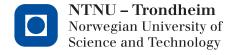
Sigrid Nakrem

Measuring quality of care in nursing homes - what matters?

Thesis for the degree of Philosophiae Doctor

Trondheim, December 2011

Norwegian University of Science and Technology Faculty of Medicine Department of Public Health and General Practice





NTNU

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Kvalitetsmål for pleie- og omsorg i sykehjem – hva er av betydning?

Sykehjem er en helsetjeneste som vil være nødvendig for eldre som ikke føler seg trygge eller kan få tilstrekkelig behandling, pleie og omsorg i eget hjem. Antall eldre over 65 år er økende i Norge, noe som innebærer et økt press på sykehjem i framtiden. Det er derfor av stor betydning at sykehjemstjenesten utvikles med tanke på å skape best mulig nytteverdi ut fra behov. Sykehjemmene har utviklet seg de siste 50 årene fra hovedsakelig et botilbud til helseinstitusjoner som gir avansert helsehjelp. Sykehjemsbeboere er skrøpelige eldre med komplekse problemstillinger, avhengig av avansert sykepleie. Kvalitetsindikatorer er kvantitative mål som reflekterer en profesjonell standard for pleie og omsorg, og slike mål benyttes i økende grad for å vurdere kvalitet i sykehjem. Imidlertid er det nødvendig å inkludere det som har størst betydning for sykehjemsbeboere i slike mål for å kunne gi god pasientsentrert sykepleie.

Hovedmålsettingen med studien var å bidra til en dypere forståelse av sykehjemskvalitet, ut fra helsepersonellets, beboernes og pårørendes ståsted. Avhandlingen omfatter en oversikt over kvalitetsindikatorer som er i bruk internasjonalt. Videre beskriver avhandlingen beboernes erfaringer med mellommenneskelige faktorer ved sykehjemskvalitet, samt hvordan de erfarer å bo i et sykehjem og opplever kvaliteten på "hjemmet" sitt. I avhandlingen blir også pårørendes forståelse av og meninger om sykehjemskvalitet utforsket. Avhandlingen er basert på dybdeintervju av beboere ved fire ulike sykehjem, og fokusgruppeintervjuer med pårørende ved to av sykehjemmene.

Funnene viser at kvalitet på pleie og omsorg i sykehjem omfatter minst fire hovedområder: Bokvalitet, personellkvalitet, helsetjenestekvalitet og sosial kvalitet. Videre er pleie- og omsorgskvaliteten påvirket av en rekke eksterne faktorer som nasjonale føringer, lovverk, ledelsesstruktur, bygningskonstruksjon og lokale forhold. Den internasjonale oversikten over kvalitetsindikatorer gir indikasjoner på at noen av dem kan brukes som pålitelige og gyldige evalueringer av kvaliteten på pleie og omsorg, samt helserelaterte resultater for beboerne. I den kvalitative intervjuundersøkelsen med beboere og pårørende, ble fysisk og psykisk velvære, mellommenneskelige forhold og det sosiale miljøet tillagt større betydning for kvaliteten. Objektive indikatorer for disse beboererfarte områdene for kvalitet må utvikles. For å sikre at disse er pasientsentrerte, bør utviklingen av kvalitetsindikatorer gjøres i tett samarbeid med sykehjemsbeboerne og pårørende, i tillegg til helsepersonell.

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Institutt: Institutt for samfunnsmedisin, Det medisinske fakultetet, NTNU Veiledere: Arnfinn Seim, Anne G. Vinsnes og Bård Paulsen Finansieringskilde: Rekrutteringsstipend ved Høgskolen i Sør-Trøndelag, tildelt fra Kunnskapsdepartementet

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Summary

Measuring quality of care in nursing homes - what matters?

Residential care in nursing homes continues to be necessary for those individuals who are no longer able to live safely and comfortably at home. The demographic change with increasing number of persons over 65 years in the next 20 years also means that the percentage of those who will require care in a nursing home some time before the end of their lives will increase. Therefore, anticipating this pressure to expand nursing home availability, it is critical that these services are developed from a profound understanding of what creates the best value. Nursing homes in developed countries have evolved over the past half-century from being places of mainly custodial care to facilities responsible for the management of an ever increasing range of complex nursing and medical conditions. Nursing home residents are frail older adults with complex needs, dependent on advanced nursing care. Determining what aspect of nursing homes should and can be measured is the current work of many national health care systems. However, uncovering what the nursing home residents perceive as the most important aspects of quality and how they experience living in a nursing home is necessary to develop effective person-centred care.

The overall aim of the present thesis was to contribute to a deeper understanding of quality of care in nursing homes, integrating the professionals', residents' and family's perspectives. The research design is a qualitative approach to explore the concept quality of care and its domains. The thesis comprises a review of internationally used nursing sensitive quality indicators for nursing homes. The indicators are evaluated

for their validity as described in the literature. The thesis further describes the residents' experiences with the interpersonal factors of nursing care quality, as well as the residents' experiences of living in a nursing home. The thesis also explores the understanding and belief about nursing home quality held by family members of residents. The thesis is based on in-depth interviews of residents in four different nursing homes, and focus group interviews of family members of residents in two different nursing homes.

The findings are that quality of care in long-term care in nursing homes encompasses at least four domains: quality of the living conditions, quality of the nursing staff, quality of direct nursing care, and quality of the social environment.

Moreover, care quality is influenced by a range of external factors such as the national policy, laws and regulations, management of the organization and the physical building. The local community provides a context in which the nursing home is more or less integrated into. The review of internationally used quality indicators indicate that some factors of care processes and health outcomes for nursing home residents could be measured and give valid and reliable evaluation of the nursing home care quality. In the explorative qualitative study, residents and family placed more emphasis on physical and psychological well-being, interpersonal relationships and the social environment if quality of care is to result. Objective indicators of essential areas of resident-experienced quality need to be developed. This should be done in collaboration with the residents and their next-of-kin, in addition to professional expertise. Methodological and practical implications of the results are discussed.

Acknowledgements

This research project is part of the research programme Clinical Nursing Home Research at Sør-Trøndelag University College, Faculty of Nursing, which aims at promoting quality of care for patients in nursing homes. Conducting the project has involved close cooperation with the research group, and I have had support, supervision and co-authorship from members of this team. However, there are many who should be acknowledged.

A four year PhD scholarship was granted by Sør-Trøndelag University College financed by a recruitment stipend from the Norwegian Ministry of Education and Research. Sør-Trøndelag University College, Faculty of Nursing also provided me with a good working environment and the best available equipment to conduct the research. I am grateful to all my colleagues there for personal support and engaging discussions. I would like to thank the Norwegian Knowledge Centre for support and advice when starting up this project. The project was also supported by grants from the Norwegian Nurses Organization.

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I am first author on all articles included in this thesis, except the fourth article: "Quality of care in Norwegian nursing homes – Typology of family perceptions" where Anne G. Vinsnes is first author. Together with Anne G. Vinsnes, I planned the study

and conducted the data collection. All four authors performed the analyses, discussed the results and contributed to writing the article. The conclusions presented in my thesis are, however, solely mine and I take full responsibility for this thesis.

I would particularly like to thank all the informants who have participated in this study. We owe a debt of gratitude to the nursing home residents who were willing to share their thoughts, and the relatives who gave us their thought-out opinions on nursing home quality in the focus group interviews. Thanks also go to the management and staff in the four nursing homes for their cooperation and contribution.

Warm thanks go to my colleagues and friends at Sør-Trøndelag University College. I am extremely thankful to my good friend and associate Susan Saga who has shared this journey along with me so far, and provided support and comfort.

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Trondheim, December 2011

Sigrid Nakrem

Acronyms and abbreviations

ACOVE Assessing Care Of Vulnerable Elders

AHRQ Agency for Healthcare Research and Quality

CMS Center for Medicare and Medicaid Services in USA

DCM Dementia Care Mapping

ICF International Classification of Functioning

IOM Institute of Medicine

IPLOS Individuell pleie- og omsorgsstatistikk

JCAHO Joint Commission on Accreditation of Healthcare Organizations

KS Kommunenes Sentralforbund - The Norwegian Association of Local and

Regional Authorities

MEDICARE United States government health insurance for people 65 or older; helps

cover skilled nursing facility

MDS Minimum Data Set

NH Nursing home

OBRA Omnibus Budget and Reconciliation Act (Federal Nursing Home Reform

Act)

OECD Organisation for Economic Co-operation and Development

QI Quality indicator

RAI Resident Assessment Instrument
RAP Resident Assessment Protocol

RN Registered Nurse (Autorisert sykepleier)

RUG Resource Utilization Group

UK United Kingdom

USA United States of America

Definitions and key concepts

Monitoring health care services Monitoring is to watch over an activity or

met. Monitoring is done by observing the services, analysing data and reacting if the

evaluation shows unsatisfactory care.

Nursing home A nursing home is a collective living place for

older people who do not require hospital service but cannot be cared for adequately and safely at

home.

Nursing home resident A resident is a person who lives, or has a long-

term stay in a nursing home, and receives accommodation, nursing care and other health

such as physicians, physiotherapists or

occupational therapists. The term has been

care from relevant health care professionals

under discussion in Norway, and terms such as

user, client, and patient are also used. Resident has been chosen for the purpose of this thesis,

with the term patient when addressing the

receivers of health care in general, however

recognizing that choice of term influences the understanding of nursing home care, and the use

of terms should be reflected upon.

Nursing sensitive quality indicator Measure of change in health status upon which

nursing care may have direct influence.

Quality indicator An indirect measure of quality for a particular

area of interest.

List of papers

This thesis is based on the following four publications:

I: Nakrem S, Vinsnes AG, Harkless GE, Paulsen B, Seim A. Nursing sensitive quality indicators for nursing home care: International review of literature, policy and practice. International Journal of Nursing Studies 46 (2009), 848-857

II: Nakrem S, Vinsnes AG, Seim A. Residents' experiences of interpersonal factors of nursing home care: A qualitative study. In press. International Journal of Nursing Studies (2011) doi:10.1016/j.ijnurstu.2011.05.012

III: Nakrem S, Vinsnes AG, Harkless G, Paulsen B, Seim A. Ambiguities; The residents' experience of "the nursing home as my home". Peer reviewed. Conditional acceptance and comments are addressed; International Journal of Older People Nursing (2011)

IV: Vinsnes AG, Nakrem S, Harkless G, Seim A. Quality of Care in Norwegian

Nursing Homes – Typology of Family Perceptions. In press. Journal of Clinical Nursing

(2011) doi: 10.1111/j.1365-2702.2011.03857.x

1.0 Introduction

This thesis focuses on measures for monitoring and improving quality of care for long-term residents in nursing homes. There is an increasing demand for measures to monitor quality of care in nursing homes in Norway (Sosial- og helsedirektoratet, 2005). Health care services do use performance measures to evaluate and compare the services, but these measures often focus on the structural factors and health care inputs, and less on nursing care processes and patient outcomes (Kise, 2004, Kommunenes sentralforbund, 2004). There is a lack of adequate care quality measures to inform providers, management and users on nursing home care quality (OECD, 2005). Therefore, this study was conducted to contribute to the development of nursing sensitive quality indicators that really matter for quality of care in nursing homes, integrating the professionals' and nursing home residents' perspectives. It was sought to find out what we can learn from international experiences on quality indicators for monitoring nursing home quality. Then it was explored how quality of care in nursing homes could be understood from the perspective of residents and family, and whether existing quality measures are suitable to measure the experienced quality of care.

The nursing home has several functions such as providing housing, household and health care. In this thesis I have focused on clinical nursing care as part of the health and social service provided in the nursing homes. Aspects of management, organizing, working environment of the staff, physical building and other adjacent areas to nursing care are not included due to the limited scope of the thesis. The focus is restricted to long-term care in nursing homes. The long-term care nursing home population is a vulnerable patient group with extensive complex care needs. This frail population also

has less ability to voice their opinion, and often they have less choice when it comes to selection of health services. It is therefore especially important to assure that the nursing care towards this patient group is of high professional standard and quality.

2.0 Background

2.1 Nursing homes in Norway

With life expectancy lengthening, the percentage of those who will require care in a nursing home some time before the end of their lives will, in Norway and other Western countries, increase dramatically in the coming decades. In 2010, there were 625,000 Norwegians aged 67 or older. By 2060 this may rise to 1.5 million with life expectancy increasing to 90.2 years for men and 93.4 years for women (Stastistics Norway, 2010). In Norway, nursing homes as part of public health services has existed in various forms for over a hundred years. These institutions have evolved over the past half-century from being places of custodial care to facilities responsible for the management of an increasing range of complex nursing and medical conditions (Hauge, 2005, Romøren, 2005a). The nursing home population constitutes a heterogeneous group of residents with a diversity of health and social needs. As of 2009, over 44,000 Norwegian citizens lived in nursing homes. Nearly 73% were 80 years and older. Most residents have advanced chronic illnesses and multiple diagnoses with as many as 80% of these individuals suffering from dementia (Nygaard, 2002).

The municipalities have a statutory obligation to provide nursing home services to those who need it (Helse- og omsorgsdepartementet, 1982). Most nursing homes are owned and run by the municipality, financed by taxes and resident payment. But there are also a few private providers, non-profit or for-profit, funded by public reimbursement and resident payment. Nursing homes as a health service have many functions, and are sanctioned by both health and social legal regulations and rules (Helse- og omsorgsdepartementet, 1991, Helse- og omsorgsdepartementet, 1982). According to the statute for nursing homes and facilities with 24 hour care services (Helsedepartementet, 1989), the nursing home should provide medical and nursing care for long-term and short-term residents, as well as rehabilitation and respite care. Nursing homes have nurses on hand 24 hours a day. The staff includes health professionals such as registered nurses (RN) and certified practical nurses, and an employed physician (Helsedepartementet, 1989). There is a legal requirement that the nursing department is managed by RNs (Helse- og omsorgsdepartementet, 1983).

For the long-term residents, the nursing home provides a total service, including advanced health care, housing and social care. The nursing home is their substitute home and final place of residence as they move through their end of life trajectory.

Nursing homes are challenged to meet the dual demands of providing a home for older people while providing professional care for complex health needs. A home represents not only a functional space, but has certain characteristics that include, but are not limited to, pattern of regular doings, solidarity and mutual decision-making on the claiming of time, space and other resources (Douglas, 1991). These characteristics may be difficult to actualize in an institutional setting because nursing homes, besides providing personal space, are also public places (Abbott et al., 2000, Hauge, 2004a,

Hauge and Heggen, 2008). There has been a redesign of nursing homes into more home-like environments during the past decades (Hauge and Heggen, 2008). Nursing homes are the work places for health workers and others, and therefore need to take into consideration the working conditions of the staff. However, often they try to integrate considerations of living conditions of the residents by for instance not having a fixed day-to-day schedule, and kitchens might be open to residents. Staff members are also encouraged to develop relationships with residents and their family (National Institutes of Health/ National Institute on Aging, 2011).

Within the limits of legislation and available economic resources, the municipalities are formally free to plan and run public health and social services in the community as they like. There is a considerably variation between the municipalities in how they organize their elder care (Statistics Norway, 2011). However, the increase in number of people needing institutional care will challenge the capacity of the society to offer this service at the same level as today. Today about 20 % of the users of public health and social care are long-term residents in institutions, and nursing homes are responsible of half of the total expenditures of municipal health and social care (Statistics Norway, 2011). There are future constraints in the resources, both economic and available workforce. Already the pressure on the nursing home service is high and there are waiting lists and prioritization problems (Garåsen, 2008). The demands will evidently exceed the supply to a much higher degree than today. This calls for a more careful consideration of how to organize the health service more effectively, safely and with high quality.

2.2 Quality of care

Defining quality of care has several challenges. Simply expressed, quality is an attribute or a property of something. In the ISO 9000 standards it's definition is: "Degree to which a set of inherent characteristics fulfils requirements" (Hoyle, 2009 p 24). Users of health care services often focus on the specification quality of a product/service, while service providers might focus on measuring the degree to which the product/service was adequately delivered (Beckford, 2002). The concept quality could also be explained philosophically as an idea of a sensation or a perception (Lloyd, 2004). Quality is a perceptual, conditional and subjective attribute and may be understood differently by different people. It is a compound of properties which is perceived on a continuum between "bad" and "good", and the extremities on each side needs to be opposite to be compared, for instance cold-warm or wet-dry. In other words, to have a sensation of good quality, there need to be an opposite sensation of what constitutes bad quality.

For health care, there have been several attempts to agree on a common definition starting with Avedis Donabedian's definition from 1980:

"Quality of care is the kind of care which is expected to maximize an inclusive measure of patient welfare, after one has taken account of the balance of expected gains and losses that attend the process of care in all its parts."

(Donabedian, 1980 p 6)

Next, the Institute of Medicine (IOM) presented an internationally recognized definition in 1990:

"Quality of care is the degree to which health services for individuals and populations increase the likelihood of desired health outcomes and are consistent with current professional knowledge." (IOM, 1990 p 21)

In the next decade, IOM published reports that continued to pursue a clarification of the term and its domains (Berwick, 2002, IOM, 2001, IOM, 1999). In the "Crossing the quality chasm"-report from 2001 six domains of quality of care are outlined: Safety, effectiveness, patient-centeredness, timeliness, efficiency, and equity (IOM, 2001 pp. 39-40).

In Norway, a commonly used definition is stated in a White Paper from the Norwegian Directorate of Social and Health Services in 2005 and incorporates a Norwegian translation of the ISO 9000 definition supplemented with the six domains listed in the IOM report from 2001 (Sosial- og helsedirektoratet, 2005). In 2010, The Norwegian Knowledge Centre for the Health Services coordinated a working group to make recommendations for a conceptual framework for a national healthcare quality indicator system in Norway (Norwegian Knowledge Centre for the Health Services, 2010). They recommended using the definition of quality based on the IOM's definition from 1990, though with a different wording (underlined by the author of this thesis):

"Quality of care is the degree to which healthcare services for individuals and populations increase the likelihood of desired <u>health welfare</u> [helserelatert velferd] and are consistent with current professional knowledge". (Rygh et al., 2010 p 41)

This definition apply the concept "health welfare" instead of "health outcomes", and thereby also focus on non-medical outcomes of care, such as quality of life, dignity and integrity, which are important from the patient perspective. The term "likelihood of desired health welfare" is a disparity from Donabedian's "absolutist" definition focusing on maximizing the patient welfare, and recognizes that there is always an unknown aspect of health care. The services are expected to provide more benefit than harm, but can only rely on the best available information, both about the patient and about the effectiveness of a particular kind of treatment for patients with similar health problems (IOM, 1999).

Moreover, patients may do well despite poor quality because humans are resilient and tend to adapt to the situation (IOM, 1999). There are relative and relational aspects of perception of quality of care. The patients' expectations change during lifetime and during a course of illness. However, low expectations may give more satisfied patients, and might lead to lower quality standards of the service (Stodel and Chambers, 2006). Correspondingly, patients with unrealistic expectations are less satisfied and may wish for more than it is possible to provide. Patient adjustments are related to higher satisfaction with care and thriving in nursing homes (Bergland and Kirkevold, 2006), and could be interpreted as a coping mechanism to achieve psychosocial congruence and balance (Slagsvold, 1995). Likewise, the environment has a relative interactional effect on the individual perception of quality (Slagsvold, 1995). The nursing home is a social system and quality of care depends on the system quality. Features of the system influence prioritizations, cooperation and relationships within the organization. Quality is a multi-dimensional concept and there is a need for a holistic approach (Rantz et al., 1999). The multiple and complex functions of the nursing home

may contribute to a condition of organizational ambiguity emerging from simultaneous presence of opposites (March et al., 1979).

However, the more complex a service is, the more complex the definition of quality. Complex services may need to be split into domains that can be described in detail to be measured. According to Donabedian (1980), quality of care can be divided into at least two interrelating parts. One aspect is the technical care, defined as the application of science and technology of health science to the management of health problems. The other aspect is interpersonal processes, or, more specific, the psychosocial interaction between client and practitioner. Further, Donabedian divides quality into three domains: Structure quality, comprising structural factors that affect the performance of care; process quality, or the direct care that the staff performs; and outcome quality, encompassing the impact for the patient or health care service outcome for the population. A variety of factors affect the processes, and these factors together with the structural factors will indirectly give the result for the individual patient, or the outcome of the care and service offered. There is a causal connection between the structure, process, and outcome quality and each dimension has to be linked together to understand the concept quality of care (Donabedian and Bashshur, 2003).

Since defining quality in nursing care imply to define what good nursing care is, how nursing can be performed and what results, outcomes or goals of nursing are desired for nursing home residents, it is necessary to look to nursing theory to elicit what it means for nursing. The purpose of nursing theory is to describe ideal nursing practice in order to provide care that support health and well-being of individuals or populations (Meleis, 2007). Even so, none of the well-recognized nursing theorists have

used the term "nursing care quality", which meant I had to look at other concepts in nursing theory relevant to care quality.

Human needs theory, such as Maslow's hierarchy of needs (Maslow, 1987), has inspired many nursing theorists (Meleis, 2007). Norwegian health care policy is influenced by these nursing theories, visible in legal documents such as the Norwegian regulation for quality of nursing care in health and social services. In the regulation it is stated that its purpose is to

"assure that users of health and social services have their basic needs met, acknowledging the individual's right to self-determination, value of selfhood and individual life style" (Sosial- og helsedepartementet, 2003 p 1)

(Translation by author of this thesis)

The service should be given in a timely fashion, and planned in a way that assures a holistic, coordinated service, characterized by continuity. Further, the regulation defines more specifically what is meant by basic needs for the users¹. The list is meant to be examples of basic needs that the service should consider when developing procedures and guidelines to assure quality care (Sosial- og helsedirektoratet, 2004). The regulation affirms basic human rights, and many of the basic needs listed in the regulation can be found in Virginia Henderson's 14 activities contributing to health or recovery

¹ The regulation for quality of nursing care in health and social services lists the following basic needs: respect, predictability and security; self-management; nutrition; social relationships and community; normal diurnal rhythm and avoiding unwanted stays in bed; rest and privacy; grooming and toileting; self care, a dignified death; medical examination and treatment, rehabilitation and nursing care that are individually adjusted; dental and mouth care; special dementia care; suitable help during meals and eating; suitable help for dressing; single room for long-term residents in institutions; and varied and suitable activities.

(Henderson, 1995, Meleis, 2007)². Norwegian researchers have used the regulation for quality of care to operationalize quality measures for research in nursing homes (Kirkevold and Engedal, 2006, Paulsen et al., 2004, Romøren, 2005b), and the regulation is frequently used by the Norwegian health authorities as guidelines for supervision and sanction of nursing homes, see for example the audit report from Trondheim kommune (Trondheim kommunerevisjon, 2010).

Other nursing theorists focus on interaction and communication as tool for assessment of the patients' needs and for building relationships. Interaction is one of the central concepts in nursing, both considering person-environment interaction and nurse-patient interaction (Meleis, 2007). A nursing home resident is in constant interaction with the environment, since the nursing home is where the resident lives and dwells 24 hours a day. The focus on the environment has continued since Florence Nightingale identified nursing actions to optimize a healing and healthy environment (Nightingale, 2003). Contemporary theorists include social systems, family, society, culture, the patient's room, the nurses and all that surrounds the patient as important interactional factors (Meleis, 2007). Client-nurse interaction is the major aspect of nursing (Kim, 1987). Kim identified four sets of variables that are related to client-nurse interaction and nursing care: actors (client and nurse); social context for contact; process of interaction; and client health outcomes (Kim, 1998, Kim, 1987). Long-term residents in nursing homes have long-term relationships with the nurses, which require a unique

-

² The 14 components in V. Henderson's need theory are: Breathe normally; Eat and drink adequately; Eliminate body wastes; Move and maintain desirable postures; Sleep and rest; Select suitable clothesdress and undress; Maintain body temperature within normal range by adjusting clothing and modifying environment; Keep the body clean and well groomed and protect the integument; Avoid dangers in the environment and avoid injuring others; Communicate with others in expressing emotions, needs, fears, or opinions; Worship according to one's faith; Work in such a way that there is a sense of accomplishment; Play or participate in various forms of recreation; and Learn, discover, or satisfy the curiosity that leads to normal development and health and use the available health facilities.

approach to interpersonal aspects of nursing. The relationship between the resident and nurse depends on the approach to care delivery the nurse adopts, which Brown Wilson and Davies (2009) describe as individualized task-centred, resident-centred or relationship-centred. Outcome of relationship-centred care is development of a shared understanding of all residents', staff's and family members' needs, and a feeling of all being included as members of the nursing home community (Brown Wilson, 2009). Positive experiences for residents, relatives and staff created by relationship-centred approach to care, are associated with the values in "The Senses Framework" developed by Nolan in 1997 (Aveyard and Davies, 2006, Nolan et al., 2001)³.

The interpersonal relationship in patient-nurse interactions have been found to be an essential factor in person-centred care, regarding the interpersonal skills as part of the nurses' professional competence and prerequisite for person-centred processes, resulting in desired outcomes for the residents and high quality of care (McCormack et al., 2010, McCormack and McCance, 2006). Hobbs (2009) did a dimensional analysis of the concept "patient-centered care", and the central organizing perspective was that care quality is strongly connected to the patient-nurse interaction, and the nurses' skills, knowledge and competencies to alleviate the patient's vulnerabilities. Therefore, the patient-health worker interaction from the patient's perspective is an essential part of the care receiver's experience that must be understood for best value in care to be realized.

³ The six senses in the framework include: sense of security; sense of continuity; sense of belonging; sense of purpose; sense of fulfillment; sense of significance.

2.3 Resident and family experiences of quality of care in nursing homes

The aim of health care is to attain desired health outcomes for the patients. Focusing on outcomes requires clinicians to take their patients' preferences and values into account (IOM, 1999). Determining what is good or bad quality of care requires knowledge of the values that individuals place on various health outcomes and how these may differ among individuals. Thus, it is fundamental to acquire knowledge about how the resident actually experience care quality in nursing homes to understand the individuals' lived experience and their subjective meaning of the everyday world. A review of findings from research on how nursing home residents experience their nursing home life, and their understanding of what is experienced as quality, is therefore presented below. Because the resident's family can provide unique knowledge of the personal history of the resident and do provide active surveillance of the professional care provided it might be useful to explore the family members' experiences. The search strategy comprised a search in the databases CINAHL and MEDLINE using the search terms "Nursing home" or "Long-term care" and "Patient experience" or "Patient satisfaction", limited to English language and going back to 1990. Then, the search terms "Nurse-patient Relations" and "Family" or "next-of-kin" were added to the search. Abstracts were read through and articles were included based on relevance. In addition, other articles were included after doing hand search in reference lists and books. Since the Norwegian nursing homes are most comparable to nursing homes in the other Nordic countries, research from the Nordic countries are presented first, then other international research.

2.3.1 Resident experiences

Eight Nordic qualitative papers have reported nursing home residents' experience of daily life in long-term care (Andersson et al., 2007, Slettebo, 2008), what contributes to resident's thriving (Bergland and Kirkevold, 2005, Bergland and Kirkevold, 2008, Bergland and Kirkevold, 2006), and meaning and quality of life (Dwyer et al., 2008, Hjaltadottir and Gustafsdottir, 2007, Westin and Danielson, 2007). In the study by Andersson et al (2007) it was described that the residents felt safe in the nursing home, but negative experiences were feeling lonely, helpless and dependent. Having someone to talk to was important factor for feeling comfortable with living in the nursing home, and dissatisfaction led to a wish to move (Andersson et al., 2007). Residents of nursing homes often report loneliness as a problem (Slettebo, 2008). There may be constraints in the nursing home community that inhibit the formation of new relationships, since only a few of the residents have ability to participate in meaningful conversations (Bergland and Kirkevold, 2008). Other research has demonstrated that the nurses have great impact on the residents' experience of "being someone" or contrarily "being nobody" in the way they include or exclude the residents in the nursing actions (Westin and Danielson, 2007).

In the study conducted by Dwyer et al (2008), it was found that meaning can sometimes be hard to realize for nursing home residents at the end of life. Finding meaning was influenced by the physical and cognitive capability of the resident, as well as feeling being needed by others and having a sense of belonging. Meaning was created through inner dialog, and communication and relationships with others (Dwyer et al., 2008). Hjaltadottir and Gustafsdottir (2007) found that residents defined quality of life as comfort and well-being, and it was connected to feeling secure in the nursing

home, having care needs met and to be recognized as an individual (Hjaltadottir and Gustafsdottir, 2007). Thriving has been found to be a useful concept for capturing the experience of well-being in nursing homes (Bergland and Kirkevold, 2001). In the study of factors that contribute to thriving, it was found that the most important aspects were the resident's attitude to becoming a nursing home resident, the quality of care in the sense of having their care needs met, (Bergland and Kirkevold, 2006) and relationship with the caregivers (Bergland and Kirkevold, 2005). Contributing factors for some of the residents were positive peer relationships (Bergland and Kirkevold, 2008), participating in meaningful activities, opportunities to go outside, positive relationships with family and qualities in the physical environment (Bergland and Kirkevold, 2006).

Internationally, the understanding of quality of care from a resident perspective has been explored in earlier work by Rantz et al (2005, 1999). They proposed a conceptual model for nursing home care from the perspectives of residents and families, and included the dimensions: features of staff, features of care, family involvement, communication, home and environment (Rantz et al., 2005, Rantz et al., 1999). Bowers et al (2001) interviewed residents about their experiences of being a nursing home resident. The residents' descriptions of quality of care fell into three categories: good service, reciprocal relationship with caregivers, and physical comfort (Bowers et al., 2001). Outcome of nursing home care includes elements of quality of life as well as quality of care. Therefore Kane (2001) conducted a study to identify domains significant to quality of life in nursing homes and link them to quality of care (Kane, 2001, Kane et al., 2003) ⁴. In an interview study with residents and families focusing on

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⁴ The study by Kane et al. identified eleven quality of life domains: comfort, functional competence, autonomy, dignity, privacy, individuality, meaningful activity, relationships, enjoyment, security and spiritual well-being.

quality of life indicators in long-term care, the interpersonal aspects of the nursing home environment was found to be of significant importance to the residents' quality of life, and included feelings of respect, involvement, reciprocity in relationships, and competency through technical nursing and attitudes (Robichaud et al., 2006). Their findings also showed that environmental characteristics such as having easy access to a private room and extra spaces to use were important, as well as availability of the caregivers, staff stability and having access to leisure and spirituality resources. Other research report that most residents quickly adjust their lives to the new setting, and try to create a meaningful life in nursing homes (Iwasiw et al., 2003, Kahn, 1999). But even with a successful adaptation to nursing home life, the residents do see potential for improvement such as more staff, better food and meal routines and meaningful activities that can enhance their quality of life (Buelow and Fee, 2000, Coughlan and Ward, 2007, Crogan et al., 2004, Evans et al., 2005, Sacco-Peterson and Borell, 2004, Street et al., 2007).

Subjective patient satisfaction with the service and care may not easily be obtained due to the frail nursing home population of whom 70-80 % suffer from dementia, which limit the possibility of response accuracy when probing into their emotions and daily life experiences (Wenger, 2002). In addition the residents are receiving an on-going service, and may have difficulty in taking a retro-perspective view of the quality. Therefore, external parties, such as family members, may be used as substitutes or advocacy for residents who cannot speak for themselves (Eika, 2006). The OECD health project Long-term Care for Older People (OECD, 2005) has emphasized incorporating family member's views on quality to improve services.

2.3.2 Family experiences

It is recognized that family caregivers have an important role in monitoring and evaluating the quality of care received (Davies and Nolan, 2006, Hertzberg and Ekman, 2000, Ryan and Scullion, 2000, Sandberg et al., 2001). Conversation with family members about what is their personal perspective on quality of care put focus on the individual and family unit and affirms the personhood and family identity of the care recipient (Andersson et al., 2007).

Gjerberg (1995) started to explore what nursing home quality means to residents, relatives and staff in Norwegian nursing homes. Gjerberg's analysis was structured to make an inventory of the themes and concepts uncovered in the interviews used in relation to the dichotomy of "good nursing home quality" and "bad nursing home quality." The relatives shared the same concerns about social activities, enough time, single room preference, and security with the residents and staff. Family members and staff differed from the resident perspective in that they distinctly valued respect toward their loved ones, provision of choice, competent nursing care, and maintaining a home-like environment. Concern about the consequence of criticising the care was shared by residents and their family members but not by the staff (Gjerberg, 1995). Other researchers have used survey methods to compare the family members rating of quality of nursing home service with the evaluation by residents and staff, using crosssectional questionnaires (Hasson and Arnetz, 2010, Isola et al., 2003, Romøren, 2005b, Teeri et al., 2007). Generally, the surveys showed that the families were satisfied with the care, and most often they rated the quality higher than staff, but closer to the residents' evaluation.

What is understood about quality nursing home care from a family member's perspective was explored in earlier work by Bowers (1988). This qualitative study of family members found that families ceded the responsibility of most direct care to the staff but held themselves responsible for monitoring and evaluating the quality of care. The family provided the care needed to preserve the resident's self (Bowers, 1988). In the family part of in the exploratory study by Rantz et al (1999), the family members believed their involvement was absolutely critical to the quality of care their family members received. The core quality variables for these respondents were staff and care, where the most important feature of nursing home care quality was reported to be the care itself. The findings highlighted the need for the basics of care to be done consistently so that residents eat well, physical care needs are met for cleanliness, toileting, and grooming, medical needs are met, and they are treated as people. Without good staff, though, quality care was not possible (Rantz et al., 1999). Relatives and next-of-kin have been included in the development of resident and family satisfaction with nursing home services questionnaires in USA and Canada (Ejaz et al., 2003, Stodel and Chambers, 2006, Straker et al., 2007).

To sum up, knowledge about how the resident and family experience care quality in nursing homes is fundamental for determining what is good or bad quality of care. Taking residents' and family members' preferences and values into account when developing quality measures, contributes to creating person-centred nursing home services.

2.4 Nursing sensitive quality indicators

There are two common quality-related functions within a service (Lloyd, 2004). One is quality assurance which is the prevention of defects, and includes activities such as deployment of a quality management system and preventative activities. The requirement of a management system for the health and safety of the workers and customers (clients) is stated in Norwegian regulations such as the Regulation of Internal Control and related body of health and social laws (Arbeidsdepartementet, 1996). This includes requirement of systematic efforts in the organization to monitor risks and potential problems. The enterprise should plan, organize, perform and maintain activities to assure that health, safety and environmental issues are cared for, and should have routines that correct inadequate practice and prevent unintentional incidents. The other function is quality control which is the detection of defects, such as recording unintentional incidents and failure to comply with standards. The Norwegian Board of Health Supervision is supervisory body responsible for inspections and monitoring in Norwegian nursing homes. The supervision imply an evaluation of whether the users' needs are met and whether the services that are provided meet the requirements laid down in the legislation (Helsetilsynet, 2010). In both the two quality-related functions, measures are needed to determine when quality standards are met, and to determine whether quality improvement efforts improve patient health outcomes. A quality indicator (QI) is defined as an indirect measure for quality for a particular area of interest, which is one of several measures that are used to monitor and document quality of health services (Agency for Healthcare Research and Quality, 2004, Castle and Ferguson, 2010). Patient outcomes and experiences vary for many reasons and reflect

the work of multiple professions. In many cases the greatest determinant of health outcome is the patient such as underlying health status, behaviour or aspects of the environment (Griffiths et al., 2008). In this thesis I am considering elements of variation that can be attributed largely to nursing care quality. Nursing sensitive quality indicators are measures of changes in health status upon which nursing care may have direct influence (International Council of Nurses, 2001).

Even if there is an increasing interest for measuring quality in western societies, few countries have developed quality measures for nursing homes (Du Moulin et al., 2010). The exception is USA, where there has been a large endeavour to follow up on the expectations of the Omnibus Budget and Reconciliation Act, Federal Nursing Home Reform Act - OBRA '87 (Department of Public Health, 1987). A Minimum Data Set (MDS) for 30 quality measures was developed, and later expanded to the Resident Assessment Instrument (RAI) (Hawes et al., 1997, Morris et al., 2003, Zimmerman et al., 1995). The QIs developed have been validated and resulted in the recommendation of 14 clinical indicators with high validity (Morris et al., 2003). Collecting resident data with RAI also has the objective to determine reimbursement from MEDICARE, by placing the resident into a resource utilization group (RUG) (Medicare, 2010). RAI was supposed to support care planning as well, and thereby contribute to adequate care (Mor et al., 2008, Morris, 2007). To attain specific outcomes, triggers in RAI are developed, directing the nurse to certain protocol guidelines called the Resident Assessment Protocols (RAP) concerning the actual care problem (Dosa et al., 2006). By implementing RAI as a mandatory assessment tool, several goals could be attained; quality monitoring, basis for reimbursement, care planning, and database for research.

No other country has developed an equivalent assessment of residents that also function for quality monitoring (Nakrem et al., 2009).

The various efforts in the Western world to define observable markers of quality most often focus on clinical issues, and there is a gap in knowledge of how to integrate the lived experience of the resident. However, efforts to operationalize measures that capture nursing care quality are valuable contributions to defining quality and should be considered as potential QIs for nursing home quality. Examples of instruments are:

Assessing Care of Vulnerable Elders (ACOVE) (Shekelle et al., 2001, Wenger et al., 2007, Wenger and Shekelle, 2001), Dementia Care Mapping (DCM) (Beavis et al., 2002), Service measurement tool for health care (SERVQUAL) (Curry and Stark, 2000), The Shift Coupon (Kellogg and Havens, 2006), and SeniorAlert (Uppsala Clinical Research Centre, 2011). None of these instruments are yet fully integrated into quality assurance or control systems on a national level.

In Norway, reporting statistical data based on resident assessment has been in place since 2006. Each municipality reports individual resident data annually in a pseudonymous database (IPLOS), administrated by Statistics Norway (Helse- og omsorgsdepartementet, 2006, Sosial- og helsedirektoratet, 2003). IPLOS is well suited for collecting data for monitoring the service utilization on a national level and allocating resources on community level, but less suited for management of clinical quality on organizational level (Kise, 2004). Indicators on resource usage and results achieved in terms of user satisfaction and quality are used by The Norwegian Association of Local and Regional Authorities (KS); the employers' association and interest organization for municipalities, counties and local public enterprises in Norway. They focus on result efficiency, and clinical quality indicators or nursing sensitive

indicators are not included (Kommunenes sentralforbund, 2011). Monitoring clinical quality is regarded as a professional responsibility, which can be controlled through internal control, quality management systems, clinical guidelines and statutory framework (Kommunenes sentralforbund, 2004). However, only a few national standards and guidelines for nursing care in nursing homes exist, and there is still limited knowledge about best practice for the nursing home population.

The number of possible QI is unlimited, but the critical issue is to find QI that have high validity for the domain of care in focus (Griffiths et al., 2008). Robust QI should be valid, sensitive, relevant, measurable, reliable and unambiguous (Lindahl and Bakke, 2010). The methods for developing QI are not very straight-forward, and include several steps to validate the indicators (Agency for Healthcare Research and Quality, 2004). Adequate risk-adjustment is preferable and includes making clinical groups (case-mix) more homogeneous according to preferences, age, disease-group, gender, level of functioning, aim of the stay and care service (Arling et al., 1997, Grabowski et al., 2004, Mor et al., 2003, Sangl et al., 2005). The first step in developing QI is to describe what the service (nursing home care) consists of and who the target group is, including any secondary interested party. Next, important properties of the service must be defined, i.e. important quality aspects according to all stakeholders (Saliba and Schnelle, 2002). Then the measure for good result or success has to be agreed upon, and evidenced-based processes and structures that underlie the result must be documented. Measurable indicators derived from this procedure must be tested in a scientific manner for relevance to nursing home care quality and patient-centredness, reliability in the way it is obtained, comparability between facilities, ability of clear interpretation and whether the indicator can be influenced by improving nursing quality, i.e. nursing

sensitive (Agency for Healthcare Research and Quality, 2004). It is preferable that the data retrieved for QIs are obtained by data that already exist, and that data collection for QIs does not mean extra workload for health personnel (Dellefield, 2008). Easily retrieved data from the patients' records is an example of such data for QIs (Arling et al., 2005). Tools to ease the use of QIs in clinical settings need to be developed. Furthermore, there are challenges regarding making the QIs available to the public to inform the residents and family (Du Moulin et al., 2010, Grabowski, 2010).

To sum up, the conceptual part of this thesis has presented existing knowledge of quality definitions and aspects of health care quality in general. The resident and family perceptions of quality of care in nursing homes in previous research have also been described. Finally, knowledge and related issues about development of quality measures for monitoring quality of care in nursing homes are outlined. A shortage of knowledge is identified regarding how to develop and verify a model of quality of care for Norwegian nursing homes that integrates resident, family and professional perspectives.

3.0 Research aims

The aim of this thesis is to explore the professionals', residents' and family's perception of key factors for quality of care in nursing homes. The research has an overall aim to contribute to the development of robust quality indicators that are relevant, sensitive and durable for measuring the quality of nursing and care for residents with long-term stays in nursing homes.

The specific aims were:

- To review the international literature, policy and practice regarding utilization of nursing sensitive quality indicators in nursing homes, and to evaluate the evidence for their reliability and validity
- To describe how the residents experience the nursing home service related to quality of care
- To develop a description of how the family members understand quality as it pertains to the resident's nursing home experience

4.0 Methods

In this section I give a presentation of the sampling and data collection, and the analysis process. I also present ethical considerations related to the interview study.

Review methods and qualitative methods were used to explore the concept quality of care and its domains, and thereby lay the foundation for developing resident-centred nursing sensitive quality indicators for nursing home care. First, review methods were employed to describe and evaluate potential nursing sensitive quality indicators.

Next, the residents' and their families' perception of important factors for care quality were explored.

Determining what aspect of nursing home care should be measured is the current work of many national health care systems. Toward this end, countries have made variable efforts to determine QIs of nursing home care to evaluate its achievement.

Gaining an understanding of the status of these varied efforts may give important insights that can be used to develop coherent local, national, and international nursing sensitive quality indicators for nursing home care. As the cost of developing and validating new quality measures is significant, a strong case can be made for international cooperation. A convenience sample of seven countries with similar elder care such as access to nursing homes when needed, payment subsidized by tax or insurance, comparable cultural conditions, and a national system for monitoring nursing home quality was selected for review. The seven countries were USA, Australia, Norway, New Zealand, England, Sweden and Denmark. Although the USA has an elder care system with a larger private market influence than the other six countries, USA was

included because there is a large amount of research concerning the development of nursing home care QIs (Capitman et al., 2005).

Quality inquiry is a valuable approach when the aim is to achieve a holistic understanding of a multifaceted phenomenon in a specific context (Patton, 2002). The method aims to elicit the interviewees' views of their world and the events they have experienced or observed, and look for the specific and detailed rather than looking for the average. The understanding of the meaning is based on those specifics (Hammersley and Atkinson, 2007). Meaning is studied as a shared meaning in a culture, recognizing that each person bring to bear the understanding held by peers, family, friends or members of the groups to which he or she belongs (Gubrium and Holstein, 2001). The long-term nursing home residents and their family members are individuals with their individual background but also have a shared meaning of the experience of living in a nursing home. What was important in this study was to explore how the residents and family members view the service and the meaning that they attribute to it.

Because nursing home residents often suffers from dementia, their opinion on quality issues is not easily obtained. To get insight into the experiences of residents who cannot speak for themselves, we included interviews with their next-of-kin. In customer satisfaction studies, focus groups are often used to define concepts, identify factors relevant to satisfaction and discover what influences the satisfaction or dissatisfaction (Krueger and Casey, 2009). Focus groups are also one of the strategies used to define quality and are well suited for exploratory studies in a new domain (Kvale and Brinkmann, 2009). The interviews with family members were done to attain knowledge and stories in a given context. The family members of the resident who were invited to participate in the focus group interviews were supposed to speak on behalf of the

residents, and the interviews were meant to be relevant for all residents in nursing homes. To achieve this, we found it useful to relate the interview to the specific context by interviewing the family members in a location in the nursing home, or nearby, and together with other family member who had similar experience and they could feel a kind of solidarity with.

4.1 Review study of literature, policy and practice (paper I)

A review of literature, policy and practice was done to review nursing sensitive indicators used across nations, and to evaluate them for their usefulness as measures of quality of nursing care for elderly residents of long-term care facilities.

4.1.1 The search process

A systematic search for relevant articles and reports was performed. The search strategy is outlined in box 1.

Box 1 Search strategy for the review study

- Electronic search in scientific databases (CINAHL, MEDLINE, PsycINFO) using the terms
 "quality indicator" or "clinical indicator" combined with "nursing home" or "long-term care",
 limited to English language and year 1990 through September 2007
- 2. World Wide Web, via GOOGLE using search terms such as "Quality indicator", "nursing/rest homes+[name of country]" or "residential nursing facilities", with equivalent search terms in Nordic languages. The first 20 hits/references were further explored. In addition relevant websites maintained by governments were explored and searched for information about quality indicators in nursing homes.
- 3. Hand searches in reference lists from relevant studies and reports found in the search number 1 and 2.
- 4. Personal communication with experts in the field, persons in appropriate government departments and relevant organizations in order to get an overview of quality indicators in use and to crosscheck information found in stages 1-3.

4.1.2 Inclusion criteria and data extraction

Material was restricted to English or Nordic language. The abstracts of the articles and reports were first read to find whether they met the inclusion criteria. Reviews were first retrieved, and then additional papers concerning evaluation and validity testing were included for data extraction. Materials gathered in the search process were included for review if the main focus was use, developing and/or testing of quality indicators for care in nursing homes for persons over 67 years. Firstly, extracted data from government web sites and other papers including legal documents, laws and regulations, and institute reports were used to obtain an overview of each country's utilization of nursing sensitive quality indicators. Secondly, from the systematic search in databases, 107 papers were retrieved in full text and studied in detail, reviewing how the QIs were developed and tested. Forty-five papers were included in the review, and formed the basis for evaluating the evidence for the nursing sensitive quality indicators. It was determined that only process and outcome QIs were evaluated for inclusion because the structural indicators, such as size of room, proportion of en-suite rooms or level of staff, were considered to be less nursing sensitive.

4.1.3 Analysis and evaluation of the indicators

The data was highly heterogeneous, due to varying definitions of quality indicator, differences in the level of operationalization of quality indicators, as well as cultural differences regarding resident characteristics in nursing home populations of different countries. Consequently, the analysis was based on qualitative content analysis of the data. First, the current practice regarding use of needs assessment of the nursing home

residents was described for each country. Then, the indicators that were determined to be nursing sensitive were listed and described in detail. Next, the reviewed indicators were categorized into nursing domain and level of measurement (outcome or process). Finally, criteria extrapolated from the evaluation process used by two internationally recognized U.S.-based health services research organizations, Agency for Healthcare Research and Quality (Agency for Healthcare Research and Quality, 2004) and the Joint Commission on Accreditation of Healthcare Organization (Joint Commission on Accreditation of Healthcare Organization, 2007) were used to evaluate the validity of each QI, see box 2. The published material extracted for the review was studied for evidence on each criterion A-H for each of the included QIs. The evaluation placed each indicator into categories "Yes" (Evidence was found in the material), "Uncertain evidence", or "No" (no evidence was found in the material).

Box 2 Evaluation criteria

- A. Relevant to nursing home care and influenced by nursing actions;
- B. Face validity demonstrating sound clinical or empirical rationale for its use;
- Construct validity demonstrating congruence with other measures intended to measure the same or related aspect of quality;
- D. Discriminant validity demonstrating meaningful differences in care;
- E. Reliability demonstrating ability to consistently measure differences in care over time with minimal random or systematic error and can be reproduced;
- F. Risk-adjustment or stratification method is considered to adjust for patient mix;
- G. Minimum standard or threshold is determined for use in accreditation processes or for benchmarking;
- H. Available in existing databases and can be extracted with minimal extra efforts.

4.2 Interview study (paper II-IV)

The interview study encompassed interviews of residents in nursing homes and relatives and next-of-kin to those residing in the same nursing homes, without exclusively matching resident and family member.

4.2.1 Study settings

A purposive sample of four public nursing homes in Norway with long-term care residents was included, comprising small-, medium- and large-sized nursing homes in both urban and rural areas (table 1). The doctoral student first contacted the management of the nursing homes, informed the staff at the ward about the project, and got permission to perform the study in the nursing home and to ask residents and family members to participate in interviews.

The nursing homes (labelled A, B, C and D) had mixed populations according to medical diagnosis, physical and cognitive functioning, age (ranging from 45 to 100 years old) and gender. All four nursing homes were somatic nursing homes, but also had a special unit intended for residents with cognitive deficits or dementia. Informants for the interviews were only recruited from the somatic units. The nursing homes in the study were municipal public enterprises, owned and run by the municipality. The nursing homes varied in size with a total of 68 residents as the largest and 24 residents as the smallest, and units varying from 8 to 35. Most residents had single rooms with a private bathroom, but there were also double rooms and shared bathrooms. Each unit had their own dining and living rooms. In addition there was a larger institutional living

room or public area where concerts, exercise activities and festivities were arranged. In nursing home A and D, food was delivered from a large central kitchen run by the municipality. Food was prepared at the nursing homes' main kitchen and delivered to the units in a trolley in nursing home B and C. Nursing home D was part of a health facility centre, with sheltered housing, office accommodation for home services in the area, a local cafeteria and an assembly hall open to all people in the neighbourhood.

4.2.2 Participants

Initially, twenty-four informants were recruited for resident interviews. Inclusion criteria were age of 65 or older and being resident of the nursing home for one month or longer. Physical and mental capability to handle the interview and ability to give informed consent to participate was assessed by one of the clinical nurses. The researcher contacted the residents consecutively, handed out the information letter and read it out loud when requested. The residents consented orally to participation and the time for each interview was determined. The informants were encouraged to ask a relative or friend to read the cover letter. Several of the informants had shown the letter to relatives, but none wanted another person to be present during the interview. Inclusion of new informants continued until the researcher felt that no new elements were emerging. Two additional residents were then interviewed, but no new information was obtained. Fifteen informants were included in the study (table 1).

To recruit the participants to the focus group interview with family members, a postal information letter was sent to one family members of each resident, stated as closest next-of-kin in the residents' record, in two of the four selected nursing homes,

with an invitation to attend a focus group interview. Three focus group interviews were then completed, one group from each nursing home and one group with relatives recruited from both nursing homes. Respectively seven, five, and four persons took part in the interviews, altogether 16 relatives (table 1).

Table 1 Participants and settings

	NH A Urban, 80 bed	NH B Rural, 68 bed	NH C Rural, 57 bed	NH D Urban, 24 bed
Women (age)		R3 (75) R4 (89)	R9 (92) R10 (84) R11 (77) R12 (77) R13 (75) R14 (85)	R15 (88)
Men (age)	R1 (84) R2 (87)	R5 (96) R6 (82) R7 (80)	R8 (87)	
Family members	2 sons 5 daughters 2 wives 1 sister	3 sons 2 daughters 1 niece		

Legend table 1:

NH = Nursing home R = Resident (informant)

4.2.3 Data collection

In the resident interview study, data were collected by in-depth interviews with the residents (Gubrium and Holstein, 2001). To assist the interviewer, an interview guide with open-ended questions and probes was used (see box 3). The guide was reviewed by three experts for its face validity and piloted with one resident. Changes were then made to improve the data collection process. However, to have an information-rich description of the informants' experiences, a narrative approach was used, with

questions such as "Tell me how your day is" or "Tell me about when you moved into the nursing home", encouraging the informant to freely tell about their life in the nursing home. All interviews were conducted by the doctoral student. The interviews were tape-recorded. During the interview, the interviewer repeated and summarized the expressions of the informants and asked them whether it was correct. Immediately after each interview, the interviewer took notes that described the setting and summarized the general impression of the interview.

Box 3 Outline of topics in the interview guide

Basic physical needs
Psychological needs
Well-being and thriving
Social needs and relationships
Nursing care and medical treatment
Dignity, human rights, respect and self-determination

In the family interviews, each of the three focus groups met once. Respectively, two groups met at the nursing home where their family member stayed, the mixed group met at the municipal library. The focus group interview is a qualitative group interview that focuses on a specific topic, selected by the researcher (Krueger and Casey, 2009), and an interview guide was used during the interviews. After the introductory information and presentation, the interview guide included five open-ended key questions, see box 4.

Box 4 Questioning route for focus group interviews

- 1) What does the concept "care quality in nursing homes" mean to you?
- 2) Can you identify factors that contribute to well-being of their resident?
- 3) Can you describe what you view as indicators of good care?
- 4) Can you describe what determines your dissatisfaction with care?
- 5) Can you share your ideas about areas of improvement?

Two researchers conducted the interview. One researcher; one of the cosupervisors of the doctoral student; moderated all interviews. This included keeping the
discussion on track, ensuring that everyone took part, and balancing the participants'
contributions. The other researcher; the doctoral student; was present as an observer
with the responsibility to assure that the five open-ended questions were posed, took
notes during all interviews, and reported the general impression of each interview
(Krueger and Casey, 2009). The tape-recorded group interviews lasted for
approximately 45 minutes. The interaction between the participants is important in
group interviews (Krueger and Casey, 2009). The participants were given the
opportunity to express their feelings about the interview immediately after the
interview. After the informants had left, the researchers continued with a debriefing
where we discussed how the interaction had been and how it could have influenced the
data collection.

4.2.3 Analysis

All resident and focus group interviews were transcribed verbatim, retaining frequent repetitions, pauses, and emotional expressions (Kvale and Brinkmann, 2009). The analysis started once the first data were gathered by reviewing the data in the light of the research questions (Gubrium and Holstein, 2001). The analysis continued when all data was collected. To get an overview of themes and a general impression of what the interviewees had expressed, the transcripts were first read through while listening to the tape recording and a matrix of the first general themes was constructed. The analysis then moved into meaning condensation and coding. Meaningful entities in the

transcripts were identified, and the text or expressions of the interviewees were sorted into more specific categories. Finally, by comparing and contrasting the content in each category, meaning categorization was achieved (Kvale and Brinkmann, 2009). The electronic tool for mind mapping MindJet MindManager (MindJet, 2004-2009) was used in process when analysing the resident interviews. The subsequent codes and subcodes that emerged analysing the focus group interviews were categorized into an index. Examples of the process are provided in table 2.

Table 2 Example of the process from text data to category

Text (meaning unit)	Condensed	Code	Category
"You just can't get out of bed" (Resident)	Fearing health decline	Health promotion	Care for medical, physical and psychological needs
"I stay in contact with friends and family but less and less often. When you come here, it seems like there isn't more. It wasn't like that when I was home and cooked and had them over." (Resident)	Loosing contact with social network	Role change	Protecting the resident's integrity
"Mary' was in pretty good shape when she arrived and so was 'Nora'. I think they lay in bed too much. There aren't enough people and it occurs to me that they should be giving more help to them. Oh, I hope that I get - so that I can die that I don't have to go through that. I know that they are all right and kind and everything, but then, they don't have any trouble with me." (Resident)	Staff too busy to take care properly	Staff routines	Personal habits and institutional routines
"It's not easy to find something to do here" (Resident)	Being bored	Activity	Meaningful activities for a meaningful day
" that I can see he is having a good time that I can see that he is pleasedI just have to see his face. I want the staff to touch himgive him a hugand they do." (Family member)	Feeling their loved one gets good care	Well-being	Resident contentment
"When others are on duty, there is a cassette player with old-fashioned music that old people have a liking for. Then you know that there is one on duty who knows what elderly people prefer. And that I think,it is good to know." (Family member)	Staff knows what the residents prefer	What a staff member do	Suitability of staff

To enhance rigor and enhance trustworthiness in the analysis, two researchers independently coded the data. The research team, consisting of the authors of paper II-IV, had meetings throughout the process to review the data, reflect on the emerging categories and validate the findings. A question arising when using group interviews as data is whether it is the group or the individual that is the analytical unit. The goal of using focus groups is to find the range of opinions of people across the groups, not to reach consensus, and thus, the individual participants' opinion were data basis for the analyses (Krueger and Casey, 2009). Since each group met only once, and the participants mostly were talking about their opinion on behalf of their loved ones, the individuals have been treated as subjects in the analysis. Even if the participants discussed with each other rather than communicating with the researchers, the interactional processes were not analysed separately, but were regarded as part of the data material in the continuous analysis.

4.2.5 Ethical considerations

The study was approved by the Regional Committee for Medical and Health Research Ethics. All participants in the focus group interviews gave their informed written consent to participate. The family members were encouraged to inform, if appropriate, their loved ones about the participation in the interview. Regarding the resident interviews, the ability to give consent to participate in the interview was assessed by the clinical nurses and by a short pre-interview of the informants carried out by the interviewer. An extended testing of mental status was not considered necessary because residents were excluded if there was any doubt about adequate cognitive function.

Before the interview started the interviewer repeated the information that the interviewees had previously received: all information would be kept confidential, participation was voluntary and refusal to participate would have no impact on their situation in the nursing home. Residents who were able to write signed the written consent, in addition to the oral consent. The care personnel in the nursing home were informed who had participated in the study so that they could give extra attention to the resident after the interview if needed.

5.0 Results - Summary of the papers

In this section the main results of the four papers are presented. Methods and material used in each paper have been presented previously in the methods section.

Paper I

Nursing sensitive quality indicators for nursing home care: International review of literature, policy and practice.

The aim of the study in paper I was to review nursing sensitive indicators used for nursing home care across seven nations with similar elder care (USA, Australia, Norway, New Zealand, England, Sweden and Denmark), and to evaluate their validity. Systematic search in the literature and other sources was done to find descriptions of development and validity testing of national QIs. An overview of each country's utilization of quality standards for nursing home care and resident needs assessment was obtained. The countries included in this study had descriptions of standards either in White Papers or legal documents, though with varying detailing level. Some of the standards had specific expected outcomes (Australia) and others were more general, only specifying some recommendations for care planning, for instance Care Standards in England. All countries, except Sweden, had nationally standardized needs assessment of the resident before admission to the nursing home. There was large variation in the way these resident assessment tools were developed and how the data is used. In USA

the Resident Assessment Instrument Minimum Data Set (RAI-MDS) has been in place since 1991 and is now used in all nursing homes in the USA. England has also developed their Single Assessment Process for Older People based on the RAI-MDS. The other countries have either developed their own instrument or integrated parts of other instruments in their national assessment instrument, for instance Australia's needs assessment instrument is based on the WHO's International Classification of Functioning (ICF). Norway has included elements of RAI-MDS and ICF in their needs assessment instrument. Only the USA has systematically developed QIs on the basis of resident assessments. Twenty-three indicators used nationally in USA, thirteen in Australia, four in Norway, three in New Zealand and three in England were judged to be nursing sensitive. These were selected for review and evaluated for their validity as described in the literature, using a set of evaluation criteria. All selected indicators had satisfactory face validity, and for the 23 indicators used in the USA there was evidence for reliability testing. None of the QIs met all the criteria for validity. Evidence that the QIs can demonstrate meaningful differences in care and that the information can be extracted with minimal extra efforts was not found. Thresholds for high or low quality were determined only for the QIs used in USA. The review concludes that indicator development and testing is sparsely documented, and gaps in knowledge exist. Evidence on how quality was conceptualized, integrating resident, family, and professional perspectives was not found in the review.

Paper II

Residents' experiences with the interpersonal factors of nursing home care: a qualitative study

The study presented in paper II aimed at getting a description of the nursing home residents' experience with the interpersonal factors of nursing care. In-depth interviews of fifteen mentally lucid residents, aged 65 and over, living in one of four nursing homes selected for the larger study of Norwegian nursing homes were performed. The residents emphasized the importance of nurses acknowledging their individual needs, which included need for general and specialized care, health promotion and prevention of complications, and prioritizing the individuals. The challenging balance between selfdetermination and dependency, the altered role from homeowner to resident, and feelings of indignity and depreciation of social status were key issues in which the residents perceived that their integrity was at risk in the patient-nurse interaction and care. Psychosocial well-being was a major issue, and the residents expressed an important role of the nursing staff helping them to balance the need for social contact and to be alone, and preserving a social network. The conclusion is that quality nursing care in nursing home implies a balanced, individual approach to medical, physical and psychosocial care, including interpersonal aspects of care. The interpersonal relationship between resident and nurse implies long-term commitment, reciprocal relationship on a personal level and interpersonal competence of the nurses to understand each resident's needs.

Paper III

Ambiguities: Residents' Experiences of "Nursing Home as My Home"

The aim of the study in paper III was to describe the residents' experiences with living

in a nursing home related to quality of care. In-depth interviews of fifteen mentally

lucid residents, aged 65 and over, living in one of four nursing homes selected for the

larger study of Norwegian nursing homes were performed. The main finding was that

the residents perceived the nursing home as their home, but at the same time not 'a

home'. This essential ambiguity created the tension from which the categories of

perceptions of quality emerged. Four main categories of quality of care experience were

identified: 'Being at home in a nursing home', 'Paying the price for 24-hour care',

'Personal habits and institutional routines', and 'Meaningful activities for a meaningful

day'. Thus, ambiguities concerning the nursing home as a home and place to live, a

social environment in which the residents experience most of their social life and the

institution where professional health service is provided were uncovered. High quality

care was when ambiguities were managed well and a home could be created within the

institution. These findings have consequences for developing quality measures.

Paper IV

Quality of Care in Norwegian Nursing Homes - Typology of Family Perceptions.

This study, presented in paper IV, aimed to elucidate the understandings and beliefs

about quality held by family members of residents of Norwegian nursing homes.

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Qualitative methodology was implemented by carrying out three focus group interviews with, in total, sixteen family members of residents in nursing homes. Three domains emerged that served as anchors for a typology of family perceptions of the quality care continuum. The first domain "Resident contentment" comprised the categories "Wellbeing", "Physical maintenance" and "Safety". The second domain was "Suitability of staff" divided into the categories "What a staff member is" and "What a staff member does". The third domain concerned "Environmental context" and included the categories "Allocation of resources: staff and time", "The physical environment" and "Public authorities". Each domain was developed with categories describing high to low quality markers, which were then clarified by enhancing and hindering factors. This typology provides a family perspective framework that may be useful to nursing leadership at all levels of the nursing home organization to identify important quality of care strengths as well as markers of poor care.

6.0 Discussion

In this section I will first present a general discussion based on the main findings and discuss implications for practice. In the last part of this section, I will discuss methodological issues. This thesis includes the results of one review and evaluation paper, two papers presenting the views of the residents and one paper presenting the family members opinions. Based on the findings presented in this thesis a multidimensional model of quality of nursing care is constructed (Figure 1).

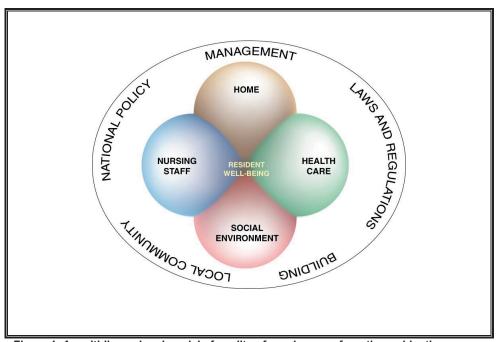


Figure 1 A multidimensional model of quality of nursing care from the resident's perspective

The core outcome of quality of care from the nursing home resident's perspective could be captured in the term subjective feeling of well-being. Four nursing sensitive areas emerged from the findings. "Home" represents the ambiguities of personal space vs. public place, care routines and meaningful activities (paper III). "Nursing staff" includes suitability of the staff, regarding attitudes, behaviour and actions, and protection of the residents' integrity in resident-nurse interactions (Paper II, III and IV). The social environment domain has a reference to the entire nursing home community, including the resident, co-residents, family members and the relationship with staff (paper II, III and IV). The health care domain comprises care and alleviation of the residents' afflictions, health promotion, and optimal prioritization according to individual needs in the current situation (Paper II and IV). The international nursing sensitive quality indicators are mainly based in this domain (Paper I). Finally, care quality is influenced by a range of external factors such as the national policy, laws and regulations, management of the organization and the physical building (Paper I and IV). The local community provides a context in which the nursing home is more or less integrated into (Paper II, III and IV). The findings added together, suggest that nurses are in a key position to optimize value in nursing home care by enhancing factors associated with quality. Thus, to measure quality of care in nursing homes, nursing sensitive quality indicators can be used.

6.1 Understanding and measuring quality

Quality of care encompasses a holistic approach that integrates all dimensions outlined in Figure 1. As resident well-being is the ultimate measure, it could be argued that this

only can be understood from an individual subjective perspective, and that quality of care in this perspective can only be observed by asking the resident directly or observing how the resident is doing over time. High nursing home care quality may be easily recognized in the subjective experience of well-being, but when it comes to determine the specific quality measures it becomes more vague (Slagsvold, 1995). High quality care is more than absence of low quality, deficiencies or unsafe care, but there is a risk of omitting areas of importance when describing good care. Furthermore, quality of care is relational and influenced by expectations and demands from the individual, the population and the society. Nonetheless, the multi-dimensional model described in Figure 1 contributes to a more nuanced understanding of quality of care. Even if quality is the whole, and the domains are not clearly separated from each other, exploring the details on what constitutes high quality could contribute to developing QIs for the most significant areas of quality of care. Quality of care in the different areas are related in that low quality in one area gives low overall quality even if there is adherence to high quality standards in another area. However, focusing on improving quality of care in one area does not cause low quality of care in other clinical areas. On the contrary, nursing homes with high quality standards in general, do well in most areas (Baier et al., 2009, Castle and Ferguson, 2010). The residents' experiences of quality of care reported in the present thesis can inform the development of nursing sensitive quality indicators in important areas.

One major issue of becoming a nursing home resident is to create a new home to where you belong. The residents in the present study perceived the nursing home as their home and a nice place to live, but at the same time not 'a home', and some residents even perceived themselves as homeless. This creates the essential ambiguity

from which the informants described their experience of quality of care. Being 'at home' in the nursing home was associated with the possibility to withdraw from the community to their room, which gave them the ability to retain self-determination. The residents wanted to be more independent and self-determined, yet their dependency on 24-hour care changed their attitude towards accepting a less satisfying life in the nursing home. This dependency of 24-hour care and the nursing staff was generally accepted, but it created an extra vulnerability. Power and control in everyday situations were placed on the nurses in their interactions with the residents. Since the residents saw that the staff were busy, they felt prioritized or lucky when they received some extra attention or even the regular care. Quality of care therefore depends on the nursing staff, and it is important to be attentive to this risk of disempowering the residents. Nurses have great impact on the residents' experience of being included or excluded in nursing actions (Westin and Danielson, 2007).

Respect for the residents as individuals with different needs is the essential attribute in a personalized model of care (Jonas-Simpson et al., 2006, Kennedy et al., 2005). However, to assess the individual needs, the nurses must put efforts into knowing each resident. Interpersonal aspects of care, such as the nurses' skills and ability to connect with, and know each resident are important factors for successful individually adjusted care (McCormack and McCance, 2006). This implies long-term commitment, reciprocal relationship on a personal level and understanding of each resident's needs. In relationship-centred care, the interactions between the parties in care are regarded as foundation of any therapeutic or healing activity (Aveyard and Davies, 2006). However, according to Nolan et al. (Nolan et al., 2004), all participants in the interaction need to experience reciprocal interpersonal relationships that promote

genuinely empowering if quality care is to result. It could be argued that the possibility of creating such relationships may be limited, since the residents in our study perceived the nurses as busy and felt that they could not expect to receive more attention from the nurses. Some of the residents were even uncertain about what relationships with staff could offer them. The caregivers' commitment to the relationship with older people is a deep human feeling that is fundamental in long-term care, and should be promoted to enhance quality of care (Haggstrom et al., 2010).

Understanding the patient's situation is essential in quality improvement work in health organizations (Lloyd, 2004). Deming (2000a) based his approach to quality improvement on the assumption that quality has no meaning without listening to the voice of the customer, and stated that quality is meeting and exceeding the customer's needs and expectations, and then continuing to improve (Deming, 2000a). Defining quality as a static measure is difficult because not only do the nursing home residents' needs change, but also the means for providing quality services change, for instance new methods or new technology are developed (Lloyd, 2004). For nursing home care this means that quality measures need to be adjusted to the actual nursing home population's needs, expectations and opportunities at the present time and the future, using a dynamic QI set. Many of the residents in the present study had lowered their expectations of the service and explained it by their age. Low self-esteem and loss of status in society may be the reason why older people, especially those who are functionally dependent, often have a feeling of being worth less (Bodner, 2009). The residents are frail and vulnerable and their dependence on the staff is evident. Therefore, it is particularly important to protect each resident's integrity by recognizing the resident as an individual with individual needs. Becoming very frail or suffering from

dementia could put the resident's perception of being treated with dignity at risk, because the resident would have difficulties in maintaining self-respect and identity (Pleschberger, 2007). It is important to acknowledge risk of low care quality for the most vulnerable residents, and to take this into consideration when it comes to clinical prioritizations in nursing homes (Slettebo et al., 2010).

However, too much focus on the individual might disregard the significance of the social context. Respect and self-worth are social emotions that are communicated in relationships (Slagsvold, 1995). The nurses have a responsibility of contributing to creating social environments, including family relations that support the quality of life for the residents. The residents appreciate that the nurses show through behaviour that both residents and staff are part of the nursing home community almost like a family, and share reciprocal information about themselves and their family. Since the residents in nursing homes often feel lonely (Slettebo, 2008), and there is often little communication between residents (Hauge and Heggen, 2008), the residents become more dependent on the nursing staff, not only for clinical care, but also for their psychosocial wellbeing. It is important, though, that the residents' social needs are assessed and that the nurses are sensitive to the preferred involvement from the nurses (Bergland and Kirkevold, 2005).

The nursing home population consists of frail older persons, and as many as 80 % suffer from cognitive impairment, which limits the possibility to elicit their opinion on quality of care. However, resident participation in evaluation of quality of care and determination of desired outcomes of health care services encompasses various levels, and can be perceived as a continuum between self-determination to limited participation (Norheim and Vinsnes, 2008). Even severe cognitive disabled residents can contribute

at some level. For instance, even though the resident cannot tell where he or she is, it doesn't mean that the resident cannot tell what he or she likes in the present situation. Residents who feel that they do not have the right to speak up to have their basic care needs met might experience low quality of life (Eika, 2006).

As a substitute for those who cannot adequately express themselves verbally, their next-of-kin can be involved. The study of family understanding of quality pointed to domains that capture the lived experience of their loved one, expanding their realm of concern beyond the presenting physical health condition. However, quality of care attributes described by family members are less readily measured than the presence or absence of a medical event such as a bedsore or use of restraints, which are QIs in the health care domain in the model presented in Figure 1. Another limitation of using nextof-kin as proxy for measuring quality is that they often are children of the residents and thus belong to a younger generation. This can limit the understanding of quality from the older resident's view. According to the theory of gero-transcendence, older people change their perspective of life as they age, which involve a redefinition of reality (Wadensten, 2007, Wadensten and Carlsson, 2007). In addition, it has been found that recent health problems give an inflated perception of limitations due to shift in their internal standards, consistent with a recalibration-type response shift (Daltroy et al., 1999). However, it has been found that in general, the evaluation of quality of care of the next-of-kin is closer to the evaluation done by the residents than of staff members, as the staff tends to be more critical over quality of their work (Andersson et al., 2007, Castle, 2006, Gjerberg, 1995, Paulsen et al., 2004, Romøren, 2005b, Teeri et al., 2008). When it comes to interpersonal relationships, it has also been found that nurses, residents and family members define close nurse-resident relationship differently

(McGilton and Boscart, 2007). In this study, nurses focused on emotional connectedness, residents based their definition on attitudes and behaviour of the caregiver and family determined the closeness of relationships by the positive effect it has on well-being. This has implications for how quality of care is defined and measured (McGilton and Boscart, 2007).

Quality of care could be understood differently from different perspectives such as the provider (the municipality), the professional health workers and the residents. This leads to a question about who is in position to determine the acceptable level of quality. About the only consistent result drawn from the empirical literature examining long-term care choice is that people generally do not want to enter a nursing home (Grabowski and Gruber, 2007). However, once admitted the residents start to adapt to the new situation, and most residents report high satisfaction with the care (Buelow and Fee, 2000, Curry and Stark, 2000, Grant et al., 2007, Romøren, 2005b). The experienced residents could be able to express when they are feeling well, happy or healthy (high quality outcomes), but do not always have the insight into how the care should be performed to achieve these aims. On the other hand, nurses may have good skills and perform the nursing well, but do not achieve the wanted outcomes for the residents because the processes are not linked to the outcomes. The provider needs to ensure that the quality is at least at a minimum level of standards, but the professional standard might reach for a higher standard, or as stated in the IOM's definition "consistent with current professional knowledge" (IOM, 1990). This means that nursing home care needs to be consistent with the most effective way to deliver the service, and at the same time ensure that the residents' preferences, hopes and prospects are attended to. Professional health care workers are obligated to take a holistic perspective and

perform their work in a professional trustworthy manner. However, this gives the nursing staff an indefinite responsibility (Vike, 2004). The health care level of service has no boundaries per se, except the restrictions due to resources such as finances and work force. Working under financial restrictions with unlimited liability results in unreasonable demands in which the health worker is unable to fulfil. This can lead to troubled conscience upon not providing adequate care (Juthberg and Sundin, 2010). The challenge for the nursing home staff is to meet the competing psychosocial and physical care needs of all residents at the same time. The diversity of the residents' needs, varying from palliative care to social stimulation, adds complexity to nursing care.

Nursing home staff are confronted with the ambiguities of the nursing home, and have to create a home despite the fact that it is not an ordinary home, ensure individual care and dignity in an environment where humiliation is almost inevitable, and create a pleasant community and fellowship, although the residents only have few, if any, things in common.

Nursing home care quality is a complex phenomenon which will require on-going conversations with all involved to understand. Using resident developed quality indicators is the next step in the nursing home improvement journey. In addition, it must be taken into account that the nursing home's organization, staffing and organizational culture influence the means for quality care (Brown Wilson, 2009). Moreover, selection of QIs is influenced by health policy, and innovations in technology or the way service is delivered. Hence, integrated research on all factors that impact the delivery of care is needed to understand how to improve quality of care in nursing homes.

6.2 Developing a quality measurement system for monitoring and quality improvement

The review of international policy and practice shows that quality indicators for nursing homes are in use and do play an important role in certification and funding (Arling et al., 2005, Berg et al., 2002, Sainfort et al., 1995), even though there is limited evidence of content and construct validity (Hawes et al., 1997, Karon et al., 1999, Rantz et al., 1997, Zimmerman et al., 1995). These gaps are being addressed through efforts in the USA to examine the validity and reliability of the RAI-MDS long-term care QI set with the aim of improving this system (Arling et al., 2005, Berlowitz et al., 2002, Goodson et al., 2008, Mor et al., 2003, Rantz et al., 2000). QIs in long-term care can be criticised for their narrow focus on clinical care problems, focusing on avoiding poor care, with less attention to fostering high quality care and improving quality of life (Arling et al., 2005). The complex relationships among dimensions of quality remain unclear. QIs for quality of care in nursing homes should reflect what the residents truly desire from nursing homes (Grabowski, 2010).

One aspect that could be discussed is who needs the measures and why put effort into developing QIs? National and local governments' role is to monitor nursing home quality to check their accountability. Information to the population in general and to new and current residents is important as assurance that the service meets quality standards. However, for the staff at micro level in the nursing home, governmental regulations may be perceived unnecessary and a strain, taking focus away from their "real" work (Deming, 2000a). In a study by Kjøs et al (2010), they found that first-line leaders in nursing homes play a key role in implementing national quality policies and regulations, which they do by maintaining the quality system and error management

system, and collect data for user surveys. However, none of the first-line leaders had initiated systematic quality work on their own, and only half of the first-line leaders in the study described that they had a role in motivating and facilitating staff to be active in quality work (Kjøs et al., 2010). Measures of performance and QIs are not commonly used in Norwegian nursing homes today. Large municipalities have more quality activities than small- or medium-sized municipalities which may indicate that smaller municipalities have better oversight of the health care services and have less need for QIs to monitor the service (Kjøs et al., 2008).

Even if sensitive measurement tools, quality standards and systems for monitoring the quality are developed, there are future challenges in ensuring that they are used correctly, implemented effectively and responded to (Wunderlich and Kohler, 2001). Providing information to health professionals on their clinical performance over time and on a regular basis (audit and feedback) is suggested as an effective way to improve practice. However, even on the basis of the best evidence available, it is reported that no strong recommendations can be given regarding the best way to introduce audit and feedback into routine practice (Flottorp et al., 2010). The report did discuss a pragmatic use of audit and feedback, especially if there the quality is low, the costs for collecting data is low, or small to moderate improvements in quality would be worthwhile. This means that there is a need for awareness when it comes to costly audits and data collection for quality monitoring with only marginal benefit. Moreover, there is little scientific evidence that quality systems have an impact on the satisfaction and health outcomes of long term care residents (Wagner et al., 2001). Despite the substantial regulation and monitoring of nursing homes in USA, quality of care in many nursing homes remains low (Schlesinger, 2004). More research on the effectiveness of

quality systems and use of QI is needed and should include qualitative as well as quantitative methods (Wagner et al., 2001).

When developing QIs for monitoring, it is important to have a balanced focus on each domain in the multi-dimensional model described in Figure 1 to prevent skewed measures for quality of care. In each domain QIs within structure, process and outcome, see section 2.2, p 7, can be applied (Donabedian, 1980). Process quality judgment, including the interpersonal aspects of care, is made by direct observation or by review of recorded information. Structure and outcome QIs are indirect measures. The use of structural indicators is relevant in that structural factors increase or decrease the probability of good performance. However, the usefulness of structure as an indicator of quality of care is limited because they are less specific and sensitive, and there is limited knowledge about the relationship between structure and performance (Donabedian, 1980). When it comes to outcome QIs, other causes for the change must be taken into consideration to be reasonably sure that previous care is responsible for the change. It might be sufficient to measure process quality if it has been established that certain procedures used in specific situations are clearly associated with good results, e.g. clinical guidelines. The presence or absence of these procedures can be accepted as evidence of good or bad quality, and there is no need for further ascertainment (Donabedian, 1980). Researchers using Donabedian's work as a basis for developing quality measures have not emphasized this causal connection to a large extent, but have assumed that any high quality structure or process could give high quality outcomes for the individual patient (Gorski and Hackbarth, 2005). The causal connection must be taken into account, and all dimensions must be measured at the same time. When using only a few QIs for comparing care quality in nursing homes and benchmarking, there

may be problems concerning case-mix and adequate risk-adjustments affecting stability over time that have to be overcome (Hoffmann and Leichenring, 2011). Unless the QIs are adjusted for differences in the population, risk factors and facility characteristics including values, target groups, size, and location, comparisons may not be valid. In the interim, as a "second-best" opportunity, nursing sensitive quality indicators that do have a recognized high to low standard can be used to flag a facility's quality of care, and thereby help direct improvement efforts for nursing care delivery (Rantz et al., 2001, Rantz et al., 2003).

It is notable that evidence that the QIs can demonstrate meaningful differences in care is lacking. This means that nursing sensitive QIs used today may not be suitable for capturing quality improvements, but are rather measures that only matters to external parties to measure accountability (Solberg et al., 1997). Moreover, it is not clear that indicators reviewed in Paper I capture the values and opinions of the residents, probably because the documentation is sparse. To examine a different dimension that moves beyond the medical care quality indicators, quality of life has been studied (Kane et al., 2003). However, there is a lack of indicators of quality of life that are more convenient and less expensive than direct, in-person interviews with residents. In a study by Degenholz et al (2006), they tested a brief self-report measure of resident quality of life, and found that it was consistently associated with QI from RAI-MDS. However, only approximately 9 % of the total variance in self-reported quality of life can be attributed to differences among facilities whereas 91 % can be attributed to differences among residents. The authors conclude that the level of prediction does not justify reliance on external indicators of resident quality of life for policy purposes (Degenholtz et al., 2006).

The development of quality assurance is based on defining minimum standards, examining structural and process quality and development of technical specifications for result and outcome indicators, and should include research to validate the QIs (Griffiths et al., 2008). More sophisticated monitoring processes combining internal quality management methods with external audits (certification) and incentives for continuous improvement are also used internationally (Leichenring, 2011). However, dialogue on quality criteria, indicators and methods between providers, professionals and other stakeholders, including residents and their families is needed to make these systems sustainable. It is worth noting that the more sophisticated the external inspection system is, the more it calls for effective internal quality management (Deming, 2000b). Otherwise a large gap between results of inspections and actual quality in daily work is possible. A comprehensive quality assessment requires a combination of internal quality management and external inspections. The key to identifying quality improvements is measurement of change, which requires determining key indicators, collecting appropriate amount of data and analysing these data (Benneyan et al., 2003, Mohammed et al., 2008, Solberg et al., 1997). Measuring outcomes with QIs requires a 100% sampling rate which can only be achieved by internal quality management, and spot checks would not be sufficient. However, internal monitoring alone would not be reliable and needs to be validated by external quality checks, for which the sampling rate can then be much lower (Leichenring, 2011). Inspections and monitoring nursing homes with QIs do not automatically improve quality, nor guarantee quality because as soon as the service has been delivered, nothing can be done with the quality. Thus, quality improvements build on learning from mistakes and its consequences, and thereby develop good practice. Exceptions and circumstances in which mistakes and

inadequate care occur are inevitable but intolerable, and inspections and improvement actions at the right point are essential (Deming, 2000b).

6.3 Strengths and limitations of the methodological approaches

There are some considerations of the methodological approaches to be discussed, regarding how the methods used could have influenced the results and interpretation of the findings presented in this thesis. In the following I will reflect upon issues of reliability, validity and generalization of the findings of the present research. Some qualitative researchers discuss reliability and validity of their findings by using ordinary language terms, and concepts such as trustworthiness, credibility, dependability and confirmability has been introduced (Kvale and Brinkmann, 2009). When it comes to generalization, the term "transferability" is often used to judge whether the findings are relevant to other situations. I will go on using these terms, acknowledging that the meaning of reliability, validity and generalization in qualitative research is best explained by these concepts.

The limitations of the review methods in paper I, are related to the extensiveness of the literature search, critical appraisal of the information extracted, and level of rigor in the analysis. The limitations with the search method and inclusion criteria are related to risk of selection bias. For instance, locally developed QIs may have been missed because we were only looking at published material about QIs used nationally. Also, the search method designed to ensure a body of relevant review material, sought information on only seven countries. However, these countries were selected because of

the similarity to the Norwegian health system and therefore most relevant. In addition, review material from the use of indicators for nursing homes in USA was included to have larger amount of research as basis for the review. Information bias might be a problem because material was limited to English or Nordic language published information available on the internet or in accessible scientific databases. This could have restricted the findings. However, a systematic and comprehensive search strategy was applied, and as the internet is increasingly used for publishing government and research reports to spread information to service users and researchers (OECD, 2005), the probability of missing information because of lack of access was judged to be low. Selection of material for review and evaluation was based on a critical judgement of the validity of the information, quality, usefulness and transferability to the area of interest. However, the knowledge base in the area was limited, and a gap in literature was discovered (Hesse-Biber, 2010). The sparse documentation of indicator development and testing required cautious and limited conclusions (Bjørndal, 2007). A qualitative approach was used in the evaluation process due to the lack of research that could satisfy doing meta-analyses. This could have been a threat to the reliability of the synthesis and evaluation. However, the review was done by more than one researcher, and thereby the results were cross-validated throughout the process (Bjørndal, 2006).

The credibility of the empirical study depends both on rigorous methods in the data collection and analysis, and the credibility of the researcher (Patton, 2002). We took several steps to ensure that the results are trustworthy. The present research was conducted in a cultural context that we had experienced only as professionals, not ourselves as residents. Our cultural assumptions may have influenced what we asked and how we perceived what we heard (Rubin and Rubin, 2005). The researchers'

presuppositions might have limited the possibility to understand the cultural assumption of the interviewees, and this could be a threat to the trustworthiness of the findings (Kvale and Brinkmann, 2009). In the focus group interviews, two researchers were present, which enhanced the trustworthiness. The transcripts of the interviews were coded by both researchers, and both were able to discuss the emerging themes and coding of the text based on having experienced the interviews ourselves. The interviews of the residents were all conducted by one researcher which is challenging to inexperienced researchers. It required an open-mindedness towards my prejudices, and demanded flexibility and creativity to complete a good interview (Hauge, 2004b).

The criteria for inclusion and exclusion of participants for the interviews are crucial when it comes to decide whether the results are credible for the nursing home population. The knowledge acquired is a synthesis of understandings that come about by combining different individuals' detailed reports of a particular event or cultural issue (Rubin and Rubin, 2005). The sampling of nursing homes, family members and residents to collect data in the present study, was done purposely to permit understanding of the phenomenon quality in depth. The aim was to have information-rich cases who could bring forward issues of central importance (Patton, 2002). However, there is need for methodological awareness, and the search for negative instances or deviant cases should be central to qualitative researchers effort (Seale, 2007). The informants for the interview study of residents were included consecutively, and the decision to include additional informants was based on a feeling of saturation of meaning in the data. To detect whether deviant cases would emerge, additional interviews of two new residents beyond saturation level were conducted. No new information was gained, and it was decided to conclude the interviews. The same

procedure was used for the focus group, where we found that after the third interview, no new information was produced.

Rigor in the analysis strengthened the dependability and confirmability of the findings. We recognize that our prejudices and subjectivity contributed to the production of knowledge, and it was important to be sensitive this influence.

Developing sensitivity involves reflecting upon the processes in this knowledge production (Kvale and Brinkmann, 2009). The coding and indexing was done independently by two researchers, based on the verbatim transcripts, then compared with each other, and finally discussed in the whole research team aiming to reach agreement upon the most trustworthy interpretation. The research team consisted of professionals of both genders and different ages, and with varying background from both medical, social and health science. This strengthened the consistency and dependability of the interpretation of the findings because we involved different viewpoints during the data coding and indexing. The advantage of using multiple researchers is that it adds confidence in the logic consistency with which data analysis has been done (Seale, 2007).

The issue of transferability involve both the context in which the research was carried out, and the target group or readers of the research papers (Seale, 2007). The readers must always make their own judgements about the relevance of findings for their own situations. This requires that there are thick contextual descriptions of the settings, methods and procedures to give the reader the premises to decide to what extent the research results can be applied to another situation (Kvale and Brinkmann, 2009). Transferability of the present research to a general account of residents

perspectives on quality of care in nursing homes is only testable by attaining further information in these other "receiving" contexts (Seale, 2007).

6.4 Conclusion

Overall the conclusion is that the quality of care in long-term care in nursing homes consists of at least four domains: quality of the living conditions, quality of the nursing staff, quality of direct nursing care, and quality of the social environment. Thus, there is a need for comprehensive quality measures for the total experience of quality of care that focus on both quality of the environment and quality of resident-nurse interactions, as well as the outcomes of health care in nursing homes. In the review of internationally used quality indicators it was found that some factors of care processes and health outcomes for nursing home residents could be measured and give valid and reliable evaluation of the nursing home care quality. In the explorative qualitative study of the perceptions of residents and family, the experiences of quality of care implied larger focus on physical and psychological well-being, interpersonal relationships and the social environment. In detail, the residents and their family emphasized a safe environment and professional nursing care characterized by being treated with respect, having a voice in everyday care and decision-making and long-term commitment of the nursing staff. Objective indicators of essential areas of resident-centred quality of care need to be developed. To ensure that the resident's individual needs and preferences are taken into account, this should be done in collaboration with the residents and their next-of-kin, in addition to professionals' expertise. Quality indicators in nursing homes

will, in the future, be a key tool towards monitoring quality of care, assisting poorly informed nursing home users in their choice of nursing home and inform professionals on improvement efforts. Important issues for future research include the design of methodologically rigorous studies and the assurance that use of selected quality indicators does not generate unintended consequences.

6.5 Areas for further research

Quality of care is a complex and multifaceted concept. The format of thesis and four papers do not give room for presenting more than parts of the total picture. There are other aspects of quality of care in nursing homes that could have been studied. The nursing home organization, staffing and organizational culture influence the care quality. Exploring these issues in elucidation of organization theory (the nursing home as an organizational system) and organizational sociology (the nursing home as a community) could give a broader picture of elements of quality of care. Moreover, the selection of only cognitively intact residents for the interview study may give a biased picture of important quality factors. Exploring the experiences of residents with cognitive deficits to elicit what a "good day" means to them could add interesting perspectives to nursing home care quality. Hence, integrated research on all factors that impact the delivery of care is needed to understand how the nursing care provided can best be designed to the residents' specific needs. One relevant research design could be to do an observational field study which aim at describing the different functions of the nursing home services, identify relevant quality indicators and validate existing

measures for nursing home care quality. It is recommended that the development of quality indicators follows a psychometrically sound process. Extensive empirical testing of quality indicators emerged from this process should be done to ensure their validity and reliability over time. The approach for such research is to use recommended stages in indicator development, evaluate the implementation and develop electronic quality tools to ease the use of QIs. Much remains in understanding how to implement QIs, cost-benefit issues in using QIs, and how to use QIs for quality improvements in nursing homes. The question is how to assure quality by activities that promote high quality of care, rather than designing follow-ups on errors that already have occurred and cause risk of low quality and safety problems. More research is needed that investigate the effect education, standardization, coaching and training of nursing home staff have on continuous quality improvement, and should include cost-benefit analyses of the interventions.

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Erratum

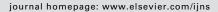
In paper I, the correct text in the first sentence in the introduction is: "Nursing homes in developed countries have evolved over the past half-*century* from being places of custodial care to facilities responsible for the management of an ever increasing range of complex nursing and medical conditions."

PAPER I



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Review

Nursing sensitive quality indicators for nursing home care: International review of literature, policy and practice

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ABSTRACT

Objectives: To review nursing sensitive indicators used for nursing home care across seven nations with similar elder care (USA, Australia, Norway, New Zealand, England, Sweden and Denmark), and to evaluate their validity.

Design: Systematic search in the literature and other sources to find descriptions of development and validity testing of national quality indicators.

Data sources: Papers from scientific databases, relevant websites, additional papers and reports, and personal communication with experts in the field. The material was included if it contributed to the description of each country's processes in defining nursing sensitive quality indicators for nursing home care, and the main focus was use, developing and/or testing of quality.

Review methods: An overview of each country's utilization of nursing sensitive quality indicators was obtained. The evidence for the validity in development and testing procedures was analyzed using a set of evaluation criteria.

Results: All countries, except Sweden, have nationally standardized assessment of the patient before admission to the nursing home. There is large variation in the way these data collection tools were developed and how the data is used. Only the USA has systematically developed quality indicators on the basis of resident assessments. Twentythree indicators used nationally in USA, thirteen in Australia, four in Norway, three in New Zealand and three in England were selected for review, and were evaluated for their validity as described in the literature. All selected indicators had satisfactory face validity, and for the twenty-three indicators used in the USA there was evidence for reliability testing. None of the quality indicators met all the criteria for validity. Evidence that the quality indicators can demonstrate meaningful differences in care and that the information can be extracted with minimal extra efforts was not found. Thresholds for high or low quality were determined only for the US quality indicators.

Conclusions: There are concerns about the validity and reliability of nursing sensitive quality indicators for nursing home care. The indicator development is sparsely documented. It is recommended that the development of quality indicators follows a sound process and that extensive empirical testing of the indicators is done.

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What is already known about the topic?

Nursing sensitive quality indicators are quantitative measures reflecting a professional care standard which are used as guides to monitor and evaluate the quality of nursing home care. Determining what aspects of nursing home care should and can be measured is the current work of many national health care systems.

What this paper adds

- An overview of nursing sensitive quality indicators used in nursing homes across countries.
- A synthesis of the evidence in the literature concerning the validity of nursing sensitive quality indicators.
- Recommendations for development and testing of nursing sensitive indicators for nursing homes.

1. Introduction

Nursing homes in developed countries have evolved over the past half-decade from being places of custodial care to facilities responsible for the management of an ever increasing range of complex nursing and medical conditions (OECD, 2005; Sosial- og helsedirektoratet, 2006). Globally, nursing homes are challenged to meet the dual demands of providing a home for older people while providing professional care for these complex health challenges as frail and vulnerable older people move through their end of life trajectory (Hauge, 2004; Helsetilsynet, 2005; Paulsen et al., 2004). Knowing when these challenges have been successfully met requires monitoring and audit. Determining what aspect of nursing homes should and can be measured is the current work of many national health care systems and the need for this has become more acute. Countries have long-term care systems bound to their own culture, history and financial resources but virtually all developed nations share the challenges of limitless demand within the context of finite resources and are struggling to bridge the quality gap in nursing home care (Iglehart, 2001).

As nursing care is the common service provided world-wide in nursing homes, it is important to understand how nursing care is evaluated. Using quality indicators that capture the outcomes of nursing care, is one way to monitor the quality of nursing homes (Norwegian Knowledge Centre for the Health Services, 2004). Efforts are underway to do this across developed nations. Gaining an understanding of the state of these varied efforts may help to provide important insights to more efficiently and effectively build coherent local, national, and international nursing sensitive quality indicators for nursing homes.

Therefore, this study aims to describe nursing sensitive quality indicators used in nursing homes across seven developed nations that have a similar system for elder care: access to nursing homes when needed, payment subsidized by tax or insurance, comparable cultural conditions, and a national system for monitoring nursing home quality. A convenience sample of seven countries, USA, Australia, Norway, New Zealand, United Kingdom (UK), Sweden and Denmark, were selected which met these criteria. Across UK there are different approaches and

the study focused on England. Although the USA has an elder care system with a larger private market influence than the other six countries, USA was included because there is a large amount of research concerning the development of nursing home quality indicators (Capitman et al., 2005). Nursing sensitive quality indicators used in these countries were evaluated for their validity and applicability. As the cost of developing and validating new quality measures is significant, a strong case can be made for international cooperation. The purpose of this work is to contribute to this effort.

2. Quality indicators as a measure of quality

Over a decade ago, a conference convened by World Health Organization (WHO) and the Milbank Memorial Fund resulted in an agreement to develop a coherent international policy on long-term care, including nursing home care, with an emphasis on quality assurance designed to satisfy both care recipients and caregivers (WHO, 2000). Toward this end, countries have made variable efforts to determine markers of quality care in nursing homes and to develop measures to evaluate its achievement. An internationally recognized, shared definition of quality states,

"the degree to which health services for individuals and populations increase the likelihood of desired health outcomes and are consistent with current professional knowledge" (IOM, 2001, no page number)

Determining quality requires defining quality indicators. Quality indicators are quantitative measures reflecting a professional care standard which are used as guides to monitor and evaluate the quality of important patient care and support service activities (Joint Commision on Accreditation of Healthcare Organization, 2007a,b). In other words, quality indicators are used as the surrogate measure of quality. Quality indicators measure within three domains of quality of care: structure quality (structural factors that affect the performance of care), process quality (the direct care that the staff performs), or outcome quality (patient outcomes/impact for the patient or health care service outcome for the population) (Donabedian, 1980). There is a causal connection between the structure, process, and outcome quality, and indicators for each dimension have to be linked together. Nursing sensitive quality indicators are measures of changes in health status upon which nursing care may have direct influence (ICN, 2001). To judge whether quality measured by quality indicators is high or low, a standard has to be defined (Donabedian and Bashshur, 2003). Furthermore, quality indicators are intended to detect differences in care, rather than differences in patient characteristics (Agency for Healthcare Research and Quality, 2004).

The number of possible quality indicators is unlimited, but the critical issue is to find quality indicators that have high validity for the domain of care in focus. Quality indicators can be derived from individual patient data, such as individual functional and needs assessment (Karon and Zimmerman, 1998). Quality indicators that already are

available in patient records and other data sets ease the burden of data collection (InfoVU-projektets nätverk för kvalitetsindikatorer, 2005; Karon and Zimmerman, 1996; Kise, 2004). Overall, the critical issue for this review is to evaluate quality indicators used in seven countries for their usefulness as measures of quality of nursing care for older residents of long-term care facilities.

3. Research questions

The research questions were as follows:

- 1. What nursing sensitive national quality indicators are used for monitoring the clinical quality of nursing homes for older (>65) long-term residents in nursing homes in USA, Australia, Norway, New Zealand, England, Sweden and Denmark?
- 2. What is the validity of these indicators?

4. Methods

Material was restricted to English or Nordic language. The abstract of the articles and reports were first read to find whether they met the inclusion criteria. Reviews were first retrieved, and then additional papers concerning evaluation and validity testing were included for data extraction.

4.1. The search process

A systematic search for relevant articles and reports was performed. The search strategy was as follows:

- Electronic search in scientific databases (CINAHL, MED-LINE, PsycINFO) using the terms "quality indicator" or "clinical indicator" combined with "nursing home" or "long-term care", limited to English language and year 1990 through September 2007.
- 2. World Wide Web, via GOOGLE using search terms such as "Quality indicator", "nursing/rest homes + [name of country]" or "residential nursing facilities", and equivalent search terms in Nordic language. The first 20 hits/ references were further explored. In addition relevant websites maintained by governments were explored and searched for information about quality indicators in nursing homes.
- 3. Hand searches in reference lists from relevant studies and reports found in the search number 1 and 2.
- 4. Personal communication with experts in the field, persons in appropriate government departments and relevant organizations in order to get an overview of quality indicators in use and to crosscheck information found in stages 1–3.

4.2. Inclusion criteria

Materials gathered in the search process were included for review if the main focus was use, developing and/or testing of quality indicators for care in nursing homes for persons over 65 years. A nursing home was defined as a health service with 24-h service, with trained nurses employed and access to physician services.

4.3 Data extraction

First, an overview of each country's utilization of nursing sensitive quality indicators was obtained from government web sites and other papers including legal documents, laws and regulations, and institute reports. Secondly, from the systematic search in databases, 107 papers were retrieved in full text and studied in detail. reviewing how the quality indicators were developed and tested. Forty-five papers were included in the review, and formed the basis for evaluating the evidence for the nursing sensitive quality indicators. Determining what quality indicators were considered to be nursing sensitive was the last step. The authors determined that only process and outcome quality indicators were evaluated for inclusion because the structural indicators, such as size of room, proportion of en-suite rooms or level of staff, were judged to be less influenced by nurses.

4.4 Evaluation criteria

Then criteria extrapolated from the evaluation process used by two internationally recognized U.S.-based health services research organizations, Agency for Healthcare Research and Quality (Agency for Healthcare Research and Quality, 2004) and the Joint Commission on Accreditation of Healthcare Organization (Joint Commission on Accreditation of Healthcare Organization, 2007a,b) were used to evaluate the validity of each quality indicator. The criteria are as follows:

- A. Relevant to nursing homes and influenced by nursing actions:
- B. Face validity demonstrating sound clinical or empirical rationale for its use;
- C. Construct validity demonstrating congruence with other measures intended to measure the same or related aspect of quality;
- D. Discriminant validity demonstrating meaningful differences in care;
- E. Reliability demonstrating ability to consistently measure differences in care over time with minimal random or systematic error and can be reproduced;
- F. Risk-adjustment or stratification method is considered to adjust for patient mix;
- G. Minimum standard or threshold is determined for use in accreditation processes or for benchmarking;
- H. Available in existing databases and can be extracted with minimal extra efforts.

5. Results

All countries, except Sweden, require that a nationally standardized evaluation of each patient be completed before admission to the nursing home (Table 1). However, there is little uniformity in how these data collection tools were developed and how the data are used. In USA the Resident Assessment Instrument Minimum Data Set (RAI-MDS) has been in place since 1991 and is used in all nursing homes in the U.S. (Hawes

Table 1
Quality monitoring and use of quality indicators (QI) in different countries.

Country	Patient admission assessment	QI for monitoring nursing home care in use (No. of QI)	Quality monitoring systems for nursing homes	Legal rules or regulations
USA	Resident Assessment Instrument-Minimum Data Set (RAI-MDS)	National QI derived from RAI-MDS (24 QI)	Accreditation by Joint Commission on Accreditation of Healthcare Organizations (QI, observations and external audits)	Omnibus Budget and Reconciliation Act (OBRA) 1987 and the Federal Nursing Home Reform Act 1987
Australia	Aged Care Assessment Program (ACAP)	Aged Care Standards (4 standards with 44 indicators for expected outcomes)	Accreditation by the Aged Care Standards and Accreditation Agency	Aged Care Act 1997
Norway	[IPLOS] Individual care needs data set	Derived from KOSTRA (national reporting, published on Bedrekommune.no) (5 QI)	Norwegian Board of Health Supervision, Supervision of health and social services	Municipal Health Service Act 1985 and the Social Service Act 1990
New Zealand	National needs assessment	Health and Disability Sector Standards for Ministry of Health Certification (6 outcomes with 42 standards)	Certification by the Ministry of Health. Certification audits by auditing agency (legal requirements met)	Health and Disability Services (Safety) Act 2001. Health and Disability Services (Safety) Hospital Care, Residential Disability Care and Rest Home Care Standards Notice 2002
UK (England)	Single Assessment Process (SAP) Minimum Data Set for Health Care in UK (MDS HC)	Standards for Care Homes for Older People (38 standards)	The Commission for Social Care Inspection (CSCI) inspection reports including rating 0–5 stars (38 standards). Self- assessment annually reported to CSCI (38 standards)	Care Standard Act 2000, National Minimum Standards Care Homes for Older People
Sweden	[SAMSPRÅK] (Shared language) (not used nationally)	-	Health care supervision boards. Internal audits	Social Services Act 1982 and the Health and Medical Services Act 1983
Denmark	[Fællessprog] (shared language)	Local standards (varying number of QI derived)	Inspections by local senior public physician	Social Service Act 1997

et al., 1997). This minimum set of clinical and demographic data are used not only for clinical care planning but has been adapted in the USA and other countries, such as Canada, Switzerland, and Finland to monitor quality and as well as to determine payment level (Mor et al., 2008). England has also developed their Single Assessment Process for Older People based on the RAI-MDS (Glasby, 2004).

New Zealand, Denmark, and Sweden have either developed their own instrument or integrated parts of other instruments in their national assessment instrument. Australia's needs assessment instrument is based on the WHO's International Classification of Functioning (ICF) (Australian Institute of Health and Welfare, 2002) and Norway has included elements of RAI-MDS and ICF in their needs assessment instrument (Arbeidsgruppe nedsatt av Sosial- og helsedepartementet, 2000).

The USA has systematically linked quality indicators to the RAI-MDS (Zimmerman et al., 1995). In contrast, the relationship in England between the Single Assessment Process and their national quality indicators is not linked (Carpenter, 2006). However, in all countries reviewed in this study, an annual review of resident's needs is required and used for care planning.

The primary aim of using data collection tools such as the RAI-MDS varies among the countries. Australia uses these data to determine whether a person is eligible for high or low-level care placement. Norway uses these data as a threshold score to decide whether there is a need for care.

New Zealand, USA and England use the data to generate an individual care plan. Sweden, Denmark and Norway use these individual level data to ascertain health and social services needs and resources used by frail older people. Lastly, Australia, New Zealand, USA and England use the needs assessment to determine the payment to the providers of care.

Payment is also dependent on accreditation. All countries have a certification or accreditation system for nursing homes which is mandatory to provide the service and obtain funding. The main focus of certification is to determine the compliance with each country's nursing home regulations. Each country's legal statutes, rules and regulation vary in the specificity of their quality standards. Text analysis of statutes was not done in this review, but an extraction of information on quality indicators showed that Australia, New Zealand, England and USA legally mandate quality monitoring with Australia, England and USA requiring nursing-sensitive quality indicators (Aged Care Standards and Accreditation Agency Ltd, 2005; Commission for Social Care Inspection, 2007; Joint Commision on Accreditation of Healthcare Organization, 2007a,b). Who acts as the certifying body differs, as some countries such as Denmark have local audits, and others have national audits that are the responsibility of the national authorities. The way accreditation is performed differs both in the frequency of inspections or audits, and the criteria used for evaluation. England has both a mandatory annual self-assessment of nursing homes and inspections and ratings by the Commission for Social Care Inspection (Commission for Social Care Inspection, 2007).

5.1. Quality indicators across countries

In Table 2 the quality indicators that satisfied one or more of the eight evaluation criteria (A–H; see Section 4.4) are listed and described. Clearly the USA contributed the most comprehensive and specific nursing sensitive quality indicators with 23 items satisfying one or more of the 8 evaluation criteria. Australia contributed 13 quality indicators and those descriptors are broader in their conceptualization than the more specifically defined items from the USA. As an example, Australia's quality indicator for continence is that "Residents' continence is managed effectively." Notably, for the same general problem of incontinence, the USA has

quality indicators for low-risk residents who lost control of their bowels or bladder, residents who have indwelling catheters, incontinence without a toileting plan, fecal impaction, and urinary tract infection. Four nursing sensitive quality indicators were abstracted from the Norwegian literature. Along with Australia, Norway identified oral and dental health and infection control as indicators of quality not identified on the USA indicator list. Three nursing sensitive quality indicators were identified in the New Zealand literature and each of these overlapped indicators from the USA, Australia and Norway. Lastly, the three quality indicators from England are very broadly worded and may subsume more specific indicators listed for the other countries. Even within the broad wording of England's nursing sensitive indicators, the wording of the "Meals and Mealtimes" standard is notable for its strong directive, including that the service users "receive a varied,

 Table 2

 Description of selected nursing sensitive quality indicators for nursing homes.

Country	Name of indicator	Description
USA	1. New fracture 2. Falls	Proportion of residents with new fractures on most recent assessment in RAI-MDS Proportion of residents with falls within past 30 days on most recent assessment in RAI-MDS
	3. Becoming more depressed or anxious	Proportion of residents whose Mood Scale scores are greater on the most recent assessment relative to the prior assessment in RAI-MDS. Stratification by excluding residents with Mood Scale at a maximum on previous assessment, or are comatose
	4. Behavioural symptoms affecting others	Proportion of residents with behavioural symptoms affecting others (being verbal abusive, physically abusive or socially inappropriate/disruptive behaviour) on most recent assessment in RAI-MDS. Risk adjustment (high risk group when presence of cognitive impairment (defined), psychotic disorder or manic-depressive)
	Depression (w/o antidepressant therapy)	Proportion of residents with depression (pre-defined symptoms) without treatment on the most recent assessment in RAI-in MDS
	Incidence of cognitive impairment	Proportion of residents who were newly cognitively impaired on most recent assessment in RAI-MDS
	7. Low-risk residents who lost control of their bowels or bladder 8. Indwelling catheter	Proportion of residents who were frequently incontinent on most recent assessment in RAI-MDS. Stratification by excluding residents who have severe cognitive impairment, are totally dependent in mobility, are comatose, have indwelling catheter, or have ostomy Proportion of resident who have/had a catheter inserted and left in the bladder on most recent assessment in RAI-MDS. Risk adjustment (high risk group when bowel incontinence all or almost all the time, or stage 3 or 4 pressure sores)
	9. Incontinence without a toileting plan	Proportion of residents with occasional or frequent bladder or bowel incontinence without a toileting plan or retraining program on most recent assessment in RAI-MDS
	10. Fecal impaction	Proportion of residents with fecal impaction on most recent assessment in RAI-MDS
	11. Urinary tract infection 12. Weight loss	Proportion of residents with urinary tract infection on most recent assessment in RAI-MDS Proportion of residents with weight loss of 5% or more in the last 30 days or 10% or more in the last 6 months on most recent assessment in RAI-MDS. Stratification by excluding residents who are receiving hospice care
	13. Tube feeding	Proportion of residents with tube feeding on most recent assessment in RAI-MDS
	14. Dehydration	Proportion of residents with dehydration (output exceeds input) on the most recent assessment in RAI-MDS
	15. Pain	Proportion of residents with moderate pain at least daily or excruciating pain at any frequency on most recent assessment in RAI-MDS. Risk adjustment (high risk when independent or modified independence in daily decision making)
	16. Need for help with daily activities has increased	Proportion of residents with worsening in Late-Loss ADL self-performance (one or two level decline on defined ADL) on most recent assessment in RAI-MDS. Stratification by excluding residents where none of the four Late-Loss ADLs can show further decline, are comatose, have end-stage disease, or are receiving hospice care
	17. Bedfast residents	Proportion of resident who spend most of their time in bed or chair on the most recent assessment in RAI-MDS. Stratification by excluding residents that are comatose
	18. Worsening in locomotion	Proportion of residents whose value for locomotion self-performance is greater at most recent assessment relative to the prior assessment in RAI-MDS. Risk adjustment (High risk group when resident has had recent falls, needs extensive support or is more dependence in eating or needs extensive support or is more dependence in toileting). Stratification by excluding residents who are totally dependent, are comatose, have end-stage disease, or are receiving hospice care
	19. Decline in range of motion (ROM)	Proportion of residents with increases in functional limitation in ROM between previous and most recent assessments in RAI-MDS. Stratification by excluding residents with maximal loss of ROM on previous assessment

Table 2 (Continued)

Country	Name of indicator	Description
	20. Physical restraints	Proportion of residents who were physical restrained daily on most recent assessment in RAI-MDS
	21. Little or no activity	Proportion of residents with little or no activity on most recent assessment in RAI-MDS. Stratification by excluding residents who are comatose
	22. Pressure ulcers	Proportion of residents with stage 1-4 pressure ulcers on most recent assessment in RAI-MDS. Risk adjustment (high risk group when impaired in bed mobility or transfer, comatose or suffer malnutrition)
	23. Standardized Needs Assessment as basis for care plan	The residents are assessed by admission
Australia	24. Behavioural management	Compliance with the standard: "The needs of residents with challenging behaviours are managed effectively" on most recent inspection
	25. Continence management	Compliance with the standard: "Residents' continence is managed effectively" on most recent inspection
	26. Nutrition and hydration	Compliance with the standard: "Residents receive adequate nourishment and hydration" on most recent inspection
	27. Pain management	Compliance with the standard: "All residents are as free as possible from pain" on most recent inspection
	28. Mobility, dexterity and rehabilitation	Compliance with the standard: "Optimum levels of mobility and dexterity are achieved for all residents" on most recent inspection
	29. Skin care	Compliance with the standard: "The residents' skin integrity is consistent with their general health" on most recent inspection
	30. Standardized Needs Assessment as basis for care plan	Initial and on-going assessment, planning and management of care for residents, carried out by a registered nurse
	31. Clinical care, specialised nursing care needs, and other health and related services	Compliance with the standard: "Residents receive appropriate clinical care, residents' specialised nursing care needs are identified and met by appropriately qualified nursing staff and residents are referred to appropriate health specialists in accordance with the
	32. Oral and dental health	resident's needs and preferences" on most recent inspection Residents' oral and dental health is maintained
	33. Sensory loss	Compliance with the standard: "Residents' sensory losses are identified and managed effectively" on most recent inspection
	34. Sleep	Compliance with the standard: "Residents are able to achieve natural sleep patterns" on most recent inspection
	35. Emotional support	Compliance with the standard: "Each resident receives support in adjusting to life in the new environment and on an ongoing basis" on most recent inspection
Norway	36. Infection control 37. Physical restraints	There is an effective infection control program Number of residents who are mentally retarded and have had a decision made according to the Social Service Act to systematically use restraints, on most recent assessment in IPLOS
	38. Standardized Needs Assessment as basis for care plan	Receivers of social and health care services are assessed for their needs for service
	39. Oral and dental health 40. Infection control	The resident receives annual dental assessment performed by dental health personnel The facility should have an infection control program that includes prevention, surveillance and notification to national authorities
New Zealand	41. Nutrition and hydration 42. Standardized Needs Assessment as basis for care plan	The individual food and nutritional needs of consumers are met on most recent inspection Consumers receive services that meet their individual assessed needs
	43. Infection control	Consumer, visitors, service providers and communities are protected from preventable exposure to infection as a result of service provision; and Essential notifications of infection, and where required treatment, occurs in a timely and efficient manner as specified by legislation
UK (England)	44. Meals and mealtimes	Compliance with the standard: "Service users receive a varied, appealing, wholesome and nutritious diet, which is suited to individual assessed and recorded requirements, and that meals are taken in a congenial setting and at flexible times" on most recent inspection
	45. Standardized Needs Assessment as basis for care plan	No service user moves into the home without having had his/her needs assessed and been assured that these will be met; and The service user's health, personal and social
	46. Health care	care needs are set out in an individual plan Compliance to the standard: "The registered person (manager of the home) promotes and maintains service users' health and ensures access to health care services to meet assessed needs" (personal and oral hygiene, pressure sores, continence, psychological health exercise and physical activity, nutrition and weight gain/loss, GP of their choice, access to specialist, hearing and sight) on most recent inspection

appealing, wholesome and nutritious diet...and that meals are taken in a congenial setting and at flexible times." No national quality indicators were identified for Sweden and Denmark.

The validity of these quality indicators was the next research question addressed. Table 3 summarizes these findings according to classification of the indicators and

evidence for relevance and validity testing. To begin, all the quality indicators in Table 2 were judged by the authors to be nursing sensitive (criteria A in Section 4.4) and to have satisfactory face validity (criteria B). However, none of the quality indicators met all eight criteria for validity. The two criteria most problematic were whether there was evidence that the quality indicator could demonstrate meaningful

Table 3 Analyses of the selected nursing sensitive quality indicators.

Quality indicator	Country	Measure level	Domain	Evidence on criteria (letter) = uncertain*
1. New fracture 2. Falls	USA USA	Outcome Outcome	Safety/accidents	A, B, E, F, G A, B, E, F, G
3. Becoming more depressed or anxious 4. Behavioural symptoms affecting others 24. Behavioural management 5. Depression (w/o antidepressant therapy)	USA USA Australia USA	Outcome Outcome Process Outcome	Mental/behavioural	A, B, E, F, G A, B, E, F, G A, B, G A, B, (C), (E), F, G
6. Incidence of cognitive impairment	USA	Outcome	Cognitive functioning	A, B, E, F, G
7. Low-risk residents who lost control of their bowels or bladder	USA	Outcome	Elimination	A, B, C, E, F, G
8. Indwelling catheter 9. Incontinence without a toileting plan 25. Continence management 10. Fecal impaction	USA USA Australia USA	Process Process Process Outcome		A, B, E, F, G A, B, C, E, F, G A, B A, B, E, F, G
12. Weight loss 13. Tube feeding 14. Dehydration 26. Nutrition and hydration 41. Nutrition and hydration 44. Meals and mealtimes	USA USA USA Australia New Zealand UK (England)	Outcome Process Outcome Process Process or outcome Process	Nutrition	A, B, C, E, F, G A, B, E, F, G A, B, E, F, G A, B A, B A, B
15. Pain 27. Pain management	USA Australia	Outcome Outcome	Pain	A, B, C, (E), F, G A, B
16. Need for help with daily activities has increased	USA	Outcome	Physical functioning	A, B, E, F, G
17. Bedfast residents 18. Worsening in locomotion 19. Decline in range of motion (ROM) 28. Mobility, dexterity and rehabilitation	USA USA USA Australia	Outcome Outcome Outcome Process	Physical activity	A, B, (C), (E), F, G A, B, E, F, G A, B, E, F, G A, B
21. Little or no activity	USA	Process or outcome	Activity	A, B, (C), E, F, G
20. Physical restraints 37. Physical restraints	USA Norway	Process Process	Restraints	A, B, (C), E, (F), (G) A, B
22. Pressure ulcers 29. Skin care	USA Australia	Outcome Outcome	Skin care	A, B, (C), E, F, G A, B, E
23; 30; 38; 42; 45. Standardized Needs Assessment as basis for care plan	USA Australia Norway New Zealand UK (England)	Process Process Process Process Process	Assessment and care planning	A, B, G A, B, G A, B, G A, B, G A, B, G
31. Clinical care, specialised nursing care needs, and other health and related services	Australia	Process	Clinical care	A, B
46. Health care	UK (England)	Process		A, B, G
32. Oral and dental health 39. Oral and dental health	Australia Norway	Process Process	Oral and dental care	A, B, G A, B, G
33. Sensory loss	Australia	Process	Sensory	A, B
34. Sleep	Australia	Outcome	Sleep	A, B
35. Emotional support	Australia	Process	Management of change	A, B
11. Urinary tract infection 36. Infection control 40. Infection control 43. Infection control	USA Australia Norway New Zealand	Outcome Process Process Process	Hygiene	A, B, E, F, G A, B A, B A, B

^{*}Note: The criteria were as follows:

A. Relevant to nursing homes and influenced by nursing actions.

B. Face validity demonstrating sound clinical or empirical rationale for its use.

C. Construct validity demonstrating congruence with other measures intended to measure the same or related aspect of quality.

D. Discriminant validity demonstrating meaningful differences in care.

E. Reliability demonstrating ability to consistently measure differences in care over time with minimal random or systematic error and can be reproduced.

F. Risk-adjustment or stratification method is considered to adjust for patient mix.

G. Minimum standard or threshold is determined for use in accreditation processes or for benchmarking.

H. Available in existing databases and can be extracted with minimal extra efforts.

differences in care (criteria D) and whether the information could be extracted with minimal extra efforts (criteria H). These issues were not addressed in the literature.

As well, construct validity (criteria C) is problematic for most of the nursing sensitive quality indicators, largely because there are few, if any, valid "gold standard" measurements of quality in nursing homes that can be used for comparison. There have been studies testing how well a specific quality indicator such as pain (Cadogan et al., 2004: Wu et al., 2005), bedfast residents (Bates-Jensen et al., 2004), restraints (Schnelle et al., 2004), pressure ulcer (Bates-Jensen et al., 2003; Berlowitz et al., 2001; Wipke-Tevis et al., 2004), depression (Schnelle et al., 2001; Simmons et al., 2004; Zisselman et al., 2002), weight loss (Simmons et al., 2003) and urinary incontinence (Mukamel et al., 2003; Resnick et al., 1996; Schnelle et al., 2003) perform compared to other instruments or observations of direct care. However, these studies reported there was low agreement between quality indicator scores and the actual care given to the residents.

For the 23 quality indicators derived from the RAI-MDS in USA for this review, there is evidence of reliability testing (criteria E) with the most common being inter-rater reliability and test-re-test reliability (Hawes et al., 1995; Mor et al., 2003a,b; Sgadari et al., 1997). For the quality indicators used in Australia, New Zealand, England and Norway, the subjective opinion of the visitor or inspection team is the measure used for accreditation or re-accreditation processes and facility supervision. No evidence of the reliability of these subjective quality indicators was found in the literature. Lastly, thresholds for high or low quality (criteria G) were determined for the US quality indicators (Rantz et al., 2000), but no description of how quality level was determined in the other countries was uncovered.

6. Discussion

This review shows that quality indicators for nursing homes are in use and do play an important role in certification and funding. In other words, there seems to be substantial use of nursing sensitive quality indicators, although they have been adopted with little formal testing (Arling et al., 2005; Berg et al., 2002; Sainfort et al., 1995). Even the quality indicators developed in the USA from the RAI-MDS lack evidence of construct and content validity (Hawes et al., 1997; Karon et al., 1999; Rantz et al., 1997; Zimmerman et al., 1995). These gaps persist but are being addressed through efforts in the USA to examine the validity and reliability of the long-term care quality indicator set with the aim of improving this system (Arling et al., 2005; Berlowitz et al., 2002; Mor et al., 2003a,b). However, threshold scores for good, average and bad quality in nursing homes are available for the nursing sensitive quality indicators used in the USA (Rantz et al., 2000).

6.1. Implications

As quality of care in nursing homes is multi-dimensional, the ideal situation would be to have a comprehensive measure that reflects the most important dimensions of quality (Arling et al., 2005; Mor et al., 2003a,b; Sangl

et al., 2005). In contrast, this analysis found that there are no internationally recognized valid and comprehensive sets of nursing sensitive quality indicators for nursing homes. Five of the seven countries reviewed for this study have selected nationally recognized quality indicators. However, these quality indicators need further development to meet commonly accepted standards for measurements. It is notable that evidence that the quality indicators can demonstrate meaningful differences in care (criteria D) and that the information can be extracted with minimal extra effort (criteria H) was not found. The explanation for this is not addressed in this paper, but should be further explored.

When using only a few quality indicators for comparing care quality in nursing homes and benchmarking, there may be problems concerning adequate risk-adjustments and stability over time that have to be overcome. Unless the quality indicators are adjusted for differences in the population, risk factors and facility characteristics including values, target groups, size, and location, comparisons may not be valid. The complex relationships among dimensions of quality remain unclear. For instance, there is uncertainty about the connection between single rooms with private bathroom (structure), good incontinence care (process) and patient satisfaction with nursing care (outcome). In the interim, as a "second-best" opportunity, nursing sensitive quality indicators that do have a recognized high to low standard can be used to flag a facility's quality of care, and thereby help direct improvement efforts for nursing care delivery. Even if sensitive measurement tools, quality standards and systems for monitoring the quality are developed, there are future challenges in ensuring that they are used correctly, implemented effectively and responded to (Wunderlich and Kohler, 2001).

6.2. Limitations

As demonstrated in this systematic analysis, knowledge about efficient and effective nursing sensitive quality indicators is incomplete. Locally developed quality indicators, though, may have been missed. However, the aim of the review was to evaluate internationally used nursing sensitive quality indicators. Also, the search method, designed to ensure retrieval of pertinent review material, sought information on only seven countries. Material was limited to English or Nordic language published information available on the internet or in accessible scientific databases. However, as the internet is increasingly used for publishing government and research reports to spread information to service users and researchers (OECD, 2005), the probability of missing information because of lack of access is low.

7. Conclusions

The use of nursing sensitive quality indicators to monitor care quality in nursing homes is held back because of concerns about validity and reliability of these measures. The review found that indicator development and testing is sparsely documented, and gaps in knowledge exist. It is recommended that the development and

evaluation of quality indicators follows a psychometrically sound process. Research that study how quality is conceptualized, integrating patient, family, and professional perspectives could be a next step. Further on, extensive empirical testing of quality indicator emerged from this process should be done to ensure their validity and reliability over time.

Conflict of interest

None declared.

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Residents' experiences of interpersonal factors in nursing home care: A qualitative study

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ARSTRACT

Background: With life expectancy lengthening, the number of those who will require care in a nursing home will increase dramatically in the next 20 years. Nursing home residents are frail older adults with complex needs, dependent on advanced nursing care. Long-term residents in nursing homes have long-term relationships with the nurses, which require a unique approach to the interpersonal aspects of nursing care. Understanding what is experienced as care quality, including quality of interpersonal processes, requires insight into the residents' perspectives for best value in care to be realized.

Objective: Main objective was to describe the nursing home residents' experience with direct nursing care, related to the interpersonal aspects of quality of care.

Design: A descriptive, exploratory design was used.

Settings: Four public municipal nursing homes in Norway with long-term residents were purposely selected for the study.

Participants: Fifteen mentally lucid residents were included. The inclusion criteria were aged 65 and over, being a resident of the nursing home for one month or longer, and physical and mental capacity to participate in the interview.

Method: In-depth interviews with the residents were performed. The transcribed interviews were analyzed using meaning categorizing.

Results: The residents emphasized the importance of nurses acknowledging their individual needs, which included need for general and specialized care, health promotion and prevention of complications, and prioritizing the individuals. The challenging balance between self-determination and dependency, the altered role from homeowner to resident, and feelings of indignity and depreciation of social status were key issues in which the residents perceived that their integrity was at risk in the patient—nurse interaction and care. Psychosocial well-being was a major issue, and the residents expressed an important role of the nursing staff helping them to balance the need for social contact and to be alone, and preserving a social network.

Conclusions: Quality nursing care in nursing home implies a balanced, individual approach to medical, physical and psychosocial care, including interpersonal aspects of care. The interpersonal relationship between resident and nurse implies long-term commitment, reciprocal relationship on a personal level and interpersonal competence of the nurses to understand each resident's needs.

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What is already known about the topic?

- Quality of nursing care is a multidimensional concept that could be described from different perspectives including the management, the professional caregivers and the care receivers and their relatives.
- The residents in nursing homes have a long-term relationship with the nurses which require a unique approach to the interpersonal aspects of nursing care.
- The care receivers are the primary source to evaluate the interpersonal factors and outcomes of care, and it is important to integrate their perspective of quality of nursing care.

What this paper adds

- This study provides a greater understanding of interpersonal factors for quality of the patient-nurse interaction in nursing homes from the residents' view.
- The study highlights dimensions in which the residents consider interpersonal aspects of care crucial for quality of care.
- Quality of care in the view of the residents means to optimize medical, physical and psychological care, to protect their integrity and to recognize their individual psychosocial needs.

1. Introduction

Globally, nursing homes are fundamental in long-term care services, and with life expectancy lengthening, the number of those who will require care in a nursing home will increase dramatically in the next 20 years (Huber et al., 2009; Statistics Norway). National quality care standards across most developed nations emphasize patient safety, excellence in care and patient satisfaction in the long-term care of older people (Du Moulin et al., 2010; Nakrem et al., 2009). Knowing when these goals have been successfully met requires determining how nursing homes quality should and can be measured. Toward this end, there have been variable efforts to determine markers of quality, and commonly accepted quality indicators in long-term care have been criticized for the narrow focus on clinical outcomes (Nakrem et al., 2009), and for not reflecting what the residents truly desire from nursing homes (Grabowski, 2010). Therefore, more research on how nursing homes quality can be understood from the residents' perspective is needed.

According to Donabedian (1980), quality of care can be divided into at least two interrelating parts: technical care, defined as the application of science and technology of health science to the management of health problems; and interpersonal processes, specifically, the psychosocial interaction between client and practitioner. Care quality can be defined as to what extent the care provided maximizes the health benefits without increasing risk, a valuation that must be shared by the patient and practitioner. Quality in the interpersonal relationship is measured by the degree of adherence to socially accepted values, which are reinforced by the ethical principles of health professions, and expectations of individual patients

(Donabedian, 1980). Client–nurse interaction is the major aspect in nursing (Kim, 1987). Kim identified four sets of variables that are related to client–nurse interactions: actors (client and nurse); social context for contact; process of interaction; and client health outcomes (Kim, 1998, 1987). Care quality, and especially the patienthealth worker interaction from the patient's perspective, is an essential part of the care receiver's experience that must be understood for best value in care to be realized (Donabedian and Bashshur. 2003).

Understanding quality of care from a resident perspective has been explored in earlier work by Rantz et al. (2005, 1999). They proposed a conceptual model for nursing home care from the perspectives of residents and families, and included the dimensions: features of staff, features of care, family involvement, communication, home and environment (Rantz et al., 2005, 1999). Bowers et al. (2001) interviewed 26 residents about their experiences of being a nursing home resident. The residents' descriptions of quality of care fell into three categories: good service, reciprocal relationship with caregivers, and physical comfort (Bowers et al., 2001). This confirms that expectations about nursing home service and individual variation in needs influence the experience of quality of the health service.

Outcome of nursing home care includes elements of quality of life as well as quality of care, both of which can be transformed, either positively or negatively by nursing care. Eleven quality of life domains significant to nursing home life were identified in a study by Kane (2001). These were: comfort, functional competence, autonomy, dignity, privacy, individuality, meaningful activity, relationships, enjoyment, security and spiritual well-being. Further, the domains were confirmed as related to an overall construct of quality of life (Kane et al., 2003). In an interview study with 27 residents and families focusing on quality of life indicators in long-term care, the interpersonal aspects of the nursing home environment were found to be of significant importance to the residents' quality of life, and included feelings of respect, involvement, reciprocity in relationships, and competency through technical nursing and attitudes (Robichaud et al., 2006).

Long-term residents in nursing homes have long-term relationships with the nurses, which is in contrast to many other health service settings where the relationships with the caregivers are short-term and fluctuate more. In an interview study with residents about their understanding of quality of care, a long-term relationship with the staff was perceived important to preserve their dignity, identity and integrity in care, and was foundation for quality of care (Coughlan and Ward, 2007). In a study by Brown Wilson and Davies (2009) the relationship between the resident and nurse was found to be dependent on the approach to care delivery the nurse adopted, which is described as individualized task-centred, resident-centred or relationship-centred. Outcomes of relationship-centred care were development of a shared understanding of all residents', staff's and family members' needs, and a feeling of all being included as members of the nursing home community (Brown Wilson and Davies, 2009). Furthermore, positive experiences for residents, relatives and staff created by

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relationship-centred approach to care, are associated with values in The Senses Framework developed by Nolan et al. (2001), which is based on six underpinning values: security, continuity, belonging, purpose, achievement and significance (Aveyard and Davies, 2006; Nolan et al. 2001)

The interpersonal relationship in patient-nurse interactions has been found to be an essential factor in personcentred care, regarding the interpersonal skills as part of the nurses professional competence and prerequisite for person-centred processes, resulting in desired outcomes for the residents and high quality of care (McCormack and McCance, 2006). In a qualitative meta-synthesis of four studies, framed in this person-centred nursing framework, these pre-requisites were confirmed as important, but characteristics of the care environment and provision of care activities that are person-centred are critical factors (McCormack et al., 2010). The nursing home residents are frail older adults, characterized by complex needs due to several concurrent chronic conditions, and thus, dependent on advanced nursing care. Hobbs (2009) did a dimensional analysis of the concept "patient-centred care", and the central organizing perspective was that care quality is strongly connected to the patient-nurse interaction, and the nurses' skills, knowledge and competencies to alleviate the patient's vulnerabilities (Hobbs, 2009). Therefore, uncovering what individuals view as important for quality patient-nurse interactions as they live in the nursing home may help to develop a more effective person-centred care for nursing home residents.

2. Aim and objective

The aim of the present study was to explore mentally lucid residents' understanding of quality of nursing care in nursing homes. The main objective was to describe the nursing home residents' experience with direct nursing care, related to the interpersonal aspects of quality of care.

3. Method

Quality inquiry is a valuable approach when the aim is to achieve a holistic understanding of a multifaceted phenomenon in a specific context (Patton, 2002). In this study, meaning is studied as a shared meaning in the nursing home culture, recognizing that each person bring to bear the understanding held by members of the groups to which he or she belongs (Gubrium and Holstein, 2001). The long-term nursing home residents are individuals with their individual background, but they also have a shared meaning of the experience of living in a nursing home. By comparing and contrasting the individual interpretations of meaning, it could be synthesized into more general accounts.

3.1. Participants and settings

The study is part of a larger programme of research focused on multi-dimensional aspects of quality of care in Norwegian nursing homes. A purposive sample of four municipal public nursing homes in Norway with long-term care residents was included, comprising a representative

sample of small-, medium- and large-sized nursing homes in both urban and rural areas. The nursing homes had mixed populations according to medical diagnosis, physical and cognitive functioning, age (ranging from 45 to 100 years old) and gender. Most residents had single rooms with en suite bathrooms, but in all nursing homes in the study there were also double rooms and shared bathrooms. Each unit, which varied in size between 8 and 35 beds, had a shared dining room in addition to the nursing home's institutional living rooms or public areas where concerts, exercise activities and festivities were arranged.

The sampling of residents to collect data in the present study, was done purposely to permit understanding of the phenomenon care quality in depth, and the aim was to have information-rich cases who could bring forward issues of central importance (Patton, 2002). Even though the population of residents in nursing homes are very frail with reduced endurance, and often have speech problems, other studies have shown that residents can successfully participate in interviews as long as these challenges are accounted for (Bergland and Kirkevold, 2006; Hauge, 2004; Wenger, 2002). The inclusion criteria were age of 65 or older, being resident of the nursing home for one month or longer, having physical and mental capability to handle the interview and ability to give informed consent to participate. Initially, 24 informants were recruited by one of the clinical nurses in the nursing home. The researcher contacted the residents consecutively, handed out the information letter and read it out loud when requested. The residents consented orally to participation and the time for each interview was determined. The informants were encouraged to ask a relative or friend to read the cover letter. Several of the informants had shown the letter to relatives, but none wanted another person to be present during the interview. Inclusion of new informants continued until the researchers felt that no new elements were emerging. Two additional residents were interviewed, but no new information was obtained.

3.2. Data collection

Data for this study were collected by in-depth interviews with the residents (Gubrium and Holstein, 2001). All interviews were conducted by one researcher. To assist the interviewer, an interview guide with open-ended questions and probes was used. The guide was reviewed by three experts for its face validity and piloted with one resident. To have an information rich description of the informants' experiences, a narrative approach was used for the interviews, encouraging the informant to freely tell about their life in the nursing home. During the interview, the interviewer repeated and summarized the expressions of the informants and asked them whether it was correct.

3.3. Data analysis

Each interview, which typically lasted for 1 h, was taperecorded and transcribed verbatim. The analytic approach consisted of meaning coding with categorization, leading to a systematic conceptualization of the interviewees' statements (Kvale and Brinkmann, 2009). Immediately

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Table 1 Participants and settings.

	NH 1 (urban, 80 bed)	NH 2 (rural, 68 bed)	NH 3 (rural, 57 bed)	NH 4 (urban, 24 bed
Women (age)		R3 (75)	R9 (92)	R15 (88)
		R4 (89)	R10 (84)	
			R11 (77)	
			R12 (77)	
			R13 (75)	
			R14 (85)	
Men (age)	R1 (84)	R5 (96)	R8 (87)	
,	R2 (87)	R6 (82)	, ,	
		R7 (80)		

NH = nursing home; R = resident (informant).

after each interview, the interviewer took notes that described the setting and summarized the general impression of the interview. The analysis continued when all data were collected (Gubrium and Holstein, 2001). First, to get an overview of themes and a general impression of what the interviewees had expressed, the transcripts were read through while listening to the tape recording and a matrix of the first general themes was constructed. Next, meaningful entities in the transcripts were identified, and the text or expressions of the interviewees were sorted into more specific categories. An electronic tool for mind mapping (MindjetMindManager 8) was used in this process. Finally, the meaning in each category was synthesized by comparing and contrasting the content and by comparing this with existing theory and literature. To enhance rigour in the analysis, the authors of this article were all involved in the discussions about development of analytical concepts (Seale, 2007). The main author of this paper coded all interviews. Two interviews were coded separately by another researcher in the team and this was compared with the coding done by the main author. As the analysis proceeded, the whole team had meetings and discussed the abstraction into categories and subgroups.

3.4. Ethical considerations

The study was approved by the Regional Committee for Medical and Health Research Ethics. Before the interview started the informants were assured that all information would be kept confidential, participation was voluntary and refusal to participate would have no impact on their situation in the nursing home. Residents who were able to write signed the written consent, in addition to the oral consent. The care personnel in the nursing home were informed who had participated in the study so that they could give extra attention to the resident after the interview if needed.

4. Findings

Fifteen informants (Table 1), representing all four nursing homes, were included in the study, nine women, aged 75-92, and six men, aged 80-96.

The interviewed residents had views on the nursing home quality that included structural factors, caring and interpersonal aspects, and the effect these have on their quality of life in a nursing home. Findings related to structural factors such as routines and staffing, are being published elsewhere. This article focuses on findings related to interpersonal factors of direct nursing care and resident outcomes of nursing care. From the interviews three main categories in interpersonal care emerged (Table 2). The informants talked about care for and alleviation of medical, physical and psychological needs, expressed concerns about issues of integrity, and engaged in psychosocial well-being in the nursing home. In all the themes, the residents considered the nursing staff's properties, such as behaviour and values, and actions, such as prioritization, as important for quality of care. It is worth noting, though, when talking about the direct care, all informants in this study referred to nurses collectively. The term "staff", without distinguishing between different nurses with different educational level was used, and the residents carefully tried not to mention any names. Only when talking about social relationships with the nurses, a few used the first name of a specific nurse they had a closer relationship to.

4.1. Getting the basics right: quality care for, and alleviation of medical, physical and psychological needs

Within this category three sub-categories were generated: general and specialized care; health promotion and prevention of complications; and too old and sick to be prioritized; describing how quality of care is associated with interpersonal processes.

4.1.1. General and specialized care

The care itself and how the residents were cared for by the staff was one of the main topics the informants engaged in. The interactions between the residents and the nurses were mainly connected to treatment and care for

Table 2 Overview of main categories and sub-categories of resident-nurse interactions

Care for and alleviation of medical, physical and psychological needs General and specialized care

Health promotion and prevention of complications

Too old and sick to be prioritized?

Protecting the resident's integrity Self-determination and dependency

Altered role from homeowner to resident

Fear of indignity and depreciation of social status

Psychosocial well-being

Balancing the need for social contact and to be alone

Preserving the social network

their medical, physical and psychological problems. The residents had many diseases and afflictions in addition to age-related functional decline. Since the age-related problems had often occurred before admission to the nursing home and had progressed over time, the residents had coped previously with it in their own way. However, most residents had experienced serious health problems that required advanced treatment and varying needs through a day that made access to 24-h service a prerequisite. The residents emphasized being safe, having access to prompt emergency care, and having their basic needs met, to be satisfied with the nursing home service. Most residents thought that the medical treatment for their current situation was as good as it could be. They said that the health service they received, which included basic nursing care and physician service, was excellent:

Well yes, you see – they do the best they can for you. They work hard all day long. They help you right away... if you need it. (R11)

The residents referred to the staff as kind, pleasant and clever. They expressed that they trusted the staff and felt they were given the most competent care available at the moment according to their needs. Most residents were grateful that some of their problems were taken seriously and that they were given adequate treatment, for instance careful follow-ups of blood status, medication side effects and symptoms of infection.

Not all the residents were focused on their physical needs and some perceived their physical state as being outside their control or responsibility. One resident (R3) who had lived in the same nursing home for years had a distanced relation to her body. She gave the nurses full control and care of her physical needs. When asked what she felt about her problems with leakage from the urostomia and skin breakdown, she answered that it was the nurses that worried most, and she did not really care. Still, she observed that some nurses were particular careful when washing and handling her; it was important to avoid scratching her skin, she explained.

However, many of the residents were uncertain about the nursing home's ability to give adequate care in case their functional level declined or they became more ill. One of the interviewees expressed that nursing home was "a lovely place to be, as long as you are healthy" (R4). Another resident said that he had given up trying to get adequate pain alleviation. He thought that the staff did not offer other treatment because they would not listen to him or no other treatment was available. He expressed ambiguous feelings about his life: "It couldn't be better - If only I could be better in my foot, I could walk around a bit alone" (R8). Another resident was severely undernourished and anaemic before a nurse, by coincidence she said, noticed that she had a health problem. Many residents expressed that they feared becoming more helpless than now and hoped that the dying process would go quickly.

4.1.2. Health promotion and prevention of complications Efforts from the nursing staff to promote their health or, at least, prevent further complications following their

chronic clinical condition were perceived as essential. Good health was related to being active, eating well, having the ability to get up in the morning without being helped, having no pain, and having a good sense of humour or good mood. Health decline meant a reduction in normal functioning or a lessened ability to participate in daily life activities: "You just can't get out of bed" (R4). Others described failed health as "pure misery" or "not managing anything" (R2). Many of the residents perceived that they had good health despite of suffering from many diseases. One extraordinary example was a man with paraplegia after a spinal nerve lesion in the neck who said that his health was "darn good" (R6). It seemed that the residents differentiated between health and disease as two different aspects. They credited their strength or hereditary characteristics if they had good health and "bad fortune" if they had a disease that required long-term care.

The residents saw the prevention of a decline in functioning as very important, and had hoped more active care was offered by the nurses in the nursing home. They missed more physical therapy, physician attention and systematic interventions to avoid falls. However, the residents were aware that the diseases they had could not be treated to the point of full remission, and some of their health problems had to be coped with, as they could not be cured. "You just have to live with it" was a typical expression on dealing with such a situation. Many talked about being prepared to die or that they already were living beyond expected lifetime.

4.1.3. Too old and sick to be prioritized?

During the interviews, it appeared that some of the interviewees perceived themselves as being of less worth. They thought that older nursing home residents received less attention, not only in the health service generally, but that this was reflected in the attitudes of the nursing staff. One resident expressed a feeling of being neglected, since the nurses did not response to the alarm bell. The residents feared being ignored or that their problems would not be noticed if they did not express themselves verbally:

It doesn't work like it should. It takes too long. Once I watched and it took over an hour before someone came. So they (other residents) lie there and holler instead. You're supposed to use the alarm but they've found out that it works if they holler. (R7)

It was common for the residents to not want to be perceived as troublesome, and they were concerned at being burdens to the nurses. With the shortage of nurses they often chose not to ask for extra help and had lowered their expectations. For instance, one resident said that she had reduced her activity after she moved into the nursing home because she did not want to ask for help (R4). They thought that it was not possible to have these needs met in the nursing home because of inadequate staffing or lack of prioritization.

The residents perceived that access to optimal care was outside their reach. Several residents thought that, for instance, surgical treatment was not offered to older people because it was too risky. Still, most residents shared

a hope that surgery was an option if there was any possibility that their afflictions could be relieved. Other residents did not want more care, even when the health personnel offered it. A resident who had severely injured her knee in a fall was offered knee prosthesis, but she said that she did not dare to be operated. Another resident explained that he was offered a shower once a week, but he refused because he became exhausted and dizzy:

I can't shower anymore. Just have to wash myself here (in the room). I did it (shower) at first but just had to give up. I would just fall, you know. It was my decision; I just said I couldn't do it. Just have to get washed, change clothes and such. (R2)

It was important to the residents that they felt in control of their own life and could participate in treatment decisions.

4.2. Protecting the resident's integrity: the foundation for quality care

In this category, three sub-categories involving interpersonal aspects of care quality emerged: self-determination and dependency; the altered role from homeowner to resident; and fear of indignity and depreciation of social status. The residents expressed that they appreciated that nurses had special attention to these aspects and compensated for the threat to their integrity.

4.2.1. Self-determination and dependency

To be self-reliant in daily activities was important for the resident's feeling of independence. Many expressed that being able to take care of oneself such as wash and dress without nurse assistance meant a better life. To be independent, to feel free or to have the possibility to live in your own way, were expressions they used:

I decide over my own schedule, I'm independent and that is a good feeling. I feel free, and I am too. But of course I am dependent. And that is a feeling of safety. . . I am safe, you know. My life is so good. . . I make my own decisions. (R15)

Control over daily issues such as being able to decide over the diurnal rhythm, whether to participate in social activities, what to eat for dinner or how to furnish a private room with personal belongings made them feel more self-determinant. Arrangements that reduced barriers to travel or to move freely in and outside the nursing home were appreciated and increased the feeling of independence. An example was when a resident (R8), who was dependent on intermittent catheterization of the bladder twice a day, got an indwelling catheter for a few days so that he could visit his children who lived a several day journey away. He proudly said that he had been able to complete the journey.

Accepting dependency of the nurses was part of a trustful ceding of the responsibility for their health. However, this dependency seemed to displace power and control over the day and made them dependent on nursing home routines. A male resident (R7), who

recently had moved into the nursing home, said that it had not been his decision to move. He constantly underpinned that he was forced to stay in the nursing home and that he wanted to go home. He had fallen several times at home and he agreed that it was not safe for him to live home alone. Independence held such an important place in his life that living in a nursing home threatened his dignity.

4.2.2. Altered role from homeowner to resident

Moving into a nursing home had been, for most residents, a role change process from an independent person to a user of institutional services. Nursing home service offers overall service that includes accommodation, household and health care. This had relieved the residents' responsibility for a house and taking care of their health, but the new role as a nursing home resident implied a change in behaviour. The changed role was particularly visible in the altered routine with visitors. When living at home, the residents were hosts, which meant they decided who to welcome and what to serve from their own kitchen. After moving into the nursing home, they no longer had a kitchen to serve from or their own living room to be with their guests in. They perceived the nursing staff as host and themselves in an unclear role as guests in their own home. Though they spoke about this altered role with sadness, most of them had accepted it as part of the general functional loss that caused them to move into the nursing home.

Another major difference between living at home and in an institution was the amount of control they had over the physical environment. Their private rooms could be locked, but residents kept the doors unlocked in case they needed the nurses to assist them. The nurses had easy access to their rooms and most nurses knocked on the door before entering. However, this meant that other residents could also enter their room, and this concerned them. One of the interviewed women (R10) said that after an episode where a confused male resident had come into her room late at night, she was afraid to go to sleep until she knew this man had gone to bed. The residents wanted the staff to look after the confused, wandering residents, so that they could feel safer.

4.2.3. Fear of indignity and depreciation of social status

The residents expressed that their dependence on assistance was a strain. They tried to take care of as much as possible by themselves. A feeling of defeat when they had to call the nurse for help was reported by the interviewees. However, none related this reluctance to ask for help to bad experiences with the care provided. On the contrary, the care they received was excellent by their evaluation. They attributed the sad feeling of defeat to loss of function, aging and frailty, and longed to be younger and in better shape. One woman said that she felt that she was no longer part of society when she moved to the nursing home:

I stay in contact with friends and family but less and less often. When you come here, it seems like there isn't more. It wasn't like that when I was home and cooked and had them over. (R14)

The feeling of being a burden to society, due to their extensive need for health care, was implicit in all interviews. As a result of this feeling, most residents were very grateful and eager to express how lucky and satisfied they were with the nursing home and nursing staff.

The residents had strategies that helped them to maintain dignity. Strategies such as to take one day at a time and not reflecting on future problems, retaining good mood, and appreciating the life they had lived, worked as a buffer against feeling less valuable as a person. Expressions such as "fortunately, I have good eyes and ears", "I'm not in any pain" and "at least I haven't had a stroke" were examples of coping with functional loss. The female residents said that it was important for their feeling of dignity to maintain their appearance, to style the hair or buying fine clothes. It was appreciated when the nurses could support their positive features instead of merely focus on their illnesses and problems.

4.3. Building relationships that enhance psychosocial wellbeing: a key issue of quality of care

The third category constituted important areas in the patient–nurse relationship pertinent to psychosocial wellbeing, focusing on the role of the nursing staff. Subcategories were: balancing the need for social contact and to be alone; and preserving the social network.

4.3.1. Balancing the need for social contact and to be alone

The residents had much contact with a wide range of staff, such as registered nurses, licensed practical nurses, assistants, the physician, and activity coordinators during the day since all residents needed help in their daily activities. To have someone to talk to during the day was considered important for the quality of life. Most residents emphasized a close relationship to the nurses as a key factor for a good day. Few, however, singled out a specific nurse as special and the nursing staff was for most residents seen as "all the same". Many of the residents, though, felt that the staff genuinely cared for them on a personal level, which they showed by giving them an occasional hug or speaking with them in a friendly manner.

A good conversation was considered one that created a good atmosphere where the nurse talked about both her life and the resident's interests. This reciprocal exchange of information was especially important in the rural nursing homes. It strengthened the residents' feeling of being a member of the local community. In NH3 and NH4 the staff would sit in the shared living room for their coffee breaks and led the conversation with the residents. This was much appreciated by the interviewees in these nursing homes and motivated them to join in.

Even though most residents felt they had a good relationship with the nurses, some residents were doubtful about what the relationship could offer them. Two of the informants (R7 and R15) mentioned that the nurses were too young to understand older people and expressed that the young nurses had interests that they did not care about. Further, the only time they had the opportunity to talk at length was during morning care which often was characterized by haste. Thus, the residents felt that nurses

could not fulfil the needs for a close relationship in the same way as friends or family could.

The residents had individual needs regarding close relationships in the nursing home community; depending on the amount of contact they had with their family and how socially active they had been before moving into the nursing home. The balance of their need to socialize and their need for time alone was regulated by the residents themselves by choosing how much time they spent in the communal rooms and their private rooms. However, an ambiguity in psychosocial well-being emerged as they said that they missed their former social environment and that appropriate, reciprocal social relationships could not be found in the nursing home. It was difficult to find someone that had similar interests, and it was problematic to relate to residents with cognitive deficits or severe disability. One resident (R7) expressed a feeling of being excluded from the nursing home community and said that there were "cliques" of residents that did not want to talk to him. The residents who made an effort to create a pleasant community by spending time in the communal rooms, trying to accept the diversity of the other residents and chatting with everyone seemed to cope better with the ambiguous social environment.

4.3.2. Preserving the social network

Since the residents were somewhat ambivalent toward the nursing home's ability to fulfil their psychosocial needs, it was important for them to preserve their former social network. The residents emphasized the importance of their family or friends feeling welcome in the nursing home as visitors. The residents noted that when the nurses greeted their relatives on arrival and offered them a seat and a cup of coffee, they felt their guests were welcome. In the rural nursing homes, the visitors were familiar with the nurses and the other residents, and they walked in and out of the nursing home with more ease than in the city nursing homes. Assistance to keep in touch with their family, for instance getting help to phone them was one way of upholding a social network for those with family and friends far away from the nursing home.

Many residents had experienced the loss of close family members or friends, and this made them feel lonely. Lack of social relationships outside the institution made them more dependent on the nursing home community, and especially dependent on the nursing staff. It was important that the nurses had information about their family because this was a common topic in daily conversation. During the interviews, all the residents talked about their family and their former life and were eager to show photos they had on their walls. The residents were proud to share that they were grandparents or great-grandparents. One resident explained that having a family and looking at family photos reminded her that she still had so much to live for (R12).

5. Discussion

The present study highlights areas in which, from the residents' perspective, the interpersonal aspects have a major influence on nursing care quality. The residents

expressed that it was important for them that the nursing staff cared for them so that their problems and afflictions were kept on a minimum level and further functional decline was prevented. The residents talked about caring relationships in which their integrity was protected, and put great emphasis on support from the nursing staff to uphold their social relationships.

It is worth noting that the residents in the present study felt that many areas of nursing home care of importance to the residents depended on the direct efforts of the nurses, such as receiving care with acknowledgment for remaining functions, being treated with respect or simply having someone to talk with. The dependency of the nursing staff was generally accepted, but it created an extra vulnerability. Power and control in everyday situations were placed on the nurses in their interactions with the residents. The fact that the residents during the interviews were reluctant to evaluate individual nurses could be attributed to their dependency of the care givers and asymmetry in power. The residents in our study expressed that having decision-making power was important in their everyday life, and thus important factors for care quality. Other research has demonstrated that the nurses have great impact on the residents' experience of "being someone" or contrarily "being nobody" in the way they include or exclude the residents in the nursing actions (Westin and Danielson, 2007). In relationship-centred care, the interactions between the parties in care are regarded as foundation of any therapeutic or healing activity (Aveyard and Davies, 2006). However, according to Nolan et al. (2004), all participants in the interaction need to experience reciprocal interpersonal relationships that promote genuinely empowering if quality care is to result.

It could be argued that the possibility of creating such relationships may be limited, since the residents in our study perceived the nurses as busy and felt that they could not expect to receive more attention from the nurses. Some of the residents were even uncertain about what relationships with staff could offer them. The nurses' skills and ability to connect with, and know each resident are important factors for successful individually adjusted care (McCormack and McCance, 2006). The caregivers' commitment to the relationship with older people is a deep human feeling that is fundamental in long-term care, and should be promoted to enhance quality of care (Haggstrom et al., 2010). Bowers et al. (2000) found in their study that time and stability in the nurse staff was crucial for assessing the residents' individual needs, which is necessary to give adequate care. Quality of care is enhanced not only by more time in care, but also by continuously adjusting to the residents' needs and hopes in caring interactions (McCormack, 2003; Perry, 2009).

The findings in the present study underpin the nurses' responsibility to be involved in creating social environments that support the quality of life for the residents. The residents appreciated that the nurses showed through behaviour that both residents and staff are part of the nursing home community almost like a

family, and shared reciprocal information about themselves and their family. Residents in nursing homes often report loneliness as a problem (Slettebo, 2008), and there is often little communication between residents (Hauge and Heggen, 2008). The formation of new relationships may be inhibited since few of the residents have the ability to participate in meaningful conversations (Bergland and Kirkevold, 2008). Consequently, the residents become more dependent on the nursing staff, not only for clinical care, but also for their psychosocial wellbeing. It is important, though, that the residents' social needs are assessed and that the nurses are sensitive to the preferred involvement from the nurses (Bergland and Kirkevold, 2005). It has also been found that nurses, residents and family members define close nurseresident relationship differently (McGilton and Boscart, 2007). Nurses focused on emotional connectedness, residents based their definition on attitudes and behaviour of the caregiver, and family determined the closeness of relationships by the positive effect it had on well-being. This has implications for how quality of care is defined and measured (McGilton and Boscart,

The many functions of the nursing home contribute to the complexity of the service. The nursing home is the residents' home and place to live, their social environment where they experience most of their social life and the place where health care service is provided. The diversity of the residents' needs, varying from palliative care to social stimulation, adds complexity to nursing care. Becoming very frail or suffering from dementia could put the resident's perception of being treated with dignity at risk, because the resident would have difficulties in maintaining self-respect and identity (Pleschberger, 2007). It is important to acknowledge risk of low care quality for the most vulnerable residents, and to take this into consideration when it comes to clinical prioritizations in nursing homes (Slettebo et al., 2010). The notion of centredness itself, conceptualized as patient-centredness, person-centredness or relationship-centredness, reflects a movement in health care away from the narrower biomedical view, in favour of a broader view, which involves increasing the social, psychological, cultural and ethical sensitivities of human encounters in health care (Hughes et al., 2008). Furthermore, the nursing home's organization, staffing and organizational culture influence the patient-nurse interaction (Brown Wilson, 2009). Hence, integrated research on all factors that impact the delivery of care is needed to understand how to improve interpersonal relationships and quality of care in nursing homes.

Some limitations of this study should be addressed. One threat to the credibility might be that the informants could have perceived the interviewer, who is a nurse, as a representative of the health care and therefore be reluctant to criticize the nursing home quality. Another element is that the authors' presuppositions may have limited the possibility to understand the cultural assumption of the interviewees (Rubin and Rubin, 2005). However, the authors discussed how this might influence the interpretation, thus enhancing the credibility of the findings.

Finally, transferability might be limited due to the relatively small sample consisting of only mentally lucid residents from four nursing homes. Even so, mentally lucid residents may hold the common voice of nursing home residents. Therefore, the findings in this study may contribute to understanding the experience of other residents in nursing homes, taking into account their individual and contextual circumstances (Kvale and Brinkmann, 2009).

6. Conclusions

Quality nursing care in nursing home implies a balanced, individual approach to medical, physical and psychosocial care, including interpersonal aspects of care. The residents are often frail and vulnerable and their dependence on the staff is evident. Therefore, it is particularly important to protect each resident's integrity by recognizing the resident as an individual with individual needs. However, to assess the individual needs, the nurses must put efforts into knowing each resident. The interpersonal relationship between resident and nurse implies long-term commitment, reciprocal relationship on a personal level and understanding of each resident's needs.

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PAPER III

Ambiguities: The Residents' Experience of 'Nursing Home as My Home'

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ABSTRACT

Background: Residential care in nursing homes continues to be necessary for those individuals who are no longer able to live at home. Uncovering what the nursing home residents view as quality of care in nursing homes will help further understanding of how best to provide high quality, truly person-centred care.

Aim: To describe the residents' experiences with living in a nursing home related to quality of care.

Design: The study has a descriptive exploratory design.

Method: In-depth interviews of fifteen residents who were not cognitively impaired, aged 65 and over, living in one of four nursing homes selected for the study were performed. The interviews were transcribed verbatim and analysed by meaning categorising.

Results: Residents perceived the nursing home as their home, but at the same time not 'a home'. This essential ambiguity created the tension from which the categories of perceptions of quality emerged. Four main categories of quality of care experience were identified: 'Being at home in a nursing home', 'Paying the price for 24-hour care', 'Personal habits and institutional routines', and 'Meaningful activities for a meaningful day'.

Conclusions: Ambiguities concerning the nursing home as a home and place to live, a social environment in which the residents experience most of their social life and the institution where professional health service is provided were uncovered. High quality care was when ambiguities were managed well and a home could be created within the institution.

Implication for practice: Achieving quality care in nursing homes requires reconciling the ambiguities of the nursing home as a home. This implies helping the residents to create a private home distinct from the professional home, allowing the resident's personal habits to guide institutional routines and supporting meaningful activities. Using these resident developed quality indicators is the next step to improve nursing homes.

Keywords:

health care users' experiences; long-term care; nursing homes; older people; quality of care; qualitative interviews; residential facility

INTRODUCTION

Although home-based services are an option for meeting the complex medical and care needs for frail older people, residential care in nursing homes continues to be necessary for those individuals who are no longer able to live at home comfortably or safely. With the shifting demographic towards an ageing population, nursing homes will continue to be an essential service provided to individuals for the foreseeable future. Nursing home staff are challenged to meet the dual demands of providing a home for the long-term residents while managing chronic and acute medical problems. Internationally recognized standards emphasise patient safety, excellence in care and patient satisfaction in the long-term care of older people. However, determining what is good or poor quality of care requires knowledge of the values that individuals place on various health experiences and how these may differ among individuals in different settings

(IOM 1999). Therefore, learning what nursing home residents view as quality, so as to develop more effective person-centred care, is the focus of this study.

National quality standards for long-term care in several countries include a range of domains relevant to nursing care quality (Nakrem, Vinsnes et al. 2009). Overall, these quality measures reflect a medical perspective. Notably, it is not clear that the quality indicators reviewed in the article capture the values and opinions of the residents. Although recent qualitative studies have explored nursing home residents' experience of daily life in long-term care (Andersson, Pettersson et al. 2007; Slettebo 2008), including what contributes to resident's thriving (Bergland and Kirkevold 2006) and quality of life (Hjaltadottir and Gustafsdottir 2007), these studies did not explore what residents perceive as quality of care.

To examine a different dimension that moves beyond the medical care quality indicators, quality of life has been studied. Kane (Kane 2001) conducted a study to identify quality of life domains significant to nursing home life, and these were subsequently confirmed as related to an overall construct of quality of life (Kane, Kling et al. 2003). Another later study sought the opinions of nursing home residents and their family about quality of life indicators (Robichaud, Durand et al. 2006). Their findings showed that environmental characteristics such as having easy access to a private room and extra spaces to use were important, as well as availability of the caregivers, staff stability and having access to leisure and spirituality resources. Older people's right to privacy in institutional settings is recognised as an important factor for quality of care (Sosial- og helsedepartementet 2003), and there has a redesign nursing homes into more home-like environments (Hauge and Heggen 2008). However, a home represents not only a functional space, but has certain characteristics that include, but are not limited to, pattern of regular doings, solidarity and mutual decision-making on the claiming of time, space and other resources (Douglas 1991). These characteristics may be difficult to actualize in an institutional setting.

Rantz et al (Rantz, Zwygart-Stauffacher et al. 1999), proposed a conceptual model for nursing home care quality from the perspectives of residents and families which included features of staff, features of care, family involvement, communication, home and environment. An instrument designed to measure this multidimensional concept of nursing home quality has been developed and tested (Rantz, Mehr et al. 2000; Rantz, Zwygart-Stauffacher et al. 2005). Although this observational instrument is for general use, these researchers recognize that individual expectations about nursing home service and individual variation in needs will influence the experience of quality

of care. For instance, in the study by Bowers et al (Bowers, Fibich et al. 2001), the residents' defined quality in three ways: good service, reciprocal relationship with caregivers, and physical comfort.

Overall, these older studies of residents' description of quality care point to the need for more current research in this area. The aim of the present study was to describe long-term residents' perspectives of what creates quality care in a nursing home.

METHOD

Participants and Settings

The present study is part of a larger research programme focused on multidimensional aspects of quality of care in Norwegian nursing homes. For this study a purposive sample of four public nursing homes in Norway with long-term care residents was included, comprising small-, medium- and large-sized nursing homes in both urban and rural areas. The nursing homes had mixed populations according to medical diagnosis, physical and cognitive functioning, age (ranging from 45 to 100 years old) and gender. Most residents had single rooms with en suite bathrooms, but in all nursing homes there were also double rooms and shared bathrooms. Each unit, which varied in size between 8 and 35 residents, had shared dining and living rooms. Each nursing home also had larger institutional living rooms or public areas where concerts, exercise activities and festivities were arranged.

Twenty-four informants that potentially could provide rich and diverse data were recruited. Inclusion criteria were age of 65 or older, not being cognitively impaired, and being resident of the nursing home for one month or longer. The ability to give consent to participate, and physical and mental capability to handle the interview was assessed by the clinical nurses. The researcher contacted the residents consecutively, handed out the cover letter and read it out loud when requested. The residents orally consented to participation and the time for each interview was determined. The informants were encouraged to ask a relative or friend to read the cover letter. None wanted another person to be present during the interview. The information in the cover letter was repeated once again before the interview began, and residents who were able to write, signed the written consent. Inclusion of new informants continued until the researcher achieved informational redundancy at which point no new information was emerging from the preliminary data analysis (Patton 2002). Fifteen

informants were included in the study, nine women, aged 75-92, and six men, aged 80-96.

Data Collection

Data were collected by in-depth interviews with the residents, as this approach elicits rich detailed information (Gubrium and Holstein 2001). An interview guide with openended questions and probes was designed to generate substantive narrative from the informant (see topic guide in box 1). The guide was reviewed by three experts for its relevance and piloted with one resident. During the interview, the interviewer repeated and summarized the expressions of the informants and asked them whether it was correct. All interviews were conducted by one researcher. Each interview, which typically lasted for one hour, was tape-recorded and transcribed verbatim. Immediately afterwards each interview, the interviewer took notes that described the setting and summarized the general impression of the interview.

Box 1 Outline of topics in the interview guide

Basic physical needs
Psychological needs
Well-being and thriving
Social needs and relationships
Nursing care and medical treatment
Dignity, human rights, respect and self-determination

Data Analysis

The analytic process consisted of meaning coding with categorization, leading to a systematic conceptualization of the interviewees' statements (Patton 2002). The analysis started once the first data were gathered by reviewing the general impression. The analysis continued when all data were transcribed. First, to get an overview of themes, the transcripts were read through while listening to the tape recording and a matrix of the first general themes was constructed. Next, meaningful entities in the transcripts were identified, and the text or expressions of the interviewees were sorted into more specific categories. During this process software for concept mapping was used (MindJet 2004-2009). Mind-mapping accommodated the requirement in this data analysis for flexibility when categories were being developed, and allowed for ease of data movement among and across levels of abstraction (Meier 2007). Overall, the

meaning in each category was synthesized by comparing and contrasting the content and by comparing this with existing theory and literature.

Study rigor

The credibility of the study depends both on rigorous methods in the data collection and analysis, and the credibility of the researcher (Patton 2002). The authors acknowledge that our presuppositions may have limited the achievement of full understanding of the interviewees, since the present research was conducted in a cultural context in which we had experienced only as professional, not ourselves as residents (Rubin and Rubin 2005). Furthermore, because the interviewer is a nurse, the informants could have perceived her as a representative of the health care system and therefore be reluctant to criticise their services. However, the authors discussed how this might influence the interpretation, thus enhancing the credibility of the findings. To strengthen the study's analytical rigor in the area of dependability and confirmability, the research team met throughout the process to review the data, reflect on the emerging categories and discuss the findings. Transferability of the findings might be limited due to the small sample consisting of only residents who were cognitively intact. Notwithstanding this limitation, the contextual findings of this study may contribute to understanding the experience of other residents in nursing homes, taking into account their individual and contextual circumstances (Kvale and Brinkmann 2009).

Ethical Considerations

The study was approved by the Regional Committee for Medical and Health Research Ethics. The informants were assured that all information would be kept confidential, participation was voluntary and refusal to participate would have no impact on their situation in the nursing home. The care personnel in the nursing home were informed who had participated in the study so that they could give extra attention to the resident after the interview if needed.

RESULTS

The residents had opinions of nursing home care quality that included structural factors, medical and nursing care, interpersonal aspects, as well as the effect these have on their quality of life in the nursing home. This article focuses on the findings related to the theme 'the nursing home as my home'. Ambiguity was dominant in the findings.

Nursing home care quality was found to be a vague concept for the residents and could not be defined simply. The nursing home was the residents' home, but at the same time not associated with home. The four major categories of this theme all showed ambiguities in the experience of living in a nursing home. Table 1 shows the analytical subcategories that encompassed the ambiguities and tension.

Essential tensions					
Nursing home as private space	←	Nursing home as public place			
Private personalized room Practical help Easy living Someone to talk to Nice meals with others Belonging to a community	Being at home in a nursing home	Not my own place Feeling confined Living with strangers No others able to talk Accepting bad manners Sharing public space			
Access to immediate help Being safe Relief to get help Unburdening the family	Paying the price for 24-h care and service	Helplessness Grief over losses Defeat to need help Losing contact with family			
Suitable routines Predictability Home-made food Kind and competent staff Stability Time with the staff Priority of the sickest	Personal habits and institutional routines	Restraining routines The day is controlled Institutional food Distrustful of the staff Discontinuity Hasty staff Care needs neglected			
Suitable activity level Ability to self-activate Meaningful activities Time passes quickly	Meaningful activities for a meaningful day	Strenuous to be active Unable to uphold activity Nothing to do Boring long days			

Being at home in a nursing home

Most residents talked about the nursing home as their home. The residents mixed with others in the nursing home community and participated in activities arranged in the nursing home. They had their own private rooms which were personalized with photos, private pictures and some private furniture in addition to the institution's bed and nightstand. The private area was much appreciated as it gave the residents the

opportunity to withdraw from the community when they needed to be alone or wanted to relax. Easy access to outdoor areas with fresh air and sun was highly valued as it gave daily life variation and provided a space in the world outside the walls of the nursing home. Most residents spontaneously expressed that the nursing home was 'a lovely place to be' and 'good in all ways'. They felt that it was an easy way of living, everything was taken care of and they did not need to worry about anything. One woman exemplified it this way:

I've dreamt that I was home many times, and was wearing myself out. And then I awoke here one night and was supposed to prepare - maybe it was salmon or something. And then I thought 'that won't work'. But I was in the dream.

The residents could not define what it was that made the nursing home feel like a home for them, but they emphasized that when telling others that they wanted to 'go home' they meant their private room in the nursing home. However, two men would not at all define their residence being 'home'. One man expressed it this way: 'I don't think there is a better place to be when you have to live away from home'. Another man stated that he was a lodger paying a high price for a small room with health service. His home was where he and his wife had lived for half their lives. Since 'home' was associated with a private room in the nursing home, a shared bedroom was unacceptable for most residents, and one man said that it would be so appalling that he would refuse to live in the nursing home.

However, sharing a bedroom was not always synonymous with low care quality. For example, one woman who had moved from another nursing home where she was very unhappy, had to share a bedroom with another woman when she moved to the new nursing home. She was so relieved to move out from the former nursing home that she did not mind sharing. For another woman sharing a room actually was an essential part of her feeling safe:

Dear Lord, how she [the roommate] watches over me. There was one morning I fell. If she had not been here and reacted as fast as she did, I wouldn't be sitting here today - very comforting that I have her.

Living together with other residents also underscored the ambiguous tension between the nursing home being 'home' in their private space and 'not home' in the public place. Everywhere outside their room there were strangers who they had nothing in common with. Visitors were welcome, but the women in particular felt that their role had been uncomfortably altered because they could not invite them in and offer coffee as they could before. Spending time with the other residents was both an opportunity to be socially active and a source of irritation. One man explained what made the nursing home a good place: 'Like to talk to people. Here I can see people and I get to talk some.' However, unbalanced mix of gender in the unit had made social relationships more superficial and some experienced that differences in interests sometimes resulted in disagreements, for instance, about what TV-program to watch. Being the only cognitively intact resident in a unit could make it impossible to talk with the other residents: 'I think they are nuts, the whole bunch. Yelling and one thing or another. Can't talk to them'. One woman said that sharing dining room and watching a resident at the dinner table eating in a disgusting manner had made her loose her appetite. Therefore, she had her meals served in her room instead.

Both withdrawal from the community and acceptance of being together with people with problematic behaviour were strategies to cope with living in the nursing home. The nursing home represents something in between a community or neighbourhood sharing public spaces, and a family sharing a private space where there might be higher tolerance for adverse behaviour. Norms for social behaviour were at times unclear and challenging to the residents: 'They are not so easy to deal with, you know. It's the same with me, sometimes I just have to pull myself together and be a little more flexible if you know what I mean.' In many ways, it was obvious to the residents that the nursing home could never replace the loss of their own home. Withdrawal to a private space to avoid a problem or trying to adjust one's behaviour kept the tension present. This tension had implications for the perceived quality of living in the nursing home, since being at home but not at home was a constant tension.

Paying the price for 24-hour care and service

The residents missed their homes and longed for the past, which reflected a wish to continue to live at home, and sadness at becoming old and helpless and being forced by circumstances to move from home. For example, the medical condition and need for technical equipment and space had made it impossible for a resident needing extensive assistance to stay at home. He bitterly said that he did not want to spend his older years in a nursing home, but had to accept it. The residents emphasized feeling safe and receiving prompt emergency help as the main advantages. They described declining

physical functioning or unpredictable nature of health status that had made home care not an option. Despite difficult and challenging experiences, many residents were pleased with the service at the nursing home. For some, acceptance was achieved by lowering their expectations, as one woman said: 'you don't need more when you are so old'. Interestingly, some residents explained that 'it could have been worse' and compared living in a nursing home to other life situations such as being a prisoner during the war, or being at home risking that help would not arrive on time if they had serious injury from a fall.

Complex medical illness and significant functional loss were not the only reasons why informants moved into the nursing home. Other circumstances, such as loss of spouse, loneliness at home, inability to take care of practical matters of a house, and a resident of a rural area with considerable distance to the home care service centre influenced the decision to make the move. An example was a quote from this resident:

After my wife died, I was alone out on the island and that just wouldn't work. Got this here thing with my foot and I just couldn't be out there alone on the island, under any circumstances, without home health care.

Another important reason for moving into a nursing home was to relieve family members of the responsibility of caring for them and helping with practical tasks such as shopping and house repairs. Though moving from home was the logical solution to remove the care burden from the family, it also meant losing frequent contact with the family and their social community.

The informants' perceptions about moving to a nursing home fell between two opposite feelings; either it was their greatest desire or their greatest defeat. Their perception was a decisive factor as to whether the new situation was accepted.

Generally the residents were grateful for the 24 hour service and therefore willing to pay the price of the loss of a traditional home for it.

Personal habits and institutional routines

A tension between the necessary institutional routines and the residents' personal habits was present. The smaller nursing homes with small units were more flexible in the daily routines, such as meal times, bedtime and bath days. However, most residents had adjusted their life to institutional routines and were content that way, as one man said: 'I go to bed at a normal time at night and get up at a normal time in the morning. One has

to follow the routines in the nursing home, and that is just fine. Have no problems with that.' Other residents felt that living in a nursing home made them feel bound and thought life in the nursing home restrained them and made them less independent:

Sometimes we are forced, yeah. The staff wants to have their way with so many things. Like with the curtains, so much fuss. They have to open them but then my eyes start to sting. They even get involved with my few possessions . . . There should be more attention given to complaints, they should give more consideration to what I want, not just pay lip-service.

The residents who needed much help, felt that they had to fit into the routines for getting up in the morning and bedtime, usually determined by the time the staff was available to help them. There were exceptions to this rule, and some residents had made their own arrangements. For example, one resident did spontaneously say that she went to bed earlier than she wanted to. However, she had noticed that some of the night shift nurses did not mind helping her to bed, and she stayed up longer when she saw that one of these 'special' nurses were working the night shift.

Being grateful if personal needs was taken care of, demonstrated an ambiguity towards having extraordinary service. One woman said that she thought that she normally was obligated to follow the routines for getting up in the morning. However, staying many hours in bed was painful for her even though she was given painkillers and was repositioned during the night. When talking about what had been done to comfort her, such as being washed and dressed earlier in the morning by the night nurses and placed in the wheelchair, she said: 'I have been so lucky'. She saw this as such an extraordinary gesture and was very grateful. Many of the residents said that they did not want to be seen as troublesome and demanding by bothering the nurses with extra service.

All the interviewed residents had opinion on the food service. Meal times were fixed in all the four nursing homes and the residents were eager to be on time. One man said that he could have his meals served later if he was away at meal times, but at the same time he was uncertain about the possibility to ask for this: 'I can decide almost everything here – except . . . watching the time . . . the meals and such'. The residents said that the food was delicious and that the meals were highlights of the day. Still, many of the residents were disappointed that the meals and food were 'institutional' and not home-like. Since the staff did not have time to sit down with the residents during

meals, they served ready-made sandwiches to save time. This was the only thing one of the more active residents was dissatisfied with. He enjoyed when the activity coordinator participated in the breakfast once a week because this made it a social happening. In all four nursing homes there was the opportunity to get a snack or be served other food from the kitchen-dining-room at each unit. However, the residents felt they could not help themselves in the unit kitchen, mainly because the area was perceived as controlled by the staff and the staff did not have time to help them.

The residents thought that the staff were too busy. Many felt and that they could not ask for more help because there was always someone else that needed to be prioritized: 'They are so busy here. You see, I know the rhythm here so sometimes I have to wait a little while. And I understand that, if they are helping others or feeding.' Some residents thought that they did not receive enough care. Walking by themselves instead of waiting for the nurses to assist them had resulted in falls and injures. They were worried about the busy staff, and one said:

'Mary' was in pretty good shape when she arrived and so was 'Nora'. I think they lay in bed too much. There aren't enough people and it occurs to me that they should be giving more help to them. Oh, I hope that I get - so that I can die . . . that I don't have to go through that. I know that they are all right and kind and everything, but then, they don't have any trouble with me.

This woman explained the kindness of the staff towards her by her not demanding much help, and that very vulnerable residents received insufficient help because there was not enough time to meet the needs.

The residents referred to the staff as 'kind', 'pleasant' and 'clever', and many thought that the staff cared for them on a personal level. However, most residents referred to nurses collectively, could not remember any of their names and felt that they did not have the energy to get to know them. They said that it was strenuous to repeatedly explain to new nurses how to do the procedures. One resident thought that nurses who did not know her well would not notice unusual problems or notice if she was miserable. The quality of the staff was judged by their interest or motivation for doing something extra for the residents. Some nurses only did tasks that were expected of them and they were not able to give emotional support. Thus, there was a tension between seeing the staff as competent and feeling the staff prioritized correctly, and the fact that they sometimes distrusted the staff and did not get enough help.

Meaningful activities for a meaningful day

A few of the residents talked enthusiastically about the activities they could participate in at the nursing home such as sit dance, the activator reading aloud from a book, bingo, spiritual services and trips to the shopping centre. Talking with others was the only activity that interested some residents, and they attended the social arrangements to meet other people in the nursing home. For residents with complex physical needs, washing, dressing, eating and training took up most part of the day, and one resident said that he needed to rest most of the day due to his dizziness when he tried to do something.

However, some of the residents were quite physically active and therefore found nursing home life boring: 'It's not easy to find something to do here'. Residents who had mobility problems wanted to have more help to go outside in the fresh air, to exercise and to be transferred between the floors in the nursing home. Social activity was sometimes limited since many of the other residents could not talk because of stroke or dementia. The importance of being able to activate oneself was illustrated by the fact that watching TV, listening to the radio or reading books and magazines were common activities for most of the residents. For residents who did not have the capacity to read anymore, this instead demonstrated shortcoming in the ability to make a meaningful day: 'I have plenty of time now; many times the day goes slowly. Can't deny that. That's just how it is, can't do anything about it.' Visits from relatives or former neighbours were pleasant breaks in everyday life. One woman felt she was an important family member because she, as a grandmother, was able to provide her grandchildren with her knitted stockings. However, because she had severe lung dysfunction she could not go to the store to buy yarn herself, and, she said, without her knitting tasks the days became very boring. Thus, for some of the residents, a little support in self-activation could make a great difference.

DISCUSSION

The main finding was that the residents perceived the nursing home as their home, but at the same time not 'a home'. This essential ambiguity created the tension from which the informants described their experience of quality of care. The residents expressed that the nursing home was their home and a very nice place to live, but at the same time they perceived themselves as homeless. Ambiguities were recognized, and the residents

had adjusted their behaviour to reconcile these tensions. In addition, their expectations of the nursing home as a home in the sense of private space (Douglas 1991) were changed. This is in line with other research showing that satisfaction with nursing home life is strongly associated with a positive transition experience (Iwasiw, Goldenberg et al. 2003; Andersson, Pettersson et al. 2009) and adaptation to a nursing home life (Kahn 1999; Bergland and Kirkevold 2006).

Being 'at home' in the nursing home was associated with the possibility to withdraw from the community to their room, which gave them the ability to retain self-determination. The residents wanted to be more independent and self-determined, yet their dependency on 24-hour care changed their attitude towards accepting a less satisfying life in the nursing home. Creating routines that suit both the individual resident and the organization was challenged by the varying and often progressively complex needs of the residents. We found that in the same nursing home, residents perceived the day as busy or boring, meaningful or devastating. Respect for the residents as individuals with different needs is the essential attribute in a personalized model of care (Kennedy, Sylvia et al. 2005; Jonas-Simpson, Mitchell et al. 2006). The residents understand that there needs to be certain routines for instance in food service, but it takes little effort to be more flexible and thereby increase the quality of care (Crogan, Evans et al. 2004).

Resident informants also described ambiguous relationships to the staff. Since the residents saw that the staff were busy, they felt prioritized or lucky when they received some extra attention or even the regular care. Many of the residents in the present study had lowered their expectations of the service and explained it by their age. Low self-esteem and loss of status in society may be the reason why older people, especially those who are functionally dependent, often have a feeling of being worth less (Bodner 2009). Residents who feel that they do not have the right to speak up to have their basic care needs met might experience low quality of life (Eika 2006).

The study findings contribute to a more nuanced understanding of residents' perspectives on quality of care in nursing homes. Ambiguity expressed by the informants reflects the multidimensionality and complexity of nursing home service. Individual tensions in care experiences required that residents continually adapt to create a home where it is not a home. This on-going tension was a dominant theme influencing the experience of the nursing home as a home as described by the residents. High quality care was recognized when the ambiguities of the nursing home as a personal home in which to live and the nursing home where professional health service

is provided were managed well and a personal home could be created within an

institutional environment.

IMPLICATIONS FOR PRACTICE

The challenge for the nursing home staff is to meet the competing psychosocial and

physical care needs at the same time. To improve nursing home care quality, the focus

should be on creating a person-centred service that integrates the competing tensions of

the nursing home as personal space and nursing home as public place so as to create a

less ambiguous care environment. In practice this means to create a home despite the

fact that it is not an ordinary home, to ensure individual care and dignity in an

environment where humiliation is almost inevitable, and to create a pleasant community

and fellowship, although the residents only have few, if any, things in common.

Achieving quality care in nursing homes requires reconciling these ambiguities. Using

these resident developed quality indicators is the next step in the nursing home

improvement journey.

Implications for practice:

• It is essential for the experience of a meaningful life that the resident feels at

home in the nursing home, and that institutional routines are adjusted to the

residents' needs for a home-like life

• Nursing home staff should support shaping a good home for the residents

according to their individual wishes for privacy, social relationships and

physical activities

Contributions to the manuscript:

Study design: SN, AGV, BP, AS.

Data collection and analysis: SN, AGV, BP, AS.

Manuscript preparation: SN, AGV, GEH, BP, AS

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PAPER IV

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Norges teknisk-vitenskapelige Universitet Det medisinske fakultetet

dd.mm.2008

Til ledelsen ved [NN sykehjem]

Henvendelse vedrørende forskningsprosjekt

Denne henvendelsen gjelder en forespørsel om deltakelse i forskningsprosjekt. Forskningsprosjektet er et doktorgradsprosjekt ved NTNU som har til hensikt å utforske kvalitetsbegrepet og å utvikle kvalitetsindikatorer for pleie og omsorg i sykehjem. For å kunne bruke målbare indikatorer på kvalitet på pleie og omsorg i sykehjem, må slike indikatorer være utviklet på en god måte og tilfredsstille vitenskapelig krav til gyldighet og pålitelighet. Et første steg i utvikling av indikatorer er å definere det teoretiske grunnlaget for begrepene som inngår i indikatoren, dvs. kvalitet og pleie og omsorg i sykehjem.

Metodene som vil bli brukt er observasjon, intervju med pasienter og diskusjonsgrupper med pårørende. Prosjektmedarbeiderne ønsker å være til stede i avdelingen for observasjon og dokumentstudie. Videre ønsker vi å intervjue inntil 5 pasienter som har langtidsopphold ved avdelingen, og dersom mulig 2-3 pasienter som står på venteliste for langtidsopphold. Til slutt ønsker vi å invitere inntil 8 pårørende til gruppediskusjon.

Dersom dere gir oss tillatelse til å benytte sykehjemmet til prosjektet, ønsker vi å få hjelp til å orientere oss på sykehjemmet (en avdeling), få forslag til pasienter som er aktuelle for intervju, samt å få en liste over pårørende som kan forespørres om deltakelse i diskusjonsgruppe. Forøvrig håper vi ikke prosjektet vil være til noen belastning for dere. Viser også til vedlagte informasjonsskriv til personalet, pasienter og pårørende.

Håper på velvillig tilbakemelding på forespørselen, og jeg vil en av de nærmeste dagene ta kontakt med dere. Har du noen spørsmål kan du ta kontakt med Sigrid Nakrem, telefon 73 55 89 69 eller 91 76 93 74.

Med vennlig hilsen

Sigrid Nakrem Anne Vinsnes (sign.) Arnfinn Seim (sign.)
PhD-stipendiat Professor Førsteamanuensis
Høgskolen i Sør-Trøndelag Høgskolen i Sør-Trøndelag NTNU

Bård Paulsen (sign.) Førsteamanuensis, NTNU Seniorforsker, Sintef Helse



Norges teknisk-vitenskapelige Universitet Det medisinske fakultetet

dd. mm. 2008

Til pasienter som har langtidsopphold ved sykehjemmet

Forespørsel om å delta i forskningsprosjektet "Kvalitet i sykehjem"

Denne henvendelsen gjelder en forespørsel om å delta i et forskningsprosjekt. Jeg ønsker å intervjue deg om hva du synes er viktig for deg når det gjelder kvaliteten på pleie og omsorg i sykehjemmet.

Hensikt

I forbindelse med min doktorgrad ved NTNU gjennomfører jeg et prosjekt om kvalitet på pleie og omsorg i sykehjem. Intervjuene med pasientene er en del av prosjektet som også omfatter observasjon av dagliglivet på avdelingen og intervju med pårørende. Hensikten er å få bedre forståelse for hva som kjennetegner god kvalitet ved pleie og omsorg ved sykehjem. Prosjektet vil bli utført av undertegnede i samarbeid med mine veiledere professor Anne G. Vinsnes ved Høgskolen i Sør-Trøndelag, 1. amanuensis Arnfinn Seim ved Det medisinske fakultetet ved NTNU og seniorforsker Bård Paulsen ved Sintef.

Gjennomføring

Sammen med noen flere andre pasienter på sykehjemmet får du derfor denne forespørselen om å delta i forskningsprosjektet. Det er ledelsen ved sykehjemmet som har valgt ut hvem som skal forespørres og denne forespørselen formidles via dem. Hvem du er, er ukjent for meg inntil du eventuelt samtykker i å delta.

Deltakelse i prosjektet innebærer at jeg får intervjue deg på sykehjemmet. Intervjuet vil tilpasses deg slik at du føler du er i stand til å gjennomføre det. Vanligvis varer et intervju ca 1 time. Du kan selv velge hvor intervjuet skal foregå, for eksempel på ditt eget rom eller et annet rom på sykehjemmet. Jeg ønsker å få svar på hva du mener er viktig for kvaliteten på pleien og omsorgen, og hvordan god kvalitet kommer til uttrykk i din hverdag på sykehjemmet. Informasjonen vil bli brukt for å finne gode måter å avdekke god og dårlig pleie og omsorg i sykehjem. For at jeg lettere skal huske hva som ble sagt under intervjuet og gjøre det mulig å bruke informasjonen etterpå, vil intervjuet bli tatt opp på bånd.

Du kan selv bestemme hva du vil gi meg av informasjon, og dersom du ønsker det kan jeg innhente andre aktuelle opplysninger fra andre som for eksempel pleiepersonalet eller dine pårørende. Intervjuet kan også gjennomføres med en av dine pårørende til stede. Dersom du ønsker det, vil jeg informere dine pårørende om at du skal delta i et intervju.

Taushetsplikten

Prosjektmedarbeiderne har taushetsplikt i henhold til Forvaltningslovens § 13 og Helsepersonellovens § 21 om informasjon som kan knyttes til personlige forhold som fremkommer under intervjuet. Det vil kun være prosjektmedarbeiderne som har tilgang til lydopptak og nedskrevet intervju. Sykehjemmet eller kommunens ansatte vil ikke ha tilgang til informasjonen. Alle persondata behandles konfidensielt og lagres i en database slik at pasientene kun er registrert med et løpenummer. Etter at prosjektet er ferdig sommeren 2012 slettes alle lydbånd og nedskrevet intervju. Resultatet av undersøkelsen vil inngå i doktorgradsavhandlingen, samt at det publiseres artikler i internasjonale tidsskrift uten at den enkelte kan gjenkjennes. Undertegnede vil være ansvarlig for at all informasjon fra deg vil bli behandlet på en korrekt måte. Prosjektet er godkjent av Regional Etisk Komité og tilrådd av Personvernombudet for forskning, Norsk samfunnsvitenskapelig datatjeneste.

Frivillighet

Det er helt frivillig å delta i prosjektet, og du kan på hvilket som helst tidspunkt trekke deg uten å måtte begrunne dette nærmere. Eventuelle uttalelser som du ikke ønsker skal benyttes i prosjektet vil da bli slettet. Hvorvidt du velger å delta i prosjektet eller ikke, har ingen betydning for videre behandling eller pleie på sykehjemmet.

Kontaktinformasjon

Dersom du ønsker å delta i prosjektet, kan du gi beskjed til pleiepersonalet som vil formidle beskjed videre til meg. Jeg tar deretter kontakt med deg. Dersom det er noe du lurer på kan du ta kontakt med meg på telefon 91 76 93 74, eller på Høgskolen i Sør-Trøndelag, Avdeling for Sykepleie, tlf. 73 55 29 77. Samtykkeerklæringen som er vedlagt, skal du underskrive når jeg kommer for å intervjue deg, eller du kan gi muntlig samtykke.

Vennlig hilsen

Sigrid Nakrem PhD-stipendiat

Samty	kkeerkl	læring
~ ******		

Jeg har mottatt skriftlig og muntlig informasjon om prosjektet "Kvalitet i sykehjem" og er villig til å delta i studien.					
Sted ,	 Dato	Signatur			



Norges teknisk-vitenskapelige Universitet Det medisinske fakultetet

dd. mm. 2008

Forespørsel og informasjonsskriv til pårørende vedrørende forskningsprosjektet "Kvalitet i sykehjem"

I forbindelse med min doktorgrad ved NTNU gjennomfører jeg et prosjekt om kvalitet på pleie og omsorg i sykehjem der jeg ønsker å undersøke nærmere hva som ligger i begrepet. I den forbindelse ønsker jeg å intervjue deg som pårørende for å få din mening om hva kvalitet i pleien og omsorgen ved sykehjem betyr. Du inviteres derfor til å delta i en diskusjonsgruppe sammen med andre pårørende.

Prosjektet vil bli utført av undertegnede i samarbeid med mine veiledere professor Anne G. Vinsnes ved Høgskolen i Sør-Trøndelag, 1. amanuensis Arnfinn Seim ved Det medisinske fakultetet ved NTNU og seniorforsker Bård Paulsen ved Sintef. Intervjuene av pårørende er en del av prosjektet som også omfatter observasjon av dagliglivet på avdelingen og intervju med pasienter. Du blir forespurt fordi ledelsen på sykehjemmet har sendt dette brevet til deg som pårørende. Hvem du er, er ukjent for meg inntil du eventuelt samtykker i å delta. Dersom du ikke ønsker å delta selv, kan du foreslå en annen pårørende som jeg kan henvende meg til.

Hensikt

Hensikten med intervjuet/diskusjonsgruppen er å få en dypere forståelse for hva som kjennetegner god kvalitet ved pleie og omsorg ved sykehjem ut fra pasientens perspektiv. Som pårørende kan du i mange sammenhenger gi et godt bilde av pasientens situasjon på vegne av din pårørende som er pasient på sykehjemmet. Vi ønsker å få svar på hva du mener er viktig for kvaliteten på pleien og omsorgen, og hvordan god kvalitet kommer til uttrykk hos din pårørende på sykehjemmet. Vi ønsker å intervjue pårørende til pasienter ved sykehjemmet som har god kjennskap til pleien og omsorgen ved sykehjemmet. Det er fint om du har interesse for å bidra med dine synspunkter på vegne av din pårørende, og ønsker å meddele disse til prosjektmedarbeiderne i diskusjonsgruppen. Informasjonen fra intervjuet vil bli brukt for å finne gode måter å avdekke god og dårlig pleie og omsorg i sykehjem. Din deltakelse vil bidra til at viktig informasjon om disse forholdene blir inkludert, og vil være svært nyttig.

Gjennomføring

Gruppeintervjuet vil foregå i gruppe bestående av 5-8 pårørende, og 1-2 forskningssykepleiere vil lede gruppediskusjonen. Gruppediskusjonen vil foregå på et egnet sted, og det vil ikke være noen av personalet fra sykehjemmet til stede. Intervjuet vil vare ca 2 timer. Dersom du ikke har mulighet til å komme til stedet på egen hånd, kan det ordnes med transport. Eventuelle utgifter til transport vil bli refundert. For at intervjuerne lettere skal huske hva som ble sagt under gruppediskusjonen og gjøre det mulig å bruke informasjonen etterpå, vil intervjuet bli tatt opp på bånd.

Taushetsplikten

Opptakene fra intervjuet skrives ned og oppbevares til prosjektet er avsluttet. Etter at prosjektet er ferdig sommeren 2012, slettes alle lydbånd og nedskrevet intervju. Det som blir sagt i diskusjonsgruppen anonymiseres slik at det ikke er mulig å spore tilbake hvem som har kommet med de ulike uttalelsene. Det vil kun være prosjektmedarbeiderne som har tilgang til lydopptak og nedskrevet intervju. Sykehjemmet eller kommunens ansatte vil ikke ha tilgang til informasjonen. Resultatet av undersøkelsen vil inngå i doktorgradsavhandlingen, samt at det publiseres artikler i internasjonale tidsskrift uten at den enkelte kan gjenkjennes.

Prosjektmedarbeiderne har taushetsplikt i henhold til Forvaltningslovens § 13 og Helsepersonellovens § 21 om informasjon som kan knyttes til personlige forhold som fremkommer under intervjuet. Undertegnede vil være ansvarlig for at all informasjon fra deg vil bli behandlet på en korrekt måte. Prosjektet er godkjent av Regional Etisk Komité og tilrådd av Personvernombudet for forskning, Norsk samfunnsvitenskapelig datatjeneste.

Frivillighet

Det er helt frivillig å delta i prosjektet og er basert på ditt samtykke. Du kan når som helst trekke deg helt eller delvis fra deltakelsen uten å måtte begrunne dette nærmere. Eventuelle uttalelser som du ikke ønsker skal benyttes i prosjektet vil da bli slettet. Deltakelse i intervju vil ikke få noen følger for pleien og omsorgen for din pårørende på sykehjemmet.

Kontaktinformasjon

Dersom du ønsker å delta på fokusgruppeintervjuet, ber vi deg ta kontakt med Sigrid Nakrem, telefon 91 76 93 74 eller på e-post <u>Sigrid.Nakrem@hist.no</u>. Du kan også gi beskjed til sykehjemmet (ledelsen eller på avdelingen), som vil formidle beskjeden videre til meg. Samtykkeerklæringen som er vedlagt, skal du signere når du kommer til intervjuet.

Vennlig hilsen Sigrid Nakrem, PhD-stipendiat

Samtykkeerklæring

Jeg har mottatt skriftlig og muntlig informasjon om prosjektet "Kvalitet i sykehjem" og er villig til å delta i studien.					
	,				
Sted	Dato	Signatur			
Telefonnummer					

INTERVJUGUIDE PASIENTER MED LANGTIDSOPPHOLD I SYKEHJEM

Hensikten med intervjuet er å finne fram til det som er viktig for deg når det gjelder kvalitet på pleien og omsorgen, trivsel og livskvalitet under oppholdet på sykehjemmet. Jeg vil spørre deg om å beskrive og fortelle historier fra dagliglivet ditt på sykehjemmet. Jeg kommer å be deg om å komme inn på ulike tema.

Tema 1: Fysisk basisbehov i tienestetilbudet

Viktige tema å få belyst her er hvordan pasienten har det til daglig, hvilke hendelser og aktiviteter i det daglige pasienten legger vekt på. Videre om de generelle forholdene ved sykehjemmet, som oppholdsrommene, eget rom, mulighet til å gjennomføre aktiviteter etter eget ønske.

- Fortell om det du gjør til daglig her.
- Hendelser som du vil fortelle om
- Aktiviteter som foregår
- Aktiviteter du brukte å gjøre før
- Oppholdsrommene
- Ditt eget rom
- Muligheten til å gjøre det du vil

Tema 2: Psykiske behov, velvære og trivsel

Pasienten bes fortelle om situasjoner der livskvalitet og trivsel ved sykehjemmet beskrives. Områder som belyses er hvordan pasienten opplever dagliglivet, hvilke faktorer som bidrar til trivsel, og hva som er viktige elementer for livskvalitet i sykehjem.

- Hvis du skulle beskrive en god dag, hva inneholder den?
- Hvordan føler du deg når du har det bra?
- Hvordan kan andre merke at du har det bra?
- Savner du noe?
- Hvordan kan du få til en endring dersom du ønsker det?

Tema 3: Sosiale behov. Relasjoner med personalet og andre pasienter

Aspekter som inngår er hvem pasienten snakker med om hvilke tema det snakkes om. Eventuelle problemer med kommunikasjon belyses.

- Kan du fortelle om en gang du fikk god kontakt med noen av personalet her?
- Hvordan viser personalet interesse for deg og det du bryr deg om?
- Er det lett å forstå personalet og det legen sier?
- Føler du at personalet her kjenner deg og det du har behov for?
- Hvem av de andre pasientene snakker du med?
- Hva snakker dere om?

Tema 4: Pleie og omsorg, behandling

Innen tema vil det være viktig å belyse områder som:

- personlig hygiene
- personlig stell
- toalettbesøk
- spisesituasjonen
- ernæring
- helsemessige forhold, sykdom og behandling.

Tema 5: Menneskeverd, menneskerettigheter. Respekt og selvbestemmelse

Indirekte vil tema om respektfull behandling og mulighet for medbestemmelse bli belyst.

- Kan du beskrive en situasjon der du følte seg spesielt godt ivaretatt.
- Hvem bestemmer i hovedsak hvordan dagen din ser ut?
- Hva innebærer det at du føler deg godt ivaretatt?
- Hvilke personer synes du ivaretar deg best, og hvordan merker du det?
- I hvilken grad kan du bestemme over deg selv?
- Hvor selvstendig føler du at du er?

Kvalitet i sykehjem (KVAPLOS)

Intervjuguide til fokusgruppeintervju med pårørende

1. Åpningsspørsmål/presentasjon

Kan du si litt om deg selv og hvilken tilknytning du har til sykehjemmet?

2. Introduksion

For å skille mellom hva som er god og dårlig pleie og omsorg, trengs det både det profesjonelle pleiepersonellet sin kunnskap og erfaring, og opplysninger om hva pasienten legger vekt på og har som preferanser. Som pårørende har dere kjennskap til dette sett både utenfra og gjennom din pårørende. Du skal nå fortrinnsvis snakke på vegne av din pårørende. Dine synspunkter er svært viktige, uansett om du snakker på vegne av pasientene på sykehjemmet eller på egne vegne.

Kan dere si noe om hvilke deler av pleien og omsorgen som det er spesielt viktig blir godt ivaretatt for din pårørende på sykehjemmet?

3. Nøkkelspørsmål 1

Hva legger du i begrepet kvalitet på pleie og omsorg i sykehjem?

4. Nøkkelspørsmål 2

Hvem eller hva bidrar til å gjøre at din pårørende har det godt på sykehjemmet?

5. Nøkkelspørsmål 3

Hvordan ser og forstår du at det blir gitt god pleie og omsorg?

6. Nøkkelspørsmål 4

Hva kunne du tenkt deg var annerledes når det gjelder pleien?

7. Nøkkelspørsmål 5

Hvordan kan det som du nevner som kunne ha vært annerledes bli bedre? Hvilke konkrete forventninger har du til forbedring i kvaliteten?

8. Avslutningsspørsmål

Er det noe som ikke er berørt som du synes er viktig å nevne?

9. Avslutning

Vi har fått mye informasjon som vi vil ta med videre i prosjektet (oppsummerer kort). Er det noe dere vil tilføye til slutt?

Dissertations at the Faculty of Medicine, NTNU

1977

- 1. Knut Joachim Berg: EFFECT OF ACETYLSALICYLIC ACID ON RENAL FUNCTION
- Karl Erik Viken and Arne Ødegaard: STUDIES ON HUMAN MONOCYTES CULTURED IN VITRO

1978

- 3. Karel Bjørn Cyvin: CONGENITAL DISLOCATION OF THE HIP JOINT.
- 4. Alf O. Brubakk: METHODS FOR STUDYING FLOW DYNAMICS IN THE LEFT VENTRICLE AND THE AORTA IN MAN.

1979

5. Geirmund Unsgaard: CYTOSTATIC AND IMMUNOREGULATORY ABILITIES OF HUMAN BLOOD MONOCYTES CULTURED IN VITRO

1980

- 6. Størker Jørstad: URAEMIC TOXINS
- 7. Arne Olav Jenssen: SOME RHEOLOGICAL, CHEMICAL AND STRUCTURAL PROPERTIES OF MUCOID SPUTUM FROM PATIENTS WITH CHRONIC OBSTRUCTIVE BRONCHITIS

1981

8. Jens Hammerstrøm: CYTOSTATIC AND CYTOLYTIC ACTIVITY OF HUMAN MONOCYTES AND EFFUSION MACROPHAGES AGAINST TUMOR CELLS *IN VITRO*

1983

- 9. Tore Syversen: EFFECTS OF METHYLMERCURY ON RAT BRAIN PROTEIN.
- 10. Torbjørn Iversen: SQUAMOUS CELL CARCINOMA OF THE VULVA.

1984

- 11. Tor-Erik Widerøe: ASPECTS OF CONTINUOUS AMBULATORY PERITONEAL DIALYSIS.
- 12. Anton Hole: ALTERATIONS OF MONOCYTE AND LYMPHOCYTE FUNCTIONS IN REALTION TO SURGERY UNDER EPIDURAL OR GENERAL ANAESTHESIA.
- 13. Terje Terjesen: FRACTURE HEALING AND STRESS-PROTECTION AFTER METAL PLATE FIXATION AND EXTERNAL FIXATION.
- 14. Carsten Saunte: CLUSTER HEADACHE SYNDROME.
- 15. Inggard Lereim: TRAFFIC ACCIDENTS AND THEIR CONSEQUENCES.
- Bjørn Magne Eggen: STUDIES IN CYTOTOXICITY IN HUMAN ADHERENT MONONUCLEAR BLOOD CELLS.
- 17. Trond Haug: FACTORS REGULATING BEHAVIORAL EFFECTS OG DRUGS.

1985

- 18. Sven Erik Gisvold: RESUSCITATION AFTER COMPLETE GLOBAL BRAIN ISCHEMIA.
- 19. Terje Espevik: THE CYTOSKELETON OF HUMAN MONOCYTES.
- Lars Bevanger: STUDIES OF THE Ibc (c) PROTEIN ANTIGENS OF GROUP B STREPTOCOCCI.
- Ole-Jan Iversen: RETROVIRUS-LIKE PARTICLES IN THE PATHOGENESIS OF PSORIASIS.
- 22. Lasse Eriksen: EVALUATION AND TREATMENT OF ALCOHOL DEPENDENT BEHAVIOUR.
- 23. Per I. Lundmo: ANDROGEN METABOLISM IN THE PROSTATE.

1986

- 24. Dagfinn Berntzen: ANALYSIS AND MANAGEMENT OF EXPERIMENTAL AND CLINICAL PAIN.
- 25. Odd Arnold Kildahl-Andersen: PRODUCTION AND CHARACTERIZATION OF MONOCYTE-DERIVED CYTOTOXIN AND ITS ROLE IN MONOCYTE-MEDIATED CYTOTOXICITY.
- 26. Ola Dale: VOLATILE ANAESTHETICS.

- 27. Per Martin Kleveland: STUDIES ON GASTRIN.
- 28. Audun N. Øksendal: THE CALCIUM PARADOX AND THE HEART.
- 29. Vilhjalmur R. Finsen: HIP FRACTURES

- 30. Rigmor Austgulen: TUMOR NECROSIS FACTOR: A MONOCYTE-DERIVED REGULATOR OF CELLULAR GROWTH.
- 31. Tom-Harald Edna: HEAD INJURIES ADMITTED TO HOSPITAL.
- 32. Joseph D. Borsi: NEW ASPECTS OF THE CLINICAL PHARMACOKINETICS OF METHOTREXATE.
- 33. Olav F. M. Sellevold: GLUCOCORTICOIDS IN MYOCARDIAL PROTECTION.
- Terje Skjærpe: NONINVASIVE QUANTITATION OF GLOBAL PARAMETERS ON LEFT VENTRICULAR FUNCTION: THE SYSTOLIC PULMONARY ARTERY PRESSURE AND CARDIAC OUTPUT.
- 35. Eyvind Rødahl: STUDIES OF IMMUNE COMPLEXES AND RETROVIRUS-LIKE ANTIGENS IN PATIENTS WITH ANKYLOSING SPONDYLITIS.
- 36. Ketil Thorstensen: STUDIES ON THE MECHANISMS OF CELLULAR UPTAKE OF IRON FROM TRANSFERRIN.
- 37. Anna Midelfart: STUDIES OF THE MECHANISMS OF ION AND FLUID TRANSPORT IN THE BOVINE CORNEA
- 38. Eirik Helseth: GROWTH AND PLASMINOGEN ACTIVATOR ACTIVITY OF HUMAN GLIOMAS AND BRAIN METASTASES WITH SPECIAL REFERENCE TO TRANSFORMING GROWTH FACTOR BETA AND THE EPIDERMAL GROWTH FACTOR RECEPTOR.
- 39. Petter C. Borchgrevink: MAGNESIUM AND THE ISCHEMIC HEART.
- Kjell-Arne Rein: THE EFFECT OF EXTRACORPOREAL CIRCULATION ON SUBCUTANEOUS TRANSCAPILLARY FLUID BALANCE.
- 41. Arne Kristian Sandvik: RAT GASTRIC HISTAMINE.
- 42. Carl Bredo Dahl: ANIMAL MODELS IN PSYCHIATRY.

1989

- 43. Torbjørn A. Fredriksen: CERVICOGENIC HEADACHE.
- 44. Rolf A. Walstad: CEFTAZIDIME.
- 45. Rolf Salvesen: THE PUPIL IN CLUSTER HEADACHE.
- 46. Nils Petter Jørgensen: DRUG EXPOSURE IN EARLY PREGNANCY.
- Johan C. Ræder: PREMEDICATION AND GENERAL ANAESTHESIA IN OUTPATIENT GYNECOLOGICAL SURGERY.
- 48. M. R. Shalaby: IMMUNOREGULATORY PROPERTIES OF TNF- α AND THE RELATED CYTOKINES.
- 49. Anders Waage: THE COMPLEX PATTERN OF CYTOKINES IN SEPTIC SHOCK.
- Bjarne Christian Eriksen: ELECTROSTIMULATION OF THE PELVIC FLOOR IN FEMALE URINARY INCONTINENCE.
- 51. Tore B. Halvorsen: PROGNOSTIC FACTORS IN COLORECTAL CANCER.

- 52. Asbjørn Nordby: CELLULAR TOXICITY OF ROENTGEN CONTRAST MEDIA.
- 53. Kåre E. Tvedt: X-RAY MICROANALYSIS OF BIOLOGICAL MATERIAL.
- 54. Tore C. Stiles: COGNITIVE VULNERABILITY FACTORS IN THE DEVELOPMENT AND MAINTENANCE OF DEPRESSION.
- 55. Eva Hofsli: TUMOR NECROSIS FACTOR AND MULTIDRUG RESISTANCE.
- 56. Helge S. Haarstad: TROPHIC EFFECTS OF CHOLECYSTOKININ AND SECRETIN ON THE RAT PANCREAS
- 57. Lars Engebretsen: TREATMENT OF ACUTE ANTERIOR CRUCIATE LIGAMENT INJURIES.
- 58. Tarjei Rygnestad: DELIBERATE SELF-POISONING IN TRONDHEIM.
- Arne Z. Henriksen: STUDIES ON CONSERVED ANTIGENIC DOMAINS ON MAJOR OUTER MEMBRANE PROTEINS FROM ENTEROBACTERIA.
- Steinar Westin: UNEMPLOYMENT AND HEALTH: Medical and social consequences of a factory closure in a ten-year controlled follow-up study.
- 61. Ylva Sahlin: INJURY REGISTRATION, a tool for accident preventive work.
- Helge Bjørnstad Pettersen: BIOSYNTHESIS OF COMPLEMENT BY HUMAN ALVEOLAR MACROPHAGES WITH SPECIAL REFERENCE TO SARCOIDOSIS.
- 63. Berit Schei: TRAPPED IN PAINFUL LOVE.
- 64. Lars J. Vatten: PROSPECTIVE STUDIES OF THE RISK OF BREAST CANCER IN A COHORT OF NORWEGIAN WOMAN.

- 65. Kåre Bergh: APPLICATIONS OF ANTI-C5a SPECIFIC MONOCLONAL ANTIBODIES FOR THE ASSESSMENT OF COMPLEMENT ACTIVATION.
- 66. Svein Svenningsen: THE CLINICAL SIGNIFICANCE OF INCREASED FEMORAL ANTEVERSION
- 67. Olbjørn Klepp: NONSEMINOMATOUS GERM CELL TESTIS CANCER: THERAPEUTIC OUTCOME AND PROGNOSTIC FACTORS.
- 68. Trond Sand: THE EFFECTS OF CLICK POLARITY ON BRAINSTEM AUDITORY EVOKED POTENTIALS AMPLITUDE, DISPERSION, AND LATENCY VARIABLES.
- 69. Kjetil B. Åsbakk: STUDIES OF A PROTEIN FROM PSORIATIC SCALE, PSO P27, WITH RESPECT TO ITS POTENTIAL ROLE IN IMMUNE REACTIONS IN PSORIASIS.
- 70. Arnulf Hestnes: STUDIES ON DOWN'S SYNDROME.
- 71. Randi Nygaard: LONG-TERM SURVIVAL IN CHILDHOOD LEUKEMIA.
- 72. Bjørn Hagen: THIO-TEPA.
- 73. Svein Anda: EVALUATION OF THE HIP JOINT BY COMPUTED TOMOGRAMPHY AND ULTRASONOGRAPHY.

1992

- 74. Martin Svartberg: AN INVESTIGATION OF PROCESS AND OUTCOME OF SHORT-TERM PSYCHODYNAMIC PSYCHOTHERAPY.
- 75. Stig Arild Slørdahl: AORTIC REGURGITATION.
- Harold C Sexton: STUDIES RELATING TO THE TREATMENT OF SYMPTOMATIC NON-PSYCHOTIC PATIENTS.
- 77. Maurice B. Vincent: VASOACTIVE PEPTIDES IN THE OCULAR/FOREHEAD AREA.
- 78. Terje Johannessen: CONTROLLED TRIALS IN SINGLE SUBJECTS.
- 79. Turid Nilsen: PYROPHOSPHATE IN HEPATOCYTE IRON METABOLISM.
- Olav Haraldseth: NMR SPECTROSCOPY OF CEREBRAL ISCHEMIA AND REPERFUSION IN RAT.
- 81. Eiliv Brenna: REGULATION OF FUNCTION AND GROWTH OF THE OXYNTIC MUCOSA.

1993

- 82. Gunnar Bovim: CERVICOGENIC HEADACHE.
- 83. Jarl Arne Kahn: ASSISTED PROCREATION.
- 84. Bjørn Naume: IMMUNOREGULATORY EFFECTS OF CYTOKINES ON NK CELLS.
- 85. Rune Wiseth: AORTIC VALVE REPLACEMENT.
- 86. Jie Ming Shen: BLOOD FLOW VELOCITY AND RESPIRATORY STUDIES.
- 87. Piotr Kruszewski: SUNCT SYNDROME WITH SPECIAL REFERENCE TO THE AUTONOMIC NERVOUS SYSTEM.
- 88. Mette Haase Moen: ENDOMETRIOSIS.
- 89. Anne Vik: VASCULAR GAS EMBOLISM DURING AIR INFUSION AND AFTER DECOMPRESSION IN PIGS.
- 90. Lars Jacob Stovner: THE CHIARI TYPE I MALFORMATION.
- 91. Kjell Å. Salvesen: ROUTINE ULTRASONOGRAPHY IN UTERO AND DEVELOPMENT IN CHILDHOOD

- 92. Nina-Beate Liabakk: DEVELOPMENT OF IMMUNOASSAYS FOR TNF AND ITS SOLUBLE RECEPTORS
- 93. Sverre Helge Torp: erbB ONCOGENES IN HUMAN GLIOMAS AND MENINGIOMAS.
- 94. Olav M. Linaker: MENTAL RETARDATION AND PSYCHIATRY. Past and present.
- 95. Per Oscar Feet: INCREASED ANTIDEPRESSANT AND ANTIPANIC EFFECT IN COMBINED TREATMENT WITH DIXYRAZINE AND TRICYCLIC ANTIDEPRESSANTS.
- 96. Stein Olav Samstad: CROSS SECTIONAL FLOW VELOCITY PROFILES FROM TWO-DIMENSIONAL DOPPLER ULTRASOUND: Studies on early mitral blood flow.
- 97. Bjørn Backe: STUDIES IN ANTENATAL CARE.
- 98. Gerd Inger Ringdal: QUALITY OF LIFE IN CANCER PATIENTS.
- 99. Torvid Kiserud: THE DUCTUS VENOSUS IN THE HUMAN FETUS.
- 100. Hans E. Fjøsne: HORMONAL REGULATION OF PROSTATIC METABOLISM.
- 101. Eylert Brodtkorb: CLINICAL ASPECTS OF EPILEPSY IN THE MENTALLY RETARDED.
- 102. Roar Juul: PEPTIDERGIC MECHANISMS IN HUMAN SUBARACHNOID HEMORRHAGE.
- 103. Unni Syversen: CHROMOGRANIN A. Phsysiological and Clinical Role.

- 104.Odd Gunnar Brakstad: THERMOSTABLE NUCLEASE AND THE *nuc* GENE IN THE DIAGNOSIS OF *Staphylococcus aureus* INFECTIONS.
- 105. Terje Engan: NUCLEAR MAGNETIC RESONANCE (NMR) SPECTROSCOPY OF PLASMA IN MALIGNANT DISEASE.
- 106.Kirsten Rasmussen: VIOLENCE IN THE MENTALLY DISORDERED.
- 107. Finn Egil Skjeldestad: INDUCED ABORTION: Timetrends and Determinants.
- 108.Roar Stenseth: THORACIC EPIDURAL ANALGESIA IN AORTOCORONARY BYPASS SURGERY.
- 109. Arild Faxvaag: STUDIES OF IMMUNE CELL FUNCTION in mice infected with MURINE RETROVIRUS.

1996

- 110. Svend Aakhus: NONINVASIVE COMPUTERIZED ASSESSMENT OF LEFT VENTRICULAR FUNCTION AND SYSTEMIC ARTERIAL PROPERTIES. Methodology and some clinical applications.
- 111.Klaus-Dieter Bolz: INTRAVASCULAR ULTRASONOGRAPHY.
- 112. Petter Aadahl: CARDIOVASCULAR EFFECTS OF THORACIC AORTIC CROSS-CLAMPING.
- 113. Sigurd Steinshamn: CYTOKINE MEDIATORS DURING GRANULOCYTOPENIC INFECTIONS.
- 114. Hans Stifoss-Hanssen: SEEKING MEANING OR HAPPINESS?
- 115. Anne Kvikstad: LIFE CHANGE EVENTS AND MARITAL STATUS IN RELATION TO RISK AND PROGNOSIS OF CANCER.
- 116.Torbjørn Grøntvedt: TREATMENT OF ACUTE AND CHRONIC ANTERIOR CRUCIATE LIGAMENT INJURIES. A clinical and biomechanical study.
- 117. Sigrid Hørven Wigers: CLINICAL STUDIES OF FIBROMYALGIA WITH FOCUS ON ETIOLOGY, TREATMENT AND OUTCOME.
- 118.Jan Schjøtt: MYOCARDIAL PROTECTION: Functional and Metabolic Characteristics of Two Endogenous Protective Principles.
- 119.Marit Martinussen: STUDIES OF INTESTINAL BLOOD FLOW AND ITS RELATION TO TRANSITIONAL CIRCULATORY ADAPATION IN NEWBORN INFANTS.
- 120. Tomm B. Müller: MAGNETIC RESONANCE IMAGING IN FOCAL CEREBRAL ISCHEMIA.
- 121. Rune Haaverstad: OEDEMA FORMATION OF THE LOWER EXTREMITIES.
- 122.Magne Børset: THE ROLE OF CYTOKINES IN MULTIPLE MYELOMA, WITH SPECIAL REFERENCE TO HEPATOCYTE GROWTH FACTOR.
- 123.Geir Smedslund: A THEORETICAL AND EMPIRICAL INVESTIGATION OF SMOKING, STRESS AND DISEASE: RESULTS FROM A POPULATION SURVEY.

1997

- 124. Torstein Vik: GROWTH, MORBIDITY, AND PSYCHOMOTOR DEVELOPMENT IN INFANTS WHO WERE GROWTH RETARDED *IN UTERO*.
- 125. Siri Forsmo: ASPECTS AND CONSEQUENCES OF OPPORTUNISTIC SCREENING FOR CERVICAL CANCER. Results based on data from three Norwegian counties.
- 126.Jon S. Skranes: CEREBRAL MRI AND NEURODEVELOPMENTAL OUTCOME IN VERY LOW BIRTH WEIGHT (VLBW) CHILDREN. A follow-up study of a geographically based year cohort of VLBW children at ages one and six years.
- 127.Knut Bjørnstad: COMPUTERIZED ECHOCARDIOGRAPHY FOR EVALUTION OF CORONARY ARTERY DISEASE.
- 128.Grethe Elisabeth Borchgrevink: DIAGNOSIS AND TREATMENT OF WHIPLASH/NECK SPRAIN INJURIES CAUSED BY CAR ACCIDENTS.
- 129. Tor Elsås: NEUROPEPTIDES AND NITRIC OXIDE SYNTHASE IN OCULAR AUTONOMIC AND SENSORY NERVES.
- 130.Rolf W. Gråwe: EPIDEMIOLOGICAL AND NEUROPSYCHOLOGICAL PERSPECTIVES ON SCHIZOPHRENIA.
- 131.Tonje Strømholm: CEREBRAL HAEMODYNAMICS DURING THORACIC AORTIC CROSSCLAMPING. An experimental study in pigs

1998

132.Martinus Bråten: STUDIES ON SOME PROBLEMS REALTED TO INTRAMEDULLARY NAILING OF FEMORAL FRACTURES.

- 133. Ståle Nordgård: PROLIFERATIVE ACTIVITY AND DNA CONTENT AS PROGNOSTIC INDICATORS IN ADENOID CYSTIC CARCINOMA OF THE HEAD AND NECK.
- 134.Egil Lien: SOLUBLE RECEPTORS FOR **TNF** AND **LPS**: RELEASE PATTERN AND POSSIBLE SIGNIFICANCE IN DISEASE.
- 135.Marit Bjørgaas: HYPOGLYCAEMIA IN CHILDREN WITH DIABETES MELLITUS
- 136.Frank Skorpen: GENETIC AND FUNCTIONAL ANALYSES OF DNA REPAIR IN HUMAN CELLS.
- 137. Juan A. Pareja: SUNCT SYNDROME. ON THE CLINICAL PICTURE. ITS DISTINCTION FROM OTHER, SIMILAR HEADACHES.
- 138.Anders Angelsen: NEUROENDOCRINE CELLS IN HUMAN PROSTATIC CARCINOMAS AND THE PROSTATIC COMPLEX OF RAT, GUINEA PIG, CAT AND DOG.
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