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Meeting ethical and nutritional challenges in elder care

**The life world and system world
of staff and high level decision-makers**

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To my family

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ABSTRACT

The overall aim of the thesis was to describe the issue of malnutrition and use it as a focal point of interest in elder care. A further aim was to illuminate how this issue could be addressed focusing on older adults' integrity and high level decision-makers' reasoning about ethically difficult situations (I-IV). Older adults, caregivers and high level decision-makers (HDMs) i.e. elected politicians and civil servants participated in the studies.

Study I focused on the frequency of underweight, weight loss and related risk factors among older adults living in 24 sheltered housing units located in one county. Measurements were obtained from 719 and were repeated after one year with the 503 still participating (I). Weight changes in older adults and changes in mealtime routines and environment were followed after a three month integrity promoting intervention. The participants were living at two nursing homes, 18 from the intervention ward (I-ward) and 15 from the control ward (C-ward) (II). The HDMs' views and reasoning regarding malnutrition in elder care were illuminated (III). Also highlighted were the HDMs' experiences of the meaning of being in ethically difficult situations related to elder care (IV). Participating in studies III-IV were eighteen HDMs from the municipality or county council level. The inclusion area encompassed two counties (I-IV). Methods used in the studies were: descriptive statistics and logistic regression (I), descriptive and comparative statistics as well as manifest content analysis (II), latent content analysis (III) and phenomenological hermeneutic analysis (IV).

A considerable percentage of the older adults in the sheltered housing units were underweight or exhibited weight loss. After a year, significant changes were found such as declined cognitive and functional capacity, eating dependencies, and chewing and swallowing problems. Risk factors associated with underweight and weight loss were cognitive and functional decline, eating dependencies and constipation (I). After the intervention that included staff training, the meal environment and routines were changed and weight increases were seen in 13 of 18 older adults from the I-ward compared with two of 15 from the C-ward. The individual weight changes correlated significantly to changes in the intellectual functions. Increased contact with the older adults and a more pleasant atmosphere was reported (II). The HDMs cited the older adults' poor health status, caregivers' lack of knowledge and inflexible routines as possible causes for the malnutrition. They suggested the need for increased physician intervention, more education and individualised care. The HDMs placed the responsibility for the issues more with caregivers and physicians than with the local managements and themselves (III). Both ethical dilemmas and the meaning of being in ethically difficult situations related to elder care were revealed by the HDMs (IV). The dilemmas mostly concerned difficulties of dealing with extensive care needs with a limited budget. Other aspects included the lack of good care for the most vulnerable, weaknesses in medical support, dissimilar focuses between caring systems and justness in the distribution of care. Being in ethically difficult situations was associated with being exposed, having to be strategic, feelings of aloneness, loneliness and uncertainty, lack of confirmation, risk of being threatened or becoming a scapegoat and avoidance of difficult decisions (IV).

Different levels in a health care system seem to be intertwined with ethical and nutritional challenges that confront and are associated with the different assumed roles. The results are reflected in the so called life world that concerns relationships, the system world that concerns routines and the governing of goals, and the tension between these two worlds. Structures that enable dialogues where ethical issues can be brought up from the different levels and between the different professionals inside the health care system seem to be important for the reduction of feelings of distrust and an improvement in elder care.

Keywords: Ethical challenges, malnutrition, older adults, elder care staff, integrity promoting care, high level decision-makers, life world, system world.

ORIGINAL PAPERS

This thesis is based on the following papers, which will be referred to in the text by their Roman numerals.

I. Mamhidir A-G., Ljunggren G., Kihlgren M., Kihlgren A., Wimo A. (2005). Underweight, weight loss and related risk factors among older adults in sheltered housing - a Swedish follow-up study. *The Journal of Nutrition, Health & Aging* 4, 255-262.

II. Mamhidir A-G., Karlsson I., Norberg A., Kihlgren M. (2006). Weight increase in patients with dementia, and alteration in meal routines and meal environment after integrity promoting care. *Journal of Clinical Nursing* (In press).

III. Mamhidir A-G., Kihlgren M., Sørli V. Nutritional deficiencies in elder care - Views from High level decision makers. Submitted.

IV. Mamhidir A-G., Kihlgren M., Sørli V. Ethical challenges related to elder care. High level decision-makers' experiences. Submitted.

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INTRODUCTION

Elder care in Sweden as in the rest of the developed countries is confronted by several ethical challenges associated with an ever-increasing older population. Older adults are often diagnosed with multiple illnesses and functional impairments that result in complex needs (Akner 2004, National Board of Health and Welfare 2005a). Reductions in the number of sheltered housing units and other forms of financial cutbacks are a reality. A greater number of older adults are living in private residences with home care support. The number of persons with origins from other countries is also increasing, which places new demands on those responsible for as well as delivering the care (National Board of Health and Welfare 2005a). Due to the strained conditions in elder care, discussions concerning ways to maintain good quality care and recruit as well as retain competent staff have arisen (Gurner & Thorslund 2003, National Board of Health and Welfare 2005a).

Ethical and nutritional challenges confronting staff

Problems fulfilling basic needs in elder care have been reported due to the over burdened system (Gurner & Thorslund 2003). Experiences of ethical dilemmas have been illuminated among different health care professionals working in elder care (Udén et al. 1992, Nordam et al. 2003). One area highlighted as being problematic concerns nutritional issues and malnutrition among older adults in different types of institutional settings in Sweden (Unosson et al. 1991, Elmståhl et al. 1997, Christensson et al. 1999, Saletti et al. 2000, Ödlund-Ohlin et al. 2005, Wikby et al. 2006a) as well as other countries (Blaum et al. 1995, Beck & Ovesen 2002, Beck et al. 2005, Suominen et al. 2005).

Malnutrition literally means insufficient or poor nutrition but there is no universal definition (Stratton et al. 2003). According to Elia et al. (2000) “malnutrition is a state of nutrition in which a deficiency or excess (or imbalance) of energy, protein, and other nutrients causes measurable adverse effects on tissue/body form (body shape, size and composition) and function, and clinical outcome”. The development of malnutrition or nutritional deficiencies may be slowed, prevented or reversed if identified (Croghan et al. 2002), which is important since it affects a persons overall health (White 1998) and well-being (Manthorpe & Watson 2003). The causes are multi-factorial with chronic illness (Cederholm et al. 1993, Akner & Cederholm 2001), cognitive and physical impairments (Poehlman & Dvorak 2000), depression, loss of appetite (Donini et al. 2002, Chen et al. 2005), stroke, eating dependencies

(Westergren et al. 2001), problems with chewing (Andersson et al. 2002) and swallowing difficulties (Terré & Mearin 2006) among the important risk factors.

Ethical dilemmas can occur among caregivers in mealtime situations when there are problems interpreting the behaviour and wishes of the older adult (Athlin et al. 1990, Norberg et al. 1994). Knowing the nature of the behaviour can make the eating experience more positive as well as easier (Athlin & Norberg, 1987). Ethical dilemmas are associated with difficulties in knowing what is the right and good thing to do when there are at least two conflicting choices and neither leads to a positive outcome (Lindseth 1992). Being in ethically difficult situations can be understood from an action and a relational ethics perspective. The former perspective concerns what a person should or ought to do and the difficulties are often centred on decision-making. The latter perspective concerns the reflections on the challenges encountered in the relationship or situation with others and how to fulfil social roles and obligations in a good way (Lindseth 1992).

Ethical challenges confronting high level decision-makers

In a public health care system, an overall responsibility for budget and quality of elder care rests with governmental high level decision-makers (HDMs) i.e. with those in high level positions in the health care system. During the last decade, the nutritional problems in elder care have received considerable public and political attention (National Board of Health and Welfare 2000). It seems quite reasonable that nutritional issues are brought up on the HDM level since they have an overall responsibility for the quality of elder care.

Ethical challenges in the health care system have involved different health care professionals, contexts and situations (Lindseth et al. 1994, Nordam et al. 2003, Sørлие et al. 2001a, 2004, 2005, Torjuul 2005a, 2005b). Through story telling it is possible to get a grasp on moral and ethical thoughts, and to signify internalized norms, values, principles and attitudes lived in relation to others, which is something we do not normally reflect upon (Lindseth & Norberg 2004). There are few reports regarding the ethical challenges confronted by HDMs when dealing with elder care issues. It seemed important to illuminate their experiences in this area especially due to the responsibilities they assume.

Shared responsibility

The responsibility for elder care in Sweden is shared between two health care systems, the local municipalities and the county councils. The main responsibility for elder care lies with the local municipalities and when acute care is required the responsibility is shifted to the

county councils. The county council employs the physicians with different specialities while the nurses are employed by either one of the two systems. The overall goals for a health care system is to promote, protect and restore health as well as deal with the expectations people have regarding access to care, all of which are associated with a sense of security. A further concern is a fair distribution of financial resources and the protection of individuals from excessive economic strains due to health care needs (WHO 2000). A health care system is the sum of the activities that aim to reach the above named goals (Andersson et al. 2003).

The shared responsibility between the two systems in elder care is governed by the Swedish Health Care Law (HSL) and the Social Services Act (SOL). Individuals that have chronic illnesses, decreased autonomy or are in need of palliative care are to have a high priority (SOU 1995, Lund 2003). In Sweden the overall responsibility for the budget and the quality of the elder care is spread between the elected politicians and appointed civil servants at a planning and control as well as executive local level (Andersson et al. 2003). The caregivers in health care are individually responsible for the care they give (National Board of Health and Welfare 1993).

Quality issues in the health care system should be addressed by the implementation of a quality assurance system, which requires that structures are in place to deal with planning, performance, evaluation and development. Cooperation throughout the system is emphasised (National Board of Health and Welfare 1998a, 2005b). However, for example when Mattson-Sydner (2002) reported on the issue of quality in elder care nutrition, lack of communication and cooperation between the different levels in the health care system were revealed. These problems even involved the kitchen personnel, which often belonged to another organisation. A sense of powerlessness over the nutritional issues existed at all levels. According to Thompsen (2005), the responsibility for the quality of care delivered in a health care system is divided into several levels and by many hands, which makes the detection of the responsible party more difficult.

Trust and ethics

Fundamental for human beings in the philosophy of ethics is trust (Løgstrup 1994). Trust is commonly understood as being associated with individuals and their relationships. Trust is not only of concern to individuals but also to institutions and therefore attention needs to be given to institutional structures that are in the position to cause harm (Thompsen 2005). Due to diverse perspectives, it is important that individual values and ways of thinking be known in

order to build trust at the different levels in a health care organisation (Boyle et al. 2001). The transformation of trust to distrust requires rather special circumstances (Løgstrup 1994).

According to Lindseth (2001) the focus in the past on economy and reorganisation in health care has repressed ethical discussions. Reports of lack of quality and high work loads may perhaps be enough incentive to reinstate ethical discussions (Lindseth 2001).

RATIONALE FOR THE STUDIES

Dealing with malnutrition is one of the ethically challenging areas in elder care. A study that included the sheltered housing units from all of the municipalities in a county in Sweden showed the complex problems, multiple diseases and extensive care needs present among the older adults (Mamhidir et al. 2003). Since these are conditions associated with malnutrition it seemed important to examine to what extent underweight, history of weight loss and eating related problems existed in that population.

Food intake has been reported to be problematic for caregivers, especially among persons with dementia disease, and has been emphasised as being a demanding and ethically difficult issue (Norberg 1996). Further attention to improved nutrition seems important since it may increase the older adults' well-being and overall condition. A question that arises is if an intervention addressing the older adults' integrity can affect weight, functional capabilities or neurochemical parameters.

Nutritional considerations in health care and elder care have lately received considerable public and political attention. HDMs are accountable for the over all quality of the care delivered. A lack of communication and cooperation between the different levels involved in and responsible for nutrition resulted in a sense of powerlessness and possible feelings of non-accountability (Mattsson-Sydner 2002). Caregivers must however provide adequate nutrition on a daily basis. It seems important to illuminate HDMs' views of these issues, as they are the citizens' representatives for health care organisations and society.

The HDMs have a responsibility for both budget and the quality of elder care. They are required to make decisions that might be ethically challenging. Ethical challenges among health care professionals in various situations and contexts have been studied. Few studies have explored challenges confronting HDMs responsible for elder care. Since their decisions affect many stakeholders; the patients, the relatives and the different health care providers, it seems important to grasp a deeper understanding of their reasoning.

AIMS

The overall aim of the thesis was to describe the issue of malnutrition and use it as a focal point of interest in elder care. A further aim was to illuminate how this issue could be addressed focusing on older adults' integrity and high level decision-makers' reasoning about ethically difficult situations.

The specific aims for studies in this thesis were:

I. To describe underweight, weight loss and related nutritional factors after 12 months in individuals 75 years or older and living in sheltered housing. A further aim was to identify possible risk factors associated with underweight and weight loss.

II. To follow weight changes in patients with moderate and severe dementia and analyse how these weight changes related to biological and psychological parameters after staff training and supportive intervention. A further aim was to describe the patients' mealtime environment relative to the intervention.

III. To illuminate the views of high-level decision-makers regarding the reasons for nutritional deficiencies among older adults in elder care and how they can be addressed.

IV. To illuminate the meaning of being in ethically difficult situations related to elder care as experienced by high level decision-makers.

METHOD

Design

This thesis focuses on ethical and nutritional challenges from an every day practice perspective and from a high level perspective. The studies (**I-IV**) involved older adults, caregivers and municipal as well as county council high level decision-makers (HDMs). There were two counties in Sweden included at one time or another in the studies (**I-IV**). A quantitative approach was used in a cross-sectional follow-up study to describe the weight status and related nutritional factors after a 12 month period among older adults living in sheltered housing units from ten municipalities in one county (**I**). The same approach was

applied in study **II** where the weight changes, psychological and biochemical parameters of the older adults from one municipality in another county were followed relative to a staff intervention. Additionally a qualitative method was used to gain insight into the changes made during the study in mealtime routines and environment as described by the staff (**II**). Qualitative analysis methods were employed to gain knowledge into the reasoning used by HDMs from two counties about malnutrition in elder care and possible ways of dealing with it (**III**) as well as the meaning of being in ethically difficult situations related to elder care as experienced by them (**IV**).

The methods and numbers of participants were chosen in an attempt to reach an in depth understanding from the different perspectives represented in the studies (**I-IV**). An overview of the studies is presented in Table 1.

Table 1: Overview of studies I-IV

Study	Focus	Sample	Data collection	Analysis method
I	Frequency of underweight, weight loss and related risk factors for older adults living in sheltered housing units. Measurements taken with one year interval	719 older adults from one county living in 24 sheltered housing units	RAI –data	Descriptive statistics Logistic regression
II	Weight change in older adults, and changes in mealtime routines and environment after a three month staff intervention	18 older adults from an intervention group and 15 from a control group living at two nursing homes	Weight changes, psychological and biochemical parameters Staff diaries	Descriptive and comparative statistics Manifest content analysis
III	High level decision-makers reasoning regarding nutritional deficiencies in elder care	18 municipality or county council high level decision-makers from two counties	Interviews	Latent content analysis
IV	The meaning of being in ethically difficult situations related to elder care as experienced by high level decision-makers	18 municipality or county council high level decision-makers from two counties	Interviews	Phenomenological-hermeneutic method

Sample

Study I

A prior survey revealed that in one county there were 4,480 older adults living in some form of sheltered housing. From 24 randomly selected sheltered housing units within that county, 800 older adults were included that represented 18% from each community (N=10). Included were adults aged 75 or older that lived permanently in community run sheltered housing units. The units were placed in alphabetical order and every other one was selected for inclusion in the study until the 18% quota per community was reached. The staff, older adults and their relatives from these units were informed about the study and asked to participate. Three housing units chose not to participate and were replaced by others accordingly. A random selection (Altman 1997) of older adults from units containing a larger number of individuals than the quota required was performed. From those initially recruited for the study, a number withdrew or died before the data collection began. Included in the first evaluation from the 24 sheltered housing units, were 719 older adults (16%), with an average age of 85.8 years, and of whom 71% were women. A year later at the time of the second evaluation, 503 patients remained resulting in 216 (30%) dropouts, i.e. 26% deceased, 2 % moved, 2 % assessment not completed (Mamhidir et al. 2003). Weight measurements and nutritional related factors were obtained and recorded with a one year interval.

Study II

Over a three-month intervention period, an integrity-promoting care training program based on Erikson's theory of the eight stages of man (Erikson 1982) was conducted with the staff of a long-term ward. Older adults, aged 75 or older, 18 from an intervention ward and 15 from a control ward where the same training was conducted after the study period were included and possible effects were evaluated. Weight measurements were conducted at the start and after completion of the intervention. Weight changes were analysed in relation to psychological and biochemical parameters. In addition, the staff wrote diaries about changes made in the mealtime routines and environment.

Study III and IV

Participants in these studies were HDMs (n=18) at the municipality and county council level from two counties in Sweden. They were elected politicians (n=9) and appointed civil servants (n=9) at a planning and control as well as executive level that had a responsibility for the budget and the quality of the elder care. They had been randomly selected from a list that

included all of the HDMs from the two counties and all agreed to participate. The HDMs had from one year to 20 years experience in their profession, ranged in age from 43 to 66 years and 13 were women.

Data Collection

The Resident Assessment Instrument RAI/MDS 2.0

Older adults' functional capacity, nutritional status and needs were evaluated by using the RAI/MDS instrument (**I**). The RAI/MDS-system was developed in the USA to assist in measuring the needs of older adults, developing their patient care plans and evaluating the quality of care given in sheltered housing (Morris et al. 1990). In this study the revised version, RAI/MDS 2.0, was used. This version has a new set of assessment items developed by Morris et al (1997). The RAI/MDS has been tested for its validity (Morris et al. 1990, Mezey et al. 1992) and reliability, with an average inter-rater reliability of 0.67 (Hawes et al. 1995), and the new version (2.0) with an average inter-rater reliability of 0.79 (Morris et al 1997). The instrument which was translated into Swedish by Hansebo (2000) consists of 16 sections with categories and defined codes. These sections are expected to capture the core elements, the minimum needed for a comprehensive assessment of the individual older adult patient (Morris et al 1990).

Weight changes, psychological and biochemical parameters and staff documentation

Weight changes, psychological ratings and biochemical parameters among the older adults (**II**) and staff diary entries (**II**) pertaining to changes in mealtime routines and environment were examined. Weighing was conducted after breakfast and morning care at the start and after completion of the intervention. The psychological ratings were conducted using the Gottfries-Bråne-Steen (GBS) scale (Gottfries et al. 1982) and the Dementia Depression (DD) scale (Bråne et al. 1989). The GBS-scale is tested for validity with correlation coefficients between 0.53 to 0.92 in motor functions, 0.83 to 0.92 in intellectual functions and 0.42 to 0.47 in emotional function. Corresponding figures for reliability are 0.83 to 0.93, 0.81 to 0.97 and 0.57 to 0.87 (Nyth & Bråne et al. 1992, Bråne et al. 2001). The biochemical parameters, measured from cerebrospinal fluid were somatostatin (SRIF), corticotropin releasing factor (CRF) and arginine-vasopressin (AVP) concentrations (Viderlöv et al. 1989). A two week diary was kept on three different occasions, at the start of the study, after the completion of a one week course in the beginning of the intervention period and after the three month

intervention. During each two week period, the staff made entries three times where they noted the older adults' mealtime environment and any changes made in their work or routines.

Interviews

The interviews (**III-IV**) were conducted in accordance with the wishes of the interviewees and took place at their work or at home. The eighteen HDMs were interviewed regarding their views on the nutritional deficiencies in elder care (**III**) and a two-part question was asked: "*From your position as a high level decision-maker, what do you think the reasons are for these nutritional deficiencies and how do you think they should be addressed?*". Follow-up questions were: "*Tell me more about that*" or "*What do you mean by that?*" (Kvale 1997). In the study concerning the meaning of being in ethically difficult situations as experienced by HDMs (**IV**) they were invited to narrate about such situations by asking "*Please tell about one or more ethically difficult situations regarding elder care that you have experienced in your position*". Additional follow-up questions were asked in a similar manner as described above (**IV**). All the interviews were tape-recorded with the respondents' permission and were transcribed verbatim. There were also notes taken during the interview by the interviewer.

Analysis

Statistical analysis

The RAI/MDS data, including the older adults' functional capacity, nutritional status, resources and needs were analysed with the statistical package SPSS 12.0. Descriptive statistics as well as logistic regression methods were used to describe the nutritional status, weight loss and potential explanatory factors for nutritional deficiencies (**I**) (Altman 1997). Descriptive and comparative statistics were used to reveal weight changes in an intervention group respectively a control group after the staff intervention (**II**).

Qualitative content analysis

In the intervention study (**II**) a content analysis with a manifest approach was used for the analysis of the staff diaries (Graneheim & Lundman 2004). Manifest content analysis implies an analysis of what the text says and describes the manifest substance in the text.

A latent content analysis was used in the study that examined the HDMs' reasoning regarding nutritional deficiencies (**III**). This method is aimed at reaching a systematically and objectively valid result. It focuses on meanings, intentions, consequences, context, and the determination and description of categories (Graneheim & Lundman 2003). Latent content

analysis implies an analysis of what the text talks about and is an interpretation of the underlying meaning in the text, which can vary in depth and level of abstraction (Graneheim & Lundman 2003). In study **III** the interview text was read several times to grasp a sense of the whole. The text was then divided into content areas and further into meaning units, which can consist of a word, a sentence, or an entire paragraph. The meaning units were condensed coded and categorised (Graneheim & Lundman 2003).

Phenomenological hermeneutic method

A phenomenological hermeneutic method (Lindseth & Norberg 2004) was used to analyse and interpret the interview text that expressed the HDMs' experiences of being in ethically difficult situations associated with elder care (**IV**). This method is useful when attempting to elucidate the meaning of a lived experience through the interpretation of an individual's narrative (Ricoeur 1976). The phenomenological hermeneutic analysis process consists of three phases: the *naïve reading*, one or more *structural analyses* and a *comprehensive understanding*. The analysis process constitutes a dialectal movement between the whole and the parts of the text and between understanding and explanation (Ricoeur 1976). The aim of the *naïve reading* is to gain a first superficial impression of the text as a whole within its context. The naïve reading indicated the direction for the subsequent analyses. In the *structural analyses* detailed analyses of the text were performed in order to explain the parts and validate or invalidate the initial understanding gained from the naïve reading (Ricoeur 1976). The text was then divided into meaning units that were condensed, abstracted and structured into sub-themes and themes (Lindseth & Norberg 2004). A meaning unit can be a part of a sentence, a whole sentence or a paragraph. In *the comprehensive understanding* the authors' pre-understandings, the naïve reading, the structure analyses and the literature are taken into account with the aim to gain a deeper understanding of what the text indicated (Ricoeur 1976). All authors (**III, IV**) took part in the analyses until agreement over the interpretation and findings were considered satisfactory. According to Ricoeur (1976) there is always more than one way of understanding a text and you can argue for an interpretation or against it. Independent assessment of an interview text increases the credibility of the analysis (Kvale 1997).

Ethical considerations

Research that involves older adults with cognitive problems or dementia disease might entail ethical difficulties as they are vulnerable and in an exposed situation (**I, II**). To perform

comprehensive and time consuming studies at times when caregivers are reporting a high work load is an ethical issue to reflect upon. However, not performing studies that can reveal the older adults' conditions and contribute to extensive understanding of the situation is even more detrimental. Research related to persons assuming high positions is also a question with ethical considerations since this is often a small group of people that can be easily recognised (**III, IV**). Precautions such as the use of two counties were taken to obscure their identities.

The Regional Research Ethical Committees granted permission for study **I, III, IV** (99310-17) and for study **II** (830214, 26-83). Verbal and written information was given to the managements, the staff, the older adults and/or their relatives prior to requesting participation (**I, II**). The managers in the sheltered housing units (**I**) obtained individual, verbal as well as written consent from the older adults and/or their relatives. In study **III** and **IV** verbal and written information was given to the HDMs and written consent was obtained after the information was provided. In all of the studies (**I - IV**) the participants were informed that their participation was voluntary, confidentiality was guaranteed, that they could leave the study at any time without having to give a reason and that there would be no possibility to trace the findings to the participants.

RESULTS

Study **I** describes weight status, weight loss and related risk factors among older adults in sheltered housing units. Study **II** presents the effects an intervention with a broad approach had on the older adults' weight, intellectual function and meal environment. Study **III** views the HDMs' reasoning regarding nutritional deficiencies in elder care and how these issues can be addressed. Study **IV** reveals the HDMs' experiences of the meaning of being in ethically difficult situations related to elder care.

Study I

A considerable percentage of the older adults were underweight or exhibited weight loss and several risk factors were identified. Among the 503 chronically ill individuals with cognitive and functional disabilities that after one year completed the follow-up, 35% were classified as underweight at the initial assessment and 38% at the second, a non-significant difference. A further analysis showed that 39% had decreased weight, 27% remained stable and 28% gained weight. The weight loss over the previous one to six months was difficult to specify since the older adults were not routinely weighed and previous weights were missing. At the initial

assessment the caregivers were unable to determine the weight loss for 27% of the individuals and at the follow-up assessment for 20%. The two weight measurements taken with a one year interval were analysed and showed that a weight loss of 5% occurred in 27% of the older adults and a loss of 10% occurred in 14%.

Several significant changes in the health status of the older adults were reported after one year such as declined cognitive and functional capacity, eating dependencies as well as chewing and swallowing problems. For example, initially 14% needed total help when eating and after a year that figure was 21%. For chewing and swallowing problems the corresponding percentages were 16% and 20% respectively. Among those initially assessed approximately one tenth exhibited some form(s) of demanding behaviour. The final assessment showed that 80% of the individuals performed dental hygiene. The use of parenteral nutrition or percutaneous endoscopic gastronomy tubes was not a common practice.

Factors associated with being underweight and weight loss, using scales derived from the assessment instrument were cognitive and functional decline. Dementia and Parkinson's disease, eating dependencies and constipation were the strongest risk factors when analyzed as single items. In the logistic regression models the r^2 varied between 5.0 to 12.3% incorporated scales and 17.0 to 27.5% single items. This indicates that the explanatory value of the models was rather low, which can be expected in a heterogeneous population.

Study II

The integrity promoting care intervention provided on the intervention ward (I-ward) affected the older adults in long term care positively. The most prominent difference observed was weight increases in 13 of 18 older adults compared to two of 15 individuals in the control ward (C-ward). No weight changes were related to type of dementia. At the I-ward the individual weight changes had a significant correlation to changes in the intellectual functions according to the GBS-scale measurements ($r = -0.574$, $p < 0.01$). This demonstrates a relationship between improved weight and improved intellectual function during the study period. Relationships between weight changes, increased motor function, increased appetite and changes in biochemical parameters were non-significant. From the diaries it could be read that the physical environment was changed such that new pictures were placed on the dining room walls and the tablecloths and curtains received new designs printed on them by the staff together with the older adults. During mealtimes the older adults sat together and ate in a more pleasant atmosphere. The food instead of being handed out in pre-portioned trays was

served in serving bowls that allowed them to help themselves. According to the staff, increased contact with the older adults and a more pleasant atmosphere resulted at the I-ward. No such changes were reported by the staff of the C-ward.

Study III

The HDMs saw different reasons for nutritional deficiencies in elder care such as the older adults' multiple illnesses, and cognitive and physical impairments. They also focused on the older adults' vulnerability as a reason for the nutritional deficiencies and used it together with the poor health status as an underlining basis as to where they placed responsibility.

Fundamental to them is that caregivers and kitchen personnel are knowledgeable in nutrition and that meals are adapted to the older adults' special needs but they felt uncertain that this was actually occurring, They stressed that the caregivers have the responsibility to identify and ensure there is enough time for eating and that the food is actually consumed since mealtimes are probably one of the few highlights of the day. The HDMs were sceptical that there could be a lack of knowledge among caregivers since educational programmes had been provided. They said it was the health care system, the personnel's schedule and the level of stress that determines the workday and were uncertain as to if the older adults' preferences and needs were addressed. They also expressed the concern that there might not be enough staffing during mealtimes.

To address these issues the HDMs suggested further educational programmes for caregivers, improved work routines, prioritisation and efficient performance of duties, and the practice of more individualised care. Furthermore, they felt that the physicians needed to take more responsibility in this area. The HDMs spoke less about their own or the managers' responsibility and stated that these issues are addressed by them when they appear on the agenda.

Study IV

When the HDMs reflected on the meaning of being in ethically difficult situations related to elder care, both ethical dilemmas and their experiences of being in ethical challenges were revealed. No differences were seen between the politicians and the civil servants. The HDMs were directly or indirectly involved with the dilemmas. The ethical dilemmas mostly concerned the difficulties of dealing with extensive care needs and working with a limited budget. Mentioned in conjunction with this was lack of good care, which was associated with vulnerable older adults residing in inappropriate care settings and weaknesses in medical

support. Other dilemmas reported were the lack of agreement concerning care, which was related to dissimilar focuses between the caring systems, to justness in the distribution of care and deficient information.

Being in ethically difficult situations was experienced as challenging by the HDMs yet possible to handle. Being in a high position carried with it heavy responsibility and important decision making was associated with feelings of aloneness and loneliness. These feelings were seen as a part of the job but were heavy feelings since there is no one else to share the burden with when things got tough. A lack of confirmation was said to accentuate these feelings. They said they must learn to live with feelings of uncertainty or resign. Reports of insufficient elder care gave feelings of uncertainty and they wondered if they could actually trust the system. The HDMs stressed that being in an exposed position also implies a risk of being threatened. Feelings of having to be strategic were mentioned when for example they avoided making difficult decisions until last and when resource allocation was up for public debate. Making decisions that would have negative consequences for elder care left them with divided feelings. They felt they failed in their mission to provide good care when their loyalties to the job forced them to make reductions. The HDMs feel that important issues and needs are at stake for elder care, as well as for themselves and that there is a risk that elder care needs are not being met.

METHODOLOGICAL CONSIDERATIONS

This thesis focuses on ethical and nutritional challenges from an every day practice perspective and from a high level perspective. One of the focuses has been on the nutritional deficiencies and the related risk factors among older adults in sheltered housing units (**I**). A second focus has been on the nutritional status among older adults after an integrity promoting care intervention involving caregivers working in long-term care (**II**). A third study focused on those in high positions i.e. HDMs who have a responsibility for the budget and the quality of elder care and what their views are concerning the causes and needed actions of the nutritional deficiencies existing in elder care are (**III**). A fourth focus has been on the ethical challenges confronting the HDMs in their positions relative to elder care (**IV**).

Quantitative methods with descriptions and comparisons (**I-II**) and qualitative methods (**II, III-IV**) that included descriptions (**II**) and illuminations of experiences (**III-IV**) were used in the studies. A deeper understanding of a process can be reached by using a combination of methods (Morgan 1998, Polit & Beck 2004). It is important, however, to let the aim determine

the method used (Down-Wamboldt 1992). Sandelowski (1998) states that the goal in quantitative research is often the wish to be able to generalize the results while in qualitative research the goal is to illuminate and to grasp an understanding of a phenomenon. The goal for both methods is to measure what should be measured and according to Graneheim & Lundman (2004) this is an important standpoint since “the findings must be trustworthy”. Different data collection approaches are required for the quantitative and qualitative methods. For quantitative research the concept of validity is used and good validity and reliability are required in order to generalise the results (Sandelowski 1998). The similar concepts related to qualitative research are creditability, dependability and transferability (Graneheim & Lundman 2004) as well as trustful interpretations (Lindseth & Norberg 2004).

Study I

This cross-sectional follow-up study was performed in order to describe underweight, weight loss and related nutritional factors after an interval of 12 months among older adults living in sheltered housing units as well as to identify possible risk factors associated with underweight and weight loss. From 24 randomly selected sheltered housing units within one county, 800 older adults were included that represented 18% from each community (N=10). From those initially recruited for the study, some declined participation, withdrew or died before the data collection began resulting in 719 older adults being included from the start. A year later at the time of the second evaluation, 503 individuals remained.

The strengths in this study are the prospective design that enabled changes to be followed over time, the large sample size and the broad spectrum of information collected concerning the status of the older adults. The standardized instrument with its categories and defined codes allows for national and international comparisons and its validity (Morris et al. 1990, Mezey et al. 1992) and reliability have been tested (Hawes et al. 1995, Sgadari et al. 1997, Morris et al. 1997). In addition, the instrument and manual was translated and revised for Swedish application (Sprinternet 2000).

The weaknesses are associated with the calculations of BMI and weight loss as they are based on height and weight data. Errors in the weight measurements could have occurred if the scales used were not calibrated and weight variations caused by such things as oedema were not controlled for. Errors in height could also have occurred if old measurements not reflecting eventual decreases in height common with old age were used. Many different caregivers performed the assessments, which could threaten the inter-rater reliability. Precautions were taken to minimize the weaknesses by having only interested caregivers

perform the assessments and by having the managements ensure there would be enough time allowed for them. The specially designed educational program and the continuous support given to the assessors were also designed to enhance reliability. Perhaps if support had been even greater it would have been possible for a more regular interval of weight measurements, which would have been preferable and more in accordance with the instrument.

An attempt to minimize the internal dropout rate for the items of weight and height was made by reminding the caregivers to complete missing assessments. Even with the limitations, the results are considered to be reliable.

Study II

There are limitations in this study such as the small sample size and the absence of a power calculation before the start of the study. That the food intake was not weighed or recorded was another limitation. Food for both wards was however delivered from the same central kitchen. The positive results are considered to be reliable since they are in line with the results from others in the main project and since a greater number of older adults in the I-ward had increased weight in comparison to those in the C-ward. Care that promotes the integrity of the older adults seems to be something that should receive serious attention.

Even though the diaries were written in a manifest fashion, they gave a further possibility to view what had happened in the physical and social environment. The study design shows that a combination of quantitative and qualitative methods can be useful and give a deeper understanding of the process (Morgan 1998, Polit & Beck 2004).

Study III

The focus of qualitative methods is to understand experiences and thoughts (Malterud 1996) and latent content analysis was used in study **III**. The interviews in study **III-IV** were carried out by the author of this thesis who had no relationship to the interviewees, which is considered to be an advantage since the risk of being too familiar is removed. It is thought that this might also stimulate the interviewees to be more open. When performing qualitative content analysis, a basic decision to be made is whether the analysis should focus on the manifest or latent content. Manifest analysis refers to the text that describes visible and obvious components. Latent analysis refers to what the text says and deals with the underlying meaning of the text. Both analyses deal with interpretations but they vary in depth and level of abstraction (Graneheim & Lundman 2003). Latent content analysis (**III**) was considered most suitable for the two questions that were asked regarding nutritional deficiencies. Even though

the interviews began with a question that pertained to the meaning of being in ethically difficult situations used for study **IV**, it was felt that the use of a pause would decrease any effect it could have on the final nutritional questions.

The trustworthiness of findings is related to credibility, dependability and transferability (Graneheim & Lundman 2004). Credibility concerns the focus of the research and refers to how well the data and the analysis process addresses the intended focus. Decisions regarding the focus of the study, selection of context, participant and approach used to collect data are critical issues. It is desirable that the narratives are as rich as possible and that requires that the participants are willing to talk (Graneheim & Lundman 2004). Also critical is the selection of the most suitable meaning units, how well the categories and themes cover the data, and that the similarities and differences between the categories were determined correctly. Using representative quotations from the text and seeking agreement among co-researchers and experts are ways of dealing with these issues. Another aspect of trustworthiness described by Graneheim & Lundman (2003) is dependability, which deals with the degree to which data changes over time and the researcher adjusts their decisions during the analysis process. Trustworthiness also includes the question of transferability that refers to the extent to which the findings can be generalised to other settings or groups (Graneheim & Lundman 2003). It seems reasonable that the findings in study **III** can be understood, transferred and applied to similar situations in a new context. To validate the outcome, the analysis was discussed and reflected upon together with the co-authors and discussed with other experts (Downe-Wambolt 1992).

Study IV

In study **IV** a phenomenological hermeneutic method was used due to the type of question asked. This method gave a possibility to interpret and understand the meaning of being in ethically difficult situations as experienced by the HDMs. Lindseth & Norberg (2004) writes that the aims of phenomenological hermeneutic interpretations are to disclose truths about the essential meaning of being in the life world. No single fundamental truth can be found but rather possible meanings in a continuing process. When using this method, the goal is to catch truthful disclosures about the lived experiences. Some interviewees might say that they cannot remember, do not understand the question, are not willing to or do not dare to talk about something or maybe are unable to find the right words. Conducting interviews is a delicate undertaking in terms of creating a permissive climate in which the interviewees can feel they can rely on the promise of confidentiality made by the interviewer (Lindseth & Norberg

2004). In study **IV** as well as in study **III**, precautions such as performing the interviews in two counties were taken to minimize the risk of participant recognition. According to Lindseth & Norberg (2004) there are risks that misunderstandings arise during an interview since both the interviewees and the interviewers can only understand and narrate their lived experience in relation to their own pre-understanding. Therefore, it is important to check the understanding during the interview. In order to achieve the most truthful interpretation of the text as possible, the process needs to be strict. The phases of the analysis consist of the naïve reading, the structural analysis and the comprehensive understanding. The most probable interpretation is one that makes sense of the greatest number of details that fit the whole and can be brought forth by the text (Lindseth & Norberg 2004).

By using this method both the ethical dilemmas and challenges as experienced by the HDMs were revealed. The HDMs were given a possibility to talk about what was important to them (**IV**). Persons in these positions are trained to handle interview situations and can tend to be a little reserved in their comments. When performing the interviews in study **IV** some of the HDMs stated: “ethical issues are not often reflected on” and “not in this way”. Lindseth & Norberg (2004) say that analyzing narratives of lived experiences can be useful for providing new insights about our world and ourselves and to see the world and ourselves in new perspectives. The richness of the material in this study (**IV**) supports the choice of the method and was so rich that only a part of the material could be addressed in the article. The richness of the material is also a result of the number of interviews performed, which also can be considered as weakness in this study since it might be difficult to grasp the essence in an extensive amount of material. The recruitment procedure can be criticized since it can mislead the reader to think the method of analysis was quantitative and can be considered inappropriate for phenomenological hermeneutic analysis. Our understanding is related to our pre-understanding and to grasp the essential meaning it can be necessary to study relevant literature and speak to knowledgeable people (Lindseth & Norberg 2004).

The results of this study cannot be generalized, but are credible if persons with similar experiences can recognize the descriptions or the interpretations (Sandelowski 1986) and if these can be transferred into similar situations (Lindseth & Norberg 2004).

Pre-understanding

A researcher’s pre-understanding within the field of the study is important. Different questions and reflections generated in this thesis stem from the author’s experiences as a clinical RN in elder care, as a clinical teacher of nursing students and as a director of

development of a primary health care organisation. The co-authors have experiences as RNs in elder care, as clinical teachers and as senior researchers in nursing science. According to Sandelowski (1998) it is important to distance oneself as researcher in order to avoid influencing the data but still at the same time maintain closeness to the clinical field and the knowledge necessary to understand it. Personal clinical experience in the research field studied is considered a strength (Sandelowski 1998).

REFLECTIONS OF THE RESULTS

Ethical challenges at different levels in the system

Ethical challenges among health care professionals in various situations and contexts have been highlighted during the years (Jansson & Norberg 1992, Udén et al. 1992, Lindseth et al. 1994, Nordam et al. 2003, 2005, Sørli et al. 2004, 2005, Torjuul et al. 2005a, 2005b). For some time now, providing good nutrition to older adults with cognitive impairment has been an area that in particular is recognised as being ethically difficult (Athlin & Norberg 1987, Norberg et al. 1994).

The results in this thesis indicate that ethical challenges associated with elder care occur at different levels in a health care system (**I-IV**). The challenges seem to persist in every day practice. This is in light of the occurrence of nutritional problems and deficiencies among older adults in sheltered housing units (**I**) and is something that needs to be dealt with by the caregivers (**II**). Ethical challenges were also highlighted among those who have assumed a high level position in the health care system (**IV**). These challenges were mostly associated with the HDMs decision-making that was related to the ever increasing older adult needs and their attempts to meet them with a limited budget. Their experiences of being in such situations and trying to deal with priorities brought about uncomfortable feelings (**IV**). In study **III** where the HDMs' thoughts regarding malnutrition in older adults were illuminated, indications of the ethical challenges involved were uncovered.

Malnutrition in daily practice

A considerable percentage of the older adults were underweight or exhibited weight loss after one year and several associated risk factors were identified (**I**). Our results are in accordance with other Swedish (Saletti et al. 2000, Wikby et al. 2006a) and international studies made over the last two decades (Blaum et al. 1995, Beck & Ovesen 1998, 2002) that report low weights among individuals in institutional settings. Underweight and weight loss are

important signals that can be used to detect malnutrition (Stratton et al. 2003, Cowan et al. 2004). In study **I**, a considerable amount of the older adults were chronically ill and had cognitive and functional disabilities. These factors are well known contributors to the older adults' complex needs (Morley 2001, Akner 2004) that can result in malnutrition. Due to the serious consequences of malnutrition such as deteriorated overall health (White 1998), decreased well-being (Manthorpe & Watson 2003) and specific problems such as hip fractures (Bachrach-Lindström 2000) it must receive further attention.

High level decision-makers' thoughts on malnutrition

The often poor health status among older adults was mentioned as a major cause of malnutrition as were factors within the health care system. The latter was exemplified by caregivers not noticing these conditions and by daily routines that might not be conducive to good nutrition (**III**). As in study **I**, the occurrence of unnoticed weight changes has been previously reported (Beck & Ovesen 1998) and is connected with a lack of regular weight taking routines. Mealtimes performed in a routine fashion often occur in institutions and can result in a care that is not congruent with the older adults' needs (Sidenvall et al. 1994, 1996). With static routines it is difficult to individualise meals and adjust them to meet different needs (Sidenvall et al. 1999). Most of the older adults in the sheltered housing units (**I**) had some degree of cognitive impairment, which had worsened after a year and in such circumstances it is preferable with stable routine meal environments. Thus, when dealing with nutritional issues many aspects have to be considered, all from well functioning relationships to good routines in the health care system.

According to the HDMs it is the responsibility of the caregivers to ensure there is enough time allotted for the meals and that the food is consumed (**III**). Caregivers have experienced ethically difficult mealtime situations with older adults with severe dementia (Norberg & Athlin 1989, Norberg 1996, Athlin & Norberg 1998, Watson 2002). Staff-patient interaction seems to influence the proportion of food consumed (Amella 1999) and the individual's willingness to eat must be observed (Wikby et al. 2004). Weight loss among older adults has been significantly associated with higher caregiver burden and stress scores (Gillette-Guyonnet et al. 2000). It has however, been reported from a study with different types of assisted living units, that the units for residents with dementia diagnoses had the greatest proportion of older adults eating three full meals per day (Saletti et al. 2000). According to Mattsson-Sydney & Fjellström (2005) the mealtime situations are often shaped by the

individuals' living arrangements and not by the individuals' needs or wishes and they found that in units similar to nursing homes there was a limited amount time allotted for meals.

More education for caregivers was a the key issue when dealing with nutritional problems and malnutrition according to the HDMs even though they were uncertain as to why there should be a lack of knowledge since education had been provided (III). This reasoning indicates that the HDMs might be feeling distrust towards the caregivers and the current health care system since even though resources were provided for education, alarming reports to the contrary still occurred. There are probably several difficulties to be considered when performing nutrition education programmes such as how to deal with the high staff turn over rate in elder care (Socialstyrelsen 2005a) as well as securing a sufficient number of qualified individuals to work in elder care (Andrews 2003).

The staff education programme in integrity promoting care was profitable (II) and contributed to a positive atmosphere during mealtimes and developed interactions, which indirectly led to the weight gain and increased intellectual function among the residents of the I-ward. It seems that the content, form and intensity of the educational programme played an important role (III). The integrity promoting care programme (II) encouraged a more holistic view of the human being in conjunction with mealtimes and eating. This focus and design emphasised developed relationships, communication and trust that affected the older adults positively, and the results are in line with previous reports based on the same intervention (Bråne et al. 1989, Kihlgren et al. 1990, Kihlgren 1992, Kihlgren et al.1996).

According to Løgstrups' (1994) philosophy of ethics all human beings are obligated to respond to the ethical demand and to interpret what is needed by the other person. The positive result in study II could probably be understood in that the caregivers responded in a good way. The results should not be interpreted as a positively affected disease but rather as the meeting of a human need, which lead to several of the individual's capabilities becoming visible that could then be measured in quantitative terms. Increased weight however, should not be striven for at all costs.

Multi professional teams are preferred (Beck & Ovesén 1998, Faxén-Irving 2004) and Cederholm (2006) emphasises that malnutrition has been a topic in health care for more that two decades yet still good routines are missing. One of the aspects highlighted is that if nutritional issues are not highly valued by the management or those responsible in the high level positions, it is not easy to expect proper nutritional care. Results from a four month intervention study that aimed to improve nutritional status and functional capacity among newly admitted persons to residential homes showed no differences in the measured variables

between the experimental and control groups (Wikby et al 2006b) Within the experimental group however, the number of individuals that were classified as having protein energy malnutrition had decreased and their cognitive and motor activity had increased, which indicates an effect of the intervention (Wikby et al. 2006b). Based on the outcomes of study **II**, it seems that the dimensions of integrity and human relationships are important to include in future nutrition education programmes. Watson & Green (2006) write that further research with standardized interventions in the area of food provision for persons with dementia disease is needed.

The life world and system world

The results in studies **I-IV** reveal that different levels in a health care system seem to be intertwined with ethical challenges that confront and are associated with the different assumed roles. Decisions made at a high level will affect every day practices in some way or another. Therefore the results (**I-IV**) could probably be interpreted from the perspective of the tension between the life world and the system world, in which the life world expresses the immediate daily experiences in a person's life (Habermas 1994, Eriksen & Weigård 1999).

The life world perspective can be understood as the perspective where the daily relationships occur, in which the older adults and the caregivers are meeting. Within their relationship, basic needs such as food provision have to be fulfilled and nutritional problems and malnutrition have to be dealt with (**I-II**). The caregivers are working close in the life world with the older adults, which makes the caregivers more sensitive to them but also vulnerable. The fact that an individual is old and ill was seen as major cause of malnutrition (**III**). If this perspective becomes too domineering it can lead to a narrow mindedness where other important perspectives are neglected and when this happens the care providers can feel that there is little meaning with giving care. A perspective of this nature could also lead the HDMs to not assume the responsibility for follow-ups in elder care.

The system world perspective concerns structures, which makes it possible to deal with complexities. It can also be understood as situations and areas where common sense, rationalities and goals are governed (Habermas 1994, Eriksen & Weigård 1999). The system world perspective can therefore provide an understanding of how the mentioned lack of routines and knowledge among caregivers could be plausible causes for malnutrition (**III**). If goal governed interactions start to take over the life world and affect the relationships then problems can exist (Habermas 1994, Eriksen & Weigård 1999) since routine oriented care can

be the result. The HDMs questioned the routines in institutional units and seemed to be uncertain as to whether there is a strong influence of the system world that could lead to the fact that individual needs are not being sufficiently addressed (III). If that is the case it can be comparable to what Sidenvall (1996) and Fjellstöm (2004) stated as a loss of cultural and psychosocial aspects, which are values that belong to the life world. There is a risk for the life world to be colonized by the system world but it is a balance that is necessary between the two perspectives. Actions that can enable these developments are continuous open dialogues between the perspectives (Habermas 1994, Eriksen & Weigård 1999). The possibility of the system world taking over aspects of the life world is likely to occur within the rigid routines and lack of knowledge and also in the atmosphere of the units and in the staffs' attitudes.

Ethical challenges confronting high level decision-makers

Both ethical dilemmas and ethically challenging situations related to elder care were confronted by the HDMs (IV). This illustrates that the system world and the life world perspectives operate simultaneously (Habermas 1994, Eriksen & Weigård 1999) i.e. when the HDMs deal with the governing of goals, structures and complexities they at the same time experience their own personal life world. Their dilemmas mostly concerned their decision-making that mirrored the tension between trying to meet the ever-increasing older adult needs and staying within the limited budget (IV). The lack of good care for the most vulnerable older adults was seen as ethically difficult and was often related to budget reductions (IV). When making decisions, the distance between the decision makers and those who experience the consequences might make it easier to enact difficult actions or ones that have unclear outcomes (Henriksen & Vetlesen 1997). However, the HDMs' life world seemed to remind them that something might be at stake for the older adults and that a failure could result. The HMDs felt there was a risk that incorrect decisions could be made due to deficient information from poor reporting systems (IV). According to Nerheim (1991) the inauthentic understanding will tell us what the "fact" is, and that might be risky as it does not include our "life" and it could therefore become a hindrance to what can be sensed and understood. Within the authentic understanding, there are moral values and responsibilities involved (Nerheim 1991). Good reporting systems will not free them however from ethical challenges.

Shared responsibility

The HDMs' position steers to a high extent their decision-making since their assumed responsibility carries with it expectations (IV) in that they have directions to follow. The HDMs are responsible for the existence of elder care that is ethically defensible and are working as representatives of the people as well as the professionals in the system. According to Christoffersen (2005) ethics is related to actions, people and what can sometimes be referred to as an unethical society, in which a continual breakdown of what is right and just exists. One example mentioned was vague health care systems (Christoffersen 2005). In study IV the HDMs with their assumed responsibility could not avoid feelings of uncertainty, aloneness and loneliness and if they could not learn to live with them they felt they had to quit their jobs. These feelings reveal the HDMs' vulnerability. Løgstrup (1994) writes that individuals are responsible for their lives but do not have control over the conditions. Intellectual capacity is not enough when trying to understand a situation, feelings must be added. A good way of understanding what is best for another is to think unselfishly. Social norms, habits and sanctions often explain why norms are obeyed (Løgstrup 1994). On the collective or political level there is a great amount of influence (Løgstrup 1994), a reasoning that can be used to understand the HDMs and their assumed level of responsibility. In study III the HDMs seemed to be deficient in the area of continuous follow-ups and they seldom mentioned management's role. Follow-ups in a health care system as well as visible managements are associated with basic responsibility.

Trust and ethics

The HDMs feelings of distrust could be sensed from their narrations regarding the caregivers' failure to fulfil older adult nutritional needs (III) and the reports of insufficient care among the older adults (IV). Distrust has been reported in other studies but it was directed in the opposite direction, namely from the health care professionals towards those higher up (Sørli et al. 2004, Nordam et al. 2005). In the philosophy of ethics (Løgstrup 1994), trust is a fundamental state of life and something is required before for trust changes to distrust. Erikson (1982) also stresses that trust is fundamental for individuals in a society and that it sheds light on the society's sense of responsibility (Erikson 1988, Kalkas & Sarvimäki 1991) regarding the care of the older persons.

One way of promoting trust while in the process of making decisions and setting priorities in a health care system is to work openly, by for example the structuring of meeting places for individuals representing the different levels where informal discussions about the decisions

can take place (Garpenby 2004). This is in accordance with what is described as organisational ethics and where it is stated that the key issue of trust between individuals must be transferable into the character of the health care system or organisations (Silva 1998, Boyle et al. 2001). Nerheim, (1991) writes that language is an important part of ethics since we communicate using language. This seems to be in line with the ethics of communication (Habermas 1994, Eriksen & Weigård 1999) where the language gives us information about the world we live in with others.

A health care system that lacks structure and policy can be referred to as unethical (Chistoffersen 2005). That which makes a person good is not only their traits but also the characteristics of the situation and the relationships in it (Lindseth 1992). This means that an organisational structure in a health care system must be built in a way that stimulates the understanding of what is right and fair and where bringing up ethical dilemmas from different levels in the system is seen as part of its development process. The responsibility for building structures that enable dialogue concerning ethical issues and ethical behaviours within a health care organisation rests with those occupying the high level positions (Silva 1998, Boyle et al. 2001). Forums where ethical issues can be brought up from different levels and from different professionals might reduce the problem of “finger pointing” and improve elder care. They can also provide an opportunity to make follow-ups and check the status of the goals set for the system. Axelsson (2000) stresses that with the ongoing process of change in the health care system it is important to involve the different levels in order to minimize the lack of trust existing between them. The issue of ethical challenges in elder care is also emphasised by Akner (2006) and Thylén et al (2006). They actualise the need for ethical discussions in order to meet the elder care demands due to the increasing number of older adults with multiple illnesses, where many have declining autonomies.

Among the HDMs feelings of uncertainty, aloneness and loneliness were revealed (**IV**) which according to Løgstrup (1994) are fundamental conditions of life. Uncertainty reveals the fact that humans are fallible, a condition that should not primarily be referred to as a lack of knowledge but rather as a lack of power over our participation in life. It might be about courage and about meeting doubt and uncertainty in relationships and situations (Sørliie 2001b). In study **IV** feelings of failure were also revealed when the HDMs felt that something was at stake for the older adults and there was a risk that their needs would not be met because of their own loyalty to their job, which forced them to make reductions with uncertain outcomes. The possibility of failure was also something that pertained to them personally since there was a risk that important needs in their lives would also go unmet (**IV**).

Based on these findings it is reasonable to assume that failure is associated with feelings of violation against one's own moral self.

Many of the results (**III, IV**) have been reflected upon in the light of Løgstrups' ethical philosophy (1994) and the relevance of his ethical perspectives has been discussed in nursing science (Norberg & Åström 1994). Holm (2001) states that in general Løgstrups' ethics is not applicable in clinics since the focus is on the concrete interaction between people who actually meet and that makes it difficult to say something about resource allocation and priority settings. Løgstrup's ethics is about the phenomena of life and can be a reminder about the vulnerability of the other. Thus it may be helpful in our reasoning regarding others and our selves.

IMPLICATIONS FOR PRACTICE

The major findings in this thesis illuminate ethical challenges confronting elder care at different levels in the health care system. All parties involved seemed to have vulnerabilities but possibilities and strengths were also revealed. The different levels in the health care system are intertwined but there seems to be a gap in the dialogue between them, in the life world and the system world. This might affect the sense of responsibility that is assumed regarding the older adult.

The caregivers are responsible for noticing nutritional problems and to ensure adequate nutrition. The fact that there are many aspects to consider that relate to malnutrition shows that education for the caregivers is important. However, multi-professional teams such as caregivers, dieticians, physiotherapists, occupational therapists as well as increased physician participation are needed due to the complexity of the issue and the condition of the older adults.

Integrity promoting care should receive serious attention since it seems to be advantageous. A holistic view of human beings, together with communication skills, and biological and medical knowledge should therefore be included in future nutrition programmes. The content, form and intensity of the nutritional programmes should also be considered.

An ongoing dialogue among the staff and managements concerning one of our most basic needs must exist. Routines for identifying malnutrition and risks for it, ensuring time for eating and appraising food intake are vital.

Increased competence among the entire staff regarding all aspects of medical care for the older adults with input from e.g. geriatrics, geropsychiatrics, psychogeriatrics and family

medicine would be beneficial due the poor health status and complex multimorbid conditions of the older adults.

The two health care systems that share the responsibility for elder care and the disagreements between them concerning the care were seen to create ethical dilemmas. More focus is needed on the consequences of what this shared responsibility brings.

The ethical challenges in the health care system will persist. There is a need to bring ethical issues and caring philosophies into the light. Informal forums and open dialogues throughout the entire system are necessary as well as more knowledge about what they can contribute.

Sometimes it may be necessary for a confrontation in order to highlight the ethical challenges. Regular follow-ups by the HDMs are needed since they also have symbolic value in that for example the domain that is addressed can therefore be considered important.

There should be more focus placed on the HDMs and their responsibilities since they seem to be trying to balance between their vision of elder care and budget realities. Feelings of failure were indicated among the HDMs which suggest that it would be of interest to study the concept of fallibility.

POPULÄRVETENSKAPLIG SAMMANFATTNING

(SUMMERY IN SWEDISH)

Etiska utmaningar inom äldreomsorg med fokus på näringsproblem

En balans mellan livsvärld och systemvärld

bland vårdare och beslutsfattare

Äldreomsorgen i Sverige liksom i resten av utvecklingsländerna står inför etiska utmaningar. Ekonomiska reduceringar med minskat antal platser vid särskilda boenden i många kommuner har blivit en vanlig situation. Därtill kommer ett ökat antal äldre i ordinärt boende med multipla sjukdomar och stora omvårdnadsbehov. Antalet äldre utrikes födda personer ökar, vilket ställer andra krav på dem som är ansvariga för vården och för dem som vårdar (Socialstyrelsen 2005a). Kraven på de formellt ansvariga för vården, att möta behoven på ett gott sätt, kvarstår. En överansträngd situation i äldreomsorgen med problem att ge den mest basala vården har beskrivits (Gurner & Thorslund 2003). Upplevelser av etiskt svåra situationer har rapporterats bland olika professioner i olika delar av hälso- och sjukvården (Sørli et al. 2004, 2005, Torjuul et al. 2005a, 2005b) bl.a. inom äldreomsorgen (Udén et al. 1992, Nordam et al. 2003). Behovet av gemensamma etiska diskussioner ökar för att kunna möta det allt större krav som finns inom äldreomsorgen med det ökande antal multisjuka äldre med en alltmer avtagande autonomi (Akner 2006, Thylén et al 2006).

Näringsproblem inom vård och omsorg, är ett av de problemområden som uppmärksammas under många år och identifiering och hantering av sådana tillstånd har betonats som mycket angelägna för att förebygga följsjukdomar och därmed ökade kostnader (Socialstyrelsen 1998b, 2000, Saletti et al. 2000, Cederholm 2006). Exempel på etiskt svåra situationer för vårdare som beskrivits är måltidssituationer, bl.a. när vårdaren skall hjälpa personer med demenssjukdom att få i sig mat (Athlin & Norberg 1987, Norberg 1996). Som ett led i att möta den problematiken behövs ytterligare kunskaper om hur den äldres nutritionsstatus kan se ut i ett län och vilka riskfaktorer som identifieras. Om utbildning av vårdare i att befrämja integriteten hos de äldre kan påverka deras viktstatus samt fysiska och psykiska förmågor är en annan frågeställning. Det formella ansvaret för äldreomsorgen är delat mellan dels kommuner och landsting och dels mellan olika professioner. Det har även känts

angeläget att belysa beslutsfattarens uppfattning om problemområdet eftersom deras beslut på ett eller annat sätt påverkar vårdarbetet. Vidare har det setts angeläget att få en ökad förståelse för beslutsfattarens erfarenheter av etiskt svåra situationer som rör äldreården utifrån deras position i ett hälso- och sjukvårdssystem.

Delarbete I som är en uppföljningsstudie, syftade till att få svar på i vilken omfattning undervikt, viktförlust och faktorer som kan relateras till näringsproblem återfanns hos vårdtagare, ≥ 75 år vid särskilt boende samt att se förändringar efter ett år. Vidare studerades möjliga riskfaktorer som kan prediktera näringsproblem. I Gävleborgs län inkluderades 719 personer från 24 särskilda boenden fördelade på samtliga kommuner. Vid start av studien samt efter ett år genomfördes funktions- och vårdbehovsbedömningar med etablerat instrument (RAI/MDS 2.0). Hos de 719 initialt inkluderade (16% av personer boende i särskilt boende) var medelåldern 85,8 år varav 71% kvinnor. Efter ett år deltog 503 personer då bortfallet vid bedömning två var 30%, varav 26% hade avlidit, 2% hade flyttat och bland 2% hade ej bedömningarna avslutats.

Av resultatet framgår att en hög andel hade undervikt eller viktförlust och flera riskfaktorer identifierades. Bland de 503 personer som bedömdes vid två tillfällen sågs i stor omfattning kroniska sjukdomar samt nedsatt kognitiv och fysisk förmåga. Vid respektive bedömningstillfälle var mer än en tredjedel (35% respektive 38%) klassificerade som underviktiga, en icke signifikant skillnad. Vid ytterligare analyser framkom att 39% hade minskat i vikt, 27% hade en stabil vikt samt att 28% hade ökat i vikt. Viktförlust som gällde senaste sex månaderna kunde inte beräknas eftersom regelbundna viktkontroller inte förekom och tillgång till tidigare viktuppgifter fattades. Vid start av studien kunde inte viktförlust beräknas i 27% och vid uppföljningen ett år senare var motsvarande andel 20%. Signifikanta försämringar sågs efter ett år när det gällde kognitiv och funktionell förmåga, att vara beroende av hjälp för att äta samt för tugg- och sväljproblem. Vid första bedömningen var 14% helt beroende av hjälp för att äta och ett år senare var andelen 21%. Motsvarande uppgifter för tugg och sväljproblem uppgick till 16% respektive 20%. Vid den uppföljande bedömningen sågs att 80% fick stöd med daglig munhygien. Initialt hade ungefär var tionde någon form av aggressivt eller annat krävande beteende. Användning av parenteral nutrition var mycket liten.

Både enskilda variabler och skalor användes för att identifiera faktorer associerade till undervikt och viktförlust. I förhållande till skalorna framkom kognitiv och fysisk funktionsförmåga som de mest betydelsefulla riskfaktorerna. När det gällde enskilda variabler

framstod demenssjukdom, Parkinsons sjukdom, hjälpberoende vid måltid samt obstipation som de starkaste riskfaktorerna. Av de logistiska regressionsmodellerna framgick att r^2 varierade mellan 5.0-12.3% (skalor) och 17.0-27.5% (enskilda variabler). Detta indikerar att förklaringsvärdet av modellerna var ganska lågt, något som kan förväntas i en heterogen population.

Delarbete **II** syftade till att undersöka om utbildning av vårdpersonal i att ge en integritetsbefrämjande omvårdnad till personer med moderat och grav demens kunde påverka viktförändringar och hur dessa förhöll sig till biologiska och psykologiska parametrar. Ett ytterligare syfte vara att beskriva hur personalen förändrade måltidsmiljön. Studien omfattade två långvårdsavdelningar med personer som var ≥ 75 år och som hade moderat till svår demens. All personal vid interventionsavdelningen (I-avd) fick genomgå en tremånaders utbildningsprogram. På I-avd hade 13 av 18 personer ökat i vikt efter utbildningen jämfört med två av 15 på kontrollavdelningen (K-avd) där personalen fick utbildning efter att projektets avslutats. Inga viktförändringar kunde relateras till typ av demens. Bland personerna på I-avd sågs en signifikant korrelation mellan viktförändring och intellektuell funktion enligt mätning med GBS-skalan (-0.574 , $p < 0.01$). Detta tyder på ett samband mellan ökad vikt och förbättrad intellektuell förmåga under perioden för undersökningen. Relationen mellan viktförändringar och ökad motorisk funktion, ökad aptit samt förändringar i biokemiska parametrar var inte signifikanta. Vårdpersonalen skrev dagböcker vid tre tillfällen under studiens genomförande och materialet analyserades med hjälp av manifest innehållsanalys. Förändring till en mer hemlik måltidsmiljö och av måltidsrutiner rapporterades i dagböckerna vid I-avd liksom en trevligare atmosfär och ökad kontakt med de äldre. Inga sådana förändringar rapporterades från K-avd.

Delstudie **III** syftade till att belysa beslutsfattares resonemang angående orsaker till näringsproblem inom äldreården och vad som kan vara möjliga åtgärder för en förbättring. I studien intervjuades 18 beslutsfattare (politiker och högre tjänstemän) från kommuner och landsting i två län, vilka var ansvariga för budget och övergripande kvalitet inom äldreården. Materialet analyserades med hjälp av latent innehållsanalys. Olika orsaker till näringsproblem framträdde t.ex. att personerna är gamla och sjuka, något som gör dem sårbara. Det mest avgörande för en förbättring enligt dem är att vårdarna har kunskap om nutrition och att måltiderna är individuellt anpassade. Det uttrycktes en osäkerhet om så skedde och det betonades att vårdarna har ett ansvar för att tid ges för ätande så att den äldre får i sig maten.

Otillräckliga kunskaper hos vårdarna ifrågasattes eftersom utbildningar inom ämnet hade genomförts. Vårdpersonalens scheman och rutiner ansågs även kunna bidra till att den äldres behov förbises, liksom antalet vårdare under måltiderna. Beslutsfattarnas förslag till åtgärder var bl.a. att ge ytterligare nutritionsutbildning, förbättra arbetsrutiner och att individualisera vården. Läkarnas ansvar efterfrågades på grund av de äldres nedsatta hälsotillstånd. Beslutsfattarna talade mindre om verksamhetschefernas och sitt eget ansvar och betonade att när dessa frågeställningar kommer upp på deras agenda så vidtas åtgärder.

Delarbete **IV** syftande till att belysa vad beslutsfattare upplever som etiskt svåra situationer inom äldrevården. Samma politiker och högre tjänstemän deltog i studie **III** och **IV**. Både etiska dilemman och upplevelsen av att befinna sig i sådana situationer framkom när fenomenet belystes. Ingen skillnad sågs mellan politiker och tjänstemän. Beslutsfattarna var direkt eller indirekt involverade i etiska dilemman. Etiska dilemman berörde ofta beslutssituationer där ökande behov av äldrevård skulle hanteras inom en begränsad budgetram. Brist på god omvårdnad lyftes fram och exemplifierades av bristen på adekvata boenden för de mest sårbara äldre. En för liten medverkan från läkare inom äldrevården betonades också här. Brist på samsyn mellan de två ansvariga huvudmännen, kommuner och landsting, ansågs även bidra till att etiska dilemman uppstod. Dilemman som nämndes handlade även om att åstadkomma en rättvis fördelning av hälso- och sjukvården dvs. mellan gruppen av äldre med stora vårdbehov i förhållande till att samtidigt tillgodose yngres tillgång till vård. Dåliga underlag producerade inom hälso- och sjukvårdssystemen ansågs problematiska, eftersom de skulle kunna leda till att beslut tas på felaktiga grunder.

Beslutsfattarna upplevde att det var utmanande att befinna sig i etiskt svåra situationer men att detta var möjligt att hantera. Att inneha en hög position med ett stort ansvar innebar att vara ensam och ha känslor av ensamhet, enligt dem. Dessa känslor betraktades vara en del av arbetet men upplevdes ändå betungande, i synnerhet när det inte finns någon att dela bördan med om situationerna blir tuffa. Den bristande bekräftelsen från andra bidrog till att det blev än mer betungande. Enligt beslutsfattarna måste man avgå om man inte kan lära sig leva med känslor av osäkerhet. Rapporter om bristande äldrevård fyllde på känslorna av osäkerhet och funderingar kom om det verkligen gick att lita på systemen. Risker för hot som följde med deras utsatta position innebar etiska svårigheter. De kände sig misslyckade när insatser för att ge en god vård inte lyckades, när beslut togs där lojaliteten till positionen ställdes emot egen övertygelse t.ex. vid vissa budgetneddragningar.

Studien visade att beslutsfattarna känner att något viktigt står på spel inom äldreården och för dem själva och att det finns en risk att behoven inom äldreården inte blir tillgodosedda.

Etiska utmaningar på olika nivåer

Etiska utmaningar tycks existera på olika nivåer inom ett hälso- och sjukvårdssystem. Avhandlingen har fokuserat på etiska utmaningar i relation till äldreården ur ett brett perspektiv samt utifrån ett av dess problemområden, nämligen näringsproblem. Undervikt och viktförlust förekommer i hög omfattning bland dem som bor på särskilda boenden. De äldre har ofta multipla sjukdomar, nedsatt kognitiv och fysisk förmåga dvs. faktorer som är kända för att kunna bidra till näringsproblem. Undervikt och viktförlust ses därför som viktiga signaler till att nutritionsstatus behöver bedömas och adekvata åtgärder sättas in utifrån den enskildes tillstånd. Enkla åtgärder som regelbundna viktkontroller kan införas omgående (Kondrup 2002). De riskfaktorer som identifierades i denna studie var kognitiv och fysiskt sviktande tillstånd, att vara helt beroende av andra för att äta samt obstipation. Detta är välkända aspekter som än mer måste följas upp inom vård- och omsorgsarbete. De äldres hälsostatus och komplexiteten kring frågeställningarna innebär att utökad läkarmedverkan är nödvändig liksom stöd från övriga i multiprofessionella team, exempelvis förutom sjuksköterskor och undersköterskor även dietister, arbetsterapeuter och sjukgymnaster.

Integritetsbefrämjande omvårdnad efter särskild utbildning visade sig vara positivt för såväl den äldre som för vårdarna. En omvårdnad som fokuserar på ett holistiskt synsätt med bl.a. skapande av tillit, autonomi och helhet som viktiga aspekter inom ramen för relationer bör lyftas fram. Förändrad måltidmiljö och måltidsrutiner uppgavs också bidra till en förbättrad atmosfär mellan de äldre och vårdarna.

Äldres nedsatta hälsostatus uppgavs av beslutsfattarna vara en möjlig orsak till näringsproblem vilket tyder på att de har kännedom om problematiken. Å andra sidan kan en stark betoning av nedsatt hälsostatus leda till upplevelser av meningslöshet inför att vidta åtgärder. För lite kunskap om nutrition, rutiner i daglig praxis angavs även kunna påverka och därför framhölls behovet av mer utbildning. I framtida utbildningar beträffande nutrition bör aspekter utifrån integritetsbefrämjande omvårdnad ingå.

Beslutsfattare har i och med sin position åtagit sig ett övergripande ansvar för budget och en god kvalitet i äldreården. Etiska utmaningar utifrån deras perspektiv har belysts, vilket omfattar såväl dilemman som att befinna sig i etiskt svåra situationer. Oftast framkom detta i förhållande till beslutsfattandet och med obekväma känslor som följd. Tillit till att det inom hälso- och sjukvårdssystemet kan ges en adekvat vård är avgörande för systemets legitimitet.

Tillit är giltigt för alla individer (Løgstrup 1994) oavsett var i systemet man befinner sig och vilken roll man har. Resultaten i avhandlingen är reflekterade i ljuset av den så kallade livsvärlden som rör relationer och systemvärlden som rör rutiner och målstyrning och den spänning som finns mellan dem. Det tycks vara viktigt att forma strukturer med informella mötesplatser inom de respektive världar där etiska utmaningar från alla nivåer tillåts belysas och uppmuntras till att ses som bidragande till en kvalitetsutveckling.

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