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COLLABORATION BETWEEN RELATIVES OF FRAIL ELDERLY PATIENTS AND NURSES IN ACUTE HOSPITAL WARDS

Dimensions, prerequisites and outcome

av

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Title and subtitle
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The aim was to investigate collaboration between relatives of frail elderly patients and nurses in acute hospital wards, and to develop and test an instrument to investigate, from the relatives' perspective, dimensions of collaboration in this context and the association between collaboration and satisfaction with the hospital care trajectory. The underpinning assumption for the study was that relatives hold knowledge of the patients' situation, which is important for nurses to make a relevant and sufficient care plan. The first two studies were qualitative, investigating relatives' and nurses' experiences of the collaboration with each other. Eight relatives of elderly patients ≥ 75 years of age, living at home and dependent on formal and informal help participated. Eight nurses (6 RN + 2 LPN) who conducted the discharge of the elderly patient participated in the second study. In the third study an instrument was developed for measuring collaboration, its prerequisites and outcomes from the relatives' perspective, and put through psychometric testing. In this study, and in the fourth study, which investigated the association between collaboration and satisfaction with the hospital care trajectory, 156 relatives of elderly patients participated. The context was acute medical and geriatric wards in two Danish hospitals.

The lived experience of being a relative to a frail elderly patient revealed itself in two main essences: *The history* reflected the relationship and care history and was the frame of reference in which the hospital admission was interpreted and understood. The constituents were: *The adult child, Parent for my mother, It is always in the back of my mind* and *A full time job*. The essence *Standing Guard* encompassed the encounter with the hospital system and the constituents were: *My God, is it now?, Powerless, If you relax, you fail, Watchdog and case manager* and *Those poor, poor people*.

The main theme in the interviews with nurses was *Encountering relatives – To be caught between ideals and practice* and reflected that the nurses seemingly held two sets of conflicting attitudes towards relatives and the collaboration with them: One ideal and in accordance with their professional values, and another seemingly governing collaboration in practice. Themes were: *The coincidental encounter – the collaboration*, which reflected that though ideally described as a structured process, collaboration appeared to be coincidental and rare; and *Relatives – a demanding resource*. The sub themes were: *Flee or fight – the nurses' response, A matter of prioritising – Barriers and promoters, The unwritten rules* and *The new relatives – the demanding and unrealistic relatives*.

A model for collaboration was developed from literature and constituted the basis for development of instrument variables and items. In the factor analysis (PCA) five factors were extracted: "Influence on decisions", "Quality of contact with nurses", "Trust and its prerequisites", "Achieved information level" and "Influence on discharge". The factor analysis supported the assumption that collaboration was a multi-dimensional construct characterised by shared decision-making and exchange of knowledge and information, with prerequisites such as quality of the contact and communication based on trust and respect. The instrument was mainly reliable and valid, although caution should be made due to the sample being small, and the design being cross sectional. Systematic dropout indicated that the study might have missed the most strained, the oldest and the least educated relatives. Further testing after a reduction of items as well as revising of the wording in some items is warranted.

Dimensions of collaboration were predictors for the relatives' satisfaction with the hospital care trajectory, and lower ratings of collaboration were significantly associated with lower level of satisfaction. Further, powerlessness, guilt, having provided help less than one year and not providing psychosocial help were predictors for relatives' satisfaction with the hospital care trajectory. Whereas relatives rated poorly on influence on decisions and exchange of knowledge and information, the contact and relationship qualities with nurses were seemingly more satisfactory, although accessibility of nurses appeared to be a problem.

Key words: Collaboration, decision-making, family care, frail elderly, acute care facility, questionnaire, instrument development and validation, outcome, guilt, powerlessness, phenomenology, content analysis

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CONTENTS

ABSTRACT

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ABBREVIATIONS

ADL: Activities of daily living
CI: Confidence intervals
ICN: International Council of Nurses
IQR: Interquartile range
LPN: Licensed practical nurse
M: Mean
OR: Odds Ratio
RN: Registered nurse
SD: Standard deviation

DEFINITIONS

Collaboration

The interaction between relatives and nurses involved in decision-making in relation to the care and treatment of the elderly patient. It is characterised by exchange of knowledge and information, and shared decision-making.

Relatives

Spouses, children, grandchildren, children-in-law, siblings, nephews or nieces, friends or neighbours. A relative as informal carer is defined as the person whom the elderly patient identifies as the main (informal) provider of help in the activities of daily living.

Help

The concept "help" was chosen, and used interchangeably with "informal care" in the questionnaire and when interviewing relatives. "Care" (pleje, omsorg), in Danish implies personal care, whereas help can be more than that.

Nurse

In the work described in this thesis the nurses involved were all either registered nurses (RN) or licensed practical nurses (LPN). Whereas the RN's training is a 3½-year course at the bachelor level, the LPN training is a basic social and health education programme at the vocational level and lasts 1 year and 8 months.

The hospital care trajectory

The Danish National Health Board (1999) defines a care trajectory (patientforløbet) as "a course of events starting when the individual contacts the health care system to obtain care or treatment for a health problem until the service has been delivered and the contact been terminated". In this thesis it covers the time-span from admission to discharge.

Frail elderly people

Frail elderly people are defined in this thesis as 75 years or older and dependent on formal and informal help with the activities of daily living.

ORIGINAL PAPERS

This thesis for the doctoral degree is based on the following papers referred to in the text by their Roman numerals:

I   Lindhardt T., Bolmsjö I., Hallberg I.R. (2006) Standing guard – being a relative to a hospitalised elderly person. *Journal of Aging Studies* (20) pp. 133 – 149

II   Lindhardt T., Poulsen I., Hallberg I.R. Nurses' experience of collaboration with relatives of frail elderly patients - A qualitative study. Accepted for publication in *International Journal of Nursing Studies*

III   Lindhardt T., Nyberg P., Hallberg I.R. Relatives' view on collaboration with nurses in acute wards. Development and testing of a new measure. Submitted for publication

IV   Lindhardt T., Nyberg P., Hallberg I.R. Collaboration between relatives of elderly patients and nurses and its relation to satisfaction with the hospital care trajectory. Submitted for publication

INTRODUCTION

Relatives of frail elderly patients have often been involved in their care prior to admission, and are likely to continue to feel responsible after it (Allen, 2000, Li et al., 2000). They may hold valuable knowledge about the elderly person, which, if they were involved in the planning and decision-making process, might improve the care trajectory. Further, legislation establishes the basic right of the patient's self-determination regarding his/her own care and treatment (Kristensen, 2000), obligating health care professionals to involve patients in decision-making based on relevant and sufficient information. However, to use this right, patients need a good deal of strength, energy and knowledge, which frail elderly patients may not possess. In these cases relatives may act as a proxy for the patient to employ the right to self-determination. Consequently, collaboration with relatives is needed for nurses to plan the care which best meets the patient's needs and wishes. Although involvement of relatives has been investigated to some extent in home care settings (e.g. Simpson, 1997, Ward-Griffin and McKeever, 2000) and in nursing homes (e.g. Bowers, 1988, Hertzberg et al., 2003) few studies investigate it in acute hospital settings, and then focusing on care provided by relatives rather than on their involvement as collaborative partners in the care planning (e.g. Laitinen, 1992, Laitinen and Isola, 1996, Li et al., 2000). Hence, knowledge is needed of collaboration between relatives and nurses concerning frail elderly people in acute care contexts.

BACKGROUND

Relatives

Elderly people often receive help from their relatives (Hellstrom and Hallberg, 2001), hence relatives of frail elderly patients may already have played a significant role helping the patient in managing his/her daily life functions prior to admission. Further, they may be standing-by to resume their helping activities after the discharge. They are likely to hold valuable knowledge about the patient relevant for decisions regarding the in-hospital care as well as the discharge. Knowledge about the patient is a prerequisite for rational and relevant decision-making in clinical practice, and studies have illuminated the importance of involvement of relatives for the quality of care, particularly in relation to frail and vulnerable persons (e.g. Harvath et al., 1994, Tanner et al., 1993, Weman et al., 2004). It has yet to be investigated whether nurses in acute hospital wards assess the specialised knowledge relatives hold about frail elderly patients. Although not all family relationships are positive and constructive, the impact of illness on the family, as well as the impact of the family on the individual's health, is well described in family nursing literature (e.g. Leahey et al., 1995, Rutledge et al., 2000). When it concerns the hospital admission it may affect the entire family and disturb routines, communication and roles; acute admission in particular may be a stressful event entailing feelings of possible threat for both patient and relatives (Rutledge et al., 2000). Hence, relatives may have enhanced needs for information, and involvement may well serve to reduce their stress. However, relatives may also be a buffer against stress, enhancing the patients' potential to cope in situations of crisis (Craddock, 1996, Sandler, 1981). Thus, involvement of relatives may be

motivated by putting to use the resources the patients bring, as well as preserving these resources in order for them to last.

Collaboration involves clarifying and attuning the involved parties' expectations and definition of the situation. Patients' and relatives' beliefs about, and perception of, the health problems are constructions of realities and may be different from that of the health care professionals (Skov Jensen, 1991, Timm, 1997). They are viewed against the background of the life history, roles and daily life functioning, and are intermingled with the lifeworld with its emotions and experiences. Thus, the present health problem and the perception of its causes and consequences are interpreted in a broader context possibly with other conclusions than may be drawn by professionals. This may be of relevance for nurses, and for health care professionals in general, as it is in this construction that they will find the meaning of the situation for the patient or relative, and the explanation for their conduct. It is also here they may find the clues to what went wrong, and why, in the time leading up to the admission, and in this lies a possibility for initiating preventive interventions. The relative's belief system is based on the relational and care history with its emotional and practical implications, and guides the relative's conduct and reactions (Rolland, 1994). Thus, the belief system may be an important precondition for collaboration. It may be vital for establishing collaboration and a mutually understood definition of the situation that the assessment involves the relatives' belief system, thereby making possible clarification and adjustment of expectations between nurses and relatives. This "Promotes the establishment of a collaborative bio-psychosocial framework for communication" (Rolland, 1994, p. 130). There is limited knowledge about nurses' practices and attitudes concerning involvement of relatives' beliefs and perception of the elderly patient's health problem. As an assessment of this may deliver indispensable knowledge for a valid care plan, and because it is an important prerequisite for collaboration, knowledge is needed of relatives' beliefs and perceptions and nurses' assessment of them, when it concerns frail elderly patients in acute hospital wards.

Emotional aspects of care
The meaning relatives attach to the care situation and their helping role is part of their belief system and may influence collaboration. Caring for a relative has been described as both a burden and a joy (Stoltz et al., 2006, van Manen, 2002). When care giving was studied, the focus was predominantly on instrumental and rational aspects of care giving; however, the burden may be related to emotional issues rather than to tasks. Bowers (1987) found protection to be the main purpose of informal care giving, and that tasks were neither the most significant nor the most stressful aspect of care giving. From 60 interviews with informal carers (n = 33) and their parents (n = 27), she identified five categories of care giving, distinguished by their purpose rather than by the type of task. The five categories were: Anticipatory, preventive, supervisory, instrumental and protective care. Nolan et al (1995) complemented Bowers' five categories of care with three more: Preservative care, (re)constructive care and reciprocal care. This model was supported in a study among elderly Swedish caregivers (Ekwall et al., 2004), which further suggested that relatives perform these dimensions of care before help for personal care is needed. The caregivers in Bower's study identified protective care as the most significant part of their work and as the most stressful one. Bowers argued that this is an overlooked

aspect of care responsibility, and that the persistent focus on instrumental tasks diverts attention from the aspects of care not observable by others. Relatives' motives for care may be of relevance for collaboration as these aspects of care are part of the relatives' belief systems and thus guide their decisions and actions. Bowers (1987), Nolan (1995) and Ekwall et al (2004) investigated informal care in the context of nursing homes and at home, however, there is limited knowledge of relatives' caring motives regarding frail elderly patients in acute hospital wards. van Manen (2002) described care as a burden of responsibility and an existential, ethical claim related to being human. When faced with the vulnerability of a loved one, this moral responsibility induces pain and worry. He found support for the worry dimension in his investigation of the meaning of the term "care" in different languages and found dimensions that, to my knowledge, have hitherto not been described in the literature of the caring sciences. The word for care in German "Sorgen", Dutch "Zorgen" and Danish "omsorg" implies a dimension of worry. Whereas "care" in English has a positive ring to it, "Sorgen" suggests also the burden associated with care-as-worry. van Manen argued, that it is because of this element that care can be experienced as a "complex moral-emotional relation of responsibility" (p. 264). Worry may be part of, or an incentive for, the protective, preventive and anticipatory elements in care as described by Bowers (1987) and an essential part of the relative's belief system. Care-as-worry is, in this way, different from formal or professional care, and it may be important to recognise this special dimension, when health care professionals collaborate with relatives. The actions taken by relatives may be guided by their worry for the elderly, and in this case it is an important precondition for collaboration. The meaning relatives of frail elderly patients attach to the situation is sparsely investigated, hence, knowledge is needed of what relatives are concerned about, find important and feel responsible for, when their elderly relatives are admitted to hospital.

The extent of informal care

Extensive international research has investigated the role of informal carers, and the consequences of this role (e.g. Bowers, 1987, Brody, 1990, Langner, 1995). The majority of research in this field has been done in the UK, Canada or the USA. The well-developed social welfare model in Scandinavia might lead to the conclusion, that the family is not usually involved in the care of elderly people. However, studies show that in spite of the welfare model, relatives do play important roles as informal carers in the Nordic countries (Kröger, 2005, Sand, 2005), hence, nurses caring for frail elderly patients are likely to encounter relatives who provide help in the patient's everyday life. The extent of informal care giving has been sparsely investigated in Denmark. One of the few studies in this area was conducted by Struck et al (2005), who in a web-based survey among 2,828 Danish relatives of frail elderly people living in their own homes, found that two thirds had experiences of helping an older person. Approximately one third helped twice a week, another third helped more often. Among a sub-sample of 817 persons recruited among members of The Elderly People's Cause, a private organisation representing elderly people's interests, a quarter had been helping for more than 5 years. Whereas almost all participants helped between one and five hours per week, in the sub-sample 10 % helped *all the time,* indicating a substantial encroachment on their lives. Further knowledge of the extent and consequences of informal care giving in Denmark is needed as well as of the way it is related to expectations for involvement when frail elderly patients are hospitalised.

The increasing demand within the last decade for community-based care and services has led to marked changes in the distribution of help in Denmark. Help is provided less frequently and some tasks have disappeared from the community's care agenda (Hansen et al., 2002). This pattern is also familiar in Sweden, Norway and Finland (Kröger, 2005, Sand, 2005), and may imply a transfer of tasks from the community care to relatives. A review of research in the area of elderly care in the Nordic countries concluded that changes due to budget constraints in municipal supply of care have entailed an "informalisation", where relatives provide care formerly delivered by the municipality (Szebehely, 2005). It is primarily middle-aged daughters and elderly wives who have taken on the role of informal carers.

Due to differences in accessibility of formal care, differences appear in the pattern and extent of informal care giving between the Nordic countries. Jacobsson (1998) investigated community care of elderly people (n = 500) and found that 70 % of Swedish, 57 % of Danish, 49 % of Norwegian, 38 % of Finnish and 23 % of Icelandic elderly persons 80 years and older did not receive any services from the community care although half of them needed help for activities of daily living (ADL). These figures reflect that Sweden seems to have performed the most radical reduction in home help in the Nordic countries. The figures further indicate that a substantial number of elderly people have needs that are not met by the community, thus, relatives may provide help if only because they feel obliged to fill the gap. This may have implications for the expectations relatives bring into the hospital situation and on the collaboration there, and knowledge is needed on how providing informal care affects relatives' expectations, and experience, of collaboration. Whether formal and informal care is supplementing one another or informal care is substituting for inadequate formal care, elderly people seem to get help from several parties, and the totality of care resembles a patchwork quilt (Szebehely, 2005). As both relatives and professional providers are seemingly involved, when it concerns the care of frail elderly people, relatives' experience with the involved interaction may be part of their belief system. This may influence their expectations and conduct during the hospital stay and is, thus, important for collaboration. The field of informal care giving is sparsely investigated in Denmark, and there is a need for research on the interplay between formal and informal care as well as on both nurses' and relatives' perspective on this interplay, when frail elderly patients are admitted to hospital.

Collaboration

Collaboration, or related concepts such as partnership, participation, and alliance have mainly been studied and analysed in the context of the nurse-patient relationship often focusing on compliance (Henneman et al., 1995, Kim et al., 2001, Sahlsten et al., 2005, Tapp, 2000). In this literature collaboration is characterised by attributes such as shared decision-making and goal setting, shared power, user influence, and exchange of information and knowledge. The conceptual base is ethical or political and rests on normative assumptions such as egalitarian principles. The ideal of shared power between professionals and users of the health care system is questioned in the literature due to an alleged asymmetrical power distribution inherent in the clinical setting (Gallant et al., 2002, Hummelvoll, 1996). Nurses and physicians, for instance, have power over information and understanding about, among other things, the disease and diagnostic procedures, its possible treatment and prognosis. Further, they can decide whether or not to request the knowledge relatives hold. Hence, collaboration is seemingly a normative construct requiring interventions possibly rendered difficult by underlying assumptions in existing practices. Whether this is the case when it concerns relatives of frail elderly patients in acute care settings has yet to be investigated. Moreover, as concept analyses in general have focused on the nurse-patient relationship, knowledge is needed of the construct and its dimensions concerning relatives in acute hospital wards.

In *Cambridge Advanced Learner's Dictionary* (2003) Collaboration is defined as a process where two people or more "work together to create or achieve the same thing", which in this study will be to contribute to a successful hospital care trajectory for the frail elderly patient. However, relatives are likely to collaborate with staff members other than nurses during the hospital stay, and this as well as other factors, such as the expertise of all involved groups of health care professionals, contributes to the care trajectory and its success. Thus, the collaboration between nurses and caring relatives is merely one aspect. Bearing that in mind, the focus in this thesis is, however, limited to the relative-nurse interaction. Contact and communication are prerequisites for shared decision-making and exchange of information and knowledge, and studies investigating relatives' needs have shown that communication and information is important for relatives to be able to participate in collaborative efforts (Eriksson and Lauri, 2000a, Polkki et al., 2002, van der Smagt Duijnstee et al., 2000). The quality of the relationship between relatives and nurses is critical for the contact; trust, respect and openness is important (Henneman et al., 1995, Kim et al., 2001, Tapp, 2000). Staff competency and attitudes toward involvement of relatives have, further, been found to be decisive (Astedt Kurki et al., 2001, DeChillo, 1993). Although speculative, the literature describes positive outcomes of collaboration, such as improved satisfaction, diminished feeling of powerlessness, improved communication, agreement between client and nurse's definition of the situation, and relevant and sufficient care and treatment (Henneman et al., 1995, Kim et al., 2001, Sahlsten et al., 2005, Tapp, 2000). However, no instrument for measuring collaboration between nurses and relatives, its dimensions and its possible outcome was found. Moreover, literature indicates a lack of well-defined theoretical frameworks for selection of study variables concerning relatives' involvement in hospital care for elderly patients (Li et al., 2004). Thus there seems to be a need for development of such frameworks to underpin instruments measuring collaboration and demonstrating its dimensions, their

relationship and possible outcome. Psychometric tests should be carried out to assess validity and reliability of a newly developed instrument.

Collaboration – Relatives' perspective

Research on informal care giving and collaboration between formal and informal carers has mostly been done in the context of home care or nursing homes (Bowers, 1988, Hertzberg and Ekman, 2000, Nolan and Grant, 1989). Collaboration with relatives in hospitals has been investigated mainly in paediatric and psychiatric wards as well as in intensive care units (e.g. Casey, 1995, Sharp, 1990, Soderstrom et al., 2003). These studies, as well as studies from other wards and nursing homes, describe problems in the collaboration, which indicate a territorial conflict when responsibility has to be shared between professionals and relatives (Allen, 2000, Hertzberg et al., 2003, Li et al., 2000). Few studies have investigated relatives' involvement in the care of elderly persons in hospitals (Allen, 2000, Laitinen and Isola, 1996, Li et al., 2000). In these studies the focus was on relatives' involvement in care, in terms of that provided by relatives during the elderly person's hospital stay, rather than their involvement as collaborative partners in decision-making, thus seemingly based on the assumption that relatives wish to undertake care actions. However, in the study of Eriksson and Laury (2000b) (n = 168) relatives reported emotional support to be their most important care action, while participation in direct physical care and decision making was considered less important. The context in Eriksson and Laury's study was oncology, where patients may be younger and, at least until the final stages of the illness, fully capable of participating in decision-making. However, for frail elderly people this may not be the case, and studies indicate that their relatives may feel responsible for care even after hospital admission (Allen, 2000, Hallstrom et al., 2002, Laitinen, 1992, Li et al., 2000).

Relatives of frail elderly people may have had care giving responsibilities for some time, and therefore may have deep insight into the elderly person's condition and into what is needed for him/her to maintain or improve their functional level. Hence, they may expect to negotiate the care plan, particularly in relation to discharge. Allen (2000) found in two acute hospital wards (n = 13 nurses, 11 patients and 6 carers) that care giving relatives considered themselves experts on the standard of care. This is supported by the study of Li et al (2000) (n = 6 relatives, 6 patients, 4 nurses) who found relatives of elderly patients to be monitoring the quality of care in order to protect the patient and act in his/her interests. These studies are concerned with the division of labour between formal and informal carers. Thus, the focus is on the *giving of care* and not on involvement in the *collaborative process* of shared decision-making and power, thus, investigation is needed into this process between relatives of frail elderly patients and nurses in acute hospital wards.

The possible benefits of involving relatives with care responsibility are reflected in the studies of DeChillo et al (1994) who found a strong correlation between collaboration and satisfaction in caregivers of mentally ill children (n = 455), and Voutilainen et al (2006) who found in their study of family members' (n = 474) perception of quality of care in residential homes that there was a significant relationship between family members' possibility for involvement in decision-making and their perception of care. As collaboration concerning relatives of elderly patients in acute hospital wards has been

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sparsely investigated, knowledge is needed of the possible association between the level of collaboration and relatives' satisfaction with care in this context. Dixon (1996) found in her literature review on research related to parent and nurse interaction that trust was critical and that parents would assess the professional care provider's trustworthiness. When trust in a provider was apparently misplaced, the resulting mistrust led parents to monitor staff behaviour. These findings were supported by Voutilainen et al (2006), who found that frequency of visits went up when perception of quality of care was low, indicating frequency of visits to be an expression of distrust. Hence, trust and influence on decisions seem to be important components of collaboration.

Collaboration between nurses and relatives of elderly patients in acute care settings has been investigated mostly from the point of view of nurses, whereas studies involving relatives' perspectives have been sparse. The acute admission of the frail elderly person into hospital is presumably an event of significance to the relative; however, the meaning of this experience has not been investigated, though this constitutes an important precondition for collaboration. Hence, investigation of the phenomenon of being a relative of a frail elderly, hospitalised person is needed. Further, as the few studies focusing on relatives of elderly hospital patients have been carried out on fairly small samples, they do not supply sufficient basis for conclusions concerning different groups of relatives' perspective on collaboration with hospital nurses, or the possible outcome of this collaboration. Thus, structured valid and feasible instruments are needed, and such instruments may, further, be used as a tool for quality assessment purposes in clinical practice.

Collaboration – nurses' perspective

Values in nursing theory are seemingly in accordance with the attributes of collaboration. Nursing models encompass the total human being focusing on functional capacity and resources, and thus include the environment such as social context and significant others (Meleis, 1991). Moreover, according to the code of nursing ethics formulated by the International Council for Nurses (International Counsil of Nurses, 2000), as well as the Danish Code for Nursing Ethics (Council of Nursing Ethics, 2004) relatives are a legitimate and necessary focus for nursing, and their involvement is frequently described in policies for "good nursing practice". Furthermore, the nursing process involving assessment of patients' needs for care and treatment, setting goals for, and prescribing, nursing interventions, and evaluation of outcome (Orlando, 1990), demarcates natural points for involvement of relatives and their knowledge. Hence, the stage is set, so to speak, for successful collaboration with relatives. However, other values and goals may govern nursing practice, where interests such as managerial and financial ones, have to be taking into account. Knowledge is needed of the conditions in acute hospital wards for collaboration between nurses and relatives of elderly patients. Studies indicate that differences between relatives and nursing staff with regard to values and objectives have the effect that relatives may be considered obstacles to efficient care and treatment (Bauer and Nay, 2003, Hertzberg et al., 2003, Tamm, 1999, Walker and Dewar, 2001). Bauer & Nay (2003) found in their literature review on family and staff partnership in long-term care that relatives and nurses appear to have disparate goals, competing agendas and un-negotiated roles. Walker & Dewar (2001) found in their study in a dementia unit (n = 20

informal carers and 29 staff members) that, although confirming that quality of care improved, when relatives were involved in planning, nurses pointed at hospital routines and the staff-relative relationship as obstacles. Relatives were often characterised as guilt ridden and vulnerable, and nurses therefore felt obliged to contain any anger expressed by relatives. They felt like "sitting ducks" unable to defend themselves against angry relatives and therefore avoided contact rather than encouraging it. In the study by Hertzberg et al (2003) nursing homes nurses (n = 19) described relatives as a resource, though time consuming, and in practice they rarely involved them. These studies do not offer knowledge of why health care professionals seemingly do not involve relatives when they care for elderly people. Reason may be plenty i.e. working conditions, contextual constraints and insufficient education. This needs to be investigated, as does the experiences of nurses in acute hospital wards when encountering relatives of frail elderly patients.

Staff attitudes towards involvement of relatives has been found to be an important factor for collaboration to happen (Astedt Kurki et al., 2001, DeChillo, 1993). DeChillo et al (1993) investigated collaboration between social workers and family members of patients (n =102) in a psychiatric ward. The strongest predictor for collaboration was staff attitude toward family involvement. Astedt Kurki (2001) (n = 320) found that hospital personnel viewed involvement of relatives as a complicating factor in their work. Family members were primarily seen as informants, interaction was marked by dissemination of information, and was primarily initiated by the family. As the majority of frail elderly patients are admitted to acute medical wards, there is a need for knowledge about nurses' attitudes towards collaboration with relatives, and the conditions for it to be successful, in this context.

The acute medical ward

The in-hospital stay has increasingly become shorter, and in 2005 the average stay lasted 4.5 days (Danish National Board of Health, 2006). This is in accordance with political and financial demands for productivity but also a result of more efficient treatment methods attained by medical- and technological developments (Danish Ministry of Health, 2001). The average number of days per hospital stay has decreased most noticeably within the group of patients over 80 years of age. In 1990 the average number of days for this group was 13.9 days whereas it in 2001 was 8.8 days (Danish Ministry of Health, 2002). Apart from reflecting the medical and technological developments, this may be an indication of a transfer of activities to outpatient clinics and community care. In medical wards in general 90 % of the intake was acute and the average bed occupancy rate above 100 % (Danish National Board of Health, 2006). As the turnover of patients increases there may be a pressure on the staff to keep the patients no longer than the medical condition justifies (Parker, 2004). Further, the workload and time pressure in relation to admission and discharge may increase accordingly, thus possibly impeding well-planned procedures. In particular the admission and discharge phases may be critical moments for involving relatives, as they represent the key occasions for assessment of patients' needs for in-hospital care, readiness for discharge and needs for care at home. Thus, conditions for nurses to engage in collaborative endeavours and to plan care that takes into account patients' and relatives' requirements and wishes may be poor. More understanding is

needed about the conditions in acute hospital wards for collaboration between nurses and relatives of frail elderly patients.

Frail elderly patients in acute medical wards

The majority of acute admissions of frail elderly patients take place in medical wards with different specialties (Danish Ministry of Health, 2001). In medical wards 31.1 % of the discharges and 40.4 % of total number of in-patient days were related to patients older than 75 years (Danish National Board of Health, 2006). Frail elderly patients are estimated to constitute 10 – 20 % of the admissions into acute medical wards in Denmark (Copenhagen County, 2000, Danish Ministry of Health, 2001). According to the Danish Ministry of Health (2001), this group of patients in particular is often subject to readmission within 3 months after discharge. The number of readmissions has risen within the past few years, and although treatment of chronic diseases has improved, perhaps involving multiple admissions into different wards and thus increasing readmission rate, it does not explain all the increase (Danish Ministry of Health, 2001). Due to their complex functional and disease related needs, frail elderly patients may fit poorly into a disease-specific contexts such as acute hospital wards, and may therefore be at risk for being under-treated and thus liable to early readmission (Fried et al., 1991). Chronic diseases and functional deficiencies often accompany the health problem causing the admission and may even interrelate with it. For example, a decline in functional capacity may have triggered the current health problem (e.g. dehydration, urinary infection or pneumonia), which may again cause a functional decline. Thus, the trajectory of the frail elderly patient requires not only a focus on the acute cause for admission, but a more comprehensive approach when assessing the patient's needs for treatment and care, whereby relatives may contribute with their special knowledge about the patient. Further, interdisciplinary co-operation as well as coordination and exchange of information across borders between the hospital and community based health care sectors (Danish Ministry of Health, 2001, Young, 2003) are required, all of which now has to be attained within a shorter time. An additional complication for this is the divergent systems' incompatibilities such as paradigmatic and administrative differences between community-based services and the hospital system, as well as the tension between episodic and chronic care management (Danish Ministry of Health, 2001, Young, 2003). Whether nurses in acute hospital wards acknowledge and involve the special knowledge held by caring relatives of frail elderly patient has yet to be investigated. Moreover, knowledge is needed of the association between the nurse-relative collaboration and the quality of the hospital care trajectory for these patients.

The Danish Government has acknowledged that the trajectory of the frail elderly patient in acute medical wards is at risk for low quality due to two essential weaknesses: 1. The sole focus on the acute illness among hospital staffs who do not pay attention to functional needs and further needs for treatment. 2. Significant information is not obtained and passed on (Danish Ministry of Health, 2001). A Cochrane review of discharge planning (Shepperd et al., 2004), involving 8 studies and 4837 patients, further indicated that one of the most important causes of discharge problems was insufficient data collection and lack of knowledge about the patient's social situation. Himmelstrup (2000) found in her study including 64 physicians and nurses and 24 elderly patients in

geriatric and medical wards that insufficient disclosure of the patient's health problems entailed inappropriate use of resources and incomplete resolution of the health problems. The visitation and diagnostic process appeared arbitrary; irrelevant examinations were performed and examinations that should have been carried out were not, due to lack of knowledge by staff about the patient. Himmelstrup (2000) concluded that the demand for productivity and high rates of acute admissions, resulting in a large flow of patients, was a fundamental working condition in medical wards and a possible reason for the problems described. Another reason may be that frail elderly patients, with their complex and diffuse disease patterns, were not part of the natural target group in a specialised ward, and problems not relevant to the ward specialty might therefore go unnoticed (Fried et al., 1991).

There seem to be weaknesses in the assessment of the health and functional problems of the frail elderly patient in acute medical wards and a need to strengthen the basis for decisions in their care and treatment. Older patients are likely to underreport symptoms and problems (Wells et al., 2003), and often suffer from additional weakness, physically, mentally or both, hence, they may need their relatives to communicate their representations of the illness, and to be their proxy participants in decision-making processes. Health care professionals, on the other hand, may need to collaborate with these relatives to attain a full picture of the patient's needs and health care problems in order to deliver relevant and sufficient treatment and care. To what extent this actually happens needs to be investigated.

Collaboration between relatives of frail elderly patients and nurses is possibly of interest for both the patient and hospital managers. A comprehensive assessment of the patient's needs for care and treatment, incorporating relatives' knowledge, may qualify the decision-making processes thereby possibly enhancing validity in care plans and quality of care. However, for relatives of frail elderly patients in acute hospital wards collaboration has been sparsely investigated, and knowledge is needed in this area in order to identify areas and potential for development and interventions. Investigation of relatives' and nurses' views on, and experience with, collaboration in this context may provide knowledge of the construct's dimensions as well as the prerequisites for, and possible outcomes of, collaboration.

AIMS

The overall aim of the study was to investigate collaboration between relatives of frail elderly patients and nursing staff in acute hospital wards from the perspective of relatives and nurses. Further the aim was to develop and test an instrument to investigate dimensions of, and prerequisites for, collaboration in this context, as well as the association between collaboration and relatives' satisfaction with the hospital care trajectory.

Specific aims were:

- To illuminate the lived experience of being a relative of a frail elderly person living at home and admitted to an acute hospital ward (Paper I)

- To illuminate nurses' experience of collaboration with relatives of frail elderly patients in acute hospital ward, and of the barriers to, and promoters for, collaboration (Paper II)

- To develop and test an instrument to assess, from the relatives' perspective, collaboration between relatives of frail elderly patients and nurses in acute hospital wards, as well as the prerequisites for, and outcome of, collaboration (Paper III)

- To investigate collaboration between relatives and nurses in those reporting high versus low satisfaction with the hospital care trajectory. Further the aim was to investigate their characteristics, dimensions of collaboration and the relationship between these and satisfaction with the hospital care trajectory (Paper IV)

METHODS

Design

The design used in this thesis was cross-sectional (Papers I – IV). Further, explorative and descriptive (Papers I, II and IV), interpretive (Paper II) as well as comparative analytic designs (Paper IV) have been applied. Triangulation of methods was applied for data collection and data analyses (Table 1). The choice of design and method arises from the research questions and aims (Berg, 2004, Brannen, 1992). Combining qualitative and quantitative data may enrich the inquiry, as the two types of data are complementary, and thus "mutually supplying each other's lack" (Webster's, 1985) rather than mutually exclusive. When, as it was the case in this study, little is known about the phenomenon being examined, starting out with an explorative, inductive, design is appropriate for attaining a deeper understanding of the phenomenon. The results provide insight into the complexity of the lived experience and expand the researcher's horizon of knowledge about the topic under investigation and possibly add validity to the instrument, which was developed. Furthermore, hypotheses may be generated from the results. These hypotheses may be tested in a larger sample applying a deductive approach, using a structured data collection method, which may provide more control over the variables and possibility for making statistic inferences (Brannen, 1992). The validity of a study's findings based on several types of data will be enhanced, making the conclusions more convincing.

Table 1 Overview of design and methods in papers I - IV

	Paper I	Paper II	Paper III	Paper IV
Design	Phenomenological, descriptive	Descriptive, interpretive	Instrument development Psychometric test	Descriptive, explorative and comparative analytic
Sample	8 relatives	8 nurses (6 RN, 2 LPN)	156 relatives of frail elderly patients	156 relatives of frail elderly patients
Data collection	In-depth interviews	Open interviews	Structured questionnaire	Structured questionnaire
Analyses	Phenomenological analysis (Giorgi, 1985)	Content analysis (Berg, 2004, Catanzaro, 1988)	Explorative factor analysis (PCA) Kaiser-Meyer-Olkin procedure for sample adequacy Cronbach's Alpha Spearman's Rho for testing correlation between factors Item-to-total correlation Inter-item correlation Comparison of factor scores and respondents' characteristics with scores for satisfaction Comparison of respondents – non-respondents. Mann-Whitney test for non-normally distributed data. Chi Square test for categorical data	Descriptive statistics Comparing means for characteristics of respondents with high vs. low satisfaction with stages of the hospital care trajectory Chi-Square test for categorical variables Mann-Whitney test for continuous variables with non-normal distribution Logistic regression analysis (backwards, stepwise)

The naturalistic approach – underpinning assumptions (Paper I and II)
In the tradition of naturalistic inquiry – as opposed to the natural science or rationalistic inquiry tradition, where reality is considered to exist independently of human beings – reality is considered to be constructed in the perception of the individual (Lincoln and Guba, 1985). The meaning is subjective; thus there are multiple realities. These subjective realities, however, never present themselves directly to others. Actions and behaviours can be observed, but the reasons for them are hidden to the observer, as are the emotions and the experiences of the situation. Understanding other human beings and their experience has to involve their experience; hence, interviewing was chosen as the method for data collection. A phenomenological approach with open in-depth interviews was chosen for the first study involving the relatives, as it was appropriate for gaining insight into the lifeworld of human beings (Dahlberg et al., 2001, Giorgi, 1983). The interviews in the second study involving the nurses were more focused and subject to a restricted time frame, thus, they were less narrative than those of the relatives, and content analysis was chosen as the method for analysis.

Instrument development and testing (Paper III and IV)

When wanting to investigate a construct among a larger sample to make general conclusions or test a theory or hypothesis, structured instruments appropriate for making use of statistical techniques need to be applied (Polit and Hungler, 1991). The first step is to search for instruments already developed and suitable for the purpose and population in interest (Streiner and Norman, 2003). If no suitable instrument is available, a new one has to be developed. This requires a meticulously planned and executed process to make the instrument reliable and valid, and involves selection of relevant variables, development of items, response alternatives and a logic structure for the instrument. Constructs are not directly observable, hence, empirical indicators of the construct have to be identified, and questions or statements representing the indicators created (Pett et al., 2003). Empirical indicators may be derived from theory, research, experts on the research area and the individuals who are in focus for the research, the key informants (Streiner and Norman, 2003). The first step in this process is the conceptualisation of the construct, which constitutes the base for *construct validity* of an instrument and for making the construct operational. It involves a study of theory and conceptual analyses on the construct of interest as well as research on the area, to enhance the understanding of the construct and the way it is related to other constructs or concepts. If a conceptual or theoretical framework does not exist a hypothesised one may be developed to describe the variables and their relationship (Pett et al., 2003). The final step in the process is to develop the wording of the items from the clusters of characteristics in the theoretical framework. Some characteristics may be identical with the empirical indicators and as such they may deliver the wording of the item, while others may need further operationalization. Involvement of key informants, such as individuals with specific professional or personal knowledge and experience, is then warranted (Pett et al., 2003).

Different methods may be applied to enhance validity and reliability of the instrument. In the development phase *content validity* is addressed in striving for the instrument to have enough items to cover adequately all aspects of the phenomenon under investigation (Streiner and Norman, 2003). This has to be balanced with the risk of enhanced dropout due to the instrument being too extensive. The choice of response alternatives must be based on considerations for the desired level of differentiation in information and statistical techniques. The level of measurement determines possibilities for analysis techniques such as means, standard deviation, and variance. A draft of the instrument may be examined for *content* and *face validity* by potential respondents and experts in the research area, who also evaluate response alternatives, structure and layout of the instrument (Streiner and Norman, 2003). There then follows a psychometric testing of the instrument properties on a larger sample, examining the reliability and validity of the instrument.

Context

The two qualitative studies (Papers I and II) were conducted in three acute medical units and one surgical unit in a large university hospital in Denmark, located in a wealthy community. Participants in the quantitative studies (Papers III and IV) were recruited

from the same acute medical ward and one geriatric ward, and, additionally, from four acute medical wards in a hospital in a rural part of Denmark. At both hospitals the wards had educational and research obligations. Specialties were liver-, bowel and endocrine diseases. Frail elderly patients were usually admitted into any medical unit with an empty bed, and in the university hospital, when the medical wards were full, into other specialised wards (e.g. paediatric or maternity ward). Medical wards were frequently subject to patient overload and nurse shortage, and more than 90 % of the intake was acute. The geriatric ward was newly established at the time of the investigation in study 3 and 4 (Paper III and IV), and consisted of 18 beds. Patients were recruited to this ward from other wards in the hospital by a multidisciplinary team; however, due to the restricted number of beds and the duration of the stay, only a small percentage of patients in need of geriatric assessment and care were admitted into the ward. Geriatric wards have been established in 10 out of Denmark's 14 counties. However, in 2000 only five percent of medical patients over 70 years of age were discharged from geriatric wards (Danish Ministry of Health, 2001).

The population in Denmark is following the same demographic trends as the rest of Europe (Denmark's Statistics, 2006). In particular the proportion of the population of people aged 65 – 74 years will increase. In 2010 there will be approximately 25 % more people than today in this age group. The age group consisting of 70 – 79 year olds is expected to show a substantial increase around 2010, which will continue until stabilising around 2024 with approximately 200.000 more individuals than in 2006; an increase of 64 %. The age group of 80 – 89 years will start to increase around 2020, and around 2030 there will be 100.000 more people in this age group an than today; an increase of 50 %. With the increase in elderly people an increase in demand for health care in both the hospital and community sectors is to be expected. However, it is difficult to predict the health care needs in older age for the generation, who are 40 – 60 years old now. Factors such as the general state of health, development of medical understanding and technology, expectations and illness pattern among the population will influence elderly people's health care consumption (Danish Ministry of Health, 2001). Currently 27.1 % of the expenditures in hospitals is deployed for patients aged 75 and older (Danish Ministry of Health, 2006).

Sample

Relatives from two samples and nurses from one were included in this thesis. Eligible were, in all four studies, relatives of patients aged 75 years or older, living at home, dependent on practical or personal help from the municipality and having a relative who provided help with activities of daily living. Cognitive impairment in the patient hindering informed consent was the exclusion criterion.

In the first study (Paper I) 8 relatives participated. Four were daughters, two sons, one daughter-in-law and one wife, their ages ranging from 40 to 71 years (mean 59 years). The sampling strategy was purposeful and aimed at maximum variation. When data seemed to become redundant, inclusion stopped. Two patients declined to let their relatives participate, one for fear of overburdening the relative, and the other through a concern

that the interview with the relative might in some way give rise to future problems for the patient. In another case, both parties gave their consent, but as the patient's condition unexpectedly became terminal, the relative needed to focus exclusively on the patient.

In the second study (Paper II) six registered nurses (RN) and two licensed practical nurses (LPN) participated. The sample was tied to the sample in the first study as the nurses were enrolled by virtue of being in charge of discharge planning for those patients whose relatives participated in the first study (Paper I). Inclusion of nurses stopped when that of relatives did, as redundancy also was achieved in the data from the nurses' interviews. The nurses were all female between 28 and 66 years of age (median 41.5 years), and had been practicing as nurses from 3½ to 42 years (median 8.5 years). All nurses approached agreed to participate.

The sample in the third and fourth study (Papers III and IV) consisted of 156 relatives of frail elderly patients, included consecutively as they were admitted to the hospital. The mean age was 60.78 years (SD 11.99) with women constituting 74.8 % of the sample (Table 2). Adult children constituted the largest group (63.9 %), spouses the second largest (20 %); 22.6 % lived with the elderly patient. University degrees, or similar, were held by 32.9 % of the relatives whereas elementary school was the highest educational level for 41.9 %. Health care professionals made up 22.6 % of the participants.

Table 2   Characteristics of respondents (Paper III and IV)

	Total % N = 156
Gender	
Men	25.2
Women	74.8
Age	
Mean (SD)	(11.99)
Range	37 – 88 years
School education	
Elementary school	41.9
High school	25.2
University degree (or similar)	32.9
Health education	22.6
Relation to the elderly patient	
Spouse	20.0
Daughter/son	63.9
Others	16.1
Co-habiting with elderly patient	22.6

The number of patients approached in studies 3 and 4 (Papers III and IV) was 234 at the university hospital (Figure 1) of whom 34 declined to participate as they had no relatives, their relative were too busy, there were disputes in the family, their relatives lived too far away, or they wanted to think about participation. 196 relatives agreed to participate (Figure 1). In the university hospital a reminder procedure was done by phone to facilitate a dropout analysis. Of the relatives who had not returned the questionnaire 23 declined to participate. Reasons given were grief and fatigue due to the death of the elderly patient, overload of care giving tasks after the elderly person's discharge, and in a couple of cases not being sufficiently involved in the elderly persons life and hospitalisation to be able to fill in the questionnaire. Four relatives described negative experiences with care, which, according to them, resulted in the patient's death. These relatives declined to participate due to emotional exhaustion. In all, 134 relatives from the university hospital completed and returned the questionnaire, giving a response rate of 68.1 %. At the rural hospital, a total of 100 questionnaires were distributed for nurses to give to relatives. Sixty-two of these were handed out. Twenty-two questionnaires were completed and returned, giving a response rate of 35.5 %. No reminder procedure was carried out.

Figure 1   Overview of the recruitment of the sample, response rate and dropout in Paper III and IV
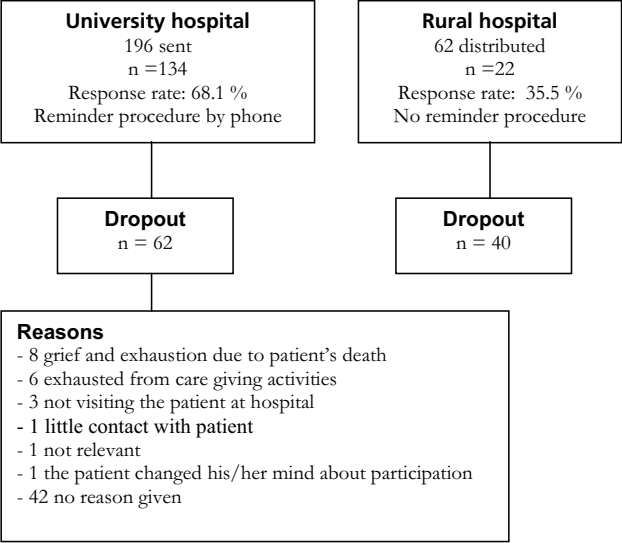
Data collection

Interviews with relatives (Papers I)
The method used was in-depth interviews with an open approach. An interview guide was developed (Appendix I), although the informants were encouraged to tell the story in their own way, and to ensure as broad a covering of the topic as possible, the informants were allowed to "leave the track". The author would probe these digressions asking further questions to explore new avenues, relevant to the research topic. At the end of the interview the participants were asked a few structured questions aimed at describing the extent of care giving. The process of investigation has an impact on what is to be investigated, and the exploration of any situation begins with its opening question (Davis, 1978). The way this first question is asked creates possibilities and limitations for the ways the answer will be given. Thus, it is important to have an open approach in the opening question in order to reduce the risk of missing aspects of possible importance to the lived experience. The opening question of the interview was "I'm interested in how it is to be a relative of a frail elderly person living in his/her own home. Could you, please, tell me about your experience?". In the lifeworld, phenomena are experienced as a whole and not as created by independent fragments of themes. Hence, the experience of being a relative of a frail elderly person admitted to hospital can be understood only when approached as a whole (Dahlberg et al., 2001) and with maximum openness without any a priori definitions according to the researcher's own perception (Giorgi, 1983). In all, 12 interviews were conducted; eight of them in the relatives' homes, whilst two were in their workplace and two in an office in the hospital ward. The intention was to conduct two interviews with each relative, one while they were still in the hospital situation and one after discharge to sum up the total experience including the discharge process. However, in four cases the patients were discharged before the first interview could take place, thus only one interview was carried out. The duration of the interviews ranged from 90 minutes to 2 hours, giving a maximum contact time of 4 hours in the cases where two interviews were conducted. The interviews were audiotape recorded and transcribed verbatim.

Interviews with nurses (Papers II)
Personal interviews were carried out. An interview guide was developed (Appendix II) to make sure that all relevant areas were covered. The central question was: "Please tell me how you perceive relatives of frail elderly and their role in the care and treatment in this ward". Further questions asked were for instance: "How do you collaborate with them in this unit?" "How would you like collaboration to work?" "Which barriers and promoters do you see for a successful collaboration?". Additional questions related to the collaboration in the present trajectory of the discharged frail elderly patient were asked at the end of the interview. The aim was to disclose specific examples of level of involvement of relatives and the nurses' knowledge about the patient, the situation at home and the relative's possible care giving burdens. The nurses were encouraged to speak their minds and bring forward digression, and the interviewer followed these asking further questions to allow new aspects, relevant to the research question, to arise. An informal atmosphere was strived for to ensure that the nurses would be comfortable enough to speak freely. The interviews took place in a secluded room off the unit and

lasted until no new information came forth, from 60 to 90 minutes. Each interview was audiotape recorded and transcribed verbatim.

The questionnaire (Paper III and IV)
A questionnaire with the aim of assessing collaboration, its prerequisites and outcome was developed and tested for content and face validity. It was then distributed to relatives of frail elderly patients and the data processed through psychometric testing.

Development and testing of the questionnaire
A systematic search for instruments measuring collaboration led to personal contact worldwide with authors of studies with similar or related focus. However, none of them could present an instrument suited for the aims of this study. Concept clarification was done through a thorough study of literature about, and concept analyses of, collaboration and related concepts such as participation, partnership, empowerment, and alliance. The concepts in all of these analyses rested on normative assumptions such as egalitarian principles, either politically or ethically based. The analyses focused on patient - or client collaboration with professionals, no analyses were found with a family perspective. A schema was made with the structure used in concept analyses (definition, antecedents, attributes, consequences/outcome, barriers) (Rodgers, 1989) to compare similarities and differences found in these elements in the literature. After analysing this, a synthesis was done including the findings of the two interview studies (Paper I and II) and resulted in a model, which constituted the basis for development of the instrument variables (Figure 2). The literature study revealed some inconsistency in the use of concepts with some analyses using other concepts when describing and defining those concepts analysed here. For instance Kim et al (2001) defined *alliance* as a process where patient and provider *collaborate* in a shared *partnership*, while Hummelvoll (1996) described it as a reciprocal *partnership* stimulating mutual *empowerment*. Seemingly, the concepts are interrelated, possibly in terms of sequence with one being the prerequisite for another. Cahill (1996) makes an explicit distinction between *patient participation* and *collaboration*, *partnership* and *involvement*. According to her, involvement and collaboration are prerequisites for patient participation, which again is a prerequisite for patient partnership. Like Cahill (1996), Sahlsteen et al (2005) in their concept analysis of patient participation described a chain of prerequisites, however they used another terminology. Here communication and interplay were prerequisites for the quality of the relationship, which was the prerequisite for effective exchange of information, which again was the prerequisite for participation.

Mutual traits were identified in definitions, attributes, antecedents (prerequisites) and outcomes, and a certain sequence was indicated, and was also adopted in this study. Based on *relationship qualities* (trust, respect, openness, non-judgemental attitude) and with *communication* as the vehicle, nurses and relatives engage in *collaboration* with attributes such as shared: decision-making, goal-setting, power, knowledge, activities and responsibility. *Outcome* was speculative as no study had been able to draw causal conclusions about the effects of collaboration. The developed model for collaboration formed the basic structure (figure 2) for the instrument, from which the variables and items were developed. The final step in the process from concepts to items was to develop the

wording of the items from the clusters of characteristics in the model (Pett et al., 2003). Some characteristics were identical with the empirical indicators and as such they could be incorporated directly in the wording of the items. Others needed further operationalization, and findings from the interviews with relatives (Paper I) and nurses (Paper II) facilitated this process. The items *"I had influence on decisions made about the care"* and *"I trusted that my relative received the care s/he needed"* were examples of indicators of shared decision-making and trust, respectively attribute of and prerequisite for, collaboration. The items *"It was easy to find a nurse who knew my relative"* and *"It was my impression that nurses were too busy"* were indicators of continuity of care as promoter for collaboration and nurses' time pressure as a barrier. The number of items for each area in the model was chosen with the aim of attaining content validity by being exhaustive and covering all conceivable items defining the property (Streiner and Norman, 2003).

Figure 2   Collaboration – A tentative model
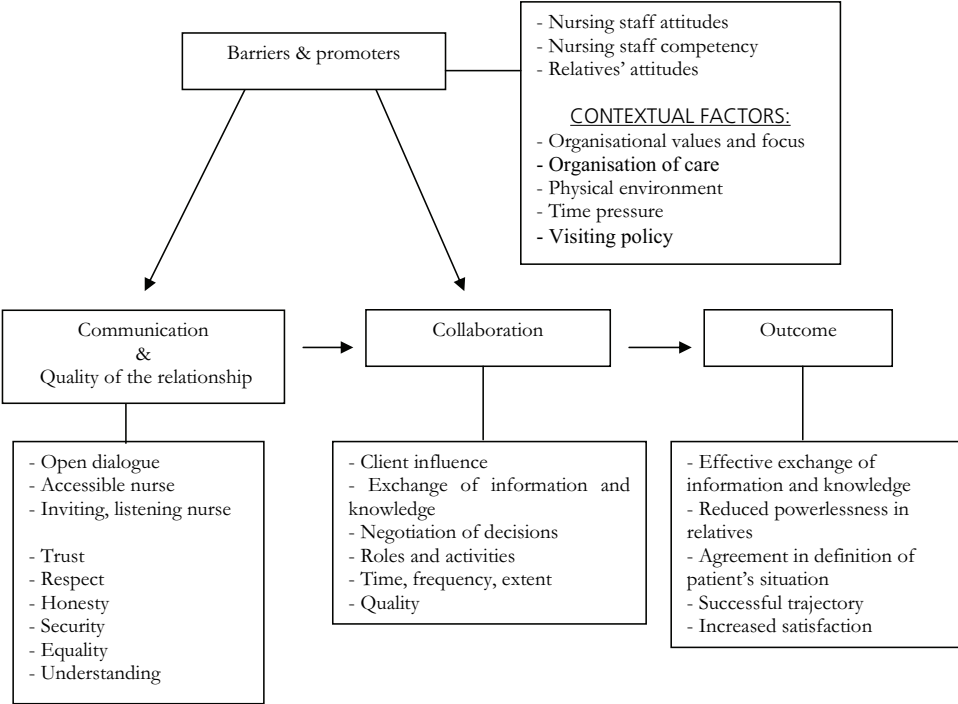
The questionnaire was tested for *face* and *content validity* by nurses experienced in the research area and by relatives. Relatives in geriatric units in two university hospitals filled in and commented on the questionnaire and the accompanying information material. Nurses and acquaintances of the first author with experiences of being a relative of a frail elderly, hospitalised person also filled in and commented on the instrument. Further, the questionnaire was discussed in the department's doctoral group specialised in research on care of the elderly. Minor adjustments were made to the wording and sequence of some

items, and the possibility of scoring "do not know" was added to some response alternatives.

The questionnaire
The instrument (Appendix III) consisted of 62 self-report Likert-type statements and ten categorical variables, in all covering four areas collaboration: 1. Attributes for collaboration, including *influence*, *exchange of information and knowledge*, *negotiation of decisions*, *roles and activities* 2. Prerequisites for collaboration, covering *contact* and *communication* with nurses (e.g. frequency and quality, accessibility of nurses, inviting and listening nurses) and the *quality of the relationship* with nurses (e.g. trust, respect, understanding). 3. Outcome of collaboration, including *satisfaction*, *agreement in definition of the patient's situation and needs*, *information level*, *successful trajectory*. 4. Barriers against and promoters for collaboration, covering *prior experiences with shortcomings in care*, *staff attitudes, organisation of care*, *staff work pressure*, *physical environment* and *visiting policy*. Response alternatives were: *High degree, some degree, less degree* and *not at all*, and in other cases *Always, very often, often, some times, seldom* and *never*. In order to be able to make a total scoring of dimensions of collaboration, response alternatives were rated from 1 – 4 and 1 – 6, respectively 1 being the highest level of collaboration and 6 the lowest. No neutral score was included, though when relevant "do not know" was included. Space was made for comments at the end, should respondents feel the need for it. Demographic data were also included (age, gender, marital status, relation to the elderly patient, whether cohabiting with the elderly patient, level school education, whether holding a health education, work, whether with children living at home), as well as data about relative's helping activity (five items) and caregiver responsibility and experience (five items).

Procedure

The administrations of medical and geriatric wards in a university hospital and of a smaller hospital in a rural part of Denmark gave permission to approach the informants in their wards. The author informed nurses at the university hospital about the project at meetings and written material informing about the project was distributed and posters put up in the wards. Nurses in the wards advised the first author as patients matching the inclusion criteria were admitted. The patients were informed verbally and in writing about the project and were asked for permission to contact their closest relative. If consent was given, the relative was telephoned, informed about the project and asked to participate. In the first study an appointment for the interview was made (Paper I) and in the survey study (Paper III and IV) permission to send the questionnaire was obtained. Written information was sent with the questionnaire. Nurses in the rural hospital were informed by their research and development nurse. They handed out envelopes containing the questionnaire, written information and a prepaid envelope to relatives of patients matching the inclusion criteria who had agreed to participate. The questionnaires were completed after the patient's discharge. Data gathering took place from September 2005 to the end of February 2006.

The nurses who performed the discharge of the frail elderly patient were approached after discharge, and asked if they would participate in the study (Paper II). The nurses decided the time and place for the interviews, which were performed during their working hours.

The author's preunderstanding

The researcher's preunderstanding is an important precondition for any kind of research. It determines what is looked for and may therefore direct and limit the researcher's awareness (Dahlberg et al., 2001). Expanding the preunderstanding by literature studies and discussions is therefore important for the researcher to broaden his/her horizon and enhance possibilities for discovering different aspects of the phenomenon. According to hermeneutics there is no understanding without preunderstanding, furthermore, interpretation is the basis for all understanding and interpretation free of preunderstanding is impossible (Dahlberg et al., 2001). Preunderstanding is a prerequisite for understanding the world, in this case collaboration between nurses and relatives of frail elderly patients as it is experienced by both parties. So the researcher has to widen his/her preunderstanding by studying the phenomenon and its aspects, but must also clarify and challenge the preunderstanding as far as it is possible to do so.

The first author's preunderstanding was challenged during a two-hour interview by a PhD student of social sciences. The interviewer strove to get experiences and prejudices out in the open, and challenged the constructions of the phenomenon the author presented. The interview was tape recorded, transcribed and analysed. Having frail elderly relatives who had been hospitalised, and being a nurse, the author was part of both cultures and had constructed a lifeworld experience of the phenomenon under study. This may constitute both a threat to, and an advantage for, the research process. The threat is that the author may not approach relatives and nurses with as open mind as a researcher with neither experience would do. Participants may be expected to share her experiences, or results in accordance with these may be unduly emphasized. However, the special insight may contribute to a broader horizon of knowledge and qualify for understanding of both relatives and nurses in other aspects. The challenge was therefore to stay curious, open and sensitive especially to experiences contradicting her own. Involving others in the data analyses and presentation of the findings became imperative.

Data analysis

Phenomenological analysis (Paper I)

Giorgi's (1983, 1985, 1997) phenomenological analysis was used. It emphasises a descriptive approach. Though the analysing process is a reflective one, researchers should strive to stay as close as possible to the original data and avoid interpretation (Giorgi, 1985). To find and describe the phenomenon per se and not what they wish to see, researchers should suspend their preunderstanding during both the data gathering and the analysing process (Giorgi, 1983). Giorgi's method of analysis has four steps and the goal is to reveal the structure of the phenomenon that best describes the essences and their relationship (Giorgi, 1985, Giorgi, 1997). Essences are the most invariant meanings for a context without which a phenomenon cannot present itself, "It is the constant that holds

together and limits the variation that a phenomenon can undergo" (Giorgi, 1997, p. 7). The first step is the initial reading of the data. This is done with maximum openness without taking the specific aim of the study into account. The reading is repeated until a sense of the whole is attained. After this the text is divided into meaning units. While re-reading the text the researcher makes a note every time there is a change in meaning. The third step is to examine the meaning units and transform them, guided by the researcher's disciplinary perspective but staying as close as possible to the original text. In this study it meant that each meaning unit was interrogated for what it revealed about being a relative to a frail elderly, hospitalised person. The transformation was the basis for the next step. The meaning units were carefully scrutinised to find patterns. In the fourth and last step, the transformed meanings were synthesised and grouped into a meaningful pattern, expressing the structure of the phenomenon. The four steps were first applied to each transcribed interview to make a specific description. When all interviews had undergone this process, the general description was made from the specific descriptions. Thus the general was extracted from the unique by a synthesis and integration of the meanings. When searching for what was the same and what was different, a structure describing the essence of the phenomenon emerged. The first author analysed all interviews, and to increase credibility, three other researchers independently read the interviews and discussed the findings with the first author.

Content analysis (Paper II)

The interviews in the second study were more focused due to the restricted time the nurses could spare in their busy work schedule, therefore content analysis was chosen as the method for analysis. Content analysis is well suited for structuring and analysing the text from problem-centred interviews, whereas it is less suited for the explorative, open and narrative interview (Knizek, 1998, Mayring, 2000). Content analysis was originally a quantitative technique developed in the mid-twentieth century for communication research as a method for handling extensive amounts of data from mass media (Graneheim and Lundman, 2004). The initial use was descriptive and produced manifest, quantitative findings, however, currently an interpretive use of the method has been added, producing so-called latent findings.

The text of the transcribed interviews with nurses was analysed using manifest and latent content analysis (Berg, 2004). Manifest analysis is the descriptive part of the analysis, in which the surface structure of the text central to the phenomenon and the research question is disclosed (Berg, 2004, Catanzaro, 1988, Morgan, 1993). The latent content analysis is the interpretive part of the analysis, in which the meaning structure of the text is sought for. The overall research question in this study was: "How do nurses experience collaboration with relatives?" involving a number of sub-questions such as e.g. "How do they perceive relatives?". Having these questions and the empirical findings in other studies in mind, the first interview was read and analysed independently by two researchers conducting open coding (Berg, 2004). The findings were discussed and compared to reach a mutual understanding of the text and the analysis process in order to reach a consistent approach. The two researchers then analysed all interviews independently. Each interview was analysed for manifest and latent content starting with several readings to reach a sense of the whole in view of the aim and research question of the study. After this the text was divided into meaning units, which again were sorted into categories and subcategories according to content. Memos with ideas, questions,
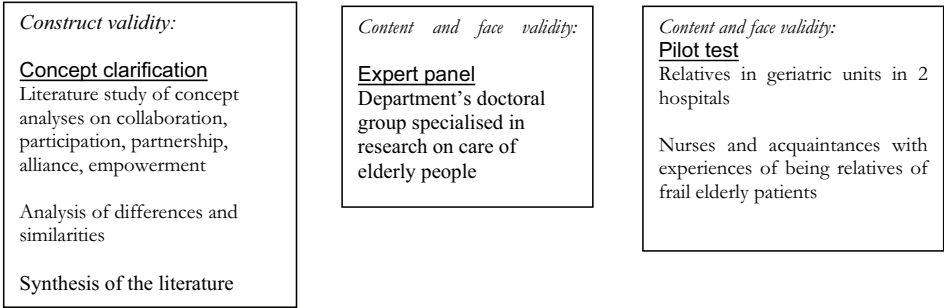
reflections and interpretative attempts were written during all phases. At this point the researchers compared and discussed the analysis of each interview to adjust the system of categories and find a hierarchy of the manifest content. The text of all interviews was sorted and pasted into Word files according to the structure of the manifest content. These were critically read, questioned and compared to reach to a valid interpretation of the latent meaning structure of the text. Finally main theme, themes and sub-themes were identified and agreed upon. The themes and sub-themes have both a manifest and a latent representation, whereas the main theme represents the interpretation of the meaning of nurses' experience of collaboration with relatives of frail elderly patients.
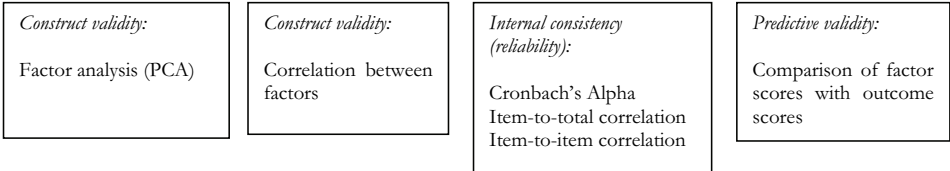
Psychometric tests (Paper III)

Validity and reliability were assessed using several approaches (Figure 3).

Figure 3   Overview of reliability and validity tests in the instrument design and test phases

Design phase

Construct validity:	Content and face validity:	Content and face validity:
<u>Concept clarification</u> Literature study of concept analyses on collaboration, participation, partnership, alliance, empowerment	<u>Expert panel</u> Department's doctoral group specialised in research on care of elderly people	<u>Pilot test</u> Relatives in geriatric units in 2 hospitals
Analysis of differences and similarities		Nurses and acquaintances with experiences of being relatives of frail elderly patients
Synthesis of the literature		

Test phase

Construct validity:	Construct validity:	Internal consistency (reliability):	Predictive validity:
Factor analysis (PCA)	Correlation between factors	Cronbach's Alpha Item-to-total correlation Item-to-item correlation	Comparison of factor scores with outcome scores

Construct validity

To evaluate construct validity, disclose underlying structures and reduce the number of variables exploratory factor analysis was carried out (Streiner and Norman, 2003). Principal component analysis (PCA) was chosen as the extraction method and Varimax rotation for normalisation was carried out (Pett et al., 2003). The Kaiser-Meyer-Olkin

procedure for measuring sample adequacy was applied and the Kolmogorov-Smirnov Test applied to test for normal distribution. Items with communalities less than 0.20 were excluded, and the cut-off point for factor loadings was 0.40 and for Eigenvalue 1.00. Missing values were excluded pair wise. Transformation into summarised scores was applied to items with possibility for multiple responses. An outcome measure (*I was satisfied with the hospital care trajectory: the admission phase, during the stay and the discharge phase*) was excluded from the analysis to be used in the assessment of predictive validity. In the final model 55 items were entered into the factor analysis covering the areas of *exchange of information and knowledge*, *influence on decisions during the hospital stay and in relation to discharge*, *quality of the relationship with nurses*, *contact and communication* and *physical environment*. Imputation with a mean substitution was carried out for internal dropouts of two or less items in factors consisting of fourteen (14 %) and thirteen (15 %) items to increase the number of eligible respondents. In the factor with eight items internal dropout of one item (12.5 %) was accepted, and in the factor with five items no internal dropout was accepted. Values in each factor were linearly transformed into values between 0 and 100 for the factor mean to appear as percentage of the maximum score. Nonparametric test (Spearman's rho) was applied to assess validity in terms of correlation between factors. Criteria for selecting numbers of factors were the inflexion point in the Scree Plot, the portion of variance explained by the last included factor and the meaningfulness of the solution (Field, 2006, Pett et al., 2003). *Construct validity* was further assessed by examining correlations between factors.

Predictive validity

Predictive validity (Streiner and Norman, 2003) is an expression of criterion validity, which expresses the extent to which the scores are correlated to an external criterion. When assessing predictive validity, this criterion would be an outcome measure in the future. In this study predictive validity was evaluated by testing the instrument's ability to predict the outcome of collaboration. Satisfaction may be an anticipated outcome of successful collaboration (Henneman et al., 1995, Kim et al., 2001, Sahlsten et al., 2005, Tapp, 2000), hence satisfaction with the stages of the hospital trajectory was chosen as global outcome criterion measure.

Reliability

Reliability was evaluated in terms of internal consistency and assessed in several ways: 1. Cronbach's alpha estimates for factor dimensions, 2. Item-to-total correlation, and 3. Item-to-item correlation (Field, 2006). All were assessed within the five factors in the factor solution. Risk for systematic internal dropout was investigated on items with dropout larger than eight (11.1 %). Variables tested were age, gender, relation to elderly patient, and educational level for respondents with and without internal dropout. Age was non-normally distributed; thus the Mann-Whitney's *U* test was applied. For categorical variables cross tabulations and chi-square test were applied.

Statistics (Paper IV)

Descriptive statistics were applied to all variables to attain frequency distribution. Comparison was carried out to explore characteristics for respondents reporting high (high degree/some degree) versus low (low degree/not at all) satisfaction with the phases in the hospital care trajectory (admission, time in the ward and discharge), and to compare ratings of satisfaction with the scores in the five factors for collaboration. T- test was applied to investigate continuous variables with normal distribution; Mann-Whitney's *U*-test was used for data with non-normal distribution. Chi-square test was applied on categorical variables.

Multivariate stepwise (backwards) logistic regression analysis was conducted for variables associated with high versus low satisfaction to examine predictors for low satisfaction with the care trajectory. The dichotomised variable *not satisfied* (1) *versus satisfied* (0) was entered as the outcome variable. Predictor variables were the collaboration factors and the variables showing association (p – values ≤ .10) with high versus low satisfaction in the comparison analyses. The collaboration factor variables were continuous.

A number of dichotomisation of response alternatives was made and new variables were created for caregiver tasks and responsibility (Table 3). *Relation to the elderly person* was categorised into spouses (reference category), children/children-in-law and others. Three categorical variables were made for *Caregiver tasks*, one called *Psychosocial support* including psychological support, social support and accompanying the elderly relative to activities, another called *Practical help* included practical help in the home, transportation, shopping, cooking, walks, taking medication, changing dressing and training, and a third variable called *Personal help* (bathing, helping at toilet visits etc). A new dichotomised variable for responsibility included the two items *Feeling responsible for the elderly person's well-being* and *Feeling responsible for the elderly person getting sufficient formal care*

Table 3   Dichotomised variables into values 0 and 1

Dichotomised variables	0	1
Distance in kilometres (km) from the elderly person	< 20 km	≥ 20 km
Educational level	Primary School	High school and university degree
Frequency of helping the elderly person	< Once a week (ref. Category)	> Once a week
Duration of help	≥2 years	≤ 1 year
Number of hours per day the elderly person can be alone	< 12 hours	≥ 12 hours
Psychosocial help	Not providing	Providing
Practical help	Not providing	Providing
Personal help	Not providing	Providing
Feeling responsible for elderly person	Some degree/less degree/not at all	High degree
Feeling powerless	Seldom, never	Very often, often
Feeling guilt	Seldom, never	Very often, often
Feeling of not doing enough	Seldom, never	Very often, often

Risk of multi co-linearity was examined by conducting bivariate correlation analyses and tests for co-linearity diagnostics for the predictor variables in the three regression analyses. Test for correlations showed the variables *Feeling guilty towards elderly relative* and *Feeling of not doing enough* to be strongly correlated (Pearson's Rho: .79 *p*-value = < .001) in the admission phase and during the stay. However, tests for co-linearity diagnostics were unproblematic (Field, 2006) with tolerance estimates between .29 and .96 and variance inflation factors (VIF) between 1 and 3.49. Hosmer & Lemeshow's test indicated the model to fit the data well and a re-run of the regression analysis without the item *Feeling of not doing enough* showed the same result as the initial regression analysis.

P-values ≤ .05 was considered significant. Data were analysed using SPSS-PC (version 11.0; SPSS Inc. Chicago, IL).

ETHICAL CONSIDERATIONS

The Ethics Committee of the County of Copenhagen was presented with a full description of the project and found formal evaluation of the project to be unnecessary. The study involved no need for access to citizen numbers or registers, as the ward nurses allocated the patients to the author. Ethical principles for research are *the principle of beneficence,* meaning that the research should do no harm, and that the risk/benefit ratio should be considered, *the principle of respect for human dignity* including the right to self-determination and informed consent, and *the principle of justice* including the right to privacy (Polit and Hungler, 1991). Special attention should be paid in studies including particularly vulnerable persons.

Beneficence

Research should not harm but contribute to doing good. In this study the harm would be in terms of psychosocial pain, as no physical or pharmacological interventions were involved. However, psychosocial pain may inflict serious damage. An interview, and particularly an in-depth one, may lead to new insights for the participant, both about him/herself, the relationship with the elderly person or about the care and life situation in itself. Nurses may attain insights about their professional work, relations and competence. This may do the participant good and even have a healing effect, if carried out gently and with competence. However, as these insights may also give rise to pain, the interviewer must pay special attention to this and preferably be able to handle participants' emotional reactions, or refer the participant to a professional person, who can. Situations may arise where the wish for new knowledge must give way to the principle of not doing harm. Relatives with care responsibility for a frail hospitalised elderly person are in a vulnerable and stressed situation where their strength and resources are called for. Consideration is therefore needed as to whether the study will bring forward new and valuable knowledge that justifies the interruption and extra demand on the relatives that the participation in the study may make. The study will presumably provide new knowledge about the situation and problems of a hitherto unacknowledged group of players in the acute health care arena. This again may provide basis for improved collaboration between nurses and relatives, which may benefit both relative, patient and the care trajectory. The author who carried out all interviews was a registered nurse with 25 years of experience. Furthermore, she was a trained and experienced supervisor in individual and group counselling. Special attention was paid to creating a supportive atmosphere during the interviews. When emotions arose, understanding was offered as well as the possibility to put them into words. On the other hand, participants were encouraged to set their own limits and it was made clear that declining to answer questions was perfectly acceptable, and that the interview could be ended whenever they felt like it.

The cost-benefit balance concerning the nurses' participation must also be taken into consideration. The time for interviews had to be taken out of a busy schedule marked by high work-pressure, thus, there has to be substantiated supposition that it will result in valuable knowledge. As little is known about collaboration between nurses and relatives of frail elderly patients in acute care contexts, and as both human and economic benefits

are presumed outcome of this collaboration, the time spent may be considered a beneficial investment. The interviews and the questionnaire survey with relatives, as well as the interviews with nurses, may reveal staff conduct inappropriate to relatives and collaboration with them. It is the author's duty to treat and present these data respectfully, in such a way that no participant feels compromised or judged.

The questionnaire was extensive and may have added to an already burdensome situation for the relatives. Furthermore, some of the questions may give rise to emotional discomfort, for instance those aimed at disclosing the extent of care and feelings related to the care situation. The first may have caused awareness of the amount of tasks and time spent providing them, thereby possibly causing dissatisfaction with the care situation. However, merely asking about the extent of care is based on the assumption that it is actually provided. This may put pressure on relatives unable or unwilling to provide care. Questions about feelings related to the care situation (e.g. feeling of not doing enough for the elderly person) may cause feelings of guilt to arise. However, attaining knowledge about how much care is actually delivered by relatives, and how they feel about the situation, is relevant and important if nurses have to establish collaboration with them concerning the plans for care and treatment for the frail elderly patient. The author's name, e-mail address and phone numbers were printed on the questionnaire along with an invitation to make contact to whatever extent was needed.

Respect for human dignity and the principle of justice

Verbal and written information was given to the elderly persons, relatives and participating nurses informing them about the aim and method of the project. They were informed that participation was voluntary, that data would be treated confidentially, and that withdrawal from the project was possible at any time. The fact that the researcher had no employment connection to the units or the hospital was emphasised. The questionnaires were returned to the university in Lund, Sweden, and not to the hospital. In most cases it was the researcher herself who approached patients and participants, and this may have constituted both a threat and a benefit for the consent to be voluntary. Patients, relatives and nurses may feel obliged to give their consent when approached by a researcher to whom the study, and their participation in it, is obviously important. On the other hand, as the researcher had no employment relationship to the hospital, and therefore had no power over the patients' trajectories, there may be little or no concern about consequences for treatment and care if a decision were taken not to participate.
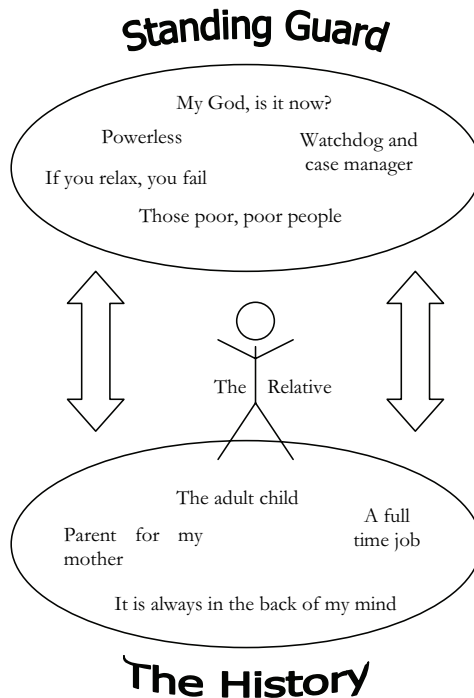
FINDINGS

Standing guard – The relatives' experience (Paper I)

The lived experience of being a relative of a frail hospitalised elderly person revealed itself in two essences *The History* and *Standing Guard* with a number of constituents (Figure 4).

Figure 4   The lived experience of being a relative to a hospitalised elderly person. Essences and constituents

Standing Guard

My God, is it now?

Powerless

Watchdog and case manager

If you relax, you fail

Those poor, poor people

The   Relative

The adult child

Parent   for   my mother

A full time job

It is always in the back of my mind

The History

The History was the frame of reference in which the encounter with the hospital system and the hospital stay of the elderly patient were interpreted and understood. It stood out as the basis for their expectations and conducts and consisted of four constituents: *The adult child, Parent for my mother, It is always in the back of my mind* and *A full time job*. The relationship history was central and brought meaning to the present situation as well as influencing relatives' conduct at the hospital. The constituent *The adult child* reflected the parent-child relationship and the significant position the parents had for these adult children, regardless of the degree of closeness. The situation brought on existential reflections about the relationship history, and for some it was even a time for reconciliation. Patterns from childhood influenced the way they felt and acted towards the current situation. The constituent *Parent for my mother* reflected the changed positions and

roles between the elderly person and the relative. For offspring it was a role reversal with the child caring for the parent and the wife became her husband's nurse while losing her complementary role as partner. The change in roles was encumbered with feelings of loss and discomfort. Worry was a constant companion and reflected in the constituent *It is always in the back of my mind*. This was related to the elderly person living alone and without help if problems occurred. Grief, worry and feelings of guilt were apparent. In spite of the help provided by the municipality, the relatives felt primarily responsible for the elderly person's well-being, functional level and life spirit. The sense of responsibility was strong and difficult to specify and reduce. With unlimited responsibility the voice of conscience was difficult to satisfy, and worry, powerlessness and guilt feelings were frequent companions, when encountering the misery and loneliness of the elderly person. The constituent *A full time job* reflected that the help these relatives provided was extensive. Help was provided from 3 to 25 hours (mean 8) per week, and where the relative was living with the elderly person hours spent were difficult to specify as it took place around-the-clock. The tasks in themselves entailed a sense of satisfaction, of doing something, and whereas only some experienced physical and social consequences, all relatives expressed emotional strain.

The essence *Standing Guard* encompassed the encounter with the hospital system. The constituents in this essence were: *My God, is it now?, Powerless, If you relax, you fail, Watchdog and case manager* and *Those poor, poor people*. The constituent *My God is it now?* reflected the hospital admission as a significant and stressful event for the relatives, entailing contemplation of death, loss or nursing home placement. It was a time of crisis and possible transition. When the elderly person was admitted to hospital the awareness of death put the relatives on high alert and they rushed to the hospital to stand by. In the end, when death seemed close, the condition of being on high alert was an everyday companion. The constituent *Powerless* reflected the relatives' powerlessness in relation to the patients' unspecified condition. Not knowing what exactly was wrong, and how to remedy the condition, was frustrating for the relatives. It made it difficult to make a realistic evaluation of the situation, and it was difficult for them to know when to try to keep the elderly person going and when to leave him/her at peace because it was time to let go. Some relatives were able to relinquish the responsibility for the elderly person's care and enjoy the hospital stay as a respite. Others, however, continued to feel primary responsible and lacked confidence in the professionals. For them the hospital stay was not a respite. This was reflected in the constituent *If you relax, you fail.* They reported experiences such as the elderly person's needs not being met, disrespectful conduct among staff, patient calls not being answered by staff, staff's work pressure and a chaotic physical environment, all of which made them uncertain and worried. They would engage in activities aimed at securing the patient's safety, and substitute in areas where they were not satisfied with the staff's performance. This was shown in the relative taking on the role of "*watchdog*" to safeguard the elderly person and the quality of care, and the "*case manager*" and "*advocate*" to plead their case before the professional system to get sufficient care and treatment both at the hospital and after discharge. The relatives claimed that the elderly persons would not be realistic when asked about their health and how they managed everyday life. The constituent *Those poor, poor people* reflected the relatives' concern with the staff's working conditions. They fully understood and sympathised with the nursing staff, and when criticism was put forward, a distinction was made between the

"system" and the people. However, comments were made on differences between nurses though working under the same conditions.

To be caught between ideals and practice - Nurses' experience (Paper II)

The main theme in the interview with nurses was called *Encountering relatives – to be caught between ideals and practice* and reflected two sets of conflicting attitudes towards relatives and the collaboration with them. One set was in accordance with the nurses' professional values, the other seemingly reflected their practice. The first set was apparent only as manifest content whereas the other one appeared both at manifest and latent level. The tension between the two sets of values ran as an undercurrent through the findings, and was apparent in the two themes *The coincidental encounter – the collaboration* and *Relatives - a demanding resource* as well as in their sub-themes (Table 4).

Table 4   Nurses' experience of collaboration. Main theme, themes and sub themes

Main theme	Themes	Sub themes
Encountering relatives – to be caught between ideals and practice	The coincidental encounter – the collaboration	Flee or fight – the nurses' response
		A matter of prioritising - Barriers and promoters
	Relatives - a demanding resource	The unwritten rules – role expectations
		The new relatives – the demanding and unrealistic relatives

The coincidental encounter reflected that although ideally described as a structured process starting immediately after admission, collaboration appeared to be by chance and rare, and determined by relatives' conduct. In practice collaboration seemed to equate with supplying information with the purpose of avoiding complaints and keeping relatives compliant. Although relatives' knowledge about the patient was considered important for the quality of the care trajectory, it was seemingly not sought. The nurses reported to have had no contact with relatives of the elderly patient they had discharged, and little or no knowledge about how the patient had managed at home before admission. Successful collaboration seemed to be related to characteristics of the relative, as those who were perceived as realistic and cooperative were more likely to be involved by the nurses. When encountering relatives who were considered demanding the nurses seemingly employed an evasive conduct and either tried to avoid them or communicated in a dismissive way, as reflected in the sub-theme *Flee or fight*. This response appeared to be unreflected and in contrast to the knowledge and intentions the nurses expressed at the normative level. It seemed to be related to uncertainty due to lack of knowledge about the

patient and a feeling of being criticised, but also to a perception of these relatives as being unduly time consuming.

Although they did not reflect on the discrepancy between their ideal and practice related attitudes, the nurses seemed aware of a lack of systematic involvement of relatives and the corresponding room for improvement. They described hindering and promoting conditions for collaboration such as time pressure, medical focus, organisation of care and competence level as indicated in the sub-theme *A matter of prioritising*. The medical focus seemingly determined the prioritising of tasks in the unit. Tasks related to assisting physicians in diagnosing and treating the diseases filled the busy day and diverted attention from patients' functional and social needs. Organisation of care in teams was considered as hindering continuity and impeding development of sufficient knowledge of the patient for the nurses to encounter relatives in a confident way. Time pressure was seemingly a constraint and the nurses described a stressful working environment with a heavy care load and many interruptions of which relatives merely constituted one. High competence level and experience were considered prerequisites for successful collaboration with relatives, as was the nurse leader's attitude.

The theme *Relatives – a demanding resource* reflected the dual attitudes towards relatives that appeared in the text. While at the ideal level relatives were considered a resource for both staff and patient, at the practical level this appeared to be the case only when the relative shared the staff's definition of the patient's situation. When this was not the case, relatives were seemingly considered difficult or demanding, and collaboration was impeded. The sub theme *The new relatives – the demanding and unrealistic relatives* reflect the experience that a certain group of relatives was demanding and had unrealistic expectations. Seemingly, the conception was that this group was increasing. The sub-theme *The unwritten rules* reflected a set of role expectations for relatives and indicated a subordinate role for them as passive recipients of information about the decisions made by the staff. This was contrary to the ideal description, which implied relatives to be active and involved in the planning of the trajectory. Ideally, setting up rules for relatives was not considered appropriate, however, they were expected to accommodate themselves to the expectations and routines of the staff. This would seemingly imply knowing when and for how long to disturb a nurse, when not to enter the patient's room, and which questions were considered appropriate for relatives to ask and which were not. Relatives seemed to be experienced as belonging to two groups, the easy ones and the difficult or demanding ones. The easy ones seemingly shared the nurses' definition of the patient's situation, whereas the demanding ones did not and therefore were experienced as unrealistic. The easy ones seemingly obeyed the unwritten rules, whereas the demanding relatives would demand answers and further examinations, and they would openly express their disagreement or dissatisfaction. The nurses' and these relatives' definition of the situation seemed to collide. At the ideal level the nurses interpreted the conduct of these relatives to be symptoms of a crisis reaction, and they would describe the professional and ideal way to deal with them. However, they expressed irritation and lack of patience with this particular group of relatives and also interpreted their conduct as disrespect, when talking about them in the interviews.

Development and testing of an instrument measuring relatives' view on collaboration with nurses in acute wards (Paper III)

Validity

Construct validity was examined in the factor analysis. The Kaiser-Meyer-Olkin estimate for sample adequacy was .696 and significant (*p*-value = < .001) and the Kolmogorov-Smirnov Test indicated data to be normally distributed. The Scree Plot showed the relative importance of each factor reflected by their Eigenvalue (Field, 2006, Pett et al., 2003) and in this case the point of inflexion justified a five-factor solution. This solution explained 57.5 % of the variance with the last included factor explaining 3.6 % of the variance, and made sense in the distribution of items in components. The five factors were labelled "Influence on decisions", "Quality of contact with nurses", "Trust and its prerequisite", "Achieved information level" and "Influence on discharge". They included items reflecting attributes, prerequisites and outcome of collaboration. After linear translation, means for the factors reflecting key attributes and outcomes of collaboration, i.e. shared decision-making, exchange of knowledge, and agreement on definition of the situation, were 60.68 (SD 21.10) for "Influence on discharge", 66.28 (SD17.72) for "Achieved information level" and 75.35 (SD 16.99) for "Influence on decisions" (Table 5). Mean scores for factors covering prerequisites for collaboration i.e. contact, communication, and relationship qualities were 47.76 (SD 16.96) for "Trust and its prerequisites" and 49.23 (SD 17.65) for "Quality of contact with nurses".

Table 5   Means and Cronbach's Alpha estimates for collaboration factors. The higher the scores, the lower the level of collaboration

Factors	Mean	Standard deviation	Cronbach's Alpha
Influence on decisions	75.35	16.99	.92
Quality of contact with nurses	49.23	17.65	.94
Trust and its prerequisites	47.76	16.96	.91
Achieved information level	66.28	17.72	.83
Influence on discharge	60.68	21.10	.85

The test for correlation between factors showed Spearman's rho values between .16 and .60.

Predictive validity was indicated, as higher scores in the five factors were related to higher scores in the outcome measures. *Satisfaction with the trajectory during the stay* and *Satisfaction with discharge* showed consistent trends, while *Satisfaction with admission* deviated from the rising trend.
The percentage of participants rating negative on dimensions of collaboration as reflected in the factors and their included items appears in table 6.

Table 6   Participants in percentage scoring in negative response alternatives in the items included in the five factors for collaboration

Factor 1: Influence on decisions	% n=156	2. Quality of contact with nurses	% n=156
I had influence on decisions made about treatment[1]	81.2	Nurses were obliging when I contacted them[1]	7.1
I had influence on decisions made about examinations[1]	82.8	It was OK to express my worry[2]	9.2
I had influence on decisions made about rehabilitation[1]	76.1	It was easy to find a nurse (in person) who knew my relative[1]	20.4
I had influence on decisions made about the care[1]	78.2	It was OK to express my feelings[2]	11.5
I was informed about decisions made about rehabilitation[1]	62.6	I was able to talk to a nurse (in person) when I needed to[1]	16.2
I was informed about decisions made about care[1]	62.9	Nurses had time to talk to me[1]	16.4
I was informed about decisions made about examinations[1]	49.6	Nurses understood my situation as a relative[2]	23.8
I was informed about decisions made about treatment[1]	49.3	It was easy to find a nurse (on the phone) who knew my relative[1]	22.3
Nurses asked about my views on decisions that had to be made[1]	61.2	I am satisfied with the quality of the contact with nurses[2]	36.3
Nurses asked for my knowledge about my relatives situation[3]	40.4	I am satisfied with the extent of contact with nurses[2]	37.0
My knowledge was used by the nurses[1]	29.4	I was rejected by nurses when I contacted them[5]	4.6
I was satisfied with the influence I had[2]	50.3	It was OK to express criticism[2]	19.0
Nurses and I were in agreement about what should happen to my relative[1]	18.3	I was able to talk to a nurse (on the phone) when I needed to[1]	19.2

3. Trust and its prerequisites		4. Achieved information level	
I had to make sure my relative got the care s/he needed [6]	38.8	I felt well informed about how best to help my relative in the future[2]	58.7
Physical environment was neat[2]	58.2	I felt well informed about my relative's care needs[2]	44.9
Physical environment was tidy[2]	45.9	I felt well informed about the plans after discharge[2]	42.0
Physical environment was clean[2]	60.7	I felt well informed about my relative's illness[2]	33.1
Experiences of mistakes and insufficient care during this hospital stay[4]	50.6	Contact with nurses was initiated by relative[5]	71.2
I trusted that my relative got the care s/he needed[2]	24.0		
Physical environment had sufficient space[2]	59.1	5. Influence on discharge	
I felt my relative was in safe hands while in hospital[2]	20.7	I had influence on decisions made about arrangements after discharge[1]	55.4
It was my impression that the nurses were too busy[6]	73.4	I was informed about decisions made about arrangements after discharge[1]	44.6
It was my impression that the nurses were competent[2]	12.3	I had influence on decisions made about the discharge[1]	63.2
Experiences of mistakes and insufficient care during prior hospital stays[4]	41.0	I found the plans after discharge acceptable[2]	20.1
Nurses treated patients with respect[1]	9.3	I was informed about decisions made about the discharge[1]	42.3
Physical environment made privacy possible[2]	68.4	My relative received sufficient (formal) help after discharge[2]	22.3
		The problem leading to the admission was solved[2]	24.8
		Need for information/training about how best to help my relative (To be answered by those who did not receive any)[6]	71.0

1   ├─┼─┼─┼─⬭─┤   seldom/never   5   ├─⬭─┼─┼─┼─┤   Always/very often

2   ├─⬭─┼─┼─┤   Less degree/not at all   6   ├─⬭─┼─┼─┤   High degree/some degree
                    Partly disagree/completely disagree
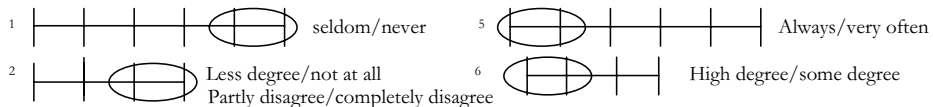
[3] Never. Categorical variable with response alternatives: At admission, during the stay, at discharge, never
[4] Percentage with one or more experiences

In the factors "Influence on decisions" and "Influence on discharge", influence on decisions was reported in the seldom/never response alternatives by between 76.1 % and 82.8 % of the respondents in relation to decisions about examinations, treatment, rehabilitation and care. Items concerning decisions about the discharge, and subsequent arrangements, were rated negatively by 55.4 % and 63.2 %. Between 42.3 % and 62.9 % reported they were seldom or never informed about decisions made, and 50.3 % were not

satisfied with the influence they had on decisions. In 61.2 % of the cases nurses seldom or never asked the relatives about their view on decisions that had to be made and 40.4 % were never asked about their knowledge about the patient's situation. In the factor "Achieved information level" between 33.1 and 58.7 % reported negatively on the items *I felt well informed about my relative's: illness, care needs, the plans after discharge* and *about how best to help my relative in the future* and 71 % reported unmet needs (high degree/some degree) for information/training about how best to help the elderly person.

The negative ratings were less frequent in the factor "Quality of contact with nurses". Respondents disagreeing with the statement *Nurses had time to talk to me* constituted 16.4 %, while 23.8 % disagreed with the statement *Nurses understood my situation as a relative.* The items *It was OK to express my feelings, worry and criticism* was rated negatively by 9.2 %, 11.5 % and 19 % respectively. In 7.1 % of the cases respondents reported seldom or never in relation to the statement *Nurses were obliging, when I contacted them.* Between 16.2 % and 22.3 % scored negative in the items reflecting the nurses' accessibility (*It was easy to find a nurse who knew my relative (in person/on the phone), I was able to talk to a nurse when I needed to (on the phone/ in person)).* Respondents scoring negatively on satisfaction with the quality and extent of contact with nurses constituted 36.3 % and 37 % respectively.

In the factor "Trust and its prerequisites" trust was reflected in the items *I felt my relative was in safe hands while in hospital* and *I had to make sure my relative got the care s/he needed* and was reported as low degree and not at all by 20.7 % and 38.8 % respectively. Physical environment was rated negative by from 45.9 to 68.4 % of respondents, and 73.4 % agreed (high/some degree) that the nurses were too busy.

Some items had large percentages rating "do not know", these were not included in the figures in table 6. This was the case for the items *My knowledge was used by the nurses* (24.8 %), *Nurses and I were in agreement about what should happen with my relative* (22.2 %), *It was OK to express my worry* (20.4 %), *my feelings* (29.1 %), *criticism* (43.5 %) and *The problem leading to the admission was solved* (10.5 %).

Reliability
Cronbach's alpha estimates for the five factors ranged between .83 and .94 (Table 5). Alpha value *if item deleted* was only in one case higher than the total alpha value. In the factor "Achieved information level" total Cronbach's alpha value was .83 and would be .88, if the item *Contact with nurses was initiated by relative* was deleted. The corrected *item-to-total* correlation for this item was .37, but the item was significantly (*p*-value = ≤ .001) correlated to the other items in this factor. The corrected *item-to-total* correlation coefficients were between .34 and .83 and with few exceptions above .60. *Item-to-item* correlations showed Spearman's rho coefficients from .18 to .87. Coefficients for mean inter-item correlation ranged between .40 and .56. Analysis for systematic internal dropout showed significant differences within age (*p*-value = .007) and educational level (*p*-value = .04) with higher age and lower educational level being related to higher internal dropout. Nineteen items of 55 had internal dropout larger than 8 distributed among 17

respondents (10.9 %). Eighty-four (53.8 %) questionnaires were fully completed. Items subject to the largest internal dropout were addressing the discharge.

Collaboration between relatives of elderly patients and nurses and its relation to satisfaction with the hospital care trajectory (Paper IV)

Help was supplied by 95.4 % of respondents with 40.9 % helping daily. Psychosocial support was supplied by 84.6 %, practical help by 89.1 %, while personal help was supplied by 19.9 %. Relatives providing help for 5 years or more constituted 49.3 %, and 82.1 % had provided help for more than 2 years. The number of hours help per week ranged from 0 – 99 with a mean of 8.81 (SD 12.02).

A high degree of responsibility for the elderly relative's well-being and getting sufficient formal help was reported by 99.4 %, and 96.1 % of the participants respectively. Emotional consequences were reported in terms of powerlessness, guilt feeling and feeling of not doing enough by respectively 53.3 %, 44.8 % and 44.8 %. The hospital stay was perceived as a respite for the responsibility for the elderly person by 40.7 % and 38.8 % reported they had to make sure the elderly person received sufficient care while in hospital. To ensure this 19.2 % spent more time at the hospital than planned. Respondents reporting (to high or some degree) that it was their job to take care of the patient's interests concerning the arrangements after discharge constituted 68.2 %. Relatives wanting influence on hospital care constituted 49.4 % while 12.7 reported to have had it (very often/often) and 49.7 % were satisfied (high/some degree) with the influence they had on decisions.

Respondents reporting themselves satisfied (high degree/some degree) with the admission phase constituted 77.8 %. Comparison between those reporting high or low satisfaction with the admission phase of the hospital care trajectory showed that the latter significantly more often had a health education (p-value = .02) and more often reported powerlessness (p-value = .02) and guilt (p-value = .04). Mean scores in the factors "Trust and its prerequisites" (p-value = < .001) and "Quality of contact with nurses" (p-value = < .001) was significantly higher for those reporting low satisfaction than for those reporting high satisfaction.

Respondents reporting themselves satisfied (high degree/some degree) with the care during the stay constituted 70.1 %. Comparisons between those reporting high or low satisfaction with the care during the stay showed that those who reported low levels were significantly more often women (p-value = .03), had helped for less than one year (p-value = .01), and more often reported powerlessness (p-value = .001) and guilt (p-value = .001). Mean scores in all five factors were significantly higher for those reporting low satisfaction (p-values from < .001 to .02) than for those reporting high satisfaction.

Respondents reporting themselves satisfied (high degree/some degree) with the discharge phase constituted 61.1 %. Comparisons between those reporting high and low satisfaction with the discharge showed that the latter significantly more often provided psychosocial (p-value = .02) and practical help (p-value = .04), and more often reported powerlessness

(*p*-value = .003) and guilt (*p*-value = .01). Mean scores in all five factors were significantly higher for those reporting low satisfaction (*p*-values from < .001 to .01) than for those reporting high satisfaction.

The logistic regression analyses revealed a low level in the collaboration factor "Trust and its prerequisites" (OR = 1.07, *p*-value = < .001) to be associated with low satisfaction with the admission phase of the hospital care trajectory (Table 7). Feeling guilty was included in the final model though was not significant. Factors associated with low satisfaction with the stay were feeling guilty (OR = 13.34, p-value = < .001), duration of helping less than one year (OR = 6.84, *p*-value = .02) and low "Influence on decisions" (OR = 1.07, *p*-value = .01) and "Trust and its prerequisites" (OR = 1.18, *p*-value = < .001) (Table 5). Factors associated with low satisfaction with the discharge were feeling powerless (OR = 1.95, *p*-value = .001), not providing psychosocial help (OR = 2.02, *p*-value = .05), and low "Influence on discharge" (OR = 1.04, *p*-value = .01) and "Achieved information level" (OR = 1.04, *p*-value = .02).

Table 7   Multivariate logistic regression analysis for dimensions of collaboration and characteristics of help associated with low satisfaction with the hospital care trajectory

	B	OR (95% CI)	p-value
Low satisfaction with admission phase[1]			
Feeling guilty	.84	2.31 (.91 – 5.89)	.08
Low level of "Trust and its prerequisites"	.069	1.07 (1.04 – 1.11)	**< .001**
Low satisfaction with the trajectory during the stay[2]			
Feeling guilty	2.59	13.34 (3.15 – 56.50)	**< .001**
Duration of help ≤ 1 year	1.92	6.84 (1.36 – 34.56)	**.02**
Low level of "Influence on decisions"	.07	1.07 (1.02 – 1.13)	**.01**
Low level of "Trust and its prerequisites"	.17	1.18 (1.10 – 1.27)	**< .001**
Low satisfaction with discharge phase[3]			
Not providing psychosocial help	2.02	7.52 (1.0 – 56.64)	**.05**
Feeling powerless	1.95	7.06 (2.28 – 21.84)	**.001**
Low "Achieved information level"	.043	1.04 (1.01 – 1.08)	**.02**
Low level of "Influence on discharge"	.036	1.04 (1.01 – 1.07)	**.01**

[1]Hosmer and Lemeshow test for goodness-of-fit: .465. Variables entered: Feeling powerless, feeling guilty, being a health care professional, number of hours the elderly person can be alone, Quality of contact with nurses, Trust and its prerequisites, Achieved information level
[2] Hosmer and Lemeshow test for goodness-of-fit: .732. Variables entered: Age, gender, hospital, feeling powerless, feeling guilty, feeling of not doing enough, being a health care professional, duration of help, Influence on decisions, Quality of contact with nurses, Trust and its prerequisites, Influence on discharge, Achieved information level
[3] Hosmer and Lemeshow test for goodness-of-fit: .263. Variables entered: Feeling powerless, gender, giving psychosocial help, giving practical help, frequency of help, feeling guilty, Influence on decisions, Quality of contact with nurses, Trust and its prerequisites, Influence on discharge, Achieved information level

DISCUSSION

Methodological considerations

Qualitative studies (Paper I and II)

The criteria used when evaluating the trustworthiness of the two first studies were: *Credibility, transferability, dependability* and *confirmability* (Lincoln and Guba, 1985). There are several ways of meeting the methodological demand for *credibility*. Intimate knowledge of the context in which the phenomenon is studied is essential, and the researcher must deal with personal distortions such as values, expectations or prejudices that may affect the research process (Lincoln and Guba, 1985). In these studies the researcher held intimate knowledge about the phenomenon as well as context, as she was a registered nurse with many years of experience in acute care contexts and had personal experience of being the relative of frail elderly people. This may increase credibility. However, these experiences may also have given rise to distortions such as a special value system, prejudices and expectations. The interview performed to clarify and challenge the researcher's preunderstanding was a measure taken to minimize these threats and enhance openness and sensitivity both in the interview situation and in the analyses. Interpretations of both verbal and non-verbal expressions were further tested in the interview situation, and multiple investigators were involved in the analyses and presentation of the findings (Lincoln and Guba, 1985). The investigator performing the study cannot assess the *transferability* of the study findings. S/he can only provide sufficient description and information for someone else to be able to make judgements about transferability of the findings (Lincoln and Guba, 1985). Striving for a thick description, the sampling strategy for the qualitative studies in this thesis aimed at a maximum of variation. The samples were small, but for the relatives heterogeneous in terms of: relation to the elderly person, gender, age, co-habiting with the elderly person and occupation, and for the nurses: age, educational background and nursing experience. Heterogeneity may add not only richness to the findings in a small sample, but also strength because the structure, which, in spite of the variation, repeats itself, captures aspects that are central for the phenomenon (Sandelowski, 1995). However, the variation among relatives was not exhausted in this sample and the results may have been different if, for instance, husbands, grandchildren and friends had been included or if the sample size had been larger within each variation. *Dependability* and *confirmability* may be assessed by an "inquiry auditor" (Lincoln and Guba, 1985), and in this case the measures taken to reduce the risk of interpretive errors in the analyses by involvement of several researchers may enhance the study's dependability and confirmability. Moreover, the doctoral supervisor and the university department's doctoral group who critically scrutinised the project process as well as the publishing process may be seen as "inquiry auditors", enhancing the study's dependability and confirmability.

Quantitative studies (Paper III and IV)

Validity

Validity reflects how well an instrument measures the aspects and properties it is supposed to measure. In other words: does it measure what it is supposed to measure?

(Streiner and Norman, 2003). In this study *face validity, content validity, construct validity* and *criterion validity* were examined. *Face validity* is usually tested in the developmental phase but involves no empirical methods. It indicates the extent to which the instrument, on the face of it, seems to be measuring the intended aspects, based on a subjective judgement by experts, which in this study were relatives of frail elderly patients and researchers experienced in care of elderly persons. *Content validity* reflects the extent to which the instrument represents all conceivable items for adequately covering the domain under investigation (Streiner and Norman, 2003). It is assessed by judgement, as there are no objective methods to ensure that the subject is sufficiently covered (Polit and Hungler, 1991). A well-planned and conducted development phase involving relevant theory and empirical material constitutes the basis for choice of variables and for ensuring content validity. In this study expert panels consisting of experienced researchers and key informants from the potential population participated in the development and initial testing of the instrument to strengthen content validity. *Construct validity* refers to how adequately the instrument items correspond with and measure the underlying, abstract construct under investigation (Polit and Hungler, 1991). As "collaboration" cannot be directly observed, the instrument attempts to measure the hypothesized expression of the construct, thus, construct validity presupposes that a theory or a model has been formulated. The thorough work developing the framework for the questionnaire aimed at strengthening construct validity. Dimensions of the construct were developed based on existing theory, literature and empirical findings, which also delivered the empirical indicators for these dimensions – the items. Construct validity cannot be established in one test, it is an ongoing process where hypotheses are tested, rejected or accepted, new ones made and tested and so on (Pett et al., 2003, Streiner and Norman, 2003). In fact both theory and instrument are tested in this process. As the construct "collaboration" has not been investigated on populations or contexts similar to those of interest in this study, the structure of the construct needs to be (re-) examined and defined for this purpose. One way of examining construct validity and the instrument's underlying structures is to perform an exploratory factor analysis. The factor solution, the items loading into each factor, and the extent to which the solution makes theoretical sense and reflect the original model derived from the literature are indications of construct validity (Pett et al., 2003). Cronbach's alpha values for each factor and correlations between factors were further indications of construct validity (Field, 2006), although caution should be applied due to the ratio between sample size and number of items. Guidelines for sample adequacy when applying factor analysis recommend five respondents per item (Floyd and Widaman, 1995). Thus the sample ought to have consisted of at least 275 respondents though in this case there were only 156. However, the Kaiser-Meyer-Olkin measures indicated the sample to be adequate for a useful factor analysis as values above .50 and as close to 1.0 as possible are considered to be sufficient (Field, 2006). Correlation coefficients indicated all factors to be part of the same construct, measuring different dimensions of it. "Trust and its prerequisites" was an exception when it concerned the factors reflecting level of influence. The hypothesis about trust and influence was that low trust would entail the need for a high level of influence. However, low correlation between the trust and influence dimensions in the factor analysis indicated otherwise. The trust factor correlated well with the factor "Quality of contact with nurses" indicating trust to be related to relational and communication aspects.

Criterion validity expresses the extent to which the scores are correlated to an external criterion (Polit and Hungler, 1991). A "criterion" is some other measure used on the construct or aspect under investigation and preferably a "gold standard". Two types of criterion validity are usually described: concurrent validity (correlation with e.g. a gold standard instrument) and predictive validity (where the criterion is an outcome measure in the future) (Streiner and Norman, 2003). As this was the first testing of an instrument developed in an area on which no evidence about future outcome exists, the criterion chosen for *predictive validity* was satisfaction with the trajectory measured after discharge. Better scores in satisfaction with the phases in the hospital trajectory were related to better scores in the five factors and may be seen as an indication of *predictive validity*. However, the scores in *Satisfaction with admission* were not consistent with this, and satisfaction with this phase may reflect not only the hospital experience and the collaboration there but also the time leading up to admission. Assessment of *predictive validity* as an expression of criterion validity involves a future criterion, which makes a cross-sectional design less suitable (Streiner and Norman, 2003); thus studies applying research designs suitable for establishing predictive validity are warranted.

Reliability

Reliability has been defined as the ratio: subject variance to subject + error variance, and is based on the assumption that to any observation there are two components: the true score and an error associated with the observation (Streiner and Norman, 2003). Reliability reflects the amount of error, random and systematic, inherent in the instrument. Reliability can be assessed in terms of *internal consistency*, which refers to the homogeneity of the instrument and the extent to which its subparts are measuring the same dimension (Streiner and Norman, 2003). Items should be moderately correlated with each other and with the total score. Cronbach's Alpha is a measure of variance – covariance of all items in an instrument and a test used for examining internal consistency (continuous data) (Field, 2006). Values of coefficients run from 0-1, and should exceed 0.70 to show good internal consistency. However, in testing measures of psychological or social constructs even lower values may be expected (Field, 2006). Other methods used are Kuder-Rickardson (for dichotomous data) or "split halves reliability". The reliability tests in this study indicated mainly good internal consistency. Cronbach's Alpha estimates for the five factors were high, however, attention should be given when alpha estimates exceed .90 (Streiner and Norman, 2003), which was the case for three of the factor components, as it may indicate redundancy in items; then considerations should be made as to which items should be excluded. Furthermore, the estimates for *corrected item-to-total correlation* and *item-to-item correlation* indicated good internal consistency. Correlation estimates lower than .30 indicate small correlation (Field, 2006), and the item-to-item correlation analyses for all factors showed some items to have estimates lower than .30, indicating they were not measuring the same thing. However, these items showed in most cases acceptable correlation coefficients for other items in the factor, and all had correlation coefficients larger than .3 in the *item-to-total* correlation indicating them to measure aspects of the factor dimension. The inter-item-correlation estimates may give indications of which items to exclude due to redundancy. Items should be moderately correlated with each other (Streiner and Norman, 2003), hence, those with estimates above .50 (Field, 2006) should be examined for redundancy. Consideration may be given

to excluding items covering theoretically and intuitively closely related aspects, or those in which one item may be implicit in the other. This is the case for instance with the items *It was OK to express my worry* and *It was OK to express my feelings*, as *worry* may be considered implicit in the concept *feeling*.

According to Streiner & Norman (2003) internal consistency is not alone a sufficient indicator of the value of a measure. Information about stability is also necessary, and suggests how reproducible the results are over time and under different conditions. Several methods can be applied to measure stability a) different observations performed by the same person "intra-observer reliability" b) correlations between observations performed by different persons "inter-observer reliability" c) correlations between scorings in a self report type of instrument by the same person on different occasions separated by time "test-retest reliability". The development of an instrument is an ongoing process and different ways of assessing reliability should be applied. As this is the early stage of the process for this instrument, homogeneity in terms of internal consistency was investigated. Future testing should involve other tests for reliability aspects, for instance stability by applying test-retest methods.

Internal and external validity

Although this first testing indicated the instrument to be mainly reliable and valid, and to confirm the model built on previous literature, some limitations were apparent. *Internal validity* addresses the adequacy of the design in relation to the study hypothesis (Aday and Cornelius, 2006). The design in this study was cross-sectional and therefore not adequate for making inferences about causal relationships. Thus, only interpretations about associations can be made about the variables in interest: collaboration and satisfaction, and therefore also the assessment of predictive validity is doubtful. Prospective or randomised controlled trials using the instrument are needed for drawing causal conclusions about the two variables. *External validity* refers to how widely the findings can be generalised (Aday and Cornelius, 2006). Systematic dropout is a threat to external validity, and the reminder procedure as well as the analysis for internal dropout revealed it to be systematic. This should be taken into consideration when interpreting the results. The study may have missed those who were the most strained as well as the oldest and least educated. Furthermore, the high educational profile and the disproportionate percentage of health care professionals among the relatives constitute a threat to external validity. Among the Danish population 3.9 % hold a university degree, 4.2 % hold a high school diploma, and health care professionals make up 2.9 % (Denmark's Statistics, 2006). Hence, the educational profile in this study was seemingly not representative of the population and arose possibly due to the university hospital being located in one of Denmark's wealthiest municipalities. This was the first application of a new measure and should be considered exploratory. A study on a larger sample, reflecting the target population with a revised, and possibly shorter, version of the questionnaire, is warranted.

Discussion of findings

Collaboration
The factor analysis (Paper III) indicated collaboration to be a multidimensional construct. This is in accordance with the model developed from the literature, which hypothesised collaboration to be based on contact and relationship qualities, using communication as the vehicle and, thus, involving dimensions other than collaboration per se. Whereas influence on decisions and exchange of knowledge and information reflected the key attributes of collaboration, contact and relationship qualities reflected prerequisites for collaboration. Hence, only a part of the instrument measured collaboration as such, and this part may well be applied separately when only this is of interest, for instance for quality assessment purposes.

The findings in the survey study (Paper IV) indicated the quality in the dimensions to be different. The key attributes of collaboration, i.e. influence and exchange of information and knowledge, rather than the contact and relationship quality, appeared to be problematic. This was apparent in the high factor means and the percentage rating negative in the factor mainly reflecting the key attributes: "Influence on decisions". The factor "Influence on discharge" further reflected the key attributes of collaboration and, though slightly better, showed poor ratings on the items concerning influence on, and information about, decisions. Despite this the majority of relatives seemingly found the plans after discharge agreeable and the provision of help after discharge sufficient. The assumption in this thesis was that relatives should have influence on decisions. However, only half of the participants wanted influence on hospital care, and while few reported to have had it, half of the participants were satisfied with the overall influence they had on decisions made during the hospital stay. Thus, the existence of two groups of relatives was indicated: one consisting of relatives who wanted influence on decisions and one consisting of those who did not. This is interesting as almost all respondents reported feeling a high degree of responsibility, in relation to both the elderly person's well-being and him/her getting sufficient formal help. Possibly for some relatives this responsibility was related to the situation at home, while others carried the responsibility into the hospital situation as well. This finding seemingly adds new aspects to existing literature, which appears to be based on the assumption that relatives in general want to be involved in the in-hospital care for elderly patients (e.g. Laitinen and Isola, 1996, Li et al., 2000). Relatives are seemingly a heterogeneous group, and there is a challenge for nurses to establish collaboration with both groups for putting to use the knowledge they hold, for the benefit of the patient and the hospital care trajectory.

Information was seemingly in general a weak point. Apart from the ratings of information items in other factor dimensions, this was indicated in the factor "Achieved information level" consisting of items which may be seen as outcome of collaboration. In particular the ratings of information level about how best to help the elderly person in the future, and of unmet needs for training, indicated a large proportion of the relatives to lack skills or knowledge in relation to the care responsibility. This is in accordance with findings in other studies (Andershed, 2006, Rogers et al., 2000). Andershed (2006) found in a review of literature (n = 93) on relatives in end-of-life care conducted in 11 countries that need for information was a main theme, and that information was needed about the patient's

condition in order to know what to expect and better be able to make plans. Moreover, it constituted the basis for relatives to better function as caregivers, and was a prerequisite for their meaningful involvement. The literature review further found information to be insufficient in many studies.

Mean scores for factors covering prerequisites for collaboration, i.e. contact, communication and relationship qualities indicated that relatives were more satisfied in these areas, although standard deviations indicated large variation. The relationship qualities were seemingly good, judging from the ratings of trust and respect, whilst the accessibility of nurses was more problematic. However, scores in the factor "Trust and its prerequisites" indicated two problematic areas related to trust: the environment, and that the nurses were too busy. This supports Rogers et al (2000) who found that relatives acknowledged nurse shortage and resource limitations as justification for nurses' apparent lack of care. However, dissatisfaction with care entailed the need in relatives to be present at the hospital to ensure the patient's care needs were met. Further, environmental factors were important, and dirty and unhygienic hospital interior caused concern (Rogers et al., 2000).

A discrepancy in role expectations was indicated, and these expectations appeared not to be clarified between the two parties. The nurses (Paper II) appeared to have a set of role expectations for relatives, indicating the subordinate role of a passive recipient of information about decisions and plans already made by the staff. This was indicated in the sub-theme *The unwritten rules*. Relatives who did not obey these rules were seemingly considered demanding and unrealistic, and the nurses would avoid them or adopt a dismissive way of communicating to cut short the encounter. However, some relatives seemingly continued to feel responsible for care after admission and wanted influence on decisions (Paper I). They assumed a supervising role to safeguard the elderly person and ensure the quality of care, indicating a superior or managerial position in relation to the staff. This was indicated in the essence *Standing Guard* and the constituent *Watchdog and case manager*. Whether these relatives were the ones the nurses considered demanding might be an interesting subject for future research. If some relatives cannot relinquish their responsibility for the care and control and watch over the care provided by nurses, and nurses do not involve them, because they consider them unrealistic and demanding, as indicated in the sub theme *The new relatives – the demanding and unrealistic relatives,* a struggle for control or power over the care may arise. Speaking against this was that ratings in the items reflecting contact and relationship qualities were fairly positive, and that few relatives reported to have been rejected by the nurses. However, other studies have found indications of struggle for control in the interaction between relatives and health care providers (Allen, 2000, Hupcey, 1998, Lynn-McHale and Deatrick, 2000). Allen (2000) found indications of a power struggle and that nurses and relatives with care responsibility challenged each other's control over the care process. Hupcey (1998) found that nurses and families displayed attempts to control when lacking trust in each other. Nurses would disagree in family decisions, question their intentions and complain about the family. Relatives would adopt a demanding behaviour, monitor the patient and nurses' actions and refuse to leave the patient. Seemingly, the struggle for control over care is related to distrust and Lynn-MacHale & Deatric (2000) found that trust was threatened when expectations were not met and relatives and health care providers had conflicting

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perspectives. Literature on the creation of problem patients is extensive and discloses similarities to the findings in this thesis (e.g. Corley and Goren, 1998, Trexler, 1996, Wright and Morgan, 1990). Wright & Morgan (1990) in their observational study as well as Corley and Goren (1998) in their literature study found that patients who violated institutional expectations were stigmatised as "problem patients". The discrepancy in role expectations may affect the encounter, as the meaning the two parties attach to the situation is likely to govern their conduct and reactions. Personal beliefs and perceptions are micro level determinants for the encounter, and are thus important prerequisites for collaboration (Rolland, 1994, Wright and Morgan, 1990). However, macro level factors such as societal and institutional values, as well as the organisation of care, may also determine the level of collaboration.

Micro level factors – Beliefs and perceptions

The relatives

Emotions presumably play an important role in the collaboration between relatives and nurses, as they are part of the relatives' beliefs and perceptions (Rolland, 1994). Hospitalisation of the elderly person constituted a time of crisis and possible transition for the relatives as indicated in the constituent *My God is it now?* (Paper I). Guilt and powerlessness were reflected in the constituents *It is always in the back of my mind* and *Powerless*, and these sentiments were further reported by half of the participants in the survey study (Paper IV). In the interview study, guilt and powerlessness were seemingly related to inability to remedy the elderly person's suffering. In the survey study the two items *Feeling guilty towards the elderly relative* and *Feeling of not doing enough* were strongly correlated, thus supporting this interpretation. Further, guilt and powerlessness were predictors for low satisfaction with the hospital care trajectory. Although such feelings may well signify the relatives' situation before entering the hospital, they seemingly also affected the experience of the hospital care, possibly entailing a special need for collaboration. Powerlessness and guilt have earlier been described in relation to relatives and appear to be common aspects of care giving (e.g. Loos and Bowd, 1997, Milberg et al., 2004, Samuelsson et al., 2001). In this literature guilt was linked to the feeling of not doing enough and the difficulties relatives may experience in keeping a balance between the time and energy spent on care giving activities and other responsibilities. However, both Mok et al (2003) among relatives of terminally ill cancer patients (n = 24), and Gililand & Fleming (1998) among spouses of chronically ill persons (n = 62), found that witnessing the sick relative suffer entailed pain and guilt feelings in the caregivers over not being able to reduce the suffering and prevent death. This is seemingly similar to the feelings and reactions relatives of frail elderly patients may have. Van Manen (2002) described care as a burden of worry and responsibility, and an existential claim the other has on one. Not being able to answer this claim may induce feelings of pain and guilt. The constellation of feeling responsible and inadequate in executing this responsibility may be the source of the powerlessness and guilt found in this thesis. Caring relatives who feel inadequate may turn to others for help in relieving the patient's suffering (Milberg et al., 2004), in this study possibly to the health care professionals at the hospital. If hopes or expectations are disappointed it is conceivable that relatives may feel dissatisfied with the care, hence, the association between guilt, powerlessness and satisfaction with the care

trajectory. Interestingly, half of the respondents reported seldom or never experiencing powerlessness and guilt, indicating that relatives have varied experiences and needs, all of which will affect the beliefs and perceptions with which relatives enter the collaborative encounter. More research is needed into the differences between relatives who experience powerless and guilt and those who do not to build a knowledge base for nursing directed at collaboration with relatives.

The relationship and care history was a main essence *(The History)* in the interview study and unsolved issues may be part of the belief system relatives bring into the collaboration encounter. The care situation seemingly evoked early relational patterns among the adult children participating in the interviews. This is in accordance with Whitbeck, Hoyt and Tyler (2001) who found that family roles, identities and interaction styles might, when established early in life, emerge when the family is in crisis. They further found that early perceived parental rejection affected adult children's provision of support to the elderly parent. Although the relatives participating in this thesis felt responsible for the elderly person's well-being and provided extensive help, it is possible that this was provided not only out of love but also from obligation, and that relationship issues may have entailed emotional reactions such as guilt. Both May et al (2001) and Allen (2000) found that the emotionally charged atmosphere may influence the interaction between caring relatives and health care professionals, thus it may be helpful for nurses who care for elderly patients to realize that they enter the realm of the family and an emotionally charged environment. Acknowledging the responsibility relatives of frail elderly patients feel, and involving them accordingly as collaborative partners may prepare the ground for a trusting relationship which might benefit the patient and the relatives, and possibly reduce their emotional distress.

The nurses

The nurses were subject to dual attitudes concerning relatives and the collaboration with them (Paper II). The main theme *Encountering relatives – to be caught between ideals and practice* reflected the nurses' two sets of conflicting attitudes: one in accordance with professional nursing values and one reflecting the values of every day practice. This is in accordance with the findings of Walker & Dewar (2001) and Hertzberg et al (2003) who found that, though ideally described as a resource for improving quality of care, relatives were considered demanding and time consuming, and in practice the nurses rarely involved them. The nurses (Paper II) seemingly lacked confidence when encountering relatives, possibly due to insufficient knowledge about the patients. The sub theme *A matter of prioritising* presented the organisation of care as a problem as it did not support continuity and left the nurses unprepared when encountering relatives. This is in accordance with Wright & Morgan (1990) who found that organisation of care had an impact on the nurse-patient interaction as it was organised to meet the needs of the system rather than the patient. Implementation of continuity-promoting organisation of care may improve nurses' knowledge about their patients, and leave them better prepared when encountering relatives. Some relatives were perceived as unrealistic, but if nurses had little knowledge about the patient, it is conceivable that "unrealistic" relatives base their definition of the situation on knowledge the nurses do not have. Both the interview study with nurses and the survey study among relatives (Paper IV) indicated that nurses did not

assess relatives' knowledge. A structured procedure for assessment of the patients' needs at admission and in relation to discharge planning, routinely involving relatives, may increase nurses' possibilities for acquiring a comprehensive knowledge about their patients, and for clarifying and attuning the expectations in relation to care and treatment.

The nurses reported competence to be an important factor for establishing collaboration (Paper II). Although the nurses were capable of describing the ideal way to deal with relatives as well as the means to attain collaboration, they seemingly lacked the ability to translate theory into practice. Thus, nursing education may provide ideal intentions but perhaps not the practical tools for collaboration. Specific standards for systematic collaboration in practice and in-clinic training may remedy this. Communication skills are important prerequisites for collaboration (Paper III). The nurse-relative encounter seemed in the interview study (Paper II) complicated by a negative circle of communication, where the nurses responded in a dismissive way to relatives they considered demanding or difficult. This response is likely to be noticed by the relatives, and will presumably increase their frustration and affect their responding behaviour. The findings in the survey study (Paper IV) showed the majority of participants to be satisfied with the quality of contact with nurses, with only a few reporting that nurses had rejected them. However, more than one third rated negatively in the items: *I was satisfied with the extent of contact with nurses* and *I was satisfied with the quality of contact with nurses*. This may indicate the communication pattern described in the interviews with nurses. The nurses interpreted the demanding relatives' conduct as a sign of crisis but also as disrespect, however, the interpretation was not verified by the relatives. Verification of interpretation and clarification of expectations are prerequisites for successful communication. Podrasky & Sexton (1988) as well as Hertzberg et al (2003) found that nurses did not validate their interpretation in relation to "problem" patients' "difficult" behaviour respectively relatives' vague communication. Increasing nurses' communication skills may enhance possibilities for establishing successful collaboration with relatives.

Macro level factors – Organisational value systems

Although nurses' professional values are in accordance with the assumptions on which collaboration is based, it takes place in an organisation where other values and assumptions may dominate and influence nurses' behaviour and beliefs (Olson, 1995, Wright and Morgan, 1990). Corley & Goren (1998) argued that nurse behaviours, apart from educative values, mirror their practice related socialisation and the ruling macro level values. A discrepancy between nursing ideals and nursing practice has been shown in earlier research and linked to moral distress and burn-out among nurses (Allen, 2004, Jameton, 1993, Olson, 1998). The current economical and political focus on increased productivity emphasises rapid patient turnover and reduction in costs; it awards measurable endpoints not easily met in soft areas of nursing such as collaboration and involvement of patients' social context. Moreover, hospitals are traditionally subject to the assumptions and values of medical tradition (Pursey and Luker, 1995, Reed and Watson, 1994). The nurses in this thesis put forward time-pressure and giving medical tasks priority as major barriers to collaboration with relatives in accordance with professional nursing values. Both Reed & Watson (1994) and Pursey & Luker (1995) found that the medical model, with its focus on diagnosing and treating disease with the goal of curing it,

was a central framework for nurses' perception of their role and organisation of their work. The medical model is a high value system in the health care system as well as in society in general and as such possibly holds a higher status in the hospital context than the model of the nursing profession. Thus, it may be difficult for the focus and goals of nursing to compete with those of the medical model.

The escape-avoidance behaviour reported by the nurses resembled classic stress responses and may be a sign of moral dilemma due to the value conflict (Allen, 2004, Jameton, 1993, Olson, 1998). The nurses in study II did not reflect upon the discrepancy between focuses and values, hence they may be unaware of the moral conflict. When unconscious about a moral dilemma and being powerless in relation to the institutional constraints, it is possible that reaction is turned towards the one who evokes it, in this case the relative (O'Kelly, 1998). The labelling of some relatives as difficult or demanding may be seen as a sign of counter transference. O'Kelly (1998) found in a literature review on counter transference that patients with non-compliant conduct evoked anger and powerlessness in nurses. By creating a collective labelling, the nurses seemingly projected the problem onto this group of patients, who then became "the villains". As long as this process remains unconscious, nurses may be unable to change or prevent it. Reflections over practice and clinical supervision may enhance the level of consciousness in nurses, and have been shown to have an effect on nurse-patient collaboration (Edberg and Hallberg, 1996). Nurse leaders play an important role in creating conditions for nursing practice at the local level; their attention and action is particularly important, when trying to overcome the conflicts of values in nurses' everyday practice. When the focus, goals and ethical obligations of nursing tend to be of low priority in the hospital environment, it is important that leaders of nursing reward – and raise a demand for – nursing activity that reflect these focuses, goals and obligations.

Figure 5 illustrates, based on interpretation of findings, factors seemingly constituting conditions for the collaboration between relatives and nurses in acute hospital wards.

Figure 5   Micro- and macro level factors, and promoting factors for collaboration
            between relatives and nurses in acute hospital wards
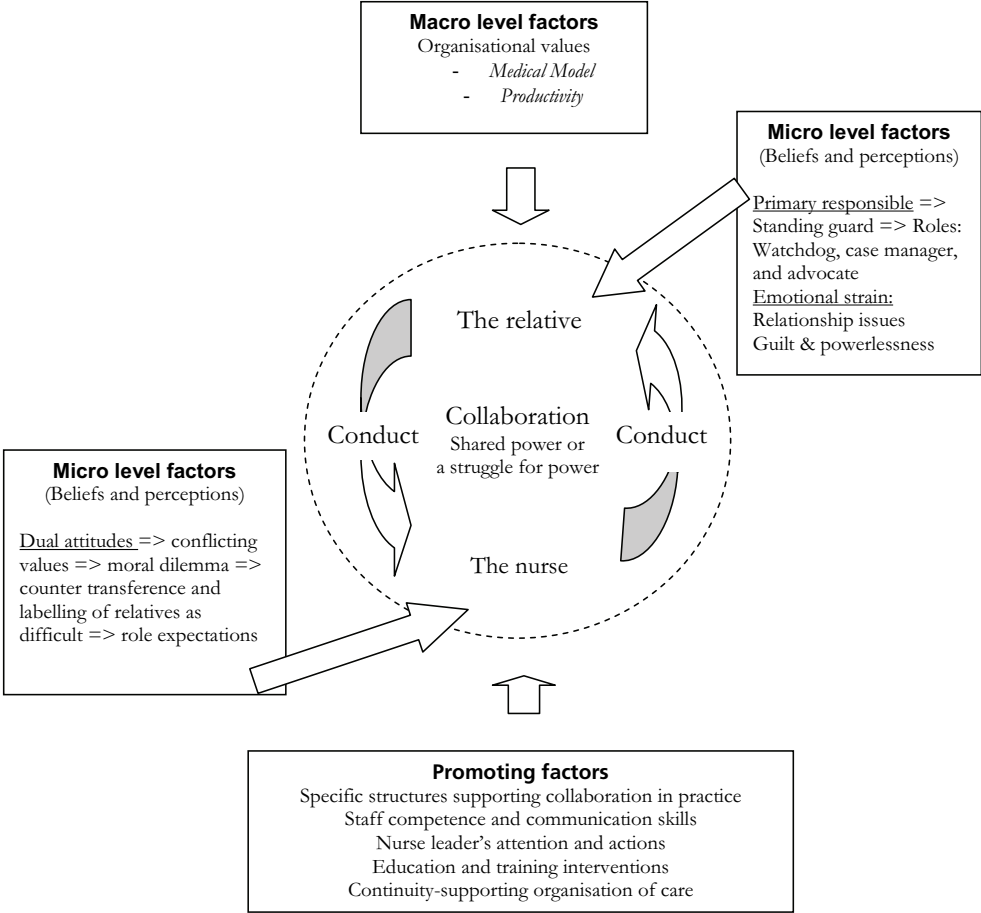
Collaboration and satisfaction with the care trajectory

As the study design was cross-sectional, only interpretations about associations, and not
about causal relationships, can be made between collaboration and satisfaction. However,
relatives who felt involved in collaboration with nurses were seemingly more satisfied
with the care trajectory than those who did not. Significant differences were found in
means for all five factor dimensions among those who reported to be satisfied and those
who did not, in relation to the trajectory during the stay and the discharge phase. In
relation to the admission phase this was the case for only two factors "Trust and its
prerequisites" and "Quality of contact with nurses". However, satisfaction with the

admission phase may reflect not only the hospital experience, but also the time leading up to admission. Furthermore, the logistic regression analyses showed four of the factor dimensions to be significantly associated with satisfaction: "Influence on decisions", "Trust and its prerequisites", Achieved information level" and "Influence on discharge". These factors may well be connected to each other, being satisfied with information and influence contributing to trust. Involving relatives in decisions and ensuring sufficient exchange of information may further be prerequisites for their satisfaction with the care trajectory. This study supports others who have found involvement of relatives in decisions regarding care to be a prerequisite for quality care (Harvath et al., 1994, Lundh et al., 2003, Voutilainen et al., 2006). In relation to long term care Voutilainen et al (2006) found associations between family members' (n = 474) opportunity to participate in decision-making and their ratings of quality of care. Lundh et al (2003) found among formal (n = 200) and informal carers (n = 200) in dementia care that according to both parties, quality care was characterised by collaboration between them. Being involved as collaborative partners is seemingly important for relatives' perception of care quality across contexts. Furthermore, trust was associated with satisfaction and may reflect the relative's disposition to relinquish responsibility and entrust it to the professionals. When a patient is subject to an unplanned admission, s/he may be in a critical state of acute illness. In this state the responsibility for care is handed over to professionals, and, for relatives who have cared for the elderly person until then, trust is likely to be crucial. In a literature review including 16 studies on parents' experiences with health care providers, Dixon (1996) found trust to be a central issue, along with information gathering, and participation in care and decision-making. The care responsibility of a parent and that of a relative of a frail elderly patient seem to have similarities in that sense. As relatives of frail elderly people are likely to feel responsible for care, involvement of them and their specialised knowledge of the patient in decision-making processes from admission to discharge may not only increase their satisfaction but also make them more confident in entrusting care to hospital nurses.

The findings in this thesis indicate that there is room for improvement in relation to collaboration between relatives of elderly patients and nurses in acute hospital wards. The findings further indicate that improvement of collaboration may entail increased satisfaction among relatives with the hospital care trajectory. Although the nurses could be seen as mere victims of conflicting values, there appeared to be potential for improving collaboration practice within the restrictions of macro level factors by interventions at the micro and local level by establishing structures and procedures that will support collaboration.

CONCLUSIONS

- The findings in this study indicated collaboration between relatives of frail elderly patients and nurses in acute hospital wards to be rare

- The findings indicated collaboration to be associated with relative's satisfaction with the hospital care, thus supporting the hypothesis that, in the case of frail elderly patients in acute care settings, collaboration between nurses and relatives is relevant and beneficial

- There was support for the assumption that collaboration is a multi dimensional construct, characterised by shared decision-making and exchange of knowledge and information, with prerequisites such as quality of the relationship, trust and respect, quality of contact and communication.

- Hospitalisation represented a time of crisis for the relatives. Feelings, roles, relationship issues and experiences were brought into the hospital setting and formed the basis for the relatives' expectations, values and conduct there. Powerlessness and guilt feelings were prominent and were determinants for satisfaction with the care trajectory.

- Two groups of relatives were indicated: one, who continued to feel responsible for care after the admission, another, who seemingly did not. While some were subject to feelings of powerlessness and guilt, others were not. Whether it was the same relatives who felt responsible in the hospital situation who also experienced powerlessness and guilt has yet to be investigated, however, relatives appeared to be a heterogeneous group with different needs.

- The text revealed two conflicting sets of attitudes among nurses towards relatives and the collaboration with them: one set was in accordance with their professional nursing values while the other seemingly governed collaboration in practice. The nurses appeared unconscious about and, thus, powerless in relation to, the value conflict.

- A discrepancy between expectations was indicated. Relatives felt responsible and provided extensive help. However, some entrusted care to the professionals, while others continued to feel primarily responsibility for care in the hospital situation. The nurses, in contrast, seemingly rarely involved relatives and categorised them into two groups: the easy and the demanding ones, with the expected role of relatives seemingly being as passive recipients of information. Relatives deviating from this role may be labelled as difficult and avoided.

- Hindering and promoting conditions for collaboration were time pressure, medical focus, organisation of care, and nurses' competence level.

FURTHER RESEARCH

The findings in the studies in this thesis gave rise to new questions and hypotheses, which may be investigated in future studies.

- Studies investigating the relationship between powerlessness, guilt, feeling responsible for the in-hospital care and wanting influence on decisions.
- Studies investigating characteristics of relatives nurses find demanding.
- Intervention studies investigating the effects of enhanced collaboration on powerlessness and guilt in relatives.
- Further testing of the survey instrument after a reduction of items carried out in a variety of populations and contexts to investigate its dimensions, and the boundaries for its use. Designs and sample sizes adequate for testing criterion validity, instrument stability and draw conclusions about outcome should be applied. Translation of the instrument and testing in other countries seems warranted, as there appears to be a lack of such instruments.
- Studies focusing on improving collaboration between relatives and nurses. This may involve development of a model for collaboration in practice and testing the effect of this. Such a model might involve adjusting the micro level factors and a standard for systematic collaboration as suggested in the discussion.

SUMMARY IN DANISH
Populærvidenskabelig sammenfatning

Denne afhandling beskriver fire forskningsarbejder og omhandler samspillet mellem pårørende til svækkede ældre patienter og plejepersonalet i hospitalsafdelinger. Med svækkede menes, at personen er afhængig af hjælp i hverdagen fra hjemmeplejen og familie eller venner. Antagelsen bag forskningsarbejdet er, at pårørende ofte er involveret i omsorgen for den ældre og dermed er en vigtig samarbejdspartner for sundhedspersonalet. Disse pårørende har ofte indgående kendskab til patientens tilstand, sundhedsproblemer og muligheder for at klare hverdagen i hjemmet, og denne viden er værdifuld for hospitalspersonalet, specielt når de skal vurdere patientens behov for pleje og behandling med henblik på at få tilrettelagt en relevant plan for indsatsen på sygehuset og i tiden efter udskrivelsen. Afhandlingens overordnede formål har været at undersøge samspillet som det opleves af pårørende og plejepersonalet, samt forudsætningerne for dette samspil og dets eventuelle effekt. Samspil mellem pårørende og plejepersonalet er kun undersøgt i begrænset omfang, når det gælder svækkede ældre patienter i akutte hospitalsafdelinger. Da det samtidigt er kendt, at hospitalsforløbet for netop disse patienter ikke fungerer optimalt, og at de er specielt udsat for hurtigt at blive genindlagt, er der behov for at udforske områder med uudnyttede ressourcer, som muligvis ville kunne forbedre kvaliteten af plejen og patientforløbet. Pårørende kunne tænkes at være en sådan ressource.

Den første undersøgelse omfatter interview med 8 pårørende (en hustru, to sønner, en svigerdatter og fire døtre i alderen 40 til 71 år) til svækkede ældre patienter indlagt i medicinsk afdeling på et universitetssygehus. Formålet var at undersøge oplevelsen at være pårørende til en svækket, ældre patient, som bliver akut indlagt på sygehus. To hovedtræk karakteriserede de pårørendes oplevelse: Den historie som de pårørende og patienten havde med sig, samt "at stå vagt" for den ældre i mødet med sundhedssystemet. Indlæggelsen bragte døden og det kommende tab frem i de pårørendes opmærksomhed. Det satte dem i alarmberedskab, og man kunne betegne den akutte indlæggelse som en krisesituation for dem. Hvor alle følte sig ansvarlige for at stå vagt om og beskytte den ældre for at sikre denne tilstrækkelig pleje, når det gjaldt situationen i hjemmet, fortsatte en del af de pårørende med at føle dette ansvar på hospitalet. Denne del af de pårørende følte sig magtesløse i mødet med sygehusvæsenet og påtog sig roller som "vagthund", "forløbsansvarlig" og "patientens advokat" for at sikre patienten tilstrækkelig og god pleje. De var bestandigt på vagt og ude af stand til at slappe af. De overvågede personalet og udførte selv plejen, hvor de syntes personalet svigtede. En anden gruppe af pårørende, derimod, overlod trygt ansvaret til sygehuspersonalet og syntes at få en slags aflastning, mens den ældre var indlagt. Det var ikke muligt at påvise andre forskelle mellem de to grupper af pårørende, og det bør udforskes nærmere, hvilke forudsætninger og karakteristika, som kan lede til at pårørende henholdsvis føler eller ikke føler sig ansvarlige for plejen i sygehussituationen. De involverede parters historie med alle dets følelser, roller og erfaringer var centralt i fortællingerne og blev bragt med ind i situationen på hospitalet, hvor den påvirkede de pårørendes forventninger, værdier og adfærd. Specielt blandt de voksne børn fyldte tankerne om forholdet til den ældre far eller mor meget, og mønstre grundlagt helt tilbage i barndommen havde indflydelse på, hvordan de reagerede og handlede i den nuværende situation. Uanset hvordan forholdet havde været, kom man

til hjælp, også, hvor forholdet var distanceret og præget af svigt. For nogen viste det sig endda at være en mulighed for forsoning. Deltagerne hjalp i gennemsnit 8 timer om ugen (fra 3 – 25 timer), og her er de to pårørende ikke medregnet, som boede sammen med den ældre og derfor hjalp væsentligt mere. Alligevel havde de følelsen af ikke at gøre nok. Sorg, bekymring og skyldfølelse blev udtrykt og var relateret til magtesløsheden overfor den ældres fremskridende svækkelse, men også til den ensomhed og elendighed, de oplevede, den ældres liv alene i eget hjem var præget af. Det kan være en hjælp for plejepersonalet at vide, at de, når de plejer svækkede ældre patienter, træder ind på familiens arena med alle de følelser, der eksisterer dér. Endvidere at det er sandsynligt, at pårørende, de møder i den forbindelse, er i krise og føler sig ansvarlige for den ældres velbefindende og for, at denne får den nødvendige pleje og behandling. De vil muligvis have behov for, at personalet anerkender dette ansvar og involverer dem i beslutningsprocesserne omkring den ældres pleje og behandling, hvilket sandsynligvis også vil kunne gavne patientforløbet.

Den anden undersøgelse omfattede interview med 6 sygeplejersker og 2 social- og sundhedsassistenter, som var ansvarlige for udskrivelsen af de patienter, hvis pårørende deltog i det første interviewstudie. Formålet var at undersøge sygeplejerskers oplevelse af samspillet med pårørende til svækkede ældre patienter samt fremmende og hindrende faktorer for et godt samspil. Hovedtemaet blev kaldt "Mødet med pårørende – at være fanget mellem idealer og praksis" og afspejlede deltagernes to sæt holdninger i forhold til samspillet med pårørende: ét sæt ideelle, som var i overensstemmelse med fagets etiske og faglige værdier og ét sæt, som afspejlende de værdier der øjensynligt styrede deres praksis. De to sæt holdninger var i konflikt med hinanden, men deltagerne virkede ubevidste om denne værdikonflikt. Ideelt blev samspil med pårørende betragtet som både ønskværdigt og nødvendigt, og noget, som burde være en struktureret og planlagt proces; men deltagerne beskrev samspillet, som det fungerede i praksis, som et tilfældigt møde, og det kom mest i stand på de pårørendes initiativ. Pårørende blev ideelt betragtet som en ressource, men når praksis blev beskrevet fremstod to grupper af pårørende: de nemme og de krævende. De nemme delte personalets forståelse af situationen, mens de krævende var uenige og stillede spørgsmålstegn ved denne. I de tilfælde, hvor man anså pårørende som krævende, undgik man dem, hvis man kunne. Godt samspil afhang tilsyneladende af den pårørendes karakteristika: eksempelvis havde pårørende, som oplevedes som "nemme" og "realistiske", større sandsynlighed for at blive involveret af plejepersonalet. På trods af, at deltagerne var i stand til at beskrive det ideelle samspil og dettes formål, blev samspil sidestillet med formidling af information, med det formål at undgå klager. Selvom pårørendes viden blev beskrevet som vigtigt for plejens og forløbets kvalitet blev den tilsyneladende ikke aktivt søgt inddraget. Deltagerne havde ikke haft nogen kontakt med pårørende til de patienter, de havde haft ansvaret for at udskrive, og rapporterede ingen eller kun lidt viden om, hvordan disse patienter havde klaret sig før indlæggelsen. Selvom deltagerne udtrykte stor forståelse for pårørende, herskede der tilsyneladende i praksis et sæt uskrevne regler for pårørende. I stedet for rollen som samarbejdspartnere, indikerede disse regler en underordnet rolle for pårørende som passive modtagere af information om de beslutninger, personalet havde truffet. Ideelt var deltagerne imod at stille regler op for pårørende, men ikke desto mindre blev de pårørende forventet at underordne sig personalets forventninger og rutiner. Dette indebar for eksempel at vide hvornår, og i hvor lang tid, man kunne tillade sig at forstyrre sygeplejersken, hvilke typer

af spørgsmål det blev anset passende for pårørende at stille, samt hvornår man kunne tillade sig at gå ind på sygestuen. De "nemme" pårørende formåede at holde sig indenfor rammerne af de uskrevne regler, men det gjorde de krævende ikke. Faktorer på makroniveau, så som de herskende værdier i samfundet og organisationen, og på mikroniveau, så som organisering af plejen, personalets kompetence og kommunikationsfærdigheder samt lederens holdning, så ud til at kunne fremme eller hindre plejepersonalets samspil med pårørende. Selv om plejepersonalet tilsyneladende kunne fremstå som magtesløse ofre for en værdikonflikt, var der et vist potentiale for forbedring af praksis for samspil med pårørende på mikroniveau, indenfor rammerne af faktorerne på makroniveau. Dette kunne være:

- At indføre en standard for inddragelsen af pårørende, som angiver strukturen for hvornår og hvordan dette skal ske
- At forbedre kontinuiteten ved at organisere plejen på en måde, så kendskabet til den enkelte patient bliver bedre
- At gennemføre kompetenceudvikling af personalet, med henblik på bl.a. forbedring af kommunikativ viden og færdigheder
- At indføre refleksion eller supervision i praksis over dilemmaer i plejen
- At den ledende sygeplejerske aktivt efterspørger og skaber vilkår for en praksis i overensstemmelse med værdierne i god sygepleje

Af de to første studier opstod hypoteser og spørgsmål, som var vigtige at undersøge blandt et større antal pårørende. Derfor blev der i 3. delstudie udviklet et spørgeskema til at undersøgelse samspillet set fra de pårørendes synspunkt. Spørgeskemaet bestod af 72 spørgsmål om følgende temaer:

1. Pårørendes indflydelse på beslutninger; udvekslingen af viden og information mellem pårørende og plejepersonalet, samt pårørendes roller og aktiviteter på sygehuset
2. Kontakt og kommunikation med personalet samt kvaliteten af relationen til dem
3. Pårørendes tilfredshed; deres enighed med personalet om patientens pleje og behandling; deres informationsniveau samt deres vurdering af patientforløbet
4. Pårørendes oplevelse af fejl og mangler i plejen; af personalets holdninger, tilgængelighed og arbejdspres; af de fysiske omgivelser samt deres kendskab til afdelingens besøgspolitik

Dertil kom spørgsmål om ansvar, aktiviteter og følelsesmæssige konsekvenser i relation til deres omsorg for den ældre pårørende. Spørgeskemaet blev i udviklingsfasen testet af pårørende ved geriatriske afdelinger samt et ekspertpanel af doktorander ved Lunds Universitet med speciel indsigt i ældreforskning. Skemaet undergik herefter yderligere testning blandt 156 pårørende til svækkede ældre patienter i akutte afdelinger ved to hospitaler i Danmark. Forskellige statistiske analyser blev gennemført for at undersøge skemaets egnethed til at frembringe troværdige resultater. Spørgeskemaet viste sig at være velegnet til at undersøge pårørendes vurdering af samspillet, men bør efterprøves yderligere.

Resultatet viste at hvad samspillet angår , så indikerer de pårørendes besvarelser, at der er betydelig plads til forbedring. De fleste pårørende havde ingen eller kun lidt indflydelse haft på beslutninger, der blev truffet om deres syge pårørende, ligesom de heller ikke var blevet informeret om disse beslutninger. De blev sjældent eller aldrig spurgt om deres viden om patienten eller deres syn på de beslutninger, der skulle tages. Mange følte sig dårligt informeret om såvel pleje som behandling, og om hvordan de kunne hjælpe den ældre fremover. Kontakten, relationen og tilliden til plejepersonalet blev vurderet noget bedre, og her så det ud til at personalets tilgængelighed var det væsentligste problem, sammen med de fysiske rammer.

I det 4. studie var formålet at undersøge om der var sammenhæng mellem samspillets kvalitet og pårørendes tilfredshed med patientforløbets faser (indlæggelsen, forløbet i afdelingen og udskrivelsen). Dette studie omfattede de samme 156 pårørende som medvirkede i 3. delstudie og samme spørgeskema blev anvendt. De pårørende, der rapporterede enten høj eller lav tilfredshed med indlæggelsesforløbet, blev sammenlignet for at undersøge om de adskilte sig fra hinanden med hensyn til f.eks. køn, alder, tilknytningsforhold til den ældre patient, uddannelsesmæssig baggrund osv., samt med hensyn til deres omsorg for den ældre patient. Endvidere blev de sammenlignet med hensyn til, hvordan de havde scoret samspillet. Resultaterne viste, at deltagerne overvejende var kvinder (74,8 %), voksne børn af patienten (63,9 %) og 60,8 år i gennemsnit. Ægtefæller udgjorde 20 %. Næsten alle (95,4 %) hjalp den ældre patient i hverdagen, 40,9 % hver dag og 83,1 % 2 gange eller mere om ugen. 82,1 % havde hjulpet mere end 2 år og 49,3% mere end 5 år. Antal timers hjælp om ugen spredte sig mellem 0 – 99 timer med et gennemsnit på 8,81. Ansvarsfølelsen blandt de pårørende var udbredt og stærk, idet 99,4 % følte ansvar i høj grad for den ældres velbefindende, og 96,1 % følte i høj grad ansvar for, at den ældre fik tilstrækkelig offentlig hjælp. At det ikke var uden omkostninger fremgik af, at 53,3 % rapporterede, at de ofte eller meget ofte følte sig magtesløse overfor den ældres situation og på trods af den store omsorgsaktivitet, rapporterede 44,8 % at de ofte eller meget ofte følte skyld, og at de ikke syntes, de gjorde tilstrækkeligt for deres ældre pårørende. Tilsyneladende fortsatte nogle med at føle ansvar for deres ældre pårørende også på hospitalet, idet 38,8 % rapporterede, at de stadig var nødt til at sikre, at patienten fik den nødvendige pleje, mens kun 40,7 % oplevede opholdet som en aflastning for ansvar. Hele 68,2 % af de pårørende svarede, at det var deres ansvar at sikre patientens interesser omkring planerne efter udskrivelsen. Mens 49,4 % ønskede indflydelse på de beslutninger, der skulle tages, var 50,3 % tilfredse med den indflydelse de fik.. Ligesom i de to interviewstudier, ser der således ud til at være to grupper af pårørende. En, som følte skyld og magtesløshed, mens den anden ikke gjorde; og en, som ønskede indflydelse på beslutninger, der skulle tages, mens den anden ikke gjorde.

Kvaliteten af samspillet var bestemmende for deltagernes tilfredshed med patientforløbet, og de som svarede at samspillet var dårligt var mindre tilfredse, end de som scorede det som godt. Desuden var skyldfølelse, magtesløshed og det at være ny i omsorgsrollen bestemmende for tilfredsheden.
Pårørende som oftere var utilfredse med *forløbet ved indlæggelsen*:
- havde en sundhedsuddannelse
- følte sig magtesløse

- følte skyld

Pårørende som oftere var utilfredse med *forløbet i afdelingen*:
- var kvinder
- havde hjulpet den ældre i mindre end ét år
- følte sig magtesløse
- følte skyld

Pårørende som oftere var utilfredse med *forløbet ved udskrivelsen*.:
- gav psykisk støtte
- hjalp den ældre pårørende med at opretholde sociale forbindelser
- gav praktisk hjælp
- følte sig magtesløse
- følte skyld.

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Appendix I

Interviewguide - Pårørende til svage ældre

Fænomenet:

Jeg er interesseret i at høre om, hvordan det er at være pårørende til en svækket ældre, der bor i eget hjem. Kan du fortælle mig om, hvordan du oplever det?

Barnets/ægtefællens/vennes osv. perspektiv i form af følelser. Hvilke følelser har datteren/svigerdatteren/ægtefællen osv. i forhold til at opleve sin /mor/svigerfar/osv. som svækket, hjælp-trængende ældre?

Hvordan oplever du din rolle? Rolle i forhold til hjemmeplejens rolle? Rolle her under indlæggelsen? (Hvad oplever du som din pligt at gøre for …)

Hvilke konsekvenser har den? (bekymringer, samvittighed, skyld, forholdet til den ældre, dilemmaer, kontroverser, interessekonflikter, problemløsninger, det givende)

Hvordan fungerer din hverdag med alle de andre aktiviteter og relationer man har? Påvirkes den af den rolle og de opgaver, du nu har i forhold til din…. (mor/far/ægtefælle/bedstemor/-far/ven/nabo/søster/bror). (begrænsninger?)

Er der noget, du ikke gør i øjeblikket, som du ville gøre, hvis ikke det var for dine opgaver i forhold til din ….

Mærker du nogle helbredsmæssige problemer hos dig selv?

Hvilke følelser/reaktioner har du?

Hvordan er jeres indbyrdes forhold? Har det ændret sig fra tidligere? (rolleforskydning, konflikter?)

Samspillet med de professionelle:

Under indlæggelsen:
Vil du fortælle mig, hvad er dine erfaringer med dette? ("er")
Hvilke ønsker har du i forhold til dette ("bør")?
Kan du pege på noget, som hindrer et godt samspil mellem dig og spl.?

Hvad tænker du om din inddragelse i beslutningsprocesserne? Bliver du inddraget i beslutningerne?
Lytter de til din viden om din ….? Har de bedt om oplysninger om din… ved indlæggelsen?
Får du tilstrækkeligt med informationer?
Føler du dig set og forstået?
Hvem tager initiativ til kontakten? (du eller spl./lægerne)
Efter din mening, hvad karakteriserer et godt samspil?
Hvad skal der til, tror du, for at det kan blive godt?/ Hvad er det, der gør, at det er godt?
Hvordan oplever du "trekanten" din…/dig/sygeplejersker og læger? (roller, "spil"?)

I forhold til hjemmeplejen:

Vil du fortælle mig, hvad er dine erfaringer med dette? ("er")

Hvilke ønsker har du i forhold til dette ("bør")?

Bliver du inddraget i beslutningerne?

Lytter de til din viden om din ….? Har de bedt om oplysninger om din… ved indlæggelsen?

Får du tilstrækkeligt med informationer?

Føler du dig set og forstået?

Hvem tager initiativ til kontakten? (du eller spl./lægerne)

Kan du pege på noget, som hindrer et godt samspil mellem dig og spl.?

Hvad skal der til, tror du, for at det kan blive godt?/ Hvad er det, der gør, at det er godt?

Hvordan oplever du "trekanten" din…/dig/sygeplejersker og læger? (roller, "spil"?)

Den ældres behov:

Hvad var det efter din mening, der bragte din …. ind på sygehuset denne gang?

Hvad bør der efter din mening gøres for din …. under denne indlæggelse?

Hvad skal der til for at undgå en hurtig genindlæggelse (evt. plejehjem)?

Og hvad skal der til for at din …. kan blive boende i eget hjem og klare sig?

Mener du, de tilbud/ydelser din …. har i hjemmet er tilstrækkelige? Hvis ikke: Hvad skal der til?

Har det nogen konsekvenser for dig? For din ….?

Ved interviewet efter udskrivelsen:

Hvordan var din oplevelse af indlæggelsesforløbet og udskrivningsforløbet (og af udskrivningskonferencen)?

Blev der afholdt en udskrivningskonference/hjemmeplejekonf.?

Deltog du i den? Hvis ikke, hvad mener du så om det?

I hvor høj grad følte du dig inddraget i beslutningsprocesserne
- under indlæggelsen (I høj grad, i nogen grad, i mindre grad, slet ikke)
- udskrivningsplanlægningen (I høj grad, i nogen grad, i mindre grad, slet ikke)

Blev problemet løst for din …. ?

Hvad har din …. brug for af hjælp fra kommunen efter udskrivelsen (Ingen, praktisk hjælp, personlig hjælp, social/psykisk støtte, overvågning, medicintagning, forbindsskiftning, andet)? Ikke som afkrydsning.

Har din…. fået den nødvendige hjælp?

Angående udskr.konf.: Hvad synes du om omgivelserne, den blev afholdt i? Hvilken betydning fik det?

Hvad synes du om "settingen"/rollefordelingen/påklædningen/placeringen andet?

Demografiske data

Alder

Køn

Relation til den ældre (barn, ægtefælle, nabo, ven etc.)

Samboende med den ældre

I arbejde   Hvis ja: fuld/deltid, jobtype

Uddannelse

Egen familiestatus (gift, hjemmeboende børn, børnebørn)

Afstand fra eget hjem til den ældre i km.

Den ældres alder:
Den ældres køn:

Grad af omsorgsforpligtelse

Hvor ofte: Mindre end 1 gang om ugen
              Ca. 1 gang om ugen
              2-3 gange om ugen
              4-6 gange om ugen
              Hver dag

Hvor mange timer om ugen?

Hvor længe har du hjulpet din… ?

Hvad hjælper du din …. med?
- Psykisk støtte, opmuntring
- Social støtte (bindeled)
- Transport
- Ledsager
- Indkøb
- Praktisk hjælp i hjemmet (Rengøring, tøjvask, reparationer, havearbejde)
- Administrativ hjælp (regnskab, bank, skattevæsenet, brevskrivning, kontakt med offentlige instanser)
- Personlig hjælp (toiletbesøg, bad, at vaske sig, hårvask, negleklipning, spisning, madning/drikke)
- Madlavning
- Madning
- At gå ture
- Medicintagning
- Forbindsskiftning
- Træning
- Andet
- 24 timers overvågning

Hvor mange timer kan du efterlade din …. uden opsyn? (Slet ikke, mindre end 2 timer, 2-5 timer, 6-12 timer, mere end 12 timer, ubegrænset)

Helbred:

Alt i alt, hvordan vil du sige dit helbred er:
- meget godt
- godt
- nogenlunde
- dårligt
- meget dårligt

Får du støtte fra nogen? (Venner, familie, hjemmeplejen, lægen, andre?)

Hvor tilfreds er du med støtten?

- meget tilfreds
- tilfreds
- nogenlunde tilfreds
- utilfreds
- meget utilfreds

Appendix II

Interviewguide – Sygeplejersken

Hvilken betydning mener du pårørende har for den ældres forløb og plejen - her og i al almindelighed? (hvor vigtig anser hun pårørende for at være for pt. og pt.s mulighed for at klare sig derhjemme og for kvaliteten af dette indlæggelsesforløb)?

Fortæl mig, om oplevelser du har med pårørende i plejen.
Hvordan du indtænker pårørende i dit arbejde?

Hvilke forventninger har du til pårørende og deres adfærd under indlæggelse og udskrivelse?

Hvordan burde det efter din mening være i dette tilfælde og generelt?
Hvordan var kontakten med denne pårørende?
Hvad har hindret det i at blive som det burde være?

Hvordan er holdningen til pårørende generelt i afdelingen?
Hvad synes du om udskrivningsplanlægningen?
Hvad synes du om udskrivningskonferencen?

Har du tænkt nærmere over den pårørendes rolle som omsorgsgiver til den ældre? Og hans/hendes
-   mulighed for at udfylde funktionen (viden, kræfter, evne, motivation)?
-   problemer med at udfylde funktionen og problemer på grund af den?
-   egne forventninger til sin indsats?

Struktureret skema

I Hvor høj grad vil du sige, at denne pårørende har været inddraget i beslutningsprocesserne?

Under indlæggelsen	Under udskrivningsplanlægningen
- I høj grad	- I høj grad
- I nogen grad	- I nogen grad
- I mindre grad	- I mindre grad
- Slet ikke	- Slet ikke

Hvad er din vurdering af den ældres behov for kommunale ydelser ved udskrivelsen?
-   Intet behov
-   Psykisk støtte, opmuntring
-   Social støtte (bindeled)
-   Transport
-   Ledsager
-   Indkøb
-   Praktisk hjælp i hjemmet (Rengøring, tøjvask, reparationer, havearbejde)
-   Administrativ hjælp (regnskab, bank, skattevæsenet, brevskrivning, kontakt med offentlige instanser)
-   Personlig hjælp (toiletbesøg, bad, at vaske sig, hårvask, negleklipning, spisning, madning/drikke)
-   Madlavning
-   Madning

- At gå ture
- Medicintagning
- Forbindsskiftning
- Træning
- Andet
- 24 timers overvågning

Hvor mange timer mener du, patienten kan være uden opsyn?
(Slet ikke, mindre end 2 timer, 2-5 timer, 6-12 timer, mere end 12 timer, ubegrænset)

Alder
- < 25 år
- 25 – 30 år
- 31 – 40 år
- 41 – 50 år
- > 51 år

År som sygeplejerske
- < 1 år
- 1 – 5 år
- 6 – 10 år
- > 10 år

Antal vagter med patienten

Viden om patienten (selvvurderet)
- megen
- nogen
- lidt
- ingen

Foretog hun indlæggelsessamtalen?
Ja/nej

Forberedte hun udskrivelsen?
Ja/nej

Deltog hun i udskrivningskonferencen
Ja/nej

Appendix III

Almene spørgsmål

1. Deres alder
   (Ét ciffer i hvert rum. F.eks. 5
   og 5 for 55 år)

2. Er De
   ☐ kvinde
   ☐ mand

3. Civilstand (kun ét kryds)
   ☐ Gift/samboende
   ☐ Ugift/fraskilt/aleneboende
   ☐ Enke/enkemand

4. Er De den ældres
   ☐ Ægtefælle
   ☐ Datter/søn
   ☐ Svigerdatter/svigersøn
   ☐ Søskende
   ☐ Barnebarn
   ☐ Niece/nevø
   ☐ Nabo
   ☐ Ven
   ☐ Andet, hvad?

5. Bor De sammen med den ældre?
   ☐ ja
   ☐ nej

   Hvis nej: Hvor langt bor De fra Deres
   ældre pårørende?
   ☐ Mindre end 10 km
   ☐ 10-19 km
   ☐ 20-49 km
   ☐ 50-100 km
   ☐ Mere end 100 km

6. Hvilken skolegang har De gennemført?
   (sæt kun ét kryds. Kryds af for det
   højeste niveau, du har gennemført)
   ☐ Folkeskole (7. klasse, mellemskole,
      realeksamen, 9. el. 10. klasse)
   ☐ Gymnasium (Inkl. HTX, HHX, HF,
      studenterkursus)
   ☐ Eksamen fra universitet
      eller anden højere læreanstalt

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7. Har De en sundhedsuddannelse?

☐ Ja
☐ Nej

8. Har De erhversarbejde?

☐ Ja
☐ Nej

Hvis ja:

☐ Fuld tid
☐ Deltid

9. Har De hjemmeboende børn?

☐ Ja
☐ Nej

Spørgsmål som handler om hjælpen til Deres pårørende

10. Hvor ofte ca. hjælper De Deres ældre pårørende? (Hjælp skal forstås bredt og kan f.eks. være alt fra telefonopkald, til omfattende praktisk og personlig hjælp)

    Ved "slet ikke": gå videre til spørgsmål 15

☐ Slet ikke
☐ Mindre end 1 gang om ugen
☐ 2-3 gange om ugen
☐ 4-6 gange om ugen
☐ Hver dag

11. Ca. hvor mange timer i gennemsnit om ugen hjælper De den ældre?
    (Ét ciffer i hvert rum. F.eks. 0 og 3 for 3 timer eller 1 og 5 for 15 timer)

12. Hvor længe har De hjulpet Deres ældre pårørende?

☐ 3 måneder eller kortere tid
☐ 4-6 måneder
☐ 7-12 måneder
☐ 2 år
☐ 3-5 år
☐ Mere end 5 år

13. Hvor længe kan Deres ældre pårørende være uden hjælp eller opsyn?

☐ Slet ikke
☐ Mindre end 2 timer
☐ 2-5 timer
☐ 6-12 timer
☐ Mere end 12 timer
☐ Ubegrænset

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14. Hvad hjælper De den ældre med?

☐ Psykisk støtte, opmuntring

☐ Social støtte (bindeled til familie og netværk)

☐ Ledsager (f.eks. til lægen, ambulatoriebesøg, o. lign.)

☐ Praktisk hjælp i hjemmet (rengøring, tøjvask, reparationer, havearbejde)

☐ Administrativ hjælp (regnskab, bank, kontakt til offentlige instanser, breve)

☐ Personlig hjælp (bad, toiletbesøg, hårvask, madning osv.)

☐ Transport

☐ Indkøb

☐ Madlavning

☐ Gå ture

☐ Tage medicin

☐ Forbindsskiftning

☐ Træning

Andet, hvad? [   ]

Nedenfor følger nogle eksempler, som pårørende til svækkede ældre personer har givet på oplevelser, man have, uanset hvor meget eller lidt, man er involveret i plejen for denne person. Sæt kryds i det omfang, det passer for Dem.

	I høj grad	I nogen grad	I mindre grad	Slet ikke
15. Jeg føler ansvar for min ældre pårørendes velbefindende	☐	☐	☐	☐

	I høj grad	I nogen grad	I mindre grad	Slet ikke
16. Jeg føler ansvar for at min ældre pårørende får den hjælp han/hun har brug for (fra det offentlige)	☐	☐	☐	☐

	Meget ofte	Ofte	Sjældent	Aldrig
17. Jeg føler mig hjælpeløs overfor min ældre pårørendes situation	☐	☐	☐	☐

	Meget ofte	Ofte	Sjældent	Aldrig
18. Jeg føler mig af og til dårlig samvittighed overfor min ældre pårørende	☐	☐	☐	☐

	Meget ofte	Ofte	Sjældent	Aldrig
19. Jeg føler mig af og til, at jeg ikke gør nok for min ældre pårørende	☐	☐	☐	☐

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Spørgsmål om Deres oplevelse af denne indlæggelse

20. Denne indlæggelses varighed i antal dage:
(Ét ciffer i hvert rum. F.eks. 0 og 3 for 3
dage eller 1 og 5 for 15 dage)

21. Hvor blev Deres ældre pårørende udskrevet
til? (Kun ét kryds)

☐ Eget hjem
☐ Genoptræningsophold (herefter eget hjem)
☐ Aflastningsophold (f.eks. på plejehjem)
☐ Beskyttet bolig
☐ Plejehjem (permanent)
☐ Andet, hvad?

22. Jeg følte mig velinformeret om:	I høj grad	I nogen grad	I mindre grad	Slet ikke
- min pårørendes sygdom	☐	☐	☐	☐
- min pårørendes plejebehov	☐	☐	☐	☐
- planerne efter udskrivelsen	☐	☐	☐	☐
- hvordan jeg bedst hjælper min pårørende fremover	☐	☐	☐	☐

23. Jeg modtog information om, hvordan jeg
bedst hjælper min pårørende (Herunder også
undervisning og vejledning)

☐ Ja
☐ Nej

Hvis ja: I hvilken udstrækning var informationen/undervisningen	I høj grad	I nogen grad	I mindre grad	Slet ikke
- relevant	☐	☐	☐	☐
- tilstrækkelig	☐	☐	☐	☐
- på et passende niveau	☐	☐	☐	☐

	I høj grad	I nogen grad	I mindre grad	Slet ikke
Hvis nej: I hvilken udstrækning havde Deres haft brug for det?	☐	☐	☐	☐

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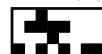
24. Under denne indlæggelse har jeg oplevet at:
    (sæt gerne flere krydser)

☐ der blev givet forkert medicin
☐ min pårørende ikke fik den medicin han/hun skulle have
☐ min pårørende ikke fik nok at spise
☐ min pårørende ikke fik nok at drikke
☐ min pårørende ikke blev plejet godt nok
☐ en eller flere af ovenstående hændelser skete for andre patienter
☐ der ikke blev talt pænt til patienterne
☐ intet af ovenstående

25. Under tidligere indlæggelser/kontakter med
    hospitalsvæsenet har jeg oplevet at:
    (sæt gerne flere krydser)

☐ der blev givet forkert medicin
☐ min pårørende ikke fik den medicin han/hun skulle have
☐ min pårørende ikke fik nok at spise
☐ min pårørende ikke fik nok at drikke
☐ min pårørende ikke blev plejet godt nok
☐ en eller flere af ovenstående hændelser skete for andre patienter
☐ der ikke blev talt pænt til patienterne
☐ intet af ovenstående

	I høj grad	I nogen grad	I mindre grad	Slet ikke
26. Jeg havde tillid til, at min pårørende fik den nødvendige pleje under indlæggelsen	☐	☐	☐	☐

	I høj grad	I nogen grad	I mindre grad	Slet ikke
27. Indlæggelsen gav mig et pusterum for ansvaret for min pårørende	☐	☐	☐	☐

☐ Ikke relevant

	I høj grad	I nogen grad	I mindre grad	Slet ikke
28. Jeg følte, min pårørende var i trygge hænder, mens han/hun var indlagt	☐	☐	☐	☐

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	I høj grad	I nogen grad	I mindre grad	Slet ikke
29. Jeg måtte passe på, at min pårørende fik den pleje han/hun havde brug for (holde øje med og påtale mangler f.eks. bede om at han/hun fik tilstrækkelig mad og drikke, kom ud af sengen o. lign.	☐	☐	☐	☐

30. Jeg tilbragte mere tid på sygehuset, end jeg havde tænkt mig (Sæt eventuelt flere krydser)

☐ for at sikre min pårørende fik den hjælp han/hun havde brug for
☐ for at hjælpe min pårørende med daglige fornødenheder
☐ fordi min pårørendes tilstand var kritisk
☐ jeg tilbragte ikke mere tid på sygehuset, end jeg havde tænkt mig

	Altid	Ofte	Sjældent	Aldrig
31. Sygeplejepersonalet behandlede patienterne med respekt (f.eks. tonen, tiltaleformen, andet af betydning for bevaring af patientens værdighed)	☐	☐	☐	☐

	Altid	Ofte	Sjældent	Aldrig
32. Jeg oplevede, at sygeplejepersonalet var fortravlet	☐	☐	☐	☐

	I høj grad	I nogen grad	I mindre grad	Slet ikke
33. Det var mit indtryk, at sygeplejepersonalet var dygtigt	☐	☐	☐	☐

34. Min pårørende havde en fast plejeperson

☐ Ja
☐ Nej
☐ Ved ikke

	Helt enig	Delvist enig	Delvist uenig	Helt uenig
35. Der var for mange forskellige involveret i min pårørendes sygepleje	☐	☐	☐	☐

☐ Ved ikke

	Helt enig	Delvist enig	Delvist uenig	Helt uenig
36. Det problem, som førte til, at min pårørende blev indlagt, blev løst under indlæggelsen	☐	☐	☐	☐

☐ Ved ikke

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37. Jeg er tilfreds med min pårørendes forløb på sygehuset:

	I høj grad	I nogen grad	I mindre grad	Slet ikke
- ved selve indlæggelsen	☐	☐	☐	☐
- under opholdet i afdelingen	☐	☐	☐	☐
- omkring udskrivelsen	☐	☐	☐	☐

Spørgsmål om personalets inddragelse af Dem i planlægning af - og beslutninger om - pleje og behandling

38. Sygeplejepersonalet spurgte om min viden om min pårørendes situation (helbred, hvordan han/hun klarer sig osv.) (Sæt gerne flere krydser)

☐ Ved indlæggelsen eller tidligt i forløbet

☐ Under forløbet i afdelingen

☐ Ved forberedelserne til udskrivelsen

☐ Nej, der blev ikke spurgt til min viden

	Altid	Meget ofte	Ofte	Nogen gange	Sjældent	Aldrig
39. Sygeplejepersonalet spurgte om mine synspunkter om beslutninger, der skulle tages	☐	☐	☐	☐	☐	☐

	Altid	Meget ofte	Ofte	Nogen gange	Sjældent	Aldrig
40. Min viden om min pårørende blev brugt af sygeplejepersonalet	☐	☐	☐	☐	☐	☐

☐ Ved ikke

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41. Jeg blev informeret om de beslutninger, der blev truffet omkring: (Kryds af for hvert område)

	Altid	Meget ofte	Ofte	Nogen gange	Sjældent	Aldrig
- undersøgelser	☐	☐	☐	☐	☐	☐
- behandling	☐	☐	☐	☐	☐	☐
- genoptræning	☐	☐	☐	☐	☐	☐
- plejen	☐	☐	☐	☐	☐	☐
- udskrivelsen	☐	☐	☐	☐	☐	☐
- arrangementerne efter udskrivelsen	☐	☐	☐	☐	☐	☐

42. Jeg havde indflydelse på de beslutninger, der blev truffet omkring: (Kryds af for hvert område)

	Altid	Meget ofte	Ofte	Nogen gange	Sjældent	Aldrig
- undersøgelser	☐	☐	☐	☐	☐	☐
- behandling	☐	☐	☐	☐	☐	☐
- genoptræning	☐	☐	☐	☐	☐	☐
- plejen	☐	☐	☐	☐	☐	☐
- udskrivelsen	☐	☐	☐	☐	☐	☐
- arrangementerne efter udskrivelsen	☐	☐	☐	☐	☐	☐

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43. Jeg ønskede indflydelse på de beslutninger, der blev truffet omkring min pårørendes: (Sæt gerne flere krydser)

☐ Undersøgelser
☐ Behandling
☐ Genoptræning
☐ Pleje
☐ Udskrivelse
☐ Arrangementer efter udskrivelsen

	Altid	Meget ofte	Ofte	Nogen gange	Sjældent	Aldrig
44. Sygeplejepersonalet og jeg var enige om, hvad der skulle ske med min pårørende	☐	☐	☐	☐	☐	☐

☐ Ved ikke

	I høj grad	I nogen grad	I mindre grad	Slet ikke
45. Jeg var tilfreds med den indflydelse, jeg fik	☐	☐	☐	☐

Spørgsmål om kontakten med personalet

46. Ca. hvor ofte var De i kontakt med afdelingens sygeplejepersonale igennem hele forløbet? (mere end goddag og farvel)

☐ Slet ikke
☐ 1-4 gange
☐ 5-10 gange
☐ Mere end 10 gange

47. Hvem tog initiativ til kontakten med sygeplejepersonalet?	Altid	Meget ofte	Ofte	Nogen gange	Sjældent	Aldrig
De?	☐	☐	☐	☐	☐	☐

☐ Der var ingen kontakt

| Sygeplejepersonalet? | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |

☐ Der var ingen kontakt

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48. Jeg kunne få sygeplejepersonalet
i tale, når jeg havde brug for det

	Altid	Meget ofte	Ofte	Nogen gange	Sjældent	Aldrig
Telefonisk	☐	☐	☐	☐	☐	☐

☐ Jeg havde ikke brug for det

	Altid	Meget ofte	Ofte	Nogen gange	Sjældent	Aldrig
Personligt	☐	☐	☐	☐	☐	☐

☐ Jeg havde ikke brug for det

49. Det var nemt at få fat i en
sygeplejerske, der kendte min
pårørende

	Altid	Meget ofte	Ofte	Nogen gange	Sjældent	Aldrig
Telefonisk	☐	☐	☐	☐	☐	☐

☐ Jeg havde ikke brug det

	Altid	Meget ofte	Ofte	Nogen gange	Sjældent	Aldrig
Personligt	☐	☐	☐	☐	☐	☐

☐ Jeg havde ikke brug det

	Altid	Meget ofte	Ofte	Nogen gange	Sjældent	Aldrig
50. Sygeplejepersonalet var imødekommende, når jeg henvendte mig til dem	☐	☐	☐	☐	☐	☐

☐ Jeg henvendte mig ikke til dem

	Altid	Meget ofte	Ofte	Nogen gange	Sjældent	Aldrig
51. Sygeplejepersonalet have tid til at tale med mig	☐	☐	☐	☐	☐	☐

☐ Jeg havde ikke brug for det

	Altid	Meget ofte	Ofte	Nogen gange	Sjældent	Aldrig
52. Jeg har oplevet at blive afvist af sygeplejepersonalet, når jeg henvendte mig til dem	☐	☐	☐	☐	☐	☐

☐ Jeg henvendte mig ikke til dem

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53. Jeg oplevede, at det var i orden at give udtryk for:
(Kryds af for hvert område)

	Helt enig	Delvist enig	Delvist uenig	Helt uenig	Ved ikke
- min bekymring	☐	☐	☐	☐	☐
- mine følelser	☐	☐	☐	☐	☐
- kritik	☐	☐	☐	☐	☐

	I høj grad	I nogen grad	I mindre grad	Slet ikke
54. Sygeplejepersonalet forstod min situation som pårørende	☐	☐	☐	☐

55. Jeg er tilfreds med kontakten med sygeplejepersonalet

	I høj grad	I nogen grad	I mindre grad	Slet ikke
- Omfanget/mængden	☐	☐	☐	☐
- Kvaliteten	☐	☐	☐	☐

Spørgsmål om udskrivelsen

56. Min ældre pårørende blev efter min mening udskrevet:
(kun ét kryds)

☐ på det rigtige tidspunkt
☐ for tidligt
☐ for sent

	Helt enig	Delvist enig	Delvist uenig	Helt uenig
57. Min pårørende får efter min mening tilstrækkelig hjælp efter udskrivelsen (f.eks. hjemmehjælp og/eller hjemmesygepleje)	☐	☐	☐	☐

	Helt enig	Delvist enig	Delvist uenig	Helt uenig
58. Jeg var enig i planerne efter udskrivelsen	☐	☐	☐	☐

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59. Det var min opgave at varetage min pårørendes interesser, når det gjaldt arrangementerne efter udskrivelsen (f.eks. tale hans/hendes sag for at få hjemmehjælp/ hjemmesygepleje, genoptræning, aflastningsophold, plejehjem osv.)

I høj grad	I nogen grad	I mindre grad	Slet ikke
☐	☐	☐	☐

60. Det var min oplevelse, at min pårørende ikke altid var realistisk i sin vurering af sin situation (Hvad han/hun kan klare, har brug for osv.)

Helt enig	Delvist enig	Delvist uenig	Helt uenig
☐	☐	☐	☐

☐ Ved ikke

UDSKRIVNINGSKONFERENCEN

Udskrivningskonference er et møde, som somme tider afholdes mellem patienten, dennes pårørende, plejepersonale fra afdelingen og hjemmeplejen. Af og til deltager også læger, fysioterapeuter og ergoterapeuter.

61. Blev der afholdt en udskrivningskonference?

☐ Ja
☐ Nej (gå til spørgsmål 74)

62. (hvis ja)
Jeg deltog i udskrivningskonferencen

☐ Ja (gå til spørgsmål 67)
☐ Nej

63. (hvis nej til deltagelse)
Jeg deltog ikke i udskrivnings-konferencen fordi

☐ jeg blev ikke informeret om, at den blev afholdt
☐ jeg blev ikke inviteret
☐ jeg var forhindret i at deltage
☐ jeg var ikke interesseret i at deltage
☐ Andet, hvad?

64. Informerede personalet Dem om resultatet af konferencen? (Skal kun besvares, hvis De ikke deltog)

☐ Ja
☐ Nej

65. Jeg var tilfreds med resultatet (Skal kun besvares, hvis De ikke deltog)

I høj grad	I nogen grad	I mindre grad	Slet ikke
☐	☐	☐	☐

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66. (hvis ja til deltagelse i udskrivningskonferencen) Jeg var tilfreds med den indflydelse, jeg havde på beslutningerne, der blev truffet på konferencen

I høj grad	I nogen grad	I mindre grad	Slet ikke
☐	☐	☐	☐

67. Jeg var tilfreds med måden, min pårørende blev behandlet på under konferencen

I høj grad	I nogen grad	I mindre grad	Slet ikke
☐	☐	☐	☐

68. Der blev lyttet til min pårørendes ønsker

I høj grad	I nogen grad	I mindre grad	Slet ikke
☐	☐	☐	☐

69. Det var min oplevelse at beslutningerne var taget på forhånd af personalet

I høj grad	I nogen grad	I mindre grad	Slet ikke
☐	☐	☐	☐

70. Det var svært at få indflydelse under konferencen

I høj grad	I nogen grad	I mindre grad	Slet ikke
☐	☐	☐	☐

71. Det var muligt at forhandle med personalet under konferencen

I høj grad	I nogen grad	I mindre grad	Slet ikke
☐	☐	☐	☐

72. Jeg var tilfreds med resultatet af konferencen

I høj grad	I nogen grad	I mindre grad	Slet ikke
☐	☐	☐	☐

73. (hvis nej, der blev ikke afholdt udskrivningskonference) Det var ikke nødvendigt at afholde en udskrivningskonference

Helt enig	Delvist enig	Delvist uenig	Helt uenig
☐	☐	☐	☐

☐ Ved ikke

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Spørgsmål om praktiske forhold

74. De fysiske omgivelser i afdelingen
(f.eks. stuerne, gangen,
dagligstuen osv.)
(Kryds af for hvert område)

	Helt enig	Delvist enig	Delvist uenig	Helt uenig
Der var tilstrækkelig plads	☐	☐	☐	☐
Der var rent	☐	☐	☐	☐
Der var ryddet op	☐	☐	☐	☐
Der var pænt	☐	☐	☐	☐
Der var mulighed for privatliv (f.eks. tale uforstyrret sammen, undgå at få krænket sin blufærdighed osv.)	☐	☐	☐	☐

	I høj grad	I nogen grad	I mindre grad	Slet ikke
75. De fysiske omgivelser havde betydning for min oplevelse af forløbet	☐	☐	☐	☐

76. Jeg kendte afdelingens besøgstid

☐ Ja (gå videre til næste spørgsmål)
☐ Nej (spring næste spørgsmål over)
☐ Der var ingen fast besøgstid (spring næste spørgsmål over)

	Helt enig	Delvist enig	Delvist uenig	Helt uenig
77. Det var OK at komme udenfor afdelingens besøgstid	☐	☐	☐	☐

Hvis De har tilføjelser om samspillet med plejepersonalet, som De ikke synes spørgeskemaet har belyst i tilstrækkelig grad, kan De skrive dem her (De er også velkommen til at tage bagsiden i brug)

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