The relationship between incontinence, toileting skills and morbidity in nursing homes
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The relationship between incontinence, toileting skills, and morbidity in nursing homes

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Woord Vooraf

Dit proefschrift is de resultante van vele jaren verwondering over incontinentieproblematiek in mijn dagelijkse verpleeghuispraktijk. Waarom zijn zoveel verpleeghuispatiënten incontinent, waar heeft het mee te maken en is er iets aan te doen? De gepresenteerde studies beschrijven onderdelen van die zoektocht.

In de dagelijkse verpleeghuisartsenpraktijk heeft incontinentie weinig aandacht. Bij artsen, verzorgenden en ouderen heerst de mening dat er toch niets aan te doen is omdat het onlosmakelijk hoort bij ouderdom en invaliditeit, en incontinentiemateriaal is immers toch overvloedig aanwezig! Maar in de dagelijkse praktijk kom je vele ouderen tegen die lijden onder de toiletgang problematiek en ik vind dat die problematiek toch een nadere wetenschappelijke analyse verdient.

In de zoektocht stuitte ik al gauw op de (on)mogelijkheden van zorgbehoevende ouderen om op tijd het toilet te bereiken. Een nadere analyse van die toiletgangproblemen zou misschien een nieuw licht op de incontinentieproblemen kunnen werpen. Een meer dan 10 jaar lang proces van denken, praten, analyseren en proberen was begonnen.

Ik draag dit proefschrift op aan alle ouderen die ik in mijn 25 jarige verpleeghuispraktijk heb mogen ontmoeten en vertrouwen hebben gesteld in mijn aanpak. Een heel bijzondere oudere is mijn moeder die al die jaren afhankelijk is geweest van zorg en mij precies heeft duidelijk gemaakt wat het betekent om als oudere van zorg afhankelijk te zijn. Haar ervaringen zijn bij de tot stand komen van dit proefschrift van groot belang geweest.
Chapter 1

General introduction

1.1 Introduction

Continence is closely related to the use of the water closet, which was designed in 1596 by John Harington. However, it was not until the 18th century that the use of the water closet became more widespread because people realized that hygienic measures could confine epidemics such as the bubonic plague(1). In the western world the water closet, now referred as the toilet, is the place to urinate and defecate in privacy.

Less hygienic and private is the use of bedpans, toilet chairs, urinals and occasionally trees. All these ‘devices’ make voluntary urinating and defecating possible, but as children we are trained to use the toilet. Disabled elderly people often find it difficult to use the toilet because of mobility problems and cognitive impairments. This can result in undesired loss of urine and feces in other places than the toilet(2). In institutionalized elderly people this is commonly the case, and they are then labeled as incontinent.

The prevalence of urinary incontinence (UI) in long-term care facilities is high. Prevalence rates that are reported vary widely due to different definitions, different populations, and different measurement methods(3). It affects 50 to 60 % of nursing home residents(4), almost 30% of whom also have fecal incontinence (FI)(5) and therefore have dual incontinence(DI). UI and FI both reduce the quality of life, but the highest reduction is caused by DI(6) (7) (8) (9). The fact that so many nursing home residents have DI suggests a common etiology(10). An important factor in this common etiology could be a decline in toileting skills (the ability of a person to perform the several tasks that are needed to urinate and defecate on a toilet) and therefore a need for assistance in toileting. Thus, it is important to investigate the extent to which toileting problems contribute to UI and FI, and to investigate the possibilities of training toileting skills.
1.1.1 Definitions

Urinary incontinence

There is ongoing debate about the definition of UI in frail elderly people. In 1988 the International Continence Society (ICS) defined UI as: “the involuntary loss of urine that is a social or hygienic problem and is objectively demonstrable”(11). Recently, a sub-committee of the ICS shortened this definition because of difficulties in making “social and hygienic problems” operational. The new definition is: “the complaint of any involuntary leakage of urine”(12). The Classification Working Group in the Netherlands (WCC) wanted to restrict the use of the term urinary incontinence to incontinence that results from impairments of urinary function and not from impaired mobility or cognitive impairments(2). However, the leakage of urine is noticeable for the resident and the caregiver, but the underlying problems are not always clear and could be complex. In general practice UI is when there is leakage of urine in the (bed) clothing, pads, on the surface of a chair or the floor.

There are different sub-types of UI: (1) Stress Urinary Incontinence, defined as “the complaint of involuntary leakage on effort or exertion, or on sneezing or coughing” and is related to problems with the sphincter or the pelvic floor, (2) Urge Urinary Incontinence, defined as “the complaint of involuntary leakage (of urine) accompanied by or immediately proceeded by urgency” and is related to the overactive bladder syndrome, (3) Mixed Urinary Incontinence, defined as “the complaint of involuntary leakage (of urine) associated with urgency and also with exertion, effort, sneezing or coughing”, and (4) Continuous Urinary Incontinence, defined as “the complaint of continuous leakage (of urine)” and is related to overflow of the bladder(12).

The studies described in this thesis non of the UI subtypes were used, because they were not predictive of responsiveness of residents in trials, concerning toileting assistance (prompted voiding)(13).

The severity of UI is often expressed in frequency, and this is measured in long-term care facilities by making wet checks(14), i.e. the residents are checked at regular intervals varying from 1 to 4 times an hour. However, a more accurate measurement is the quantity of urine that is lost. In the research described in this thesis we measured both frequency and amount.
Fecal incontinence

Fecal incontinence (FI) is the inability to control stool or the recurrent involuntary passage of stool or gas through the anus\(^{15}\). The leakage may vary in severity, from causing soiling of the underclothes to evacuating the rectum completely. The factors that play a role in the development of FI are: altered stool consistency, inadequate reservoir capacity, inadequate rectal sensation, direct sphincter injury, and pelvic floor denervation\(^{15}\). In long-term care residents factors that play a very important role are constipation (maximum of two bowel movements per week)\(^{4}\), fecal impaction (accumulation of stool in the rectum and inability to evacuate) and diarrhea\(^{16;17}\). Constipation and fecal impaction are associated with lack of fiber dietary intake, poor fluid intake, concurrent use of medications and immobility\(^{16-18}\). Diarrhea is associated with fecal impaction and the use of laxatives\(^{17}\). The severity of FI is often expressed in frequency, but the degree of soiling is also used\(^{19}\). In the research described this thesis we only measured frequency. We did not investigate extensively the cause of FI, but we did study the relationship between FI and toileting skills and the relationship between FI, incident constipation and other morbidities.

Continence status

In the research described in this thesis the term continence status is used for the classification of residents into 4 categories: continent, UI only, FI only, and DI. In disabled elderly people UI and FI are frequently combined, and this is referred to as dual incontinence (DI)\(^{6}\). From the perspective of the residents, the burden of incontinence is probably not only determined by the frequency of episodes of UI and FI or the quantity lost, but more by type of incontinence: UI only or FI only, or DI\(^{6}\). Pads can use for UI, because they are designed to absorb a large quantity of urine, but for FI there are two problems: the pads are not designed to absorb feces and there is a foul smell. Moreover FI also causes a higher percentage of incontinence-related wounds than UI\(^{20}\). These consequences of incontinence are the reason why we have characterized DI as the most severe type of incontinence, followed by FI only and then UI only. This is in accordance with the
findings of Fialkow(6), when he reported that DI has more impact on quality of life than UI and FI alone.

Because UI and FI are frequently combined, it is likely that there is a common etiology. Nelson investigated the factors associated with FI and UI in nursing homes in Wisconsin in a cross-sectional study(21). The factors that were found to be positively associated with FI were: tube-feeding, diarrhea, truncal restraints, pressure ulcers, dementia, impaired vision, fecal impaction, constipation, and increasing body mass index. Significant inverse associations were noted for heart disease, depression and arthritis. Diabetes was not associated with FI. The following factors were also risk factors for UI(22): truncal restraints, dementia, impaired vision, stroke, and constipation. Inversely associated risk factors were: body mass index, tube-feeding, and pressure ulcers. Diabetes, heart disease, arthritis, and fecal impaction were not associated with UI. In conclusion: there are common risk factors for UI and FI, but there are also factors associated with UI and not with FI, and visa versa. In the overlap between the risk factors for UI and FI, elements of impaired mobility (truncal restraints) and cognitive decline (dementia) are present. This is in line with the findings of Chiang, who reported that almost all patients with DI had impaired cognition and mobility(10).

Toileting skills

Toileting skills refer to the ability of a person to perform several tasks to urinate and defecate on a toilet. Those tasks are: getting up from a chair or bed, walking or in a wheelchair, finding the toilet, manipulating of clothing, and sitting down on the toilet.

Although it is widely recognized that there is an association between UI and FI on the one hand, and mobility and cognition on the other, very little research has focused on to the relationship of the specific tasks needed for toileting and the development of incontinence. There are reports of interventions to improve general functioning (13;14;23;24), but research on toileting skills as a concept or on the individual tasks that are involved is scarce. Only Ouslander described a test carried out by Williams in 1982(25), and Burgio described the assessment of toileting skills in adult day care center(26).
1.2 The objectives of this thesis

The results of earlier cross-sectional studies show that both UI and FI in disabled elderly people are related to mobility and cognitive impairment (22,27) apart from factors related to bladder, gut and pelvic floor. This is not surprising, because the tasks needed for going to the toilet (transfers, walking or riding in a wheelchair, finding the toilet, manipulating of garments) (25) all depend more or less on adequate mobility and cognitive functioning. It is presumed that morbidity is also a major causal factor in the development of both UI and FI in disabled elderly people (28,29). Morbidities associated with a decline in continence are: neurological conditions (delirium, Parkinson’s disease, stroke, spinal cord injury), musculoskeletal conditions that impair mobility, disorders of volume (congestive heart failure, pedal edema, polyuria), cancer (bladder, prostate, rectal), stool impaction, depression, and dementia (30).

Thus, risk factors for incontinence in nursing home clients are multifaceted, and interact with each other which makes incontinence a complex problem. Growing older and becoming more frail is associated with an increase in risk factors, and therefore the continence status changes. In this thesis we focus primarily on toileting skills, and study the relationship of these skills with change in continence status. Furthermore, we found important to investigate the relationship between incident morbidity, and the resulting changes in toileting skills and continence status, because this will generate possibilities for prevention and intervention strategies.

The objectives of the research described in this thesis were: (1) to investigate relationships between incontinence (UI, FI and DI), toileting skills and morbidity, and (2) to study the effect of training toileting skills on incontinence.

1.3 Research questions

The research questions addressed in this thesis are:

1. What is the prevalence and incidence of different types of incontinence in nursing home residents?

2. What is the relationship between different types of incontinence and change in toileting skills?
3 What is the relationship between the incidence of the different types of and incident diseases and disabilities?

4 What is the effect of training toileting skills on toileting skills? Is the effect of a targeted toileting skills intervention on urinary incontinence?

1.5 Settings and data sources

Long-term care facilities in the Netherlands

In the Netherlands, elderly people who need assistance with the activities of daily living and nursing care, can receive that care in a residential home ('verzorgingshuis') or a nursing home ('verpleeghuis'), the latter being a more skilled facility providing general care for a heavier case-mix. Nursing homes in the Netherlands differ from their counterparts in other countries in that the staff includes specially trained nursing home physicians, physical therapists, occupational therapists, speech therapists, dieticians, psychologists and social workers, all of whom are employed by the nursing home(31). Multidisciplinary care is provided by these professionals, together with the nursing staff. In these nursing homes there are units for people with dementia, somatic disorders and rehabilitation, and there are also day-care centers in the nursing homes. There are separate day-care facilities for clients with primarily physical problems and clients with dementia. Due to capacity problems in the nursing homes and the expected increase in the number of frail elderly clients, nursing home care is also provided in homes for the elderly (residential homes).

Incontinence in long-term care facilities

The prevalence of incontinence in Dutch nursing and residential homes is high. In a survey that was carried out in 2006, the prevalence of UI was 76.2% in the nursing homes and 60.5% in residential homes, the prevalence of FI was 55.4% in nursing homes and 20.1% in residential homes, and the prevalence of DI was 52.7% in nursing homes and 18.5% in residential homes(20).

UI and FI are a great burden for nursing home residents and care-givers because of their high prevalence and negative impact on quality of life(6;32-34). They also have important economical implications due to the amount of both care-giver time and costly materials that are required(33-37).
In institutional health care in the Netherlands, there are multidisciplinary guidelines about the intake of food and fluids, mouth care, and problem behavior, but there are no multidisciplinary guidelines for continence care. There are guidelines for nurses concerning continence problems(38), and there are instructions for nursing aids with regard to care concerning toileting and incontinence(39), but these are not multidisciplinary. However, indicators for good care have recently been developed, and there are also indicators for continence care, namely catheter-use and diagnosis of incontinence(40), and because of the existence of these indicators for continence care, the management of institutions now give more priority to continence problems.

Differences between the Netherlands and the USA

In the USA there are no nursing home physicians employed by the nursing home. Assessment of the client and care-planning is primarily the task of nurses, unlike the situation in Dutch nursing homes. There are some nursing homes that have guidelines for the nursing care of incontinent clients, and some of these include scheduled toileting plans. It is possible that in the USA more nursing homes have a policy for incontinence problems, compared to the Netherlands, although there is no information available to verify this.

There is also a difference in government policy between the USA and the Netherlands. In the USA, facilities are obliged to attain the highest possible functioning for all residents(41). In the Netherlands the emphasis of the national policy is on participation of the chronically disabled(42). This difference has consequences for the (in) continence policy in the long-term care facilities. In the USA the emphasis is on providing as much nursing care as possible so that a resident has the lowest number of incontinence episodes that is feasible, and in the Netherlands the emphasis is on social engagement, and providing (in)continence care that enables the resident to participate socially as much as possible.

Data sources

Three data sources were used for the research described in this thesis. We used two databases (SIVIS and MDS-RAI) and the third data source was data from our intervention study.

1. SIVIS database

Until 1997 data from almost all Dutch nursing homes were collected in the SIVIS database. A questionnaire containing 56 items was filled in by the nursing staff for all new clients on admission.
and thereafter quarterly. We used the 1995 dataset for our research. The SIVIS database contained
data on all residents in 292 out of the 340 nursing homes in the Netherlands, and therefore the data can
be considered to be representative for all nursing homes in the Netherlands.

2. MDS-RAI database
The second data source we used was the MDS-RAI (Minimum Data Set of the Resident Assessment
Instrument) database from the state of Ohio in the USA. We used data on 89,716 residents, of 65 years
of age or older. The MDS 2.0 was used to collect a broad range of information on the functioning of
the residents(43). It is used in all nursing homes in the USA, and translated versions have been
implemented in many other countries(44). The structured and comprehensive questionnaire provides
information on several aspects of the resident’s functioning, health, well-being and behavior. The
information is collected through observations made by care-givers and interviews with the residents
and their family members(45), and the MDS items have been found to have good reliability in several
studies and many countries(43;46;47). In the USA the MDS-RAI is used to assess nursing home
clients, to trigger assessment protocols, to develop quality indicators, and for reimbursement purposes,
and the use of this instrument is mandatory in nursing homes. The data are collected on admission and
quarterly. In most nursing homes in the USA the quarterly reviews are based on a short form
questionnaire, but in Ohio a full MDS assessment is made every 3 months. This full MDS is necessary
for the analysis of morbidities, and because there is a good system for tracking clients, longitudinal
data can be obtained.

3. Intervention study
The toileting skill intervention focused on clients from somatic wards or from somatic day-care.
Twenty-three institutions in Amsterdam and neighboring cities agreed to participate in the study:
twelve nursing homes, four homes for the elderly and seven combinations of a nursing home and a
residential home. Five of these institutions also had a day-care unit for non-demented residents from
which we also recruited participants.
The selection procedure aimed to include incontinent women, aged 65 or over, with mild or moderate
mobility and transfer impairments, but with no dementia, with UI episodes at least twice a week and
for at least the past 3 months, able to go to the toilet (walking or in a wheelchair) and able to transfer
to a toilet independently or with the aid of one person. In the final selection, residents who for medical reasons did not meet the criteria were excluded.

The intervention consisted of a specifically developed training program for mobility and toileting skills. The intervention was provided by physiotherapists and/or occupational therapists on an individual basis.

1.6 Concepts

Measuring incontinence

For this study we used the ‘incontinence’ item scores from the databases (SIVIS and RAI-MDS) and for the intervention study we used the most exact measurement, i.e. measurement of the amount of urine lost by weighing the pads. For the purposes of this study we defined ‘continent’ as completely continent, i.e. in the databases a score of incontinence less than once a week. This strict definition of continence was also used for the assessment of continence status in the intervention study.

The severity of incontinence in the intervention study was measured by means of the Pad-test(1), which is an objective, quantitative measure of involuntary urine loss, based on pad weight gain. For the PAD-test, the pads collected during the day (8.00-22.00 hours) and at night (22.00-8.00 hours), for 3 successive periods of 24 hours, after which the average pad weight gain per day, night and 24-hour period was calculated. If there was more than 90% weight reduction on the PAD-test the participant was considered to have become ‘continent’ at follow-up.

Measuring toileting skills

In the existing databases of residents in residential and nursing homes (for instance the MDS) toileting skills are assessed implicitly as part of the ADL, and the ADL score is used in reports about those databases. The general concept of ADL comprises not only mobility, transfers and toileting, but also bathing and eating, and is therefore not suitable for specific research in toileting skills. However, an instrument with proven reliability for the assessment of toileting skills does not exist, so on the basis of the single items of ADL instruments we constructed toileting skill scales for use with the Dutch SIVIS database and the MDS database.

Toilet Index (SIVIS)
The Toilet Index (TI) is based on Dutch SIVIS registration items: dressing, standing, walking, and transfer. The summed total score ranges from 0 (no assistance needed) to 13 (maximum assistance needed), and the TI assesses the amount of assistance needed.

Toilet Dependency Score (MDS)
The Toilet Dependency Score (TDS) was developed with items from the MDS. For independent toileting a resident should be able to go to the toilet (walking or in a wheelchair and find the toilet), handle clothing and sit down on the toilet without assistance. Therefore the scale was constructed with the MDS items; ‘locomotion on the unit (score 0-4)’, ‘toilet use (score 0-4)’ and ‘find room (score 0-1)’. We also constructed a scale for change in the TDS (change TDS) based on the TDS score at two points in time.

The TI, the TDS, and the change TDS were constructed to express toileting skills as a single value, for use in databases that are not intended to measure toileting skills as a concept. The items on which the scores are based were assessed by nurses, and express the need for assistance with the individual tasks. A higher score for a task reflects a greater need for assistance.

The Toilet Timing test
For the intervention study we developed the Toilet Timing test (TT-test). The TT-test measures the time needed to perform the subsequent tasks associated with going to the toilet under standardized circumstances. The TT-test was developed to measure each individual task and to identify residents with slow performance on the individual tasks, and also to evaluate an intervention focusing on those tasks. Two versions were developed: one for residents who usually walk to the toilet, and one for residents who use a wheelchair.

There is a set threshold time for each task (based on the average performance time observed in a separate group of continent elderly volunteers with no mobility disorders). If a task was performed faster than the threshold time it was considered unlikely that this specific task hindered continence. If a task was performed slower than the threshold time, it was assumed that it could be an obstacle for normal toileting.

In addition to the TT-test under standardized circumstances, as described above, we also developed a version for measuring the time needed to go to the toilet in the actual, individual daily circumstances.
This version included the same tasks, but instead of using threshold times, the actual circumstances were described in parameters such as distance to the nearest toilet, dimensions of the toilet, etc. These measurements were performed for comparison before and after the intervention.

1.7 Content of this thesis

Chapter 2 reports on the prevalence of continence status among newly admitted residents in Dutch nursing homes, and explores the relationship between continence status, gender, type of care (psychogeriatric, somatic) and need for assistance with toileting. We used cross-sectional data from the SIVIS concerning all new admissions in Dutch nursing homes in 1995. For this study toileting skills were operationalized with the Toilet Index.

Chapter 3 focuses on the change in continence status in post-acute and long-term nursing home residents, using data from a cohort study, with assessment at baseline and at 3-month follow-up, based on RAI-MDS data on residents in nursing homes in the state of Ohio in the USA.

Chapter 4 describes the relationship between change in toileting skills and the development of FI in nursing home residents, using data from a cohort study, with assessment at baseline and at 3-month follow-up, based on RAI-MDS data on residents in nursing homes in the state of Ohio in the USA. Toileting skills were scored with the TDS.

Chapter 5 describes the effect on UI and FI of incident morbidity in relation to toileting skills in nursing home residents, using data from a cohort study, with assessment at baseline and at 3-month follow-up, again based on RAI-MDS data on residents in nursing homes in the state of Ohio in the USA.

Chapter 6 describes the effect of an individualized 8-week training program of mobility and toileting skills, provided by physiotherapists and/or occupational therapists, and aimed at reducing the time
needed for specific toileting tasks. The study is based on a randomized single-blinded controlled trial among disabled elderly female, clients in Dutch long-term care facilities. The intervention was based on the performance of the tasks included in the Toilet Timing test.

Chapter 7 describes the effect of an individualized 8-week training program for mobility and toileting skills, provided by physiotherapists and/or occupational therapists, on the severity of UI measured with the Pad-test. The study is based on a randomized single-blinded trial among disabled elderly female, clients in Dutch long-term care facilities. The intervention was based on the performance of the tasks included in the Toilet Timing test.

Chapter 8 summarizes the main findings of this thesis by addressing the research questions. The strengths and limitations of the study are then discussed, followed by recommendations for future research and the clinical implications for health professionals, nursing home management, and policy-makers. The chapter ends with suggestions for future research and a general conclusion.
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General introduction


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Incontinence in the nursing home; mostly a problem of dual incontinence

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Abstract

Objectives: To determine the prevalence of incontinence (urinary [UI], fecal [FI], UI only, FI only and dual incontinence [DI]) among newly admitted residents in Dutch nursing homes. As well to explore the relationship between incontinence on the one hand, and gender, type of care (psychogeriatric, somatic) and need for assistance in toileting on the other.

Design: Cross-sectional, all new admissions based on data from the Dutch SIVIS registration system over the year 1995.

Method: In the SIVIS system, the presence of incontinence (urinary, fecal) are registered by nurses. In the Netherlands residents with predominantly cognitive problems are admitted on psychogeriatric wards, all others on somatic wards. In SIVIS the type of ward (psychogeriatric and somatic) on which residents are admitted is registered. The need for assistance in toileting was operationalised according to the Toilet Index, a sum-score on four SIVIS items.

Results: The analysis included data on 33592 residents who were newly admitted to a Dutch nursing home. The prevalence of UI on admission was 47.1% and of FI 29.4%. The prevalence of UI only on admission was 19.1%, FI only was 1.4% and of DI was 28.0%. No major differences in prevalence were found between men and women. A higher prevalence of UI, FI and DI was found in psychogeriatric compared to somatic residents. A higher Toilet Index score (i.e. more need for assistance) was related to a higher prevalence of DI. While in somatic residents the association between the Toilet Index score and the prevalence of DI was gradual over the whole range of the Toilet Index score, in psychogeriatric residents even moderately higher scores were associated with a high prevalence of DI.

Conclusion: The prevalence of both UI and FI is high among newly admitted residents in Dutch nursing homes. The highest prevalence is found in psychogeriatric residents compared to somatic residents. Need for assistance in toileting is related to a higher prevalence of DI. In psychogeriatric residents, even a slight need for assistance is related to a high prevalence of DI.
2.1 Introduction

Incontinence is one of the most frequent problems among nursing home residents. The onset and severity of incontinence in dependent elderly men and women are influenced by many factors (1-5). However, little is known about the prevalence of the different types of incontinence (i.e. urinary [UI], fecal [FI] and dual incontinence [DI]) and to what extent urinary and fecal incontinence co-incide.

Research in psychogeriatric nursing home patients in the Netherlands showed a prevalence of 65% for UI and 32% of FI. Data about the co-incidence of both types of incontinence are not available (6).

While traditionally, these two have been treated as separate entities; in the elderly they may very well share a common aetiology. In middle aged women, urinary incontinence is probably mainly related to anatomic changes and decreased or improper functioning of the bladder and pelvic floor (7). With ageing, however, urinary incontinence becomes more prevalent in men as well, and is more often combined with fecal incontinence (4,8-12). This suggests that other factors play a role in its aetiology.

Indeed, some studies have found that urinary incontinence is related to cognitive functioning and decreased mobility (1,3,13,14). Also for FI (11,15) and DI (16) this relation is found. This may be due to the increased dependency on help and the time it takes to reach the toilet, remove the necessary clothing and get seated on the toilet. To what extent dependency for toileting and cognitive decline play a role in the emergence of urinary, fecal and combined incontinence has, to our knowledge, never been reported on.

In this paper we will present data on the prevalence of the different types of incontinence of newly admitted, male and female nursing home residents. Especially, the relation with toileting dependency and dementia are examined.
2.2 Methods

The population consisted of all newly admitted patients to a nursing home in 1995 in the Netherlands, as recorded in the SIVIS-registration. This SIVIS registration contains data on all newly admitted residents of 292 out of the total of 340 Dutch nursing homes. The SIVIS-forms are completed by nurses. All data used in this study are based on this registration. Residents with an indwelling catheter, urinary or fecal stoma were excluded.

Registration of incontinence.

The SIVIS-registration contains separate items for urinary and fecal incontinence. The response categories for these are: continent (0), 1 or 2 times a week incontinent (1), and more than 2 times a week incontinent (2). For the purposes of this study, score 0 was considered ‘continent’, score 2 or 3 was considered ‘incontinent’. UI only and FI only was defined as the presence of only one type of incontinence, dual incontinent as the presence of urinary incontinence as well as fecal incontinence.

Cognitive status.

In Dutch nursing homes, two main categories of residents can be distinguished: psychogeriatric and somatic residents. Psychogeriatric residents mainly suffer from dementia and are admitted to the nursing home for long term care. Somatic residents mainly suffer from a physical handicap and are admitted to a nursing home for long term care or rehabilitation. The distinction between somatic and psychogeriatric residents was made on the basis of the SIVIS-item ‘type of care’.

Toileting dependence (Toilet Index).

For this study we developed a measure, the Toilet Index, to summarise the amount of assistance needed for going to the toilet. This measure was based upon the POTTI-test developed by Ouslander(17) and the Toilet Timing Test developed earlier by our group. The items of the Toilet Index represent the individual tasks needed to perform urinating or defecating on a toilet. These SIVIS-items are: dressing, standing, walking, and transfer (table 1). The summed total-score has a range from 0 (no assistance needed) to 13 (maximum assistance needed). While the POTTI-test and the Toilet Timing Test are based upon the capacities of the subjects, the Toilet Index is based upon the amount of assistance needed.
Incontinence in nursing home, mostly a problem of dual incontinence

Table 1. Item content of the Toilet Index

<table>
<thead>
<tr>
<th>Item</th>
<th>Score</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Dressing</td>
<td>0</td>
<td>No supervision or assistance needed.</td>
</tr>
<tr>
<td></td>
<td>1</td>
<td>Supervision or slight assistance needed.</td>
</tr>
<tr>
<td></td>
<td>2</td>
<td>Maximum aid needed.</td>
</tr>
<tr>
<td>Standing</td>
<td>0</td>
<td>Without assistance (incl. independent use of walking aids etc.).</td>
</tr>
<tr>
<td></td>
<td>1</td>
<td>With assistance by a person.</td>
</tr>
<tr>
<td></td>
<td>2</td>
<td>Not possible, but not totally bedridden.</td>
</tr>
<tr>
<td></td>
<td>3</td>
<td>Totally bedridden.</td>
</tr>
<tr>
<td>Walking</td>
<td>0</td>
<td>Walking without assistance by a person or supervision.</td>
</tr>
<tr>
<td></td>
<td>1</td>
<td>Operates a wheelchair without supervision or assistance by a person.</td>
</tr>
<tr>
<td></td>
<td>2</td>
<td>Walking with assistance by a person now and then.</td>
</tr>
<tr>
<td></td>
<td>3</td>
<td>Walking with constant supervision and/or assistance by a person.</td>
</tr>
<tr>
<td></td>
<td>4</td>
<td>Can not operate a wheelchair independently and/or is bedridden.</td>
</tr>
<tr>
<td>Transfers</td>
<td>0</td>
<td>Needs no supervision and/or assistance by a person in moving around.</td>
</tr>
<tr>
<td></td>
<td>1</td>
<td>Needs now and then supervision and/or assistance by a person.</td>
</tr>
<tr>
<td></td>
<td>2</td>
<td>Needs a person for constant supervision and/or assistance.</td>
</tr>
<tr>
<td></td>
<td>3</td>
<td>With transfers 2 persons are needed.</td>
</tr>
<tr>
<td></td>
<td>4</td>
<td>Totally bedridden.</td>
</tr>
<tr>
<td>Total</td>
<td>0-13</td>
<td></td>
</tr>
</tbody>
</table>
Analysis

Point-prevalences of incontinence were calculated as percentages. Standard \( \chi^2 \) tests for contingency tables were used to test the relation between two dichotomous variables. The relation dichotomous and ordinal variables (i.e. prevalences and the Toilet Index) was tested using a Mantel extension for trend(18).

2.3 Results

Data on 33592 residents were available for analysis, with a median age of 78.9 year. The majority of the subjects was female (65.9% female, 34.1% male), and admitted as somatic patient (66.4% somatic, 33.6% psychogeriatric). In the total group, the prevalence of UI was 47.1% and the prevalence of FI was 29.4% (Table 2). The prevalence of UI only was 19.1%, of FI only 1.4%, and of DI 28.0% (Table 3). The differences between men and women were only slight. There were, however, substantial differences in the prevalences of incontinence between the two types of residents. Psychogeriatric residents had a much higher prevalence of UI (62.9%) and FI (42.5%) than somatic residents (UI 37.9% and FI 21.8%). In both somatic and psychogeriatric residents the prevalence of UI only and FI only even more so, was low compared to the prevalence of DI (Table 3). Higher scores on the Toilet Index were significantly related to higher prevalences of UI, FI and DI, as shown in Figure 1 (all \( p<0.001 \)). In psychogeriatric residents, however, even slightly higher scores on the Toilet Index were associated with higher prevalences of incontinence, while in somatic residents the association was spread out more over the whole range of the scale. The high number of psychogeriatric residents with little need for assistance is remarkable (Figure 2).
Table 2. Prevalence (%) of urinary and faecal (in)continence (n=33592).

<table>
<thead>
<tr>
<th></th>
<th>Urinary incontinence</th>
<th>Fecal incontinence</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Continent</td>
<td>Incontinent</td>
</tr>
<tr>
<td>Total</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Population</td>
<td>52.9</td>
<td>47.1</td>
</tr>
<tr>
<td>Women</td>
<td>55.0</td>
<td>45.0</td>
</tr>
<tr>
<td>Men</td>
<td>48.5</td>
<td>51.5</td>
</tr>
<tr>
<td>Somatic</td>
<td>62.1</td>
<td>37.9</td>
</tr>
<tr>
<td>Psychogeriatric</td>
<td>37.1</td>
<td>62.9</td>
</tr>
</tbody>
</table>

Table 3. Prevalences (%) of urine only, fecal only and dual incontinence.

<table>
<thead>
<tr>
<th></th>
<th>Continent</th>
<th>UI only</th>
<th>FI only</th>
<th>DI</th>
</tr>
</thead>
<tbody>
<tr>
<td>Total population</td>
<td>51.5</td>
<td>19.1</td>
<td>1.4</td>
<td>28.0</td>
</tr>
<tr>
<td>Women</td>
<td>53.8</td>
<td>18.6</td>
<td>1.3</td>
<td>26.3</td>
</tr>
<tr>
<td>Men</td>
<td>46.9</td>
<td>20.0</td>
<td>1.7</td>
<td>31.5</td>
</tr>
<tr>
<td>Somatic</td>
<td>60.5</td>
<td>17.6</td>
<td>1.5</td>
<td>20.3</td>
</tr>
<tr>
<td>Psychogeriatric</td>
<td>35.9</td>
<td>21.6</td>
<td>1.1</td>
<td>41.3</td>
</tr>
</tbody>
</table>
Incontinence in nursing home, mostly a problem of dual incontinence

Fig. 1 Prevalence (%) of incontinence by Toilet Index group in psychogeriatric (a) and somatic nursing home residents (b)

a. Psychogeriatric residents

b. Somatic residents

UI: Urinary incontinence only
FI: Fecal incontinence only
DI: Dual incontinence
2.4 Discussion

Although in the literature UI and FI are described as separate phenomenons, this study shows that incontinence in the nursing home is mostly of FI. This is the case for both women and men, for somatic and psychogeriatric residents. The prevalence of DI is associated with assistance in with toileting. While in middle-aged populations, women have a much higher prevalence of UI than men (12), in this study no substantial differences between the sexes were found (10). A possible explanation is the selection of residents at admission in the nursing home. It is also possible that sex-specific factors related to UI (prostate-enlargement, number of deliveries and oestrogen deficiency (2;19-21) have a similar effect on the prevalence of UI. Another explanation could be that in dependent elderly people the not sex specific factors are dominant as mobility disorders and cognitive loss. Positive arguments in support is that, for FI and DI also no substantial differences between the sexes were found, and the strong relationship between incontinence and need of assistance with toileting.
In somatic residents, the prevalence of DI increases gradually with increasing need for assistance. In psychogeriatric residents, however, even a small need for assistance was related to high prevalences of DI.

An explanation can be that psychogeriatric residents are unable to develop a strategy to maintain continence when mobility declines. In this cross-sectional study, causality cannot be proven. This relation may well be confounded by the impact of the severity of dementia on both incontinence and functional status.

A relatively high percentage of psychogeriatric residents had a low need of assistance with toileting. There is a high prevalence of incontinence, when there is a relatively small increase in need of assistance. Previous studies have shown that prompted voiding is a successful method of treatment for UI and even FI in this category of residents (22-25). As of prompted voiding is used in Dutch nursing homes, it may well be an effective measure to treat incontinence.

The prevalence of pure UI differs little between somatic residents 17.6% and psychogeriatric residents 21.6%. This is also the case for FI. In contrary the prevalence of DI (somatic residents 20.3%, psychogeriatric residents 41.3%) differs greatly between types of residents. This supports the hypothesis that UI only and FI only are specifically related to disorders of the bladder and pelvic floor, and that DI is specifically related to a greater need for assistance. It is important that further research addresses this hypothesis, because of its implications for daily practice.

A cross-sectional study based on administrative data has some limitations. Bias in the study-base is possible and conclusions must be drawn cautiously. The Toilet Index score was specifically developed for this study to measure the need for assistance in toileting. Using SIVIS-items, it was possible to achieve content validity, as they cover all the tasks needed for going to the toilet, as defined by Ouslander. Moreover, the tasks that are the most difficult and take the most time (walking and transfer) also contribute most to the sumscore. Indeed, the prevalence of incontinence appeared to increase with each following step in the Toilet Index score, indicating adequate construct validity.

In this study we used a division between psychogeriatric and somatic residents. This is only a rough indication for the presence of a cognitive disorder. There was no information on the severity of the cognitive disorder. Dementia has a relationship with loss of ADL function, and this could influence...
the relationship between need of assistance in toileting and incontinence. However, also with somatic residents the relationship between need of assistance in toileting and incontinence is clear.

The conclusions of this study are that the prevalence of both UI and FI is high in Dutch nursing homes, and incontinence is mainly a problem of dual incontinence. The prevalence of DI is highly related to the need for assistance with toileting and cognitive disorders, while UI only and FI only are not. Interventions aimed at prevention of decrease in toileting skills in nursing home residents could be effective. Further longitudinal and experimental studies are needed to support this hypothesis and to demonstrate the causality of the relationships found in this study.
Incontinence in nursing home, mostly a problem of dual incontinence

**References**


Incontinence in nursing home, mostly a problem of dual incontinence


Incontinence in nursing home, mostly a problem of dual incontinence


Chapter 3

Change in continence status in nursing home patients

P van Houten
WP Achterberg
MG Dik
JN Morris
MW Ribbe
Abstract

Objectives: To establish change in continence in post-acute and long-term nursing home patients.

Design: Descriptive cohort study with assessment at baseline and at 3 month follow-up.

Methods: All patients, in post acute care (PAC) and long term care (LTC), aged 65 or over in nursing homes in Ohio in the USA, were included in the months October, November and December 2002. The Minimum Data Set (MDS) was used at baseline and three months later. Continence status was categorized as continent, urinary incontinence only (UI only), fecal incontinence only (FI only) or dual incontinence (DI). From a total of 101189 patients, data on 76084 patients (74.3% female) were included.

Results: The overall prevalence of UI was 65.5% and for FI 38.4% (99.4% DI). 33.9% of the nursing home patients were continent. The overall 3-month incidence of FI (22.2%) was higher than the incidence of UI (14.8%).

Deterioration of continence status occurred in 17.5% of the PAC patients and 15% of the LTC patients and was predominantly from continence to UI only (PAC 10.0%, LTC 8.7%) and from UI only to DI (PAC 29.0%, LTC 34.3%).

Improvement in continence status occurred in 9.4% of the PAC patients (mainly UI only to continence 4.6%), compared with 2.4% of the LTC patients.

Conclusion

Deterioration of continence status was predominantly from continence to UI only and from UI only to DI. In addition to the prevention of urine incontinence, prevention of the transition from UI only to DI (acquiring FI) deserves more attention.
3.1 Introduction

Urinary incontinence (UI), fecal incontinence (FI) and dual incontinence (DI) are prevalent in nursing home patients. UI and FI are both associated with impaired quality of life (1) (2) (3). From the perspective of the patients, the burden of incontinence is probably not only determined by the frequency of incontinent episodes or the quantity lost, but more by the type of incontinence: urinary or fecal or both. Pads can be used for UI, as they are designed to absorb a large quantity of urine, but for patients with FI there are two problems: the pads are not designed to absorb feces, and there is a foul smell. This would characterize DI as the most severe type of incontinence, followed by FI only and then UI only. This presumption is supported by Fialkow (4), who found that DI has more impact on quality of life than UI and FI alone.

In 1995 the prevalence of UI among patients admitted to Dutch Nursing homes was 47.1% and the prevalence of FI was 29.4% (5). The prevalence of UI only on admission was 19.1%, for FI only it was 1.4% and for DI it was 28.0%. In a cross sectional study in nursing homes in the USA it was also found that DI was the most prevalent type of incontinence (6). In line with this is it was found that FI almost always coexists with UI in nursing home patients in Wisconsin (7).

However, little is known about the change in continence status during a patient’s stay in a nursing home. In a prospective cohort study of newly admitted nursing home patients, Ouslander found a prevalence of UI on admission of 39% (8). After two months there was a 23% remission of UI in patients who were still in the nursing home, and an additional 22% remission after one year. The continence status of nursing home patients is therefore not a stable condition or only a declining condition. However apart from transitions form incontinence to continence and vice versa, it is also of interest to study other transitions. For instance, are there remissions from DI to UI, or from DI to continence? And does DI occur instantly, or is it usually preceded by UI?

It was found that the prevalence and incidence of UI, FI (7) and DI in particular, are related to cognitive status and mobility (6). Therefore, it can be assumed that remission of UI, FI and DI is higher in patients who are admitted for post-acute care (PAC) than in patients in long-term care (LTC) in nursing homes, because PAC patients have less cognitive problems, and their mobility is likely to
improve during rehabilitation. It is therefore interesting to compare the changes in the continence status of PAC patients and LTC patients.

Incontinence gives considerable socio-economic costs, although the exact costs are unknown(9). There are reports about successful strategies in managing incontinence in nursing homes, such as functional incidental training, prompted voiding, and managing bowel function.(10) More knowledge about changes in the continence status of nursing home patients can contribute to the refinement of those strategies and thus lower the costs of incontinence.

The objective of this study was to describe the change in continence status over a 3-months period in PAC patients and LTC patients.

3.2 Methods

Subjects
All nursing home patients in Ohio, USA, were included in the study in October, November and December 2002 if they were aged 65 or over. Patients with a catheter or ostomy at baseline were excluded. The RAI Minimum Data Set (MDS) was used for assessments. Patients admitted for PAC are patients who are transferred to a nursing home from a hospital for rehabilitation. For the present study, only PAC patients who stayed for at least 3 months were included, because MDS data are only available after a 3 month interval.

Data were available for 101189 patients, 87915 of whom were 65 years of age or older. 11.832 patients were excluded; 9528 with an indwelling catheter, 2302 with an ostomy, and 1444 with both indwelling catheter and ostomy. Data on 76084 patients were finally included in the analysis.

Measurement instruments
The MDS 2.0 was used to collect a broad range of information on the functioning of the patients(11). It is used in all nursing homes in the USA, and translated versions are implemented in many other countries(12). The structured and comprehensive questionnaire provides information on several aspects of the patient’s functioning, health, well-being and behavior. The information is collected through observations made by caregivers and interviews with the patients and family members(13). MDS items have shown good reliability in several studies and many countries(11;14;15).
Continence

Continence status was assessed with the MDS items bladder incontinence and bowel incontinence, reflecting UI and FI, respectively.

Bladder incontinence scores were: 0 (no bladder incontinence, complete control), 1 (usually continent: incontinent episodes once a week or less), 2 (occasionally incontinent two or more times a week, but not daily), 3 (frequently incontinent: tended to be incontinent daily but some control present), 4 (incontinent, multiple daily episodes).

Bowel incontinence scores were: 0 (no bowel incontinence, complete control), 1 (usually continent: incontinent less than weekly), 2 (occasionally incontinent: once a week), 3 (frequently incontinent: two or three times a week), 4 (incontinent, all, or almost all of the time).

Because we were interested in the prevalence of UI and FI, which has been shown to be accurately assessed with the MDS(16), we dichotomized incontinence in 0 ‘continent’ versus 1 ‘incontinent’ (categories 1 to 4).

On the basis of these scores, we categorized subjects as ‘continent’, ‘UI only’, ‘FI only’ and ‘DI’ (dual incontinence: UI and FI).

The MDS Activities of Daily Living (ADL) and the MDS Cognitive Performance Scale (CPS) were used to assess the baseline characteristics and to compare this sample group with the group lost to follow-up. The (hierarchical) ADL-index ranges from independent to highly dependent(17) and the CPS is a seven-category index, ranging from cognitively intact to very severely impaired(18). It has shown substantial agreement with the Mini-Mental State Examination (MMSE) for the identification of cognitive impairment in research settings(19).

Continence status cannot be accurately assessed in the presence of a catheter or ostomy, so we created a separate group of patients who acquired a catheter and/or an ostomy during the follow-up period.

3.3 Data-analyses

Separate analyses were performed for PAC patients and LTC patients.
3.4 Results

On inclusion 24.9% were PAC patients and 75.1% were LTC patients. The baseline characteristics are shown in Table 1. In the total sample, 74.3% of the patients were female; 76.1% in the LTC group and 68.9% in the PAC group were female.

The baseline prevalence of UI was 65.5%, and for FI it was 38.4%. Only 33.9% were totally continent. The percentage of patients with FI only was very small (0.6%). The ADL scores of the PAC and the LTC patients were similar, but the cognitive status of the PAC patients was better.

Follow-up (Table 1)

Three month follow-up data were available for 56316 patients (74.0% of the baseline sample), 6701 PAC and 49615 LTC patients. The main reasons for loss to follow-up were discharge and death: PAC patients mainly due to discharge and LTC patients mainly due to death. In the group of patients who were lost to follow-up 61.6% were PAC patients (Table 1). The group patients who were lost to follow-up scored lower on the CPS, and UI and FI prevalence than the patients in the incidence sample.

Change in continence status (Tables 2a and 2b, Figures 1a and 1b)

The overall 3-month incidence was 22.2% for FI and 14.8% for UI. In the PAC patients there was more change (26.9%) in continence status than in the LTC patients (17.4%).

Deterioration of continence status was found in 17.5% of the PAC patients and 15% of the LTC patients. The deterioration in the PAC patients was: UI only to DI (29.0%), FI only to DI (17.6%), continence to UI only (10.0%), continence to DI (6.7%). In LTC patients the deterioration was: UI only to DI (34.3%), FI only to DI (32.4%), continence to UI only (8.7%), and continence to DI (4.7%).

Improvement in continence status was found in 9.4% of the PAC patients and only 2.4% of the LTC patients. The improvements in the PAC patients were: FI only to continence (36.5%), UI only to continence (16.8%), DI to UI only (7.0%), and DI to continence (4.1%). The improvements of the LTC patients were: FI only to continence (14.0%), UI only to continence (4.6%), DI to UI only (1.6%) and DI to continence (0.4%).

38 Change in continence status in nursing home patients
Table 1 Baseline characteristics for all patients, Post Acute Care (PAC) patients and Long Term Care (LTC) patients, and patients who were lost to follow-up at 3 months

<table>
<thead>
<tr>
<th></th>
<th>Long-Term Care</th>
<th>Post-Acute Care</th>
<th>Total baseline sample</th>
<th>Lost to follow-up at 3 months</th>
</tr>
</thead>
<tbody>
<tr>
<td>N=57169</td>
<td>N=18915</td>
<td>N=76084</td>
<td>N=19768*</td>
<td></td>
</tr>
<tr>
<td>(75.1%)</td>
<td>(24.9%)</td>
<td></td>
<td>(26.0%)</td>
<td></td>
</tr>
<tr>
<td>Female</td>
<td>76.1</td>
<td>68.9</td>
<td>74.3</td>
<td>69.3</td>
</tr>
<tr>
<td>Activities of Daily</td>
<td>3.4(1.6)</td>
<td>3.4(1.5)</td>
<td>3.4(1.6)</td>
<td>3.5 (1.5)</td>
</tr>
<tr>
<td>Living, mean (standard deviation)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Cognitive Performance</td>
<td>3.0(1.7)</td>
<td>1.6(1.6)</td>
<td>2.7 (1.8)</td>
<td>2.0(1.9)</td>
</tr>
<tr>
<td>Scale, mean (standard deviation)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Continence</td>
<td>27.1</td>
<td>54.5</td>
<td>33.9</td>
<td>48.5</td>
</tr>
<tr>
<td>Urinary incontinence</td>
<td>29.1</td>
<td>23.3</td>
<td>27.7</td>
<td>21.5</td>
</tr>
<tr>
<td>only</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Fecal incontinence</td>
<td>0.4</td>
<td>1.1</td>
<td>0.6</td>
<td>0.9</td>
</tr>
<tr>
<td>only</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Dual incontinence</td>
<td>43.4</td>
<td>21.1</td>
<td>37.8</td>
<td>29.1</td>
</tr>
</tbody>
</table>

% unless otherwise indicated

* PAC 61.6%, LTC 38.4%
Table 2a Change in continence status for Post-Acute Care patients in percentage and numbers, as presented in Figure 1a

<table>
<thead>
<tr>
<th>Continence at Follow Up % (n=6701)</th>
<th>Catheter/</th>
<th>Continence</th>
<th>UI only</th>
<th>FI only</th>
<th>DI</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Continence baseline</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>UI only</td>
<td>7.36</td>
<td>16.79</td>
<td>46.19</td>
<td>0.64</td>
<td>29.02</td>
<td>100</td>
</tr>
<tr>
<td></td>
<td>(139)</td>
<td>(317)</td>
<td>(872)</td>
<td>(12)</td>
<td>(548)</td>
<td>(1888)</td>
</tr>
<tr>
<td>FI only</td>
<td>12.16</td>
<td>36.49</td>
<td>5.41</td>
<td>28.38</td>
<td>17.58</td>
<td>100</td>
</tr>
<tr>
<td></td>
<td>(9)</td>
<td>(27)</td>
<td>(4)</td>
<td>(21)</td>
<td>(13)</td>
<td>(74)</td>
</tr>
<tr>
<td>DI</td>
<td>8.68</td>
<td>4.09</td>
<td>7.03</td>
<td>0.65</td>
<td>79.55</td>
<td>100</td>
</tr>
<tr>
<td></td>
<td>(174)</td>
<td>(82)</td>
<td>(141)</td>
<td>(13)</td>
<td>(1595)</td>
<td>(2005)</td>
</tr>
<tr>
<td>Total</td>
<td>7.49</td>
<td>36.85</td>
<td>19.24</td>
<td>1.51</td>
<td>34.92</td>
<td>100</td>
</tr>
<tr>
<td></td>
<td>(502)</td>
<td>(2496)</td>
<td>(1289)</td>
<td>(101)</td>
<td>(2340)</td>
<td>(6701)</td>
</tr>
</tbody>
</table>

UI=Urinary incontinence
FI=Fecal incontinence
DI=Dual incontinence
Table 2b Change in continence status for Long-Term Care patients in percentage and numbers, as presented in Figure 1b

<table>
<thead>
<tr>
<th>Catheter/Ostomy</th>
<th>Continence</th>
<th>UI only</th>
<th>FI only</th>
<th>DI</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Continence</td>
<td>1.79</td>
<td>82.90</td>
<td>8.66</td>
<td>1.96</td>
<td>4.69</td>
</tr>
<tr>
<td></td>
<td>(241)</td>
<td>(11180)</td>
<td>(1168)</td>
<td>(264)</td>
<td>(633)</td>
</tr>
<tr>
<td>UI only</td>
<td>2.51</td>
<td>4.58</td>
<td>58.39</td>
<td>0.26</td>
<td>34.26</td>
</tr>
<tr>
<td>baseline</td>
<td>(375)</td>
<td>(683)</td>
<td>(8717)</td>
<td>(39)</td>
<td>(5114)</td>
</tr>
<tr>
<td>FI only</td>
<td>6.15</td>
<td>13.97</td>
<td>3.35</td>
<td>44.13</td>
<td>32.40</td>
</tr>
<tr>
<td></td>
<td>(11)</td>
<td>(25)</td>
<td>(6)</td>
<td>(79)</td>
<td>(58)</td>
</tr>
<tr>
<td>DI</td>
<td>2.83</td>
<td>0.39</td>
<td>1.56</td>
<td>0.18</td>
<td>95.06</td>
</tr>
<tr>
<td></td>
<td>(594)</td>
<td>(81)</td>
<td>(327)</td>
<td>(37)</td>
<td>(19983)</td>
</tr>
<tr>
<td>Total</td>
<td>2.44</td>
<td>24.12</td>
<td>20.59</td>
<td>0.84</td>
<td>51.98</td>
</tr>
<tr>
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<td>(11969)</td>
<td>(10218)</td>
<td>(419)</td>
<td>(25788)</td>
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</table>

UI=Urinary incontinence  
FI=Fecal incontinence  
DI=Dual incontinence
Figure 1a  Change in continence status in Post-Acute Care

![Bar chart showing change in continence status in Post-Acute Care](image1a)

Figure 1b  Change in continence status in Long-Term Care

![Bar chart showing change in continence status in Long-Term Care](image1b)
Considering change categories as a percentage of all PAC patients, the following change categories were substantial: UI only to DI (8.7%), UI only to continence (5.3%), and continence to UI only (4.3%). In the LTC patients only the change from UI only to DI (10.7%), as a percentage of all LTC patients, was substantial.

The change to DI was predominantly from UI only to DI. Of the PAC patients who were continent at baseline, 6.7% changed to DI, while 29% of the patients with UI only at baseline changed to DI. Of the LTC patients who were continent on baseline, only 4.7% changed to DI, while 34.3% of the patients with UI only at baseline changed to DI.

The percentage of patients who acquired a catheter during the 3-month follow-up was 2.1%. A new ostomy was rare (0.2%). Most catheters/ostomies were acquired in the group with FI only at follow-up (PAC: 42.1%, LTC: 45.8%). In this group over 50% of the patients had a catheter/ostomy. The remaining catheters/ostomies were evenly distributed over the continence status groups at follow-up. These patients were excluded from the analysis of incidence of continence/UI/FI/DI.

3.5 Discussion

In this large nursing home cohort study, we found that the incidence of FI was higher than the incidence of UI, although the prevalence of UI was higher than the prevalence of FI. This means that most nursing home patients are UI, but when incontinence deteriorated it was mostly caused by FI.

The pattern of deterioration of continence status in this cohort was mainly from continence to UI only and from UI only to DI. The most frequent change was from UI only to DI, which suggests that it is important to treat existing UI and to prevent the development of FI in nursing home patients.

An improvement in continence status was mainly found in the PAC patients. The change from UI only to continence in this group was substantial. Although there was a small percentage of PAC patients who changed from DI to UI only, and even to continence. It is probable that regaining mobility and toileting skills in the process of rehabilitation is a causative factor in this improvement. It would be
interesting to study these transitions to UI only and continence more closely to get a better
understanding of the underlying mechanisms.

The changes in continence status of PAC and LTC patients differed substantially. In PAC patients
there was more change (26.9%) than in LTC patients (17.4%): PAC patients had relatively more
deterioration as well as more improvement in continence status, compared with LTC patients. The
greater improvement in PAC patients is not surprising, but it is remarkable that there was also more
deterioration. PAC patients are mainly admitted for rehabilitation, but during rehabilitation the
continence status can evidently deteriorate. The rehabilitation process gives a patient the chance to
regain mobility and ADL skills, but if it is not successful the patient must adjust to a life in the nursing
home, and thereby will probably not feel motivated to retain a higher level of continence.

It is important to realize that the PAC patients in this study were patients who stayed for 3 months or
longer in the nursing home, so they do not represent the group of rehabilitation patients who are
admitted to a nursing home. The PAC patients in this study had a long rehabilitation process, or the
rehabilitation did not result in discharge to their own home. Therefore, it can be expected that these
patients were more disabled on admission than the patients who were discharged within 3 months.

Further research is needed to investigate the causative factors for transitions to UI and FI. Is
deterioration merely a symptom of declining mobility and cognition, or do other factors play a
role?(20). Is prompted voiding technique a promising method, not only for UI but also for FI and DI?
Will it act as a preventative measure for DI?

More research is also needed to understand the development of FI, and more specifically DI. It is also
of importance to determine whether or not incident morbidity plays a role in the incidence of the
different types of incontinence in the nursing home.

In this longitudinal study we described changes in the continence status of nursing home patients in a
very large population, but did not study the severity of UI and FI. The combined study of changes and
the severity of UI and FI may lead to a better understanding of the development of incontinence in
nursing home patients. In these patients more can be achieved with prevention than with treatment.
Studying the changes can elucidate the factors that play a role in the development of incontinence and
thus help us to develop better prevention strategies. The results of this study show that it is very important to investigate more closely the transition from UI only to DI (acquiring FI).

MDS data are observational data that are gathered on a routine basis, and therefore one must consider the reliability and sensitivity to change of these data when used for research purposes. A study of the validity of the MDS incontinence items from the early MDS period revealed that they identify urinary incontinence accurately in nursing home residents (16). However, the same study questioned their clinical utility because of variability between direct observational measures of wetness and the MDS incontinence severity scores. In this study we only used the score for complete control, which means that a patient also scored UI or FI if the incontinence occurred once a week or less often. Complete control is clinically very important because it gives patients a feeling of security and they don’t have to wear a pad.

In conclusion, our longitudinal study showed that the most important changes in nursing home patients are: UI only to DI, continence to UI only and UI only to continence. Continence status does not only decline in these patients, but can also improve. Improvement is predominantly seen during the rehabilitation process, and deterioration is mainly the development of FI. Most patients change from UI only to DI, whereas only a small percentage of patients change from continence to DI. This means that DI does not usually occur instantly. When they deteriorate, most patients first develop UI followed by FI after a certain period of time. In addition to the prevention of UI in nursing home patients, the prevention of FI needs more attention.
References


Chapter 4

Fecal incontinence and loss of toileting skills in the nursing home

P van Houten
WP Achterberg
MG Dik
JN Morris
MW Ribbe
Abstract

Objectives: To establish the relationship between change in toileting skills and the development of fecal incontinence (FI) in nursing home patients.

Design: Cohort study with assessment at baseline, and a 3 month follow-up.

Methods: All patients aged 65 or over in nursing homes in the state of Ohio in the USA were included in October, November, and December 2002. Exclusion criteria were: FI at baseline, and indwelling catheter or ostomy at baseline. Assessments were made with the Minimum Data Set (MDS) at the start of the study and three months later. Fecal incontinence was assessed with the MDS item bowel incontinence. Toileting skills were scored according to the toilet dependency scale (TDS), which is based on the MDS items ‘locomotion on unit’, ‘toilet use’ and ‘find room’. A total of 33037 patients out of 101189 patients, were included in the analysis.

Results: There was a strong correlation between change in toileting skills (as measured with the TDS) and the risk of developing FI. When toileting skills deteriorated, the relative risk of FI increased significantly, and with each step of decline in TDS the risk of FI doubled. However when the toileting skills improved, the relative risk of FI decreased significantly. The same pattern was found for the correlation between change in toileting skills and the severity of FI.

Conclusion: Deterioration in toileting skills is associated with a greater risk of FI and worsening of FI. An increase in toileting skills is associated with less risk of FI and less severe FI.
4.1 Introduction

Urinary incontinence (UI) and fecal incontinence (FI) impose a considerable burden on nursing home patients and staff caregivers because of their high prevalence and impact on quality of life (1,2). They also have major economical implications, due to the costs of care-giving and the use of necessary materials (3-5). FI prevalence rates of more than 50% have been reported in nursing homes (6). Little research has focused on the incidence of FI. One study reported a cumulative incidence of 20% in 296 days (7). But UI and FI frequently coexist in nursing home patients, and for each condition it is speculated that it is the most important risk factors for the development of the other condition (8). The results of cross-sectional studies show that the development of both UI and FI is related to mobility and cognitive impairment (8,9). This is not surprising, because the tasks needed for going to the toilet (transfers, walking or propelling a wheelchair, finding the toilet, manipulation of clothing) (10) all depend more or less on adequate mobility and cognitive functioning. The ability of a person to perform those tasks is referred to as toileting skills (11).

It is assumed that, in addition to other important causal factors (for instance bladder disorders or pelvic musculature and neurological problems) a decline in toileting skills, and therefore a greater need for assistance in toileting, is a major factor in the development of both UI and FI. The aim of this longitudinal study was to investigate the relationship between a change in toileting skills and the development of or improvement in FI.

The incidence of FI is higher than the incidence if UI in a nursing home population, and the impact of FI on quality of life is substantial (12). UI has been found to be a risk factor for development of FI, and we will therefore also establish the effect of the presence of UI at baseline, independent of toileting skills, on the incidence of FI.

4.2 Design and methods

All nursing home patients in Ohio, in the USA, were included in October, November, and December 2002 if they were aged 65 or over. Patients with a catheter or ostomy at baseline were excluded.
Measurement instruments

The Minimum Data Set (MDS) 2.0 was used to collect a broad range of information on the functioning of patients\(^{13}\). The MDS is a structured and comprehensive clinical assessment tool, which produces a considerable amount of information about a patient. It is used in all nursing homes in the United States, and has been translated and implemented in many other countries\(^{14}\). The assessment items elicit information about several aspects of a patient: functioning, health, well-being and behavior. This information is collected during observations made by care-givers, and interviews with patients, family members, and other care staff\(^{15}\). The MDS items have demonstrated good reliability in various studies and in different countries\(^{13;16;17}\).

Continence

Bowel incontinence was assessed according to the MDS bowel incontinence items. Bowel incontinence scores: 0 (no bladder incontinence, complete control), 1 (usually continent: incontinent, but than weekly), 2 (occasionally incontinent: once a week), 3 (frequently incontinent: two or three times a week), and 4 (incontinent, all, or almost all of the time). For the incidence of FI we dichotomized FI incontinence as 0 = continent and 1-4 = incontinent.

The MDS uses the same item scores for urinary incontinence. In this study we dichotomized UI in 0 = continent and 1-4 = incontinent.

Toileting Skills

The Toilet Dependency Score (TDS) was developed as a measure for toileting skills. Independent toileting implies the ability to go to the toilet (walking or in wheelchair and to find the toilet) and to handle clothing and to sit down on the toilet without assistance. Therefore, the scale was constructed on the basis of the MDS items; ‘locomotion on the unit (score 0-4)’, ‘toilet use (score 0-4)’ and ‘find the room (score 0-1)’. The scale ranges from 0 to 8. The scores for locomotion on the unit and toilet use are summarized. If the score for find the room was 1, the score for locomotion on the unit was adjusted to 4, because when residents cannot find their own room or the toilet the resident need assistance in finding the toilet, and this equals a score of 4 on the item locomotion on the unit. The scale for change in TDS ranged from –4 to +4, and a change of more than 4 points was scored as ‘4’.
The MDS-Activities of Daily Living and MDS- Cognitive Performance Scale (CPS) were used as alternative instruments to the TDS to measure the relationship with the change in fecal incontinence. The (hierarchical) ADL-index ranges from minor oversight to highly dependent(18). The CPS is a seven-category index, ranging from cognitively intact to very severely impaired(19). It has been found to have substantial agreement with the Mini-Mental State Examination (MMSE) in the identification of cognitive impairment in research settings(20). By analogy with the change in TDS, the change in ADL and CPS also ranged from –4 to +4. A change in ADL and CPS of more than 4 points was also scored as 4.

We also studied the relationship of the change in FI with the changes in the single MDS items ‘locomotion on the unit’ and ‘toilet use’ for comparison with the scores for TDS. Locomotion on the unit and toilet use scores range from 1 (independent), 2 (supervision), 3 (limited assistance), to 4 (extensive assistance). Locomotion on the unit can be independent when a patient is in a wheelchair. The change on these items also ranged from –4 to + 4.

Statistical analysis

A logistic regression model was constructed (SPSS), with the incidence of FI as outcome and change in TDS as independent variable. Relative risks and 95% confidence intervals were calculated and adjusted for the baseline TDS and the prevalence of UI at baseline.

4.3 Results

At baseline, MDS data were available for 101189 patients. 87915 of whom were 65 years of age or older. 11 832 patients were excluded; 9528 with an indwelling catheter, 2302 with an ostomy, and 1444 with both indwelling catheter and ostomy. Of the remaining 76084 patients, 46861 patients had no FI, and were therefore included in the analysis. The majority of these patients were female (76.2%) and approximately one half had UI (50.9%). However, for 13824 patients there were no follow-up data. The reasons for lost to follow-up were death and discharge. The group of patients who were lost to follow-up had better cognition, less UI, and performed better on the TDS than did the sample group (Table 1). The incidence of FI in the 3-month period was 22.2%.
Table 1 Characteristics

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>Sample N=33037</th>
<th>Lost to follow-up (N=13824)</th>
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</thead>
<tbody>
<tr>
<td>Age, mean (standard deviation)</td>
<td>83.5(8.1)</td>
<td>81.0(7.8)</td>
</tr>
<tr>
<td>Female</td>
<td>76.2%</td>
<td>70.0%</td>
</tr>
<tr>
<td>Activities of Daily Living</td>
<td>2.6(1.4)</td>
<td>3.0(1.4)</td>
</tr>
<tr>
<td>Cognitive Performance Scale</td>
<td>2.2(1.3)</td>
<td>1.3(1.4)</td>
</tr>
<tr>
<td>Urinary incontinence prevalence</td>
<td>50.9%</td>
<td>30.7%</td>
</tr>
<tr>
<td>Fecal incontinence follow-up</td>
<td>22.2%</td>
<td></td>
</tr>
<tr>
<td>Toilet Dependency Score</td>
<td>3.5(2.3)</td>
<td>4.3(2.0)</td>
</tr>
<tr>
<td>(mean and standard deviation)</td>
<td></td>
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Table 2  The Odds Ratio (OR) and 95% confidence interval (95%CI) of incident fecal incontinence for different levels of change in the Toilet Dependency Scale (TDS).

<table>
<thead>
<tr>
<th>Toilet Dependency Score</th>
<th>OR</th>
<th>95% CI</th>
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</thead>
<tbody>
<tr>
<td>-4</td>
<td>0.15</td>
<td>0.10-0.21</td>
</tr>
<tr>
<td>-3</td>
<td>0.25</td>
<td>0.19-0.33</td>
</tr>
<tr>
<td>-2</td>
<td>0.28</td>
<td>0.24-0.34</td>
</tr>
<tr>
<td>-1</td>
<td>0.58</td>
<td>0.52-0.65</td>
</tr>
<tr>
<td>1</td>
<td>1.56</td>
<td>1.41-1.72</td>
</tr>
<tr>
<td>2</td>
<td>2.92</td>
<td>2.58-3.29</td>
</tr>
<tr>
<td>3</td>
<td>4.91</td>
<td>4.18-5.77</td>
</tr>
<tr>
<td>4</td>
<td>10.13</td>
<td>8.79-11.69</td>
</tr>
<tr>
<td>Urinary Incontinence prevalence</td>
<td>4.78</td>
<td>4.45-5.13</td>
</tr>
<tr>
<td>Toilet Dependency Score at baseline</td>
<td>1.36</td>
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Toilet Dependency Score negative means an improvement in toileting skills
Toilet Dependency Score positive means a decline in toileting skills
Figure 1a: Severity of fecal incontinence in relation to toileting skills (TDS). Higher TDS score indicates a deterioration in toileting skills.

![Figure 1a](image1.png)

Figure 1b: Severity of fecal incontinence in relation to change in toileting skills. Negative change means deterioration, positive change means improvement.

![Figure 1b](image2.png)
The correlation between change in toileting skills (TDS) and change in FI status was strong: a decline in toileting skills resulted in a significant increase in the relative risk of FI (Table 2). With each step of decline in TDS the risk of FI doubled, and when the toileting skills improved, the relative risk of FI decreased significantly.

Patients with UI at baseline had a relative risk of 4.78 (95% CI 4.45-5.13) for developing FI, adjusted for toileting skills at baseline and change in toileting skills. Patients with impaired toileting skills at baseline had a higher risk of developing FI (OR= 1.36; 95% CI: 1.34-1.38), independent of the change in toileting skills.

The relationship between toileting skills and the severity of FI at follow-up is shown in Figure 1a. With a decline in toileting skills the percentage of patients with severe FI increased. Figure 1b shows the relationship between change in toileting skills and the severity of FI. With a decline in toileting skills the percentage of patients with more severe FI increases. However, when toileting skills improve the percentage of patients with more severe FI decreased. We found no major differences in these relationships when a separate analysis was performed for men and women (data not shown).

The effect on incident FI of a change in scores for MDS-ADL and a change in scores for the single MDS-item ‘locomotion on the unit’ showed similar relative risks as the change scores on the TDS. Logistic regression with the MDS-item ‘toilet use’ and the MDS-CPS resulted in very large standard errors as a result of too little variation or uneven distribution in 3 months (data not shown).

4.4 Discussion

The ability to ‘go to the toilet’ is the cornerstone of continence, and the development of FI is strongly related to this functional ability. In this study, data on a large cohort of nursing home residents were used to relate the change in FI with changes in toileting skills. The results showed that changes in these skills, controlled for UI and toileting skills at baseline, have a strong relationship with the risk of developing FI. In addition, the extent of decline in toileting skills correlated with the severity of FI. Improvement in toileting skills is correlated with a lower risk of FI and with less severe FI.

Patients with UI at baseline had a 5.8 times greater risk of developing FI, independent of their toileting skills at baseline, and independent of the change in toileting skills. This implies that other important
Fecal incontinence and loss of toileting skills in the nursing home

Factors (apart from a decline in toileting skills) play a role in the development of FI. Parity and stress UI was found to be risk factors for FI in a study of 271 identical twin sisters. Childbirth with perineal injury and sphincter surgery can even after many years, result in FI. This implies that the condition of the pelvic floor is an important factor. However, the use of psychoactive drugs is also associated with a significantly higher risk of developing FI, and the severity of FI is associated with stool consistency and defecation urgency.

We hypothesized that for independent toileting a person should be able to perform several tasks: go to the toilet (walking or in a wheelchair and find the toilet), handle clothing and sit down on the toilet without assistance. Therefore, in addition to mobility, this function also includes ADL and cognitive (find the room) tasks. Changes in the TDS that we developed should therefore more accurately predict the changes in FI status than the MDS locomotion or toilet-use items only, or the MDS-CPS and MDS-ADL scales. The toilet-use items and the MDS-CPS were bad predictors, but the ADL-scale and even the single locomotion-item, correlated just as strongly with change in FI as with change in the TDS score. There might be several explanations for this. Change in locomotion on the unit is possibly a very good indicator of change in overall functional ability, and therefore also of change in continence status. If this is confirmed, it might be very important for use in everyday nursing home practice, not only because of the prognostic value of the change in this item, but (although this should be confirmed by experimental studies) also because of the interventions that could possibly be aimed at independent locomotion.

Another explanation might be that the sensitivity to change is higher for the ADL and locomotion, and lower for ‘find the room’ and ‘toilet-use’. We did find that changes in ‘toilet-use’ and the MDS-CPS were too small or uneven distributed to produce valid results in the logistic regression models. It is very important that, in addition to reliability and validity data, comprehensive data on the sensitivity to change of the MDS items are published.

In spite of the results of the regression models, we want to stress the possible benefits of the TDS. The aim of the TDS is to assess the toileting skills or the assistance that is needed in toileting, and a change in TDS is associated with the risk of FI. A change in ADL and locomotion is also associated with the risk of FI, but the concept of TDS differs from the concept of ADL. The TDS reflects toileting skills.
and ADL reflects the overall need for care (also with eating and bathing). However, when a study focuses on the relationship between toileting skills and continence status it is better to use an instrument that assesses toileting skills than an instrument that assesses the broader concept of overall need for care, even though toileting skills are closely related to the overall need for care.

In this study we also found that patients with less toileting skills at baseline were more at risk of developing FI, independent of any change in toileting skills. This indicates that the development of FI is a problem for the most frail. Our study into the change of continence status in nursing home patients showed that the development of FI indicates that, in fact, it is associated with the development of Dual Incontinence (DI). DI is known as a condition of the most frail(26).

The present study has several limitations. First of all, it is a naturalistic cohort study, and the relationships that were found can have only weak claims to causality. Another limitation is that we used MDS data that were routinely collected in nursing homes in Ohio, and the reliability and validity of the MDS is a source of intense and ongoing discussion(27). Can the MDS, which provides data collected in this way, be a reliable source of data for epidemiological research?

Crooks concluded in a study that was carried out to assess the relationship between MDS incontinence severity ratings with direct measures of UI frequency: “Although the MDS appears to identify incontinent NH residents accurately, its clinical utility may be limited by disagreements between actual wet check data and MDS categorical severity rankings for residents known to be incontinent. The wide variability between direct observational measures of wetness and the MDS scores denoting incontinence severity we observed may limit the potential usefulness of the MDS for detecting changes in incontinence severity”. It is possible that the same conclusion can have some applicability to FI, so there is a need for further research on these relationships, based on measures of incontinence.

The relationship between a decrease in the need for assistance (improved toileting skills) and a decrease in the risk of FI, and the fact that ‘locomotion on the unit’ is the most important factor that can change in a short time, leads to the conclusion that maintaining and improving mobility are important in the prevention of FI in nursing home patients. Mobility (endurance and strength) can be enhanced by training, and this has a positive effect on UI, as was found by Ouslander in a study based on Functional Incidental Training(28). In that study, training did not result in more independence in
toileting. This was also found in a study to improve toileting skills in nursing home patients in the Netherlands(11). However, the results of the present study suggest that it is also important to train mobility to maintain independence in toileting and to prevent the development of FI.

4.5 Conclusion
Changes in toileting skills were strongly associated with changes in FI status. When there is a decline in toileting skills, the risk of developing FI increases and FI is more severe. When the need for assistance declines, the risk of developing FI decreases and FI is less severe. However, a decline in toileting skills is a major, but not the only factor in the development of FI. There are other important factors, partly related to the presence of UI, which play a role in the development of FI.
References


Fecal incontinence and loss of toileting skills in the nursing home


Chapter 5

Incident morbidity and incontinence in nursing homes.

P van Houten
MG Dik
WP Achterberg
JN Morris
MW Ribbe
Abstract

Objectives: To establish the effect of incident morbidity on the development of urinary incontinence (UI) and fecal incontinence (FI) in nursing home patients.

Design: Cohort study with assessment at baseline and at the 3 month follow-up.

Methods: All patients aged 65 or over in nursing homes in the state of Ohio in the USA were included in the study in October, November, and December 2002 (N=16,420 for UI, and N=32,965 for FI analyses). The Patients were assessed with the Minimum Data Set (MDS) at baseline and 3 months later. Data were analyzed with multinomial regression, adjusted for age, gender, morbidity, and toileting skills.

Results: Incident morbidity was associated with both incident UI and incident FI, which remained significant for stroke (UI; OR 1.77, CI 1.21-2.59 and FI; OR 1.58, CI 1.24-2.01), cognitive decline (UI; OR 1.88, CI 1.64-2.16 and FI; OR 1.91, CI 1.74-2.09), and hip fracture (FI; OR 2.45, CI 1.84-3.27) after adjustment for change in toileting skills. Change in toileting skills is associated with a 6.55 (CI 5.60-7.28) times higher risk of UI and a 3.46 (CI 3.22-3.72) times higher risk of FI. UI at baseline is associated with a 6.84 (CI 6.40-7.31) times higher risk of FI, independent of change in toileting skills.

Conclusion: Incident morbidity has considerable influence on the development of UI and FI, independent of loss of toileting skills, which proved to be a very important factor. UI at baseline is associated with a high risk of developing FI.
5.1 Introduction

Urinary incontinence (UI) and fecal incontinence (FI) are great burdens for nursing home patients and their caregivers because of their high prevalence and impact on quality of life(1,2). There are also important economical implications in terms of care-giver time and the cost of materials(3-5).

Cross-sectional studies show that the development of both UI and FI is related to mobility and cognitive impairment(6). This is not surprising, because the tasks needed for going to the toilet (transfers, walking or riding in a wheelchair, find the toilet, manipulate garments)(7) all depend more or less on adequate mobility and cognitive function. The ability to perform those tasks is referred to as toileting skills(8).

UI and FI frequently coexist in nursing home patients, and it is speculated that each condition is the most important risk factor for the development of the other condition(6). It is presumed that, in addition to other important factors (for instance disease of the bladder or pelvis, and declining toileting skills), morbidity is a major causal factor in the development of both UI and FI(9,10).

To test this presumption, this longitudinal study investigated the relationship between incident morbidity and incident incontinence. The study also assessed whether a change in toileting skills is a mediator of the possible association between incident morbidity and incontinence.

5.2 Methods

Subjects

The sample consisted of all nursing home patients in the state of Ohio (USA) in October, November, and December 2002, who were 65 years of age or over. Patients with a catheter or an ostomy at baseline were excluded.

Data were available for 101,189 patients, 87,916 of whom were 65 years of age or older. 11,832 patients were excluded: 9,528 with an indwelling catheter, 2,302 with an ostomy, and 1,444 with both indwelling catheter and an ostomy. Data on 76,084 patients were finally included in the analysis.

There were 26,235 (34.5%) patients with no UI at baseline, and data on 9,815 patients were missing at follow-up (due to discharge or death), so 16,420 patients were included in the analysis of incident UI. At follow-up, 14.2% had UI and 2.5% had an indwelling catheter. (See Figure 1)
There were 46,871 (61.6%) patients with no Fl at baseline, and data on 13,896 patients were missing at follow-up (due to discharge or death), so 32,965 patients were included in the analysis of incident Fl. At follow-up, 22.1% had Fl and 0.2% had an ostomy.

Measurement instruments
The Minimum Data Set (MDS) 2.0 was used to collect a broad range of information on the functioning of the patients(11). This structured and comprehensive staff assessment tool provides information on several aspects of a patient’s functioning, health status, well-being and behavior. This information is collected by means of observations made by caregivers and interviews with the patients and members of their family(12). The MDS is used in all nursing homes in the USA, and has been translated and implemented in many other countries(13). MDS scales have been shown to have good reliability in several studies and in various countries(11;14).

Continence
Continence status was assessed with the MDS items bladder and bowel incontinence, reflecting UI and Fl, respectively.

MDS bladder incontinence scores are: 0 (no bladder incontinence, complete control), 1 (usually continent: incontinent episodes once a week or less), 2 (occasionally incontinent two or more times a week, but not daily), 3 (frequently incontinent: tended to be incontinent daily, but some control present), 4 (incontinent, multiple daily episodes).

MDS bowel incontinence scores are: 0 (no bowel incontinence, complete control), 1 (usually continent: incontinent less than weekly), 2 (occasionally incontinent: once a week), 3 (frequently incontinent: two or three times a week), 4 (Incontinent all, or almost all of the time).

Because we were interested in the presence of UI and Fl in this study, both of which have been shown to be accurately assessed with the MDS(15), we dichotomized incontinence in ‘continent’ (score 0) versus ‘incontinent’ (scores 1 to 4).

Continence status cannot be accurately assessed in the presence of a catheter or an ostomy, so we created separate groups for patients who acquired a catheter or an ostomy during the follow-up period.
Toileting skills

There is no established instrument for measuring toileting skills, therefore we developed the Toilet Dependency Score (TDS) (9). For independent toileting a patient should be able to go to the toilet (walking or ride in a wheelchair and find the toilet), and manipulate clothing and sit down on the toilet without assistance. The TDS is based on the MDS items; ‘locomotion on the unit (score 0-4)’, ‘toilet use (score 0-4)’ and ‘find the room (score 0-1)’. The scale has a range from 0 to 8, and the scores on locomotion on the unit and toilet use are summed. If there was a score of 1 for ‘find room’, the score for locomotion on unit was adjusted to 4, because a patient who cannot find his room or the toilet needs assistance in finding the toilet, and this equals a score 4 for locomotion on the unit. The scale for change in TDS ranged from –4 to +4, and a change of more than 4 points was scored as ‘4’. Incident decline in the TDS was defined as TDS change <0.

Morbidity

The incident morbidity score was also based on MDS items. Stroke, congestive heart failure (CHF) and constipation are scored in the diagnosis section of the MDS. Patients were considered to have incident stroke, incident CHF or incident constipation if they had a negative score for stroke, CHF or constipation at baseline and a positive score at follow-up. Hip fracture was scored positive if ‘hip fracture in the past 180 days’ was positive at follow-up. Cognitive decline was scored according to the Cognitive Performance Scale (CPS), which has a 7 category index, ranging from cognitively intact to very severely impaired(16), and has shown substantial agreement with the Mini-Mental State Examination (MMSE) in the identification of cognitive impairment in research settings(17). If the CPS score at follow-up was higher than the baseline score, this was scored as incident cognitive decline. Mood decline was scored according to the item ‘change in mood’ as follows: no change improved or deteriorated. If a patient had deteriorated at follow-up, this was scored as incident mood decline.
Data analyses

The MDS Activities of Daily Living (ADL) and the CPS were used to assess the baseline characteristics and to compare the study sample with the patients who were lost to follow-up. The ADL index ranges from minor oversight to highly dependent(18).

The association between incident morbidity and both UI and catheter use was analyzed with multinomial regression analyses, with continent patients as reference group. Because there were too few patients with incident ostomy (N=73; 0.2% of the study sample), the association between incident morbidity and both FI and ostomy could not be analyzed with multinomial regression analyses. Therefore, the association between incident morbidity and FI was analyzed with logistic regression analyses, after the exclusion of patients with an ostomy. Incident stroke, hip fracture, CHF, constipation, cognitive decline, mood decline, and gender were included together in all the models. For FI the models also included UI as independent variable. Additionally, all models were adjusted for TDS at baseline and TDS change.

Because the number of patients with a hip fracture (N=126; 0.8% of the study sample) appeared to be too small to yield reliable results in the UI analyses, hip fracture was excluded from the UI models.

5.3 Results

The baseline characteristics are shown in Table 1. In the group of patients who were lost to follow-up, cognitive function had improved (lower CPS score), ADL impairment was greater (higher ADL score), and toileting skills were worse (higher TDS score). This could be expected because the patients who were lost to follow-up were primarily rehabilitation patients who, at the start of rehabilitation had high ADL needs and a better prognosis because of less cognitive problems.

The incidence of loss of toileting skills and morbidity is shown in Table 2. The incidence of loss of toileting skills and mood decline is relatively high, but the incidence of stroke and hip fracture is relatively low.

Urinary incontinence

Associations between morbidity and UI are shown in Table 3.
Incident morbidity and incontinence in nursing homes

Stroke was associated with a high risk of UI (odds ratio [OR] 2.58, CI 1.82-3.65). After correction for (change in) toileting skills the risk of UI became lower (OR 1.77, CI 1.21-2.59), but did not disappear. The same pattern was found for the relationship between stroke and an indwelling catheter. Stroke is associated with a high risk for catheter (OR 4.98, CI 3.07-8.09), and after correction for (change in) toileting skills (OR 2.86, CI 1.68-4.86) a substantial risk remained. Incident CHF was associated with a moderate risk of UI (OR 1.67, CI 1.29-2.17), but after correction for (change in) toileting skills, this moderate risk disappeared. There was, however, a high risk of a catheter (OR 4.67, CI 3.28-6.66), which stayed substantial (OR 3.07, CI 2.09-4.53) after correction for (change in) toileting skills.

Cognitive decline was associated with a high risk of UI (OR 3.07, CI 2.71-3.47). After correction for (change in) toileting skills the risk of UI (OR 1.88, CI 1.64-2.16) was lower, but still evident. Cognitive decline is also associated with a very high risk of a catheter (OR 7.54, CI 6.08-9.34), which stayed high after correction for (change in) toileting skills (OR 3.52, CI 2.79-4.44).

Mood decline (OR 1.48, CI 1.34-1.64) and constipation (OR 1.69, CI 1.41-2.03) were associated with a low risk of UI, which remained significant after correction for (change in) toileting skills.

Fecal incontinence

Associations between morbidity and FI are shown in Table 4.

Stroke was associated with high risk of FI (OR 2.08, CI 1.65-2.63). After correction for (change in) toileting skills the risk of FI (OR 1.58, CI 1.24-2.01) was lower, but significant. The risk of FI after a hip fracture (OR 4.19, CI 3.13-5.56) was high, and after correction for (change in) toileting skills (OR 2.45, CI 1.84-3.27), the risk remained high.

Incident CHF was associated with a moderate risk of FI (OR 1.61, CI 1.35-1.92), which remained after correction for (change in) toileting skills (OR 1.32, CI 1.10-1.59).

Cognitive decline was associated with a high risk of FI (OR 2.69, CI 2.47-2.92). After correction for (change in) toileting skills the risk of FI (OR 1.91, CI 1.74-2.09), was lower, but still evident.

Mood decline (OR 1.15, CI 1.08-1.23) and constipation (OR 1.27, CI 1.13-1.44) were associated with a low risk of FI, which lost significance after correction for (change in) toileting skills (OR 1.06, CI 0.99-1.14), respectively (OR 1.12, CI 0.99-1.27).
Figure 1: Selection procedure for the analysis of the effect of morbidity on urinary incontinence (UI) and fecal incontinence (FI) in a cohort of 100189 nursing home patients in Ohio (USA)
Table 1 Baseline characteristics for all patients: patients with incident urinary incontinence and incident fecal incontinence and patients who were lost to follow-up at three months

<table>
<thead>
<tr>
<th></th>
<th>Total baseline sample N=76084</th>
<th>Sample with incident UI N=16420</th>
<th>Sample with incident FI N=32965</th>
<th>Lost to follow-up N=13896</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age, mean (standard deviation)</td>
<td>83.3(8.1)</td>
<td>82.3(8.2)</td>
<td>83.5(8.1)</td>
<td>81.0(7.8)</td>
</tr>
<tr>
<td>Female</td>
<td>74.3%</td>
<td>72.8%</td>
<td>76.2%</td>
<td>70.0%</td>
</tr>
<tr>
<td>Activities of Daily Living, mean (standard deviation)</td>
<td>3.4(1.6)</td>
<td>2.2(1.4)</td>
<td>2.6(1.4)</td>
<td>3.0(1.4)</td>
</tr>
<tr>
<td>Cognitive Performance Scale, mean (standard deviation)</td>
<td>2.7 (1.8)</td>
<td>1.9(1.3)</td>
<td>2.2(1.3)</td>
<td>1.3(1.4)</td>
</tr>
<tr>
<td>Toilet Dependency Scale, mean (standard deviation)</td>
<td>4.8(2.4)</td>
<td>2.6(2.2)</td>
<td>3.5(2.3)</td>
<td>4.3(2.0)</td>
</tr>
</tbody>
</table>

UI= urinary incontinence
FI= fecal incontinence
### Table 2 Patient characteristics at the 3 month follow-up

<table>
<thead>
<tr>
<th></th>
<th>Sample with incident urinary incontinence</th>
<th>Sample with incident fecal incontinence</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>N=16420</td>
<td>N=32965</td>
</tr>
<tr>
<td>Continence</td>
<td>13670 (83.3%)</td>
<td>25594 (77.6%)</td>
</tr>
<tr>
<td>Incontinence</td>
<td>2336 (14.2%)*</td>
<td>7298 (22.1%)#</td>
</tr>
<tr>
<td>Incident catheter/ostomy</td>
<td>414 (2.5%){}</td>
<td>73 (0.2%){}</td>
</tr>
<tr>
<td>Incident loss of toileting skills</td>
<td>2962 (18.0%)</td>
<td>6317 (19.2%)</td>
</tr>
<tr>
<td>Incident stroke</td>
<td>178 (1.1%)</td>
<td>378 (1.1%)</td>
</tr>
<tr>
<td>Incident hip fracture</td>
<td>126 (0.8%)</td>
<td>257 (0.8%)</td>
</tr>
<tr>
<td>Incident congestive heart failure</td>
<td>383 (2.3%)</td>
<td>720 (2.2%)</td>
</tr>
<tr>
<td>Cognitive decline</td>
<td>1586 (9.7%)</td>
<td>3268 (9.9%)</td>
</tr>
<tr>
<td>Mood decline</td>
<td>3556 (21.7%)</td>
<td>6999 (21.2%)</td>
</tr>
<tr>
<td>Incident constipation</td>
<td>766 (4.7%)</td>
<td>1628 (4.9%)</td>
</tr>
</tbody>
</table>

* urinary incontinence

# fecal incontinence

{ catheter

φ ostomy
Table 3  Association between incident morbidity and both urinary incontinence and catheter use (N=16,420)

<table>
<thead>
<tr>
<th>Incident morbidity</th>
<th>OR(95% CI)</th>
<th>OR(95% CI)</th>
<th>OR (95% CI)</th>
<th>OR (95% CI)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>urinary</td>
<td>urinary</td>
<td>catheter</td>
<td>catheter</td>
</tr>
<tr>
<td>urinary incontinence</td>
<td>Model 1*</td>
<td>Model 2#</td>
<td>Model 1*</td>
<td>Model 2#</td>
</tr>
<tr>
<td>Stroke</td>
<td>2.58 (1.82-3.65)</td>
<td>1.77 (1.21-2.59)</td>
<td>4.98 (3.07-8.09)</td>
<td>2.86 (1.68-4.86)</td>
</tr>
<tr>
<td>Congestive heart failure</td>
<td>1.67 (1.29-2.17)</td>
<td>1.27 (0.96-1.67)</td>
<td>4.67 (3.28-6.66)</td>
<td>3.07 (2.09-4.53)</td>
</tr>
<tr>
<td>Mood decline</td>
<td>1.48 (1.34-1.64)</td>
<td>1.25 (1.12-1.40)</td>
<td>1.72 (1.39-2.14)</td>
<td>1.37 (1.09-1.71)</td>
</tr>
<tr>
<td>Cognitive decline</td>
<td>3.07 (2.71-3.47)</td>
<td>1.88 (1.64-2.16)</td>
<td>7.54 (6.08-9.34)</td>
<td>3.52 (2.79-4.44)</td>
</tr>
<tr>
<td>Constipation</td>
<td>1.69 (1.41-2.03)</td>
<td>1.39 (1.15-1.69)</td>
<td>2.38 (1.70-3.34)</td>
<td>1.87 (1.30-2.67)</td>
</tr>
<tr>
<td>TDS change</td>
<td>--</td>
<td>6.55 (5.90-7.28)</td>
<td>--</td>
<td>19.93 (15.57-25.51)</td>
</tr>
<tr>
<td>TDS baseline</td>
<td>--</td>
<td>1.24 (1.21-1.27)</td>
<td>--</td>
<td>1.51 (1.44-1.60)</td>
</tr>
<tr>
<td>Female</td>
<td>0.81 (0.73-0.90)</td>
<td>0.88 (0.79-0.99)</td>
<td>1.12 (0.90-1.40)</td>
<td>1.32 (1.05-1.67)</td>
</tr>
</tbody>
</table>

Reference group: continent (no urinary incontinence at follow-up)

TDS= Toilet Dependency Scale

* Model 1: adjusted for gender, and all incident morbidities as mentioned in the Table.
# Model 2: additionally adjusted for TDS baseline and TDS change.
### Table 4  
Association between incident morbidity and fecal incontinence (N=32,965)

<table>
<thead>
<tr>
<th>Incident morbidity</th>
<th>OR (95% CI)</th>
<th>OR(95% CI)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>fecal incontinence</td>
<td>fecal incontinence</td>
</tr>
<tr>
<td>Model 1*</td>
<td>Model 2#</td>
<td></td>
</tr>
<tr>
<td>Stroke</td>
<td>2.08 (1.65-2.63)</td>
<td>1.58 (1.24-2.01)</td>
</tr>
<tr>
<td>Hip fracture</td>
<td>4.19 (3.16-5.56)</td>
<td>2.45 (1.84-3.27)</td>
</tr>
<tr>
<td>Congestive heart failure</td>
<td>1.61 (1.35-1.92)</td>
<td>1.32 (1.10-1.59)</td>
</tr>
<tr>
<td>Mood decline</td>
<td>1.15 (1.08-1.23)</td>
<td>1.06 (0.99-1.14)</td>
</tr>
<tr>
<td>Cognitive decline</td>
<td>2.69 (2.47-2.92)</td>
<td>1.91 (1.74-2.09)</td>
</tr>
<tr>
<td>Constipation</td>
<td>1.27 (1.13-1.44)</td>
<td>1.12 (0.99-1.27)</td>
</tr>
<tr>
<td>TDS change</td>
<td>--</td>
<td>3.46 (3.22-3.72)</td>
</tr>
<tr>
<td>TDS baseline</td>
<td>--</td>
<td>1.29 (1.27-1.31)</td>
</tr>
<tr>
<td>Urinary incontinence</td>
<td>6.84 (6.40-7.31)</td>
<td>5.04 (4.67-5.41)</td>
</tr>
<tr>
<td>Female</td>
<td>1.20 (1.12-1.28)</td>
<td>1.33 (1.24-1.43)</td>
</tr>
</tbody>
</table>

Reference group: continent (no fecal incontinence at follow-up)

TDS= Toilet Dependency Score

* Model 1: adjusted for gender, urine incontinence , and all incident morbidities mentioned in the Table.

# Model 2: additionally adjusted for TDS baseline and TDS change.
**Effect of change in toileting skills**

Change in TDS was associated with a 6.55 (CI 5.90-7.28) times higher risk of UI, a 3.46 (CI 3.22-3.72) times higher risk of FI, and a 19.93 (CI 15.57-25.51) times higher risk of a catheter. UI at baseline was associated with a 6.84 (CI 6.40-7.31) times higher risk of FI, independent of TDS at baseline and change in TDS.

5.4 **Discussion**

This study showed that incident morbidity is associated with UI, catheter use, and FI, independent of loss of toileting skills. This suggests that other factors than loss of toileting skills contribute to the development of incontinence. The risks were highest for stroke, cognitive decline and hip fracture, and lowest for mood decline and constipation.

Stroke was associated with a high risk of both UI and FI in this large sample of nursing home patients. This implies that there are other factors in stroke, apart from toileting skills, that have a negative influence on continence. However, although toileting skills did not fully attribute to the decline in continence status, it is important to focus on toileting skills in the treatment of post-stroke continence problems(19;20). Pettersen found that in patients with UI, bladder awareness and attentiveness in UI play an important role after stroke(21). However, in the study population the influence of stroke on decline of continence status is in the general population was small because, the incidence of stroke was low (1.1% in this study).

Cognitive decline was also associated with a high risk of UI and FI in nursing home patients, and the incidence of UI and FI associated with cognitive decline could partially be attributed to a decline in toileting skills. It is possible that there is residual confounding, because there are factors (for instance apathy or endurance problems) that are not included in the TDS, but it is also possible that there were still other, unidentified factors that contributed to the decline in continence status. Cognitive decline can be caused by progressive dementia and delirium. Dementia progresses slowly and gradually, but delirium induces a rapid and sudden cognitive decline, and it is possible that cognitive decline is caused to a certain extent by delirium. In delirium, awareness and attentiveness decreases. Treatment of the delirium can therefore improve the continence status, but toileting skills should also be
addressed simultaneously. Furthermore, the incidence of cognitive decline was high (9.7%) in the
study population. These findings indicate that treatment of delirium may be a factor that is of great
importance in the treatment of continence problems in nursing home patients.

The strong relationship between incident cognitive decline and an indwelling catheter is remarkable.
This might be based on an inverse relationship, because an indwelling catheter can induce urinary tract
infection (UTI), and this in turn can induce delirium.

Incident CHF is associated with moderate and comparable risks of UI and FI. One could have
expected a higher risk of UI, because diuretics are used in the treatment of CHF. However, CHF also
has an effect on endurance, which can be an important problem in toileting, because patients who have
no endurance do not feel able to go to the toilet. After correction for toileting skills, the risk of UI
disappeared and the risk of FI became low, indicating that a decline in continence status was
predominantly a problem resulting from a decline in toileting skills.

Mood decline was associated with a low risk of UI and FI. Although mood decline had an incidence of
21.7%, this longitudinal study showed that it was not an important factor in the development of UI or
FI. Furthermore, there can be an inverse relationship, because cross-sectional studies have shown that
incontinence is associated with depressive symptoms(22;23).

Constipation was associated with a low risk of UI and FI, and the incidence of constipation was low
(4.7%). Therefore, constipation is not a major factor in the decline in continence status in this study
population. Schnelle reported a less dramatic effect of consistent toileting assistance on patients with
FI, compared with patients with UI, because of constipation(24). This suggests that incident
constipation is not a factor in the development of FI, but it is an important factor in resolving FI. In the
literature, fecal impaction is mentioned as an important factor in the development of UI and FI, and
fecal impaction is also included in the MDS. However, the incidence of fecal impaction in our large
study population was too small for analysis. It is possible that fecal impaction can be a factor in some
cases, but our data suggest that it is not a factor that is of importance for the general population, or that
impaction is not measured accurately enough in the MDS.

Change in toileting skills is associated with a 6.5 times higher risk of UI and a 3.5 times higher risk of
FI. Change in toileting skills (adjusted for incident morbidity) had the greatest impact on the risk of UI
and FI. Therefore, it seems to be the most important factor for inclusion in prevention and treatment strategies. Change in toileting skills is also associated with a 20 times higher risk of an indwelling catheter. It is possible that an indwelling catheter is considered to be an acceptable solution for UI when there is a mobility disorder. However, an indwelling catheter is almost always associated with UTI and sometimes even death from urosepsis(25). Therefore, more effort must be made to reduce the use of an indwelling catheter by providing enough assistance in toileting, or by the use of condom catheters, bedpans and pads.

UI at baseline is associated with a 6.8 times higher risk of FI, and this is independent of toileting skills at baseline and change in toileting skills. In this study we did not collect data to investigate probable causes for this phenomenon, but our hypothesis is that it is associated with lack of motivation (patient and care-giver) to defecate on the toilet once the patient has UI. Other explanatory factors might be rapidly declining condition of the pelvic floor, rapidly declining endurance, decreasing awareness and reduced attentiveness.

The strengths of this study are its longitudinal design, the very large sample size and the opportunity provided to study the contribution of several incident morbidities and toileting skills on both UI and FI. In addition, we took into account the presence of an indwelling catheter or an ostomy, both of which prominently affect continence status. A limitation of the study is the variable time-frame between the incidence of morbidity and the assessment. It is not known at what moment within the time-frame the morbidity’s arose, and the relationship of an incident factor with incontinence can change within a 3-month time-frame. It is well known that directly after a stroke or a hip fracture incontinence can occur, but this can disappear over time, so much the reversible UI and FI that results from the incident morbidity is missed. It is possible that toileting skills are not completely assessed with the TDS, because apathy and endurance problems were not included in the TDS, so there can be residual confounding. Therefore, the correlation’s we found must not be interpreted as causal relationships.
5.5  Conclusion

Stroke and cognitive decline are influential in the development of UI and FI, independent of loss of toileting skills, which was found to be also a very important factor. UI at baseline is associated with a high risk of developing FI.
References


Incident morbidity and incontinence in nursing homes


Chapter 6

Training toileting skills in disabled incontinent elderly women

P van Houten
WP Achterberg
MG Dik
MW Ribbe
Abstract

Objective: To establish the effect of training disabled elderly women with the aim to decrease the time they need for specific toileting skills.

Design: Randomised single-blinded controlled trial on the effect of a training program for mobility and toileting skills.

Population: Disabled elderly non-demented women with mild or moderate mobility and transferring disorders (n=57).

Intervention: A specifically developed training program for mobility and toileting skills provided by trainee physiotherapists and/or occupational therapists. The intervention is based on the performance of the tasks in the Toilet Timing Test, which was specifically developed to measure mobility and toileting skills. The exercises took place in the patient’s home environment, 3 times a week, and lasted for 30 minutes.

Methods: The most important outcome measure was the day-time and the night-time sum-score for the TT test under standardised circumstances. The ratio of improved participants was also used as outcome measure. This ratio was calculated for tasks performed under standardised and daily circumstances. The TT test was adjusted for ambulant participants and participants in a wheelchair. Data were analysed with non-parametric tests.

Results: The intervention had a statistically significant effect on the number of women who improved their day-time sum-score from the TT test under standardised circumstances (p=0.05). The effect on the number of women who improved on their night-time sum-score was borderline significant (p=0.06). The intervention had a significant effect on speed in the wheelchair group, measured with the TT test under daily circumstances, although the effect was in favour of the control group. There was a tendency towards significance on the following tasks of ambulant participants, also measured with the TT test under standard circumstances: the speed of walking, rising from a chair and sitting down on the toilet. In the intervention group there were 6 patients who achieved independent toileting compared with 2 in the control group.

Conclusion: Toileting skills can be improved by a targeted training program.
6.1 Introduction

Mobility disorders are related to urinary incontinence in nursing home patients (1, 2), and it has been found that dependency in toileting is related to urinary incontinence. When mobility disorders and dependency in toileting are predisposing factors for urinary incontinence, it is important to know whether or not these factors are reversible. Positive results of mobility training programs for frail elderly have been reported in the literature. In the Functional Incidental Training program (FIT) (3-10) the exercises are incorporated in daily care. It was concluded that the FIT intervention increased both physical activity and mobility endurance in extremely frail and deconditioned nursing home residents. However the cost of the FIT intervention was very high and it had no effect on independent locomotion and toileting. The main reason for the high costs was the time that the nursing aids had to invest each day in order to prompt the patient to go to the toilet and to give the necessary assistance. It is possible that a tailor-made, targeted intervention provided by therapists could also be effective, and would probably be more cost-effective.

Elsewhere we reported on our study of the effects of training toileting skills on urinary incontinence in non-demented elderly disabled women (11). In that study the target of the intervention was toileting tasks.

The current article describes the modular intervention we used in the fore-mentioned study. The research question that we addressed was: Is it possible to reduce the time needed for toileting by training specific skills related to toileting in non-demented, disabled elderly women?

6.2 Methods

We used data from a randomised single-blinded controlled trial on the effect of a specifically developed training program for mobility and toileting skills on chronic urinary incontinence in disabled elderly women with a mild or moderate mobility disorder (11).

Twenty three institutions participated (twelve nursing homes, four retirement homes, and seven combinations of a nursing home and a retirement home).

The selection, inclusion and randomisation procedures have already been described elsewhere (11) (chapter 7). The study protocol was approved by the Medical Ethics Committee of the VU University.
Medical Center in Amsterdam, and written informed consent was obtained from all participants. There were 29 patients in the intervention group and 28 in the control group.

**Measuring toileting skills**

A test was developed for the measurement of toileting skills. This test, the Toilet Timing test (TT test) is based on the POTTI test described by Ouslander (12). The TT test (fig 1) measures the time a patient needs under standardised circumstances to perform the tasks associated with going to the toilet. Contrary to the POTTI test, we developed not only a version for patients who are able to walk, but also a version for patients who use a wheelchair. The version for ambulant patients measures the time needed to perform the following tasks: (1) get out of bed and get up from a chair, (2) walk 5 meters, (3) undo a hook, zip and button, (4) pull down clothing and sit down on the toilet, (5) stand up from the toilet and adjust clothing. The version for patients who use a wheelchair measures the time needed to perform the following tasks: (1) get out of bed, (2) ride 5 meters in a wheelchair, (3) undo a hook, zip and button, (4) transfer from the wheelchair and pull down clothing and (5) sit down on the toilet, (6) transfer from the toilet to the wheelchair and adjust clothing. A threshold time was calculated for each task, based on the performance of a group of continent elderly volunteers with no mobility disorders and a group of continent elderly service flat inhabitants with a mild mobility disorder (the threshold time was calculated as 2 times the difference between the groups added to the median of the service flat inhabitants). The threshold time was used for the selection of patients and for targeting the intervention. If the task was performed within the threshold time, we assumed that it was unlikely that there was a relationship between the performance of this task and incontinence. If the task took longer than the threshold time, we assumed that this slow performance was an obstacle for normal toileting. The time that was needed to perform the separate tasks was summed to reflect the day and night situation in sum-scores. The day-time sum-score = walk or ride five meters + stand up from a chair + undo clothing and sit down on the toilet. Night-time sum-score = get out of bed, walk or ride 5 meters, undo clothing and sit down on the toilet. Performance of the task was considered to be impossible if it took more than five minutes, in which case a sum-score could not be calculated.

In addition to the TT tests under standardised circumstances, modifications were developed for measuring the time needed to go to the toilet in individual daily circumstances. These modifications...
(both for ambulant patients and patients in a wheelchair) consisted of the same tasks, but instead of comparisons with threshold times, the daily circumstances were described in parameters such as distance to the nearest toilet, dimensions of the toilet, etc.

Selection, inclusion and randomisation

The inclusion procedure consisted of two steps. First, the nurses were asked to list all women with no evidence of dementia, who were incontinent and had a mild or moderate mobility and transfer disorder. These women were invited to participate in step 2 of the selection procedure, in which women who consented, were checked for the following inclusion criteria: female, age 65 or over, episodes of urinary incontinence at least twice a week, urinary incontinence for longer than three months, able to walk or ride in a wheelchair to a toilet independently, and able to transfer to a toilet independently or with the aid of one person.

Exclusion criteria, which were assessed by means of a questionnaire and investigation by a doctor and a research nurse, were: current paramedic intervention for urinary incontinence, indwelling urinary catheter, intervention for incontinence in the past 6 months, other known bladder pathology, urinary tract infection not responding to treatment, haematuria, post-void residue greater than 150 ml (measured by means of catherisation), a TT test score for all tasks in standardised circumstances below the threshold (i.e. no mobility disorder that could have had any relationship with incontinence), Mini Mental State Examination (MMSE) (13) of less than 18.

Randomisation to the intervention group or the control group took place done after the final inclusion. There were two strata based on the ability of a participant to perform the tasks needed for toileting independently or with aid. In practice, this implied that the time needed to perform one or more tasks on the TT test in standardised circumstances did or did not exceed 5 minutes.

The intervention

The intervention consisted of a specifically developed modular training program for mobility and toileting skills, provided by physiotherapists and/or occupational therapists. The therapist based the choice of therapy on the participant’s performance of the TT test tasks under standardised circumstances, needing time more than the threshold time. One or more of the following three intervention goals were assigned to each individual participant: increase in the speed of transfer, the
speed of walking or riding in a wheelchair and the speed of manual skills. The intervention goals were assigned to participants, both in the intervention group and in the control group. In the intervention group the tasks corresponding with the goals were practised 3 times a week for 30 minutes. The therapist stopped the training when the patient was able to perform the task in less than the threshold time. If more than one task took longer than the threshold time all of the tasks were practised. In addition to the training, the therapist could also change the circumstances in the environment so that patients could get to the toilet quicker. The therapists kept diaries to record the duration of the treatment sessions, the exercises, the performance of the exercises and any changes made in the daily circumstances. The patient’s family doctor had to approve the intervention plan, and the intervention period lasted for a maximum of 8 weeks and 24 treatment sessions. An extensive modular program for the therapists was developed by the Department of Physiotherapy of the Academic Hospital of the Vrije Universiteit (RC Wagenaar and G Kwakkel). This program was based on existing literature on interventions for three major mobility disorders in the elderly (hemiparesis, arthrosis and extrapyramidal problems). The most important guidelines are described in Appendix 1. The participants in the control group did not receive any treatment.

Compliance with the intervention was expressed in the following manner: the compliance was coded as 1 (full compliance) if the treatment was stopped because the goals of the TT test items were achieved, or a total of 24 treatment sessions had been completed. If not all the treatment sessions had been completed and the goals were not achieved, the compliance was calculated as the result of the number of completed treatment sessions divided by 24 (i.e. the maximum number of treatment sessions).

**Outcome measures**

The most important outcome measure was improvement in the TT test scores under standard circumstances. TT test scores were calculated as a day and a night sum-score for each participant. A subject scored ‘improved on TT test’ if the sum-score for day-time respectively night-time was lower at the end of the intervention period, or if a sum-score (day, respectively night) could be calculated after the interventions, whereas this was not possible at baseline.
An ‘improved participants ratio’ (IP ratio) was also calculated as follows: the number of participants who improved for each intervention goal (transfer, speed, manual skills) divided by the total number of participants who had the same intervention goal. The ratio was calculated for tasks performed under standardised circumstances and also for the same tasks performed under daily circumstances. For the tasks concerning speed and transfers a distinction was made between ambulant participants and participants in a wheelchair.

The therapists were allowed to change environmental circumstances, the most important of which was the distance from a chair or bed to the toilet and clothing. These changes were also recorded.

The following potential confounders or effect modifying factors were recorded at baseline: age, cognitive functioning assessed MMSE(13) (range 0-30), the Barthel index (range 0-20), motivation (a score, range 0-6, the score for three questions about perceived burden of the incontinence, perceived feasibility of successful treatment, and willingness to invest time in the treatment), feeling ill, type of mobility disorder (pyramidal, extrapyramidal, arthrosis, mixed), comorbidity (number and nature of validity-defining diagnoses) and medication.

The following confounders were monitored during the intervention period: changes in morbidity and medication, and also co-interventions, based on data obtained from the physician.

Comparison of groups

The data were analysed in SPSS. Significance was calculated with Chi-square test (Fisher’s exact 2-tailed test).

6.3 Results

Baseline characteristics

The study population consisted of women with urinary incontinence for more than 3 months. These women had no impairment, or only a mild cognitive impairment and a moderate need for assistance with daily activities. The average Barthel index score was 12 and the average MMSE score was 24. The baseline characteristics of the intervention group and control group are listed in Table 1. There were only minor non-significant differences between the two groups: participants in the intervention...
group were slightly older and had a somewhat higher mean Barthel index score. In the intervention group, typical urge incontinence was more often present than in the control group.

**Table 1  Baseline characteristics of intervention and control group**

<table>
<thead>
<tr>
<th></th>
<th>Intervention group (n=29)</th>
<th>Control group (n=28)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age (average and standard deviation)</td>
<td>80.9 (7.35)</td>
<td>84.5 (6.36)</td>
</tr>
<tr>
<td>Barthel Index (average and standard deviation)</td>
<td>13.36 (4.21)</td>
<td>11.72 (3.60)</td>
</tr>
<tr>
<td>Mini Mental State Exam (average and standard deviation)</td>
<td>23.93 (3.69)</td>
<td>24.32 (3.09)</td>
</tr>
<tr>
<td>Ambulant/Wheelchair</td>
<td>18/11</td>
<td>17/11</td>
</tr>
<tr>
<td>Number of validity-defining diagnoses (median)</td>
<td>4</td>
<td>3</td>
</tr>
<tr>
<td>Urge/stress/mixed/not classified</td>
<td>18/0/5/6</td>
<td>12/1/6/9</td>
</tr>
<tr>
<td>Number of medicines (median)</td>
<td>5</td>
<td>4.5</td>
</tr>
<tr>
<td>Type of primary mobility disorder</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Type of mobility disorder:</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Pyramidal/extrapyramidal/arthritis/other</td>
<td>9/4/9/7</td>
<td>11/4/6/7</td>
</tr>
<tr>
<td>Motivation</td>
<td></td>
<td></td>
</tr>
<tr>
<td>-score (average and standard deviation)</td>
<td>3.89 (1.26)</td>
<td>3.56 (1.31)</td>
</tr>
<tr>
<td>-feeling ill</td>
<td></td>
<td></td>
</tr>
<tr>
<td>no/ neither yes or no/yes</td>
<td>16/12/1</td>
<td>16/9/2 (one missing)</td>
</tr>
<tr>
<td>One or more TT tasks &gt; 5 min</td>
<td>10</td>
<td>9</td>
</tr>
</tbody>
</table>
Intervention

During the intervention period three women in the intervention group and two women in the control group dropped out. In the intervention group, one woman was admitted to hospital with a heart condition, one woman developed severe back-ache, and one woman had an acute delirium. In the control group, one woman died from pneumonia after she injured her leg during a fall, and one woman was unwilling to participate in the follow-up because she found it too much of a burden.

There was 0.8 median compliance with the therapy.

Outcome of the intervention

Table 2 shows the number of participants with standardised TT tasks scores above threshold. In 16 women the scores for all tasks were above threshold, followed by 12 with only transfer above threshold. In 11 women the scores for transfer and manual skills were above threshold. Other (combinations of) task were less frequent. The intervention had a statistically significant (p=0.05) effect on the number of women who improved on their day-time sum-score for the TT test under standardised circumstances (Table 3). The effect on the number of women who improved on the night-time sum-score was borderline significant (p=0.06). The intervention had a significant effect (p=0.05) on the speed of riding a wheelchair, measured with the TT test under daily circumstances in favour of the control group (Table 4). There was a tendency toward significance for the following tasks of ambulant participants, also measured with the TT test under standard circumstances: rising from a chair (p<0.10), speed of walking (p<0.20), and sitting down on the toilet (p<0.20).

There were 8 women who changed from dependent to independent toileting on TT day-time and/or night-time tests; 6 in the intervention group and 2 in the control group. There were 7 women who changed from independent to dependent toileting; 4 in the intervention group and 3 in the control group. There were 34 women with no change in dependency.

Only 4 participants achieved all their intervention goals. They received all four interventions for manual skills and needed an average of only 6 treatment sessions.
Table 2  Number of subjects with standardised Toilet Timing tasks above threshold

<table>
<thead>
<tr>
<th>TT Tasks</th>
<th>Intervention group (N=28)</th>
<th>Control group (N=29)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Transfer</td>
<td>5</td>
<td>7</td>
</tr>
<tr>
<td>Speed</td>
<td>4</td>
<td>0</td>
</tr>
<tr>
<td>Manual skills</td>
<td>6</td>
<td>1</td>
</tr>
<tr>
<td>Speed and manual skills</td>
<td>1</td>
<td>0</td>
</tr>
<tr>
<td>Transfer and manual skills</td>
<td>5</td>
<td>6</td>
</tr>
<tr>
<td>Transfer and speed</td>
<td>3</td>
<td>3</td>
</tr>
<tr>
<td>All 3 tasks</td>
<td>5</td>
<td>11</td>
</tr>
<tr>
<td>Total</td>
<td>29</td>
<td>28</td>
</tr>
</tbody>
</table>

Table 3  Effect of the intervention on the standardised Toilet Timing test sum-scores

<table>
<thead>
<tr>
<th></th>
<th>Intervention group (n=25)</th>
<th>Control group (n=28)</th>
<th>P</th>
</tr>
</thead>
<tbody>
<tr>
<td>TT day sum</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Improved</td>
<td>17</td>
<td>11</td>
<td>0.05*</td>
</tr>
<tr>
<td>Not improved</td>
<td>8</td>
<td>17</td>
<td></td>
</tr>
<tr>
<td>TT night sum</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Improved</td>
<td>15</td>
<td>9</td>
<td>0.06</td>
</tr>
<tr>
<td>Not improved</td>
<td>10</td>
<td>19</td>
<td></td>
</tr>
</tbody>
</table>

* significant

4 subjects were missing because of comorbidity
Table 4 Results of the intervention on the Toilet Timing test: ratio improved/total above threshold per task

<table>
<thead>
<tr>
<th></th>
<th>Standard TT test</th>
<th>Daily circumstances TT test</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Walking</td>
<td>Wheelchair</td>
</tr>
<tr>
<td></td>
<td>Interv</td>
<td>Control</td>
</tr>
<tr>
<td>Getting out of bed</td>
<td>6/8</td>
<td>6/16</td>
</tr>
<tr>
<td>Rising from a chair</td>
<td>6/8</td>
<td>5/16**</td>
</tr>
<tr>
<td>Sitting down on the</td>
<td>6/8</td>
<td>5/16***</td>
</tr>
<tr>
<td>toilet</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Speed</td>
<td>5/8</td>
<td>0/3***</td>
</tr>
</tbody>
</table>

Fisher’s exact test
* p<0.05
** p <0.10
*** p<0.20

6.4 Discussion
This study showed that an improvement in the performance of tasks related to toileting can be achieved by a tailored training program for disabled elderly women. However, although the day-time sum-score (under standardised circumstances) improved significantly, this is probably of no clinical significance because there was no improvement in toileting tasks under daily circumstances. The conclusion must therefore be that with this training program no meaningful improvement was achieved. This negative outcome could be explained by a ceiling effect, if the participants had already received physiotherapy and occupational therapy with a maximum result, so that no additional benefit
could have been achieved by additional training programs. However, we have no information to verify this hypothesis.

Another explanation for the different findings after therapy for the tasks measured by the TT test and the performed tasks might be due to the one-dimensional way in which we measured the tasks, i.e. we only measured the time needed to perform a toileting task. There are also several other factors that might play a role, such as the fluency of motion in performing the tasks, endurance, and self-efficacy (14). These are important because the effect of the intervention is not only to speed up the performance of the task but also to give the patients confidence that she can perform the task successfully, and this may also motivate the patient to go to the toilet more often. The continence charts showed no improvement in the number of visits of the toilet. It is possible that this aspect of motivation did not receive enough attention in the intervention, so that too little use may have been made of the improvement in toileting skills.

Lack of motivation can also occur when there is no meaningful progress. The major goal of the intervention was to reduce urinary incontinence. It is possible that if the participant noticed no meaningful change in this respect her motivation for training the skills diminished. Dependency can change for the worse or for the better, but the natural course of the primary illness is probably of greater importance than therapy when the intervention period lasts for more than a few weeks.

The intervention might be more successful in elderly people with a temporary mobility disorder (for instance stroke patients or patients with hip fractures). Motivation in this group is greater, and dependency can be reduced.

For the analysis of IP ratios the numbers of patients are very small. The only significant effect was an improvement in the speed of riding in a wheelchair in daily circumstances in the control group, but this significant improvement was not seen in the test results in standardised circumstances. One must take into account the fact that the test on riding in a wheelchair in daily circumstances is not only influenced by speed, but also by the distance to the toilet. Because the actual speed in standardised circumstances did not improve, the factor of the distance to the toilet could have an important effect on this finding. Analysing the data on distance to the toilet, we found that the distance to the toilet for 2 patients in the wheelchair control group was shorter at T1, whereas there was no change in distances in
the intervention group. The primary aim of the intervention was to improve toileting skills, so the outcome of the TT test under standardised circumstances is of more importance, while the outcome of the daily circumstances is more important in relation to incontinence.

There was a tendency towards significance in the TT test under standardised circumstances in ambulant patients with regard to rising from a chair (p<0.10), sitting down on the toilet (p<0.20) and speed of walking (p<0.20). However there was no improvement under standardised circumstances for wheelchair patients. These findings suggest that the intervention may only be effective for ambulant patients.

Only 4 (out of 57) participants achieved all their intervention goals and were able to go to the toilet independently. Remarkably, they all received the intervention on manual skills, and needed only 6 treatment sessions. This means that improving manual skills can give a relatively quick result for a certain participants.

In the intervention group 6 patients changed from dependent to independent toileting, and only 2 in the control group. The numbers are small, but clearly in favour of the intervention group. This means that a reduction in nursing time is possible with a targeted intervention. However, further research is needed to investigate the duration of this positive effect and the cost /benefit ratio.

The TT test was designed for 3 purposes: to identify patients with a mobility disorder that could be a problem in toileting, to target an intervention, and to measure change after the intervention. Therefore mobility disorder is sub-divided into specific skills needed for going to the toilet (based on the POTTI test). In the training program for toileting tasks, one does not want too include to many participants with an unlikely relationship between mobility disorder and incontinence. A threshold time was calculated for each task, based on the performance of a group of continent elderly volunteers with no mobility disorders and a group of continent elderly service flat inhabitants with a mild mobility disorder (the threshold time was calculated as 2 times the difference between the groups, added to the median of the service flat inhabitants). The threshold times are relatively high, and it is possible that certain patients who could benefit from the intervention were excluded, and that exceeding a threshold time is not enough to ensure that a specific task is no longer a problem in toileting. All TT tests were
scored by the research nurse, ruling out any interrater variability. The intervention was aimed directly at physical capability, and not motivation, endurance or coping strategies for incontinence.

Strengths of this study are: the use of a targeted intervention based on measurement of skills needed for toileting, and performance of the tasks under standard and daily circumstances. Limitations are: small sample size, and problems with selection and drop out during the intervention.

In conclusion, with a targeted intervention it is possible to decrease the time needed for going to the toilet and achieve independent toileting, but this positive effect was only found in a few participants. The majority of the incontinent women in this study did not improve, so that the effectiveness of the intervention is limited.
References


Chapter 7

Urinary incontinence in disabled elderly women: a randomised clinical trial on the effect of training mobility and toileting skill to achieve independent toileting.

P van Houten
WP Achterberg
MG Dik
MW Ribbe

Gerontology, 2007, 53:205-10
Abstract

Objective: To determine the effect and feasibility of training mobility and toileting skill on the severity of urinary incontinence in elderly, dependent women.

Design: Randomised, single-blinded trial.

Subjects: Fifty-seven dependent, non-demented, elderly women with long-standing urinary incontinence and a mild to moderate disorder in mobility and transfers were recruited in 24 long term care institutions.

Methods: Participants were randomised to receive either no treatment (n=28), or an individualised 8-week training program of mobility and toileting skill (n=29), provided by physiotherapists and/or occupational therapists.

Results: The intervention resulted in a 37.7% reduction in the daily amount of urine loss, and 3 women in the intervention compared to none in the control group became continent. A change from dependent to independent toileting occurred in 6 women in the intervention group and 2 in the control group. All these results, however, were not statistically significant. The intervention did have a significant effect on the day-time sum-score of the Toilet Timing-test.

Conclusion: This study suggests that it is possible to influence long-standing incontinence in dependent elderly women by training mobility and toileting skill. Future studies should have with larger samples and more attention for the motivation of participants.
7.1 **Introduction**

Urinary incontinence is a major burden for the patient and their care-givers (1) and the impact on cost of health care is considerable (2). For community dwelling elderly, urinary incontinence can have a detrimental effect on daily live, especially on social contacts (3,4). The onset and severity of urinary incontinence in elderly women is influenced by many factors, including disorders of the bladder and pelvic floor. Over the last decades the role of decreased mobility and cognitive functioning, comorbidity, medication and care-aspects have received increasing attention (5-9).

In a prospective cohort study among nursing home patients, Ouslander (9) found that spontaneous remission of urinary incontinence was related to achieving independent walking and transfers. Schnelle (10) performed a randomised controlled trial (n=256) in a nursing home population on the effect of a ‘functional incidental training’, a combination of exercise and regular prompting to go to the toilet. After 18 and 32 weeks the intervention resulted in a significant increase in mobility and endurance as well as a reduction of urine incontinence. The question remains, however, to what extent regaining independent toileting or prompting contributed to the effects.

The main goal of the present study is to investigate the effect of training toileting skill to increase independence in toileting, on the severity of incontinence. It addresses the question whether increasing toileting skill as such (i.e. without prompting) will reduce urine incontinence.

7.2 **Methods**

The study was designed as a randomised, single-blinded, controlled trial to determine the effect of a specifically developed training program for mobility and toileting skill on chronic urinary incontinence in dependent elderly women with a mild or moderate mobility disorder. Women with a severe mobility disorder were excluded because it was considered unlikely that they can reach independent toileting. The study population was recruited from nursing homes, homes for the elderly and day-care centres for non-demented elderly people. The study protocol was approved by the Ethical Committee of the VU University Medical Center, Amsterdam. Written informed consent was obtained from all participants.
Table 1: selection procedure for the randomised clinical trial on the effect of training mobility and toileting skill to achieve independent toileting.

<table>
<thead>
<tr>
<th>Inclusion criteria</th>
<th>Exclusion criteria</th>
</tr>
</thead>
<tbody>
<tr>
<td>population: patients in twenty-three institutions in Amsterdam and neighbouring cities who are:</td>
<td>(assessment by physician (PvH) and research nurse after inclusion but before randomisation):</td>
</tr>
<tr>
<td>- female</td>
<td>- current treatment for urinary incontinence</td>
</tr>
<tr>
<td>- age &gt; 65</td>
<td>- indwelling urinary catheter,</td>
</tr>
<tr>
<td>- urinary incontinence =&gt; 2/week</td>
<td>- surgical intervention for incontinence in the past 6 months</td>
</tr>
<tr>
<td>- urinary incontinence =&gt; 3 months</td>
<td>- a history of bladder pathology other than incontinence</td>
</tr>
<tr>
<td>- mild or moderate mobility/ transfer impairment</td>
<td>- urinary tract infection not responding to treatment</td>
</tr>
<tr>
<td>- able to go to the toilet (walking or in a wheelchair) and transfer to a toilet independently or with the aid of one person.</td>
<td>- haematuria</td>
</tr>
<tr>
<td>- No evident dementia</td>
<td>- post-void residue greater than 150 ml (measured by PvH using a catheterization procedure)</td>
</tr>
</tbody>
</table>

n = 220 selected

selected but not included:

n = 99 declined to participate in trial
n = 22 denied being incontinent
n = 21 other reasons for not participating

total not included: 142

included before randomisation n = 78

Excluded before randomisation

n = 14 one or more exclusion criteria
n = 7 no consent physician (too much a burden)

Total included for randomisation n= 57
(29 intervention 28 control)
Selection, inclusion and randomisation

The procedure (described in more detail in table I) aimed to include incontinent women with a mild or moderate mobility and transfer impairment without dementia. The women (age 65 or over) were to have urinary incontinence episodes at least twice a week and existing for at least 3 months, able to go to the toilet (walking or in a wheelchair) and transfer to a toilet independently or with the aid of one person. In the last step, patients with medical exclusion criteria were excluded (see table 1).

Block randomisation to the treatment or the control group took place after final inclusion and consent. The randomisation-lists were kept by a nurse, which was not involved in the study. The randomisation was stratified based on the ability of a person to perform the tasks needed for toileting independently or with aid. This meant that the time needed to perform one or more tasks in the TT-test in standardised circumstances did or did not exceed 5 minutes.

Measuring mobility and toileting skill

To measure mobility and toileting skill the Toilet Timing test (TT-test) was developed, based on Ouslander’s POTTI-test(11). The TT-test measures the time a participant needs to perform the subsequent tasks associated with going to the toilet under standardised circumstances. Two versions were developed: one for participants who usually walk to the toilet, and one for participants that use a wheelchair (see table 2).

For each task a threshold time had been set, based on the average performance observed in a separate group of continent elderly volunteers with no mobility disorders. If a participant performed a task faster than the threshold time, it was considered unlikely that this specific task hindered continence. If a task was performed slower than the threshold time, it was assumed it could be an obstacle for normal toileting. The sum score of the time that was needed to perform the separate tasks reflect the day-time or night-time scores. The day-time sum-score = walk or ride 5 meters + stand up from a chair + undo garments and sit down on the toilet. Night-time sum-score = get out of bed, walk or ride 5 meters, undo garments and sit down on the toilet. A specific task was considered to be impossible if it took more than 5 minutes, in which case no sum-score was calculated.

In addition to the TT-test under standardised circumstances presented above, a version was developed for measuring the time needed to go to the toilet in the actual, individual daily circumstances. This
version included the same tasks but instead of using threshold times, the actual circumstances were described in parameters such as distance to the nearest toilet, dimensions of the toilet, etc. These measurements were performed for comparison before and after the intervention.

All TT-tests were carried out by a research nurse who was blinded for the intervention and were all performed in the morning.

Table 2  the Toilet Timing test for walking participants and for participants in a wheelchair.

<table>
<thead>
<tr>
<th>The Toilet Timing test</th>
<th>Time needed to perform task:</th>
</tr>
</thead>
<tbody>
<tr>
<td>for walking participants</td>
<td>1. get up from a bed/get up from a chair</td>
</tr>
<tr>
<td></td>
<td>2. walk 5 meters</td>
</tr>
<tr>
<td></td>
<td>3. undoing a hook, zipper and button</td>
</tr>
<tr>
<td></td>
<td>4. let down garments and sit down on the toilet</td>
</tr>
<tr>
<td></td>
<td>5. rise from the toilet and adjust garments.</td>
</tr>
<tr>
<td>for participants in a wheelchair</td>
<td>1. get up from a bed</td>
</tr>
<tr>
<td></td>
<td>2. ride 5 meters in the wheelchair</td>
</tr>
<tr>
<td></td>
<td>3. undo a hook, zipper and button</td>
</tr>
<tr>
<td></td>
<td>4. transfer from the wheelchair to the toilet (including letting down garments and taking seat on the toilet)</td>
</tr>
<tr>
<td></td>
<td>5. transfer from the toilet to the wheelchair and adjust garments.</td>
</tr>
</tbody>
</table>

Interventions

The intervention consisted of a specifically developed training program for mobility and toileting skill. The intervention was provided by physiotherapists and/or occupational therapists on an individual basis. An extensive list of instructions for the therapists was made by the Department of Physiotherapy, VU University Medical Center (RC Wagenaar and G Kwakkel) based on a literature study of established interventions for the three major mobility disorders in the elderly (hemi paresis, arthrosis and extra pyramidal problems). The therapists focussed the therapy on the performance of the tasks in the TT-test under standardised circumstances that took longer than the threshold time. These
tasks were then practised 3 times a week for 30 minutes. When more than one task took longer than the threshold time, all of these tasks were practised. In addition to the training, the therapist was allowed to change the residential environment so that participant could more easily reach the toilet. The therapists kept diaries to record the attendance and duration of the treatment sessions, the exercises, the performance on the tasks and any changes made in the residential environment. The intervention period had a maximum of 8 weeks (24 treatment sessions), and a minimum of one week (3 sessions). The therapist was allowed to end the training program if a participant was able to perform all targeted tasks within the threshold time. The control intervention was care as usual. Compliance with the experimental intervention was defined as follows: If the maximum of 24 treatment sessions had been completed, or all goals of the tasks in the TT-test had been achieved earlier, the compliance was coded as 1 (maximal). If not all of the treatment sessions had been completed, the compliance was calculated as the number of actually completed treatment sessions divided by 24.

Outcome measures and control variables
The severity of incontinence was measured by the PAD-test (12) which is an objective, quantitative measure of involuntary urine loss, based on diaper weight gain. For the PAD-test, diapers were collected during the day (8.00-22.00 hours) and at night (22.00-8.00 hours), for 2 or 3 successive periods of 24 hours, after which the average diaper weight gain per day, night and 24-hour period were calculated. The PAD-test was carried out by a research nurse who was blinded for the allocation of the subjects. The diapers were collected in special, marked containers, and numbered sequentially to ensure that no diapers were lost. Weighing took place once every 24 hours. If there was faeces present in a diaper, this measurement was discarded and replaced by an additional 24-hour measurement period. When there was more than 90% weight reduction on the PAD-test the participant was considered to have become ‘continent’.

Secondary outcome measures
1. Change from dependent to independent toileting (when a participant was able to complete all tasks in less than 5 minutes per task the participant was considered independent in toileting), and
2. The alteration on the TT-test. The scores on the TT-test were calculated as day and night sum-score for each participant. A subject scored ‘improved on TT-test’ if the sum-score for day-time respectively night-time was at the end of the intervention period lower, or when after the intervention period a sum-score (day respectively night) could be calculated while this was not possible at baseline.

The number of micturitions on the toilet in relation the total number of micturitions was measured with a micturition diary and Activities of Daily Life with the Barthel index(13). All of these measurements were assessed by the research nurse or the professional caregivers at baseline and at the end of the 8-week intervention period.

Type of incontinence (urge, stress, mixed, not classifiable) was classified by an especially developed algorithm based on the score on a questionnaire concerning urge and the Ouslander stress-test(11) At baseline the following control variables were also registered: age, cognitive functioning as measured by the Mini Mental State Examination(14), motivation (a score, range 0-6, i.e. the sum of three questions about the perceived burden of the incontinence, the perceived feasibility of successful treatment, and the willingness to invest time in the training), feeling ill (yes/no), type of mobility disorder (hemi paresis, extra pyramidal, arhrosis, mixed), co morbidity (number and nature of diagnosis with an impact on dependence) and medication use.

During the intervention period participants were monitored for incident morbidity and medication changes, as well as co-interventions for urinary incontinence. These data were obtained from the general practitioners or nursing home physicians.
Analyses

The effect of the intervention on the PAD test was analysed using analysis of covariance (ANCOVA). Logarithmic transformation was used for the PAD test to normalise the residuals, allowing to define the effect of the intervention as the mean percentage difference between the groups, calculated as \((e^\beta - 1)\) x100 where \(\beta\) is the regression coefficient of the variable indicating the group assignment. Covariates were added to test for possible confounding. \(\chi^2\)-test for contingency tables with continuity correction was used for binary outcomes. When necessary, exact p-values were calculated. For contingency tables, Fischer exact p's were calculated when the expected number in one of the cells was lower than 5.

7.3 Results

Twenty-three institutions in Amsterdam and neighbouring cities agreed to participate in the study: twelve nursing homes, four homes for the elderly and seven combinations of a nursing home and a home for the elderly. Five of these institutions also had a day-care unit for non-demented patients from which participants were recruited as well.

Baseline characteristics.

The baseline characteristics of the women in the intervention and the control group are listed in Table 3. There were only minor differences between the groups. Participants in the intervention group were slightly older and had a somewhat higher mean Barthel index score. More participants in the intervention group had typical urge incontinence than in the control group. The daily amount of urine loss was considerable in both groups.

Intervention period.

During the intervention period three women in the intervention group and two in the control group dropped out. In the intervention group, one woman was admitted to hospital with a heart condition, one woman developed severe backache and one woman suffered from an acute delirium. In the control group, one woman died from pneumonia after she had injured her leg during a fall. One woman completed the second TT-test, but refused the PAD-test at the end of the intervention period because she found it too much of a burden. Six participants were excluded from the final analyses on the PAD-
test due to significant co-interventions or incident morbidity. One woman in the intervention suffered from recurrent urinary tract infections. Two women in the control group had an increase of more than 100% in the distance from chair and bed to the toilet. Three women in the control group had been prescribed medication for incontinence (1) or diuretics (2). Of the 57 participants, 29 had one or more new diagnoses by the end of the intervention period, and 22 had made a change in their medication. Median compliance in the intervention group was 0.8.

**Effect of the intervention.**

As presented in table 4, the intervention resulted in an 8 to 35% decrease in the amount of urine loss relative to control, though not reaching statistical significance. Three women in the intervention group and none in the control group showed a reduction of the amount of urine loss of more than 90% (p=0.24). All three had a baseline Barthel index score that was average or above (12, 14, and 17 respectively), a high compliance (0.9 to 1.0) and no changes to their toilet circumstances had been made. None of these women had a clear change in their TT-score.

There were 6 women who changed from dependent to independent toileting on the day-time and/or night-time TT-test in the intervention group and 2 in the control group (p=0.14). Besides, there were 7 women who changed from independent to dependent toileting on the day-time and/or night-time TT-test: 4 in the intervention group and 3 in the control group (p=0.70). Four participants achieved all goals set in the intervention. They all had received a training of hand skill and had needed on average only 6 treatment sessions to achieve their goals.

The intervention did have a positive and statistically significant effect on the day-time sum-score for the TT-test under standardised circumstances (Table 5). The positive effect on the night-time sum-score was of borderline significance. The intervention had no significant effect on the number or percentage of micturitions on the toilet. Moreover, no significant effects on the Barthel index score and the micturition diary were observed (data not shown). All effects were similar for both randomisation strata, and no modification of the effects by other characteristics were found either, although the power to detect these differences was small.

On the 6-point motivation scale, the women scored on average, between 3 and 4 points, indicating that the motivation was moderate. Only 32 women (56%), reported that they did not feel ill at all.
### Table 3  Baseline characteristics of women in the intervention and the control group

<table>
<thead>
<tr>
<th></th>
<th>Intervention (n=29)</th>
<th>Control (n=28)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age (average, std)</td>
<td>80.9 (7.35)</td>
<td>84.5 (6.36)</td>
</tr>
<tr>
<td>Barthel index (average, std)</td>
<td>13.4 (4.2)</td>
<td>11.7 (3.6)</td>
</tr>
<tr>
<td>MMSE (average, std)</td>
<td>23.9 (3.7)</td>
<td>24.3 (3.1)</td>
</tr>
<tr>
<td>Walking/Wheelchair</td>
<td>18/11</td>
<td>17/11</td>
</tr>
<tr>
<td>PAD (median/25-75 perc) in gram</td>
<td>462 (97/779)</td>
<td>448 (88/736)</td>
</tr>
<tr>
<td>Post-void residue (residual?) (median/25-75th percentile)</td>
<td>30 (11/70)</td>
<td>30 (5/50)</td>
</tr>
<tr>
<td>Urge/stress/mixed/not classified/unknown type of incontinence</td>
<td>18/0/5/6</td>
<td>12/1/6/9</td>
</tr>
<tr>
<td>Number of validity-defining diagnoses (median)</td>
<td>4</td>
<td>3</td>
</tr>
<tr>
<td>Number of medicines (median)</td>
<td>5</td>
<td>4.5</td>
</tr>
<tr>
<td>Hemi paresis / extra pyramidal / arthrosis / other type of mobility disorder</td>
<td>9/4/9/7</td>
<td>11/4/6/7</td>
</tr>
<tr>
<td>Motivation -score (average, std)</td>
<td>3.89 (1.26)</td>
<td>3.56 (1.31)</td>
</tr>
<tr>
<td>-feeling ill no/ neither yes or no/yes</td>
<td>16/12/1</td>
<td>16/9/2*</td>
</tr>
<tr>
<td>One or more TT-test task &gt; 5 min</td>
<td>10</td>
<td>9</td>
</tr>
</tbody>
</table>

* 1 missing value

Urinary incontinence in disabled elderly women a randomised clinical trial
Table 4  Effect of intervention (compared to the control group) on PAD-test (% difference) and statistical significance in analysis of covariance.

<table>
<thead>
<tr>
<th></th>
<th>% difference*</th>
<th>P value</th>
</tr>
</thead>
<tbody>
<tr>
<td>24 hours</td>
<td>-38</td>
<td>0.07</td>
</tr>
<tr>
<td>Day-time</td>
<td>-22</td>
<td>0.47</td>
</tr>
<tr>
<td>Night-time</td>
<td>-35</td>
<td>0.15</td>
</tr>
</tbody>
</table>

* negative value means less involuntary urine loss in the intervention group

Table 5  Effect of the intervention as an improvement on the Toilet-timing-test (TT) under standardized circumstances and statistical significance

<table>
<thead>
<tr>
<th></th>
<th>Intervention (n=26)</th>
<th>Control (n=27)</th>
<th>P $\chi^2$-test</th>
</tr>
</thead>
<tbody>
<tr>
<td>TT day improved</td>
<td>17</td>
<td>11</td>
<td>0.05</td>
</tr>
<tr>
<td>TT night improved</td>
<td>15</td>
<td>9</td>
<td>0.06</td>
</tr>
</tbody>
</table>

7.4  Discussion

In this study, only a small effect of training mobility and toileting skill on the amount of urine loss in dependent elderly women was observed. The training, however, did have a significant effect on the time needed for toileting. Also, there was a positive effect on achieving independence in toileting. Women visiting day-care centres in a Dutch nursing home consider incontinence a severe problem(3), therefore we were surprised by the poor motivation in these women. This, combined with the high prevalence of ‘feeling ill’, could explain why the improvement of toileting skill did not result in more frequent toileting and only a small reduction in the amount of involuntary urinary loss. In the intervention group three women became totally continent. All three had complied with the intervention, had no improvement on the TT-test, but had a more than average motivation. This high motivation may have been the key factor in the use of toileting skill. Again, this suggests that simply
training skill is not enough and that extra encouragement is necessary. If so, prompting or encouragement from the nursing staff might have improved the effect. This is supported by the results of a similar study among elderly men and women by Schnelle(10) In this study, a significant effect of training mobility combined with prompting on urinary incontinence was found, with no major difference between men and women. The intervention lasted 32 weeks and was integrated in the daily nursing routine. Urinary incontinence was measured with wet checks in the study by Schnelle; the intervention (called ‘FIT’) was embedded in daily nursing routine, while the intervention in our study was done by therapists. Probably this is of great importance, as the nursing staff can actually encourage and prompt in daily practice.

In this study we assessed severity of urinary incontinence with the PAD test, which is the most valid measure for the total amount of urine lost. However, frequency (of loss of urine) can also be reliably assessed by wet checks, and this might have given a different and perhaps more favourable outcome. In our study the speed of going to the toilet in a day-time situation had clearly improved, while there was a smaller effect on the speed in the night-time situation. Indeed, the therapists reported that most women preferred undisturbed sleep over getting up and going to the toilet at night.

We aimed for a study size of at least 60 participants in total. It proved necessary to approach no less than 23 institutions to find enough women who were willing to participate, mainly due to a lack of motivation and the restrictions of the selection criteria. We had anticipated a significant drop-out due to death and disease, which is why we kept the intervention period relatively short. Nevertheless, during follow up, one participant died and a large number of new diagnoses and changes in medication occurred.

Despite randomisation, there were some differences between the control and intervention groups. There were more women with typical urge-type incontinence in the intervention group than in the control. It is possible that the intervention would have been more effective for the functional type of incontinence and less effective for the urge-type incontinence, as the functional type focuses more on functional aspects than on the functioning of the bladder. The study sample however, was too small to test this assumption.
This study found that it is feasible for research purposes to measure incontinence with the PAD-test. For this test, the diapers were specially marked and numbered. Also the distinction between day-time and night-time incontinence was easily made. Measuring toileting skill with the TT-test also proved to be well feasible.

The toilet provisions in the participating nursing homes were poor. The average distance to the toilet from a chair or a bed was 11.4 meters (ranging from 4 to 26 meters), the wards and hallways were full of obstacles, the toilets were often not clean enough, and were often occupied by other patients. There was also a lack of privacy (nurses walking in and out and patients become stressed when other patients are waiting to use the toilet). These circumstances may have had a negative influence on the motivation to go to the toilet. It was not possible to alter these circumstances during the intervention period.

7.5 Conclusion

It proved not to be possible to significantly reduce long-lasting incontinence in elderly women by training mobility and toileting skill or adjustments in residential circumstances. Nevertheless, the training resulted in a slight positive effect on the time needed to perform toileting tasks during the day and on achieving independence in toileting. This and results from other studies suggest that regaining continence requires not only regaining skill but internal or external motivation as well.

Acknowledgement:
We want to express our thanks to Marcel Ooms who has played an important part in the design and analysis
References


Chapter 8

General discussion

8.1 Introduction

This chapter summarizes the main findings of this thesis by addressing the research questions. The strengths and limitations of the study are then discussed, followed by recommendations for future research and the clinical implications for health professionals, nursing home management and policymakers. The chapter ends with a general conclusion.

8.2 Summary of the main findings

1 What is the prevalence and incidence of different types of incontinence in nursing home residents?

In 1995 the prevalence of incontinence on admission in Dutch nursing homes was high (Chapter 2). In the total group the prevalence of UI was 47% and the prevalence of FI was 29%. The prevalence of UI only was 19%, of FI only 1%, and of DI 28%. Although there were only slight differences between men and women, there were substantial differences in the prevalence of incontinence between two types of residents: there was a much higher prevalence of UI and FI among psychogeriatric residents than among somatic residents. In both somatic and psychogeriatric residents the prevalence of UI only and FI only was low, compared to the prevalence of DI.

In nursing homes in the state of Ohio in the USA, there was an overall prevalence of 65% of UI and 38% for FI (Chapter 3). 34 % of the nursing home patients were continent. The overall 3-month incidence of FI (22%) was higher than the incidence of UI (15%).

Deterioration in continence status occurred in 17 %of the Post Acute Care (PAC) patients and 15% of the Long-Term Care (LTC) patients and the change was predominantly from continence to UI only and from UI only to DI.
Improvement in continence status occurred in 9% of the PAC patients (mainly from UI only to continence), compared with only 2% of the LTC patients.

2 What is the relationship between different types of incontinence and changes in toileting skills?
In the Dutch nursing homes higher scores on the Toilet Index (measure for toileting skill, a higher score indicating a greater need for assistance with toileting) were significantly related to higher prevalences of UI, FI and DI (Chapter 2). In psychogeriatric residents, however, even slightly higher scores were associated with a higher prevalence of incontinence, while in somatic residents the association was spread out over the whole range of the scale.
In the nursing homes in Ohio there was a strong correlation between a change in toileting skills and the risk of developing FI (Chapter 4). When toileting skills deteriorated, the relative risk of FI increased significantly. However, when toileting skills improved, the relative risk of FI decreased significantly. The same pattern was found for the correlation between changes in toileting skills and the severity of FI.

3 What is the relationship between the incidence of the different types of incontinence and incident diseases and disabilities?
Incident stroke and incident cognitive decline were associated with a high risk of incident UI and incident FI. In addition, incident hip fracture was associated with a high risk of incident FI. These high risks could partially be attributed to declining toileting skills. The association of congestive heart failure, decline in mood, and constipation with incident UI and FI was less strong. However, UI at baseline was associated with a very high risk of FI, indicating that other factors, apart from change in toileting skills and morbidity, also contributed to the development of FI.
4. **What is the effect of training toileting skills on toileting skills?**

Toileting skills can be improved by a targeted training program (Chapter 7). The intervention with this program had a statistically significant effect on the number of women with an improvement in their daytime sum-score for the Toilet Timing-test (TT-test) under standardized circumstances (p=0.05). The effect on the number of women with an improvement in their nighttime sum-score was borderline significant (p=0.06). The intervention had a significant effect on speed in the wheelchair group, measured with the TT-test under daily circumstances, although the effect was in favor of the control group. There was a tendency towards significance on the following tasks performed by walking subjects, also measured with the TT-test under standard circumstances: the speed of walking, rising from a chair and sitting down on the toilet. In the intervention group, 6 patients achieved independent toileting, compared with 2 in the control group.

5. **What is the effect of a targeted toileting skills intervention on urinary incontinence?**

The training program (Chapter 8) resulted in a 38% reduction in the daily amount of urine loss, compared to the control group, although not statistically significant (p=0.07) or clinically relevant. Three women in the intervention group, but none in the control group had a reduction of more than 90% in the amount of urine loss. A change from dependent to independent toileting occurred in 6 women in the intervention group and 2 women in the control group. The intervention had no significant effect on the number or percentage of micturitions on the toilet. The motivation of women to train their toileting skills was moderate.

8.3 **Methodological reflections**

8.3.1 **Assessment of UI and FI**

In the studies focusing on the prevalence and incidence of UI and FI we dichotomized in complete control and incontinence, because this is most meaningful for the patient and can be accurately assessed by nursing staff (1). In addition, it makes it possible to compare the results with the SIVIS (Chapter 2) and RAI-MDS databases (Chapters 3, 4, 5), because in the SIVIS the next response
category is ‘once or twice a week’ for both UI and FI, and in the RAI-MDS database the next response category for UI is ‘usually continent: incontinent episodes once a week or less’ and for FI ‘usually continent: incontinent less than weekly’. This definition of incontinence is more strict than the definitions that is sometimes used in other studies(2). A study carried out by Remmers in Dutch residential homes illustrates the differences: using a definition of “daily loss” the prevalence was 30.5%, but using a definition of “any involuntary loss” the prevalence was 48.8%(3). The prevalence and incidence rates of UI and FI in our studies are therefore higher than those found in other studies(4). Chassagne found a 10-month incidence of 20% in French long-term care facilities (nursing homes and geriatric wards) using the definition of ‘at least one time one involuntary loss of feces’(5). We found a 22.2% incidence of FI in 3 months, but the reason for this difference is not clear. It is possible that the study populations are not comparable, but this could not be established because Chassagne did not reported on ADL status at baseline. Among members of an admission cohort remaining in nursing homes, Ouslander found daytime an UI incidence of 19% between 2 months and 1 year after admission(6). This percentage is also lower than our findings, but Ouslander used an admission cohort and we used a cohort of residents who were already in nursing homes at baseline, and this can result in the same difference as reported by Remmers for the prevalence rates.

The inter-rater reliability of continence items of all grades on the MDS-RAI is excellent (weighted kappa correlation coefficient = 0.90), although reliability is greater at the extremes of measurement than for incontinence of intermediate severity(1). Good reliability of the MDS continence items was also reported on by Sgadari(7). Crooks(8) examined the difference between UI (MDS) and the measured humidity of pads (wet checks), and concluded that, although the MDS appears to identify incontinent nursing home residents accurately, its clinical utility may be limited by disagreements between actual wet check data and MDS categorical severity rankings for residents who are known to be incontinent, because a statistically significant improvement in the severity of incontinence measured with wet checks was not confirmed with chance in the MDS severity ranking. Schnelle challenged the MDS measures in use as quality indicators (prevalence of incontinence and prevalence of incontinence without a toileting plan) because MDS incontinence quality indicators were not associated with clinically important differences in related care processes between nursing homes
scoring on the quality indicators in the lower 25th percentile (low prevalence) versus nursing homes scoring in the upper 75th percentile (high prevalence)(9). We used the MDS continence items mainly in the extremes.

The prevalence of UI (47.1%) and FI (29.4%) found in the SIVIS study seems to be lower than the prevalence of UI (65.5%) and FI (38.4%) in the MDS-RAI study. The SIVIS study consisted of residents on admission, and the MDS-RAI study consisted of all residents of the nursing home, within a 3 month time-frame, who were available at baseline and at the 3-month follow-up. This means that rehabilitation patients who were discharged within 3 months were not included in the study, and these are the patients who are most likely to have a better continence status.

The most important limitations of the studies based on SIVIS and MDS-RAI data is that the measurements are secondary data that were not gathered primarily for research purposes. However, the nursing homes in the USA have been using the MDS-RAI since 1991(10), so the nurses are well trained in using the instrument.

For the intervention study we used the 24 hour Pad test(11). With this test we obtained an accurate measurement of UI, which can also be used in an intervention study. The number of pads and total weight gain appeared to be reliable measures of the 72-hour Pad-tests in a test-retest design(11). In this study we considered that a patient who had more than 90% weight reduction on the Pad-test to be ‘continent’.

An alternative for the Pad-test is the so-called ‘wet check’(12), in which the resident is checked at 1-4 hourly intervals by nurses. However in one earlier study, when an electronic monitor was used to document incontinence, considerable disagreement was found because the care-givers under-reported wet episodes(13). Therefore, education and close supervision of staff is necessary for these measurements(12).

In our study the feasibility of the Pad-test was good. There were only 4 instances in which a 24-hour period was considered invalid, out of a total of 89. In one instance a pad was wrongly disposed of by the resident, and in 3 instances there was fecal contamination.

We also used 48-hour micturition diaries to assess the frequency of (in)continent episodes. Groutz(11) studied the test-retest reliability of micturition diaries and used the Lin's concordance correlation...
coefficient (CCC) with a cut-off value of 0.7 for test-retest reliability. He found that for the 24-hour diary the total number of incontinence episodes was a reliable measure, while the total number of voiding episodes was marginally reliable (mean CCC 0.785 and 0.689, respectively). For the 48-hour diary the number of incontinence episodes and total number of voiding episodes were reliable measures (mean CCC 0.78 and 0.83, respectively), while for the 72-hour diary each parameter was highly reliable (CCC 0.86 and 0.826, respectively). However, an increase in the test period was associated with decrease in patient compliance with diary-keeping.

8.3.2 Instruments to assess toileting skills

1. The toilet index, the toilet dependency score and the change toilet dependency score

Toileting skills refer to the ability of a person to perform several tasks that are needed to urinate and defecate on a toilet. The concept of toileting skills is not directly measurable, but the tasks needed for toileting (getting up from chair or bed, walking or in a wheelchair, find the toilet, manipulating clothing, sitting down on the toilet) can be measured separately. They can be measured in terms of the amount of assistance needed to perform the task or by time needed to complete the task. However, there is no available validated instrument that can be used to assess toileting skills, either in terms of amount of assistance needed or the time needed to perform the tasks. We therefore developed instruments with face and construct validity to assess the assistance needed, and also the time needed to perform the tasks (see Appendix). As a result of the findings reported in Chapter 3, we made some adjustments in the concept by adding the item ‘finding the room’ to the TDS.

The change TDS was developed to measure the change in TDS at two points in time. We expected that the change TDS score would predict the changes in FI status more accurately than the MDS locomotion or toilet-use items only, or the MDS-CPS(14) and MDS-ADL(14;15) scales. The toilet-use items and the MDS-CPS proved to be bad predictors, but the ADL scale, and even the single locomotion item, correlated just as strongly with change in FI as the change TDS score. There might be several explanations for this. Change in locomotion on the unit is possibly a very good indicator of change in overall functional ability, and therefore also of change in continence status. If this is confirmed, it might be very important for use in everyday nursing home practice, not only because of
the prognostic value of the change in this item, but also because of the interventions that could possibly be aimed at independent locomotion, although this needs to be confirmed in experimental studies.

Another explanation might be that the sensitivity to change is better for ADL and locomotion, and worse for ‘find the room’ and ‘toilet-use’. It is known that the MDS-ADL scale has limited ability to assess dementia related change in ADL, so the ADL score is limited as an outcome instrument(15). We did find that changes in toilet-use and the MDS-CPS were too small, or too unevenly distributed to produce valid results in the logistic regression models. It is very important that, in addition to data on reliability and validity, more comprehensive data on the sensitivity to change of the MDS items are reported.

2. The toilet-timing test

The aim of TT-test is to identify patients who have problems with toileting to such extent that this could result in incontinence, to identify the specific tasks that are impaired, and to measure improvement in performing these tasks after the intervention. It is intended for use with mobility-impaired elderly people who are not demented. The TT-test in the study described was performed by a single instructed and trained research nurse, thus ruling out the possibility of inter-rater variability. However, each task could only be measured once, because of the low level of endurance of the residents. Therefore, test-retest reproducibility could not be assessed. However, the therapists stated that identification of the tasks that are a problem in toileting, and therefore the target of the intervention was feasible.

A modification of the TT-test was used in the INCOnditie project carried out by TNO health and prevention(16). In this single-blinded intervention study, elderly female residents with UI in Dutch residential homes participated in a program to enhance mobility and toileting skills. This program was not individualized or targeted, but the residents participated in group sessions. They only assessed three tasks (getting up from a chair, walking to the toilet and sitting down on the toilet). These were not assessed in standardized circumstances, but in the patient’s own apartment. The results were calculated as results for standardized circumstances, and the scores for the tasks were summarized.
The tests were carried out by several different interviewers. There were difficulties in the calculating the standard time per task, and there was poor inter-rater variability and reproducibility for this modification of the TT-test. Further research is therefore needed to establish the test-retest reproducibility of the TT-test.

8.3.3 The intervention

We conducted an RCT, which for us was the best available research design (Chapters 7,8). The intervention was single-blinded, because a double-blind design is not possible when patients are offered therapy.

We aimed for a total study size of at least 60 participants in total, and the intervention was aimed at women to rule out the possibility of overflow incontinence due to prostate enlargement in men. To make sure that we did not include residents with overflow incontinence, bladder residue after micturition was measured at baseline by catheterising the resident. Because in man there is a risk of damaging the prostate we only included women.

It proved necessary to approach no less than 23 institutions to find enough women who were willing to participate, mainly due to a lack of motivation and the limitations of the selection criteria, which also limit the generalisability of the results to the average nursing home patient.

We considered to stratification according to incontinence type before randomisation, because it is possible that the intervention could be more effective for functional type of incontinence and less effective for urge incontinence, since the functional incontinence depends more on functional aspects than on the functioning of the bladder. However, women with functional incontinence could also have urge incontinence at the same time. We decided to focus primarily on the functional status and to introduce type of incontinence as a confounder. After randomisation there were more women with typical urge incontinence in the intervention group than in the control group. However, the study sample was too small to perform an analysis on the type of incontinence. Because of the limited effects on incontinence, we did not study the duration of the effects after the intervention.

With the intervention we aimed at reducing UI and not at reducing FI, for practical reasons; the prevalence of UI in residents with moderate mobility is much higher than the prevalence of FI, UI is
easier to measure with the Pad-test, and there are more episodes of UI within 24 hours, so the power of
the study can be smaller.

The INCOnditie study(16) had some resemblance with our study, and was performed in residential
homes after our intervention study had been completed. The results of the INCOnditie intervention
showed similarity with our results, and the researchers also had a problem in finding residents who
were motivated to participate. Their study included 111 women (51 intervention in the in the
intervention group and 60 in the control group) and UI (frequency and amount) was measured with a
micturition diary for a period of three days. The average age of the women was the same as that of our
patients, but the Barthel index was higher, meaning that they needed less assistance with ADL. The
intervention consisted of group therapy, not targeted or individualised, for 20 weeks lasting for one
hour per session. The outcome measures were a modification of the TT-test and the Physical
Performance Test (PPT). The only positive significant effect (p=0.002) was found on the PPT; there
was no significant effect on the modified TT-test and no significant effect on UI. Thus, in this
group of elderly women who needed less assistance with ADL, there was an improvement in their
performance but no effect on UI. In our intervention we used a more precise measure for the amount
of urine loss (the Pad-test) and we found an effect on urine loss during the day (22% reduction),
although this was not a significant or clinically relevant reduction. In conclusion, our study
participants needed more assistance in ADL, they received a targeted intervention, and UI was
measured with the more sensitive Pad-test, compared with the INCOnditie study.

In our study and in the INCONdition study the participants received no prompts. Both studies were
designed for non-demented disabled elderly women, because it was thought that they would benefit
from regained toileting skills. However, it is possible that prompting could improve the use of the
regained toileting skills, as was found by Schnelle(17) with the Functional Incidental Training (FIT)
program and Collins with the Pattern Urge Response Toileting(PURT) program(18).

In our study the speed of going to the toilet during the day clearly improved, although there was a
smaller effect on the speed during the night. Indeed, the therapists reported that most women preferred
undisturbed sleep, in stead of getting up and going to the toilet at night. The importance of undisturbed
sleep has also been reported(19). However, there are data that suggest that incontinence is not relevant

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to sleep disruption, because only 4% of the awakenings are associated with an incontinence episode, and only 23% of the incontinence episodes occur during periods of at least 10 consecutive minutes of sleep. Of the latter episodes, only 12% appeared to awaken the resident(20). So, although residents are incontinent, they experience little sleep disruption because of the incontinence, and they are, in general, poorly motivated to disrupt their sleep to go to the toilet.

8.3.4 Assessment of morbidities

We wanted to assess the risk of incident UI and FI in relation to incident morbidity in a nursing home population. Therefore, we did not study chronic diseases, but diseases with an acute onset. From the conditions that have previously been described in the literature(21-24), we chose: stroke, hip fracture, congestive heart failure, constipation, fecal impaction, a decline in cognitive function (measured with the CPS), and a decline in mood (measured with a single MDS item ‘mood change’).

We adjusted the risk for decline in toileting skills to determine the extent to which the risk of the morbidity-related incident UI and FI can be attributed to that decline. The reliability of the MDS items that we used to establish incident morbidity can be disputed, because little research has focused on the reliability of these specific items (apart from the CPS). Our results must therefore be interpreted with care.

In residents with stroke, hip fracture, and cognitive decline the risks for UI and FI did not disappear after correction for toileting skills. It is possible that impaired alertness, impaired awareness of urge, and impaired endurance are (partially) responsible for this finding. Valk found that that poor alertness is a determinant for UI(25), delirium has been associated with poor alertness(26), and residents with dementia have been found to have a higher risk of delirium(27). Therefore, it is possible that incident delirium is of great importance in the development of UI and FI in a nursing home population. In view of the high incidence of cognitive decline and the fact that delirium can be treated(28), this association can be very important for the development of guidelines for incident UI and FI.

Pettersen indicated that a large percentage of stroke survivors with UI also have an impaired awareness of urge(29). However, it not known whether impaired awareness is also an important factor in FI.
Palmer found that hospital-acquired incontinence affects 21% of female hip fracture patients, and that the use of a wheelchair or device for walking significantly increases the odds of developing incontinence during hospitalization (30). However, the risk for FI in our study did not disappear after correction for TDS, indicating that other factors are important. One of these factors could be endurance, because endurance is not included in the TDS. Further research is needed to investigate these assumptions.

8.4 Recommendations for future research

There are some important factors that make an RCT on incontinence in long-term care residents very difficult. One very important characteristic of nursing home residents is their lack of motivation to participate in research and training (16). There is also much variety in morbidity among the residents, and much change in continence status. Therefore, it is necessary to tailor an intervention to the individual resident, and this makes comparisons difficult. It is very burdensome for residents to come to a center or a hospital, so the intervention and the measurements must be carried out in the nursing home. The endurance of the residents differs in the morning and the afternoon, so to be reproducible all the tests must be carried out within a short timeframe. In the nursing home, not only the residents must be motivated, but the cooperation of the nursing staff is also of vital importance. Despite these difficulties, intervention studies are necessary to provide evidence on which to base treatment decisions at individual resident level. Sometimes this means opting for a methodologically second-best solution, and that makes interpretation of the results difficult.

More research is needed to establish the risk factors for incidence FI in long-term care residents. We established the association with toileting skills, but other risk factors (alertness, endurance) are possibly also important (see Chapter 7). Especially, our finding that a resident with UI has a very high risk of becoming FI needs to be further investigated.

It is also important to develop the concept of toileting skills in more detail, and to improve the assessment instrument. It is possible that including endurance and alertness could improve the concept. An instrument to assess toileting skills has advantages above instruments to assess only mobility and...
ADL, because it can be based on tasks and factors (for instance alertness and endurance) that are related to going to the toilet. General interventions on mobility and prompting are costly(31), and it is not likely that these interventions can be used in Dutch long-term care facilities because their budgets and manpower are limited. A short individualized and targeted intervention at the moment when UI or FI develop could possibly be less costly and could be provided by the professionals who are already working in the nursing homes. Moreover, in an early stage it is likely that a resident is more motivated to undergo assessment and therapy than when the incontinence becomes chronic. Therefore further research into the concept of toileting skills, the assessment instruments and also the sensitivity to change of the instruments is recommended.

Future research should focus on the prevention of DI in patients with UI. It is possible that a program to maintain toileting skills in continent nursing home residents can be effective in preventing UI and FI, and this also needs further research. This program could be integrated in a program for maintaining mobility in elderly people by exercising in a group, although there are no data to support this suggestion(16).

8.5 Clinical implications

1. Implications for health professionals

The high prevalence and incidence rates of UI and FI are of major importance from a nursing perspective. They spend more time taking residents to the toilet than treating them for incontinence. The nursing staff must provide care for all the residents on a unit, and therefore need to work with a care plan. Together with the residents, they have to decide whether the resident whether the residents are self-toileting, whether they can ask for assistance with toileting, or whether they should be offered a scheduled toileting plan (with or without the principles of prompted voiding). They also have to provide incontinence care for residents with pads or a catheter. This research has shown that the continence status of residents is not stable, and that the main changes are from UI only to DI and from continent to UI only. This means that they must not only provide care, but also be alert for changes, and take the appropriate measures. It is important to analyze the probable causes of the change,
together with therapists and physicians. Special attention must be paid to incident cognitive decline, and nursing home staff must bear in mind that in psychogeriatric residents a slight change in toileting skills correlates with steep increase in incontinence. When this happens, they have to assess whether there are remedial causes such as problems in finding and using the toilet (toileting skills), problems with endurance, or problems with constipation or fecal impaction. If this is not the case, causal factors such as diseases of bladder, gut and pelvic floor must be considered, while ample attention must be paid to motivation and coping problems. Normal toileting must be re-established if possible. However, all this is time-consuming for both nurses and physicians. They all have to be aware of the importance of maintaining continence where possible, at least in the daytime situation, or giving the resident the (in)continence care he or she prefers. Although in Dutch long-term care facilities little is known about preferences, this has been the topic of research in nursing homes and residential homes in Los Angeles, in the USA(32); nursing home residents preferred pads and prompted voiding, and residents in residential care preferred medication and electrical stimulation (interventions directed at the underlying cause), indicating that mainly residents with a higher level of functioning prefer a solution that includes treatment of the underlying causes. It is not known what the preferences will be of future generations of elderly people, but knowledge about these preferences is crucial for the development of intervention strategies and they need to be further investigated and monitored in Dutch long-term care facilities.

It is important that there is a policy for continence care on the ward and that nurse, physicians and therapists are aware of their role. Nursing home physicians must be aware of the high prevalence and incidence of continence problems, and know about the probable causes. They must realize that the incidence of FI is highest, and they must be alert and react when residents or nurses report a change in continence status. They must investigate the probable causes immediately (declining toileting skills, cognitive deterioration, problems in endurance, and factors of bladder, gut and pelvic floor) there are. They can involve physiotherapists and occupational therapists to help with the assessments and to eliminate problems with toileting.

In rehabilitation projects, special attention must be paid to toileting. For a person who is dependent on assistance with toileting, that assistance must be available 24 hours a day, but for elderly people living
at home this is often not possible when there is no spouse, so the chance that they will remain institutionalized is high.

2. Implications for nursing home management

The nursing home management has to provide the resources that are needed in terms of manpower, training, transfer-aids, pads, etc. There must also be a policy concerning continence problems, taking into account the limited financial and manpower resources that are available. There are proven methods to reduce incontinence in nursing homes, for instance the FIT protocol(17). However these protocols can only be effective if there is enough manpower, and decisions about the allocation of resources in healthcare are made by policy-makers. Schnelle calculated that in a daytime situation one nursing aid for three residents is still not enough to provide the necessary care according to the FIT protocol(31). A policy must therefore take into account the restrictions due to the limited resources that are allocated to nursing home care, otherwise both health professionals and residents will become frustrated. The most prevalent and disabling morbidities in nursing home residents are progressive (dementia, Morbus Parkinson, cerebrovascular diseases) and at some point most residents are bound to become incontinent. In the recommendations supported by the results of this thesis, three basic assumptions are of importance: (1) maintaining continence or maintaining present continence status (prevention of FI if a patient is already UI), and therefore also maintaining the toileting skills, (2) when a patient becomes incontinent or continence status is deteriorating (change from UI only to DI), immediate assessment and (if possible) treatment of the probable causes, and (3) the intervention that is chosen must comply with the patient’s preferences.

3. Implications for policy-makers

The quality indicators for continence care must relate to the policy of the nursing homes. In the USA, facilities are obliged to attain the highest possible functioning for all residents(33). The FIT protocol resulted in better functioning of the residents, but it increases staff requirements, and does not lower health care costs(17). Nursing homes in the USA can not implement this protocol, due to a lack of nursing staff. Therefore, it is important that policy-makers redefine what they require from long-term
facilities are facilities obliged to attain the highest possible functioning for all residents, (2) are facilities obliged to attain the highest level of participation for all residents, or (3) are facilities obliged to give care according to preferences of residents within a budget limit? In terms of continence care, the choices that have to be made can be rephrased as follows: (1) implementation of prompted voiding or FIT protocol with the consequences for manpower and budget (the consequence that these resources cannot be used for other purposes, for instance social activities), (2) emphasis on social aspects, so less attention is paid to incontinence care, or (3) allowing residents to choose between high quality continence care or high quality social care within a defined resident budget. The implementation of prompted voiding and FIT protocol is recommended when policy-makers choose the first possibility. For the second possibility, guidelines for incontinence care and an assessment followed by a short targeted intervention program (also including toileting skills) is recommended when there is change in continence status. When the third possibility is chosen, it enables facilities to develop their own policy, together with the residents.

In any case, policy-makers must provide guidelines that are feasible with the resources that are available, and they can do so by making quality indicators for facilities. However, in the USA it was found that guidelines based on 9 quality indicators for a scheduled toileting plan did not result in additional assistance with toileting. The nursing home staff was not able to provide the necessary care. Therefore, also with quality indicators, it is important to ensure that the requirements for providing the necessary care are available. In the Dutch situation it is very important that research is carried out to develop a policy for incontinence care that is feasible with the limited resources that are available in Dutch long-term care facilities. The present quality indicator regarding the number of residents with an indwelling catheter is a good quality indicator, because indwelling catheters are a source of serious infection. We therefore recommend that the present quality indicator regarding the diagnosis of UI by a physician should also made applicable for FI.

All other interventions in long-term care facilities are probably more costly than pads, because it was calculated that an intervention with physiotherapy for pelvic floor muscles is only cost-neutral if a resident subsequently remains continent for 5 years. In long-term care even 5 year-survival seldom occurs, so reducing costs for incontinence care by reducing the use of pads (either through prompted
voiding or targeted physiotherapy interventions) is not possible. There is still room for improvement because the prevalence rates for incontinence differ substantially between comparable facilities (36).

8.6 General conclusion

The prevalence and incidence of UI, FI and DI in long-term care facilities is high. With regard to newly-developed incontinence, the 3-month incidence of FI is highest (22%). Continence status deteriorates stepwise, from continence to UI only, and from UI only to DI, so when a resident has UI, then apart from treating the UI it is also necessary to investigate possibilities to prevent FI. The incidence of FI correlates with toileting skills: when toileting skills deteriorate, the risk of FI increases significantly, and when toileting skills improve, the relative risk of FI decrease significantly. Therefore, improving toileting skills in residents who became FI could be effective. UI is associated with a very high risk of FI, independent of toileting skills, indicating that factors other than a change in toileting skills and morbidity also contribute to the development of FI. There could be problems with the pelvic floor, but it is also possible that these are reduced alertness, endurance and motivation. Stroke and cognitive decline are associated with a high risk of incident UI and incident FI, and hip fracture is associated with a high risk of FI, but these high risks are only partially attributed to a decline in toileting skills. However, it is still important to improve toileting skills, if possible, in patients with incident stroke, hip fracture and cognitive decline.

Toileting skills can be improved by a targeted training program. The training program described in this thesis resulted in a 38% reduction in the daily amount of urine loss relative to control. However, this reduction is not statistically significant, and not clinically relevant. The intervention had no effect on the number of micturitions on the toilet, and the motivation of residents to train their toileting skills was moderate. However, there is still enough evidence that monitoring and training toileting skills in nursing home residents during their stay in the long-term care facility is feasible and effective in reducing incontinence, although further research is necessary to support this evidence.
References


General discussion


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(33) Omnibus Budget Reconciliation Act of 1987, publication number 100-203. 2008.


Summary

Continence is highly related to the use of the water closet in the western society. Disabled elderly have problems with using the toilet because of mobility and cognitive disabilities. This can result in undesired loss of urine and feces on other places than the toilet. If a person is dependent in toileting the problem is that assistance must be available 24 hours a day. For elderly living at home this is often not possible when there is no spouse, so they have a big change to get institutionalized.

Institutionalized elderly have commonly problems with using the toilet. Therefore it is of importance to investigate in which extend problems in toileting contribute to incontinence of urine and feces, and explore the possibilities of training toileting skills.

Toileting skills represents the ability of a person to perform several tasks to urinate and defecate on a toilet. Those tasks are; rising up from chair or bed, walking or riding a wheelchair, finding the toilet, manipulation of clothing, sitting down on the toilet. Research on toileting skills is scarce.

The definition of the International Continence Society for urinary incontinence (UI) is: “the complaint of any involuntary leakage of urine”. Fecal incontinence (FI) is the inability to control stool or recurrent involuntary passage of stool or gas through the anus. The severity of UI and FI is often expressed in amount of frequency. In disabled elderly UI and FI are frequently combined. The combination is called dual incontinence (DI).

This thesis comprises several studies on toileting skills, association between toileting skills and incontinence, and training toileting skills in nursing home patients. The objectives of the thesis are: (1) to investigate relations between incontinence (UI, FI and DI), toileting skills and morbidity, and (2) to influence UI by training toileting skills.

Chapter 2 describes a cross-sectional study, based on SIVIS data of all new admissions from Dutch nursing homes over the year 1995. Prevalences of incontinence ad admission in the Dutch nursing
homes in 1995 were high. The prevalence of UI was 47.1 % and the prevalence of FI was 29.4 %. The prevalence of UI only was 19.1 %, of FI only 1.4 %, and of DI 28.0 %. The differences between men and women were only slight. There were, however, substantial differences in the prevalences of incontinence between the two types of residents. Psychogeriatric residents had a much higher prevalence of UI (62.9 %) and FI (42.5 %) than somatic residents (UI 37.9% and FI 21.8 %). In both somatic and psychogeriatric residents the prevalence of UI only and FI only even more so, was low compared to the prevalence of DI.

Toileting skills was made operational with the Toilet Index. In the Dutch nursing homes higher scores on the Toilet Index were significantly related to higher prevalences of UI, FI and DI. In psychogeriatric residents, however, even slightly higher scores on the TI were associated with higher prevalences of incontinence, while in somatic residents the association was spread out over the whole range of the scale.

Chapter 3 describes a cohort study, based on RAI-MDS data of patients in nursing homes in Ohio USA, with assessment on baseline and at 3 months follow up, to establish the change in continence status in post-acute care (PAC) and long term care (LTC) nursing home patients. The overall prevalence of UI was 65.5% and for FI 38.4%. 33.9% of the nursing home patients were continent. The overall 3-month incidence of FI (22.2%) was higher than the incidence of UI (14.8%). Deterioration of continence status occurred in 17.5% of the PAC patients and 15% of the LTC patients and was predominantly from continence to UI only (PAC 10.0%, LTC 8.7%) and from UI only to DI (PAC 29.0%, LTC 34.3%). Improvement in continence status occurred in 9.4% of the PAC patients (mainly UI only to continence) , compared with 2.4% of the LTC patients.

Chapter 4 describes a cohort study, based on RAI-MDS data of patients in nursing homes in Ohio, with assessment at baseline and at 3 months follow up to establish the relation between change in toileting skills and the development of FI in nursing home patients. Toileting skills were scored with the TDS. There was a strong correlation between change in toileting skills and the risk of developing FI . When toileting skills deteriorated, the relative risk of FI increased significantly, and with each step
of decline in TDS the risk of FI doubled. However when the toileting skills improved, the relative risk of FI decreased significantly. The same pattern was found for the correlation between change in toileting skills and the severity of FI.

**Chapter 5** describes a cohort study, based on RAI-MDS data of patients in nursing homes in Ohio, with assessment at baseline and at 3 months follow up, to establish the effect on UI and FI of incident morbidity in relation to toileting skills in nursing home patients. Stroke and cognitive decline were associated with a high risk of incident UI and incident FI. In addition incident hipfracture was associated with a high risk of incident FI. These high risks could partially be attributed to decline in toileting skills. The association of congestive heart failure, decline in mood and constipation with incident UI and FI are lower. However UI at baseline is associated with a very high risk of FI, indicating that other factors apart from change in toileting skills and morbidity also contributed to the development of FI.

**Chapter 6** describes a randomized single blinded controlled trial on disabled elderly women, clients of Dutch long-term care facilities, to establish the effect of an individualized 8-week training program on mobility and toileting skills with the aim of improving the time needed for specific toileting tasks. The intervention was based on the performance of the tasks of the Toilet Timing test (TT-test).

Toileting skills can be improved by a targeted training program. The intervention had a statistically significant effect on the number of women with improvement on the daytime sumscore from the TT-test under standardised circumstances ($p=0.05$). The effect on the number of women with improvement on the nighttime sumscore was borderline significant ($p=0.06$). The intervention had a significant effect on speed in the wheelchair group measured with the TT-test under daily circumstances, although the effect was in favor of the control group. There is a tendency towards significance on the following tasks of walking subjects also measured with the TT-test under standard circumstances: the speed of walking, rising from chair and sitting down on toilet. In the intervention group 6 patients reached independent toileting against 2 in the control group.
Chapter 7 describes a randomized, single-blinded trial on disabled elderly women, clients of Dutch long-term care facilities, to determine the effect of training mobility and toileting skills on the severity of UI measured with the Pad test. The intervention consisted of an individualized 8-week training program of mobility and toileting skill, provided by physiotherapists and/or occupational therapists. The intervention was based on the performance of the tasks of the Toilet Timing test. The training program resulted in a 37.7% reduction in the daily amount of urine loss relative to control. Three women in the intervention group compared to none in the control group showed a reduction of the amount of urine loss of more than 90% (p=0.24). A change from dependent to independent toileting occurred in 6 women in the intervention group and 2 women in the control group. The intervention had no significant effect on the number or percentage of micturitions on the toilet. The motivation of women to train their toileting skills was moderate.

Chapter 8 summarizes the main findings of this thesis by addressing the research questions. Strengths and limitations of the study are discussed, followed by the implications for researchers, physicians, carers, nursing home management and policy makers. The chapter ends with suggestions for future research and a general conclusion.

In conclusion: The prevalence and incidence of UI, FI and DI in long-term care facilities were high. The 3 month incidence of FI was highest (22.2%). Deterioration of continence status was stepwise, from continence to UI only and from UI only to DI. So when a patient has UI, then apart from treating the UI it is also necessary to look at possibilities to prevent FI. The incidence of FI correlated with toileting skills, when toileting skills deteriorated, the risk of FI increased significantly, when the toileting skills improved, the relative risk of FI decreased significantly. Therefore, improving toileting skills in patients how became FI could be effective. UI is associated with a very high risk of FI independent from toileting skills, indicating that other factors apart from change in toileting skills and morbidity also contributed to the development of FI. This could be factors of pelvic floor but also it is possible that reduced alertness, endurance and motivation are important.
Stroke and cognitive decline were associated with a high risk of incident UI and incident FI, hip fracture was associated with a high risk of FI. These high risks could partially be attributed to decline in toileting skills. Still it is important to improve toileting skills if possible in the case of incident stroke, hip fracture and with cognitive decline.

Toileting skills can be improved by a targeted training program. The training program resulted in a 37.7% reduction in the daily amount of urine loss relative to control. However this reduction is probably not clinical relevant. The intervention had no effect on the number of micturitions on the toilet and the motivation to train toileting skills was moderate. Still there is enough evidence to state that monitoring and training toileting skills in nursing home patients during the stay in the long-term care facility is feasible and effective in reducing incontinence and incontinence related problems in the nursing home. Independent toileting is an important outcome of rehabilitation programs in geriatric rehabilitation. Further research is recommended to investigate the assessment of toileting skills with the TT-test and the results of the targeted training program in geriatric rehabilitation programs.
Samenvatting

De relatie tussen incontinentie, toiletgangvaardigheden en morbiditeit in verpleeghuizen.

Continentie gaat in de westerse wereld samen met het gebruik van het water closet, in de volksmond WC of toilet. Zorgbehoevende ouderen hebben problemen met het gebruik van het toilet door beperkingen in mobiliteit en cognitie. Dat kan aanleiding geven tot ongewenst verlies van urine en ontlasting op andere plaatsen dan het toilet. Wanneer iemand afhankelijk is van hulp bij de toiletgang, dan moet die hulp 24 uur per dag aanwezig zijn. Voor thuiswonende ouderen is dit vaak niet mogelijk als er niet een inwonegende echtgenoot of andere mantelzorger is. Zij hebben dus een grote kans om opgenomen te worden in een verpleeg- of verzorgingshuis. Deze instellingen zijn opgericht om ouderen met beperkingen en handicaps zoals onder andere afhankelijkheid met betrekking tot persoonlijke verzorging of toiletgang, te ondersteunen. Dit geldt zowel voor patiënten die opgenomen zijn vanwege bijvoorbeeld dementie, zij worden verzorgd op zogenaamde ‘psychogeriatrische’ afdelingen, als voor patiënten die deze beperkingen en handicaps hebben als gevolg van een primair lichamelijke ziekte- zij worden op somatische (chronisch verblijf) of revalidatie afdeling (met als doel herstel en terugkeer naar huis) opgenomen.

Ouderen die opgenomen zijn in het verpleeghuis hebben (mede daarom) vaak problemen met het gebruik van het toilet. Daarom is het belangrijk te onderzoeken op welke manier problemen met de toiletgang bijdragen aan incontinentie van urine of ontlasting, en de mogelijkheden om die problemen te verhelpen door middel van het trainen van toiletgangvaardigheden bij de oudere zelf.

Het begrip toiletgangvaardigheden staat voor het vermogen van een persoon om een aantal taken uit te voeren die benodigd zijn om zelfstandig op het toilet te kunnen urineren en defeceren. Die taken zijn: opstaan uit stoel of bed, lopen of rijden in een rolstoel, vinden van het toilet, laten zakken van kleding en op het toilet plaatsnemen. Er is weinig onderzoek bekend naar deze toiletgangvaardigheden.

De definitie van de International Continence Society voor urine-incontinentie (UI) is: “de klacht van elk onvrijwillig urineverlies”. Fecale incontinentie (FI) is het onvermogen om de ontlasting vast te houden.

Dit proefschrift bevat een aantal studies naar toiletgangvaardigheden, relatie tussen toiletgangvaardigheden, incontinentie en morbiditeit (ziektelast). De doelstellingen van dit proefschrift zijn: (1) onderzoeken van de relatie tussen incontinentie (UI, FI en DI), toiletgangvaardigheden en morbiditeit, en (2) beïnvloeden van UI door training van toiletgangvaardigheden. Daarbij worden verschillende databases gebruikt: Hoofdstuk 2 is gebaseerd op SIVIS data, hoofdstuk 3 tot en met 5 RAI-MDS data uit de Verenigde Staten, en hoofdstuk 6 en 7 op een zelf uitgevoerde gerandomiseerde trial. In hoofdstuk 1 worden de achtergronden van de studie en de opzet van het proefschrift besproken.

In hoofdstuk 2 wordt een cross-sectionele studie beschreven die gebaseerd is op SIVIS data van alle nieuwe opnames in Nederlandse verpleeghuizen in 1995. Prevalentie (het vóórkomen) van incontinentie bij opname in 1995 was hoog. De prevalentie van UI was 47.1% en de prevalentie van FI was 29.4%. De prevalentie van zuivere UI (UI zonder aanwezigheid van FI) was 19.1%, van zuivere FI (FI zonder aanwezigheid van UI) 1.4% en van DI 28.0%. De verschillen tussen mannen en vrouwen waren klein. Er was echter wel een substantieel verschil in de prevalentie van incontinentie tussen twee soorten bewoners. Psychogeriatrische bewoners hadden een veel hogere prevalentie van UI (62.9%) en FI (42.5%) dan somatische bewoners (UI 37% en FI 21.8%). Bij zowel somatische als psychogeriatrische bewoners waren de prevalenties van zuivere UI en zuivere FI laag in vergelijking met de prevalentie van DI.

Toiletgangvaardigheden werden voor dit onderzoek meetbaar gemaakt met behulp van de voor dit onderzoek ontwikkelde Toilet Index. In Nederlandse verpleeghuizen waren hoge scores op de Toilet Index significant geassocieerd met hogere prevalenties van UI, FI en DI. Bij psychogeriatrische bewoners ging een kleine verhoging van de Toilet Index gepaard met hoge prevalentie van incontinentie, terwijl bij somatische bewoners deze verhoging was verspreid over de hele range van de
Toilet Index. Dit betekent in de praktijk dat demente patiënten al bij een kleine verslechtering van de mobilitéit incontinent kunnen worden.

In hoofdstuk 3 wordt een cohort studie beschreven waarbij gebruik is gemaakt van de RAI-MDS. De MDS is een uitgebreide vragenlijst waarmee verzorgenden iedere 3 maanden de patiënt op meerdere domeinen in kaart brengen- lichamelijk, sociaal en psychisch- met als doel te komen tot een goed zorgplan. De gegevens die gebruikt zijn, waren afkomstig van patiënten van verpleeghuizen in de staat Ohio (Verenigde Staten). Deze patiënten zijn op twee momenten, met een tussenliggende periode van 3 maanden, beoordeeld (‘assessment’) om de verandering in continentiestatus van revalidatie patiënten (‘post acute care’, PAC) en verblijfpatiënten (long term care, LTC) vast te stellen. Daartoe werd de assessment op baseline vergeleken met de vervolgmeting (follow-up) na 3 maanden. De totale prevalentie van UI was 65.5% en van FI 38.4%. 33.9% van de verpleeghuispatiënten was continent. De totale (3-maands) incidentie (het aantal nieuwe gevallen in 3 maanden) van FI (22.2%) was hoger dan de totale(3-maands) incidentie van UI (14.8%). Verslechtering van de continentie status vond plaats in 17.5% van de PAC patiënten en in 15% van de LTC patiënten, voornamelijk door een verandering van continentie naar zuivere UI (PAC 10.0%, LTC 8.7%) en van zuivere UI naar DI (PAC 29.0%, LTC 34.3%). Verbetering van de continentiestatus vond plaats bij 9.4% van de PAC patiënten (voornamelijk zuivere UI naar continentie), vergeleken met 2.4% van de LTC patiënten.

In hoofdstuk 4 wordt hetzelfde cohort dat in hoofdstuk 3 genoemd is, gebruikt om de relatie tussen verandering in toiletgangvaardigheden en de ontwikkeling van FI vast te stellen. Toiletgangvaardigheden werden gemeten met de speciaal voor dit onderzoek ontwikkelde Toilet Dependency Scale (TDS). Er was een sterke correlatie tussen verandering in toiletgangvaardigheden en de ontwikkeling van FI bij verpleeghuispatiënten. Wanneer toiletgangvaardigheden verslechterden nam de kans op FI significant toe, en met elke stap verslechtering van de toiletgangvaardigheden verdubbelde de kans op FI. Vice versa gold dat bij verbetering van de toiletgangvaardigheden de kans op FI significant af nam. Een zelfde patroon werd gevonden voor de verandering van toiletgangvaardigheden en de ernst van FI.
In hoofdstuk 5 wordt de cohort studie gebruikt om het effect van incidente morbiditeit (nieuwe ziektes) vast te stellen op UI en FI in relatie met toiletgangvaardigheden, met assessment op baseline en een follow-up na 3 maanden. Beroerte en cognitieve achteruitgang waren geassocieerd met een grote kans op incidentie van UI en FI. Incidente heupfracturen waren geassocieerd met een grote kans op incidentie van FI. Deze hoge risico’s konden voor een belangrijk deel worden toegeschreven aan een verslechtering van toiletgangvaardigheden. De associaties tussen hartfalen, verslechtering van stemming en constipatie met incidentie van UI en FI waren laag. UI op baseline (patiënten die bij de eerste meting al incontinent voor urine waren) is geassocieerd met een hoog risico op FI, hetgeen aangeeft dat andere factoren dan verandering in toiletgangvaardigheden en morbiditeit ook bijdragen aan de ontwikkeling van FI.

In hoofdstuk 6 wordt een gerandomiseerde enkel geblindeerde trial beschreven bij zorgbehoevende oudere vrouwen, in Nederlandse verpleeg- en verzorgingshuizen (N=29 in interventiegroep; N=28 in controle groep), om het effect van te stellen van een geïndividualiseerd 8 weken durend training programma gericht op mobiliteit en toiletgangvaardigheden, uitgevoerd door fysio- en/of ergotherapeuten. Het doel van het trainingsprogramma is het verbeteren van de tijd die nodig is voor taken die van belang zijn bij de toileergang. Het trainingsprogramma was gebaseerd op de prestatie van het individu op die taken, gemeten met de Toilet Timing test (TT-test). Er zijn 2 varianten van de TT-test: onder gestandaardiseerde omstandigheden en onder dagelijkse omstandigheden. Daarnaast werden zowel lopende als rolstoelgebonden vrouwen geïncludeerd en apart geanalyseerd. Toiletgangvaardigheden konden worden verbeterd met een gericht trainingsprogramma. Het programma had een statistisch significant effect op het aantal vrouwen met verbetering op de overdag somscore van de TT-test die werd afgenomen onder gestandaardiseerde omstandigheden (p=0.05). Het effect op het aantal vrouwen met verbetering op de nachtelijke somscore was niet niet significant (p=0.06). Bij rolstoelgebonden vrouwen was de interventiegroep significant langzamer op de TT-test onder dagelijkse omstandigheden, dan de controle groep. Er is een tendens naar significantie voor de volgende taken voor lopende vrouwen, gemeten met de TT-test onder gestandaardiseerde
omstandigheden: snelheid van lopen, opstaan uit stoel en plaatsnemen op het toilet. In de interventiegroep bereikten 6 van de 29 vrouwen een zelfstandige toiletgang tegen 2 van de 28 in de controle groep.

In hoofdstuk 7 wordt het effect van het trainingsprogramma voor mobiliteit en toiletgangvaardigheden op de ernst van UI onderzocht, gemeten met de Pad test (luierweeg-test). Het trainingsprogramma resulteerde in een 37.7% afname van de dagelijkse hoeveelheid onvrijwillig verloren urine, vergeleken met de controle groep. Drie vrouwen in de interventie groep, vergeleken met geen in de controle groep, hadden een afname van ongewenst verloren urine van meer dan 90% (p=0.24). Een verandering van afhankelijke naar onafhankelijke toiletgang kwam voor bij 6 vrouwen in de interventie groep tegen 2 in de controle groep. De interventie had geen significant effect op het aantal en het percentage micties op het toilet. De motivatie van de vrouwen om toiletgangvaardigheden te trainen was matig. Dit betekent dat verbetering van de vaardigheden met een intensieve therapie mogelijk is, maar dat dit niet vanzelfsprekend leidt tot vermindering van de incontinentie.

In hoofdstuk 8 worden de belangrijkste bevindingen van dit proefschrift beschreven in het licht van de onderzoeksvragen. Sterke punten en beperkingen van het onderzoek worden bediscussieerd, gevolgd door de aanbevelingen voor onderzoekers, artsen, verzorgenden, management van verpleeghuizen en beleidmakers. Het hoofdstuk eindigt met aanbevelingen voor toekomstig onderzoek en een algemene conclusie.

Samenvattend kunnen de volgende conclusies uit dit proefschrift worden getrokken: De prevalentie en incidentie van UI, FI en DI in verpleeg- en verzorgingshuizen zijn hoog. De incidentie in 3 maanden van FI was het hoogst (22.2%). Verslechtering van continentiestatus voltrekt zich stapsgewijs, van continentie naar zuivere UI en van zuivere UI naar DI. Dus wanneer een patiënt incontinent van urine is, dan moet afgezien van de behandeling van UI ook naar de mogelijkheden gekeken worden ter preventie van FI. De incidentie van FI was gecorreleerd met toiletgangvaardigheden, als de toiletgangvaardigheden verslechteren dan nam de kans op FI significant toe, en als de...
toiletgangvaardigheden verbeteren dan neemt de kans op FI significant af. Het verbeteren van
toiletgangvaardigheden van patiënten die incontinent voor onlasting zijn kan dus effectief zijn. UI is
gassociated met een zeer grote kans op FI, onafhankelijk van toiletgangvaardigheden. Deze
constatering is een argument voor de stelling dat apart van toiletgangvaardigheden en morbiditeit ook
andere factoren van belang zijn voor de ontwikkeling van FI. Deze factoren kunnen te maken hebben
met de toestand van de bekkenbodem, maar het is ook mogelijk dat verminderde alertheid (iemand
heeft immers al incontinentiemateriaal), uithoudingsvermogen en motivatie belangrijk zijn. Zo is het
ook bekend uit onderzoek dat de motivatie van ouderen om met veel moeite de incontinentie te
bestrijden niet altijd groot is.

Beroerte en cognitieve achteruitgang waren geassocieerd met een grote kans op incidente UI en FI,
een heupfractuur was geassocieerd met een grote kans op FI. Dit kon gedeeltelijke worden
toegeschreven aan verslechtering van toiletgangvaardigheden. Het is toch belangrijk om
toiletvaardigheden, waar mogelijk, te verbeteren in geval van een beroerte, heupfractuur of cognitieve
achteruitgang.

Toiletgangvaardigheden kunnen verbeteren door een gericht trainingsprogramma. Het
trainingsprogramma gaf een 37.7% afname van de dagelijks ongewenst verloren hoeveelheid urine
vergelijken met de controle groep. Deze afname is echter niet klinisch relevant. Het
trainingsprogramma had geen effect op het aantal micities op het toilet en de motivatie om de
toiletgangvaardigheden te trainen was matig. Toch is er genoeg bewijs in de literatuur voor de stelling
dat monitoren en trainen van toiletgangvaardigheden, gecombineerd met aansporingen om naar het
toilet te gaan, bij verpleeghuispatiënten tijdens het verblijf in het verpleeghuis effectief is in het
verminderen van incontinentie en aan incontinentie gerelateerde problemen. Onafhankelijke toiletgang
is een belangrijk resultaat van revalidatie programma’s. Het is overigens maar de vraag of het
vóór komen van UI en FI in verpleeghuizen binnen de mogelijkheden van de V&V verblijfs
zorgzwaartepakketten belangrijk naar beneden kan. Het ‘aansporen’ vraagt veel meer verzorgenden
dan op dit moment aanwezig zijn in verpleeghuizen in Nederland en de Verenigde Staten.

Verder onderzoek wordt aanbevolen om de assessment van toiletgangvaardigheden met de TT-test te
verbeteren en de mogelijkheden te onderzoeken van gerichte trainingsprogramma’s op
toiletgangvaardigheden in geriatrische revalidatie programma’s. Want de gegevens in dit proefschrift wijzen erop dat snel herstel van het vermogen om zelf naar het toilet te gaan, als dat vermogen door een ploteling ziekte is verminderd (beroerte, heupfractuur), het herstel van continentie aanmerkelijk zal bevorderen.
Dankwoord

Er is meer dan 10 jaar gewerkt aan het onderzoek dat in dit proefschrift wordt besproken. Er zijn heel veel onderzoekers, cliënten, zorginstellingen, verzorgenden en collega artsen betrokken geweest. Aan die contacten heb ik heel veel plezier beleefd en hebben mij enorm geholpen, niet alleen bij de uitvoering van het onderzoek maar ook bij het ontwikkelen van inzichten die ik elke dag weer in de praktijk gebruik. Ik kan een ieder aanraden om op deze manier met je beroep bezig te zijn. Het vak van verpleeghuisarts is op zich een mooi beroep, maar voortdurende verwondering over hetgeen je meemaakt, het spreken met collega’s over die waarnemingen en vervolgens het toetsen van hypothesen (en ondertekken dat het net even anders is dan je denkt) is een enorm verrijkende bezigheid.

Het is allemaal begonnen doordat het onderwerp incontinentie werd gekozen in een onderlinge toetsingscyclus. Uiteindelijk resulteerde die toetsingscyclus in een publicatie in Vox Hospitii (het huidige Tijdschrift voor Verpleeghuisgeneeskunde). Dat artikel bracht mij in contact met professor Jannes Janssens (toen emeritus hoogleraar verloskunde en gynaecologie). Hij was ter gelegenheid van zijn eremitaat een project gestart gericht op urine-incontinentie bij oudere vrouwen. Voor dit project was financiering verkregen van het toenmalige Preventiefonds. Met dit project wilde hij onderzoek stimuleren zowel in het ziekenhuis als in het verpleeghuis. Hij was attent gemaakt op de publicatie in de Vox en vroeg mij mee te denken over de mogelijkheden om ook iets te doen met urine-incontinentie bij oudere vrouwen in het verpleeghuis. Na enkele gesprekken besloot hij Angela Kok (onderzoeker vanuit gynaecologie) en mij te stimuleren onderzoek in onze sectoren op te starten. Er werd een epidemiologisch onderzoek gedaan naar de prevalentie van urine-incontinentie bij oudere vrouwen in Amstelveen en professor Janssens stimuleerde dat Angela en ik daarover een publicatie lieten verschijnen. Na dit onderzoek richtte de aandacht van Angela op de mogelijkheden van electrostimulatie en ik besloot mij bezig te gaan houden met de relatie tussen mobiliteitstoornissen en urine-incontinentie. In dit stadium waren de gesprekken met Angela Kok en haar begeleiders (Curt Burger en prof Kenemans) beslissend voor de verdere voortgang. Professor Janssens wilde zelf alleen van afstand betrokken zijn en wendde zich voor de dagelijkse sturing van mijn project tot professor

Na de interventie was het geld op. Miel wist nog voor aanvulling te zorgen vanuit de academiseringsgelden die de overheid toen beschikbaar stelde. Zoals het altijd gaat met onderzoek leverde de resultaten van het interventieonderzoek meer vragen op dan beantwoord werden en er ontstond het voornemen om die vragen te gaan beantwoorden met behulp van SIVIS data en later ook MDS-RAI data. Dinnus Frijters was behulpzaam bij de analyse met SIVIS data en voor de MDS RAI data zocht Miel contact met John Morris van het Hebrew Rehabilitation Center for Aged in Boston.
Het onderzoek met SIVIS data kon snel gerealiseerd worden door de prompte medewerking van Dinnus. Het onderzoek met MDS-RAI data was echter ingewikkelder. We konden niet zelf over de dataset beschikken maar moesten het onderzoek doen via assistenten in Boston. Via Sam Simon en later Margaret Bryan konden de data worden geëxplorereerd, maar de afstand tussen Nederland en Amerika bleek zeer vertraging. De exploratie van de data kostte veel tijd, maar na een bezoek aan het HRCA te Boston kwam er versnelling. Sindsdien zijn er honderden emails uitgewisseld met Margaret om uiteindelijk de definitieve gegevens te verkrijgen. Vooral het geduld en de inzet van Margaret waren daarbij beslistend. John zag over de schouder toe en adviseerde over data-sets en keek soms wat meewarig naar wat we allemaal van plan waren. Maar altijd constructief en to the point stuurde hij bij.

Een langjarig project kent natuurlijk ook tegenslagen. De belangrijkste tegenslagen waren de ziekte van Angela, het overlijden van professor Janssens en de ziekte van Marcel. De initiator en de methodologische steunpilaar waren dus weggevallen. Ik miste vooral de gesprekken met Marcel erg en de vaart was uit het project. Een korte tijd werd Annemagriet Pot aan het onderzoek toegevoegd, maar zij aanvaarde al snel een baan elders. Met de komst van Wilco Achterberg en later Miranda Dik kwam er weer vaart in het project. Zij hebben zich in korte tijd in de materie ingewerkt en waren in staat zeer belangrijke onderliggende methodologische vraagstukken op te lossen, daarbij af en toe gebruik makend van de statistische expertise van Dick Bezemer. Wilco en Miranda werden de co-promotoren.

Ondanks alle tegenslagen heeft Miel altijd vertrouwen gehouden in de goede afloop. Hij heeft alle tegenslagen weten op te vangen en hield er rekening mee dat ik na het interventieonderzoek alleen in de avonduren en weekenden aan het project kon werken. Op de beslissende momenten zorgde hij voor voldoende ondersteuning vanuit het EMGO en de afdeling verpleeghuisgeneeskunde.

Nadat uiteindelijk het geheel was afgerond kan het manuscript worden voorgelegd aan de promotiecommissie, bestaande uit Curt Burger, Marian van der Weide, Gert Kwakkel, Toine Lagro-Janssen en John Morris.

Tot slot, mijn dank voor de twee paranimfen die mij bijstaan bij de promotie. Allereerst mijn schoonzus Joke Bottcher, die na de opvoeding van haar drie kinderen onlangs is gaan werken in een groepswoning voor dementerende ouderen en inmiddels alles weet over de problematiek die in dit

Dankwoord
proefschrift wordt besproken en mijn dochter Irja die al mijn verhalen heeft aangehoord en op basis van die verhalen de omslag heeft verzorgd.

In 2001 stapte hij over naar de stichting Zorgbalans te Heemstede alwaar hij ging werken als hoofd medische dienst. In 2005 aanvaarde hij de positie van hoofd medische dienst bij de Zonnehuisgroep Amstelland alwaar hij werkt als verpleeghuisarts en als manager van het Kennis en Behandelcentrum voor Ouderen (samen met collega manager Hans van Willenswaard). In deze functie is hij tevens verpleeghuisarts en hoofd medische dienst van Beth Shalom te Amsterdam. Momenteel is hij betrokken bij de ontwikkeling van de richtlijn ‘Vrouwen met urine-incontinentie’ door het CBO en de richtlijn ‘Urine-incontinentie bij ouderen’ door het LEVV. Tevens is hij betrokken bij het Zorg voor beter project dat zich richt op incontinentie en toiletgangproblematiek.
Algemene uitgangspunten


Het mobiliteitsprobleem wordt gemeten met de Toilet-Timing Testen, waarbij de drie componenten van de toiletgang, opstaan, voortbewegen en handelingen op het toilet, apart worden gemeten.

Specifieke doelstellingen van de toilettgangtraining kunnen hiërarchisch worden afgestemd op de uitslag van de Toilet-Timing Testen.

Bij het maken van doelstellingen en richtlijnen voor toilettgangtraining wordt uitgegaan van resultaten van gedegen effectonderzoeken van fysio- en ergotherapeutische interventies. Hierbij richten we ons op drie veel voorkomende diagnose groepen in de patiëntenpopulatie van de verpleeghuispatiënten, namelijk patiënten met cerebrovasculaire aandoeningen (CVA), patiënten met extrapiramidale bewegingsstoornissen (Parkinson) en patiënten met orthopedische en/of traumatólogische aandoeningen van het bewegingsapparaat. De behandelrichtlijnen zijn gebaseerd op bestaande onderzoeken naar de effectiviteit van fysio- en ergotherapeutische interventies bij bovengenoemde drie patiëntengroepen. Verder is rekening gehouden met de beroepomschrijving en al bestaande consensus afspraken die in het verleden zijn gemaakt.
Uit de literatuurstudie kan geconcludeerd worden dat behandeleffecten van fysio- en ergotherapeutische interventies vooral specifiek zijn en significante effecten laten zien op functies die direct getraind worden. Dit betekent dat de training zo functioneel mogelijk gericht zal moeten zijn.

Tevens komt uit de literatuur naar voren dat er een relatie bestaat tussen de intensiteit van trainen en de gemeten vooruitgang. Er zal dus gestreefd worden naar een goede intensiteit van training.

In het algemeen zal de therapie gericht zijn op het verhogen van de snelheid van handelen van de drie componenten van de toiletgang (zonder dat de veiligheid in het geding komt) en het bevorderen van de zelfstandigheid van handelen.

Binnen de behandelrichtlijnen zal geen prioriteit worden gegeven aan één specifieke oefenmethode; de therapeut kan naar eigen inzicht kiezen voor een behandelconcept dat voldoet aan de bovengenoemde eisen van specificiteit, intensiteit en doelgerichtheid.

Hulpmiddelen en instructies naar verpleging en familie zullen worden gebruikt om de veiligheid, snelheid en zelfstandigheid te bevorderen.

De fysiotherapie en ergotherapie zullen in onderling overleg hun specifieke inbreng in de training van elke patiënt bepalen. Zij leggen dit vast in de patiënten interventie-registratie-agenda. De behandeldende arts zal zijn/haar goedkeuring aan het aldus verkregen behandel plan geven. Voor een effectieve behandeling zal regelmatig overleg nodig zijn om zo nodig gestelde doelen te kunnen bijstellen.

In veel gevallen zal gezien het chronisch karakter van de onderliggende pathologie geen noemenswaardige verbetering in het functioneren van de patiënt zelf te verwachten zijn. In dat geval zal eerder de verbetering gezocht moeten worden in aanpassingen die het zelfstandig, veilig en efficiënt functioneren kunnen vergroten.

De therapeuten zullen van elk behandelfase vastleggen (in de patienteninterventie-registratie-agenda) hoelang het contact heeft geduurd, welke doelstelling de behandeling tijdens dit contact had en waaruit de behandeling heeft bestaan.

*Richtlijnen voor het trainen van uit bed komen en opstaan uit de stoel.*

Vanuit rug lig komt de patiënt via zijaan tot zit op de rand van het bed.

Summary intervention
Mondelinge aanwijzingen over de meest efficiënte techniek worden hierbij gegeven door de therapeut. Indien nodig kan bij de CVA patiënten het verbeteren van de zitbalans nog specifiek worden getraind. Bij het gaan staan vanaf de rand van het bed of vanuit de stoel wordt vooraf gelet op een goede positionering van de voeten en worden vervolgens aanwijzingen over de juiste techniek gegeven; het lichaamswaartepunt moet naar voren worden gebracht en benen en lichaam moeten worden gestrekt. Het loophulpmiddel dat gebruikt gaat worden moet binnen handbereik van de patiënt zijn. Bij CVA patiënten zal er naar gestreefd worden om het paretische been bij het gaan staan maximaal te belasten en zonodig kan de balans in stand geoefend worden. Bij Parkinsonpatiënten kan als ondersteuning van het gaan staan auditieve en visuele feedback gegeven worden (tellen, visuele cue). Bij orthopedische/traumatologische patiënten kan zonodig extra oefeningen gegeven worden voor paretische spiergroepen en gewrichten met een mobiliteitsbeperking.

*Richtlijnen voor het trainen van het voortbewegen (lopen en rolstoelrijden).*

De looptraining zal vooral gericht zijn op verhogen van deloopsnelheid en het bevorderen van het veilig zelfstandig kunnen lopen. Het kiezen van een loophulpmiddel waarmee de patiënt sneller en zelfstandig zou kunnen lopen, is een belangrijke voorwaarde hierbij. Correcties van het looppatroon moeten individueel afgestemd gegeven worden, afhankelijk van de bestaande afwijkingen van het looppatroon. Bij CVA patiënten kan ter ondersteuning van het opvoeren van de loopsnelheid vooraf in stand het ritmisch uitvoeren van bekkenverplaatsingen naar het linker en rechter been geoefend worden (‘rocking’ technieken). Het streven om symmetrisch te lopen, zoals gepropageerd door het NOT-concept, zal niet binnen de behandeling worden nagestreefd, omdat dit ten koste zal gaan van de gemiddelde loopsnelheid. Bij Parkinsonpatiënten kan tijdens het lopen zonodig ritmische auditieve en visuele feedback gegeven worden. Bij orthopedische/traumatologische patiënten kan zonodig balans op het aangedane been extra worden geoefend.
De training van het rolstoelrijden zal zijn gericht op het hanteren van de rolstoel en de snelheid van voortbewegen.

Voor wat betreft het hanteren van de rolstoel zal de therapeut een op de individuele patiënt toegesneden instructie-programma vervaardigen waarin deelhandelingen (bijv. rolstoel op rem zetten, positioneren van de voetsteun, positioneren handen op hoepel) zijn geformuleerd. Deze deelhandelingen worden in 3 fasen aangeleerd; therapeut leest voor, patiënt leest zelf, patiënt voert direct uit.

Bij de training van de snelheid van voortbewegen in de rolstoel zal aandacht zijn voor de bewegingscoördinatie door te trainen op een achtbaan parcours en de fysieke conditie van de patiënt. De fysieke conditie zal getraind worden door veelvuldig een afstand met een submaximale snelheid te laten afleggen om de patiënt niet te overbelasten.

*Richtlijnen voor het trainen van de handelingen op het toilet.*

De training zal gericht moeten zijn op het snel en zelfstandig kunnen losmaken en laten zakken van kledingstukken op het toilet. Aanpassingen aan de kleding om dit te bevorderen zijn hierbij aan te raden.

Bij de groep CVA patiënten zal per patiënt beoordeeld moeten worden wat de bijdrage van de paretische arm zal zijn bij het snel en zelfstandig uitvoeren van handelingen op het toilet en welke oefenстрategie hierbij gekozen moet worden.
Appendix II

Construction of instruments for measuring toileting skills

Toileting skills.

Toileting skills refer to the ability of a person to perform several tasks that are needed to urinate and defecate on a toilet. Those tasks are: getting up from chair or bed, walking or riding in a wheelchair, find the toilet, manipulating clothing, sitting down on the toilet.

Although it is widely recognized that there is an association between urinary incontinence (UI) and fecal incontinence (FI) on the one hand, and mobility and cognition on the other, there is little research done into the relationship of the specific tasks needed for toileting and the development of incontinence. There are reports of interventions on improving general functioning; however research on toileting skills as a concept is only found in two studies.

Ouslander reported on a test performed by Williams in 1982(1). This test is called the POTTI (performance on timed toileting instrument) which consist of the performance on 5 tasks: walking 15 feet, sit down on a table, opening a hook, opening a zip, take off a piece of clothing. For those tasks a threshold time was set (respectively 55, 55, 35, 25, and 25 seconds). The threshold time for all tasks combined was set on 195 seconds. It is not clear how the threshold times were calculated.

Burgio(2) reported on a test on toileting skills on adult day care center clients. Clients were localized 15 feet from a toilet and asked to sit down on the toilet ready for urinating. The time needed for doing so was recorded. All of the continent clients (n=19) and only 46.2% of the incontinent clients (n=13) were able to self-toilet. Continent clients required 13 to 49 seconds (mean 24.6 seconds) and incontinent clients required 49 to 203 seconds (mean 115 seconds).

In reports about functional status of nursing home residents mostly activities of daily life (ADL) instruments are used. The general concept of ADL is not suitable for specific research on toileting skills because it assesses not only mobility, transfers and toileting, but also bathing and eating.

However, an instrument for the assessment of toileting skills with proven reliability does not exist.
We wanted to construct instruments to measure toileting skills with a good face and construct validity for use with existing databases and for targeting an intervention on toileting skills. In this chapter the assessment instruments on toileting skills, used in this thesis, are described and compared with each other.

**Development of assessment instruments for toileting skills**

Toileting skills as a concept is not directly measurable. The tasks needed for toileting (getting up from chair or bed, walking or riding in a wheelchair, find the toilet, manipulating clothing, and sitting down on the toilet) can be measured separately. They can be measured in terms of the assistance needed to perform the tasks or by the time needed to complete the task.

1. **Toilet Index**

   The Toilet Index (TI) uses items of the Dutch SIVIS-registration. This registration has been used in Dutch nursing home care from 1981 to 2004, and provided clinical information of the majority of the nursing home patients(3). We used the item-scores available in the database to express the assistance needed for the individual tasks: for dressing there is a 3 point score, for standing a 4 point score, and for walking and transfers a 5 point scale. The summed total-score has a range from 0 (no assistance needed) to 13 (maximum assistance needed).

2. **(Change in) Toilet Dependency Score**

   The Toilet Dependency Score (TDS) was developed with items from the RAI-MDS. For independent toileting a resident should be able to go to the toilet (walking or riding in a wheelchair and find the toilet) and handle clothing and get seated on the toilet without assistance. Therefore the scale was constructed using the MDS items; ‘locomotion on the unit (score 0-4)’, ‘toilet use (score 0-4)’ and ‘find room (score 0-1)’. The item scores for locomotion on the unit and toilet use is; 0 (independent), 1(supervisions), 2 (limited assistance), 3(extensive assistance), 4(total dependence). The scale has a range from 0 to 8. The scores on locomotion on unit and toilet use are summed. When find room scored 1 (room not found), the score on locomotion on unit was adjusted to 4, because when a resident cannot find his room or toilet the resident needs assistance in finding the toilet and this equals a score 4 on the item locomotion on unit. We also constructed also a scale for change in TDS based upon the...
TDS score on two points in time, ranging from –4 to +4, a change of more than 4 points was scored ‘4’.

3 Toilet Timing Test

For the intervention study we developed the Toilet Timing test (TT test). The TT test measures the time a participant needs to perform the subsequent tasks associated with going to the toilet under standardized circumstances. Two versions were developed: one for participants who usually walk to the toilet, and one for participants that use a wheelchair. Toilet timing was determined for both daytime and night-time toileting. For day-time toileting the following tasks were assessed: stand up from a chair, walk or ride 5 meters, undo clothing, and sit down on the toilet. For night-time toileting time needed to get out of bed was determined instead of time needed to stand up from a chair.

For each task a threshold time was set. Threshold times were based on the average performance observed in a separate group of continent elderly volunteers with no mobility disorders. These elderly volunteers were divided in two groups, a group of volunteers working in the nursing home (n=8) and a group of residents of a service-flat (n=21). The time needed for the separate tasks was in the group of residents of the service flat in average two times longer than in the group of volunteers working in the nursing home. The difference between the average of the two groups was multiplied with two and added to the average of the residents of the service-flat. In this way a meaningful impairment of the specific task is probable. The derived threshold times were; 7 seconds for get up from a bed and get up from a chair, 20 seconds for patients in wheelchair to rise up from bed en get seated in the wheelchair, 40 seconds for walk or ride 5 meters, 10 seconds for undoing a hook, zip and button, 30 seconds for let down clothing and sit down on the toilet, and 20 seconds for get up from the toilet and adjust clothing.

If a participant performed a task faster than the threshold time, it was considered unlikely that this specific task hindered continence. If a task was performed slower than the threshold time, it was assumed it could be an obstacle for normal toileting. A specific task was considered to be impossible if it took more than 5 minutes, in which case no sum-score was calculated (the patient is dependent in toileting). The sum of the threshold times for walking patients is 77 seconds and is much lower than the threshold time of the POTTI-test (195 seconds) and the mean time for incontinent clients reported by Burgio (115 seconds), but higher than the lowest time Burgio found for incontinent clients (49 sec).
However, in the test performed by Burgio participants were not asked to stand up. In the TT test a threshold time for this task of 7 seconds was calculated.

In addition to the TT test under standardized circumstances presented above, a version was developed for measuring the time needed to go to the toilet in the actual individual daily circumstances. This version included the same tasks but instead of using threshold times, the actual circumstances were described in parameters such as distance to the nearest toilet, dimensions of the toilet, etc. These measurements were performed for comparison before and after intervention.

**Discussion.**

There are no established instruments to measure toileting skills, which is remarkable because toileting skills are very important in remaining continent, and incontinence is a major burden for especially elderly individuals and society. We wanted to study the concept in a large Dutch database (SIVIS), a large USA-database (MDS) and in an randomized controlled trial. Therefore, we developed the Toilet Index (TI), Toilet Dependency Score (TDS) and Toilet Timing test (TT test). There are distinct differences between the TI, TDS and change TDS on the one hand and the TT test on the other. The TI, the TDS, and change TDS were constructed to express assistance in toileting skills for use in databases that are not constructed to measure toileting skills as a concept. The items on which the scores are based were scored by nurses. The task on the TT test and the sum-scores reflects the ability of a subject to perform the toileting tasks. The TT test is developed to measure each individual tasks and to find patients with slow performance on the individual tasks and to evaluate an intervention on those tasks. The test in the intervention was scored by a research nurse.

**Differences between TI and TDS**

Although the TI and TDS are constructed to assess the same concept, namely the need of assistance in the process of toileting, there are some differences. The items in the TI express the need for assistance in capabilities to walk, transfer, and stand upright and dress. The TDS consists of items in which some of the capabilities are integrated in one item; locomotion on the unit and toilet use. Also there is a correction in the TDS for the cognitive capability of orientation, namely find room. This was done because the prevalence of incontinence in patients with dementia showed a steep increase when there
was a small increase in TI scores (see Chapter 2). So the TI is purely based on physical capabilities, but in the TDS there is also a cognitive element.

Comparing TI and TT test
Compared to the TT test, it is possible that in the TI the task of dressing has too little weight and transfer (standing up) has too much weight. In the TI there is a 3 point score for dressing, a 4 point score for standing, and a 5 point score for both walking and transfers to express the assistance needed for the individual items. The threshold time for comparable tasks in the TT test were: 7 seconds for getting up from a bed and stand up from a chair, 20 seconds for patients in wheelchair get up from a bed and get seated in the wheelchair, 40 seconds for walk or ride 5 meters, 30 seconds for let down clothing and sit down on the toilet. Thus compared with the TT test, in the TI the task of dressing has to little weight and transfer (standing up) has to much weight. However, the prevalence of incontinence of patients with a physical disability appeared to increase with each following step in the Toilet Index score, indicating adequate construct validity for patients with a physical disability.

Comparing TDS and TT test
The TDS is more in line with the threshold times from the TT test. The TDS was constructed using the MDS items; ‘locomotion on the unit (score 0-4)’ and ‘toilet use (score 0-4)’ with a correction for the item ‘find room (score 0-1)’. If a patient scored find room =1, than locomotion was adjusted to 4. Walking and transfer are contained in locomotion on the unit and dressing and transfer in the item toilet use. The weight of these items was equal and there was a correction for finding the toilet. The incidence of FI increased with each step of the TDS, indicating that there was also adequate construct validity. These results suggest that the TDS is more accurate in measuring toileting skills than the TI.

Change TDS
The change-TDS measure was created for assessing the change in TDS on two points in time. The change TDS score we developed should be able to predict the changes in FI status better than the MDS locomotion or toilet-use items only, or the MDS-CPS(4) and MDS-ADL(4;5) scales. The toilet-use
items and the MDS-CPS proved to be bad predictors, but the ADL-scale and even the single locomotion-item, correlated just as strongly with change in FI as the change TDS score.

The TT test
The aim of TT test was to identify patients who are hindered in toileting in such extend that this could result in incontinence, to identify the specific tasks that are impaired and to measure improvement on the tasks after intervention. The test in this thesis is performed by a instructed and trained research nurse ruling out any inter-rater variability. Measurement of each task was only feasible once, because of the endurance of the participants. Therefore test-retest reproducibility could not been established.

Conclusion
TI, TDS, Change TDS and TT test were constructed with tasks a patients needs to perform in toileting. The TI had good construct validity for patient with a physical disability. The TDS has good construct validity for patients with a physical and cognitive disability. Change TDS correlates with the risk of FI. The calculated threshold times for tasks from the TT test are probably adequate to find residents by whom the performance on the tasks could have a relation with UI. However, for the TT test inter-rater variability and test-retest reproducibility needs to be established.

References