite frequently. Other studies also confirm these findings, at least in various population studies (Kinnunen, 1991, Harari et al., 1996, Talley et al., 1996, Meiring and Joubert, 1998, Robson et al., 2000, Ruby et al., 2003). There is a risk when focusing on one single health complaint that these other problems are overlooked. This result clearly demonstrates the importance of assessing health complaints at a functional level, which means that overall bowel function should be focused on and not faecal incontinence isolated. This interpretation is supported by intervention studies, which have shown that improved bowel function with improved stool consistency also improves faecal incontinence (Bentsen and Braun, 1996b, Harari et al., 2004). Interventions like increased fluid and fibre intake are examples that have shown to be effective (ibid.). Like urinary incontinence, faecal incontinence should not be considered as an isolated problem but rather as a complex of bowel problems. This approach may be useful in clinical practice as well as in research aiming to improve stool consistency and overall bowel function.

As a majority of those with faecal incontinence also report urinary incontinence, it seems even more important to regard incontinence as a concept covering leakage of urine as well as faeces and to have common terminology also for double incontinence. Just as urinary incontinence is closely related to other urinary problems, faecal incontinence seems to be closely related to other bowel problems. Therefore the results of this thesis demonstrate that incontinence among older people should be investigated covering both urinary and faecal incontinence, which in turn should cover both overall bowel function and urinary tract function.

The questionnaire used to assess bowel symptoms was new, although some questions had been used in other studies or in clinical practice. Comparisons with instruments constructed after this study have been made (Reilly et al., 2000, Barber et al., 2001, Bugg et al., 2001, Cockell et al., 2003, Bharucha et al., 2004) and several questions were found to be similar to those in this study. Most of these questionnaires constructed previously aimed to capture the special problems of female faecal or anal incontinence and consist of questions about pregnancy and labour. Only two questionnaires have been found that had a perspective of faecal incontinence as a problem in the population (Osterberg et al., 1996, Reilly et al., 2000). The instrument used in Paper IV showed a high internal consistency in the factors of leakage and consistency but lower in discomfort and contractility. Thus, further development of it is needed. However, it was useful to describe bowel problems and incontinence and their relation to help seeking and quality of life. There is a need for further testing of questionnaires aiming to capture the special

aspect of the oldest old with regard to bowel dysfunction, for use in clinical practice as well as in research. The study in Paper IV may serve as inspiration in that matter.

Dependency in relation to incontinence and other health complaints
There seems to be an inverse relationship between need for help in daily activities and quality of life, as women had greater need of help and lower quality of life in all age groups (Figures 5 and 6). Vulnerable groups such as women, those living alone, in older age, with mobility and/or elimination problems had higher risks of being dependent (Paper I). Furthermore, complaints related to frequency (urine) and distress (faeces) were those most related to being dependent on help in ADL and not the actual leakage (Papers III and IV), indicating that leakage perhaps can be handled but not the insecurity related to fear of leakage. Constructing dependency as a dichotomous variable, as was done in the analyses in these studies, does not correspond to real life. Individuals are rarely totally dependent or totally independent; rather they are independent in some respects and dependent in others (Arber and Evandrou, 1993). However, the result demonstrated areas which contribute to "the turning point" when dependency was predominant.

A better economic situation, physical functioning, living together with someone and higher mental quality of life were variables that in this thesis contributed to independency. The result was also found in variables that influenced dependency, such as being a women, having mobility problems, living alone and having distress over urinary or faecal incontinence. These findings are supported by Arber and Evandrou (1993), who also identified four inter-related areas which promote independency: financial resources, housing and home, physical health or functional resources and social, emotional and sexual interdependency (ibid.). The factors that were found to relate to dependency in this thesis could easily be interpreted in the model (Figure 9) as female gender is known to relate to lower income (financial resources), living alone to home situation (housing and home), older age, mobility and elimination problems to declined function (physical health). Furthermore, the urinary problems such as frequency could be interpreted as a question of having to go to the toilet often and therefore an environmental factor (housing and home) and feeling of distress relate to social or emotional factors. Independence could thus be supported by focusing on these four areas.
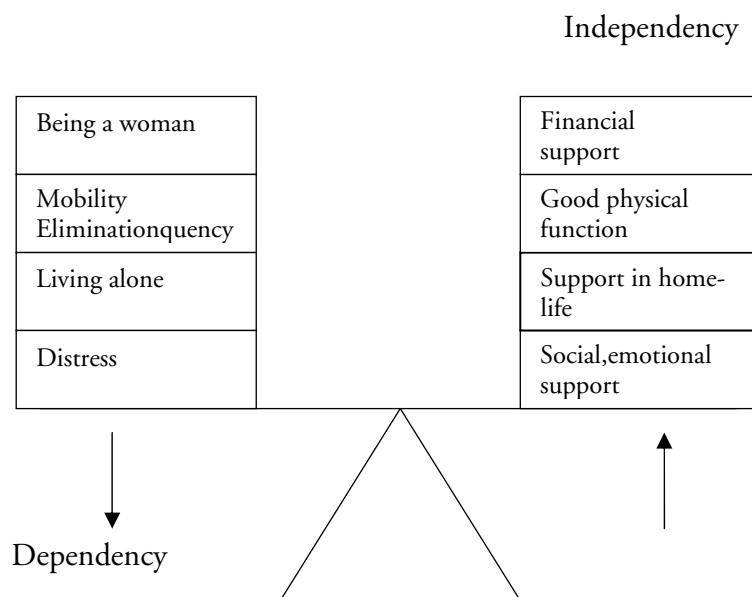
Independency

Being a woman		Financial support
Mobility Eliminationquency		Good physical function
Living alone		Support in home-life
Distress		Social,emotional support

Dependency

Figure 9. Factors shown in this thesis related to increased risk of dependency and factors that perhaps should be supported to improve independence.

Help seeking and incontinence

As few had sought any medical help for their incontinence or wore any protection, either the problem is not considered big enough or there are obstacles or barriers that hinder people from seeking and/or receiving help. Previous reports put forward different explanations for this. In one study only half of those with incontinence wanted treatment (Andersson et al., 2004), others reported that incontinence was embarrassing or not worth talking about (Saleh et al., 2005) or that advice from others and the media played a positive role in help seeking (Wolters et al., 2002). On the other hand, another study reported that health education about for instance hearing and visual impairment, UI, LUTS and depression among older people did not increase doctor visits (van Eijken et al., 2004). There are also signs that those in need of help do not get adequate help or are not offered investigations or treatments. In an official report (Socialstyrelsen, 2003) in Sweden it was shown that only 24% in ordinary housing and 37% in special accommodations received as much help they needed for their incontinence, investigations and treatments were unusual as only one third had received any further help other than protective aids (Socialstyrelsen, 2003). The results of this thesis, in addition to the results of other studies, indicate a need for health education for older people but also for health care providers about available treatment and information that incontinence may not be a natural part of ageing.

The low help seeking among those with urinary and faecal incontinence in this thesis could be understood in the light of sociological theories (Kubie, 1937, Elias, 1989, Widding Isaksen, 2001, Widding Isaksen, 2002), which may be helpful in

understanding why symptoms like incontinence are neglected, and also guide in how to take action to reduce such feelings. In other areas such work has been more successful, for example, concerning sexuality. Combining social theories, the findings in this thesis and others could result in a model (Figure 10), which may help in understanding the low help seeking among older persons with incontinence. Reduction of smell would be one example to break down one barrier of shame, for example, improving protecting aids so that urinary and faecal content could be neutralized as regards smell when absorbed in a diaper. Giving words to explain the problem, words with a neutral value which can be used without shame, may help people to talk openly about their problems. Thus, the model below tries to exemplify areas which could be focused on in order to increase the level of help seeking.

Hierarchy of dirt and smell			
Lack of information	Lack of words	Attitudes from carer	Professionals not asking
Fear of death and destruction	Fear of disturbed integrity		Fear of decivilization and disorder
Incontinence as normal part of old age			
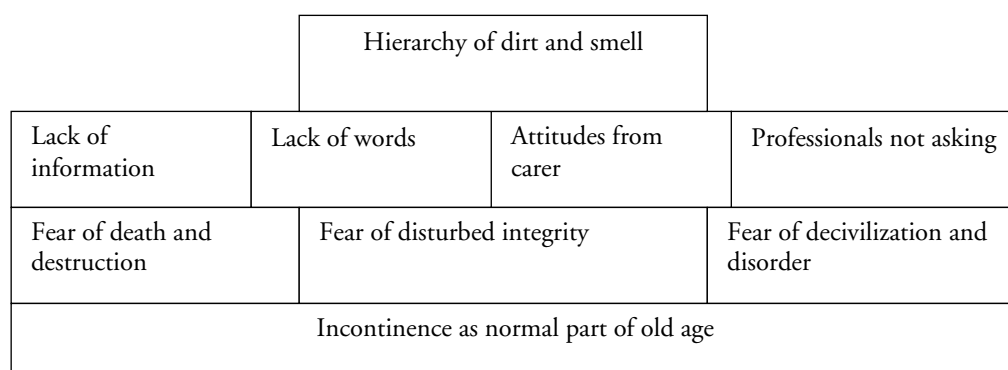
Figure 10. Possible barriers preventing incontinent persons from seeking medical help.

The result showed that health complaints that make a person feel worried about something that is dangerous, such as pain, had an influence on daily life, caused discomfort and were more related to help seeking than the actual leakage. Only a few studies have reported relations between different urinary or bowel symptoms and help seeking among older ages. However, urgency has been reported to be more strongly related to help seeking than, for instance, stress incontinence (Hagglund et al., 2001). Help seeking and low use of protection can also be discussed in a health economy perspective. As costs of incontinence are considered to be very high (Hu, 1990, Ekelund et al., 1993, Cummings et al., 1995, Wyman, 1997, Wagner and Hu, 1998, Dowell et al., 1999, Wilson et al., 2001, Langa et al., 2002, Morris et al., 2005), interventions that are cost-effective should be focused on. Conservative treatment and intervention aiming to improve stool consistency, walking training to reduce urinary incontinence episodes are examples. However, preventive work, for example, intensive training of pelvic floor muscles post-partum, mobility and physical exercise among younger older persons at an early stage may be even more effective.

CONCLUSIONS

Coexisting health complaints were of importance for the need for help in daily activities as well as quality of life. Mobility, psychosocial, communication and elimination problems were strongly related to dependency and low health-related QoL. Women seem to be more at risk as they were more often affected in three of these functions and thus more often dependent and had lower QoL. Women also seemed to have more additional negative socio-economic factors. Dysfunctions that were most common should be focused on and interventions aiming to reduce such complaints should be of high priority. Overall urinary and bowel functions seem to be equally important as incontinence *per se* and therefore a wider perspective when investigating these symptoms would benefit decisions about investigations and help. Men and women have different needs and none of them should be overlooked, but there is a risk that men are neglected as incontinence is regarded as a female problem. Urinary, faecal and double incontinence were common conditions, but also other urinary and bowel problems, and few had sought help although they reported considerable problems. All urinary problems as well as bowel-related problems seemingly interacted and had equal effect on daily life and quality of life. Therefore these areas should preferably be seen together and not separately.

FURTHER RESEARCH

Future research in this area should perhaps have four major aims: instrument testing, studies of particularly vulnerable groups, studies that could prove causalities, and interventions in randomized controlled trials that can improve effectiveness.

Further development and testing of instruments covering multi-complaints is needed, especially with regard to which problems to include, terminology to be used, scoring and labelling of the factors. Furthermore, the need to develop instruments that could also be used in clinical settings in screening older people and their need for interventions seems essential. Instruments covering urinary problems as well as bowel-related symptoms in an older population in both sexes need to be further tested.

Research is needed that focuses on groups which were shown in this thesis to be most difficult to reach, as it is supposed that they have most health problems, especially with regard to incontinence, for example older women and men in special accommodations or dependent on help in ADL. Specially designed studies are needed in order to overcome obstacles to reaching them, the risk of high dropout and other threats, especially to external validity.

The low help seeking and frequency of aids use need to be further investigated. With such knowledge it may be possible to construct interventions that could increase help seeking. When investigations and treatment are optimized, protective aids should be the last choice.

As health care personal are essential in the care of older people, their knowledge of and attitudes to incontinence need to be investigated.

Research about how to prevent, treat or delay known health complaints that sooner or later affect older people seems to be urgently needed. Such health complaints are within the functions of communication, mobility, psychosocial and elimination. A reduction of these problems would increase quality of life and delay dependency.

Intervention studies to prove earlier studies that have shown positive results – such as walking exercise to reduce urinary incontinence episodes, improved bowel function to reduce faecal incontinence – should be tested further so that evidence-based data could be available also among older persons.

POPULÄRVETENSKAPLIG SAMMANFATTNING

Urin och avföringsinkontinens hos äldre kvinnor och män i relation till andra hälsoproblem, livskvalitet, beroende och hjälpsökande

Äldre människor har ofta många hälsoproblem som t.ex. svårigheter att gå, se, höra, smärta och inkontinens men hur vanligt det är bland de allra äldsta är lite undersökt. De olika hälsoproblemen kan finnas samtidigt och i särskilda mönster men få studier har gjorts om detta. När ett hälsoproblem läggs till ett annat kommer det kanske till en punkt när behov av hjälp är nödvändigt för att klara dagliga aktiviteter och detta kan vara avgörande för behov av vård i hemmet eller på institution. Vilka faktorer som bidrar till denna "vändpunkt" är dock inte klart. Inkontinens betyder egentligen läckage av urin eller avföring, men få studier har belyst bägge problemen i de högre åldrarna och bland både kvinnor och män, även om vissa studier påpekar att problemet är vanligt även hos män och påverkar livskvalitet negativt. Det övergripande syftet med denna avhandling var därför att undersöka förekomst av hälsoproblem och inkontinens bland kvinnor och män 75 år och äldre. Dessutom var syftet att undersöka urin- och avföringsbesvär och dess relation till andra hälsoproblem, livskvalitet, dagligt liv, hjälpsökande och beroende.

Studierna genomfördes som en populationsstudie i södra Sverige. Datainsamlingen gjordes från hösten år 1999 fram till september år 2000 i en grupp av slumpmässigt urval i åldersgrupperna 75–79, 80–84, 85–89 och 90 år och äldre. Urvalets storlek syftade på att få ett tillräckligt antal beroende av hjälp i dagligt liv även i de yngre åldersgrupperna. Därför ingick fler i de yngre åldersgrupperna jämfört med de äldre. De som svarade, både män och kvinnor, att de hade någon form av besvär som urin- eller avföringsinkontinens eller andra urinvägsbesvär fick en uppföljande enkät om symtomens art. De som var oberoende fick en postenkät och de som var beroende av hjälp en gång i veckan eller mer uppsöktes för en personlig intervju med samma frågor.

<u>Delstudie 1:</u> Hälsoproblem hos personer 75 år och äldre i relation till livskvalitet och hjälpbehov.

Syftet med denna studie var att undersöka förekomst av vanliga symtom/besvär hos personer över 75 år samt att undersöka om det fanns skillnader mellan män och kvinnor och mellan olika åldersgrupper. Dessutom undersöktes samband mellan olika symtom utifrån ett funktionellt perspektiv. Urvalet bestod av 4277 personer som besvarat en postenkät som distribuerats till 8500 personer boende i Skåne. Urvalet av personer skedde stratifierat för ålder i åldersgrupperna 75–79, 80–84, 85–89 och 90 år och äldre, d.v.s. i fyra åldersgrupper. Medelåldern var 84,3 år för kvinnor och 82,7 år för män. Enkäten innehöll frågor om socioekonomi, behov av hjälp i dagligt liv, livskvalitet och hälsa. Som livskvalitetsinstrument användes SF-

12 som omfattar två komponenter av hälsorelaterad livskvalitet, mental och fysisk (MCS och PSC). De vanligaste sjukdomarna, hämtade från Socialstyrelsens klassifikation av sjukdomsgrupper, besvarades med ja eller nej. De vanligaste hälsoproblemen under den senaste tremånadersperioden var inspirerad av Tibblins frågeformulär, totalt 30 hälsoproblem, som i denna studie besvarades på en fyrgradig skala från lite till mycket besvär.

Resultaten visade att kvinnor rapporterade fler hälsoproblem jämfört med män (9,5 jämfört med 9,0) och fler sjukdomar (2,1 jämfört med 1,9). Kvinnors hälsorelaterade livskvalitet var också signifikant lägre, både fysisk (35,8 jämfört med 40,1) och mental (49,4 jämfört med 51,7), jämfört med män. De som var beroende av hjälp i dagliga aktiviteter hade också lägre hälsorelaterad livskvalitet jämfört med dem som inte behövde hjälp. De 30 olika hälsoproblemen analyserades med s.k. faktoranalys för att identifiera mönster snarare än enskilda problem och den resulterade i sex områden av hälsoproblem. Dessa var relaterade till kommunikation, mobilitet, elimination, psykosociala problem, andning/cirkulation och matsmältning. Av dessa var kommunikation, mobilitet och psykosociala problem vanligast förekommande. Dessa områden av hälsoproblem användes också för att undersöka faktorer som förklarade låg hälsorelaterad livskvalitet och beroende. Den statistiska analysen visade att mobilitets- och matsmältningssymtom var de största riskfaktorerna för låg fysisk livskvalitet medan psykosociala och digestionsrelaterade problem förklarade låg mental livskvalitet. Mobilitets- och eliminationsproblem var de största riskfaktorerna för beroende i personliga aktiviteter i dagligt liv (PADL) och kommunikationsproblem för beroende av instrumentella aktiviteter i dagligt liv (IADL) efter ålder och kvinnligt kön. Resultaten demonstrerar dels den höga förekomsten av olika hälsoproblem bland äldre, dess relation till livskvalitet och betydelsen av att se till flera problem samtidigt då de interagerar med varandra och därmed kan såväl positivt som negativt influera varandra.

Delstudie 2: Urin- och avföringsinkontinens bland män och kvinnor 75 år och äldre, i relation till andra hälsoproblem och livskvalitet.

Denna studie syftade till att undersöka förekomst av urin- och avföringsinkontinens hos äldre och även att undersöka hur dessa symtom var relaterade till andra hälsoproblem och livskvalitet. Urvalet bestod av 4277 personer i åldrarna från 75 år och uppåt och var detsamma som i delstudie 1. Materialet delades in i grupper bestående av dem som uppgav urininkontinens, dem som uppgav avföringsinkontinens och dem med dubbel inkontinens, d.v.s. både urin- och avföringsinkontinens, och dessa jämfördes med dem som inte hade några inkontinenssymtom. Den tidigare genomförda faktoranalysen som gett upphov till områden av hälsoproblem (arbete I) användes för att undersöka vilka hälsoproblem som förklarade urin-, avförings- och dubbel inkontinens. Resultaten visade en förekomst av urininkontinens på 39 % totalt, vanligare hos kvinnor än män. Totalt uppgav 16,9 % (lika

bland kvinnor och män) avföringsinkontinens och 14,5 % dubbel inkontinens (lika bland kvinnor och män). Jämförelser mellan dem med olika typer av inkontinens och med dem som inte hade inkontinens visade att alla med inkontinens, oavsett typ, hade lägre livskvalitet i dimensioner som fysisk, mental, nuvarande och livs-loppskvalitet än dem som inte hade inkontinens. De hade också i större utsträck-ning behov av hjälp i dagligt liv, personlig och instrumentell aktivitet i dagligt liv (PADL, IADL), och hade fler rapporterade fallolyckor, fler mediciner, större antal andra hälsoproblem och sjukdomar än dem som inte hade inkontinens. De som uppgav att de hade dubbel inkontinens var den värst utsatta gruppen avseende antal andra hälsoproblem, livskvalitet och beroende jämfört med dem som enbart hade urin- eller avföringsinkontinens. Kommunikationsrelaterade och mobilitetsrela-terade hälsoproblem förklarade starkast urininkontinens medan diarré förklarade avföringsinkontinens. När det gäller dubbel inkontinens var diarré den starkaste förklarande faktorn tillsammans med kommunikations- och mobilitetsproblem. Studien är unik så till vida att förekomst av urin och avföringsinkontinens vanligen inte undersökts samtidigt och särskilt inte samtidigt hos män och kvinnor i dessa åldersgrupper. Resultaten understryker betydelsen av att inte utgå från att inkontinens bland äldre är ett unikt kvinnligt problem och måhända kan den samtidiga förekomsten av urin- och avföringsinkontinens bidra till nya infalls-vinklar på förståelsen och behandlingen av dessa problem. Betydelsen av dessa hälsoproblem och deras relation till äldres livskvalitet bör inte heller underskattas.

Delstudie 3: Äldre kvinnor och män med urinvägsbesvär – hjälpsökande, beroende och inverkan på dagligt liv.

Syftet med denna studie var att jämföra förekomst av urinbesvär och deras påverkan på dagligt liv bland kvinnor och män (75+) som rapporterat svårighet att hålla urin, andra urinvägsbesvär eller både och. Syftet var också att identifiera förklarande mönster och samband av olika urinvägsbesvär, och att identifiera vilka som har betydelse för att söka hjälp och att vara beroende av hjälp för dagligt liv. Urvalet bestod av 771 personer som besvarat ett frågeformulär riktat till dem som i tidigare studie rapporterat urininkontinens och/eller andra urinvägsbesvär (n=1881). Det frågeformulär som användes är väl känt, Bristol Female Lower Urinary Tract Symptom questionnaire (BF-LUTS), utvecklat för att användas till kvinnor. Till männen användes International Continence Society male questionnaire (ICS-male). Anledningen till att två olika formulär användes var att det inte fanns något könsneutralt formulär att tillgå. I analysen användes de frågor som var lika i de båda formulären.

Resultaten visade att urinvägsbesvär kunde kategoriseras i följande områden: miktion, lagring, smärta, frekvens och dagligt liv. Män, kvinnor, de med inkonti-nens och de med andra urinvägsbesvär rapporterade samma grad av besvär till följd av många miktionstillfällen dag och natt, samt hur besvären inverkade på det

dagliga livet. Däremot hade männen mer miktionsbesvär och kvinnor mer besvär med att lagra urin. Trots att män och kvinnor hade olika typer av besvär var det ingen skillnad i deras uppfattning om hur besvären påverkade socialt liv, att undvika platser och situationer på grund av sina urinvägsbesvär. Endast 43,3 % av respondenterna hade sökt hjälp för sina symtom. Miktionsfrekvens var, av alla urinbesvären, den starkaste förklarande faktorn för beroende av andra för hjälp i dagligt liv oavsett ålder och kön. Besvärens inflytande på dagligt liv, lagrings-relaterade symtom och smärta förklarade huruvida de valde att söka hjälp för miktionsproblemen. Studiens betydelse ligger främst i att den indikerar att skillnaderna mellan män och kvinnor måhända är mindre än förväntat, i dessa åldrar. Dessutom visar den att andra urinvägsbesvär än inkontinens har lika stor inverkan på det dagliga livet som inkontinens. Betydelsen ligger också i att den bekräftar föreställningen om att äldre personer oftast inte söker hjälp för dessa problem och därmed kvarstår i en del fall onödig inskränkning av det dagliga livet och deras livskvalitet.

Delstudie 4: Avföringsproblem bland personer 75 år och mer som hade besvär av avföringsinkontinens i relation till, hjälpsökande, beroende och livskvalitet.

Syftet med denna studie var att jämföra avföringsinkontinens och relaterade mag-tarm symtom mellan kvinnor och män och mellan dem som var beroende för dagligt liv i en grupp som rapporterat att de hade avföringsinkontinens. Syftet var också att undersöka vilka symtom som förklarade hjälpsökande, beroende av hjälp för dagligt liv samt låg livskvalitet. Urvalet bestod av 248 personer över 75 år (medelålder 82 år, 82,6 för kvinnor och 81,3 för män) som besvarade en uppföljande enkät riktad till 581 personer som uppgett att de hade svårighet att kontrollera avföringen. Svarsfrekvensen varierade från 29,6 % i den äldsta åldersgruppen (90+) till 57,3 % i den yngsta gruppen (75–79 år) i gruppen som var oberoende av hjälp i dagliga aktiviteter. I gruppen som var beroende av hjälp var svarsfrekvensen endast 12,9 % bland de äldsta och 59,3 % bland de yngre. Frågeformuläret innehöll frågor om mag-tarmfunktion och avföringsinkontinens och hade tidigare använts i två kliniska verksamheter. Vidare användes egna konstruerade frågor som var relevanta för frågeställningen. Vid den aktuella tidpunkten fanns inga välutvecklade instrument för den aktuella befolknings-gruppen. Frågorna angående mag-tarmbesvär analyserades med hjälp av faktor-analys som resulterade i fyra huvudgrupper, d v s besvär med läckage, obehag, konsistens och bristande knipförmåga.

Resultaten visade att kvinnor i större utsträckning hade besvär med läckage och svag knipförmåga medan det inte fanns någon skillnad mellan kvinnor och män i de andra grupperna av besvär. De som var beroende av hjälp för dagligt liv hade också mer symtom vad gällde läckage men också när det gällde att känna obehag. Ungefär 40 % av alla hade sökt hjälp någon gång för sina besvär och män och kvinnor

skiljde sig inte åt i det fallet. Ungefär 30 % använde någon form av skydd trots att 62 % hade rapporterat att de hade läckage av avföring. Kvinnor använde skydd i högre grad än männen men hade också läckage i större omfattning. Det som förklarade hjälpsökande var obehag samt läckage förutom ålder och kön. Beroende och låg fysisk livskvalitet förklarades av obehag, ålder och kvinnligt kön medan inget av symtomen, ålder eller kön hade någon signifikant betydelse för mental livskvalitet.

Sammanfattningsvis visade studierna på fördelar med att se på hälsoproblem ur ett funktionellt perspektiv, och genom att gruppera symtom har studierna visat möjlighet att identifiera tydligare samband mellan olika typer av funktionsnedsätt-ningar och deras relation till beroende av hjälp i dagliga aktiviteter, livskvalitet och hjälpsökande. Studierna visade att både urin- och avföringsinkontinens var mycket vanliga bland äldre personer, men också att andra urinvägs- och avföringsrelaterade besvär var vanligt förekommande. Dessutom är det få som söker hjälp för sina problem. Både män och kvinnor som var beroende av hjälp för att klara aktiviteter i dagligt liv hade lägre livskvalitet än dem som var oberoende av hjälp oavsett typ av problem. Ett helhetsperspektiv i vården av äldre där åtgärder riktas mot funktion kan vara till hjälp i rehabilitering och för att förbättra äldres livskvalitet och fördröja beroende. Inkontinens hos äldre bör omfatta analys både för urin- och avförings-inkontinens då de ofta förekommer samtidigt.

ACKNOWLEDGEMENTS

This thesis for the doctoral degree was carried out at the Department of Nursing, Lund University. I wish to express my sincere gratitude to:

All the persons who participated in these studies, who responded to questionnaires and were interviewed. I wish especially to thank those whom I visited in their homes giving me a part of their lives and telling the most interesting stories. For example, the starvation in Landskrona during the First World War, where charcoal were added to the grain to get bread for the day or seeds left over after the harvest were picked to get grains. Furthermore for describing the happiness in the celebration of peace in the streets in Stockholm in May 1945. Thank you also for giving me insights in the positive and negative sides of becoming older, for offering me coffee, photo viewing of children and sharing a couple of hours with me. These interviews gave me a lot of knowledge of life that I do not want to be without.

- My first supervisor, Ingalill Rahm Hallberg, for believing in me from our first meeting and not ceasing to do so even when things looked dark. Your enormous capacity in reading and giving good comments is something I have learned a lot from. I am thankful also for the favour of being your student and thereby receiving a stimulating education. Thank you for your supervision, guidance and encouraging conclusions. I will never forget trying to reach a higher level in the discussions.

- Albert Westergren, my second supervisor. Thank you for always being there when I was stuck, for fruitful discussions, good support and guidance with the statistics, methodology, tips of literature and the English language. You have become a friend who have helped me a lot through peaks and troughs.

- Anders Mattiasson, who was the one who got me into research in the first place. You inspired me to become interested in the world of incontinence and put the subject on my agenda. You taught me that curiosity and patience are the most important ingredients for research work. Thank you for personal and academic support. Thank you also for friendship with you as well as with your wife, Elisabeth.

- I specially want to thank those who assisted me in statistical matters, first Per Nyberg who helped me a lot in getting to know the statistical software and methods. I want also to thank Per-Erik Isberg for your pedagogical teaching on statistical courses in Malmö. A specially thank goes to Alan Crozier for revising my English, for your smooth cooperation and fast response.

REFERENCES

Abrams, P., Blaivas, J. G., Stanton, S. L., Andersen, J. T., 1988. The standardisation of terminology of lower urinary tract function. The International Continence Society Committee on Standardisation of Terminology. Scand. J. Urol. Nephrol. Suppl. 114, 5-19.

Abrams, P., Cardozo, L., Fall, M., Griffiths, D., Rosier, P., Ulmsten, U., van Kerrebroeck, P., Victor, A., Wein, A., 2002. The standardisation of terminology of lower urinary tract function: report from the Standardisation Sub-committee of the International Continence Society. Neurourol. Urodyn. 21, 167-178.

Abrams, P., Donovan, J. L., de la Rosette, J. J., Schafer, W., 1997. International Continence Society "Benign Prostatic Hyperplasia" Study: background, aims, and methodology. Neurourol. Urodyn. 16, 79-91.

Aggazzotti, G., Pesce, F., Grassi, D., Fantuzzi, G., Righi, E., De Vita, D., Santacroce, S., Artibani, W., 2000. Prevalence of urinary incontinence among institutionalized patients: a cross-sectional epidemiologic study in a midsized city in northern Italy. Urology. 56, 245-249.

Album, D., 1991. Sykdommers og medisinske specialiteters presisje. (The prestige of diseases and medical specialities). Tidskrift for den Norska laegeforeningen. 1001, 2127-2133.

Altman, D. G., 1999. Practical statistics for medical research. Chapman & Hall/CRC, London.

Andersson, G., Johansson, J. E., Garpenholt, O., Nilsson, K., 2004. Urinary incontinence--prevalence, impact on daily living and desire for treatment: a population-based study. Scand. J. Urol. Nephrol. 38, 125-130.

Araki, I., Zakoji, H., Komuro, M., Furuya, Y., Fukasawa, M., Takihana, Y., Takeda, M., 2003. Lower urinary tract symptoms in men and women without underlying disease causing micturition disorder: a cross-sectional study assessing the natural history of bladder function. J. Urol. 170, 1901-1904.

Arber, S., Evandrou, M., 1993. Ageing, indepence and the life course. Jessica Kingsley Publishers, London.

Ashworth, P. D., Hagan, M. T., 1993. The meaning of incontinence: a qualitative study of non-geriatric urinary incontinence sufferers. J. Adv. Nurs. 18, 1415-1423.

Baltes, M. M., 1996. The many faces of dependency in old age. Cambridge University Press, Cambridge.

Baltes, P. B., Baltes, M. M., 1993. Successful aging, perspectives from the behavioural sciences. Cambridge University Press, New York.

Baltes, P. B., Mayer, K. U., 1999. The Berlin aging study aging from 70 to 100. Cambridge University Press, Cambridge.

Barber, M. D., Kuchibhatla, M. N., Pieper, C. F., Bump, R. C., 2001. Psychometric evaluation of 2 comprehensive condition-specific quality of life instruments for women with pelvic floor disorders. Am. J. Obstet. Gynecol. 185, 1388-1395.

Barry, M. J., Fowler, F. J., O'Leary, M. P., al, e., 1992. The American Urological Association Symptom index for benign prostatic hyperplasia. J. Urol. 148, 1549-1557.

Beauchamp, T. L., Childress, J. F., 1994. Principles of biomedical ethics. Oxford University Press, Oxford.

Bengtsson, C., Edstrom, K., Furunes, B., Sigurdsson, J. A., Tibblin, G., 1987. Prevalence of subjectively experienced symptoms in a population sample of women with special reference to women with arterial hypertension. Scand. J. Prim. Health Care. 5, 155-162.

Benton, J. M., O'Hara, P. A., Chen, H., Harper, D. W., Johnston, S. F., 1997. Changing bowel hygiene practice successfully: a program to reduce laxative use in a chronic care hospital. Geriatr Nurs. 18, 12-17.

Bentsen, D., Braun, J. W., 1996a. Controlling fecal incontinence with sensory retraining managed by advanced practice nurses. Clin. Nurse Spec. 10, 171-175.

Bentsen, D., Braun, J. W., 1996b. Controlling fecal incontinence with sensory retraining managed by advanced practice nurses. Clin. Nurse Spec. 10, 171-176.

Bharucha, A. E., Locke, G. R., 3rd, Seide, B. M., Zinsmeister, A. R., 2004. A new questionnaire for constipation and faecal incontinence. Aliment. Pharmacol. Ther. 20, 355-364.

Blaivas, J. G., Groutz, A. (2002): Urinary incontinence pathophysiology, evaluation and management overview. In. P. Walsh, E. D. Vaughan, A. Wein, Campell´s Urology, Saunders, London. 1027-1052.

Bland, J. M., Altman, D. G., 1995. Multiple significance tests: the Bonferroni method. BMJ. 310, 170.

Bland, J. M., Altman, D. G., 1986. Statistical methods for assessing agreement between two methods of clinical measurements. Lancet. 307-310.

Bliss, D. Z., Fischer, L. R., Savik, K., Avery, M., Mark, P., 2004. Severity of fecal incontinence in community-living elderly in a health maintenance organization. Res. Nurs. Health. 27, 162-173.

Bo, K., 1994. Reproducibility of instruments designed to measure subjective evaluation of female stress urinary incontinence. Scand. J. Urol. Nephrol. 28, 97-100.

Bogner, H. R., Gallo, J. J., Samuel, M. D., Ford, D. E., Armenian, H. K., Eaton, W. W., 2002. Urinary incontinence and psychological distress in community dwelling older adults. Journal of American Geriatrics Society. 50, 489-495.

Bolognese, J. A., Kozloff, R. C., Kunitz, S. C., Grino, P. B., Patrick, D. L., Stoner, E., 1992. Validation of a symptom questionnaire for benign prostatic hyperplasia. The Prostate. 21, 247-254.

Borglin, G., Jakobsson, U., Edberg, A. K., Hallberg, I. R., 2005. Self-reported health complaints and their prediction of overall and health-related quality of life among elderly people. Int. J. Nurs. Stud. 42, 147-158.

Borrie, M. J., Davidson, H. A., 1992. Incontinence in institutions. Can. Med. Assoc. J. 147, 322-328.

Bortolotti, A., Bernardini, B., Colli, E., Di Benedetto, P., Giocoli Nacci, G., Landoni, M., Lavezzari, M., Pagliarulo, A., Salvatore, S., von Heland, M., Parazzini, F., Artibani, W., 2000. Prevalence and risk factors for urinary incontinence in Italy. Eur. Urol. 37, 30-35.

Bovarosky, S., Jones, G., Paulson, D. F., Prout, G. R., 1977. New look at bladder neck obstruction by the food and drug administration regulators. American Association of Genito-Urinary Surgery. 68, 29-32.

Bowling, A., 2002. Research Methods in Health. Investigation health and health services. Open University Press, Buckingham.

Boyle, P., Robertson, C., Mazzetta, C., Keech, M., Hobbs, F. D., Fourcade, R., Kiemeney, L., Lee, C., 2003. The prevalence of lower urinary tract symptoms in men and women in four centres. The UrEpik study. BJU Int. 92, 409-414.

Brink, P., Wood, M., 1998. Advanced design in nursing research. Sage Publications, London.

Brockelhurst, J. C. (1994): Ageing, bladder function and incontinence. In. J. C. Brockelhurst, Urology in the elderly, Churchill Livingstone, London.

Brown, J. S., Vittinghoff, E., Wyman, J. F., Stone, K. L., Nevitt, M. C., Ensrud, K. E., Grady, D., 2000. Urinary incontinence: does it increase risk for falls and fractures? Study of Osteoporotic Fractures Research Group. J. Am. Geriatr. Soc. 48, 721-725.

Brunnstrom, G., Sorensen, S., Alsterstad, K., Sjostrand, J., 2004. Quality of light and quality of life--the effect of lighting adaptation among people with low vision. Ophthalmic Physiol. Opt. 24, 274-280.

Bugg, G. J., Kiff, E. S., Hosker, G., 2001. A new condition-specific health-related quality of life questionnaire for the assessment of women with anal incontinence. Br. J. Obstet. Gynaecol. 108, 1057-1067.

Burgio, K. L., Ives, D. O., Locher, J. L., Arena, V. C., Kuller, L. H., 1994. Treatment seeking of urinary incontinence in older adults. Journal of American Geriatrics Society. 42, 208-212.

Cacciatore, F., Napoli, C., Abete, P., Marciano, E., Triassi, M., Rengo, F., 1999. Quality of life determinants and hearing function in an elderly population: Osservatorio Geriatrico Campano Study Group. Gerontology. 45, 323-328.

Cassells, C., Watt, E., 2003. The impact of incontinence on older spousal caregivers. J. Adv. Nurs. 42, 607-616.

Chancellor, M. B., Yoshimura, N. (2002): Physiology and pharmacology of the bladder and urethra. In. J. Walsh, A. Retik, Vaughan, A. Wein, Campell′s Urology, Saunders, Philadeliphia. 831-886.

Chassagne, P., Jego, A., Gloc, P., Capet, C., Trivalle, C., Doucet, J., Denis, P., Bercoff, E., 2000. Does treatment of constipation improve faecal incontinence in institutionalized elderly patients? Age Ageing. 29, 159-164.

Chassagne, P., Landrin, I., Neveu, C., Czernichow, P., Bouaniche, M., Doucet, J., Denis, P., Bercoff, E., 1999. Fecal incontinence in the institutionalized elderly: incidence, risk factors, and prognosis. Am. J. Med. 106, 185-190.

Chiang, L., Ouslander, J., Schnelle, J., Reuben, D. B., 2000. Dually incontinent nursing home residents: clinical characteristics and treatment differences. J. Am. Geriatr. Soc. 48, 673-676.

Chronbach, L. J., Meehl, P. L., 1955. Construct validity in psychological tests. Psychological Bullentin. 52, 281-302.

Cockell, S. J., Oates-Johnson, T., Gilmour, D. T., Vallis, T. M., Turnbull, G. K., 2003. Postpartum flatal and Fecal Incontinence Quality-of-Life Scale: a disease- and population-specific measure. Qual. Health Res. 13, 1132-1144.

Cockett, A., Khoury, S., Aso, Y., eds, e. a., Eds, 1993. Proceedings of the second WHO International Consultation on Benign Prostatic Hyperplasia. Jersey, Scientific Communication International Ltd.

Cohen, S. J., Robinson, D., Dugan, E., Howard, G., Suggs, P. K., Pearce, K. F., Carroll, D. D., McGann, P., Preisser, J., 1999. Communication between older adults and their physicians about urinary incontinence. J. Gerontol. A. Biol. Sci. Med. Sci. 54, M34-37.

Crabtree, H. L., Gray, C. S., Hildreth, A. J., O'Connell, J. E., Brown, J., 2000. The Comorbidity Symptom Scale: a combined disease inventory and assessment of symptom severity. J. Am. Geriatr. Soc. 48, 1674-1678.

Crowther, J., Ed. 1995. Oxford Advanced Learner´s Dictionary of current English. Oxford, Oxford University Press.

Cumming, D., Newell, D., McCaffey, I., 1960. Disengagement - a tentative theory of ageing. Sociometry. 73, 23-35.

Cummings, V., Holt, R., van der Sloot, C., Moore, K., Griffiths, D., 1995. Costs and management of urinary incontinence in long-term care. J Wound Ostomy Continence Nurs. 22, 193-198.

Cunningham-Burley, S., Allbutt, H., Garraway, W. M., Lee, A. J., Russell, E. B., 1996. Perceptions of urinary symptoms and health-care-seeking behaviour amongst men aged 40-79 years. Br. J. Gen. Pract. 46, 349-352.

Dahl, T. H., 2002. International classification of functioning, disability and health: an introduction and discussion of its potential impact on rehabilitation services and research. J Rehabil Med. 34, 201-204.

Damian, J., Martin-Moreno, J. M., Lobo, F., Bonache, J., Cervino, J., Redondo-Marquez, L., Martinez-Agullo, E., 1998. Prevalence of urinary incontinence among Spanish older people living at home. Eur. Urol. 34, 333-338.

De Lillo, A. R., Rose, S., 2000. Functional bowel disorders in the geriatric patient: constipation, fecal impaction, and fecal incontinence. Am. J. Gastroenterol. 95, 901-905.

Dehlin, O., Rundgren, Å., 1995. Geriatrik. Studentlitteratur, Lund.

Denny, E., Earle, S., 2005. Sociology for nurses. Polity Press, Cambridge.

Doll, H., McPherson, K., Davies, J., Flood, A., Smith, J., Williams, G., Ginzler, M., Petticrew, M., Black, N., 1991. Reliability of questionnaire responses as compared with interview in the elderly: views of the outcome of transurethral resection of the prostate. Soc. Sci. Med. 33, 1303-1308.

Donovan, J., Brookes, S. T., de la Rosette, J. J., Peters, T. J., Porru, D., Kondo, A., Dabhoiwala, N., Millard, R., Bosch, R., Nordling, J., Matos Ferreira, A., Höfner, K., Mostafid, H., Walter, S., Nissenkorn, I., Frimodt Moller, C., Mendez Silva, M., Chapple, C., Abrams, P., 1999. The responsiveness of ICSmale questionnaire to outcome evidence from the ICS-BPH study. Br. J. Urol. 83, 243-248.

Donovan, J. L., Abrams, P., Peters, T. J., Kay, H. E., Reynard, J., Chapple, C., De La Rosette, J. J., Kondo, A., 1996. The ICS-'BPH' Study: the psychometric validity and reliability of the ICSmale questionnaire. Br. J. Urol. 77, 554-562.

Doughty, D., 2000. Urinary and faecal incontinence. Nursing management. Mosby, Inc., St. Louis.

Douglas, M., 1997. Renhet och fara, Swedish version of Puity and danger, 1966. Nya Doxa, Falun.

Dowell, C. J., Bryant, C. M., Moore, K. H., Simons, A. M., 1999. Calculating the direct costs of urinary incontinence: a new test instrument. BJU Int. 83, 596-606.

DuBeau, C., Levy, B., Mangione, C. M., Resnick, N., 1998. The impact of urge urinary incontinence on Quality of Life: Importance of patients perspective and explanatory style. J. Am. Geriatr. Soc. 46, 683-692.

DuBeau, C. E., Kiely, D. K., Resnick, N. M., 1999. Quality of life impact of urge incontinence in older persons: A new measure and conceptual structure. Journal of the American Geriarics Society. 47, 989-994.

DuBeau, C. E., Resnick, N. M., 1991. Evaluation of the causes of geriatric incontinence: a critical appraisal. Urol Clin N Am. 18, 243-256.

Dugan, E., Cohen, S. J., Bland, D. R., Preisser, J. S., Davis, C. C., Suggs, P. K., McGann, P., 2000. The association of depressive symptoms and urinary incontinence among older adults. J. Am. Geriatr. Soc. 48, 413-416.

Dugan, E., Cohen, S. J., Robinson, D., Anderson, R., Preisser, J., Suggs, P., Pearce, K., Poehling, U., McGann, P., 1998. The quality of life of older adults with urinary incontinence: determining generic and condition-specific predictors. Qual. Life Res. 7, 337-344.

Edwards, N. I., Jones, D., 2001. The prevalence of faecal incontinence in older people living at home. Age Ageing. 30, 503-507.

Eguare, E. I., Neary, P., Crosbie, J., Johnston, S. M., Beddy, P., McGovern, B., Torreggiani, W. C., Conlon, K. C., Keane, F. B., 2004. Dynamic magnetic resonance imaging of the pelvic floor in patients with idiopathic combined fecal and urinary incontinence. J. Gastrointest. Surg. 8, 73-82; discussion 82.

Ekelund, P., Grimby, A., Milsom, I., 1993. Urinary incontinence: social and financial costs high. Br. Med. J. 306, 1344.

Elias, N., 1989. Sedernas historia del 1 (Uber den Prozess der Zivilisation). Atlantis, Stockholm.

Elliott, S. P., Gulati, M., Pasta, D. J., Spitalny, G. M., Kane, C. J., Yee, R., Lue, T. F., 2004. Obstructive lower urinary tract symptoms correlate with erectile dysfunction. Urology. 63, 1148-1152.

Evans, D., Cooper, K., Barron, W. j., 2001. An ageing world: 2001. International Population reports. U.S. Census Bureu, U.S. Goverment Printing Office, Washington.

Evans, J. G., Williams, T. F., Beattie, B. L., Michel, J.-P., Wilcock, G. K., 2000. Oxford textbook of Geriatric Medicine. Oxford University Press, Oxford.

Fagerström, C., Holst, G., Hallberg, I. R., in manus. People′s (60+) perception of feeling hindered by health problems.

Faltin, D. L., Sangalli, M. R., Curtin, F., Morabia, A., Weil, A., 2001. Prevalence of anal incontinence and other anorectal symptoms in women. Int. Urogynecol. J. Pelvic Floor Dysfunct. 12, 117-120; discussion 121.

Ferrucci, L., Guralnik, J. M., Studenski, S., Fried, L. P., Cutler, G. B., Jr., Walston, J. D., 2004. Designing randomized, controlled trials aimed at preventing or delaying functional decline and disability in frail, older persons: a consensus report. J. Am. Geriatr. Soc. 52, 625-634.

Fonda, D., Benvenuti, F., Castleden, M., Cottenden, A., O'Donnell, P., Resnick, N., Colling, J., Trigo Rocha, F. (1999): Management of incontinence in older people. In. P. Abrams, S. Khoury, A. Wein, Incontinence 1st International Consultation on Incontinence, Monaco 1998, Health Publications Ltd, Plymouth. 733-773.

Fonda, D., Woodward, M., D'Astoli, M., Chin, W. F., 1995. Sustained improvement of subjective quality of life in older community-dwelling people after treatment of urinary incontinence. Age Ageing. 24, 283-286.

Fowler, F. J., Wennberg, J., Timothy, R., Barry, M. J., Mulley, A., Hanley, D., 1988. Symptom status and quality of life following prostatic ectomy. JAMA. 259, 3018-3022.

Fries, J. F. (1993): Medical perspectives upon successful aging. In. P. B. B. Baltes, M:M, Successful aging, perspectives from the behavioural sciences, Cambridge University Press, Cambridge.

Gabriel, Z., Bowling, A., 2004. Quality of life from the perspectives of older people. Ageing & Society. 24, 675-691.

Gandek, B., Ware, J. E., Aaronson, N. K., Apolone, G., Bjorner, J. B., Brazier, J. E., Bullinger, M., Kaasa, S., Leplege, A., Prieto, L., Sullivan, M., 1998. Cross-validation of item selection and scoring for the SF-12 Health Survey in nine countries: results from the IQOLA Project. International Quality of Life Assessment. J. Clin. Epidemiol. 51, 1171-1178.

Gannon, K., Glover, L., O'Neill, M., Emberton, M., 2004. Men and chronic illness: a qualitative study of LUTS. J Health Psychol. 9, 411-420.

Gavira Iglesias, F. J., Caridad y Ocerin, J. M., Perez del Molino Martin, J., Valderrama Gama, E., Lopez Perez, M., Romero Lopez, M., Pavon Aranguren, M. V., Guerrero Munoz, J. B., 2000. Prevalence and psychosocial impact of urinary incontinence in older people of a Spanish rural population. J. Gerontol. A. Biol. Sci. Med. Sci. 55, M207-214.

George, L. K., Bearon, L. B., 1980. Quality of life in older persons. Human Sciences Press, New York.

Getliffe, K., Dolman, M., 1997. Promoting continence - A clinical and research resource. Bailliére Tindall, London.

Given, B., Given, W. C., 1989. Cancer nursing for the elderly: a target for research. Cancer Nurs. 12, 71-77.

Goode, P. S., Burgio, K. L., Halli, A. D., Jones, R. W., Richter, H. E., Redden, D. T., Baker, P. S., Allman, R. M., 2005. Prevalence and correlates of fecal incontinence in community-dwelling older adults. J. Am. Geriatr. Soc. 53, 629-635.

Grimby, A., Milsom, I., Molander, U., Wiklund, I., Ekelund, P., 1993. The influence of urinary incontinence on the quality of life of elderly women. Age Ageing. 22, 82-89.

Grimby, A., Svanborg, A., 1997. Morbidity and health-related quality of life among ambulant elderly citizens. Aging (Milano). 9, 356-364.

Grimby, A., Wiklund, I., 1994. Health-related quality of life in old age. A study among 76-year-old Swedish urban citizens. Scand. J. Soc. Med. 22, 7-14.

Hagglund, D., Walker-Engstrom, M. L., Larsson, G., Leppert, J., 2001. Quality of life and seeking help in women with urinary incontinence. Acta Obstet. Gynecol. Scand. 80, 1051-1055.

Hair, J. F., Anderson, R.E., Tatham, R.L., Black, W.C., 1998. Multivariate data analysis. 5th ed. Prentice-Hall International, London.

Hald, T., Nordling, J., Andersen, J. T., Bilde, T., Meyhoff, H. H., Walter, S., 1991. A patient weighted symptom score system in evaluation of uncomplicated benign prostatic hyperplasia. Scand. J. Urol. Nephrol. suppl 138, 59-62.

Harari, D., Gurwitz, J. H., Avorn, J., Bohn, R., Minaker, K. L., 1996. Bowel habit in relation to age and gender. Findings from the National Health Interview Survey and clinical implications. Arch. Intern. Med. 156, 315-320.

Harari, D., Norton, C., Lockwood, L., Swift, C., 2004. Treatment of constipation and fecal incontinence in stroke patients: randomized controlled trial. Stroke. 35, 2549-2555.

Havighurst, R., Albrecht, T., 1953. Older people. Longmans Green, New York.

Hellstrom, Y., Andersson, M., Hallberg, I. R., 2004a. Quality of life among older people in Sweden receiving help from informal and/or formal helpers at home or in special accommodation. Health Soc Care Community. 12, 504-516.

Hellstrom, Y., Hallberg, I. R., 2004. Determinants and characteristics of help provision for elderly people living at home and in relation to quality of life. Scand. J. Caring Sci. 18, 387-395.

Hellstrom, Y., Hallberg, I. R., 2001. Perspectives of elderly people receiving home help on health, care and quality of life. Health Soc Care Community. 9, 61-71.

Hellstrom, Y., Persson, G., Hallberg, I. R., 2004b. Quality of life and symptoms among older people living at home. J. Adv. Nurs. 48, 584-593.

Hellström, L., Ekelund, P., Milsom, I., Mellström, D., 1990. The prevalence of urinary incontinence and use of incontinence aids in 85-year old men and women. Age Ageing. 19, 383-389.

Herbst, F., Kamm, M. A., Morris, G. P., al, e., 1997. Gastrointestinal transit and prolonged ambulatory colonic motility in health and feacal incontinence. Gut. 41, 381-389.

Herzog, A. R., Diokno, A. C., Brown, M. B., Fultz, N. H., Goldstein, N. E., 1994. Urinary incontinence as a risk factor for mortality. J. Am. Geriatr. Soc. 42, 264-268.

Heymen, S., Jones, K. R., Scarlett, Y., Whitehead, W. E., 2003. Biofeedback treatment of constipation: a critical review. Dis Colon Rectum. 46, 1208-1217.

Hirt, M., Ross, W. D., Kurtz, R., Gleser, G., 1969. Attitudes to body products among normal subjects. J. Abnorm. Psychol. 74, 486-489.

Hjalmas, K., 1992. Urinary incontinence in children: suggestions for definitions and terminology. Scand. J. Urol. Nephrol. Suppl. 141, 1-6; discussion 18-19.

Holroyd-Leduc, J. M., Mehta, K. M., Covinsky, K. E., 2004. Urinary incontinence and its association with death, nursing home admission, and functional decline. J. Am. Geriatr. Soc. 52, 712-718.

Horrocks, S., Somerset, M., Stoddart, H., Peters, T. J., 2004. What prevents older people from seeking treatment for urinary incontinence? A qualitative exploration of barriers to the use of community continence services. Fam. Pract. 21, 689-696.

Hu, T. W., 1990. Impact of urinary incontinence on health care costs. Journal of American Geriatrics Society. 38, 292-295.

Hunskaar, S., Arnold, E., Burgio, K., Diokno, A. C., Herzog, A. R., Mallett, V. (1999): Epidemiology and natural history of urinary incontinence. In. P. Abrams, S. Khoury, A. Wein, Incontinence, Health Publication Ltd, Plymouth.

Hunskaar, S., Sandvik, H., 1993. One hundred and fifty men with urinary incontinence. III. Psychosocial consequences. Scand. J. Prim. Health Care. 11, 193-196.

Hyltén-Cavallius, C., 1998. Beretninger om den aldrende krop (Narratives about the ageing body). Gerontologi og Samfund. 14, 82-84.

Jackson, S., Donovan, J., Brookes, S., Eckford, S., Swithinbank, L., Abrams, P., 1996. The Bristol Female Lower Urinary Tract Symptoms questionnaire: development and psychometric testing. Br. J. Urol. 77, 805-812.

Jakobsson, U., Hallberg, I. R., 2002. Pain and quality of life among older people with rheumatoid arthritis and/or osteoarthritis: a literature review. J. Clin. Nurs. 11, 430-443.

Jakobsson, U., Hallberg, I. R., Westergren, A., 2004. Overall and health related quality of life among the oldest old in pain. Qual. Life Res. 13, 125-136.

Jakobsson, U., Klevsgard, R., Westergren, A., Hallberg, I. R., 2003. Old people in pain: a comparative study. J. Pain Symptom Manage. 26, 625-636.

Jensen, E., Dehlin, O., Hagberg, B., Samuelsson, G., Svensson, T., 1998. Insomnia in an 80-year-old population: relationship to medical, psychological and social factors. J. Sleep Res. 7, 183-189.

Jirovec, M. M., 1991. The impact of daily exercise on the mobility, balance and urine control of cognitively impaired nursing home residents. Int. J. Nurs. Stud. 28, 145-151.

Johanson, J. F., Irizarry, F., Doughty, A., 1997. Risk Factors for Fecal Incontinence in a Nursing Home Population. J. Clin. Gastroenterol. 24, 156-160.

Johanson, J. F., Lafferty, J., 1996. Epidemiology of fecal incontinence: the silent affliction. Am. J. Gastroenterol. 91, 33-36.

John, R., Kerby, D. S., Hennessy, C. H., 2003. Patterns and impact of comorbidity and multimorbidity among community-resident American Indian elders. Gerontologist. 43, 649-660.

Johnson, T. M., Bernard, S. L., Kincade, J. E., Defriese, G. H., 2000. Urinary incontinence and risk of death among community-living elderly people. J. Aging Health. 12, 25-46.

Jylha, M., Jokela, J., Tolvanen, E., Heikkinen, E., Heikkinen, R. L., Koskinen, S., Leskinen, E., Lyyra, A. L., Pohjolainen, P., 1992. The Tampere Longitudinal Study on Ageing. Description of the study. Basic results on health and functional ability. Scand. J. Soc. Med. Suppl. 47, 1-58.

Kamm, M. A., 1998. Faecal incontinence. BMJ. 316, 528-532.

Kane, R. A. (1991): Personal autonomy for residents in long-term care: concepts and issues of measurement. In. J. E. Birren, J. E. Lubben, J. Cichowlas Rowe, D. E. Deutchman, The concepts and measurement of quality of life in the frail elderly, Academic Press, INC, San Diego.

Kane, R. L., Kane, R. A., 2000. Assessing older persons. Measures, meaning and practical applications. Oxford University Press, Oxford.

Kapoor, D. S., Thakar, R., Sultan, A. H., 2005. Combined urinary and faecal incontinence. Int. Urogynecol. J. Pelvic Floor Dysfunct.

Katz, S., Akbom, C. A., 1976. A measure of primary sociobiological function. Int. J. Health Serv. 6, 493-507.

Kazdin, A. E., 1998. Reseach design in clinical pschology. Allyn and Bacon, Boston.

Kearney, P. M., Pryor, J., 2004. The International Classification of Functioning, Disability and Health (ICF) and nursing. J. Adv. Nurs. 46, 162-170.

Kim, J.-O., Mueller, C.W., 1982. Factor analysis: Statistical methods and practical issues. Sage University Papers, Beverly Hills.

Kinchen, K. S., Burgio, K., Diokno, A. C., Fultz, N. H., Bump, R., Obenchain, R., 2003. Factors associated with women's decisions to seek treatment for urinary incontinence. J Womens Health (Larchmt). 12, 687-698.

Kinnunen, O., 1991. Study of constipation in a geriatric hospital, day hospital, old people's home and at home. Aging (Milano). 3, 161-170.

Kok, A. L. M., Voorhorst, F. J., Burger, C. W., van Houten, P., Keneman, P., Janssens, J., 1992. Urinary and faecal incontinence in community-residing elderly women. Age Ageing. 21, 211-215.

Kubie, L. S., 1937. The fantasy of dirt. Psychoanal. Q. 6, 388-424.

Lacima, G., Espuna, M., Pera, M., Puig-Clota, M., Quinto, L., Garcia-Valdecasas, J. C., 2002. Clinical, urodynamic, and manometric findings in women with combined fecal and urinary incontinence. Neurourol. Urodyn. 21, 464-469.

Lacima, G., Pera, M., 2003. Combined fecal and urinary incontinence: an update. Curr. Opin. Obstet. Gynecol. 15, 405-410.

Langa, K. M., Fultz, N. H., Saint, S., Kabeto, M. U., Herzog, A. R., 2002. Informal caregiving time and costs for urinary incontinence in older individuals in United States. Journal of American Geriatrics Society. 50, 733-737.

Last, J. M., 1963. The Iceberg: Completing the clinical picture in general practice. The Lancet. 28-31.

Laukkanen, P., Leskinen, E., Kauppinen, M., Sakari-Rantala, R., Heikkinen, E., 2000. Health and functional capacity as predictors of community dwelling among elderly people. J. Clin. Epidemiol. 53, 257-265.

Lawton, M. P., 1983. Environment and other determinants of well-being in older people. The Gerontologist. 23, 349-357.

Lawton, M. P. (1991): A multidimensional view of quality of life in frail elders. In. J. E. Birren, J. E. Lubben, J. Cichowlas Rowe, D. E. Deutchman, The concept and measurement of quality of life in frail elderly, Academic Press Inc, San Diego.

Liao, S., Ferrell, B. A., 2000. Fatigue in an older population. J. Am. Geriatr. Soc. 48, 426-430.

Lim, L. L., Fisher, J. D., 1999. Use of the 12-item short-form (SF-12) Health Survey in an Australian heart and stroke population. Qual. Life Res. 8, 1-8.

Liu, C., Andrews, G. R., 2002. Prevalence and incidence of urinary incontinence in the elderly: a longitudinal study in South Australia. Chin. Med. J. (Engl). 115, 119-122.

Macintyre, S., Ford, G., Hunt, K., 1999. Do women 'over-report' morbidity? Men's and women's responses to structured prompting on a standard question on long standing illness. Soc Sci Med. 48, 89-98.

Macmillan, A. K., Merrie, A. E., Marshall, R. J., Parry, B. R., 2004. The prevalence of fecal incontinence in community-dwelling adults: a systematic review of the literature. Dis. Colon Rectum. 47, 1341-1349.

Madsen, P. O., Iversen, P. A. (1983): A point system for selecting operative candidates. In. F. Hinman, Benign Prostatic Hypertrophy, Springer Verlag, New York. 763-765.

Maggi, S., Minicuci, N., Langlois, J., Pavan, M., Enzi, G., Crepaldi, G., 2001. Prevalence rate of urinary incontinence in community-dwelling elderly individuals: the Veneto study. J. Gerontol. A. Biol. Sci. Med. Sci. 56, M14-18.

Malmsten, U. G., Milsom, I., Molander, U., Norlen, L. J., 1997. Urinary incontinence and lower urinary tract symptoms: an epidemiological study of men aged 45 to 99 years. J. Urol. 158, 1733-1737.

Mattiasson, A., 2001. Characterisation of lower urinary tract disorders: a new view. Neurourol. Urodyn. 20, 601-621.

Mattiasson, A. (2005): De nedre urinvägarnas normala funktion. In. L. Malmberg, A. Mattiasson, I vått och torrt, Studentlitteratur, Lund.

McDowell, B. J., Engberg, S. J., Rodriguez, E., Engberg, R., Sereika, S., 1996. Characteristics of urinary incontinence in homebound older adults. J. Am. Geriatr. Soc. 44, 963-968.

Meiring, P. J., Joubert, G., 1998. Constipation in elderly patients attending a polyclinic. S. Afr. Med. J. 88, 888-890.

Milsom, I., Fall, M., Ekelund, P., 1992. Urininkontinens - en kostnadskrävande sjukdom. Läkartidningen. 89, 1772-1774.

Mitnitski, A. B., Graham, J. E., Mogilner, A. J., Rockwood, K., 2002. Frailty, fitness and late-life mortality in relation to chronological and biological age. BMC Geriatr. 2, 1.

Mitnitski, A. B., Mogilner, A. J., Rockwood, K., 2001. Accumulation of deficits as a proxy measure of aging. ScientificWorldJournal. 1, 323-336.

Mitnitski, A. B., Song, X., Rockwood, K., 2004. The estimation of relative fitness and frailty in community-dwelling older adults using self-report data. J. Gerontol. A. Biol. Sci. Med. Sci. 59, M627-632.

Molander, U., 2001. Urininkontinens folksjukdom bland äldre - drabbar både kvinnor och män (Urinary incontinence a public disease among the elderly -- affects both women and men). Läkartidningen. 98, 946-949.

Molander, U., Sundh, V., Steen, B., 2002 a. Urinary incontinence and related symptoms in older men and women studied longitudinally between 70 and 97 years of age. A populations study. Arch. Gerontol. Geriatr. 35, 237-244.

Molander, U., Sundh, V., Steen, B., 2002 b. Urinary incontinence, its influence on daily life, and use of incontinence aids in two cohorts of 85/86-year-old free living men and women, born 10 years apart. Arch. Gerontol. Geriatr. 35, 275-281.

Moons, P., 2004. Why call it health-related quality of life when you mean perceived health status? Eur J Cardiovasc Nurs. 3, 275-277.

Morris, A. R., Ho, M. T., Lapsley, H., Walsh, J., Gonski, P., Moore, K. H., 2005. Costs of managing urinary and faecal incontinence in a sub-acute care facility: a "bottom-up" approach. Neurourol. Urodyn. 24, 56-62.

Nahemow, L. (2000): The ecological theory of aging: Powell Lawton´s legacy. In. R. L. Rubinstein, M. Moss, M. H. Kleban, The many dimensions of aging, Springer Publishing Company, New York.

Nakanishi, N., Tatara, K., Shinsho, F., Murakami, S., Takatorige, T., Fukuda, H., Nakajima, K., Naramura, H., 1999. Mortality in relation to urinary and faecal incontinence in elderly living at home. Age Ageing. 28, 301-306.

Nelson, R., Furner, S., Jesudason, V., 1998. Fecal incontinence in Wisconsin nursing homes: prevalence and associations. Dis. Colon Rectum. 41, 1226-1229.

Neugarten, B. L., Havinghurst, R., Tobin, S., 1961. The measurement of life satisfaction. J. Gerontol. 16, 134-143.

Nordbeck, B., 1989. Quality of life, health and ageing. Rapport III:10. Gerontologiskt centrum, Lund University, Lund.

Nordbeck, B., 1992. Quality of life. Measurement and factors related to degree of rehabilitation and quality of life among stroke patients. Rapport VI:5. Gerontologiskt centrum, Lund University, Lund.

Nordbeck, B., Hagberg, B., Jadbeck, G., Johansson, B. (1993). Factors related to degree of rehabilitation and quality of life among stroke patients. XV:th World Congress of Gerontology, Budapest, Hungary.

Noro, A., Aro, S., 1996. Health-related quality of life among the least dependent institutional elderly compared with the non-institutional elderly population. Qual. Life Res. 5, 355-366.

Norton, C., 1996. Faecal incontinence in adults. 1: Prevalence and causes. Br. J. Nurs. 5, 1366-1368, 1370-1364.

Nygren, C., 2003. The complexity of geriatric rehabilitation. A one-year follow-up of clients, caregiver and administration perceptions, Faculty of Medicine. Lund University, Lund.

O'Keefe, E. A., Talley, N. J., Zinsmeister, A. R., Jacobsen, S. J., 1995. Bowel disorders impair functional status and quality of life in the elderly: a population-based study. J. Gerontol. A. Biol. Sci. Med. Sci. 50, M184-189.

Ostbye, T., Seim, A., Krause, K. M., Feightner, J., Hachinski, V., Sykes, E., Hunskaar, S., 2004. A 10-Year Follow-Up of Urinary and Fecal Incontinence among the Oldest Old in the Community: The Canadian Study of Health and Aging. Can J Aging. 23, 319-331.

Osterberg, A., Graf, W., Karlbom, U., Pahlman, L., 1996. Evaluation of a questionnaire in the assessment of patients with faecal incontinence and constipation. Scand. J. Gastroenterol. 31, 575-580.

Ouslander, J. G., Abelson, S., 1990. Perceptions of urinary incontinence among elderly outpatients. Gerontologist. 30, 369-372.

Ouslander, J. G., Morishita, L., Blaustein, J., Orzeck, S., Dunn, S., Sayre, J., 1987. Clinical, functional and psychosocial characteristics of an incontinent nursing home population. J. Gerontol. 46, 631-637.

Palmer, M. H., 2004. Use of health behavior change theories to guide incontinence research. Nurs. Res. 53, S49-S55.

Palmer, M. H., Fitzgerald, S., 2003. Urinary incontinence in working women: A comparison study. Journal of Women's Health. 11, 879-888.

Peet, S. M., Castleden, C. M., McGrother, C. W., 1995. Prevalence of urinary and faecal incontinence in hospitals and residential and nursing homes for older people. Br. Med. J. 311, 1063-1064.

Perry, S., Shaw, C., McGrother, C., Matthews, R. J., Assassa, R. P., Dallosso, H., Williams, K., Brittain, K. R., Azam, U., Clarke, M., Jagger, C., Mayne, C., Castleden, C. M., 2002. Prevalence of faecal incontinence in adults aged 40 years or more living in the community. Gut. 50, 480-484.

Pettit, T., Livingston, G., Manela, M., Kitchen, G., Katona, C., Bowling, A., 2001. Validation and normative data of health status measures in older people: the Islington study. Int. J. Geriatr. Psychiatry. 16, 1061-1070.

Podock, G., Richards, C. D., 1999. Human Physiology. The basis in medicine. Oxford University Press, Oxford.

Polit, D. F. (1996): Data analysis & Statistics for nursing research. In Prentice Hall, New Yersey. 249.

Quander, C. R., Morris, M. C., Melson, J., Bienias, J. L., Evans, D. A., 2005. Prevalence of and factors associated with fecal incontinence in a large community study of older individuals. Am. J. Gastroenterol. 100, 905-909.

Reilly, W. T., Talley, N. J., Pemberton, J. H., Zinsmeister, A. R., 2000. Validation of a questionnaire to assess fecal incontinence and associated risk factors: Fecal Incontinence Questionnaire. Dis. Colon Rectum. 43, 146-153; discussion 153-144.

Resnick, B., Nahm, E. S., 2001. Reliability and validity testing of the revised 12-item Short-Form Health Survey in older adults. J. Nurs. Meas. 9, 151-161.

Resnick, N. M., 1984. Urinary incontinence in the elderly. Medical Grand Rounds. 281-290.

Resnick, N. M., Beckett, L. A., Branch, L. G., Scherr, P. A., Wetle, T., 1994. Short-term variability of self report of incontinence in older persons. J. Am. Geriatr. Soc. 42, 22-207.

Roberts, R. O., Jacobsen, S. J., Reilly, W. T., Pemberton, J. H., Lieber, M. M., Talley, N. J., 1999. Prevalence of combined fecal and urinary incontinence: a community-based study. J. Am. Geriatr. Soc. 47, 837-841.

Robson, K. M., Kiely, D. K., Lembo, T., 2000. Development of constipation in nursing home residents. Dis. Colon Rectum. 43, 940-943.

Rockwood, K., Mogilner, A., Mitnitski, A., 2004. Changes with age in the distribution of a frailty index. Mech. Ageing Dev. 125, 517-519.

Roe, B., Doll, H., Wilson, K., 1999. Help seeking behaviour and health and social services utilisation by people suffering from urinary incontinence. Int. J. Nurs. Stud. 36, 245-253.

Ross, C. E., Bird, C. E., 1994. Sex stratification and health lifestyle: consequences for men's and women's perceived health. J. Health Soc. Behav. 35, 161-178.

Ross, W. D., Hirt, M., Kurtz, R., 1968. The fantasy of dirt and attitudes toward body product. The Journal of Nervous and Disease. 146, 303-309.

Rubenowitz, S., 1980. Method development for mapping psychosocial factors to consider with regional development planning. Psykologiska institutionen, Göteborgs universitet.

Ruby, C. M., Fillenbaum, G. G., Kuchibhatla, M. N., Hanlon, J. T., 2003. Laxative use in the community-dwelling elderly. Am J Geriatr Pharmacother. 1, 11-17.

Sagar, P. M., Pemberton, J. H., 1996. Anorectal and pelvic floor function. Relevance of continence, incontinence, and constipation. Gastroenterol. Clin. North Am. 25, 163-182.

Saleh, N., Bener, A., Khenyab, N., Al-Mansori, Z., Al Muraikhi, A., 2005. Prevalence, awareness and determinants of health care-seeking behaviour for urinary incontinence in Qatari women: a neglected problem? Maturitas. 50, 58-65.

Salonia, A., Zanni, G., Nappi, R. E., Briganti, A., Deho, F., Fabbri, F., Colombo, R., Guazzoni, G., Di Girolamo, V., Rigatti, P., Montorsi, F., 2004. Sexual dysfunction is common in women with lower urinary tract symptoms and urinary incontinence: results of a cross-sectional study. Eur. Urol. 45, 642-648; discussion 648.

Sandvik, H., Kveine, E., Hunskaar, S., 1993. Female urinary incontinence. Scand. J. Caring Sci. 7, 53-56.

Savoye-Collet, C., Savoye, G., Koning, E., Leroi, A. M., Dacher, J. N., 2003. Defecography in symptomatic older women living at home. Age Ageing. 32, 347-350.

SCB, 2004. Befolkningsstatistik 2004. Återstående medellivslängd för åren 1751 - 2004 (Population statistics. Remaining mean living length from 1751 to 2004) www.scb.se. SCB (The Swedish official statistics).

Schlenk, E. A., Erlen, J. A., Dunbar-Jacob, J., McDowell, J., Engberg, S., Sereika, S. M., Rohay, J. M., Bernier, M. J., 1998. Health-related quality of life in chronic disorders: a comparison across studies using MOS SF-36. Qual. Life Res. 7, 57-65.

Schroots, J. (1988): On growing, formative change and ageing. In. J. E. Birren, V. L. Bengtson, Emergent Theories of Ageing, Springer Publishing Company, New York.

Schumaker, S. A., Wyman, J. F., Uebersax, J. S., McClish, D., Fantl, J. A., 1994. Health-related quality of life measures for women with urinary incontinence: the Incontinence Impact Questionnaire and the Urogenital Distress Inventory. Qual. Life Res. 3, 291-306.

Scott, I. U., Smiddy, W. E., Schiffman, J., Feuer, W. J., Pappas, C. J., 1999. Quality of life of low-vision patients and the impact of low-vision services. Am. J. Ophthalmol. 128, 54-62.

Sgadari, A., Topinkova, E., Bjørnson, J., Bernabei, R., 1997. Urinary incontinence in nursing home residents: a cross-national comparison. Age Ageing. 26, 49-54.

Shaw, C., Tansey, R., Jackson, C., Hyde, C., Allan, R., 2001. Barriers to help seeking in people with urinary symptoms. Fam. Pract. 18, 48-52.

Shiwach, R. S., Peris, L., 2000. Treatment of major depression complicated by bilateral foot drop and double incontinence with ECT. J. ECT. 16, 419-420.

Simeonova, Z., Milson, I., Kullendorff, A.-M., Molander, U., Bengtsson, C., 1999. The prevalence of urinary incontinence and its influence on the quality of life in women from an urban Swedish population. Acta Obstet. Gynecol. Scand. 78, 546-551.

Skårderud, F. (2001): Det tragiske mennesket (The tragedy of human). In. T. Wyller, Skam. Perspektiver på skam, äre og skamlöshet i det moderne. (Shame. Perspectives on shame, honour and shamelessness in the modern), Fakboksförlaget, Bergen. 53-67.

Socialstyrelsen, 2003. Inkontinensvården i ordinärt och särskilt boende (Incontinence care in ordinary and special accomodations), Stockholm.

Socialstyrelsen, 1997. Klassifikation av sjukdomar och hälsoproblem 1997 (Swedish version of International Statistical Classification of Diseases and Related Health Problems, Tenth version (ICD-10)). Almqvist & Wiksell, Uppsala.

Soligo, M., Salvatore, S., Milani, R., Lalia, M., Malberti, S., Digesu, G. A., Mariani, S., 2003. Double incontinence in urogynecologic practice: a new insight. Am. J. Obstet. Gynecol. 189, 438-443.

Steeman, E., Defever, M., 1998. Urinary incontinence among elderly persons who live at home: a literature review. Nurs. Clin. North Am. 33, 441-455.

Stenzelius, K., Westergren, A., Thorneman, G., Hallberg, I. R., 2005. Patterns of health complaints among people 75+ in relation to quality of life and need of help. Arch. Gerontol. Geriatr. 40, 85-102.

Stoddart, H., Donovan, J., Whitley, E., Sharp, D., Harvey, I., 2001. Urinary incontinence in older people in the community: a neglected problem? Br. J. Gen. Pract. 51, 548-552.

Streiner, D. L., Norman, G. R., 1998. Health measurements scales. A practical guide to their development and use. Oxford City Press, Oxford.

Stuck, A. E., Walthert, J. M., Nikolaus, T., Bula, C. J., Hohmann, C., Beck, J. C., 1999. Risk factors for functional status decline in community-living elderly people: a systematic literature review. Soc. Sci. Med. 48, 445-469.

Sullivan, M., Karlsson, R.A., Taft, C., 1997. SF-12 Hälsoenkät svensk manual (Swedish manual of SF-12 health questionnaire). Gothenburg University, Göteborg.

Talley, N. J., Fleming, K. C., Evans, J. M., O'Keefe, E. A., Weaver, A. L., Zinsmeister, A. R., Melton, L. J., 3rd, 1996. Constipation in an elderly community: a study of prevalence and potential risk factors. Am. J. Gastroenterol. 91, 19-25.

Talley, N. J., O'Keefe, E. A., Zinsmeister, A. R., Melton, L. J., 3rd, 1992. Prevalence of gastrointestinal symptoms in the elderly: a population-based study. Gastroenterology. 102, 895-901.

Teleman, P., 2003. Urinary incontinence in middle-aged women - a population-based study on prevalence, risk factors and the role of urethra, Department of Obstetrics and Gynecology. Lund University, Lund.

Temml, C., Haidinger, G., Schmidbauer, J., Schatzl, G., Madersbacher, S., 2000. Urinary incontinence in both sexes: prevalence rates and impact on quality of life and sexual life. Neurourol. Urodyn. 19, 259-271.

Teunissen, T. A., van den Bosch, W. J., van den Hoogen, H. J., Lagro-Janssen, A. L., 2004. Prevalence of urinary, fecal and double incontinence in the elderly living at home. Int. Urogynecol. J. Pelvic Floor Dysfunct. 15, 10-13; discussion 13.

Thom, D. H., Haan, M. N., Van Den Eeden, S. K., 1997. Medically recognized urinary incontinence and risks of hospitalization, nursing home admission and mortality. Age Ageing. 26, 367-374.

Thomas, V. S., Rockwood, K., McDowell, I., 1998. Multidimensionality in instrumental and basic activities of daily living. J. Clin. Epidemiol. 51, 315-321.

Thornstam, L., 1994. Åldrandets socialpsykologi. Rabén Prisma, Kristianstad.

Tibblin, G., Bengtsson, C., Furunes, B., Lapidus, L., 1990a. Symptoms by age and sex. The population studies of men and women in Gothenburg, Sweden. Scand. J. Prim. Health Care. 8, 9-17.

Tibblin, G., Tibblin, B., Peciva, S., Kullman, S., Svardsudd, K., 1990b. "The Goteborg quality of life instrument"--an assessment of well-being and symptoms among men born 1913 and 1923. Methods and validity. Scand. J. Prim. Health Care. Suppl. 1, 33-38.

Uebersax, J. S., Wyman, J. F., Schumaker, S. A., McClish, D. K., Fantl, J. A., Group, C. P. f. W. R., 1995. Short forms to assess life quality and symptom distress for urinary incontinence in women: The Incontinence Impact Questionnaire and the Urogenital Distress Inventory. Neurourol. Urodyn. 14, 131-139.

Wagner, T. H., Hu, T. W., 1998. Economic costs of urinary incontinence in 1995. Urology. 51, 355-361.

Valvanne, J., Juva, K., Erkinjuntti, T., Tilvis, R., 1996. Major depression in the elderly: a population study in Helsinki. Int. Psychogeriatr. 8, 437-443.

van Dijk, P. T., Mehr, D. R., Ooms, M. E., Madsen, R., Petroski, G., Frijters, D. H., Pot, A. M., Ribbe, M. W., 2005. Comorbidity and 1-year mortality risks in nursing home residents. J. Am. Geriatr. Soc. 53, 660-665.

van Eijken, M., Wensing, M., de Konink, M., Vernooy, M., Zielhuis, G., Lagro, T., Rikkert, M. O., Grol, R., 2004. Health education on self-management and seeking health care in older adults: a randomised trial. Patient Educ Couns. 55, 48-54.

Ware, J., Jr., Kosinski, M., Keller, S. D., 1996. A 12-Item Short-Form Health Survey: construction of scales and preliminary tests of reliability and validity. Med. Care. 34, 220-233.

Ware, J. E., Jr., Sherbourne, C. D., 1992. The MOS 36-item short-form health survey (SF-36). I. Conceptual framework and item selection. Med. Care. 30, 473-483.

Wein, A. (2002): Patophysiology and categorization of voiding dysfunctions. In. J. Walsh, A. Retik, Vaughan, A. Wein, Campell′s Urology, Saunders, Philadelphia. 887-899.

Verbrugge, L. M., 1985. Gender and health: an update on hypotheses and evidence. J. Health Soc. Behav. 26, 156-182.

Verbrugge, L. M. (1990): The iceberg of disability. In. S. M. Stahl, The legacy of longevity, Sage Publications, London.

Wetle, T., Scherr, P., Branch, L. G., Resnick, N. M., Harris, T., Evans, D., Taylor, J. O., 1995. Difficulty with holding urine among older persons in a geographically defined community: prevalence and correlates. J. Am. Geriatr. Soc. 43, 349-355.

WHO, 2002a. Active ageing: a policy framework. World Health Organisation, Madrid.

WHO, 1998. Growing older. Staying well. Ageing and physical activities in everyday life. Prepared by Heikkinen, R.L. World Health Organisation, Geneva.

WHO, 2001. International Classification of Functioning, Disability and Health - ICF. World Health Organisation, Geneva.

WHO, 2002b. Towards a common language for disability and health, ICF. World Health Organisation, Geneva.

Widding Isaksen, L. (2001): Om angsten for de andres avsky (About the agony for others loathe). In. T. Wyller, Skam. Perspektiver på skam, äre og skamlöshet i det moderne. (Shame. Perspectives on shame, honour and shamelessness in the modern), Fagbokforlaget, Bergen. 213-242.

Widding Isaksen, L., 2002. Toward a Sociology of (Gender) Disgust. Journal of Family Issues. 23, 791-811.

Wiggins, R. D., Higgs, P., Hyde, M., Blane, D., 2004. Quality oflife in the third age: key predictors of the CASP-19 measure. Ageing & Society. 24, 693-708.

Viidik, A., 2002. Boken om kroppens åldrande. Liber, Falköping.

Wilson, L., Brown, J. S., Shin, G. P., Luc, K. O., Subak, L. L., 2001. Annual direct cost of urinary incontinence. Obstet. Gynecol. 98, 398-406.

Wolters, R., Wensing, M., van Weel, C., van der Wilt, G. J., Grol, R. P., 2002. Lower urinary tract symptoms: social influence is more important than symptoms in seeking medical care. BJU Int. 90, 655-661.

Wyman, J. F., 1997. The 'costs' of urinary incontinence. Eur. Urol. 32, 13-19.

Äldrecentrum, S. S. l., 2001. Äldres hälsa och välbefinnande. En utmaning för folkhälsoarbetet. Stockholms läns landsting, Stockholm.

APPENDIX

Appendix 1. Comparisons of different instruments measuring multi-complaints of health complaints included.

Stenzelius et al (2005)	Tibblin et al (1990)	Jylha et al (1992)	Mitnitski et al (2002) fraily index 20 items	Mitnitski et al 2004) 40 items frilty index	Crabtree et al (2000)
Difficulty talking		Temporary loss of sensation, movement or speech			
Difficulty reading	Eye-problem		Vision loss	Eyesight	Visual problems
Difficulty hearing	Impaired hearing		Hearing loss	Hearing	hearing problems
Memory problems		Worsening of memory			
Abdominal pain	Abdominal pain	Stomach pain	Gastrointestinal problems	Trouble with stomach	Upper gastrointestinal symptom
Nausea	Nausea				
Loss of appetite	Loss of weight	Lack of appetite			
Difficulty swallowing					
Constipation	Constipation	Constipation			Constipation
Headache	Headache	Headache			
Dizziness	Dizziness	Sense of giddiness			Unsteadiness
Nervous and anxious	Nervousness	Nervous tension, nervousness		Trouble with nerves	Anxiety and depression
Low mood depression	Depression	Low spirits or depression			
Difficulty sleeping	Sleeping disturbance	Difficulties falling to sleep	Changes in sleep		
Fatigue	General fatigue	Tiredness/feeling of faintness		Feeling tired	
		Unwillingness to do things/lack of energy			
Nervous and anxious	Nervousness	Nervous tension, nervousness			
Breathlessness	Breathlessness	Difficult in breathing/shortness of breath without physical effort			Breathlessness/secondary to cardiovascular cause
Dyspnoea					Breathlessness respiratory cause
Palpitations		Palpitation of the heart			
Chest pain	Chest pain	Heart trouble		Chest problems	Angina
Protracted coughing	Coughing			Having a cough	
Difficulty controlling faeces				Loosing control of bowels	
Difficulty controlling urine	Difficulties in passing urine	Problems in passing urine	Loosing control of bladder	urinary problems	
Diarrhoea	Diarrhoea	Diarrhoea			Diarrhoea
Other urinary symptom			Urinary complaints		
Slow healing wounds			Skin problems	Skin problems	Skin disease

Stenzelius et al (2005)	Tibblin et al (1990)	Jylha et al (1992)	Mitnitski et al (2002) fraily index 20 items	Mitnitski et al (2004) 40 items frilty index	Crabtree et al (2000)
Difficulty walking			Gait abnormality/ vibration sense		Walking and mobility
Mobility limitation	Pain in legs		Impaired mobility		Pain
Pain from extremities	Pain in the joints	Aching in joints or back trouble		Arthritis or rheumatism	Arthritis/osteoporosis
Oedema in legs				Trouble in feet and ankles	
	Sweating	Excessive sweating without physical effort			
	Restlessness				
	Impaired concentration				
	Irritability	Irritability of burst of anger			
	Cries easily				
	Exhaustion	Nightmares			
	Difficulty to relax	Tremor of hands	Resting tremor		
	Anorexia		Limb tone abnormality		
	Overweight	Significant changes in weight			
		Thirst or polyuria	Diabetes	Diabetes	Diabetes
	Feeling cold			Nose stuffed up or sneezing	
			Vascular problem	Stroke or effect of stroke	Cerebrovascular disease
			Hypertension	Parkinson's disease	Parkinsons disease
					Epilepsy
					Pheripheral vaascular disease
					Side effects of medications
					Any other condition
				Fractures	
				Heart and circulation problems	
				Kidney trouble	
				Eye trouble	
	Back ache			Ear trouble	
				Dental problem	
		Difficulty dressing		Help to dress and undress	

Stenzelius et al (2005)	Tibblin et al (1990)	Jylha et al (1992)	Mitnitski et al (2002) fraily index 20 items	Mitnitski et al 2004) 40 items frilty index	Crabtree et al (2000)
			Difficulty toileting	Help to go to the bathroom	
			Difficulty cooking	Help to prepare own meals	
			Difficulty bathing	Help to take bath or shower	
			Difficulty going out	Help to get out of walking distance	
			Difficulty grooming		
				Help to eat	
				Help to do house work	
				Help to use telephone	
				Help to walk	
				Help to get in and out if bed	
				Help in shopping	
				Ability to take medicine	
				Ability to handle own money	
				Ability to take care of appearance	
				Self-rating of health	
				Living alone	
				Troubles prevent normal activities	