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## ICELANDIC NURSING HOME RESIDENTS: THEIR MORTALITY, HEALTH, FUNCTIONAL PROFILE, AND CARE QUALITY, USING THE MINIMUM DATA SET OVER TIME

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2012

[Link to publication](#)

*Citation for published version (APA):*

Hjaltadottir, I. (2012). *ICELANDIC NURSING HOME RESIDENTS: THEIR MORTALITY, HEALTH, FUNCTIONAL PROFILE, AND CARE QUALITY, USING THE MINIMUM DATA SET OVER TIME*. [Doctoral Thesis (compilation), Department of Health Sciences]. Lund University: Faculty of Medicine.

*Total number of authors:*

1

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Department of Health Sciences, Faculty of Medicine,  
Lund University, Sweden. Bulletin No.35 from the Unit of Caring  
Sciences, 2012

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## ICELANDIC NURSING HOME RESIDENTS

Their mortality, health, functional profile, and  
care quality, using the Minimum Data Set over time

Ingibjörg Hjaltadóttir



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ISBN 978-91-86871-71-0  
ISSN 1652-8220  
Lund University, Faculty of Medicine  
Doctoral Dissertation Series 2012:9  
Printed in Sweden by Media-Tryck

*To my children*

*Laufey, Kristján and Salóme Ósk*



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## ABSTRACT

The overall aim of this thesis was to investigate trends over time in residents' health status, functional profile and predictors of mortality at admission to Icelandic nursing homes and in addition to determine upper and lower thresholds for Minimum Data Set (MDS) Quality Indicators, to investigate the prevalence of quality indicators over time and their association with the health status and functional profile of residents in Icelandic nursing homes. Studies I and II included 2,206 persons assessed over 11 years (1996-2006). In study III a modified Delphi method and a panel of 12 members were used to determine the thresholds for Minimum Data Set Quality Indicators. Data from residents (N=2,247 representing 47 nursing homes) were analysed, applying the thresholds developed. In study IV the sample was 11,034 MDS assessments of 3,694 residents (2003-2009) and in the framework the sample was 11,912 MDS assessments of 3,704 residents (1999-2009).

Study I showed that 28.6-61.4% of residents had intact cognitive performance and 42.5-68% were independent in ADL performance. A weak, but significant, linear trend over the eleven years was seen in residents' health becoming less stable, their cognitive performance improving, more pain being reported and greater participation in social activities. Study II showed that the median survival time was 31 months. No significant difference was detected in the mortality rate between cohorts. Age, gender (HR 1.52), place admitted from (HR 1.27), ADL functioning (HR 1.33-1.80), health stability (HR 1.61-16.12) and ability to engage in social activities (HR 1.51-1.65) were significant predictors of mortality. In study III upper and lower thresholds for 20 Minimum Data Set Quality Indicators were established. Residents not having a quality indicator present numbered from 32.5-99.3% depending on the indicator in question. The quality indicators with the median value above the upper threshold, indicating poor care, were: depression (49.4%); symptoms of depression without antidepressant (18.2%); use of 9 or more medications (63.8%); anti-anxiety or hypnotic drug use (69.2%); little or no activity (52.5%). Findings from study IV showed that 16 out of 20 quality indicators increased in prevalence, indicating a decline in quality of care ( $p < 0.05$ ) over the study period. In 12 out of 20 indicators the prevalence was lower than 25%. One quality indicator showed improvement, i.e. 'Bladder and bowel incontinence without a toileting plan' from 17.4% in 2003 decreasing to 11.5% in 2009 ( $p < 0.001$ ). Residents' health and functional status partially explained the increased prevalence of the quality indicators over time.

At admittance many residents had a relatively high level of independence, the mortality rate did not change over the study period and health stability and ADL performance were strong predictors of mortality. More than 50% died within 3 years, and almost a third of the residents may have needed palliative care within a year of admission. Pain management, social engagement and palliative care are areas where more staff knowledge seems to be needed. The thresholds established aims for Icelandic nursing homes, uncovering areas of care requiring improvement. Icelandic nursing homes seem to be doing best in handling incontinence and nutritional care, and in several quality indicators the prevalence was quite low. The areas of care that indicated poor care and needed improvement included treatment of depression, number of medications and resident activity level. Quality Indicator results and trends over time can be used for improvement, planning of services and staff knowledge.



## ABBREVIATIONS AND DEFINITIONS

Nursing home	A nursing home in Iceland is an institution or ward where nursing care is provided to the residents 24 hours a day. The care includes assistance with the activities of daily living (ADL), moving about, recreation, psychosocial care, room and board as well as medical care. A doctor visits the nursing home 3-5 times a week and attends to residents that are in need of medical care, as well as being on call for emergencies. The nursing hours provided per patient are, on average, 4.1-5.0/ 24 hours, the registered nurse-patient ratio is 0.31, and the total staff- patient ratio is 0.88.
RAI	Resident Assessment Instrument
MDS	Minimum Data Set
QI	Quality Indicators
RAP	Resident Assessment Protocols
RUG	Resource Utilization Groups
ADL	Activities of Daily Living
CHESS	Changes in Health, End-stage disease and Signs and Symptoms scale
CPS	Cognitive Performance Scale
DRS	Depression Rating Scale
ISE	Index of Social Engagement
PS	Pain Scale
ICF	International Classification of Functioning, Disability and Health
Model of Functioning and Disability	The Model of Functioning and Disability is presented by the World Health Organization in the International Classification of Functioning, Disability and Health.

### **The Model of Functioning and Disability defines the following model components and umbrella terms in the following way:**

Health condition	The disorders or diseases an individual may have.
Functioning	An umbrella term encompassing two components: a) all body functions and structures and b) activities and participation.

Body functions	The physiological and psychological functions of body systems.
Body structures	The anatomical parts of the body such as organs, limbs and their components.
Activity	Execution of a task or action by an individual.
Participation	Involvement in a life situation.
Disability	An umbrella term encompassing two components: a) impairments and b) activity limitations and participation restrictions.
Impairments in body function or structure	Problems in body function or structure such as significant deviations or loss.
Activity limitations	The difficulties an individual may have in executing activities.
Participation restrictions	The problems an individual may experience in involvement in life situations.
Contextual factors	An umbrella term encompassing two components: a) environment and b) personal factors.
Environment	The environment is defined in its broadest sense and stands for the physical, social and attitudinal environment where people live and play out their lives.
Personal factors	Personal factors are the particular background of an individual's life and living, and comprise features of the individual that are not part of a health condition or state of health. These factors may include gender, race, age, lifestyle, habits and upbringing.

## ORIGINAL PAPERS

- I Hjaltadóttir, I., Hallberg, I. R., Ekwall, A. K. & Nyberg, P. (2011). Health status and functional profile at admission of nursing home residents in Iceland over 11-year period. *International Journal of Older People Nursing*. August (Epub ahead of print).
- II Hjaltadóttir, I., Hallberg, I. R., Ekwall, A. K. & Nyberg, P. (2011). Predicting mortality of residents at admission to nursing home: A longitudinal cohort study. *BMC Health Services Research*, 11, 86.
- III Hjaltadóttir, I., Ekwall, A. K. & Hallberg, I. R. (2011). Thresholds for Minimum Data Set Quality Indicators developed and applied in Icelandic nursing homes. (Accepted with revisions by the Journal of Nursing Care Quality, 2011)
- IV Hjaltadóttir, I., Ekwall, A. K., Nyberg, P. & Hallberg, I. R. (2011). Quality of care in Icelandic nursing homes measured with Minimum Data Set Quality Indicators: Retrospective analysis of nursing home data over 7 years. (Submitted)

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## INTRODUCTION

In Europe, as in the rest of the world, the number of old people is rising, especially those who are 80 years and older. They are also more likely to be chronically ill, frail and in need of assistance or nursing home placement (Schulz, Leidl, & Konig, 2004; Statistics Iceland, 2011). Nursing homes are therefore faced with the assignment of providing care for residents with an increased burden of chronic disease and disabilities (Larizgoitia, 2003). It is important that staff be knowledgeable in order to address residents' special needs as provide for their well-being and maintenance of functional capability as well as palliation of the residents (Hommel et al., 2008). Those who organize and provide nursing home care need both personal and specialised knowledge about the people they are providing service to, and how their needs may change over time, in order to be able to provide appropriate care. Knowledge on how health, functional profile and mortality of residents at admission to nursing homes develop over time is scarce. Yet such knowledge is needed among the nursing home staff in order to plan the care and take decisions effectively.

Demographic changes and increased demand affect the service nursing homes provide (Meijer, Van Campen, & Kerkstra, 2000) and need to be responded to wisely. Expectations of quality of care are at the same time increasing (Meijer et al., 2000), as well as that care is provided by professionals (Larizgoitia, 2003). Knowledge on how well nursing homes have been coping with changes in the population that already have taken place and how this has affected quality of care is lacking and further research is needed (Sorenson, 2007). Furthermore it needs to be clear toward what level of quality of care nursing homes should aim and measures on where they stand in relation to these aims (Rantz et al., 2000). However research on what are constructive and global aims for quality of care for nursing homes is lacking

Efforts have been made in European countries to measure quality of care, although more needs to be done. Standardised assessment of care needs of residents and quality of care has a long tradition in the US. (Sorenson, 2007). There the Minimum Data Set (MDS) and Quality Indicators for the MDS have been used for this purpose in recent decades (Wiener, Freiman, & Brown, 2007). Standardised assessment such as with the MDS is important in observing changes over time. Trends that are observed over extended periods of time provide important information that is invaluable in assessing needs, planning services and for decision-making in public policy (Rosenberg, 1997). In this respect standardised clinical data such as is collected with the MDS is important (Goolsby, Olsen, & McGinnis, 2010). Knowledge on how admission status of nursing home residents has changed over time is crucial for health officials who make decisions on what form of service needs to be developed and for nursing home managers so they can plan the delivery of care and prepare knowledgeable staff that can respond to needs the residents may have.

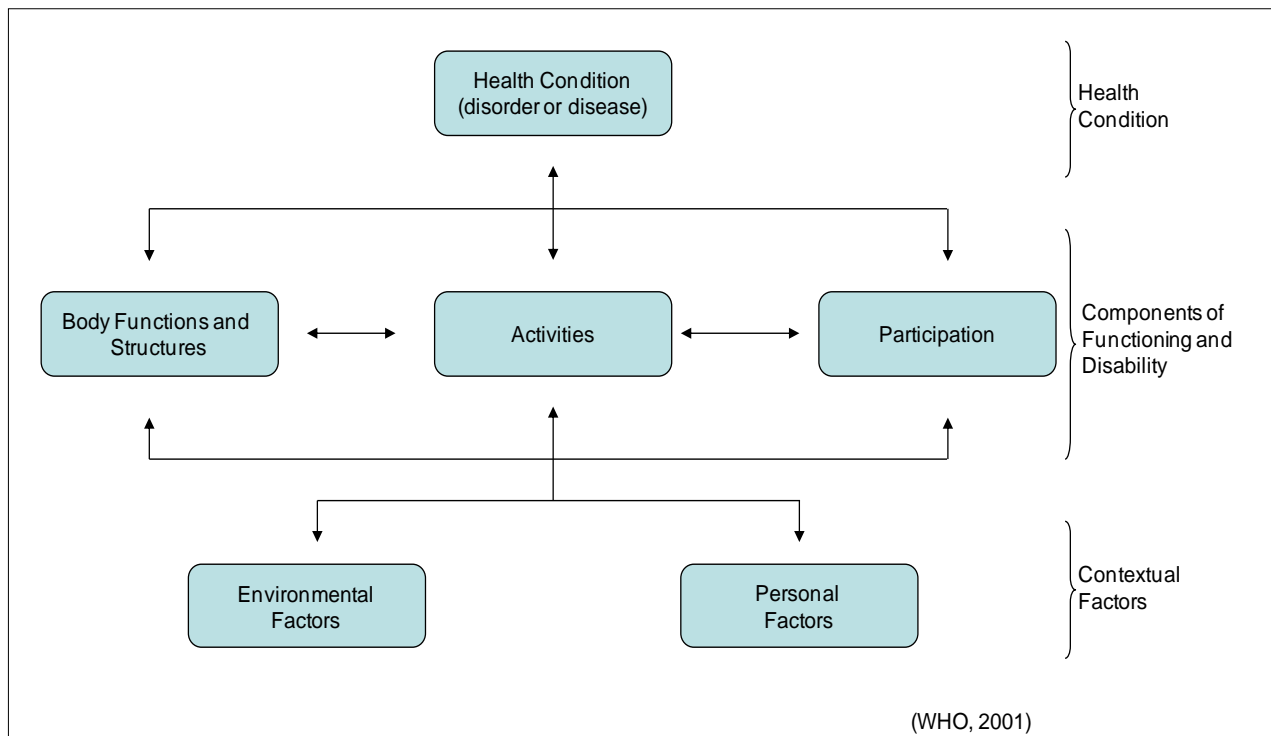
## **BACKGROUND**

Functional decline and disabilities are most often the reason elderly people need nursing home care. The main predictors for nursing home placement have been reported to be dementia, old age (Andel, Hyer, & Slack, 2007; Bharucha, Pandav, Shen, Dodge, & Ganguli, 2004), psychiatric disorders (Smith Black, Rabins, & German, 1999), functional impairment, myocardial infarction, living alone (Luppa, Luck, Matschinger, Konig, & Riedel-Heller, 2010), female gender and socioeconomic status (Martikainen et al., 2009). In some countries financial reasons may be a contributing factor in persons' moving to a nursing home rather than residential care (Grando et al., 2005). The increasing demand for nursing home placement has led some countries to apply more selective criteria for nursing home placement and develop services that are less expensive outside the nursing homes (Meijer et al., 2000). This has led to those admitted to nursing homes being frailer and more dependent and the nursing homes being under increased pressure to operate at lower cost at the same time as providing a better quality of care. In response to this some nursing homes have improved nursing staff training and offered a wider selection of services and comfort, as well as offered more single rooms or fewer residents in each room. These changes have generated an increase in workload for the staff as well as higher demands (Meijer et al., 2000). Although clinical data and information on health of residents and quality of care may often be fragmented it has the potential to transform clinical practise (Goolsby et al., 2010). With recent improvements in documentation and ever-growing information databases, the data can be used to generate knowledge that is useful in organizing services and to enhance quality of care. Thus trends in nursing home care and services need to be monitored in order to manage the increasing number of people in need of nursing home care. Only by having knowledge on how the health and functioning of people in need of nursing home care has developed over time is it possible to deliberate on future trends (Rosenberg, 1997). Nursing homes need not only to prepare for future needs in service but also to respond to how quality of care in the nursing home has developed. Such knowledge enables nursing homes to respond with improvements and turn around possibly undesirable trends that can only be uncovered in longitudinal data. This will in turn be beneficial to people in need of nursing home care as well as the community.

### **Conceptual Framework**

The model of functioning and disability as brought forward by the World Health Organization (WHO) in the International Classification of Functioning, Disability and Health (ICF) was used as a conceptual framework for this research. The ICF can be used for different applications and has a universal application for all people, not only those with disabilities. The interaction between the ICF components in the model is explained further in figure 1. The model clarifies how a person is functioning and how disability can be looked upon as an interacting and evolving process between a person's health condition and contextual factors such as environment and personal factors (Figure 1) (WHO, 2001). As in life in general, it may be difficult to detect all

the components that influence the life of a nursing home resident. The model is useful in this sense and helpful in highlighting and understanding the association of the many different components of nursing home life. Research has identified several factors that influence the life of nursing home residents, for instance their health, functioning, and surroundings at the nursing home (Kane, 2001), staffing and quality of care (Bostick, Rantz, Flesner, & Riggs, 2006). All these factors come together and are explained in the model of functioning and disability as brought forward by the World Health Organization (WHO, 2001). The model suggests how these factors interact and may as a result influence the wellbeing of the nursing home resident (Figure 1).



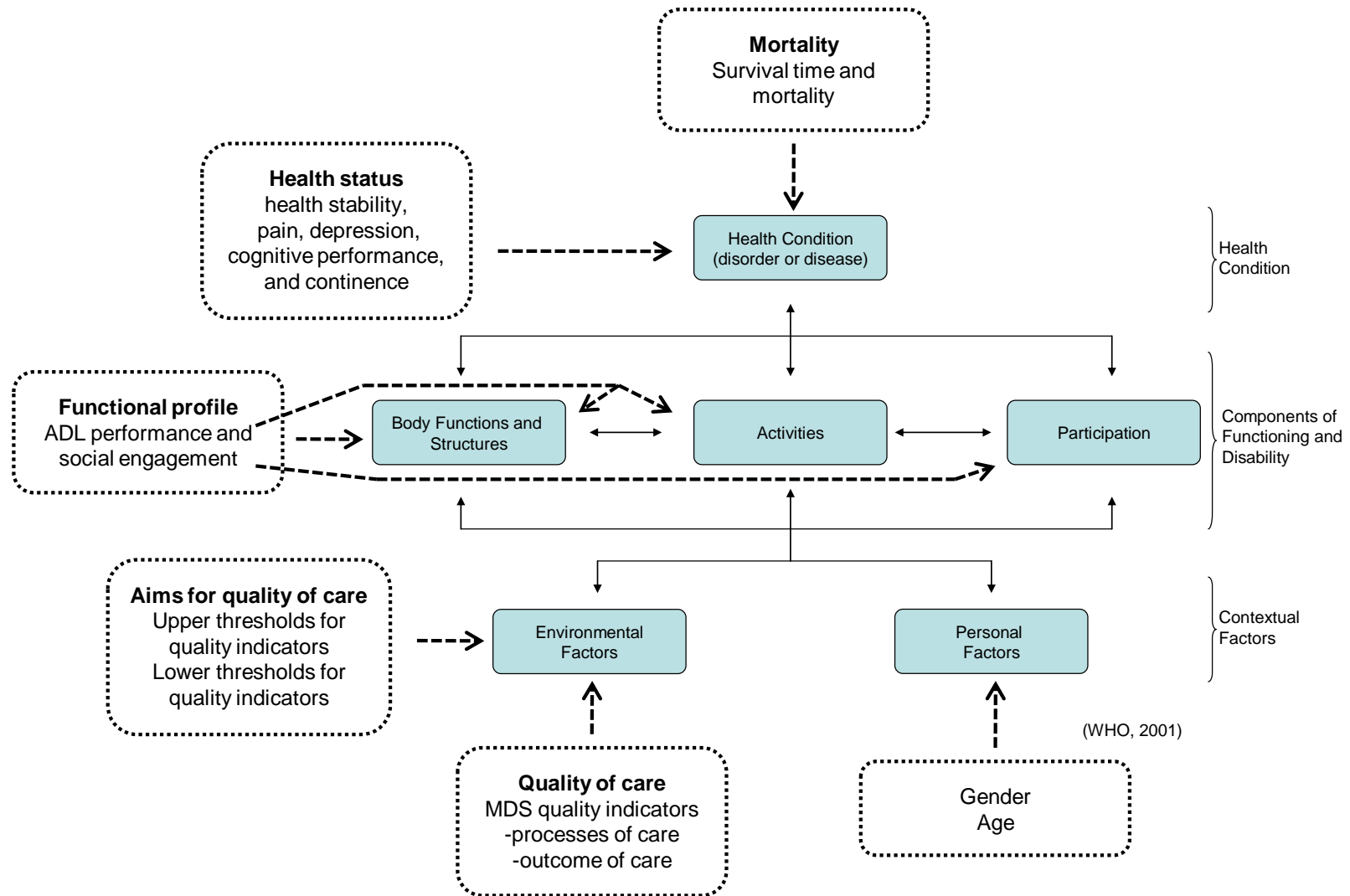
**Figure 1.** The Model of Functioning and Disability (WHO, 2001, pp. 18).

Nursing home residents need to cope with various health-related changes and disabilities within the nursing home environment. The model explains the interaction between ‘health condition’, ‘components of functioning and disability’ and ‘contextual factors’ and how this will influence how the old person will be able to function and how prominent the disabilities will be (WHO, 2001). In the model ‘functioning’ and ‘disability’ are umbrella terms, where functioning encompasses all body functions, activities and participation and disability is an umbrella term for impairments, limitations of activities and participation restrictions. Body functions stand for physiological and psychological functions of body systems and body structures are the anatomical parts of the body such as organs and limbs. Activities represent the actions of an individual or his execution of tasks. Participation is the person’s involvement in a life situation. The person’s health condition, i.e. disorder or disease, influences and is influenced by body functions and structures, activities and participation. These

components then again influence or are influenced by the environmental factors and personal factors.

The model portrays ‘contextual factors’ being ‘personal’ and ‘environmental factors’. The personal factors are described as age and gender, although in the model they entail much more such as lifestyle, habits and upbringing. Personal factors are based on aspects that make the person unique, not only gender or age but outlook on life, experiences in the past, upbringing and more (WHO, 2001). These factors may have affected the person’s health condition in some way such as personal habits or preferences that may affect health. Both health condition and personal factors will interact with and be reflected in the person’s body functions and structures, activities and participation (WHO, 2001). Environmental factors stand for the physical, social and attitudinal environment people live in. The environment in its broadest term and the individual’s personal factors will then in turn interact with functions and disabilities and influence what the person does or can do (Figure 1) (WHO, 2001).

The components in the model of functioning and disability further clarify and connect to certain elements in the life of the nursing home resident. (Figure 2). Applying the model to residents in nursing homes suggests that ‘health condition’ may be indicated by mortality, survival time, health stability, pain, depression, cognitive performance and continence. In addition, death can be viewed as the end result of serious disorders and disease and is presumably associated with all of the models’ components. The ‘components of functioning and disability’ may be indicated by the ADL performance and social engagement of residents. These elements connect further with the components of the model, i.e. ADL performance relates to ‘body functions and structures’ as well as ‘activities’ and social engagement relates to ‘participation’. The ‘contextual factors’ relate to environmental and personal factors (Figure 2). The ‘environmental factor’ is defined in the broadest sense in the model such as physical, social and attitudinal environment where people live and conduct their lives (WHO, 2001). The reason for moving to a nursing home environment is to receive the care that is delivered in the nursing home and care may thus be viewed as an important part of the nursing home environment. Whether or not nursing home staff measure quality of care and have decided on what goals or aims to work toward in order to maintain and increase the quality of care provided constitute a part of the attitudinal environment of the nursing home (Figure 2). Quality of care, however, is only a part of the nursing home environment. All of the model’s components interact, such as ‘environmental factors’ (quality) on the one hand and ‘health conditions’ (health status) and ‘components of functioning and disability’ (functional profile) on the other hand. The interaction between components in the model is complex but these interactions influence and determine how the residents will be able to function and enjoy life in a nursing home. The model helps therefore in distinguishing the many elements in nursing home life that are important for the person’s quality of life.



**Figure 2.** The model of functioning and disability (WHO, 2001) applied to the situation of nursing homes residents.



## **Health condition and components of functioning and disability**

Health condition, functioning and disability influence whether a person will need to move into a nursing home, what kind of care is needed and how the person adjusts to new circumstances (WHO, 2001). How well needs are met at the very beginning of moving to a nursing home may affect how the person adapts and enjoys life. Knowledge of characteristics' of residents on admission to a nursing home is fundamental to those who organise care in order to plan the care and take decisions on knowledge needed among the staff. How this information is used, for instance in preparing knowledgeable staff, can influence quality of care (Bostick et al., 2006) and the well-being of residents (Hommel et al., 2008).

### ***Health status and functional profile on admission to a nursing home***

People moving to nursing homes are frail in many senses. The age of residents at admission has been reported to be 79-84 and the proportion of women being 65-70% (Achterberg, Pot, Scherder, & Ribbe, 2007; Scocco, Rapattoni, & Fantoni, 2006). The majority of residents suffer from dementia on admission or 59-72% (Buchanan, Barkley, Wang, & Kim, 2005; Scocco et al., 2006; Travis, Buchanan, Wang, & Kim, 2004), the mean value for the Resident Assessment Instrument (RAI) Cognitive Performance Scale has been reported as 2.06 [from 0 (cognitively intact) to 6 (severe cognitive impairment)] (Boyington et al., 2007) and 19% suffer from psychiatric symptoms other than dementia (Scocco et al., 2006). Residents were also physically frail at admission, the mean score for RAI Activities of daily living reported was 3.28 [from 0 (independent in ADL) to 6 (severe impairment in ADL)], 50 % needed extensive support with ADL (Burge, Berchtold, & von Gunten, 2011), 65.4% had urinary incontinence (Boyington et al., 2007) and between 50-54% needed extensive assistance or were totally dependent in going to the toilet (Buchanan et al., 2005; Travis et al., 2004). The residents therefore may be in need for specialized service immediately on admission. In a Dutch study 50% of residents were experiencing some pain at admission though only 60% of those in pain were receiving pain medication (Achterberg et al., 2007). The number of residents who were experiencing less than daily pain came to 17.8%, and 32.4% experienced daily pain. Residents with dementia at admission have other care needs from those who are cognitively intact (Magaziner et al., 2005) and residents with diabetes may have more burden of illness and need more special treatments than do others (Travis et al., 2004). The residents' health and functional status needs to be assessed for problems that will affect their quality of life and their ability to adapt to new surroundings (Mezey, Lavizzo-Mourey, Brunswick, & Taylor, 1992). Research has indicated that residents may become more dependent and in need of more care than earlier (Beck, Damkjaer, El Kholy, & Schroll, 2008). Although many studies present data on the health and functional profile of residents living in nursing homes, fewer studies present findings on their admission status. Thus knowledge on the status of residents on admission and especially how their status has changed over time is lacking. Care providers need to be prepared for changes that may occur over time to be able to provide the best care possible for the residents.

### ***Mortality and death rate***

Knowledge on the mortality and death rate of residents is needed in order to properly organise appropriate services in nursing homes, as the residents will spend their last years of their lives there. Dying is a central issue in life in nursing homes although it is often not openly discussed (Hockley, Dewar, & Watson, 2005). The main goal for nursing care is to add quality to the life of residents so that they enjoy more the life they have left, rather than prolonging life at any cost (Sund-Levander, Grodzinsky, & Wahren, 2007). Planning need also to take into account that, as more emphasis is put on people living at home longer, it is likely that survival time in nursing homes will shorten and the aspects of the care needed most likely will therefore be affected.

Official data from Icelandic nursing homes indicate that men's survival time in nursing homes was 3.6 years in 1994 (Jensdottir et al., 1995) and had shortened to 3.3 years in 2005 (Icelandic Ministry of Health 2005). The mean survival time reported for newly admitted nursing home residents differs and has been reported to be 5.9 years (Dale, Burns, Panter, & Morris, 2001) and 2.3 years (McCann, O'Reilly, & Cardwell, 2009; Wieland, Boland, Baskins, & Kinosian, 2010) for both genders, and 76 days for men and 134 days for women (Sutcliffe et al., 2007). Furthermore, a Canadian study reported survival time for residents receiving poor quality of care being 28 months while for those receiving good quality of care it was 41 months. Those receiving poor quality of care had thus more than a year shorter to live than those with good quality of care (Bravo, Dubois, De Wals, Hebert, & Messier, 2002). The reported death rate of residents also varies and has been reported to be 17.5% (Dale et al., 2001) and 34% (Flacker & Kiely, 2003). In a Swedish study on people 65-98 years old (N=626;) receiving public long-term care, the mortality rate was 9-14% within the first year of decision about long-term care (Jakobsson & Hallberg, 2006). Increasing numbers of deaths occur in nursing homes (Hockley et al., 2005) and thus knowledge on average survival time and death rates over time is needed as this will have an impact on the care and service needed.

### ***Predictors of mortality***

Awareness of factors influencing mortality at admission is critical to managers and health officials. This knowledge is needed as some factors affecting mortality may indicate the need for specialised care and resources to ensure the comfort and well-being of the residents. Several factors assessed at admission to a nursing home have been found to predict mortality. Studies have reported predictors of mortality at admission to be cancer or history of malignancy, physical disability (Sutcliffe et al., 2007), problems with eating (Dale et al., 2001; Flacker & Kiely, 2003), use of medication (Dale et al., 2001; Sutcliffe et al., 2007), infection at admittance (Sutcliffe et al., 2007), a pressure ulcer, bowel incontinence, shortness of breath, congestive heart failure (Flacker & Kiely, 2003), age, male gender, sleep disturbance, where admitted from, and respiratory disease (Dale et al., 2001). Studies reporting predictors of mortality at admission and for those who have been living in a nursing home differ somewhat. Social engagement has for instance been reported to be a predictor of mortality for residents already living in nursing homes (Dale et al., 2001) (Kiely & Flacker, 2003) i.e. greater levels of social engagement were associated with

longer survival (Agahi & Parker, 2008; Kiely & Flacker, 2003). Furthermore, several studies have found cognitive performance not to be an independent predictor of mortality but demonstrated a relationship between ADL status and dementia (Sund-Levander et al., 2007; van Dijk et al., 2005).

## **Environmental factors**

There are various reasons why people leave their own homes to move into a nursing home, but they all come together in the need to be safe and cared for (Hjaltadottir & Gustafsdottir, 2007). Thus the expectation most people have of nursing homes is that they incorporate a safe environment that provides care and fulfils the needs of those who live there. Nursing homes provide an intricate environment which interacts with the person's health condition and personal factors. The model of functioning and disability views the environment in the broadest sense as the extrinsic world of the person. This entails the physical environment, attitudes, social relationships, services and care (WHO, 2001). Even the attitude of the staff may be influential, including whether there is an interest in quality of care and whether there is a culture of quality improvement. The most important aspect of a nursing home may be the care that is delivered there. As an environmental factor the quality of care will interact with the person's health condition and personal factors and this will be reflected in the functioning and disability of the person (WHO, 2001). Several factors in quality of care are influential in this way such as the availability or lack of activities and social engagement. The wellbeing and health status of residents may influence their activity level (WHO, 2002) and social isolation may increase mortality and morbidity (House, 2001). Several factors in the nursing home environment, such as quality of care, are influential in this way and therefore need to be better understood, both in general and by nursing home staff.

### ***Quality of care***

Quality of care may be regarded as a multidimensional phenomenon. Seven dimensions of quality of care have been reported: individualized care, staff, safety, milieu, central focus of service and interaction (Rantz et al., 1998). How well goals for health improvement are met and how well legitimate expectations of the person are responded to has been pointed out as one way to define quality of care (Legido-Quigley, McKee, Nolte, & Glinos, 2008). Another way of viewing quality of care may be in the light of maximizing benefits and minimising risks to the person. This view of quality of care and protecting, promoting and improving quality of health care is inherent in the values and ethics of health care professionals (Donabedian, 1979). Both these definitions contribute to the understanding of the concept of quality of care in this study. The view is taken that quality of care involves providing the residents with care that assists him or her in attaining the best life possible and to honour and fulfil his or her expectations.

Studies have investigated residents' perception of quality of care (H. Hasson & Arnetz, 2011) and how to measure quality (Donabedian, 2003; Mor, 2007) as well as how to

improve quality of care (Cohen-Mansfield & Parpura-Gill, 2008; Rantz et al., 2009). The process of improving quality of care can be a demanding and time consuming process (Cohen-Mansfield & Parpura-Gill, 2008) and in the last decade the advancement in quality of care has been less than anticipated (Sales et al., 2011). Diminishing funds in health and nursing home care make it necessary to monitor the influence of budget restrictions on quality of care. Furthermore consumers and those who fund the service are increasingly becoming aware of quality of care (Castle & Lowe, 2005). The need for measures of care quality in nursing homes is urgent and the large variations between countries on how quality of care is measured hinder comparison (Nakrem, Vinsnes, Harkless, Paulsen, & Seim, 2009). Knowledge on quality of care in nursing homes is needed to stimulate quality improvement (Mor, 2007). Moreover this information is needed to disclose what to aim for and how quality develops over time to ensure that residents receive the best care possible.

Clinicians and nursing home managers are accountable to residents and their families as well as to the community to provide good care. Thus quality of care needs to be assessed and monitored. Donabedian proposed three ways to assess quality of care: structure, process and outcome (Donabedian, 1989, 2003). Structure is the surroundings of care, i.e. the physical environment, staff and their education and organizational characteristics such as the nursing home's theoretical framework and payment system. Process is the care that is provided by the staff, i.e. nurses, doctors and physiotherapists. Outcome is the result of the process and structure. This might be improvement in health, prevention of decline or even if the outcome or care is bad, deterioration of health. Outcome also refers to the knowledge of patients and family and their satisfaction with care (Donabedian, 2003). Others concur and state that a mixture of structure, process and outcome give the best representation of quality of care (Goodson, Jang, & Rantz, 2008). Goodson and colleagues conclude that quality of care in nursing homes is related to five measures: the staffing level of certified assistants, occupancy rate, prevalence of bedfast residents, prevalence of daily physical restraints and number of deficiencies issued to a facility on inspection (Goodso et al., 2008). Patients have different attributes and risk factors that will affect outcome and these need to be taken into consideration (Donabedian, 2003; Zimmerman, 2003). Other researchers have recommended using only process quality measures for frail elderly people as adjusting for health related risk factors for outcome measures can be complex. They suggest that detecting deficits in processes of care may be more straightforward and it may also be more evident how to improve these processes (Wenger, Roth, & Shekelle, 2007).

Although some European Union member countries have developed national quality measures for long term care there is awareness that too little is being done. Thus it has been pointed out that further development in quality of care measures in Europe should be grounded on systems already developed and in use, such as in the United States (Sorenson, 2007). Further initiatives in implementing standardised measures for quality of care which will enable comparison between countries and quality improvement initiatives are needed.

## *Quality Indicators*

Clinically based data are fundamental to generating knowledge to guide improvements and development of nursing home services (Goolsby et al., 2010). The availability of clinical data from large national or, in the US, federal databases have inspired researchers to investigate various aspects of nursing home life such as quality of care (Berlowitz et al., 2005). Thus the availability of data from a comprehensive instrument such as the Minimum Data Set (MDS) raised the possibility of obtaining data that could provide information on the quality of care delivered in nursing homes and expose areas of care that needed improvement. This access to data led to the development of the MDS Quality Indicators (QIs) (Mor, 2004; Zimmerman, 2003; Zimmerman et al., 1995). The quality indicators are measurements of certain aspects of care that are thought to reflect quality of care and were developed to provide a foundation for both external and internal quality assurance and quality improvement activities. The development of the QIs involved interdisciplinary input, empirical analysis and field testing (Zimmerman et al., 1995).

From one to several items from the MDS are used to calculate each quality indicator. The quality indicator will then indicate either yes, a certain treatment or condition is present for the resident, or no, it is not. Furthermore the QIs have been constructed to indicate either good care practices or poor (Rantz et al., 2000). For instance, if an individual has had a pressure ulcer within the 7 days before the assessment the answer to the QI for pressure ulcers is yes, i.e. the individual has this quality indicator suggesting poor care. If the individual does not have a pressure ulcer the answer is no and the QI is not present. The outcome of QIs for a ward or a nursing home can be calculated as the % of residents that have an active QI, e.g. a pressure ulcer (Zimmerman et al., 1995). A high % of residents with pressure ulcers in a nursing home is likely to indicate the care is of low quality. Thus the QIs are indicators of potential care problems in nursing homes but do not identify definite quality problems (Karon & Zimmerman, 1996).

The MDS quality indicators have been used for assessing and monitoring quality of care in the United States since the 1990s. They are considered to be valid and developed markers of quality (Karon & Zimmerman, 1997), comprehensive (Nakrem et al., 2009), having a high level of accuracy and reliability (Zimmerman et al., 1995) and stable over short periods (Karon, Sainfort, & Zimmerman, 1999). It has nonetheless been pointed out that the quality indicators should be interpreted with caution (Hutchinson et al., 2010) and further testing of reliability and validity is needed (Arling, Kane, Lewis, & Mueller, 2005). The quality indicators give information on two out of the three approaches Donabedian (2003) mentioned as needed to measure quality of care, i.e. the process and outcome of care practices (Zimmerman, 2003; Zimmerman et al., 1995). To give a more extensive view on quality of care the structure of the nursing home, i.e. staffing and surroundings, also need to be considered (Donabedian, 2003). Although MDS quality indicators are an accomplished way of measuring quality of care and valuable in determining which areas of care need to be improved (Berlowitz et al., 2005), a broader approach may also be needed (Goodson et al., 2008; Rantz et al., 1998).

### ***Objectives for quality of care***

Criteria and standards need to be defined to facilitate monitoring of clinical performance. A standard specifies what is good or poor in the expected outcome. What Donabedian (2003) calls ‘normative derivation’ are the criteria or standards known to be good or bad which are based on research findings reported in the scientific literature or the recommendations of experts. ‘Empirical derivation’, on the other hand, is based on existing practise, i.e. mean, median and percentiles indicating the outcome of measurement of one’s performance against the performance of peers, though this may be a problem if a quality problem is widespread among the facilities that are being compared. Donabedian (2003) stated that goals for improvement should be set at a level that encourages the performer to progress toward fulfilling them, not so high that almost every one will fail and not so low that almost every one has already reached the goal (Donabedian, 2003). Furthermore standards of care can be used in comparison between countries (Sorenson, 2007), though the lack of internationally recognised standards (Nakrem et al., 2009) and improvement methods may explain quality of care problems in some countries (Larizgoitia, 2003) and make comparisons more difficult.

Standards or goals for care can be disclosed and their application made easier by setting so called thresholds (cut points), i.e. one threshold that indicates good care and another that indicates poor care. Methods such as the Delphi method have been used to attain a consensus of experts (Goodman, 1987; McKenna, 1994) and can be used to define thresholds in the light of existing practice. To facilitate the use of MDS quality indicators Rantz and colleagues (1997) used a modified Delphi method and a panel of experts to determine quality indicator thresholds for nursing homes in Missouri (Rantz et al., 1997). The panel of experts was a group of 13 professionals: four medical directors of nursing homes, four directors of nursing, three advanced practice nurses and two nursing home consultants. The setting of thresholds was organized in three phases. The expert panel was provided with the MDS instrument; information on what items of the MDS were used to calculate each quality indicator; and state-wide minimum, 5<sup>th</sup> percentile, median, 95<sup>th</sup> percentile and maximum scores from nursing homes in Missouri. This enabled the panel to compare their own clinical judgement with actual quality indicator distributions (Rantz et al., 1997). In all three Delphi rounds the participants were asked to answer for each of the quality indicators in question what they judged to be an achievable score indicating good resident outcomes and what they considered to indicate potentially poor resident outcomes and poor care quality, based on their clinical experience and professional knowledge. The experts discussed in this way each quality indicator separately and then recorded their individual judgement (Rantz et al., 1997). In the second and third round the experts adjusted their own scores. Finally after the third round, the researchers reviewed the data from phase two, phase three, and a state-wide distribution before setting the final thresholds (Rantz et al., 1997).

Those who have criticized the Delphi method have pointed out that as there were only a few panel members and they were selected by the researcher they may not represent the area of knowledge that is being studied and therefore threaten the content validity.

Furthermore there is no evidence of the reliability of the method (F. Hasson, Keeney, & McKenna, 2000) and although the anonymity of the method may facilitate panel members in expressing their honest opinion this may also lead to lack of accountability (Goodman, 1987). Others confidently feel that if the method is used rigorously that it can be used to add valuable knowledge to the health and social sciences (F. Hasson et al., 2000).

### ***Development of quality of care over time***

Knowledge on how quality of care develops over extended periods is lacking. Longitudinal data must however be interpreted with caution because the reason for changes may be various and not always known, i.e. issues within the nursing homes, changes in the survey (Wiener et al., 2007), time itself, the case mix of residents (Stevenson & Mor, 2009), competitive markets and occupancy (Castle, Engberg, & Liu, 2007). Reform and assessment of quality of care in nursing homes has been on-going in the United States since the 1990s. This reform was initiated because of concerns about the quality of care in nursing homes that led to the OBRA 87 reform which set higher standards for nursing homes, with the residents in the forefront (Wiener et al., 2007). Improvements in nursing home quality of care were initiated and for instance restrictions set on the use of antipsychotics as chemical restraints and limitations to the use of physical restraints. This has resulted in reduction of the use of physical restraints from 9.7% of residents in 2000 to 5.6% in 2007. Furthermore there has been decline in reported pain from 10.7% in 2002 to 4.5% in 2007. The improvements have though reached a plateau in the last few years (Wiener et al., 2007). Thus measurements of quality of care over time add to our knowledge on the development of quality in nursing homes which is imperative for those who organise nursing home care, but more needs to be learned.

Another improvement initiative in long-term care institutions was established in 29 institutions in three Finnish cities in 2000 (Finne-Soveri, Hammar, & Noro, 2010). This project has been on-going and now includes 95 long-term institutions in most major cities in Finland. Comparison of MDS quality indicators between 2001 and 2009 revealed improved quality of care in 16 out of 26 quality indicators and decline in only four areas of care (N=29 long-term institutions) (Finne-Soveri et al., 2010). The greatest improvement has been in the prevalence of occasional or frequent bladder or bowel incontinence without a toileting plan from 62% in 2001 to 42% in 2009. There has also been a considerable reduction in the use of certain medications, i.e. in the use of hypnotics three or more times a week (44% in 2001; 18% in 2009), the use of anti-anxiety or hypnotic use (59% in 2001; 38% in 2009), the use of antipsychotic use in the absence of indications (36% in 2001; 27% in 2009) and in the use of 9 or more different medications for the same resident (47% in 2001; 39% in 2009) (Finne-Soveri et al., 2010).

A study reporting changes in quality of care over a three year period on quality of care in Veterans Affairs Nursing Homes in the United States (134 units) also revealed improvements. The improvements in quality of care were for 14 out of 24 quality indicators and a decline in quality of 4 quality indicators.

These changes occurred despite there was an increase in the care needs of residents over the same period (Tsan, Davis, Langberg, & Pierce, 2007). By observing findings from standardised measures of quality of care over extended periods trends can be observed and future occurrences predicted (Rosenberg, 1997). This may enable officials and nursing home managers to respond to trends to ensure that quality is maintained or is developing in the intended direction.



## AIMS

The overall aim of this thesis was to investigate trends over time in residents' health status, functional profiles and predictors of mortality at admission to Icelandic nursing homes and in addition to determine upper and lower thresholds for Minimum Data Set Quality Indicators, to investigate the prevalence of quality indicators over time and their association with the health status and functional profile of residents in Icelandic nursing homes.

The aims of individual studies were as follows:

**Study I:** To investigate trends in residents' health status (health stability, pain, depression, cognitive performance, and continence) and functional profile (ADL and social engagement) at admission to nursing homes and compare rural and capital areas in Iceland over an 11-year period.

**Study II:** To investigate the time from residents' admission to Icelandic nursing homes to death and the predictive power of demographic variables, health status (health stability, pain, depression and cognitive performance) and functional profile (ADL and social engagement) for 3-year mortality in yearly cohorts from 1996-2006.

**Study III:** To determine upper and lower thresholds for Minimum Data Set Quality Indicators for Icelandic nursing homes and apply them to quality outcomes in Icelandic nursing homes data from 2009 as well as identify areas for improvement.

**Study IV:** To investigate quality of care in Icelandic nursing homes during 2003-2009 as shown by Minimum Data Set quality indicators and to investigate the association of Minimum Data Set quality indicators with residents' health status (health stability, pain, depression and cognitive performance) and functional profile (ADL and social engagement).

## METHOD

### Design

The design used for studies I, IV and the framework analysis was retrospective analysis of nursing home data, whilst study II was a longitudinal cohort study observing 3 year mortality. The Delphi method with an expert panel and cross-sectional data for 2009 was used for study III (Table 1).

**Table 1.** Design and samples for studies I-IV

Study	I	II	III	IV	Framework
Design	Retrospective analysis	Longitudinal cohort study	Delphi method Cross-sectional	Retrospective analysis	Retrospective analysis
Sample	N=2,206 residents	N=2,206 residents	12 panel members N=2,247 residents	N=3,694 residents N=11,034 assessments	N=3,704 residents N=11,912 assessments
Data	MDS data from 1996-2006	MDS data from 1996-2006	MDS data from 2009	MDS data from 2003-2009	MDS data from 1999-2009
Analysis	Kruskal–Wallis test; Mann-Whitney U-test with Bonferroni correction; $\chi^2$ test for trend; Linear regression	$\chi^2$ test Mann-Whitney U-test with a Bonferroni corr; Kaplan-Meier analysis; Non-parametric correlation analyses; Multivariate Cox regression analysis	Prevalence (%) median, Q1, Q3, maximum and minimum	$\chi^2$ test for trend; Multivariate logistic regression	$\chi^2$ test for trend

### Study population

The population for this research project were all residents living in nursing homes in Iceland. For studies I and II the sample was all newly admitted nursing home residents, each year from 1996-2006, who had been assessed with the Minimum Data Set within 90 days from admittance (N=2,206). For study III the sample for analysis was all residents that had been assessed using the Minimum Data Set in 2009 in 47 nursing homes in Iceland (residents N=2,247). The residents' most recent assessment for each year was used and the admission assessments of the residents and readmission assessments were omitted, for example readmission to nursing home after spending a

period in an acute hospital, as these assessments reflected residents' health problems that may have been the result of conditions outside the nursing home. Assessments from nursing homes having 9 or fewer assessments were omitted (n=10) as their score was likely to skew the findings when reviewing the distribution of individual nursing homes. The median number of assessments for the nursing homes was 29 (minimum 11; maximum 159). In study IV and in the analysis for the framework the residents' most recent assessment for each year was used and the admission assessments of the residents and readmission assessments were omitted, as in study III. Although each resident only had one assessment within each year, many residents have had assessments recorded from several years; these were therefore mixed groups in study IV and the framework analysis. For study IV the sample was 3,694 residents from nursing homes in Iceland who were assessed with the MDS instrument over the period 2003 -2009. The number of assessments for analysis was therefore 11,034. In the framework the sample was 3,704 nursing home residents assessed over the period 1999-2009. The sample for analysis was 11,912 MDS assessments.

## **Context of the study**

The Icelandic health care system as well as the institutional care for the elderly is in many ways similar to the health care systems of the other Nordic countries. The main difference in the services for the elderly is that the emphasis is on institutional care and the care model is considered to be medical, as in Norway and Finland. In Denmark and Sweden, the care model is more towards a social model (Szbehely, 2005).

A nursing home in Iceland is an institution where nursing care is provided to the residents 24 hours a day. The care includes assistance with activities of daily living (ADL), moving about, recreation, psychosocial care, room and board, as well as medical care. A medical doctor visits the nursing home 3-5 times a week and attends to residents that are in need of medical care, as well as being on call around the clock for emergencies. Most nursing homes also provide physiotherapy and some occupational therapy. In nursing homes, the care is delivered by registered nurses, licensed practical nurses and nursing assistants. The number of nursing hours provided per patient per 24 hours is on the average 4.1-5.0. Registered nurses comprise 18% of the staff, licensed practical nurses 20%, other professionals 1% and nursing assistants 61% (National Audit Office, 2005). Some institutions for the elderly in Iceland provide residential accommodations, where nursing hours provided per patient per 24 hours are on the average 1.7 hours (National Audit Office, 2005), as well as care in nursing wards. The care in the nursing wards is identical to the care provided in the nursing homes, as explained earlier. In this research, the nursing wards will also be referred to as nursing homes.

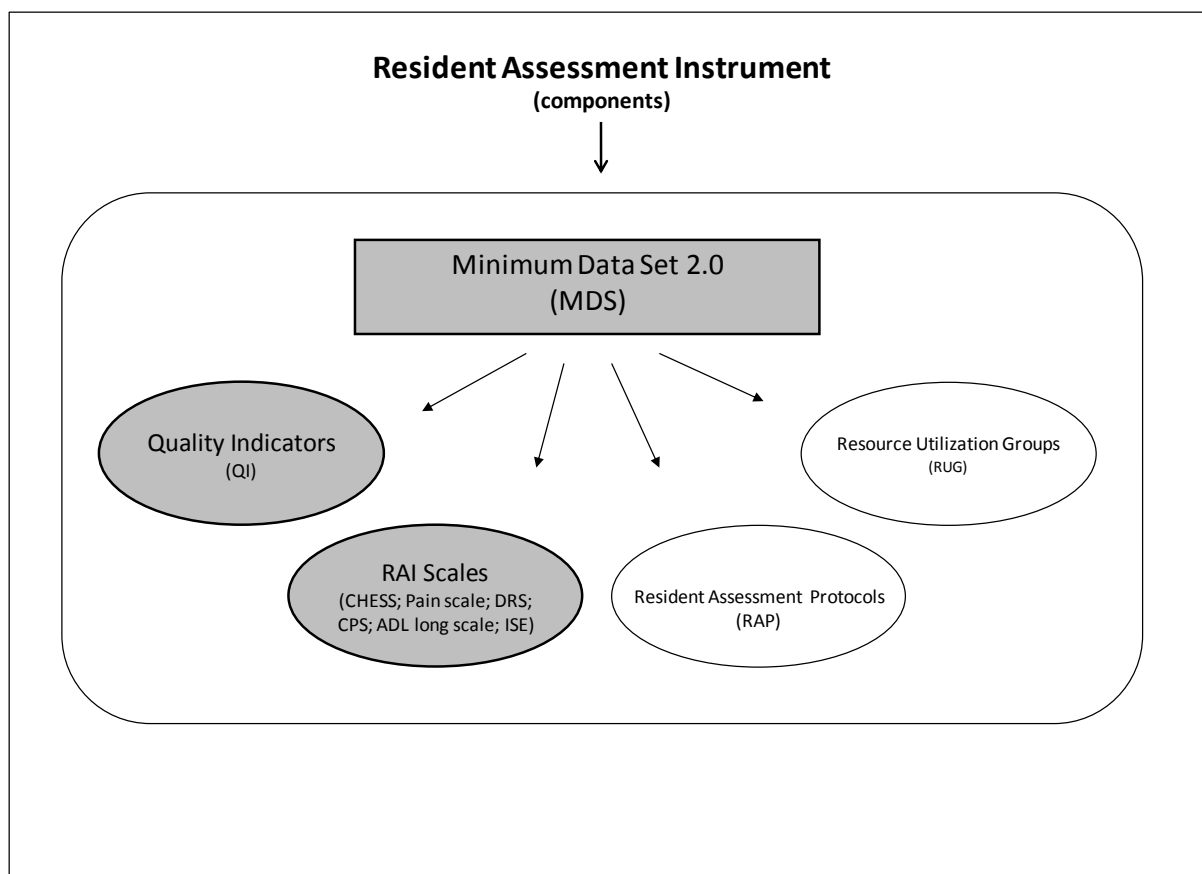
The proportion of elderly people 67 years and older is growing in the Icelandic population. In 1990 the proportion was 8.6% of the total population and in 2011 it was 10.6% (Statistics Iceland, 2011). The number of people living in nursing homes has also been growing. Official statistics show that in 1999 approximately 1,970 residents

were living in nursing homes (Icelandic Ministry of Health, 2006) but in 2011 there are approximately 2,500 (Icelandic Ministry of Welfare, 2011). Institutional care in Iceland has therefore increased, whereas it has decreased in Sweden (Socialstyrelsen, 2005). Home care in Iceland varies greatly between urban and rural areas, being scarcer in the rural areas. The average home care service provided per week was 2.4 hours per individual for 13% of the elderly population (67 years and older) in Iceland in 2003. In Sweden average service time per week was 7 hours of similar type of care provided to 5% of the Swedish population, 65 years and older. In Sweden the service seems to be concentrated more intensely on a smaller group and mostly those over 80 years of age (National Audit Office, 2005). In Iceland the service seems to be spread more thinly for a bigger group and thus may not be enough for those who need more service. There remains, however, that official statements declare the intention to enable elderly people to remain in their own home as long as possible (Icelandic Ministry of Welfare, 2008).

## **Instrument**

In the 1980s the nursing home sector in the United States had suffered from some pronounced cases of neglect. It was therefore in response to complaints on lack of quality of care in nursing homes in the United States that the Residents Assessment Instrument (RAI) was developed. To increase the quality of care in nursing homes, the US federal government mandated reforms with the Omnibus Budget Reconciliation Act (OBRA) of 1987 (Fries et al., 1997; InterRAI, 2011a; Mor, 2004). A multi-disciplinary team of researchers from a consortium of academic medical centres designed and tested the Minimum Data Set (MDS), which is the data element of the RAI, under a contract with the Health Care Financing Administration (HCFA). The research and testing took place in 1989 through 1991. The instrument was designed to be a clinical instrument that would be used to document basic information concerning each individual and to facilitate care planning. The MDS was then implemented nationally in all nursing homes participating in Medicare and Medicaid programs in the United States in late 1990 (Mor, 2004). The implementation of RAI in nursing homes in the United States and other factors resulting from the OBRA of 1987 reform led to improvement in several outcome measures, i.e. a significant decrease in dehydration, stasis ulcer and decline in nutrition and vision (Fries et al., 1997).

The Resident Assessment Instrument (RAI) is a clinical instrument comprised of these major components: Minimum Data Set (MDS), which is the data assessment element (Morris et al., 1990); Quality Indicators (QIs) for improving and measuring quality of care (Zimmerman et al., 1995); RAI scales for evaluation of residents' health and functional profile (InterRAI, 2011b); Resident Assessment Protocol (RAP) or clinical guidelines (Fries et al., 1997); and the Resident Utilization Group's (RUG's) a case mix classification system to measure work load and care cost (Mor, 2004) (Figure 3). The three components of the instrument that are used in this research were MDS, QIs and the RAI scales, which will be discussed further.



**Figure 3.** Components of the Resident Assessment Instrument. The components used in this research are coloured dark grey.

### ***The Minimum Data Set***

The Minimum Data Set, which is the core component of the Resident Assessment Instrument, is a widely used instrument and has been translated into approximately 30 languages. The MDS is first and foremost a clinical tool intended to improve care but has also been used internationally for research purposes (Allen, 1997; Mor, 2004). The Minimum Data Set for nursing homes (MDS), version 2.0 which was used in this research, has 21 sections with some 350 clinical data elements (Table 2). It summarizes the residents' functioning and health care needs and can be used to generate categorical as well as ordinal measures of resident outcome (Allen, 1997; Mor, 2004). The MDS is a comprehensive, reliable and valid instrument and has facilitated comparison between facilities and countries (Mor, 2004). It has been used in Iceland for research purposes since 1994 and as a mandated clinical and research tool as well as for quality measures since 1996. Since 2003, three annual assessments have been mandatory and data from the instrument used for reimbursement purposes.

**Table 2.** Sections of the Minimum Data Set

<b>Section</b>	<b>Content</b>	<b>Section</b>	<b>Content</b>
<b>AB</b>	Demographic information	<b>H</b>	Continence
<b>AC</b>	Customary routine	<b>I</b>	Disease diagnosis
<b>AD</b>	Face sheet signatures	<b>J</b>	Health conditions
<b>A</b>	Identification and background information	<b>K</b>	Oral and nutritional status
<b>B</b>	Cognitive patterns	<b>L</b>	Oral and dental status
<b>C</b>	Communication and hearing	<b>M</b>	Skin condition
<b>D</b>	Vision patterns	<b>N</b>	Activity pursuit patterns
<b>E</b>	Mood and behaviour patterns	<b>O</b>	Medications
<b>F</b>	Psychosocial well-being	<b>P</b>	Special treatments and procedures
<b>G</b>	Physical functioning and structural problems	<b>Q</b>	Discharge potential and overall status
		<b>R</b>	Assessment information

### ***Quality Indicators***

The use of MDS in nursing homes and the data derived from these assessments led to the development of a set of 30 quality indicators covering 12 domains. The domains are: Accidents; Behavioural and emotional patterns; Clinical management; Cognitive functioning; Elimination and continence; Infection control; Nutrition and eating; Physical functioning; Psychotropic drug use, Quality of life; Sensory functioning and communication; Skin care (Zimmerman, 2003; Zimmerman et al., 1995). The original set of quality indicators has been modified and tested and the 20 quality indicators used in this research from version 6.2, which represent 11 of the original domains of care, can be seen in Table 3 (Zimmerman, 2003). The quality indicators indicate either good or poor care practices. They can be observed either at the individual level or at the department or facility level and can be aggregated for the level of service that needs to be observed or compared (Zimmerman et al., 1995). The quality indicators of nursing homes can be compared to the quality indicators of other nursing homes in the same area or in other countries.

**Table 3.** The domains of the 20 quality indicators used in this research and whether they demonstrate either process or outcome of care (Zimmerman, 2003).

<b>Domain</b>	<b>Quality Indicators</b>	<b>Process/Outcome</b>
Accidents	Prevalence of falls	Outcome
Behavioural and emotional patterns	Prevalence of behavioural symptoms affecting others	Outcome
	Prevalence of symptoms of depression	Outcome
	Prevalence of symptoms of depression without antidepressant therapy	Both
Clinical management	Use of nine or more different medications	Process
Elimination and continence	Prevalence of bladder/bowel incontinence	Outcome
	Prevalence of occasional bladder/bowel incontinence without a toileting plan	Both
	Prevalence of indwelling catheters	Process
	Prevalence of faecal impaction	Outcome
Infection control	Prevalence of urinary tract infections	Outcome
Nutrition and eating	Prevalence of weight loss	Outcome
	Prevalence of tube feeding	Process
	Prevalence of dehydration	Outcome
Physical functioning	Prevalence of bedfast residents	Outcome
Psychotropic drug use	Prevalence of antipsychotic use in the absence of psychotic and related conditions	Process
	Prevalence of anti-anxiety/hypnotic use	Process
	Prevalence of hypnotic use more than two times in last week	Process
Quality of life	Prevalence of daily physical restraints	Process
	Prevalence of little or no activity	Both
Skin care	Prevalence of stage 1-4 pressure ulcers	Outcome

The quality indicator is presented as the proportion of residents having a certain condition (Zimmerman, 2003). They represent either the prevalence of a condition, i.e. how many residents have this condition at one point in time, or they present the incidence of the condition, i.e. how the condition has developed over time and shows how many residents have developed the condition since the last assessment was done (Zimmerman, 2003; Zimmerman et al., 1995). Zimmerman and colleagues (1995) also pointed out that by using quarterly or annual assessments and omitting the first assessment of the residents and readmission assessments the quality indicator's will give a more realistic picture of the residents' condition(s) that result from care practices in the nursing home as opposed to conditions which might result from a short hospitalization or conditions at home before admittance to the nursing home. The selection of assessments used in configuring the quality indicators has been shown to impact their prevalence rate (Karon et al., 1999; Zimmerman et al., 1995). Another characteristic feature of the quality indicators is that they measure processes and outcomes of care, and sometimes a combination of both. Prevalence of an injury is an

example of an outcome of a care quality indicator, prevalence of daily physical restraints is a process of care quality indicator, and finally a prevalence of symptoms of depression without antidepressant therapy is both process and outcome (Table 3).

When comparing data between different facilities, it must be noted that residents have different risk factors such as ADL and cognitive functioning which need not be related to the care they are receiving in the nursing home. Risk factors of residents were therefore considered in the development of the quality indicators. Care must be taken, however, to avoid using risk factors that are directly related to care and are affected by the quality of care provided (Zimmerman, 2003; Zimmerman et al., 1995). By adjusting risk factors it is possible to compare quality of care between facilities that provide care to different resident groups. In this way it is possible to compare quality indicators for groups of residents that are at high risk for some problem to groups of residents that are at low risk for the same problem (Zimmerman, 2003; Zimmerman et al., 1995). Some researchers have found this to be a methodologically superior approach in determining quality of care (Karon & Zimmerman, 1996). Others have pointed out that risk adjustment such as for greater ADL dependency can in some cases take into account factors that can be related to care practices. Poor care in a nursing home may lead to deterioration in ADL and thereby increased risk of pressure ulcers. Adjusting for ADL dependency when measuring the prevalence of pressure ulcers in a nursing home might therefore let nursing homes delivering poor care off the hook (Arling et al., 2005). The quality indicators in this research are not risk adjusted.

Studies of the validity of the quality indicators have shown that they are valid markers of quality (Karon & Zimmerman, 1997). Karon and Zimmerman (1996) found that the quality indicators have a high level of accuracy and reliability as well as a reasonably high predictive power. Facilities that flagged a problem at the 90<sup>th</sup> percentile had a 70% chance that a follow-up review would find a problem with care and this chance would rise to 88% with the 95<sup>th</sup> percentile (Karon & Zimmerman, 1996). The input of clinicians has been a necessary part of establishing face validity of the quality indicators (Zimmerman et al., 1995). Other researchers, on the other hand, have found that many of the quality indicators were valuable indicators for quality, while others were more questionable. Rantz and colleagues (2004) identified 10 quality indicators that were more sensitive in categorizing facilities as good, average or poor. The sensitive quality indicators are: Falls; Depression; Depression without treatment; Use of 9+ different medications; Urinary tract infection; Weight loss; Dehydration; Bedfast residents; Decline in late-loss ADLs; Stage 1-4 pressure ulcers. They also point out that when measuring changes in quality of care, external factors such as resident turnover may influence the quality indicator stability (Rantz et al., 2004). Other researchers have found the quality indicators to be reasonably stable over a short period of time, i.e. 3 months, and indications of high stability for most quality indicators, which is necessary for them to be good indicators of quality and a strong basis for quality improvement measures (Karon et al., 1999). Quality indicator percentages for nursing homes provide more useful information about a facility's performance over time than the nursing home's QI changes in rank within the peer group (defined as all nursing homes in a specific area). Therefore, it is more accurate



to use absolute rather than relative thresholds when investigating quality of care in facilities (Karon et al., 1999).

### ***RAI scales***

Within the RAI instrument, various scales and indices have been developed to evaluate the current status of the residents. These scales can also be used to monitor changes over time. The scales have been tested and compared to other comparative scales or instruments, among them scales that would be considered to be ‘gold standard’ (InterRAI, 2011b). The validity and alpha reliability of the RAI scales indicate their usefulness in research (Mor, Intrator, Unruh, & Cai, 2011). Six of the RAI scales will be introduced here.

#### **CHES Scale**

The Changes in Health, End-stage disease and Signs and Symptoms scale is used to identify residents that are unstable and in serious risk of decline. CHES is a six point scale where 0 means that the individual is stable. A score of 5, on the other hand, indicates that the individual is highly unstable and in risk of mortality, hospitalization, pain, caregiver stress and poor self-rated health. The MDS variables used in the scale concern advanced directives, pain frequency, parenteral nutrition, special treatments, physician’s orders and abnormal lab values. The scale has been reported to be a strong predictor of mortality (HR 1.60 for 1-point increment;  $P=0.0001$ ) (Hirdes, Frijters, & Teare, 2003; InterRAI, 2011b).

#### **Pain Scale**

The Pain Scale (PS) is a 4 point scale ranging from 0-3. The scale combines points from two selected variables: Pain frequency and pain intensity. A score of 0 indicates no pain and a score of 4 means that the resident is in severe (horrible/excruciating) pain (Fries, Simon, Morris, Flodstrom, & Bookstein, 2001; InterRAI, 2011b). Researchers have stated that the scale has been showed to be valid in detecting pain (Fries et al., 2001) though others have pointed out that the scale may be lacking in sensitivity ( $r = 0.33$ ) (Fisher et al., 2002).

#### **Depression Rating Scale**

The Depression Rating Scale (DRS) is a 15 point scale ranging from 0-14. The scale combines points from 7 selected variables: Made negative statements; Persistent anger with self or others; Expressions (including non-verbal) of what appear to be unrealistic fears; Repetitive health complaints; Repetitive anxious complaints/concerns (not health related); Sad, pained, worried facial expressions; Crying, tearfulness. A score of 0 shows no indication of depression and then increasing indications of depression as the score gets higher. A cut point of 3 on the scale indicates mild depression (Burrows, Morris, Simon, Hirdes, & Phillips, 2000; InterRAI, 2011b). Contradictory findings have been reported concerning the clinical value of the scale for evaluation of depression in elderly residents in nursing homes. Some claim that the scale is of limited clinical value for identifying depression in nursing home residents (Anderson, Buckwalter, Buchanan, Maas, & Imhof, 2003) or, in contrast, that it’s sensitivity is

excellent (91%) and specificity acceptable (72%), though recommending further testing (Burrows et al., 2000).

#### Cognitive Performance Scale

The Cognitive Performance Scale (CPS) is a 7 point scale ranging from 0-6. Six variables in the MDS assessment are used for this scale: Comatose; Short-term memory; Long-term memory; Cognitive skills for daily decision-making; Making oneself understood; Eating. A score of 0 indicates that the resident is cognitively intact and a score of 6 indicates that the resident has a very severe cognitive impairment (InterRAI, 2011b; Morris et al., 1994). The scale correlates moderately well with the MMSE scale ( $r = -0.65$ ) and a score of 2-3 is considered to indicate moderately intact cognition whereas a score of 4-6 implies severe cognitive impairment (Gruber-Baldini, Zimmerman, Mortimore, & Magaziner, 2000).

#### ADL Long Scale

The Resource Utilization Groups' (RUG) case mix classification system includes a summary measure of Activities of Daily Living (ADL). The RUG-III ADL Index, sometimes referred to as the long version of the MDS-ADL scale, ranges from 0-28. The scale combines points from ADL variables selected from the MDS instrument, i.e. bed mobility, transfer, locomotion, dressing, toileting, personal hygiene and eating. A higher score indicates a greater need for assistance in the ADL activities. A score of 0 indicates that the individual is either independent or only needs supervision. A score of 28 indicates a severe impairment in ADL activities. The scale has been shown to be sensitive to clinically relevant change as well as a valuable research tool (Carpenter, Hastie, Morris, Fries, & Ankri, 2006; InterRAI, 2011b; Morris et al., 1999).

#### Index of Social Engagement

The Index of Social Engagement (ISE) score ranges from 0 indicating the resident's severe withdrawal from social engagement, to 6, indicating that the resident has much initiative and participates in social activities. Variables used in the ISE scale concern activity patterns; Interaction with others; Doing planned or structured activities; Doing self-initiated activities; Establishing own goals; Involvement in life of facility; Accepting invitations (InterRAI, 2011b; Mor et al., 1995). A cut-off value of 2 has been used to differentiate between people with low social engagement (0-2) from those participating in social activities (3-6) (Resnick, Fries, & Verbrugge, 1997). The scale is reported to be a valid and stable measurement (Mor et al., 1995) as well as being associated with survival of residents (Kiely & Flacker, 2003).

### **Reliability and validity**

The MDS has repeatedly been tested for inter-rater reliability in various settings and has been found to have high average levels of reliability (Hawes et al., 1995; Morris et al., 1990). Researchers have questioned whether the MDS, which was designed and used as a clinical tool, is a usable data source for research purposes (Teresi & Holmes, 1992). Others have pointed out that it has moderate to high

reliability as a research tool (Casten, Lawton, Parmelee, & Kleban, 1998) and thus is a valuable resource of research data (Shin & Scherer, 2009). Hawes and colleagues' (1995) conducted two final reliability trials when the MDS 2.0 version was developed. The first test took place in eight nursing homes in three states in the United States and 80 residents were assessed twice by a group of 16 licensed nursing home personnel. The latter test took place in five nursing homes in three states where 43 residents were assessed twice by a group of 10 nurses. The facilities that were selected had a reputation of providing adequate quality of care and having above average levels of staffing. The assessment for each resident was conducted simultaneously by two licensed staff members who did not consult each other or discuss the assessment. The analysis was done using the Spearman-Brown intraclass correlation coefficient. The reliability was interpreted as being adequate if the intraclass correlation was 0.4 or higher and 0.7 or higher was interpreted as excellent reliability (See Fleiss, 1986 and Winer, 1962 in (Hawes et al., 1995)). The general finding indicated that the reliability in these studies was adequate as 89% of the items in the final version of the MDS 2.0 showed an intraclass correlation of 0.4 or higher and 60% of the items showed an intraclass correlation of 0.6 or higher. A few items were not seen to give adequate reliability such as those concerning delirium, but because they were considered to be of great clinical value they were retained in the final version. The MDS 2.0 has 18 clinical sections and the average interclass correlation value was calculated for each section. Five sections had an excellent average interclass correlation value ( $\geq 0.7$ ), i.e. Identification and background; Physical functioning and structural problems; Disease diagnosis; Oral and nutritional status; and Medication use. Seven sections had an average interclass correlation value of  $\geq 0.6$ , one had an average interclass correlation value of 0.5-0.59 and finally the remaining five had an average interclass correlation value of 0.4-0.49. The mean value for the interclass correlation for the MDS 2.0 was 0.61 (Hawes et al., 1995).

A later study done by Morris and colleagues (1999) on ADL scales developed for the MDS further confirmed the reliability of items in the MDS concerning ADL within the target group of nursing home residents. This study was done using data from 187 residents in 21 nursing homes assessed twice with different assessors. The weighted kappas all showed excellent reliability, i.e. above the 0.75 threshold. The ADL items showed the following weighted kappa values: Dressing (0.90), Personal hygiene (0.87), Toilet use (0.93), Locomotion on unit (0.92), Transfer (from bed) (0.91), Bed mobility (0.91) and Eating (0.94) (Morris, Fries, & Morris, 1999). The items for the ADL's have shown some of the highest inter-observer reliabilities in the MDS instrument (Hawes et al., 1995).

Casten and colleagues (1998) conducted a confirmatory factor analysis to determine the reliability of MDS data gathered over a two year period for Philadelphia Geriatric Centre residents (N=733). The data were gathered by clinical staff for usual clinical purposes. The items in the MDS were clustered into domains of competence, i.e. Cognition, ADL, Time use (in activities), Social quality (interaction with others), Depression and Problem behaviours. The tenability of how these items were assigned to domains was tested with confirmatory factor-analytic methods. Then the within-

domain confirmed factors were tested for replicability by dividing the residents into two groups, i.e. high cognitive functioning and low cognitive functioning. The findings confirmed five of the six domains. The adjusted goodness of fit indices were close to acceptable levels (0.90) as follows: 0.89 for cognition, 0.88 for time use, 0.89 for depression, 0.94 for problem behaviour, and the ADL domain was lower or 0.56 and did not meet the criterion. Social quality, however, was not found to be a coherent factor (Casten et al., 1998). Reliability was also assessed by two independent raters for 33 residents. The reliability was found to be within acceptable limits. The Pearson correlation and kappas for the six domains were cognition ( $r=0.80$ ;  $\kappa=0.63$ ), ADL ( $r=0.99$ ;  $\kappa=0.61$ ), time use ( $r=0.75$ ;  $\kappa=0.75$ ), social quality ( $r=0.94$ ;  $\kappa=0.74$ ), depression ( $r=0.89$ ;  $\kappa=0.56$ ), problem behaviour ( $r=0.95$ ;  $\kappa=0.84$ ) (Casten et al., 1998). Mor and colleagues (2003) have also confirmed the reliability of the MDS for a nursing home population in a study revealing that 85% of the MDS data elements had adequate inter-rater reliability ( $\kappa > 0.6$ ). They also point out that some items showed substantial inter-facility variation in reliability while the ADL measures were reliable across almost all providers (Mor et al., 2003).

The validity of the MDS has been investigated in various studies where either the MDS or parts of the MDS have been compared to established instruments. Studies have indicated good validity in many parts of the instrument such as the ADL scales (Morris et al., 1999) and cognitive scales (Gruber-Baldini et al., 2000). The validity of the MDS was tested in a second phase of a study mentioned earlier (Casten et al., 1998) conducted at the Philadelphia Geriatric Centre, where it was used to assess 513 nursing home residents (Lawton et al., 1998). The scores for the domains within the MDS explained in a study by Casten and colleagues (1998) were correlated with various independent measures from other instruments. The domain of cognition was correlated with the Blessed Information-Concentration measure of mental status,  $r=0.66$  ( $p<0.05$ ) (Blessed et al., 1968; see (Lawton et al., 1998)) and the Reisberg Global Deterioration Scale measure for cognitive status,  $r=0.59$  ( $p<0.05$ ) (Reisberg et al., 1982; see (Lawton et al., 1998)). The ADL was correlated with Lawton and Brody's (1969) 6-item PSMS scale,  $r=0.58$  ( $p<0.05$ ) (See (Lawton et al., 1998)). Depression was correlated with the 30-item Geriatric Depression Scale,  $r=0.15$  ( $p<0.05$ ) (Yesavage et al., 1983; see (Lawton et al., 1998)) and the Raskin Depression Ratings,  $r=0.26$  ( $p<0.05$ ) (Guy, 1976; see (Lawton et al., 1998)). No measures were analogous with the domain of time use and problem behaviour. They were significantly correlated with other core variables, however. Problem behaviour correlated with poorer cognitive performance: Blessed Information-Concentration measure of mental status,  $r=0.34$  ( $p<0.05$ ) (Blessed et al., 1968; see (Lawton et al., 1998)); Reisberg Global Deterioration Scale measure for cognitive status,  $r=0.24$  ( $p<0.05$ ) (Reisberg et al., 1982; see (Lawton et al., 1998)). Lawton and colleagues (1998) concluded that the MDS is usable as a research instrument even though the validity coefficient measures were modest. They point out, that the training and some sections of the MDS may need improvement (Lawton et al., 1998).

## Data analysis

### *Statistical analysis*

Descriptive and analytical statistics were used. In studies III, IV and the framework quality indicators were calculated from the data. Each quality indicator is presented as the percentage of residents per nursing home having a certain treatment or condition. When calculating the QI for 'Antipsychotic drug use in the absence of psychotic and related conditions' and 'Anti anxiety or hypnotic drug use' residents having Schizophrenia and hallucinations were excluded.

### Comparison between groups and years

Non-parametric tests were used for categorical data and for skewed continuous data. The Kruskal-Wallis test was applied to determine whether there were any differences between individual years (1996-2006) regarding health status and functional profile and  $p < 0.05$  was considered significant (Study I). Subsequent analyses of differences between pairs of years were performed using the Mann-Whitney U-test with a Bonferroni correction for multiple comparisons (Studies I-II). The Chi square test was used for nominal data (Study II) and the Chi square test for trend was used for categorical data (Study I, II, IV and the framework) (Altman, 1991).

### Survival analysis

In study II the association between survival and categorical potential risk variables (where admitted from, year of admission) were analysed, using Kaplan-Meier analysis (log-rank test). The association between survival time and potential ordinal risk variables was analysed by non-parametric correlation analyses (Spearman's rho) (Altman, 1991). A multivariate Cox regression analysis was performed controlling for age and gender to determine predictors of mortality. Variables associated with survival time with a  $p$ -value  $< 0.05$  were entered into the regression model (Backward stepwise; Likelihood-ratio). The variables entered were: Gender, CHESS, Pain scale, Cognitive Performance Scale, Depression Rating Scale, ADL Long Scale, Index of Social Engagement and Where admitted from. The ADL scale was collapsed into four categories (Altman, 1991). No multi-collinearity problem was detected. Partial correlation was performed to illuminate the relationship between social engagement and survival time while controlling for ADL functioning and health stability.

### Regression analyses

Linear regression was used to analyse time trends for health status and functional profiles at admission. The year 1999 was regarded as an outlier in trend analysis because of extraordinary conditions (increased death rate probably due to an outbreak of influenza), resulting in higher ADL and cognitive performance than in other years (Study I). Multivariate logistic regression controlled for age and assessment year (Forward stepwise, Likelihood ratio) (Norman & Streiner, 2008) was performed to determine the association between variables representing health status and functional profile and residents quality indicator outcome (Study IV). Variables entered into the regression to investigate the association of health status and functional profile to the outcome of quality indicators were: Gender, CHESS, Pain scale, Cognitive

Performance Scale, Depression Rating Scale, ADL Long Scale and Index of Social Engagement. The regression analyses were checked for multi-collinearity, but no such problem could be detected. To limit the number of categories when entering the variables into the logistic regression scales having more than a 4 point score were collapsed into three categories. For quality indicator 'Little or no activity' the ISE was not entered and for quality indicator 'Symptoms of depression' the DRS were not entered. These quality indicators and respective scales are aggregated partially from the same or similar variables and therefore related. Data analysis was conducted with the software program SPSS version 11, 14, 17 and 19, and PASW Statistics 18.

### ***Expert panel***

In study III an expert panel of 12 members conducted two Delphi rounds. For reference for the expert panel the prevalence of quality indicators in the sample from the year 2009 (n=2,247) was calculated (n %) and the distribution of the nursing homes in relation to the prevalence of each quality indicator within each nursing home. At the end of each round each panel member decided on what % to recommend for the upper and lower thresholds for MDS quality indicators (cut points). All panel members' recommendations for each quality indicator were then used to calculate a mean value (%). The panel's final decisions were then presented as the percentages for upper and lower thresholds from the second Delphi round for each quality indicator.

## **ETHICAL CONSIDERATIONS**

This research follows the ethical principles presented in 1964 by the World Medical Association Declaration of Helsinki (WMA, 2008). These principles stress the importance of respect for all human beings and protection of their health and rights. They also point out that special attention is required for populations that are vulnerable, those who can not give or refuse consent and for those for whom the research is combined with care, as is the case in this research. The residents in nursing homes are a vulnerable population, dependent on their carers, and are often not able to give or refuse participation because of dementia or inability to communicate. The research instrument is also in this case a clinical tool used in combination with care delivery. This research used data from a central RAI database that stores MDS assessments. These assessments are mandatory since 1996 for all nursing home residents in Iceland by regulation from the Minister of Health (Icelandic Ministry of Health, 1995). Therefore, the residents were not asked for consent. The assessment, as well as medical and nursing documentation, is not optional for the residents. The information from the assessment is required for clinical care, quality assurance, reimbursement for the nursing homes and research. It was therefore not possible in this research to obtain informed consent. The main ethical consideration for this research is to respect the confidentiality of the residents' information. The data, for this research, were obtained from the RAI database stored by the Icelandic Ministry of Welfare. The data are without names or personal identification numbers, so it is not possible to recognise individuals.

The Helsinki declaration emphasizes the need for approval from national ethical review committees. This research project was conducted according to and with the approval of the National Bioethics Committee (Study I-II licence number (07-0330-S1); Study III-IV and the framework licence number (VSNb2010010028/03.7)) and the Data Protection Authority of the Icelandic Ministry of Justice (Study I-II licence number (2007020171); Study III-IV and the framework licence number (2010010115LSL)).

## RESULTS

In the sample included in studies I and II the mean age was 82.5 years (SD 7.6) and women accounted for 59.8% of the sample (n=2,206) (table 4). The mean age of those who were assessed 90 days or later from admittance and were excluded from the sample was 81.2 years (SD 9.1) and 65.5% were women (n=2,527). No significant difference was seen in age or gender within years between the residents that were included and those who were excluded.

**Table 4.** Characteristics of the sample in studies I-II

Year	Residents included (assessed within 90 days of admittance)		
	n	Mean age (S.D.)	Females %
1996	58	80.9(8.8)	65.5
1997	73	81.1(7.8)	67.1
1998	42	80.1(7.6)	66.7
1999	197	82.7(6.8)	66.5
2000	146	82.2(7.8)	52.7
2001	142	81.8(8.3)	53.5
2002	149	82.6(7.5)	56.4
2003	266	82.8(7.1)	56.0
2004	434	82.4(8.4)	60.4
2005	401	82.2(8.2)	61.6
2006	298	82.5(8.7)	59.7

When investigating differences in health status and functional profile between those included and those excluded the only significant difference was seen in the year 1999 where a lower level of ADL competence was revealed in those who were excluded (12.36 vs. 7.48;  $P < 0.0001$ ). Residents were not all assessed with an MDS the year they were admitted. The residents included in this study over the years 1996-1998 were from 13.1% (lowest) to 22.1 (highest) of those who were actually admitted to a nursing home each year. The remaining years from 1999-2006 the residents included were from 28.9% (lowest) to 84.1 (highest) of those admitted to a nursing home each year according to official data. The low percentages of included residents' over the years 1996-1998 stems from these were the first years the MDS assessment was mandatory in Icelandic nursing homes. Also, in the first years compliance was low and those who were assessed with the MDS were often not assessed until a considerable time after their admittance to a nursing home. Residents admitted each year in 1996-2006 came from private homes, either receiving home care/service (range: 15.0-37.6%) or without home care/service (7.5-20.4%), from hospitals (20.0-42.1%) and residential care, assisted living or other (10.3-57.5%).



In the sample included in study III (N=2,247) the mean age was 85.2 years (SD 8.3) and 65.6 % were female. In study IV (N=11,034) and the analysis presented in the framework only (N= 11,912) covering 1999-2009 the mean age ranged from 79.0 (SD 9.5) to 85.1 (SD 8.3) and the number of women ranged from 64.0% to 67.8% over the research period (Table 5).

**Table 5.** Characteristics of the samples in study III, IV and the framework

Year	Individuals n	Mean age (S.D.)	Females %
<b>Sample in Study III</b>			
2009	2,247	85.2 (8.3)	65.6 %
<b>Sample in Study IV and the framework</b>			
	Assessments n		
1999*	112	79.6 (8.6)	65.2
2000*	172	79.0 (9.5)	64.0
2001*	277	80.2 (9.3)	62.5
2002*	317	81.4 (9.4)	65.3
2003	447	82.3 (9.1)	65.5
2004	1,038	82.7 (8.4)	67.8
2005	1,435	83.3 (8.3)	66.6
2006	1,794	84.3 (8.0)	66.6
2007	2,025	84.6 (7.9)	66.0
2008	1,990	84.7 (8.2)	66.2
2009	2,305	85.1 (8.3)	65.2

\*Additional years used for analysis in framework

### ***Health status and functional profile***

Mean values for health stability (CHESS scale), pain, depression, cognitive performance, ADL performance and social engagement showed some significant differences when comparing years (Study I). Residents' health was more unstable in 2004 than in 1999 ( $p < 0.0009$ ), a higher mean score for depression was seen in 2004 and 2005 than in 1999 ( $p < 0.0009$ ) and worse cognitive performance was seen in 1996-1998 and 2001-2006 than in 1999 ( $p < 0.0009$ ). Comparisons between years also revealed a lower ADL performance in 1997, 1998 and 2001-2006 than in 1999 ( $p < 0.0009$ ); and that more people were socially engaged at a higher level in 2003 and 2006 compared with 1996; and again in 2002, 2003, 2005 and 2006, compared with the year 1997 ( $p < 0.0009$ ).

The percentage of residents scoring in the lower third of each scale over the years occurred as follows (Study I). Regarding health stability 55.5-79.3 % of the residents had scores from 0-1, 24.7-53.4% of residents scored 0 for no pain, and no one

scored 3, i.e. excruciating pain. Residents who scored below 3, the cut point for mild depression, i.e. having no depression, ranged from 69.0 to 83.8%, from 28.6 to 61.4% of residents had a score of 0-1, indicating intact cognitive performance and residents who scored between 0-9 on the lowest third of the ADL scale each year, i.e. having a high ADL performance, ranged from 42.5 to 68.0%. Residents scoring over the years in the higher third of the index in social engagement (score of 5-6), having good ability in social engagement ranged from 4.8 to 22.3%. The percentage of residents scoring in the highest third of each scale was: Regarding health stability 1.72 to 12.3% of residents had scores from 4-5; Pain 31.7 to 40.9% of residents scored 2; Depression 0.0 to 5.3% of residents had scores from 9-14; Cognitive performance 12.7 to 38.1% of residents had scores from 4-6; ADL performance 11.2 to 32.9% of residents had scores from 20-28; Social engagement 46.3 to 81.0% of residents had scores from 0-2 indicating severe withdrawal from social engagement.

The analysis revealed that in 1999 there was higher ADL and cognitive performance than in other years; thus this year was regarded as an outlier in trend analysis. Consequently a linear trend was found over time towards residents having less stable health ( $p=0.003$ ; R square 0.004), better cognitive performance ( $p=0.034$ ; R square 0.002) and reporting more pain when admitted ( $p=0.017$ ; R square 0.003), and more residents reported participating in social activities at a higher level ( $p=0.0001$ ; R square 0.018). The ADL performance and level of depression were similar throughout the period 1996-2006 (Study I). Furthermore a linear regression analysis performed for the period 2000-2006 revealed a weak, but significant, linear trend towards increased social engagement with time ( $p=0.032$ ; R square 0.002). However no significant trend was found for age, in either the period 1996-2006 or 2000-2006. No significant change was found in the frequency of bladder and bowel continence, hearing, vision and gender over 1996-2006 (Study I).

Comparison of residents in the capital and rural area within each year revealed no significant difference in the mean age (Study I). A significant difference in gender ratio was only seen in 2005, when women accounted for 70.4% in the capital area and 54% in the rural area ( $p<0.001$ ). Comparison of places from which residents were admitted, i.e. whether from hospital or home, revealed no significant difference between the capital and rural areas. A comparison of health status and functional profile between the capital and rural areas within each year revealed the following differences: residents in rural areas were in more unstable health in 2003 ( $p<0.0045$ ) than those in the capital area and residents in the capital area had worse cognitive performance in 2004 ( $p<0.0045$ ) and 2006 ( $p<0.0045$ ).

### ***Survival time and mortality***

Residents admitted in 1996-2003 had a median survival time of 31 months (IQR 40). No significant difference was seen in median survival and mortality rates between cohorts (Study II). During the first 3 years of living in a nursing home 53.1% ( $n=1,171$ ) of the residents died. In the first year 28.8% ( $n=636$ ) of the residents died; during the second year 14.6% ( $n=322$ ) died, and during the third year 9.7% ( $n=213$ ) died. Over the years 1996-2003 residents dying in the first year after moving to

nursing homes ranged from 24.7% to 38.9% of the total, in the second year 9.1% to 23.2% and in the third year 11.7% to 19.0%. Residents living longer than 3 years numbered 46.9% (n=1,035) of the total. The death rate for men and women increased with higher scores for the CHESS Scale, Depression Rating Scale, Cognitive Performance Scale, and the ADL Long Scale. In contrast, the death rate decreased with increased activity, i.e. higher scores for the Index of Social Engagement (Study II).

Residents dying in the first year after moving to a nursing home had more unstable health ( $p<0.001$ ) and their ADL performance was worse ( $p<0.001$ ) at admittance than for those dying in the second and third year (Study II). They also had more pain ( $p=0.02$ ) than those dying in the second year and were more depressed ( $p=0.009$ ) and less involved in social engagement ( $p<0.001$ ) than those dying in the third year. Residents dying in the second year after admission to a nursing home had less stable health than those dying in the third year ( $p<0.001$ ). Residents who lived more than 3 years from admission had better ADL performance ( $P=0.004$ ), better cognitive performance and were more involved in social engagement ( $p<0.001$ ) than those dying in the first to third year from admittance. They had more stable health than those dying in the first and second year ( $p<0.001$ ), and they were less depressed and in less pain than those dying in the first year ( $p<0.001$ ).

The probability of dying increased with age, male gender, admission from a hospital, more disability in ADL function and less stability in health (Study II). Furthermore the probability of dying decreased with a higher ability to participate in social engagement. The ADL performance scores from 10-17 and 18-28 were significant predictors of mortality, whereas scores 4-9 were not. A score of 18-28 meant a 1.80 times greater likelihood of dying than the reference group which had scores 0-3. The changes in health score (CHESS) were significant in all categories except the lowest score (1). A score of 5 meant a 16.12 times greater likelihood of dying than the reference group, which were those with a score of 0. The scores 0-2 (withdrawal) on social engagement were significant predictors of mortality. A score of 0 (severe withdrawal from social engagement) meant a 1.65 times greater likelihood of the residents dying than the reference group (score 6, i.e. resident has much initiative and participates in social activities).

### ***Developing thresholds***

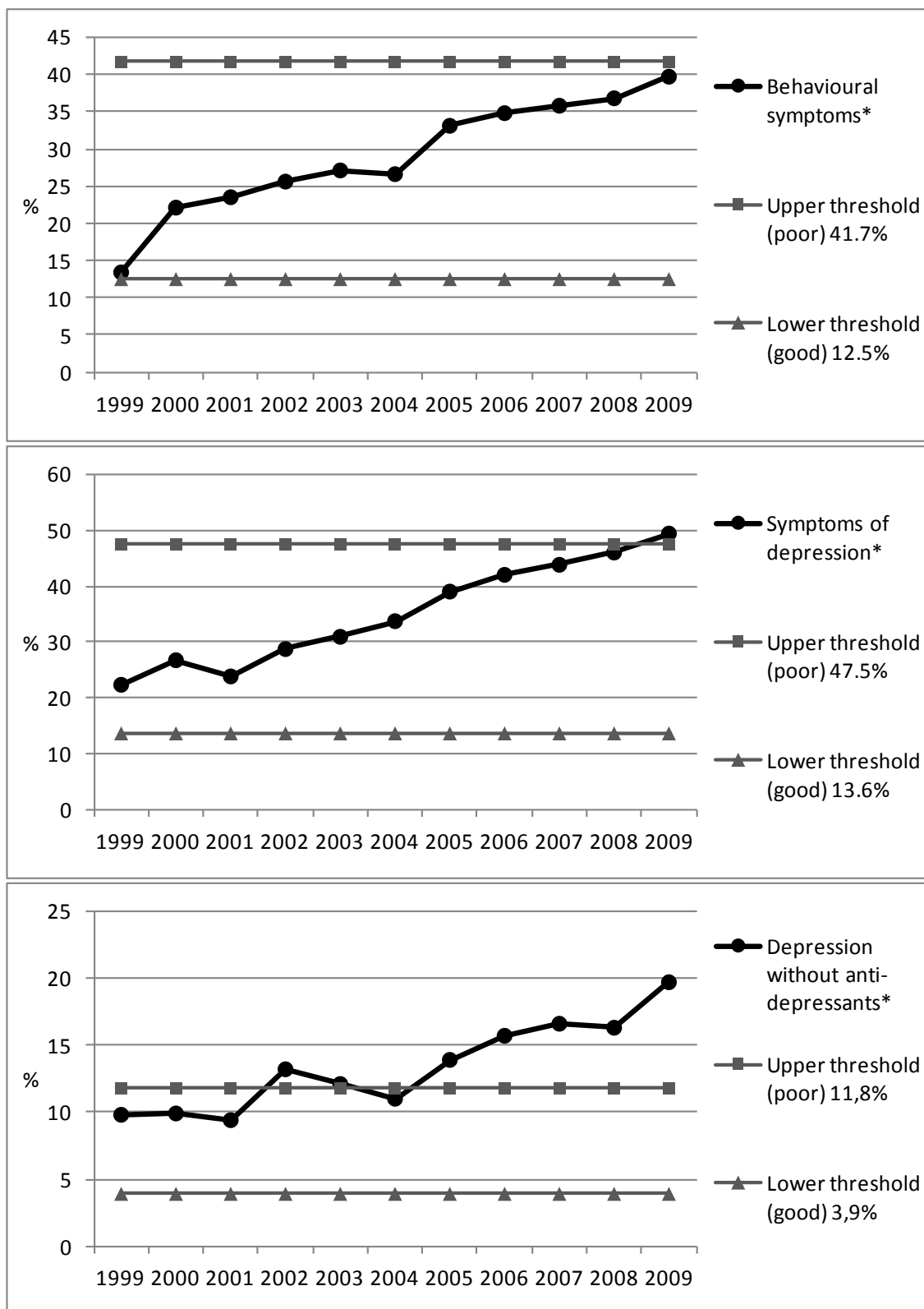
The expert panel agreed on thresholds for the MDS quality indicators for Icelandic nursing homes (Study III). The upper and lower thresholds for the quality indicators are shown in Figures 4-10. The change from first to second Delphi round was from 0.0-3.3 % for the lower threshold, the greatest change being for 'Prevalence of anti anxiety or hypnotic drug use', i.e. changing from 32.5% to 35.8%. The change from the first to the second round was 0.0-3.8 % for the upper threshold, the greatest change being for QI for 'Prevalence of little or no activity' from 47.7% to 51.5%.

### ***Quality of care measured with MDS quality indicators***

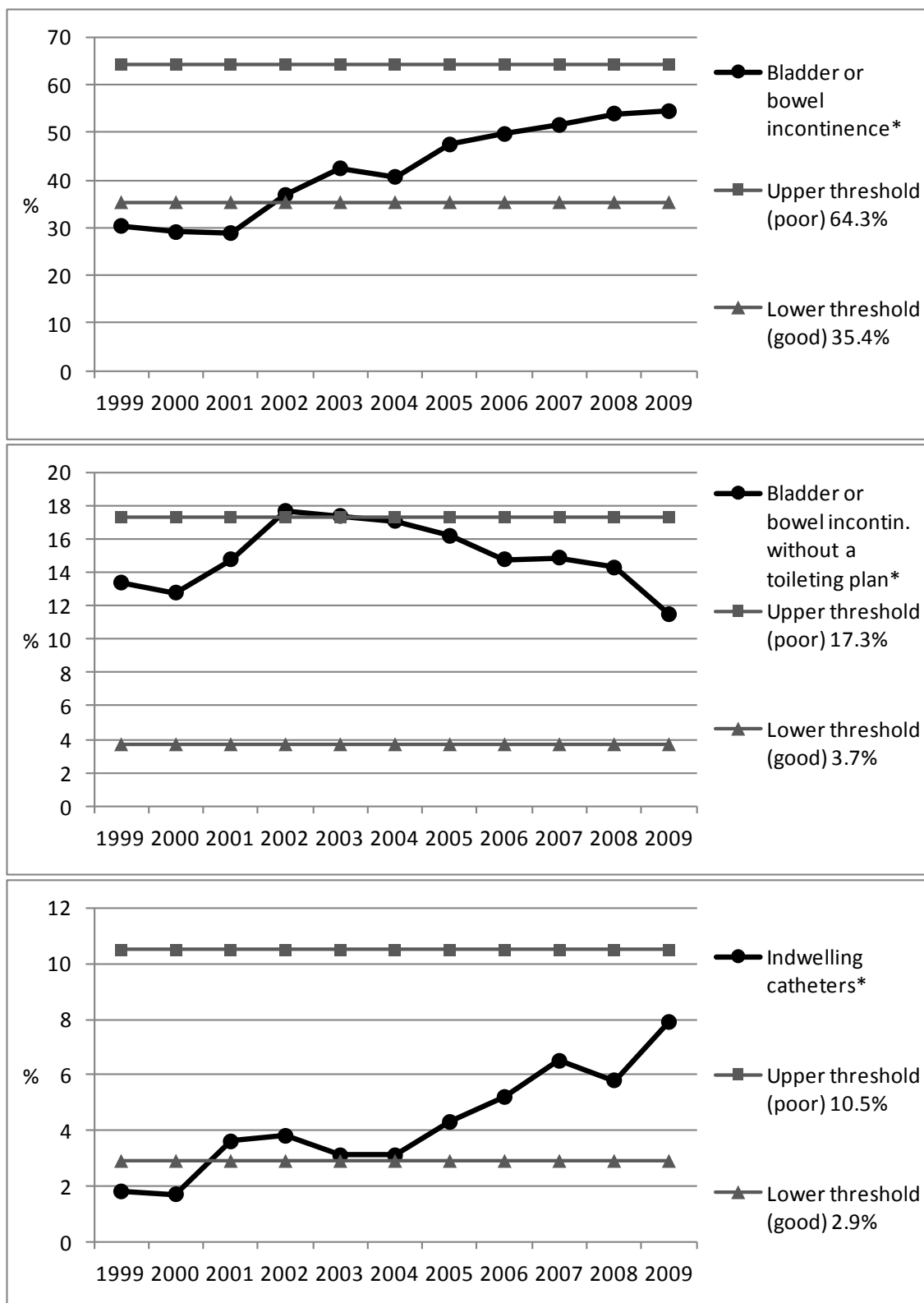
The distribution of the 47 nursing homes in regard to their outcome in the quality indicators in 2009 showed that the median value was above the upper threshold for

depression (49.4%), symptoms of depression without anti-depressant therapy (18.2%), use of 9 or more medications (63.8%), anti-anxiety or hypnotic drug use (69.2%), and little or no activity (52.5%), indicating poor care in these areas of care (Study III). The median values of quality indicators where the inter-quartile range fell below the upper threshold, indicating average quality of care were: bladder and bowel incontinence (59.3%), occasional or frequent bladder and bowel incontinence without a toileting plan (7.4%), indwelling catheter (7.7%), and weight loss (8.1%). The quality indicator for tube feeding (0.0%) had a median value below the lower threshold, indicating excellent care.

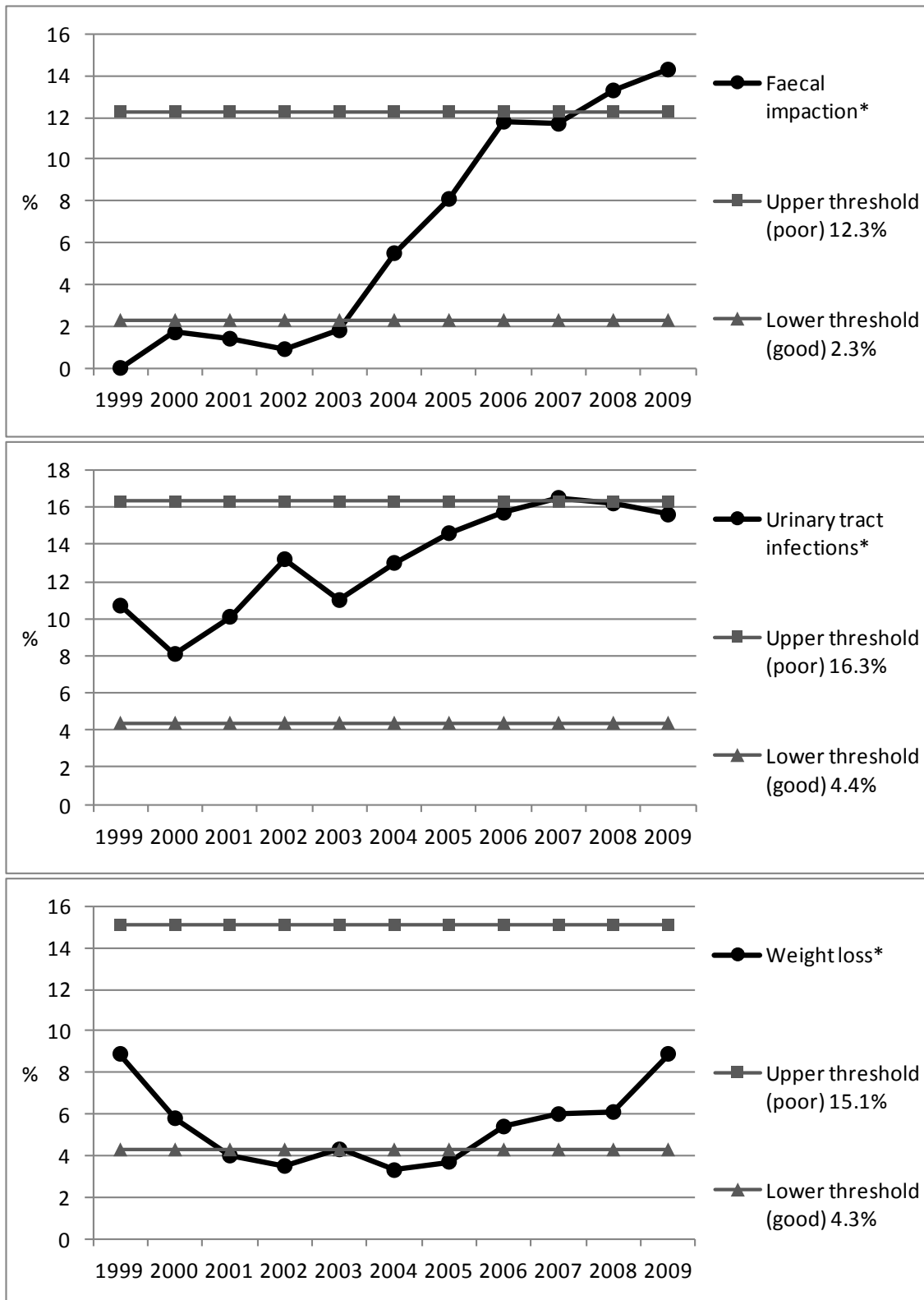
The outcomes for quality indicators (%) for residents in Icelandic nursing homes in 1999-2009 are shown in figures 4-10 as they relate to the thresholds established by the expert panel (Study III, IV and framework). The prevalence of quality indicators was low, indicating good quality in many areas of care, and from 29.9% to 100% did not present a quality indicator, depending on the type of indicator (Framework). The quality indicator 'Bladder and bowel incontinence without a toileting plan', as shown in figure 5b, indicated a significant trend over the years 1999-2009 ( $p < 0.001$ ) i.e. after reaching a peak in 2002 there was a significant downward slope. The figure also shows that the quality indicator had decreased from the level of the upper threshold (poor care) in 2002 and in 2009 was between the upper and lower thresholds, indicating average care i.e. improvement in quality. The quality indicators that revealed no significant change over the research period were: 'Anti-anxiety or hypnotic drug use' (Figure 8c) and 'Tube feeding' (Figure 7a). Seventeen quality indicators showed an increase in prevalence over the period, i.e. a significant upward slope ( $p < 0.05$ ) as shown in figures 4-10. The chi square for trend p values for each quality indicator is shown in figures 4-10. The quality indicator 'Antipsychotic drug use in the absence of psychotic and related conditions' showed a significant trend over the years 1999-2009 ( $p < 0.001$ ) (framework); however from 2003 this trend levelled out (study IV) (Figure 8b). The quality indicator for weight loss (Figure 6c) showed a significant trend over the years 1999-2009 ( $p < 0.001$ ) with an upward slope from 2004. Comparison of the outcome of quality indicators to the upper and lower thresholds shows that values for quality indicators for weight loss and tube feeding were close to the lower threshold, indicating good care (Figures 6c and 7a). The following had quality indicators with values close to or above the upper thresholds, indicating poor care: symptoms of depression without anti-depressant therapy (Figure 4c); urinary tract infections (Figure 6b); use of 9 or more different medications (Figure 7c); hypnotic drug use more than two days in past week (Figure 8a); antipsychotic drug use in the absence of psychotic and related conditions (Figure 8b); anti anxiety or hypnotic drug use (Figure 8c); and little or no activity (Figure 9c).



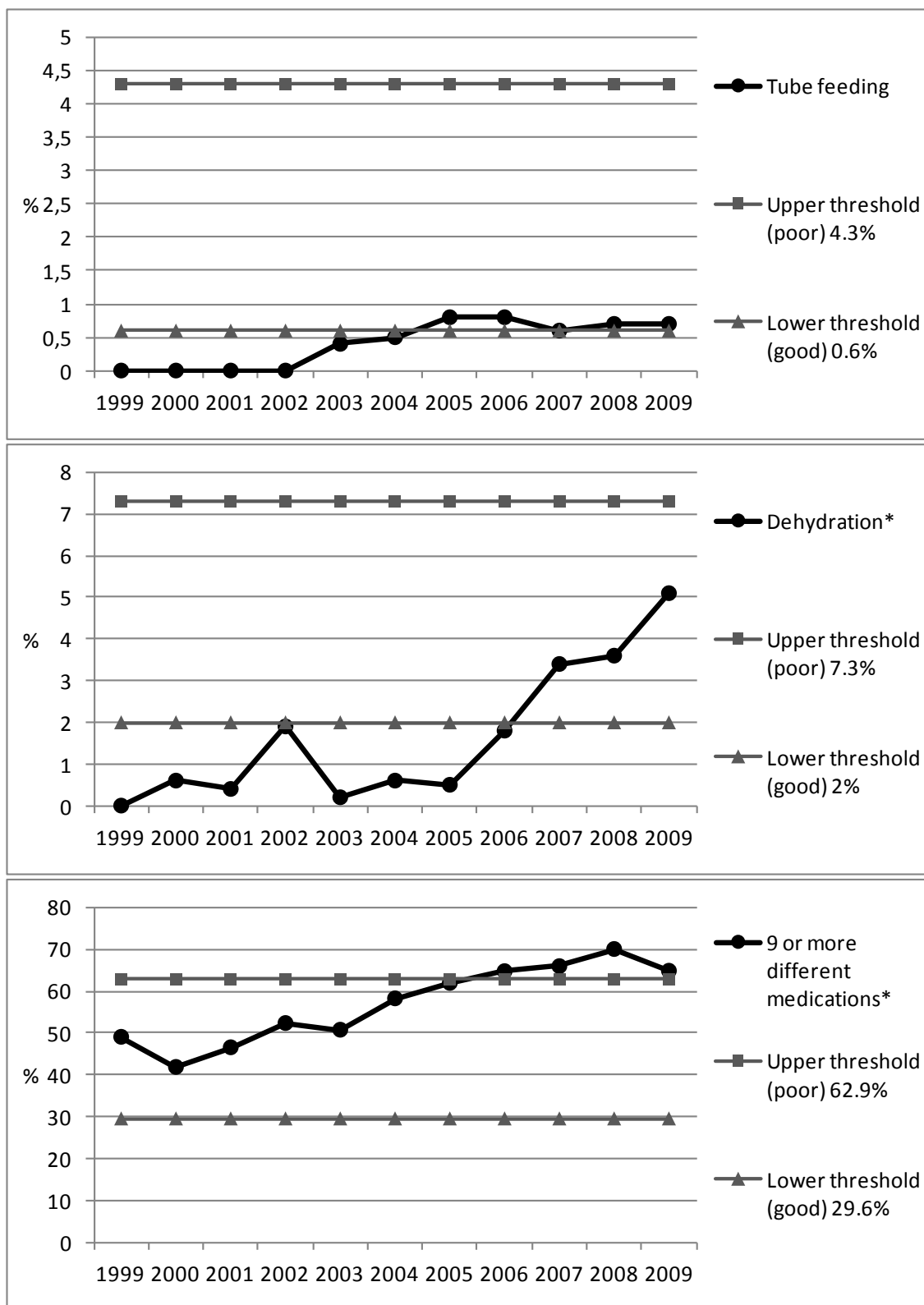
**Figure 4 a-c.** Residents in Icelandic nursing homes (%) showing behavioural problems (4a), symptoms of depression (4b), residents with symptoms of depression without anti-depressant therapy (4c) in 1999-2009 in relation to quality indicator thresholds. Number of assessments in 1999-2002 n=112-317; 2003-2009 n=447-2,305. Chi Square test for trend \* p<0.001.



**Figure 5 a-c.** Residents in Icelandic nursing homes (%) having bladder or bowel incontinence (5a), bladder or bowel incontinence without a toileting plan (5b), indwelling catheter (5c) in 1999-2009 in relation to quality indicator thresholds. Number of assessments 1999-2002 n=112-317; 2003-2009 n=447-2,305. Chi Square test for trend \* p<0.001.

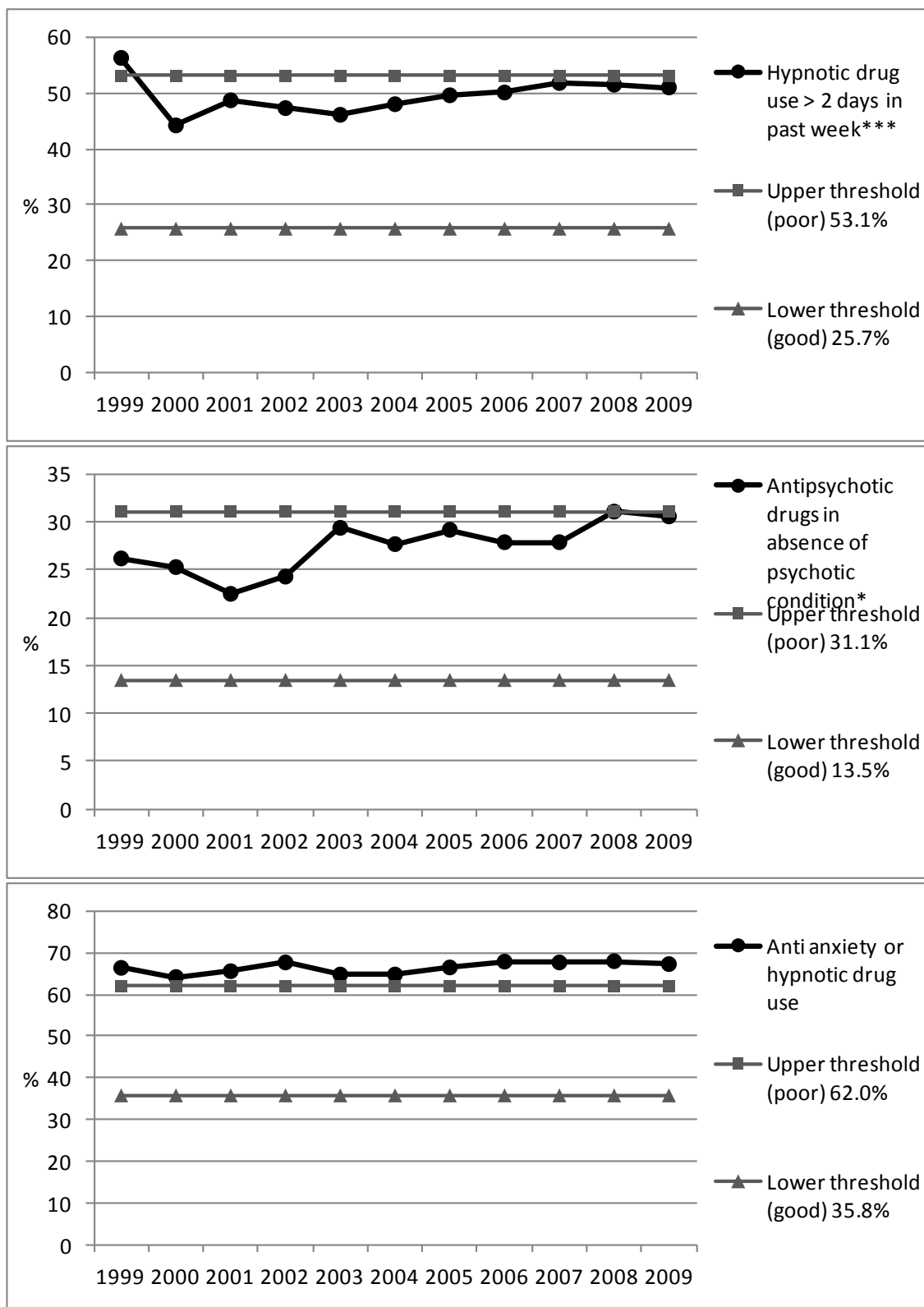


**Figure 6 a-c.** Residents in Icelandic nursing homes (%) having faecal impaction (6a), urinary tract infections (6b), weight loss (6c) in 1999-2009 in relation to quality indicator thresholds. Number of assessments 1999-2002 n=112-317; 2003-2009 n=447-2,305. Chi Square test for trend \* p<0.001.

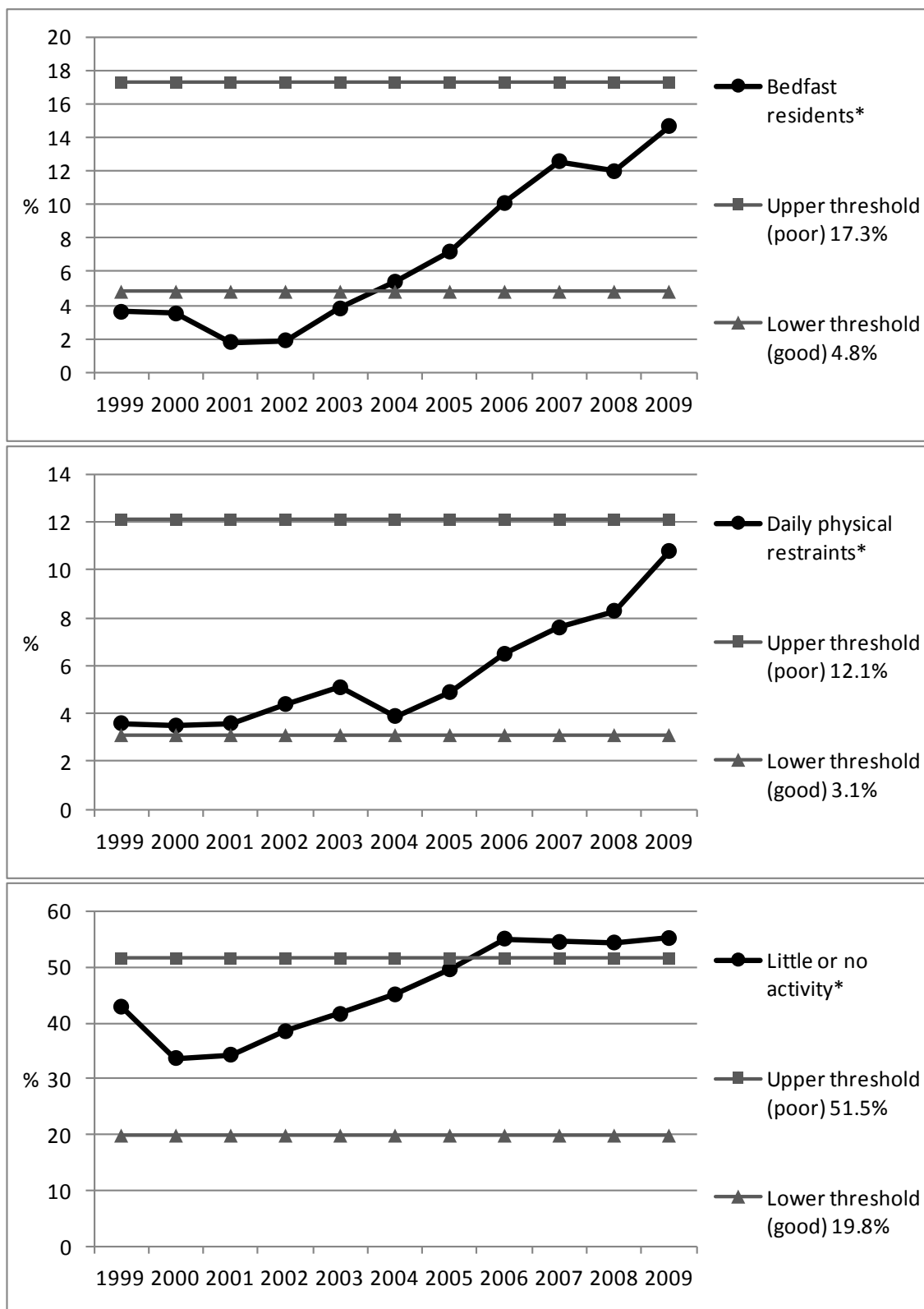


**Figure 7 a-c.** Residents in Icelandic nursing homes (%) who were getting tube feeding (7a), were dehydrated (7b), used 9 or more different medications (7c) in 1999-2009 in relation to quality indicator thresholds. Number of assessments 1999-2002 n=112-317; 2003-2009 n=447-2,305. Chi Square test for trend \* p<0.001.

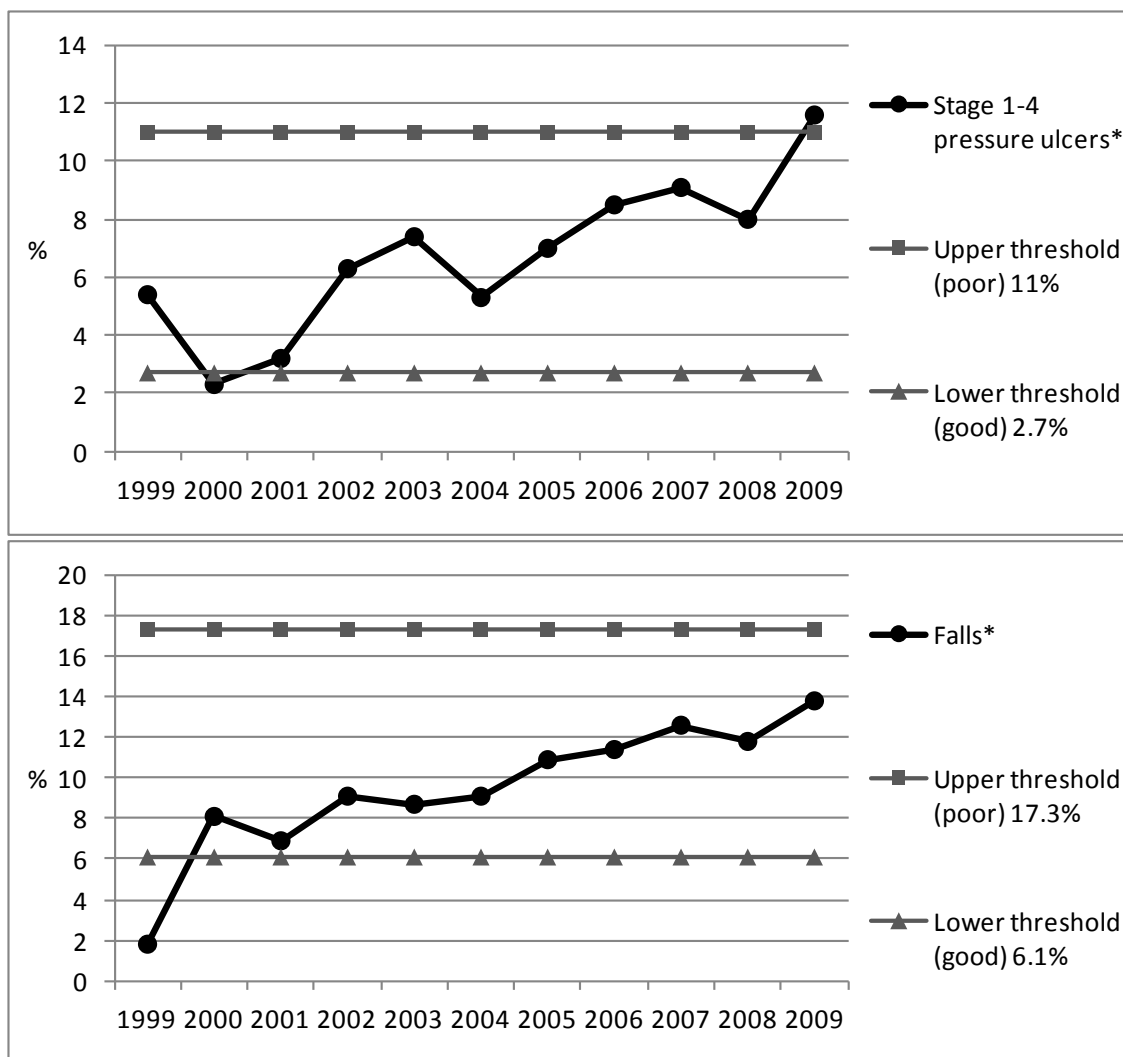




**Figure 8 a-c.** Residents in Icelandic nursing homes (%) who were using hypnotics (8a), antipsychotic drugs in the absence of psychotic and related conditions (8b), anti-anxiety or hypnotic drugs (8c) in 1999-2009 in relation to quality indicator thresholds. Number of assessments 1999-2002 n=112-317; 2003-2009 n=447-2,305. Chi Square test for trend \* p<0.001; \*\*\*p<0.05.



**Figure 9 a-c.** Residents in Icelandic nursing homes (%) who were bedfast (9a), were with restraints (9b), participated in little or no activity (9c) in 1999-2009 in relation to quality indicator thresholds. Number of assessments 1999-2002 n=112-317; 2003-2009 n=447-2,305. Chi Square test for trend \* p<0.001.



**Figure 10 a-b.** Residents in Icelandic nursing homes (%) who had stage 1-4 pressure ulcers (10a) and had fallen (10b) in 1999-2009 in relation to quality indicator thresholds. Number of assessments 1999-2002 n=112-317; 2003-2009 n=447-2,305. Chi Square test for trend \* p<0.001.

The quality indicators with values close to the lower threshold (excellent care) at the beginning of the research period and close to the upper threshold (poor care) at the end of the period were: behavioural symptoms affecting others (Figure 4a); symptoms of depression (Figure 4b); faecal impaction (Figure 6a); bedfast residents (Figure 9a); daily physical restraints (Figure 9b); and stage 1-4 pressure ulcers (Figure 10a).

Logistic regression was performed for each of the 17 quality indicators, revealing a significant trend (Study IV). The year of assessment was a significant predictor for 15 out of 17 quality indicators analysed. The greatest risk associated with the variable 'year of assessment' was for the quality indicator for dehydration (OR 1.41 (95% CI 1.29-1.54), p<0.001). Nine quality indicators showed a slight increase in the risk of an active QI in relation to the year of assessment variable. They were: Weight loss (OR 1.13 (95% CI 1.07-1.19), p<0.001); Bedfast residents (1.06 (1.02-1.11), p<0.01); Daily physical restraints (1.06 (1.01-1.11), p<0.05); Falls (1.04 (1.01-1.08), p<0.05); Bladder or bowel incontinence (0.96 (0.94-0.99), p<0.001); Indwelling catheters ( 1.10 (1.04-

1.15),  $p < 0.001$ ); Faecal impaction (1.15 (1.11-1.19),  $p < 0.001$ ); Symptoms of depression (1.04 (1.02-1.07),  $p < 0.001$ ); 9 or more different medications (1.07 (1.05-1.10),  $p < 0.001$ ); Hypnotic drug use more than 2 days in past week (1.04 (1.02-1.06),  $p < 0.001$ ). There was however reduced risk associated with the year of assessment for the quality indicator 'Little or no activity' (0.95 (0.93-0.98),  $p < 0.001$ ). The CHES scale, i.e. scores 2 and higher indicating residents in unstable health and in serious risk of decline, was a significant predictor for the outcome of 16 quality indicators. One quality indicator showed reduced risk of a resident having the quality indicator present, i.e. increased health instability, lowered the risk for the residents having daily physical restraints. Residents with unstable health showed an increased risk associated with having a quality indicator present in 15 out of 17 the quality indicators. In the quality indicators analysed, residents in increased pain had a higher risk of having the quality indicator present in 15 quality indicators. Mild or severe depression in a resident increased the risk for having the quality indicator present in 10 of the quality indicators. On the other hand, with mild depression there was a slightly lower risk of having the 'Bladder and bowel incontinence' quality indicator. The cognitive status of resident's was a significant predictor for 15 quality indicators. In 6 quality indicators the risk of having an indicator increased with increased cognitive impairment. The risk declined with increased cognitive impairment in 9 quality indicators. ADL functioning was a significant predictor of outcome for all 17 quality indicators. In 14 instances increased ADL dependency increased the risk for having a quality indicator. Only for the quality indicators 'Bladder or bowel incontinence without a toileting plan' and 'Hypnotic drug use > 2 days in past week' did the risk for having a quality indicators diminish with increased ADL dependency. Residents' social engagement was a significant predictor for 10 quality indicators. For 7 quality indicators the risk increased for a quality indicator as the residents' social engagement diminished. However, decreased social engagement decreased the risk of '9 or more medications', 'Hypnotic drug use' and an 'Indwelling catheter'. The Nagelkerke R square was above 0.20 for seven of the logistic regressions. However, in the logistic regression for the quality indicators for hypnotic drug use, bladder and bowel incontinence without a toileting plan, urinary tract infections, faecal impaction and falls the Nagelkerke R square was below 0.09.

## DISCUSSION

### General discussions of the findings

At admittance the majority of the residents had stable health and many were relatively independent in ADL (Study I). Compared to a Swedish study their ADL dependency was more in line with those who live at home where 45% had low levels of ADL dependency rather than those living in nursing homes where 8% of residents had low levels of ADL dependency (Karlsson, Edberg, Westergren, & Hallberg, 2008). The relatively small proportion of residents having a high level of ADL dependence in this study (11.2-32.9%) is further highlighted in comparison with a US study where 50-54% of newly admitted residents were considered to be extensively or totally dependent in ADL performance (Buchanan et al., 2005). Furthermore cognitive performance was similar or somewhat better in this study where 28.6-61.4% were cognitively intact at admittance compared to 27% reported for nursing home residents in Sweden (Karlsson et al., 2008). The proportion of residents suffering depression (DRS  $\geq 3$ ) and pain was similar to that reported for Dutch nursing homes, where 26.9% were reported having depression (Achterberg, Pot, Kerkstra, & Ribbe, 2006) and 32% experienced daily pain at admittance (Achterberg et al., 2007). Moreover the findings show that a majority of residents had stable health at admission, ADL performance did not change over the period and cognitive performance improved. Considering this and that 46.9% of the residents lived longer than 3 years in the nursing home (Study II) some of those who were admitted to a nursing home over the research period might have been able to stay at home longer had they been provided with more support. Decisions on what is the most appropriate service for a person needing care must be based on valid and reliable measures. The findings show that health stability (CHESS Scale) and ADL performance are valid predictors of mortality (Study II) and thus could be used when selecting which type of service is appropriate for the person. The assessment needed for these measurements is not costly or complicated. As reasons for moving to a nursing home may not only be physical but rather mental or social (Bharucha et al., 2004; Gaugler, Duval, Anderson, & Kane, 2007), using only these measures would be too simple. A person may have a serious mental disease or social circumstances may be very difficult, and these factors need to be considered and may warrant nursing home placement. It is important, both for the individual as well as society, that services are provided at the appropriate level and resources that might delay nursing home placement explored.

Although many residents were relatively stable in health and independent at admission others may have needed palliative care or end of life care right from their admittance. In other words the care needs of those who were admitted to nursing home varied considerably. The share of residents who were not so fragile in health lived longer than 3 years while over half of the recently admitted residents lived less than 3 years in the nursing home and 28.8% died during the first year (Study II). The median survival time (2.6 years) was stable over the research period 1996-2006 (Study II) and similar to what was reported in two recent studies (2.3 years) (McCann et al., 2009; Wieland et al., 2010), although others have reported a longer survival time (5.9 years)

(Dale et al., 2001) or shorter (men 76 days; women 134 days) (Sutcliffe et al., 2007). Comparing such findings across countries is complicated as local conditions may vary considerably. The findings also show that more pain was reported over the research period (Study I), indicating more need for symptom treatment. Other studies have shown the suffering of nursing home residents because of lack of symptom treatment and access to palliative care (Davies & Higginson, 2004; Hall, Schroder, & Weaver, 2002) and that increasing numbers of residents are dying in nursing homes instead of hospitals (Jonsson, Bernhöft, Bernhardsson, & Jonsson, 2005; Whittaker, Kernohan, Hansson, Howard, & McLaughlin, 2006). The nursing home is thought of as the last home people have before they die and much effort has been put into making it homelike and providing restorative care. The nursing home is however a place where death is a central issue, and providing residents with symptom treatment and palliative care is important (Hockley et al., 2005). Furthermore it has been suggested that the framework of palliative care may be appropriate not only for residents who are dying but also for those needing long term care (Hallberg, 2006). Research has shown that knowledge of how to provide symptom treatment and palliative care for residents (Whittaker et al., 2006; Wowchuk, McClement, & Bond, 2007), as well as those who have dementia (Chang et al., 2009) is lacking in nursing homes. The findings of this study indicate the need for staff in nursing homes to be knowledgeable in providing symptom treatment and palliative care.

In many areas of care the prevalence of quality indicators was low, indicating good quality, and from 29.9% to 100% did not present a quality indicator, depending on the type of indicator (Framework). In some cases, however, the indicator should not be present at all and even a low prevalence would be considered detrimental in relation to quality. To be able to detect where there is need for improvement the thresholds for MDS quality indicators were needed. They were determined with the Delphi method to provide Icelandic nursing homes with directions for what to aim for in care practices. They are aimed at being not too high or too low but to encourage improvement (Donabedian, 2003). The best outcome in relation to the thresholds (Study III) was in relation to physical care in the areas of incontinence, nutrition and falls (Framework). Additionally, for the 20 quality indicators, the prevalence of 12 was below 25% and four of these had a prevalence below 10%, i.e. weight loss, tube feeding, dehydration and indwelling catheters (Framework and Study IV). The low prevalence of weight loss, tube feeding and dehydration in this study was a positive outcome for a population at high risk of nutritional problems (Pauly, Stehle, & Volkert, 2007) where 26.7% of nursing home residents have been reported malnourished (Volkert, Pauly, Stehle, & Sieber, 2011).

Compared to the thresholds the prevalence of some quality indicators has changed over the years from indicating average quality to poor quality or from indicating excellent quality to average quality. The thresholds set by the expert panel (Study III) either indicated poor care (prevalence above the threshold), average care (between thresholds) or excellent care (below the lower threshold). The trend over the period 1999-2009 (Framework) showed that 6 quality indicators changed from indicating average care toward indicating poor care. These quality indicators were: 'symptoms of

depression', 'symptoms of depression without antidepressant therapy', 'urinary tract infections', 'use of 9 or more different medications', 'little or no activity' and 'stage 1-4 pressure ulcers'. Furthermore 5 quality indicators changed from what the expert panel decided indicated excellent care toward indicating average care. These quality indicators were: 'bladder or bowel incontinence', 'indwelling catheters', 'dehydration', 'bedfast residents' and 'falls'. Even the quality indicator for 'faecal impaction' changed from being indicating excellent care toward indicating poor care. In comparison to thresholds set for nursing homes in Missouri (Rantz et al., 2000), the thresholds set in the present study were set at a higher level, indicating higher expectations for quality of care in Missouri. Furthermore, five quality indicators were so much higher in this study that the lower threshold (excellent care) was above or very similar to the upper threshold (poor care) in Missouri (Rantz et al., 2000). These quality indicators were: 9 or more different medications; hypnotic drug use more than two days in the past week; anti-anxiety or hypnotic drug use; bedfast residents and little or no activity. In other words, care considered excellent in this study would be considered poor in Missouri (Rantz et al., 2000). These different expectations can not be explained by a slightly dissimilar resident profile in this study compared to what has been reported for nursing home residents in Missouri (N=43,510) (van Dijk et al., 2005). Where the mean age for residents in Missouri was slightly lower (84.4, SD 7.8), a higher proportion of women (73.6%) and slightly fewer had dementia (65.5 %). The difference may however reflect the formal support for quality improvement that has been available to nursing homes in Missouri since the 1990s (Rantz et al., 1997) or different care practices. The thresholds used in Iceland send the decided message that over half of Icelandic nursing homes have potential care problems regarding residents' symptoms of depression, use of many different medications per individual, and little or no activity of residents. They also indicate a greater tolerance toward variance in care in Iceland compared to Missouri, since the difference between upper and lower thresholds was greater in this study than in Missouri (Rantz et al., 2000). The longer experience with using thresholds has resulted in a narrower range between thresholds in Missouri (Rantz et al., 2000; Rantz et al., 1997). Although greater latitude in variation in care delivery may be needed, as this is the first time thresholds have been set for Icelandic nursing homes, officials and nursing home managers need to be aware of the trends shown in this study. The findings imply that some official initiative needs to be taken to encourage and support Icelandic nursing homes in improving the care provided. Many of the smaller nursing homes may not have the resources to manage this without official support. The results from the improvement initiative in Missouri (Rantz et al., 2009) and Finland (Finne-Soveri et al., 2010) are examples of how this may be accomplished.

The increased prevalence in most quality indicators over the research period indicated the declining quality in Icelandic nursing homes. This may be partially related to the decline in health and functional status of the residents (Study IV). The increased dependency of residents, however, need not lead to increased prevalence of the quality indicators. Despite the increased dependency of residents over time a US study reported a decreased prevalence of quality indicators, i.e. improved quality of care (Tsan et al., 2007). Although the prevalence of 17 quality indicators increased,

indicating declining quality, the prevalence for the quality indicator ‘bladder and bowel incontinence without a toileting plan’, decreased indicating improvement in quality (Framework). Two other studies investigating changes in quality over time using the MDS quality indicators have reported a better outcome than the present study. A Finnish study reported improved quality of care in 16 out of 26 indicators and decline in only four areas of care in a comparison of data from 2001 to data from 2009 (N=29 long-term institutions) (Finne-Soveri et al., 2010). A study in the US reported improvements in quality of care for 14 out of 24 quality indicators and a decline in quality of 4 quality indicators in a study evaluating quality over three years (2003-2005; n=15,544-16,064) (Tsan et al., 2007). The common outcome in this study as well as the Finnish and US study is improvements in quality concerning the indicator for ‘bladder or bowel incontinence without a toileting plan’ and decline in quality concerning increased prevalence of residents receiving 9 or more medications. When comparing the outcomes of such studies the reference point of measures needs to be considered. The % of residents receiving 9 or more medications changed in this study from 49.1-64.9% (1999-2009) (Framework) compared to the US results from 66.0-72.8% (2003-2005) and the Finnish results of 39-47% (2001 vs. 2009). The best result was reported in the Finnish study, although all studies showed a decline in quality of care. Moreover, the quality indicators for pressure ulcers in this study showed a decline in quality of care. Comparison of the outcome for pressure ulcers 5.4-11.6% (1999-2009) showed that the prevalence was still lower than in the US study where these quality indicators improved 14.5-13.3% (Tsan et al., 2007). The prevalence in this study was increasing while the prevalence of pressure ulcers in the Finnish study was decreasing (10-8%) (Finne-Soveri et al., 2010). Others have reported a lower prevalence for pressure ulcers such as 4.3-5.1% in German nursing homes (Kottner, Dassen, & Lahmann, 2010), or higher, e.g. 31.4% in Dutch nursing homes (Tannen, Dassen, & Halfens, 2008). Comparing quality of care between countries can however be problematic as circumstances may vary between countries. Admission criteria for nursing homes, for instance, can influence the prevalence of health related problems of residents and thereby influence the outcome of quality indicators. International discussion and comparison of quality in nursing homes is however necessary and may motivate improvements.

Measuring quality is a complex issue and the outcome of the quality indicators is likely to be influenced by several factors outside the scope of this study. A dismal Nagelkerke R square in the logistic regression (Nagelkerke, 1991), for instance, for the quality indicators for hypnotic drug use, bladder and bowel incontinence without a toileting plan, urinary tract infections, faecal impaction and falls indicates that the model would not explain the variation in quality indicator outcome (Study IV). For seven of the quality indicators the Nagelkerke R square for the logistic regression was above 0.20 and would therefore be considered highly satisfactory, indicating that the model from the logistic regression partially explained the change over time in the quality indicators. This study investigated the association of health and functional profile with the outcome of MDS quality indicators. However, many other factors can impact quality of care outcomes in nursing homes (Bravo, De Wals, Dubois, & Charpentier, 1999). Considering the increase in prevalence of most quality indicators it



could be expected that some change could be detected in the residents that were admitted over the period. The admission status of residents showed no significant change in ADL status or improvement in cognitive performance but rather a decline in health stability over the period 1996-2006 (Study I). These findings on admission status therefore do not shed light on the worse outcome of the quality indicators (Framework; Study IV). The system of reimbursement to nursing homes was altered in 2003 and this may have influenced the care in nursing homes. Reimbursement, from that year on, was based on data from the MDS assessment of nursing home residents and Resource Utilization Groups III calculations of the cost of resident care, i.e. linking payments to nursing homes to care needs of the residents (Icelandic Ministry of Welfare, 2011). The admission criteria for Icelandic nursing homes in 2003-2007 were consistent, only changing early in 2008 when the admission criteria were made stricter (Icelandic Ministry of Welfare, 2011). These changes may have influenced the trend in the prevalence of quality indicators seen in this study. Although the reasons for the increase in prevalence of most quality indicators over the years are not fully explained, predictions can be made of future occurrences by observing trends in standardised measures such as the quality indicators (Rosenberg, 1997). Although data has been collected by the nursing homes since 1996 nothing has been reported that has indicated awareness of the trend portrayed in these findings (Study III-IV, Framework). Officials who organize health and social care and those who deliver care need to be aware of these trends and respond appropriately so that quality is maintained or is developing in the intended direction.

## **LIMITATIONS**

The strength of the studies presented in this thesis is the availability of data from all nursing homes in Iceland over the period 1996-2009. However, there is also the limitation that the year 1996 was the first year the MDS assessment was mandatory for all residents in Icelandic nursing homes. It took some years for the assessment to be fully implemented and in the first years some residents were not assessed and many others were only assessed after staying in the nursing homes for a considerable length of time. After the MDS assessments was linked to reimbursement in 2003 the compliance of the nursing home sector increased greatly. Research based on clinical data is certain to be influenced by events in the nursing homes and this delay in assessment was most likely due to workload and absence of staff rather than the residents' characteristics. The error this may have caused should therefore be random rather than systematic. Another limitation may be that the data used for this study was collected for clinical use, not research. The MDS has nonetheless been deemed a valuable resource for research (Shin & Scherer, 2009) and as a research tool it has been rated as having moderate to high reliability (Casten, Lawton, Parmelee, & Kleban, 1998). Moreover the validity and alpha reliability of the MDS scales aggregated from MDS data have indicated their usefulness in research (Mor, Intrator, Unruh, & Cai, 2011). Furthermore, the registered nurses who carried out the MDS assessments were qualified to do so, worked at the nursing homes and had access to a detailed instruction manual.

The strength of studies I and II was the inclusion of data over a period of 11 years. Since the timeframe for the admission assessment was 90 days the residents may have suffered some changes in their health before they were assessed. Studies have shown varying results and reported nursing home residents to be stable or to improve over a 12-month period (Grando et al., 2005), to decline over a six-month period (Scocco et al., 2006), or a lower mortality risk of recently admitted residents compared to others (McCann et al., 2009). The researchers concluded however that data from assessments within 90 days would sufficiently reveal the admission status of the residents. Another limitation of concern was the variation in the sample from 13% to 84% of the total residents admitted to nursing homes each year, due to the sample consisting of newly admitted residents assessed within 90 days from admission. Data for 1999 and 2003-2006 represents over 50% of those admitted to nursing homes each year so this potential bias mainly affects the data from 1996-1998 and 2000-2002.

The research in study III had the advantage that data from 97% of residents in all Icelandic nursing homes was used for the analysis. Furthermore, the expert panel represented nursing homes in both the capital and rural areas in Iceland and, additionally, the members had extensive knowledge and experience in the field of geriatric nursing and medicine. The very small size of some nursing homes (11-20 residents) may however be considered a limitation to the study. Moreover the expert panel had access to the quality indicator thresholds from Missouri (Rantz et al., 2000) when deciding on the Icelandic thresholds, which may have affected their decisions. It was thought better to present actual figures for the Missouri thresholds, as many knew of them, rather than having the panel members rely on memory.

The strength of study IV and the framework analysis was the inclusion of data from 7 and 11 years respectively. A limitation that needs to be considered is that the quality indicators do not consider positive characteristics of quality but rather tap into negative signs of quality, which may influence the outcome. Furthermore the quality indicators only measure two of three aspects of care, i.e. process and outcome of care but not structure. Moreover some quality indicators measure outcome of care where it may be difficult to differentiate between deterioration as a result of poor quality or due to the natural course of the residents' worsening health condition.

The findings present important knowledge on residents' health status, functional profile, mortality and quality of care in Icelandic nursing homes. Although it may be considered a limitation that the context of the study is Icelandic, and the findings will clearly be of use to Icelandic nursing homes, the results will nonetheless be an important contribution to the international discussion on the quality of care in nursing homes. Studies I, II, IV and the framework analysis are unique in that they cover long periods where increasing financial constraints in society have had the potential to impact nursing home services.

Further research is needed, both in Iceland and across countries, which takes into account not only process and outcome but also structure. All three aspects of quality measurement are needed to fully evaluate the quality of care in nursing homes. More

accurate measures would be useful to distinguish between the natural deterioration of residents' health because of age and illness and the care provided by the nursing homes. A further factor is that the longer the elderly are able to remain in their own homes, a precept supported by Icelandic law, the more the deterioration of their own health will show on their arrival at the nursing homes. These factors constitute not only limitations to the present research but also to the research in other countries.

## **CONCLUSIONS AND CLINICAL IMPLICATIONS**

The findings showed that residents, admitted each year, were becoming less stable in health, even though, at the same time, their cognitive performance improved during 1996–2006, if the year 1999 is excluded. The findings also showed that older people with a relatively low level of dependence were admitted to nursing homes and almost half of the residents lived longer than 3 years. However, others were very fragile dying, within 3 years and some so fragile that they died within one year. This indicates that many may have needed palliative care from the time of admission and that the concept of palliative care may be appropriate as a model for care in nursing homes. The findings therefore present residents with very different care needs and perhaps some of those who were admitted to a nursing home with relatively low dependency might have been able to stay at home longer had they been given appropriate home care and the opportunity of rehabilitation. The importance of selecting the appropriate service for each individual is therefore clear. Health stability and ADL performance stand out as important predictors of mortality and could be used as part of the admission criteria for nursing home admission as well as being suitable to use for selecting the appropriate service for older people in need of long-term care.

The thresholds determined by the expert panel provide attainable goals for Icelandic nursing homes. As progress is made the thresholds need to be revised. A considerable number of the residents did not present a quality indicator and the nursing homes are coping best with incontinence and nutritional care. Furthermore the observed increase in prevalence of quality indicators and the decline in quality of care in Icelandic nursing homes in 1999 – 2009 were partially explained by the health and functional status of residents. The areas of care that need to be improved in over half of Icelandic nursing homes are care practices in relation to depression, medication and activity. Diagnosis of depression, antidepressant therapy and care for residents with symptoms of depression, need to be improved. Residents' medication needs to be adjusted in accordance with the best practice and reviewed with regard to poly-pharmacy. Furthermore, resident activity levels need to be reconsidered, and the involvement of cognitively impaired and disabled residents in activities may need special attention.

The study showed that the MDS instrument and MDS quality indicators may be useful in measuring changes in residents' health status, functioning, mortality and quality of care. Furthermore, such measures are beneficial for monitoring quality in care organisations and to facilitate improvement in clinical care. Health assessment at admission and its implications in relation to predictors of mortality are needed when

planning individual care and give insight into areas of care where more staff knowledge needs to be developed. Moreover, knowledge of the course of development over the years in residents' health and death rates and predictors of mortality seems important when planning nursing home services, both for health officials and nursing home managers. Knowledge about developments over time such as how to promote and maintain quality of care may disclose trends otherwise overlooked. These are trends that need to be recognized and responded to by officials and policy makers. Further developments in quality of care in Icelandic nursing homes need to be monitored, as well as the complex relationship between quality of care and residents' health and functional status.

## **FURTHER RESEARCH**

Selecting the appropriate service for old people in need of long-term care is crucial, both for the individual as well as for society. Major changes were made in 2008 in admission criteria for Icelandic nursing homes. Some nursing home managers as well as families of people in need of care have criticised the new admission criteria for being too strict. Changes in health status, functional profile and the death rates of the nursing home residents who were admitted since the change was made in the admission criteria need to be investigated.

Several areas of care need improvement in Icelandic nursing homes. The nursing homes are likely to need support and encouragement in undertaking these improvements. In addition several factors may obstruct or delay changes that may be needed in practice. Changes in practice and improvements in care need to be prepared carefully and the outcome studied and evaluated.

Several factors outside the scope of this research are likely to have influenced the trend in quality indicator outcome observed in this study. Staffing models and the staff mix in Icelandic nursing homes may be an important factor in relation to quality of care outcomes. Thus it is important to discover the relationship of staffing in Icelandic nursing homes to the observed trend in quality indicator outcome seen in this study.

Standards of care need to be discussed internationally as well as comparisons made between countries. Furthermore internationally recognised standards need to be established with collaboration and research across countries. Knowledge from such research may be the foundation for continuing improvement in quality of care in nursing homes across countries.

## SUMMARY IN ICELANDIC

### Samantekt á íslensku

Hlutfall eldra fólks í Evrópu sem og annars staðar í heiminum hefur aukist og þá sérstaklega þeirra sem eru 80 ára og eldri. Vegna hrumleika og langvinnra sjúkdóma er líklegt að þessi aldurshópur þarfnist aðstoðar frá hinu opinbera, m. a. vistunar á hjúkrunarheimilum. Því má ætla að á komandi árum muni hjúkrunarheimilin standa frammi fyrir auknum verkefnum er varðar umönnun eldra fólks sem í mörgum tilvikum býr við flókin og margþætt veikindi og skerta færni til sjálfsumönnunar. Því er mikilvægt að starfsfólk hafi þekkingu og færni til að meta og fullnægja sérhæfðum þörfum íbúanna, geti viðhaldið færni þeirra og veitt góða einkenameðferð sem og líknandi meðferð. Þeir sem skipuleggja og veita umönnun á hjúkrunarheimilum þurfa að hafa þekkingu á helstu þörfum eldra fólks, heilsufari og færni og hvernig þessir þættir breytast frá einum tíma til annars. Slík þekking er forsenda þess að hægt sé að veita viðeigandi umönnun á hjúkrunarheimilum og skiptir máli fyrir ákvarðanatöku varðandi þróun í öldrunarþjónustu. Á sama tíma og hjúkrunarheimili þurfa að bregðast við aukinni þörf fyrir umönnun eru auknar kröfur um gæði þjónustunnar og að hún sé veitt af fagfólki. Hins vegar hefur skort skýr markmið til að hægt sé að bregðast við þessum auknu kröfum og meta hvernig til hefur tekist.

Löng hefð er fyrir því í Bandaríkjunum að meta með markvissum hætti heilsufar íbúa og gæði á hjúkrunarheimilum. Slík vinna er hins vegar mislangt komin hjá Evrópuþjóðum. Mælitækið „Minimum Data Set“ (MDS; einnig kallað RAI mat) og gæðavísar fyrir MDS hefur verið notað í þessum tilgangi í Bandaríkjunum á síðustu tveimur áratugum. Með stöðluðu mælitæki eins og MDS er hægt að greina breytingar yfir ákveðið tímabil. Skoða má heilsufar og færni íbúa við komu á hjúkrunarheimili og fylgjast með breytingum sem verða á ákveðnum tímabilum. Slíkar upplýsingar eru mikilvægar til að átta sig á þörfum íbúanna á ólíkum stigum og tryggja að starfsmenn búi yfir viðeigandi þekkingu og færni til að veita góða umönnun og meðferð. Þekking á þessu sviði er mikilvæg við skipulagningu öldrunarþjónustu og við ákvarðanatöku fyrir stjórnendur og opinbera aðila.

Meginmarkmið doktorsverkefnisins var að kanna heilsufar (stöðugleika heilsufars, verki, þunglyndi og vitræna getu), færni (athafnir daglegs lífs og virkni) og spáþætti fyrir andláti hjá íbúum á íslenskum hjúkrunarheimilum yfir ákveðið tímabil. Auk þess að ákvarða efri og neðri gæðaviðmið fyrir MDS gæðavísa, kanna algengi gæðavísa á ákveðnum tímabilum og tengsl þeirra við heilsufar og færni íbúa á íslenskum hjúkrunarheimilum. Verkefnið byggði á fjórum rannsóknum.

Í rannsókn I var markmiðið að kanna heilsufar og færni hjá íbúum á íslenskum hjúkrunarheimilum yfir 11 ára tímabil og bera saman höfuðborgarsvæðið og landsbyggðina. Gögnin sem notuð voru í rannsókninni var MDS mat (einnig kallað RAI mat) 2206 íbúa á íslenskum hjúkrunarheimilum sem metnir höfðu verið innan 90 daga frá komu á hjúkrunarheimilið á árabílinu 1996 - 2006. Niðurstöðurnar sýndu að meðalaldur íbúanna var frá 80,1 ári til 82,8 ára og hlutfall kvenna var frá 52,7% til 67,1% yfir rannsóknartímabilið. Ekki kom fram munur á heilsufari þeirra sem fluttu á

hjúkrunarheimili á höfuðborgarsvæðinu annars vegar og á landsbyggðinni hins vegar. Þeir sem voru með óskerta vitræna getu voru 28,6 - 61,4% og þeir sem höfðu óskerta færni í athöfnum daglegs lífs (ADL) voru 42,5 - 68,0%. Heilsufar íbúanna varð óstöðugra eftir því sem leið á tímabilið og meira var um verki, færni í ADL var óbreytt en vitræn geta varð betri og þátttaka í virkni varð meiri. Því má ætla að einhverjir íbúanna hefðu getað dvalið lengur heima hefðu þeir fengið endurhæfingu og viðeigandi heimaþjónustu. Enn fremur er aukin þörf íbúa fyrir verkjameðferð og virkni vísbending um að auka þarf þekkingu stafsfolks á þessum sviðum hjúkrunar.

Í rannsókn II var markmiðið að kanna tímalengd frá komu á hjúkrunarheimili til andláts og hvaða þættir í heilsufari og færni væru spáþættir fyrir andláti. Gögnin sem notuð voru í rannsókninni var MDS mat 2206 íbúa á íslenskum hjúkrunarheimilum sem metnir höfðu verið innan 90 daga frá komu á hjúkrunarheimili á árabílinu 1996 - 2006. Íbúum var fylgt eftir yfir 3 ára tímabil frá komu á hjúkrunarheimili til að kanna lifun. Meðallifun íbúanna var 31 mánuður og var enginn munur milli ára. Þættir sem marktækt spáðu fyrir um andlát voru aldur, kyn, hvaðan íbúinn kom, ADL færni, stöðugleiki heilsufars og færni til að taka þátt í virkni. Fyrsta árið eftir komu á hjúkrunarheimili létust 28,8% af íbúnum, 43,4% létust innan tveggja ára og 53,1% lést innan þriggja ára. Niðurstöðurnar sýna að stöðugleiki heilsufars og ADL færni eru sterkir spáþættir fyrir andláti og því væri hægt að líta til þessara þátta þegar metið er hvaða þjónusta gæti nýst einstaklingum best. Dánartíðnin sýndi að meira en helmingur íbúa dó innan þriggja ára frá komu á hjúkrunarheimili og næstum þriðjungur hefur líklega þarfnast líknandi meðferðar og lífslokameðferðar innan við ári eftir komu á hjúkrunarheimili. Að teknu tilliti til þessa er ljóst að áherslu þarf að leggja á þekkingu starfsfolks í að veita líknandi meðferð og lífslokameðferð jafnt sem þekkingu í að viðhalda færni íbúanna.

Í rannsókn III var markmiðið að ákvarða efri og neðri gæðaviðmið fyrir MDS gæðavísa, bera þau saman við niðurstöður hjúkrunarheimila árið 2009 og greina hvar umbóta var þörf. Gæðaviðmiðin voru ákvörðuð með Delphi aðferð og tók 12 manna hópur sérfræðinga þátt í þeirri vinnu. Sérfræðingarnir voru hjúkrunarfræðingar og lækna með mikla þekkingu og reynslu af öldrunarþjónustu og voru í þeim hópi bæði fulltrúar hjúkrunarheimila í þéttbýli og á landsbyggðinni. Gögnin sem notuð voru í rannsókninni var MDS mat 2247 íbúa sem dvöldu á 47 íslenskum hjúkrunarheimilum árið 2009, en heimili sem aðeins voru með 9 mót eða færri voru undanskilin (10 heimili). Nýjasta mat hvers einstaklings var notað og undanskilin voru mót við fyrstu komu og endurkomu. Þannig var reynt að velja mót sem endurspegluðu þjónustu sem veitt var á hjúkrunarheimilinu fremur en þeim stað sem íbúar höfðu komið frá. Efri og neðri gæðaviðmið voru ákvörðuð fyrir 20 MDS gæðavísa. Þeir gæðavísar sem sýndu miðgildi fyrir ofan efri gæðaviðmiðin sem gaf til kynna lök gæði voru: þunglyndiseinkenni (49,4%); þunglyndiseinkenni án meðferðar (18,2%); notkun 9 eða fleiri lyfja (63,8%); notkun róandi lyfja og svefnlyfja (69,2%); algengi lítillar eða engrar virkni. (52,5%). Þeir gæðavísar sem sýndu miðgildi fyrir neðan neðra gæðaviðmið sem gaf til kynna framúrskarandi gæði var gæðavísirinn um sondugjafir (0,0%). Gæðavísar sem voru með miðgildi á milli efra og neðra gæðaviðmiðs og gáfu til kynna miðlungs gæði voru þvag- eða hægðaleki (59,3%); þvag- eða hægðaleki án

reglubundinna salernisferða (7,4%); notkun þvagleggja (7,7%); þyngdartap (8,1%). Delphi aðferðin reyndist árangursrík aðferð til að ákvarða gæðaviðmiðin og nýta til þess þekkingu og reynslu þeirra sem voru í sérfræðingahópnum. Gæðaviðmiðin eru markmið sem íslensk hjúkrunarheimili geta stefnt að og um leið gefa þau vísbendingar um hvar veitt er framúrskarandi umönnun og hvar umbóta er þörf. Íslensk hjúkrunarheimili virðast standa sig best í að veita umönnunina vegna þvag- og hægðaleka og í umönnun sem tengist næringu. Sé horft til niðurstaðna þessarar rannsóknar þarf rúmlega helmingur íslenskra hjúkrunarheimila að endurskoða lyfjameðferð, auka virkni íbúanna og bæta umönnun og meðferð þeirra sem hafa einkenni þunglyndis. Gæðavísarnir nýtast við skipulagningu þjónustu, gefa vísbendingar um hvar umbóta er þörf og hvar þarf að auka þekkingu starfsmanna.

Í rannsókn IV var markmiðið að kanna algengi gæðavísa yfir 7 ára tímabil og tengsl þeirra við heilsufar og færni íbúa á íslenskum hjúkrunarheimilum. Gögnin sem notuð voru í rannsókninni var MDS mat 3694 íbúa á íslenskum hjúkrunarheimilum sem metnir höfðu verið á árabílinu 2003-2009 (heildarfjöldi mata var 11.034). Aðeins var notað eitt mat fyrir hvern einstakling fyrir hvert ár en margir áttu eitt mat á ári yfir nokkurra ára tímabil. Eins og í rannsókn III var nýjasta mat hvers einstaklings notað og undanskilin voru mót við fyrstu komu og endurkomu. Meðalaldur íbúanna yfir rannsóknartímabilið var frá 82,3 árum til 85,1 árs og hlutfall kvenna var frá 65,2% til 67,8%. Hlutfall þeirra íbúa sem ekki voru með gæðavísi var frá 29,9% til 99,6% eftir því hvaða gæðavísir átti í hlut en lágt hlutfall gæðavísis er vísbending um betri gæði. Yfir rannsóknartímabilið sást að hlutfall íbúa sem voru með ákveðna gæðavísa var hækkandi í 16 MDS gæðavísunum af 20, sem er vísbending um minnkandi gæði. Hlutfall íbúa sem var með gæðavísinn þvag- eða hægðaleka án reglubundinna salernisferða lækkaði þó úr 17,4% árið 2003 í 11,5% árið 2009 sem er vísbending um bætt gæði. Aukið hlutfall ákveðinna gæðavísa hjá íbúum tengdist þó að hluta til heilsufari þeirra og færni. Mikilvægt er að fylgjast með áframhaldandi þróun gæða á íslenskum hjúkrunarheimilum sem og tengslum heilsufars og færni íbúanna við útkomu MDS gæðavísa. Þeir þættir sem íslensk hjúkrunarheimili þurfa að huga sérstaklega að varðandi umbætur eru lyfjameðferð, virkni íbúanna og bætt umönnun og meðferð hjá þeim íbúum sem hafa einkenni þunglyndis.

Niðurstöður doktorsverkefnisins sýna að vitræn færni íbúa sem nýlega höfðu flutt á hjúkrunarheimili hvert ár varð betri en heilsufar varð óstöðugra yfir tímabilið 1996 - 2006. Enn fremur að aldraðir einstaklingar með tiltölulega litla umönnunarþörf fluttu inn á hjúkrunarheimili og tæpur helmingur íbúanna lifði lengur en 3 ár á hjúkrunarheimili. Hluti þeirra sem flutti á hjúkrunarheimili hefði því hugsanlega getað dvalið lengur heima ef þeir hefðu fengið endurhæfingu og heimaþjónustu við hæfi. Stöðugleiki heilsufars og færni í athöfnum daglegs lífs (ADL) reyndust vera mikilvægir spáþættir fyrir andlát og því gagnlegir þættir til að kanna þegar þörf fyrir hjúkrunarheimilisdvöl eða aðra þjónustu er metin. Umönnunarþörf þeirra sem fluttu á hjúkrunarheimili var mjög breytileg og lést um þriðjungur íbúa strax á fyrsta ári eftir flutning á hjúkrunarheimili. Þetta bendir til þess að margir íbúar hafi þurft á líknandi meðferð eða lífslokameðferð að halda strax við flutning á hjúkrunarheimili.

Hugmyndafræði líknandi meðferðar getur því vel átt við á hjúkrunarheimilum jafnframt áherslu á að viðhalda færni.

Við ákvörðun gæðaviðmiða fyrir íslensk hjúkrunarheimili var tekið mið af raunverulegum niðurstöðum hjúkrunarheimila og ættu því að vera raunhæf. Þau þarf síðan að endurskoða reglulega eftir því sem hjúkrunarheimilin ná betri árangri eða aðstæður breytast. Verulegur hluti íbúa var ekki með þau vandamál sem tilgreind eru í gæðavísunum, en þó að hlutfall margra gæðavísa hafi verið lágt þá eru sumir þeirra þess eðlis að jafnvel lág prósentu getur verið óásættanleg, s.s. fyrir þrýstingssár. Bestum árangri náðu hjúkrunarheimilin í umönnun sem tengdist næringu íbúa og í meðferð við hægða- og þvagleka. Vaxandi hlutfall þeirra íbúa sem voru með einkenni gæðavísis yfir árabilið 2003 - 2009 var hins vegar að hluta til tengt heilsufari þeirra og færni. Sú umönnun og meðferð sem hjúkrunarheimili á Íslandi þurfa að leggja áherslu á að bæta er greining þunglyndis, lyfjameðferð við þunglyndi og hjúkrun íbúa með einkenni þunglyndis. Lyfjameðferð íbúa þarf að endurskoða m.t.t. gagnreyndrar meðferðar og fjöllyfjameðferðar. Enn fremur þarf að endurskoða virkni og afþreyingu íbúa og þá sérstaklega m.t.t. íbúa sem eru með skerta vitræna getu og skerta færni.

Niðurstöðurnar sýna að MDS mælitækið og MDS gæðavísar eru gagnlegir við að meta breytingar á heilsufari, færni og lifun íbúa og gæði umönnunar sem og við umbótavinnu. Heilsufarsmat við komu á hjúkrunarheimili og útkoma þess m.t.t. bráðleika heilsufars, þunglyndis, verkja, færni og virkni einstaklingsins veitir mikilvægar upplýsingar sem eru gagnlegar við skipulagningu meðferðar. Einnig gefur það vísbendingar um á hvað sviðum umönnunar eða meðferðar þarf að auka þekkingu starfsmanna. Heilsufarsupplýsingar og upplýsingar um gæði sem safnað er yfir lengri tímabil gefa einnig ábendingar um í hvað átt þjónustan hefur þróast og slíkar upplýsingar eru mikilvægar fyrir opinbera aðila og þá sem skipuleggja þjónustu á hjúkrunarheimilum. Upplýsingar um þróun yfir lengri tíma geta gefið til kynna þróun á þjónustu sem annars yrði ekki uppgötvuð en mjög mikilvægt getur verið að bregðast við. Nauðsynlegt er að fylgjast áfram með þróun gæða á íslenskum hjúkrunarheimilum sem og flóknu samspili heilsufars og færni íbúa og í því skyni kemur MDS mælitækið (einnig kallað RAI mat) að góðum notum.



## ACKNOWLEDGEMENTS

This research was carried out at the Department of Health Sciences, Lund University. I wish to express my gratitude to everyone who has given me their support or assisted in this work. I wish to thank especially:

- All the residents in the Icelandic nursing homes who contributed to this research by participating in the assessment. Also the registered nurses and other nursing home staff who have spent untold hours over the years in doing the assessments and thereby contributing to greater knowledge and insight into the life of residents in Icelandic nursing homes.
- My supervisor, Professor Ingalill Rahm Hallberg at the Department of Health Sciences, for being an inspiration to me, for her excellent guidance, and for teaching me so much, in the last 5 years, for always responding unbelievable quickly to all my questions and writing, giving me valuable comments and constructive criticism. Also for the valuable experience in EANS.
- My co-supervisor Dr Anna Kristensson Ekwall, Lecturer in the Department of Health Sciences, for her guidance through the doctoral studies and constructive criticism, for being always so warm and supportive when life was weighing heavily on my shoulders.
- My co-supervisor Dr Per Nyberg, Senior Lecturer, Department of Health Sciences, for helping me find my way through a forest of RAI data and solving research problems and being brilliant in teaching statistics, making everything seem so clear and simple and sharing my enthusiasm for opera.
- The doctoral students at the Department of Health Sciences who have travelled this road with me the last 5 years, and taught me many things about Sweden and Swedes. Encouraged me and given me many good comments and constructive criticism in the seminars. Invited me with them countless times to “Fika” (have a coffee break) in the beginning I had no idea what that was, and talked to me in English and later in Swedish and made this journey so enjoyable.
- My co-workers at Landspítali - the National University Hospital of Iceland for being encouraging and interested in my research. Especial thanks to Anna Stefánsdóttir, Chief Nursing Executive, for her good advice when I was taking the decision to begin my studies and encouragement and interest in my research.
- My co-workers at the Faculty of Nursing at the University of Iceland for being supportive and interested in my research. Especial thanks to Professor Guðrún Kristjánsdóttir, Dean, and Professor Rúnar Vilhjálmsón for their encouragement and help in solving challenges on the way.
- Anna Blomgren for her help in solving the many everyday problems of a foreign student and for help concerning layout and making tables.
- Terry G. Lacy PhD, and Daniel Teague, both translators, and Sigríður Egilsdóttir MA for their language assistance and proofreading of thesis and articles.

- My family and friends who have supported me and encouraged through the years. Without them this work would not have been possible. Especially I would like to thank my children Laufey Jónsdóttir, Kristján Jónsson and Salóme Ósk Jónsdóttir for their love and belief in me and for always being independent and resourceful, and never complaining about their mother's trips to Sweden and endless writing.

This work was supported by grants from the Department of Health Sciences at Lund University, Sweden; the Scientific Fund of the National University Hospital, Iceland; the Scientific Fund of the Icelandic Nurses Association; the Scientific Fund of the Icelandic Geriatric Council; the Icelandic Geriatric Society; the Research Fund of Hrafnista Nursing Homes, and the Research Fund of Ingibjörg R. Magnúsdóttir at the University of Iceland

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