A Palliative Approach to Dementia Care

Leadership and organisation, existential issues and family support

BY

LARS ALBINSSON
The main purpose of this thesis was to apply the WHO and NHS palliative care approach to dementia care. Thirty-one staff-members in mid-Sweden (studies I and II) and 20 next-of-kin (study IV) were interviewed. In study III, 316 staff-members from dementia care and 121 staff-members from palliative cancer care responded to a questionnaire about family support. The interviews were tape-recorded and analysed with a qualitative phenomenographic (I and II) and a hermeneutic approach (IV). The questionnaires (III) were analysed using qualitative and quantitative content analysis.

The staff-members stated almost unanimously that daily leadership was lacking, and consequently clear goal formulations and care planning were rare (I). Proper teamwork between the doctor and the staff who worked on a daily basis with the patients was absent (I). With respect to existential issues, education and staff discussions were lacking (II). The staff were at a loss concerning how to deal with these issues. Nevertheless, these issues are central to family-members who have to deal with an existential crisis (IV). Important questions emerged about obligation and guilt, faithfulness, responsibility, and paying back what you once received. Existential isolation could be identified e.g. in the reversal of roles experienced as “being a parent to your parent” and in the burden of “visiting a living dead person”.

There were no routines for bereavement visits. The type of support suggested for dementia family members is partly similar to support in palliative cancer care, but it also differs in other respects such as feelings of guilt because the early signs of the disease are misunderstood, the need for respite because of the long trajectory of dementia diseases, and the occurrence of anticipatory grief because in the late phase family members can no longer make any contact at all with the patient (III).

A palliative approach can improve the quality of life for the dementia patient and for the family. It can be used as a basis for a clear goal formulation. Some of the suggestions listed in this thesis for improving the quality of care are more a reflection of the need for a change in attitudes rather than the need for substantial budget increases.

Key Words: Dementia, palliative care, leadership, staff, existential issues, family support.
This thesis is based on the following papers, which will be referred to in the text by their Roman numerals.


III. Albinsson L, Strang P. Differences in supporting families of dementia patients and cancer patients – a palliative perspective. *Palliative Medicine (Accepted 2002)*.

IV. Albinsson L, Strang P. Existential concerns of families of late-stage dementia patients – questions of freedom, choices, isolation, death and meaning. *Journal of Palliative Medicine (Accepted 2002)*.

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INTRODUCTION

There is so far no cure for dementia. The main goal for staff in municipal care and health care services consequently must be to try to support the patient and his/her family during the illness trajectory in order to facilitate quality of life despite the difficult situation. The aim of this thesis is to provide staff with conceivable tools for improving quality of life. The Swedish Constitution (100) establishes that all people are of equal worth and that the state has a special responsibility to work in behalf of the care and security of all citizens. The parliamentary report on care at the end of life pointed out in particular that this premise concerning people’s equal worth must be stressed regarding those whose self-determination is on the decline, which can be the case in the final stage of life and also for those with early stages of dementia (112). The report also establishes the fact that there is an association between a good quality of care and:

- clear leadership
- a clear philosophy of care
- the competence of those providing the care..

In this thesis the palliative philosophy of care is used as a point of departure (132, 89) and will be presented in detail later. This philosophy of care has seldom been applied to dementia care (85), although there are a few exceptions (53, 116). A well-functioning organisation is a prerequisite for good care (46, 60). Consequently, Swedish dementia care administered by the municipalities is therefore a recurrent topic in this thesis. The existential crisis that strikes both the patient and the family when facing a dementia diagnosis is another neglected issue. Two of the studies in this thesis will therefore focus on this central perspective. Dementia has been referred to as the illness of the family (8), and there are many articles from the perspective of spouses, daughters and sons (19, 23, 26, 48, 54, 66, 145). Support for the family is also a central issue in this thesis. On the other hand, palliative measures of a purely medical or psychological character are not the focus.
BACKGROUND

Workload in dementia care

In Western societies the number of dementia patients is increasing with age. For every five-year interval after the age of 65 years the prevalence doubles (41). Several studies show that 6-8 % of the population over 65 years of age suffer from dementia (64, 103). According to a Swedish estimate in 1991, about 103 000 persons suffered from moderate to severe dementia, with an expected increase to 121 000 in the year 2000 and an estimated increase to 154 000 persons by the year 2025 (103). In 1991 it was estimated that 82 % of all patients at nursing homes were suffering from dementia and that the total cost for dementia was SEK 20 –36 billion per year (135).

The increasing prevalence and the economic burden on society comprise some of the factors contributing to an increased interest in dementia. There is also greater awareness concerning the severe suffering associated with dementia from the perspectives of both the patient and the family (31, 33) The course is often protracted and can constitute a most painful experience for the patient and family. The average duration of Alzheimer’s disease and other forms of dementia is estimated at 8-10 years (64).

Initially, family members do not understand the changes that occur in behaviour and mood. This is a source of conflict and later also of guilt on the part of the family (139). The illness progresses with successive loss of function, and eventually institutional care might be needed (49). At that point the family is often deeply involved in the process of the illness. In a successive fashion the patient completely loses his/her capacity to communicate with the family, signifying a social death, whereas physical death will occur sometimes years later. Blieszner et al. describe this tragedy as a transition from being a partner to being a caregiver in order to cope with a nonexistent but non-terminal relationship (10). As a consequence, the mourning process sometimes starts during this phase (anticipatory grief) (130).

The care of dementia patients in Sweden

Before 1992 dementia patients with modest institutional needs could reside at a municipal home for the elderly. In more advanced cases psychogeriatric wards, geriatric wards or nursing homes run by geriatric clinics were used. Nursing homes and long-term care facilities were part of the health services system financed by the county councils. The management was
similar to that in most other medical disciplines: a physician was the head of the clinic and performed regular medical rounds, and a senior registered nurse was the head of the ward and supervised the staff who worked there.

In 1992 new national legislation was introduced ("Ädelreformen", Swedish law 1990:1402) that transferred nursing homes and most of the geriatric wards for long-term patients over to the municipalities. The focus was now on housing. Despite their serious medical conditions, the former patients were now officially considered to be “guests” or “residents” and were to have individual contracts for their lodging and to pay for their other living expenses.

According to current regulations, the municipality must be able to offer health services up to the level of those provided by a senior registered nurse. In every municipality there is a senior registered nurse who is responsible for the medical care at this level and who supervises several dwellings or nursing homes, sometimes with up to several hundred residents. However, the manager of an individual dwelling or nursing home is not required to have formal medical training. Of the total number of employees in municipal elderly care today, fewer than 5 percent are registered nurses and most of these are involved in administrative work (124). When needed, a doctor from primary health care services, most often a general practitioner, is summoned.

Organisation and leadership in municipal dementia care

Today there is both Swedish and international literature concerning organisation and leadership within health care (11, 27, 45, 92, 128). However, there are few studies that explicitly focus on organisation and leadership within dementia care. In guidelines and consensus reports concerning dementia care (3, 129) the content of good care is described in detail, but there are no descriptions of what the leadership and organisation of such care should be like. While it seems self-evident that a high quality outcome of care is related to the attitude, commitment and interpersonal skills of the nurse in charge, this has also been shown in studies, such as an Australian study of 200 nursing homes (95). In an American study Sheridan et al. found a lack of interpersonal communication, a more laissez-faire attitude, and more hierarchies in two nursing homes that were not recertified as compared with 23 nursing homes that met the standards for recertification (108). From a Swedish perspective it is of interest to study the care given by the municipalities, care which was previously provided by
the county councils. The Swedish National Board of Health and Welfare evaluated the 1992 reform (Ädelreformen) in several reports 1995-1996. The housing accommodation for dementia patients was mostly of a high standard. But surprisingly, there were no correlation between the workload of the patients and the number of staff (115). In an audit 1995, the municipal health services for elderly were visited in 70 randomly selected municipalities. It was found that staff members quite often didn’t recognise who was in charge for the unit and the registered nurses didn’t know what kind of medical examinations were performed for the dementia patients in the unit. Regarding dementia patients there was often a lack of communication between the doctor and nurse in charge (115). In a questionnaire study of general practitioners over 60% answered that the cooperation between them and the nurses in the new organisation for municipal health services was worse than before, when the district nurses were in the same organisation as the doctors (113).

The Palliative philosophy of care

Palliative care comprises patients with incurable diseases where death is expected within a relatively limited period of time. The World Health Organization’s definition of palliative care is (132):

“The active total care of patients whose disease is not responsive to curative treatment. Control of pain, of other symptoms, and of psychological, social and spiritual problems, is paramount. The goal of palliative care is achievement of the best quality of life for patients and their families. Many aspects of palliative care are also applicable earlier in the course of the illness in conjunction with anticancer treatment.”

WHO further expands upon and explains that definition as follows:

“Palliative care: ...affirms life and regards dying as a normal process, ... neither hastens nor postpones death, ... provides relief from pain and other distressing symptoms, ... integrates the psychological and the spiritual aspects of care, ... offers a support system to help patients live as actively as possible until death, ... offers a support system to help the family cope during the patient's illness and in their own bereavement.”

Palliative care has primarily come to deal with incurable cancer. Despite this, the founder of the modern hospice-movement, Dame Saunders, stressed as early as 1983 that: “...many of
the symptoms to be treated and much of the general management will be relevant to other situations... Terminal care should not only be part of oncology but of geriatric medicine, neurology, general practice and throughout medicine...” (105). The palliative needs of non-cancer patients are being recognized in a new special textbook over this theme (1).

The NHS (National Health Service) in the UK defines three directions within palliative care: 1) A palliative care approach, 2) Palliative interventions and 3) Specialist palliative care (89). In this thesis the first direction is applicable. This involves promoting the philosophy of palliative care as an integral part of all clinical practice, whatever the illness or stage, when needed as a result of the illness trajectory.

Dementia is incurable, with steady deterioration that leads to death, and can thus be considered a terminal illness to which the palliative philosophy of care is applicable. In a theoretical article Rango exemplified how the physical, psychological and social needs of the patient with dementia can be met. He emphasised the importance of supporting next-of-kin during the time the patient is receiving care and during the period of bereavement after the patient’s death. He specified how staff from the church can be part of a multi-professional team in order to provide the patient with religious/spiritual support. The article largely concurs with the palliative philosophy of care presented in the WHO definition, and how it can be applied to patients with dementia (99).

In a study by McCarthy et al., patients who died of dementia were compared with patients who died of cancer (85). The patients with dementia had symptoms and health care needs that were comparable to those of the cancer patients. However, the dementia patients did not have their needs provided for to the same extent, e.g. as regards access to hospice services or medical help from GPs or district nurses. This issue is crucial, as a palliative approach is desirable in dementia care. Luchins et al. found that when asked, the majority of doctors and other members of the American Gerontological Society, as well as next-of-kin of dementia patients, recommended care at a palliative level focusing on control of symptoms, nursing care and good quality of life (77). Some American studies point out that the Hospice philosophy, which is largely synonymous with the palliative philosophy of care, is also applicable to end-stage dementia care (13, 134). In a review of 1694 American hospices, however, it was found that fewer than one percent of admitted patients had a primary diagnosis of dementia (52).
The fact that dementia is not seen as a palliative illness is probably due to the long period of time it often takes from detection of the illness until death occurs. The WHO definition of palliative care is derived from the concept of "terminal care" and refers therefore to the late phase of an incurable illness, although there is an additional paragraph stating that the philosophy of palliative care is also applicable earlier in the course of the illness. The course of illness in dementia and the suffering incurred by the patient and next-of-kin make the association with palliative care very relevant. Recently, issues relating to end-stage dementia have also been recognised as important challenges for palliative care services (53, 116). With respect to dementia, however, the elements of the philosophy of palliative care outlined by WHO could be applicable throughout the whole process of dementia, even before the end-stage period. This was also stressed by Hurley et al. in a research letter in JAMA (Journal of the American Medical Association) in 2000 (61). The NHS definition of “palliative care approach” is also applicable to all stages of dementia (89).

Existential issues
The few existing existential studies about life, death and meaning in conjunction with dementia often focus on religion and spirituality. These concepts deal with existential questions in a broad sense. An American study described how religious ceremonies, hymns and spiritual perspectives can enrich and create structure for the patient afflicted with dementia (68). Another study focused on improved coping for families through a belief in God and through prayers (119).

Religion and spirituality can be regarded as central meaning-bearing elements in life. *Religio* (Latin) means “tie together”. Life is tied to or governed by God, but religion also ties people to earth and to a congregation, and it constitutes a social institution in which religious rites play an important role in creating meaning and structure (18). *Spirituality* is a broader concept than religion and refers not only to a belief in a God, but also to other higher powers, to nature, and to the cycle of the seasons and of mankind (118, 120). Kellehear discusses spirituality in palliative care in terms of situational needs (purpose, hope, social presence, etc), moral and biographical needs (peace and reconciliation, forgiveness, etc.) and religious needs (religious reconciliation, rites, sacraments, etc.) (65). Spirituality has also been defined as whatever or whoever provides meaning and purpose in our lives (86). Transcendence is also a
central concept in spirituality (2). In Sweden, the general spiritual dimension seems to have a greater impact than religion. Only six percent of the adult population attends church regularly (63).

Existential issues are discussed in a stricter philosophical sense within the philosophical movement of existentialism, represented by philosophers such as Kierkegaard, Heidegger and Sartre (56, 67, 104). Existentialism deals with questions of life, its origin and its conditions, and the basic condition of being human. Although many attempts have been made to define existential questions, there is no single, commonly accepted definition. However, one way of categorising existential domains was proposed by Yalom, who identified four recurrent basic conditions that always challenge man’s existence. These four conditions capture the central elements of existentialism and comprise: 1) death, 2) freedom that involves responsibility and choices, and therefore also anxiety and guilt, 3) existential isolation, which forces us to establish relationships, and 4) meaninglessness, which makes us search for meaning or create meaning (141). These four basic conditions have opposite (positive/negative) dimensions. The central question about meaning/meaninglessness has been extensively discussed by thinkers such as Frankl, who developed meaning as a concept (40). Antonovsky stresses the central importance of finding meaning in order to create a sense of coherence (4). Rollo May has also outlined basic concepts of existential psychology, such as being or not being, existential anxiety and guilt (83). To summarise, there are similarities and differences between the three concepts of religion, spirituality and existentialism. Dividing lines are difficult to draw, and instead the concepts can be characterised by their core elements. Susan Strang has listed core elements of the three concepts, which are shown in table 1 (121).

Table 1. A summary of key words for the concepts of religion, spirituality and existentialism.
From the dissertation of Susan Strang, with permission (121)

<table>
<thead>
<tr>
<th>RELIGION</th>
<th>SPIRITUALITY</th>
<th>EXISTENTIALISM</th>
</tr>
</thead>
<tbody>
<tr>
<td>God</td>
<td>Meaning</td>
<td>Freedom</td>
</tr>
<tr>
<td>Worship</td>
<td>Transcendence</td>
<td>Isolation</td>
</tr>
<tr>
<td>Rituals</td>
<td>Higher power/source of energy</td>
<td>Meaning/meaninglessness</td>
</tr>
<tr>
<td>Social manifestation</td>
<td>Relationship</td>
<td>Death</td>
</tr>
<tr>
<td></td>
<td>Religious dimension</td>
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</tbody>
</table>
There are few articles on existential issues in dementia care, although Levine et al. discussed existential issues in their strict meaning (76). Issues of death, freedom, isolation and meaning were applied to dementia patients and their next-of-kin. In several articles Farran has also considered how these existential themes can contribute to coping on the part of family caregivers (36, 37). While it is obvious that existential issues are important, they have been neglected in dementia care.

**Special aspects related to the dementia family**

Dementia greatly affects the family of the dementia patient (14). A number of reviews describe the vulnerable situation of family members, their risk for physical and psychiatric illness, as well as for social isolation and financial problems. (17, 33, 106, 138). Ory et al. found that next-of-kin who cared for dementia patients, as compared to those who were informal caregivers for patients with other diseases, spent more time doing caregiving tasks, were more physically and psychologically burdened, and were more often forced to devote less time to other tasks (91).

Many studies focus on the life situation of the spouse with respect to coping strategies and depression (6). Problem-focused coping strategies seem to be associated with a lesser degree of depressive symptomatology than emotion-focused coping strategies. Knop et al. found that previous marriage problems were associated with a higher degree of depression in spouses of patients with Alzheimer’s disease (71). Thus, not only is the disease trajectory a decisive factor with respect to the spouse’s burden, but previous experiences and problems must also be taken into account. Other studies describe the ongoing, frequent contact between spouses after admission to institutional care, with a focus on continuing caregiving because of love and devotion, duty and obligation (102). There are also studies that focus on children and their relationships with a parent with dementia. Jansson et al. concluded that daughters were more involved and more physically and psychologically burdened in care situations than was the case for sons (62). However, there are also sons who take an equal amount of responsibility for their parents with dementia (54).

Nevertheless, despite the existential character of the transition/borderline situation when a spouse or a parent is diagnosed with dementia and expected to fade away, it has not been
possible to identify any studies in Medline that explicitly focus on the existential crisis of the dementia family.

**AIMS**

**General aims**
The aim of this thesis was to connect and apply the palliative care approach to dementia care as illustrated by the following important aspects
- studying organisational and leadership aspects as these impact on the quality of care.
- meeting existential needs
- supporting family members
- studying attitudes regarding follow-up after a patient’s death

**Specific aims**

**Paper I.** To study how municipal dementia staff in Sweden perceive the actual care of today with focus on organisational factors and leadership.

**Paper II.** To explore how staff working in municipal dementia care describe and tackle the existential issues of patients and next-of-kin, how they handle the situation when a patient is dying, and the kind of follow-up they do after the patient’s death.

**Paper III.** To identify similarities and differences in perceived good family support as suggested by dementia staff and palliative cancer care staff, respectively.

**Paper IV.** To increase understanding of the existential questions of family members of patients with dementia.
SUBJECTS AND METHODS

Papers I and II

Sampling. An information-rich sampling was aimed at (94) by approaching a positive selection of motivated staff whose positive occupational choice had been to work in dementia care. Thirty-one persons (22 women and 9 men) were interviewed. Their mean age was 34 years (24-51 years) and they had worked for a period ranging from two to over 25 years within the areas of elderly care and dementia care. The interviewees were 13 assistant nurses from 13 different units in central Sweden who were especially interested in dementia care and who had completed a one-year training programme with national coverage at the Silvia Home Foundation (110, 111). The remaining 18 interviewees (4 registered nurses and 14 assistant nurses or nurse’s aides), from five units in central Sweden, were considered by their managers to be especially involved in and successful in their work with dementia patients.

The questions. Study I. The main questions were: How do you think dementia patients should be cared for and what is the care actually like where you work? In every interview themes about leadership and organization arose. These themes were then followed up with more specific questions (73). Study II. The main questions were: Does the patient/next-of-kin address issues concerning life and death, the meaning of life, and similar questions of an existential nature? What do they say? How do you answer? 2) How do you handle the situation when someone is going to die/ has died? 3) Do you get in touch with the next-of-kin after the patient’s death? The initial responses were decisive regarding subsequent questions.

Paper III

Sampling. The total sample consisted of 437 informants (316 from dementia care and 121 from palliative care) who attended four national courses on dementia in 1999 and one national course on palliative care in 2000. The overall response frequency was 78% for the four courses. Most of the course participants were expected to be experienced and motivated staff seeking new information. Patton terms this kind of non-random sampling intensity sampling (Patton, p.182) (93). This means that the cases/informants manifest the phenomenon intensely, but not extremely, i.e. the sample consists of information-rich cases/informants, without their being rare exceptions.
The dementia staff consisted of 25 nurse’s aides, 165 assistant nurses, 91 registered nurses, and 34 persons from other professional groups (mainly doctors, almoners, occupational therapists, and physiotherapists). The palliative care staff consisted of 21 assistant nurses, 76 registered nurses and 24 persons from other professional groups. The groups of staff had long experience in their respective areas. Over 60% of the dementia care staff had worked in the area for more than five years, and the corresponding figure for the palliative care staff was almost 50%. Only 8% and 10% had worked less than one year in dementia care and palliative care, respectively.

The participants from dementia care came from approximately 70 different units and those from palliative care from about 60 different units throughout the country. These estimates constitute minimum values based on applications to attend the different courses. Due to the character of their work, there were more assistant nurses than nurses in the dementia care group, and the reverse was true for the palliative care group.

**The questions.** The respondents answered one open-ended question, either *In your experience, what are the two most important measures for supporting families of dementia patients?* or *In your experience, what are the two most important measures for supporting families of severely ill cancer patients in a palliative phase?*

**Paper IV.**

**Sampling.** A written inquiry about participating in an interview was distributed by the staff in four units (Two group-dwellings, one nursing home and one day-care unit). Next-of-kin who were interested in participating telephoned the interviewer or left their phone number with the staff, who forwarded it to the interviewer. Twenty family members were interviewed. They comprised nine daughters, three sons, one wife, three husbands, one brother, one niece, one daughter-in-law and one brother-in-law. The sample is a purposeful sample of interested persons in regular contact with their relative with dementia (94). The patients had moderately severe or severe dementia (late-stage dementia). Eight patients were not able to communicate at all.

**The questions.** In order to create good contact with the interviewees, initial questions dealt with the support the respondents had received from the health care system and from the
municipality. The existential questions were approached through questions about what it was like to care for their relative with dementia, how often they visited the person, and what that was like. This was the starting-point for a dialogical interview about life and death, about meaning, existential isolation and choices in life.

Ethics
The interview studies (Studies I, II and IV) were approved by the regional ethics committee. Written and oral information was given to all respondents. Confidentiality and anonymity were guaranteed; no feedback beyond the written research papers would be given to the units where the staff worked or where the dementia patient was cared for. As a psychiatrist, the interviewer is accustomed to handling staff members and serious subjects in depth. All of the interviewees related that the interviews had been a positive experience. This is in accord with other studies of palliative care comprising qualitative interviews (5, 133).

For study III, contact was taken on 19 November 2001 with the chairman of the regional ethics committee, who stated that there was no need for formal approval, as there was no obvious ethical conflict involved with the simple and straightforward questions and participation was totally voluntary and anonymous. Only questions related to the respondents’ work were posed; there were no personal questions.

Phenomenography
Studies I and II were qualitative studies, and the interviews that were conducted were tape-recorded and transcribed verbatim (74, 78). In analysing the material we have mainly relied on naturalistic phenomenography (55), which alludes to the possibilities of collecting empirical material from authentic social situations: “…to collect data about what actually happens in particular situations without involvement from researchers and then analysing that data phenomenographically…” (cited from the official home-page for the Gothenburg group, www.ped.gu.se/bjorn/paragraph/wild/natur/naturalis.html)

Phenomenography (not to be confused with phenomenology) was developed within the domain of pedagogic research in Gothenburg, Sweden, by professor Marton. It was first described in the 1970s, although the word “phenomenography” was used as early as 1954 by
the psychologist Sonnemann as “..a descriptive recording of immediate subjective experience as reported.”, i.e. without in-depth interpretation (117). Since then, phenomenography has been developed to comprise several variants of the method (55). It is the empirical study of the limited number of qualitatively different ways in which we experience, conceptualise, understand, perceive, apprehend, etc., various phenomena in and aspects of the world around us. These descriptions of differing experiences, understandings, etc., are characterised in terms of categories of description, logically related to each other. Phenomenography uses a second-order perspective, i.e. it focuses on how issues are described by the informants without in-depth interpretation of possible underlying meanings, rather than a first-order perspective, i.e. how things “objectively” are (80, 82).

The categorisation in studies I and II was mainly done according to steps suggested by Dahlgren and Fallsberg (28). In summary, the material was read through carefully (familiarisation). Comments were made in the margins; in this step these were the researcher’s direct associations, without any detailed strategy. Then significant statements were selected (condensation). The statements were compared to find sources of variation or agreement (comparison). Answers within the same area (grouping) were placed together based on the above-mentioned comparison and questioning. Statements within the respective preliminary groups were critically analysed and compared in order to find the central content within each group of answers (articulating and labelling). Finally, all the categories were compared and contrasted with each other (contrasting), and scrutinised and co-ordinated to constitute a common structure. This is called the outcome space in phenomenography.

Hermeneutic analysis

Study IV was also a qualitative study with explorative interviews. The interviews were transcribed verbatim (74, 78). The data were interpreted using a hermeneutic approach (74, 97) and in light of Yalom’s definitions of four basic existential domains (141). The larger domains were preconceived (freedom, isolation, death and meaninglessness), but the final subcategories emerged from the data. The scientific assumptions were mainly derived from existential hermeneutics, as developed by Heidegger (56) and Gadamer (42). A central idea in hermeneutics involves paying attention to context and original purpose in order to enrich previous understanding. The analysis is based on the following seven components. 1) The hermeneutic circle is used (a continuous movement between the whole and the parts, a
dialogue with the text in which the meaning of separate parts is determined by the global meaning of the text). 2) The interpretation of meaning is completed when a coherent concept is attained without contradictions (“good gestalt”). 3) Partial interpretations are compared with other sources of knowledge. 4) The autonomy of the text is emphasised (meaning that the researcher should interpret how the text itself also implicitly describes a theme). 5) Comprehension of the themes of the text is essential to the interpretation. 6) The researcher must be aware of his/her assumptions and presuppositions; there is no unprejudiced interpretation of the text and the researcher cannot neglect his/her own comprehension. 7) Creativity is to be used so that the interpretation enriches the previous understanding of the themes (74, 97).

**Content analysis**

Study III was a questionnaire study. The responses were initially read through in order to obtain an overall picture. Qualitative and quantitative content analyses were used to analyse the open-ended responses (58, 131). With this approach the aim was to obtain a qualitative description by identifying categories emerging from the data, and to use these categories in order to quantify the responses by counting the frequencies and comparing the groups (dementia care and cancer care), with the focus on individual items of interest. The categorisation was straightforward and interpretation of the responses was not needed, as the responses were explicit.

For statistical comparisons the Chi-square test was used. When the observed frequencies were very low, Fisher’s exact test (two-tailed) was performed (Statistical Software version 6.0).

**Some aspects of trustworthiness**

In the interview studies a dialogical validation (78) was carried out with the interviewee, as similar questions were addressed several times during the interview. This was done to ensure their genuine perceptions. Dialogical validation also means that the interviewer checks that he has understood the message and intention by check-up questions such as “Did I understand you right when you said that?…” Dialogical intersubjectivity was used (74), meaning that the interviews were analysed separately by both authors and then compared for similarities and differences. The material was then discussed until agreement was reached.
The coding in the questionnaire study was straightforward and interpretation of the responses was not needed, as the responses were explicit. The final categorisation was done by both authors in collaboration.
RESULTS

Paper I.

The results are summarised and categorised in six areas.

1. Staff leadership
A few informants described the occurrence of explicit staff leadership involving knowledgeable managers and supervisors who participated in the daily care. In most of the interviews opinions emerged about very vague, inadequate leadership. In many cases staff leadership at the group dwelling or ward level was totally lacking. It was common for the unit manager to be responsible for up to 50 to 60 employees at 5 to 6 different units. At best, staff members saw the manager for about one or two hours per week. The informants did not feel any clear support when they found themselves in a difficult situation at work. The interviewees wanted explicit leadership. Above all, they wanted access to a senior registered nurse with good knowledge in dementia care

2. The unit’s goal formulation and care planning
In some of the units continual, individual care planning took place on a regular basis, but at other units it seemed that there was no discussion at all about why the unit existed, nor was there any care planning for the individual resident/patient. And finally, there were units where there had been goals at the start, but they had become outdated and were not followed due to changes in the resident/patient population.

3. Teamwork focusing on the doctor’s role
None of the 31 interviewees was satisfied with the teamwork in the care of the dementia patient. They particularly wanted better contact with the doctor. The doctor closed himself/herself in with the nurse, and those working closest to the patients were seldom involved unless they forced their way in. What they wanted was information but also to inform the doctor, as they felt as if they were patient advocates.

4. Support for family members
Despite the lack of formal continued education and training, informal contacts between the interviewees and the family were found to function well in spite of the fact that there were no formal plans for family support

5. Education of the staff – guidance/supervision
There were no individual development plans for the staff. Almost everyone felt that there was insufficient continued education where they worked. Only at one single unit were there good opportunities for continued education for all staff members. Finally, there were units where
staff had voluntarily financed more education for themselves. Guidance and supervision groups at some of the units were very much appreciated.

6. Care forms and the principle of remaining in the same unit versus the nursing workload principle

Many respondents spontaneously stated that there should be a clear chain of care for dementia patients. The municipality should be called in much earlier and immediately appoint a supportive contact person for those patients still living at home. Day care was stressed as a good early form of support although it needed to be extended, as there were often queues to obtain a place. A few units offered respite care, where the patients stayed in a nursing home for one to two weeks. This was perceived to be good relief for the family. When the patient could no longer be cared for at home, a group dwelling for six to eight patients was perceived to be a good, calm care form. The general opinion was that group dwelling facilities should be designed according to the “wheel principle”, meaning that as soon as the patient opens the door to his/her room he/she comes out to the shared areas of the facility and can see the staff. Access to an enclosed terrace or small garden was stressed.

An important issue raised by many of those interviewed concerned whether the patient should continue living at the same unit for the remainder of his/her life, irrespective of the degree of dementia, in accordance with the so-called principle of remaining in the same unit. Some supported this ideology in principle. They felt it provided security both for dementia patients and their families, and thought that it would function well if staffing were more flexible. Often, however, the rooms were too small for such necessities as ceiling lifts and other aides that are needed in terminal care. Time-consuming care of those with the most severe dementia meant that there was not always time enough for the other patients. Many of those who raised this issue instead wanted the care to be differentiated in accordance with the nursing workload principle, with special units for patients in a terminal stage.

Paper II

In this study the focus was directed toward existential issues, death, meaning/meaninglessness, suffering, existential isolation and responsibility/freedom, the latter especially as regards next-of-kin. None of those interviewed experienced these
questions as easy, and most felt lost. For the majority of respondents it was difficult to know how to respond.

1 Existential issues
Some of the interviewees could not remember that clear-cut existential issues had ever come up with patients or next-of-kin. Many of the patients on the unit were in such poor shape that they were unable to talk. Approximately half of those interviewed had experienced when patients, in particular, directly took up existential issues. Even if the respondents felt powerless when discussing meaning and death, they had to come up with something. Three patterns of answers emerged.
1) The interviewee tries to minimise or ignore the question.
2) The interviewee responds that no one has control over life and death. You have to wait for your turn.
3) The third way of acting is to show affection. The staff member hugs the patient.

Almost none of those interviewed had had the experience of a relative bringing up these vital questions with the staff. When this was done, the dialogue was often short and without much depth. Surprisingly enough, only three of those interviewed spontaneously mentioned contacts with a chaplain. One of those interviewed said that the doctor was consulted even when existential issues arose. The doctor was considered responsible for helping with these issues as well.

It was found throughout the interviews that the person interviewed seemed to be alone in trying to deal with existential issues. Discussions among staff members did not occur, nor were existential issues taken up in any planned way by staff management. Each individual had to tackle these difficult questions on his/her own.

2. Dying and death
When faced with dying patients, the staff mustered their strength, put conflicts aside, and tried to make things easier for the family. The goal was that the patient would not be left alone. They often called in extra staff and did not bother about budgetary constraints.
3. Follow-up after death

Whether or not there was some follow-up after the patient’s death seemed to depend on the staff member himself/herself, or on the relative. About half of the informants stated that they had some contact with the next-of-kin. They sometimes sent a Christmas card, occasionally met the next-of-kin in a store or something similar. A few of the informants systematically took contact with the next-of-kin after a few weeks. There were no directives from management concerning follow-up that emerged from the interviews. Many of those interviewed had pointed out at their place of work that there should be routines for follow-up of next-of-kin.

Paper III

The respondents of two staff groups, one in dementia care and one in palliative cancer care, responded to an open-ended question in the questionnaire, either In your experience, what are the two most important measures for supporting families of dementia patients? or In your experience, what are the two most important measures for supporting families of severely ill cancer patients in a palliative phase? Most of the respondents actually reported more than two items. The 316 respondents in the dementia staff group listed a total of 1091 proposals for support, and in the palliative staff group with 121 respondents the total number of items was 434. On average, those who responded to the question regarding support of families in dementia care gave 3.5 suggestions each, and those in palliative care gave 3.6 suggestions each. A total of 61 different items could be categorised.

Main categories

The 61 items could be allocated into ten main categories. Staff in dementia care put significantly greater emphasis on the importance of providing information to families about all aspects and giving them education, as well as giving families the possibility of obtaining respite. Staff in palliative cancer care emphasised instead the importance of good professional conduct, providing practical support, and being available. Both groups stressed the importance of having good communication with family members and that the families should feel involved in the care.
Individual items
In table 2 the different items felt to be most important in supporting families in dementia care and in palliative care, respectively, are listed in order of precedence. The completely predominant items in both groups were listening to family members and giving them information, although the importance of listening was brought up more often in palliative cancer care. Both groups gave the same ranking to the importance of family involvement in the care and showing empathy with respect to the family’s situation.
Items focused upon significantly more by staff in dementia care were forming support groups for families (P<0.001), giving families knowledge by means of education (P<0.001), and providing families with respite care (P<0.001). Finally, the importance of trying to relieve the family’s feelings of guilt emerged in dementia care (P<0.001). This item was far down on the list in palliative care. Staff in palliative care gave significantly greater emphasis to the importance of being available (P<0.05), of creating a sense of security (P<0.001), and also affirming the family (P<0.001). In contrast to staff in dementia care, they also pointed out the importance of supporting the family after the patient’s death (P<0.01).
Table 2. Ranking of the 10 most important items for supporting families of dementia patients (n= 316) and cancer patients (n=121), respectively. The 95% CI (confidence intervals) for the differences in percent (%) and the p-values are shown.

<table>
<thead>
<tr>
<th>Item</th>
<th>Ranking 1–10</th>
<th>Number (%)</th>
<th>Difference</th>
<th>P</th>
</tr>
</thead>
<tbody>
<tr>
<td>Giving information</td>
<td>1</td>
<td>153 (48)</td>
<td>63 (52)</td>
<td>- 4</td>
</tr>
<tr>
<td></td>
<td>2</td>
<td>63 (20)</td>
<td>153 (48)</td>
<td>- 93</td>
</tr>
<tr>
<td>Listening</td>
<td>2</td>
<td>134 (42)</td>
<td>78 (65)</td>
<td>- 23</td>
</tr>
<tr>
<td></td>
<td>1</td>
<td>78 (25)</td>
<td>134 (42)</td>
<td>- 56</td>
</tr>
<tr>
<td>Forming support groups</td>
<td>3</td>
<td>76 (24)</td>
<td>1 (1)</td>
<td>23</td>
</tr>
<tr>
<td></td>
<td>-</td>
<td>1 (1)</td>
<td>76 (24)</td>
<td>22</td>
</tr>
<tr>
<td>Providing knowledge/education</td>
<td>4</td>
<td>75 (24)</td>
<td>3 (3)</td>
<td>21</td>
</tr>
<tr>
<td></td>
<td>-</td>
<td>3 (3)</td>
<td>75 (24)</td>
<td>22</td>
</tr>
<tr>
<td>Providing respite care</td>
<td>5</td>
<td>74 (23)</td>
<td>9 (7)</td>
<td>16</td>
</tr>
<tr>
<td></td>
<td>-</td>
<td>9 (7)</td>
<td>74 (23)</td>
<td>22</td>
</tr>
<tr>
<td>Being available</td>
<td>6</td>
<td>59 (19)</td>
<td>37 (31)</td>
<td>- 12</td>
</tr>
<tr>
<td></td>
<td>3</td>
<td>37 (12)</td>
<td>59 (19)</td>
<td>- 22</td>
</tr>
<tr>
<td>Offering involvement</td>
<td>7</td>
<td>46 (15)</td>
<td>13 (11)</td>
<td>4</td>
</tr>
<tr>
<td></td>
<td>7</td>
<td>13 (11)</td>
<td>46 (15)</td>
<td>23</td>
</tr>
<tr>
<td>Showing empathy</td>
<td>8</td>
<td>44 (14)</td>
<td>13 (11)</td>
<td>3</td>
</tr>
<tr>
<td></td>
<td>7</td>
<td>13 (11)</td>
<td>44 (14)</td>
<td>23</td>
</tr>
<tr>
<td>Having regular conversations</td>
<td>9</td>
<td>43 (14)</td>
<td>1 (1)</td>
<td>13</td>
</tr>
<tr>
<td></td>
<td>-</td>
<td>1 (1)</td>
<td>43 (14)</td>
<td>22</td>
</tr>
<tr>
<td>Relieving feelings of guilt</td>
<td>10</td>
<td>42 (13)</td>
<td>4 (3)</td>
<td>10</td>
</tr>
<tr>
<td></td>
<td>-</td>
<td>4 (3)</td>
<td>42 (13)</td>
<td>23</td>
</tr>
<tr>
<td>Creating a sense of security</td>
<td>-</td>
<td>18 (6)</td>
<td>27 (22)</td>
<td>- 16</td>
</tr>
<tr>
<td></td>
<td>4</td>
<td>27 (8)</td>
<td>18 (6)</td>
<td>11</td>
</tr>
<tr>
<td>Affirming the family member</td>
<td>-</td>
<td>25 (8)</td>
<td>24 (20)</td>
<td>- 12</td>
</tr>
<tr>
<td></td>
<td>5</td>
<td>24 (20)</td>
<td>25 (8)</td>
<td>11</td>
</tr>
<tr>
<td>Giving practical support</td>
<td>-</td>
<td>14 (4)</td>
<td>14 (12)</td>
<td>- 8</td>
</tr>
<tr>
<td></td>
<td>6</td>
<td>14 (12)</td>
<td>14 (4)</td>
<td>8</td>
</tr>
</tbody>
</table>
In addition to the 10 key items listed in table 2, the importance of the arrival interview was also focused on in the dementia group. In palliative care the importance of teamwork was stressed more than in the dementia group.

**Paper IV**

The interviews with the 20 family members were analysed using the four existential domains comprising the theoretical framework: freedom (choices-responsibility), existential isolation, death and meaninglessness. The four domains are strongly associated with one another, e.g. assuming responsibility (freedom, choice) creates meaning, and existential isolation is associated with a sense of meaninglessness. For purposes of clarity, the four domains are nevertheless reported separately. In each domain the following categories could be extracted from the material.

**Freedom (responsibility - choices – anxiety – guilt)**

**Obligation – guilt.** Some of the informants felt guilt and found that visiting the ill family member felt like an obligation. They visited too infrequently and found the visits difficult. It was hard to see the family member so ill.

**Being faithful** to the relationship was very important for most of the informants. In these cases caring for or visiting the family member with dementia was natural and was based on free choice.

**Paying back what you have received** was associated with faithfulness. Both spouses and children stated that they had shared so much and received so much, in a psychological way, that it now was natural to “pay back”. It was also important to act as a role model for their own children by showing respect for the elderly. Perhaps the informant would need help from their own children in the future; this was a way to “pay in advance”.

**Having always taken care of others.** Six of the informants spontaneously related that they had always taken care of other persons during their lives, in their professional life or their family life. They perceived themselves as strong and as having the capacity to do so.
Existential isolation

**Being the only relative.** Being the only relative left in the world together with the ill family member created a special existential feeling. It was felt that the bloodline was cut off.

**Not having anyone to discuss things with** was the situation that some of the informants experienced in spite of siblings or spouses. They felt alone with their existential questions.

**The patient can no longer communicate.** Eight of the interviewees could no longer establish any verbal or even physical communication with the patient. This was described as visiting a living dead person, and as being extremely burdensome and emotionally trying.

**Being a parent to your parent** was a role-reversal expressed by four of the daughters and one of the sons. The informants were now alone in life and could no longer rely on advice and support from their parent. The role of the parent could not be filled by spouses or other persons.

Death

**Denial/disavowal.** Some of the respondents did not want to think about the impending death, although they were aware of it.

**Previous death of other relatives** and not only the current situation coloured some of the respondents’ thoughts about the dementia patient’s impending death.

**Not wasting your life/ an authentic way of living.** The illness of their parent made some of the children more aware of how short life is and of the importance of not wasting one’s own life, but giving priority to important things.

**Confronting the dementia patient’s wish to die.** It was hard to be confronted with the ill family member’s wish to die. It was difficult to respond in a good way.

**Anticipatory grief.** Six of the interviewees wished that the patient would die. There was no longer any perceived dignity in the patient’s life. It was evident that the grieving process had begun some time ago.

Meaning/meaninglessness

**The meaning of the illness.** Only one informant stated that there might be some hidden meaning in the situation. The other respondents could see no meaning in the patient being stricken by dementia. None of the informants described their thoughts in religious terms.

**Current meaning.** Knowledge and daily routines created security and meaning for some of the informants in their everyday lives. It gave structure to their lives.
**Meaning in the past.** For others it was meaningful to think of all the good memories they shared with the patient.

**Meaning in the future.** Several informants described in detail the importance of passing the achievements and interests of the dementia patient on to the next generation.
DISCUSSION

Organisation and leadership (Papers I and III)

The palliative philosophy of care according to WHO (132) presupposes the contribution of a multiprofessional and multidisciplinary team. No single profession can cover all important aspects of care. One of the most serious findings (paper I) was the remarkable lack of teamwork among the staff, the nurse, and the doctor. The informants provided a most concordant picture. If worse comes to worst, the doctor bases his/her decision on third-hand information (patient – nurse’s aide – registered nurse). An explanation may be that in accordance with the legislation outlined in the section on dementia care in Sweden, the dementia patient is formally considered only as a “resident”. The patient is therefore expected to behave toward the doctor like any other person living in his/her own home. The patient should take the initiative and call for the doctor when necessary. The situation is further hampered by the fact that staff in the dementia units are employed by the municipality, but the doctors come from the county council’s health care sector. The principle of confidentiality is in force between the health care sector and the municipality.

In comparison, palliative care staff dealing with cancer patients (Paper III) emphasised significantly more often the impact of teamwork in supporting the family. The importance of teamwork is also underscored in an American study by Kovach et al. (72). One hundred and eighty-one staff working in dementia care were asked to rank the most important factors for improving care, and teamwork was ranked in first place. Other important factors were to obtain support from management, staff attitudes, and having knowledge.

Another problem raised by the interviewees (Paper I) was the doctor’s insufficient knowledge about dementia. This is in accordance with findings from other studies (15, 16). Patients were also not always medically diagnosed, which is a recognised problem (90).

The lack of care leadership and goal formulation in everyday work was a frequent and serious finding. Municipal elderly care constitutes one of the largest employers in Sweden, with approximately 200,000 employees (124). If the findings from this study indicating unclear or absent staff leadership and a lack of goal formulation can be generalised, this means that in practice, tens of thousands of employees lack clear leadership in their work. This naturally has consequences. It can probably explain some of the inadequacies with respect to routines of
care that have recently emerged in the national debate in Sweden and in the media. This is supported by Sheridan et al. who found poor leadership to be an important factor in two nursing homes that failed to meet resident care standards required for State recertification (108). In a cross-sectional study of 420 nursing homes Castle found that nursing homes with illness and a high turnover on the part of top-level managers had patients with more pressure sores, more patients with catheters, more patients who were restrained, and more extensive use of psychotropic drugs than nursing homes with a lower turnover of managers (22). The Swedish National Board of Health and Welfare investigated 10 representative nursing homes/group dwellings in Sweden and found that at units with a less favourable social working climate more neuroleptic agents were used per patient than in nursing homes with a better social working climate. On the other hand, no differences were found in the use of tranquillisers and sleeping pills (114).

Good leadership constitutes the obvious basis for a high-quality care (47, 59). The interviewees wanted a senior registered nurse to be the leader of the unit. A registered nurse with special training in dementia care is a good candidate for such a leadership position (98).

No one mentioned the doctor as a possibility for leadership at this level. However, there are articles in the literature concerning the doctor’s role in supporting patients and families (3, 29, 127) although an impact on the support and leadership of the nursing home staff is seldom emphasised. Nevertheless, Streim thinks that a psychiatrist with geriatric training would be well-suited for a leadership role in dementia care (123).

One interesting way of formulating concrete goals for care in a group of dementia patients is described by Bradley et al.(12). This is done in interaction with the patient, family and staff, signifying that characteristics of the individual, the disease and the interactions of patients, families and clinicians are central components in the goal-setting process. In Sweden, Ternestedt pointed out that an explicit philosophy of care constitutes the basis for planning and carrying out the care of gravely ill patients in the final phase of life (126).

Special educational plans were rare in the units where the interviewees worked. According to the Swedish Association of Local Authorities, approximately 40 percent of those employed in elderly care (approximately 80,000) have not undergone any formal health care education at all (personal communication, Brander, Svenska kommunförbundet). Based on the interviews,
it seems that the individual employee’s motivation and interest are often what determine whether he/she receives any form of continued education and training.

Nevertheless, this issue is of central importance. Bauer Alfredsson et al. found that a group training programme for the staff led to better motivation, work satisfaction, and better care for dementia patients compared to a similar control group (7). Hallberg found that clinical guidance and supervision of the staff at a dementia unit resulted in numerous changes in their way of working and their way of viewing patients as compared with the situation at a comparable control unit (51). Instead of focusing on routines, the focus was now on creating conditions for as good a quality of life as possible. The supervision and guidance affirmed the staff who in turn could more easily affirm the patients. Wimo et al. showed that one of the results of staff education was that patients became calmer (136). These and similar findings (72, 84, 107), namely that staff who receive adequate education and guidance/supervision are better motivated and more effective in giving care, have calmer patients and enjoy their work more, do not seem to be utilised in everyday practice. It is probable that this issue also indicates the need for clear leadership. A staff manager who is involved in the care and who has a good relationship with the staff member and can clarify his/her need for knowledge and guidance/supervision by means of developmental conversations can certainly contribute greatly to better care.

The interviewees were up-to-date in their opinions about the importance of a chain of care. This ranged from support and in-home respite care, to day care, to respite care in the form of temporary care in a nursing home / overnight respite, and finally care in specially designed small group dwellings for dementia patients. This is in agreement with a review article by Day et al. who surveyed 71 articles (30). In general, it was found that care in small, specially designed units for dementia patients was clearly preferable to more traditional care in a nursing home. The residents were calmer, and both family members and staff felt more satisfied. This is also supported in a Canadian study by Donovan et al. who found that a small special care unit for dementia patients created feelings of personal space for the patients and the family, provided a better expression of personhood, and led to more unforced routines (32)
Existential issues (Papers II and IV)

Religion and spirituality. Only three of the staff members interviewed (Paper II) mentioned that there were routines for contacting a chaplain to visit the patient when that was needed. When questions of an existential nature emerged, one of the informants stated that the physician should be contacted and that he/she had the responsibility to provide help. In Sweden, which is a secularised country, the general role of the physician has expanded. Even existential issues are perceived today as a part of their duty, as patients do not find it natural to contact a chaplain for such issues. Thus in Sweden health care has partly mantled the duties of the church. On the other hand, Strang et al. found in a current study that palliative patients asked hospital chaplains mainly about existential and medical questions, and addressed religious issues to only a limited degree (122).

None of the 20 family members who were interviewed (Paper IV) spontaneously addressed religious questions. Only one of them had attended church regularly, but several described that they found peace and a spiritual atmosphere by simply sitting in a church building. Nevertheless, they did not attend services. Sweden is probably one of the most secularised countries in the world. In a recent study it was concluded that only 2.3 percent of the total population participated in divine service on Sundays (109).

Dementia staff and existential issues (Paper II). Without exception, all the staff members found it difficult to handle existential issues. They also stated that there was no discussion among the staff or between the staff and the management concerning these issues.

Certain patients expressed a longing for death that can be related to three of the great existential issues: meaninglessness, isolation and death (141). These issues were difficult for the staff to deal with. The results clearly indicate that the individual interviewee had to handle the patient’s and next-of-kin’s existential questions alone. Yalom talks about existential isolation as “the unbridgeable gulf between the individual and the world.” (141)p. 355. Some of those interviewed spontaneously demonstrated their presence by hugging the patient and saying that they cared about the patient and that he/she was important to them. This can be seen as an attempt to help the patient create some meaning in a world that the patient feels has lost all meaning. Relationships, and implicitly also physical contact, are powerful ways of creating meaning (141) at the same time as decreased social isolation alleviates the suffering.
present in existential isolation. Social support, relations, closeness and love do not take away existential isolation, but they make it possible to endure (141).

It is also important that a clinical depression is not overlooked. In a modern textbook on dementia, it is stated based on various studies that nearly 50% of dementia patients have depressive symptoms and 10 – 30% have a clinical depression (34). Death wishes are central factors in clinical depression and the new SSRI-antidepressive drugs might be helpful in certain cases. Forsell found in a longitudinal Swedish study (Kungsholmsprojektet) that a group of elderly people with persistent death wishes all fulfilled the criteria for a clinical depression (39). Thus, proper attention should be given to diagnosing a depressive disorder and differentiating it from existential anxiety, and from what Kissane calls the demoralisation syndrome, i.e. a nihilistic pessimistic attitude that does not fulfil the criteria for depression (70).

A central aspect of communication is to dare to listen and not shut off the questions. Communication is improved and the patient and next-of-kin are affirmed and feel supported if communication takes place in a professional way (38). When one can no longer have an effect on the patient’s illness, one can still influence the patient’s and next-of-kin’s approach to the situation, i.e. help to create transcendence (69). One can help to confirm those losses that both the patient and next-of-kin have had through empathetic resonance. The goal is to attain acceptance (69). In Sweden this acceptance and coping are less often cloaked in religious terms (63), such as God’s meaning with illness and life, as compared with the situation in other countries such as the USA (119).

When a dementia patient at a care unit enters the final stage of life and is dying, a rather unanimous approach found in the interviews was that the staff united and strove to give good care. Conflicts were put aside. Things were serious now. The staff demonstrated flexibility. Other tasks were abandoned, extra staff were called in if necessary, and the next-of-kin were contacted.

In everyday life and even in the area of routine care, one does not think much about death. Heidegger describes this as “idle chatter”. When a patient is dying, the staff unite because of the seriousness involved in death. According to Heidegger, death reflects life. Life becomes more intensive and more authentic in the presence of death (56). Despite this co-operation,
some of those interviewed wanted fixed, written routines. This reflects the uncertainty that staff can nevertheless feel, in spite of many years of experience, when faced with death. Written routines can provide a feeling of control in a difficult situation and constitute a problem-oriented form of coping (75).

**Existential questions central to next-of-kin** (Paper IV). For several of the informants it was a natural thing to want to visit and help the patient at a group dwelling. This was a way of showing faithfulness in the relationship. Ross et al. found that wives visited their chronically ill husbands because of affection, but also because of a sense of obligation; their husbands needed help, and by providing that help they also made things easier for the staff. In this way meaning was created (102). However, it was concluded that wives of mentally well-functioning husbands continued with their visits, whereas wives of cognitively-impaired husbands re-oriented their lives. In another study, on the other hand, it was found that the majority of family members maintained the frequency and length of their visits to the dementia patient for extended periods of time (142). Kelley et al. found in an American dementia study that visits were made to demonstrate faithfulness. It was a question of both obligation and gratitude, a way of paying back (66).

An interesting finding in our study was that six of the informants explicitly stated that they had always assumed responsibility for others, both at work and in their private lives. They gave the impression of being strong and capable. This obviously results in their being acknowledged and also creates a strong sense of meaning, which is in good agreement with a study by Harris (54). The existential psychotherapist Yalom (p 218) stated that “Responsibility means authorship. To be aware of responsibility is to be aware of creating one’s own self, destiny, life predicaments…” (141).

Despite a lack of explicit focus on existential dimensions, it is obvious from several studies that there is a redefinition of roles involving the dementia patient and the children (24, 54, 66). The new role definition for the children can be expressed as ”being a parent to one’s own parent”. For the first time in their lives they felt alone in the world. They did not have a last resort on which to rely, i.e. a devoted parent who could provide advice and support. Obviously the support one receives within a marriage cannot replace the strong bond between a child and parent, a bond that has a different existential character and function. Yalom describes this as “The loneliness of being one’s own parent” (p357) (141).
Many of the family members who were interviewed reported that despite having siblings and a spouse they nevertheless had no one with whom to share their deepest feelings and their reactions related to the dementia patient. This is in agreement with what Tebb et al. found in a study of spouses’ pronounced isolation within different dimensions (125). They also found that health care staff did not see or understand the spouse’s isolation.

Eight of the patients were no longer able to communicate with the family member in any way. It is impossible for the staff to fully comprehend this tragedy. Blieszner et al. discuss “coping with a nonexistent but non-terminal relationship” (10). The staff can nevertheless be supportive in helping family members find new roles, at least to some extent. The necessary redefinition of meaning is facilitated if the family member perceives a sense of coherence, strengthened by knowledge and participation (43). It should also be possible to strengthen the impact of good memories, to stress the positive aspects of the succession of generations, where spirituality, although not in religious terms here in Sweden, might deepen existential meaning, i.e. meaning through transcendence.

Although the patient is still alive, the family might experience grief. Worden provides extremely helpful guidelines that are applicable to any form of grief, with focus on tasks of mourning and mediators of mourning (140). He also stresses the importance of identifying the “at-risk bereaved”, who are characterised by having no close relatives, by being clinging and overly dependent on the patient, and by having ambivalent feelings about their previous relationship.

**Family support** (Papers I, II and III)

Family support is one of the cornerstones of the palliative philosophy of care. Although the WHO definition is not merely applicable to cancer, palliative care has been utilised mainly for cancer patients.

**Comparison of family support in dementia care and palliative cancer care** (Paper III).

Because of some basic differences, guidelines for supporting families of patients with advanced cancer cannot be uncritically transferred to dementia care, which was clearly demonstrated in paper III. There are several explanations for this. In comparison with disseminated cancer, the trajectory of dementia is often very protracted (many years), early
signs are misunderstood and create irritation, and the dividing line between uncertainty and the diagnosis of dementia is often blurred.

With cancer, there is a more clear-cut dividing line between curative and palliative care. For patients with cancer and their families the hospital’s palliative efforts initially constitute security while tumour-specific treatment is underway, but toward the end, the importance of spending time at home together becomes central, in contrast to the situation of exhausted dementia families. The cancer patient can communicate, the relationship has not ended, the family’s situation is characterised by anxiety rather than by grief, and the trajectory is therefore in many ways different from the trajectory for relatives of dementia families. Therefore, the results in paper III show both similarities as well as interesting differences.

**Information and education.** The two totally predominant items for supporting families were giving information and listening. Within pedagogy, a differentiation is made between information and education (20). In this context information means specific information about the individual patient and his illness. However, the goal of education is to give a general understanding of the situation. The dementia staff placed great emphasis on the need families have for general education about dementia. This is an important factor (25, 50, 79), as studies indicate that families have inadequate knowledge, which results in misunderstandings and guilt. Through education groups and dementia associations, families can get increased understanding and acceptance.

Although families of cancer patients also experience teaching groups as important psychosocial support (21), regular information is even more important in a cancer context, as the time perspective is shorter and the changes more rapid. While dementia families experience a situation of slow change over the course of years, where support from other families is important, cancer families sometimes experience significant changes every month, sometimes every week. Perhaps this disparity in the illness trajectories can explain why staff in palliative cancer care focus more on continuous availability, creating a sense of security and affirming the anxious family member.

**Respite care.** Among dementia staff there was strong emphasis on providing families with respite care, including day care and night respite, and on the importance of having the patient come to the correct care form, which is in good agreement with the literature (30, 137, 143,
This reflects most protracted courses. Dementia staff also pointed out the importance of helping families set limits.

**Guilt.** Since families often do not understand the clinical picture at the beginning (the importance of an early diagnosis was stressed by the staff), and since the family gradually becomes unable to care for the patient, feelings of guilt easily arise. The value of relieving guilt was therefore stressed significantly more often by the dementia staff. In this late phase families have usually taken farewell of the patient, and their reaction is characterised more by loss and grief, many times anticipatory grief (130, 140).

Problems with guilt were not apparent in the responses of staff in palliative cancer care. Cancer families are not perceived as having taken farewell of the patient. Instead, in palliative home care closeness and support in the home setting become important, and many cancer patients and families would prefer a home death (101). The crisis and anguish on the part of the family is of a more acute character. Staff in palliative care therefore gave greater emphasis to the importance of creating as great a sense of security as possible and of affirming the family’s difficult situation, which is in good agreement with the literature (87).

Availability in palliative home care was stressed, with care around the clock (9, 87). This reflects a large security factor. Availability is undoubtedly also important for families of dementia patients, but the need here can differ during different phases. In the first phase, during which the family cares for the patient at home for many years, support efforts and availability are generally poor. Studies have indicated that families do not know where they should turn for help (44). In later phases, when the patient is being cared for in a group dwelling or nursing home, the need is probably different but nevertheless fully present.

**Follow-up after death** (Papers II and III). Finally, staff in palliative care (paper III) pointed out the importance of supporting families when the patient dies and following them up after the death, in agreement with the WHO definition of palliative care. Staff in dementia care put much less emphasis on this item. This is in good agreement with data from paper I, where staff were interviewed. As reported in the study, no systematic follow-up of next-of-kin occurred after a patient’s death. If some type of follow-up did take place, this was most likely due to the individual staff member or to the relative initiating the contact. These findings are in good accord with those reported by Murphy et al. in a study of 121 nursing homes in
Michigan, where there was also inadequate follow-up of family members after the death of the patient (88).

**Education in family support** (Paper I).

Although the general impression obtained from the interviews in paper I was that the staff have good contact with the families, who visited the dementia patient, the interviewees were at a loss as to how to approach family members who seldom come for a visit or family members they experienced as bothersome. One way of improving this situation could be to teach staff and family members to give each other more direct feedback. Hertzberg et al. found that both family members and staff rarely asked for or gave feedback concerning one another’s manner of communicating (57).

A finding in paper I that is in good agreement with Jansson et al. was family members’ lack of information and knowledge about dementia and about where to turn for help (62). Educating the staff so that they can establish good communication and relationships with relatives is also a leadership task and results in improved well being of the patients (84).

**Methodological discussion**

Except for paper III, all the studies in this thesis use qualitative research methods. Qualitative studies do not aim to address quantitative questions, e.g. percentages or proportions of a certain phenomenon. Instead, the aim is to describe or explore the phenomenon with respect to the variation and contents. The comprehensive data are categorised in order to give both structure and “thick descriptions”, i.e. in-depth knowledge of a previously unknown phenomenon. Phenomenography was used in papers I and II. The aim was to describe the subjective experiences of the interviewees using a second-order perspective, i.e. how people experience and conceive the world, rather than trying to describe a first-order perspective, i.e. how things “objectively” are. Thus, the analysis proceeded from the experiences and perceptions offered by the respondents, without any particular interpretation. If managers or consulting doctors had been interviewed, it is conceivable that a partly different picture would have been obtained. However, it is of interest to obtain the opinions and perceptions of the staff who actually provide daily care to dementia patients. The findings are of importance in the discussion concerning how to improve the care of dementia patients.
The results of the qualitative studies cannot be generalised to all situations in Swedish dementia care, but data can of cause be transferred to similar situations. The use of information-rich sampling, i.e. a group of knowledgeable staff with deep involvement in their work in dementia care, aimed at capturing a great variation of opinions and perceptions in order to create a common structure. As there was a high level of agreement among the informants despite the purposeful sampling, this increases the probability that the results also partially capture the first order perspective, although this was beyond the scope of the study. A strength of phenomenography is that it describes a second order perspective, i.e. the informant’s subjective perception, which constitutes his/her objective reality. As the method is descriptive in nature and deep interpretations are avoided, data generation is more straightforward than in interpretative approaches. The relative lack of interpretation in phenomenography might, however, constitute a weakness, as it could be more difficult to explore complex situations, especially if contradictions are present (78). It is therefore essential that phenomenography is used for appropriate purposes. There is a general trend within phenomenography today to include more interpretations (81).

In study IV a hermeneutic approach was used. The four existential domains to be explored were preconceived, but the subcategories emerged from the data. Some researchers perceive and express that a totally inductive analysis is the only ideal approach in a hermeneutic qualitative study. However, in a more “mature” area of research, with generally accepted terms/theories, these concepts may theoretically be important to use openly and consistently as a platform for further analysis and conceptualisation (35). E.g. death anxiety is a generally accepted concept, that does not need to be redefined, but analysing the concept in a new situation may enrich the understanding.

It should be possible to generalise the results obtained from the interviews in study IV to similar situations, although they cannot be generalised to all next-of-kin due to the purposeful sampling. The participants constitute a positive purposeful sample of individuals who regularly visited the patient or who, in two cases, cared for the patient at home. This constitutes a limitation. We do not know the degree to which our findings apply to relatives who seldom or never visit the dementia patient. We do not know why they refrain from visiting them. Port et al. acknowledge this and stress the importance of educating families about dementia, thereby lessening the psychological stress associated with visits (96).
The written responses to the open-ended question in the questionnaire in paper III were analysed with a combination of qualitative and quantitative content analysis. In total, the 437 informants provided 1525 meaningful units, which were possible to allocate to 61 different items. Intensity sampling was used instead of random sampling, in that those individuals who attended the continuing education courses probably constituted a selection of highly motivated staff and would therefore be expected to be able to provide well-presented suggestions for supporting families. Supposing that the 437 respondents had worked in their current jobs for a mean of at least five years, the data are then based on more than 2000 years of clinical experience and should therefore have a reasonable validity. A weakness with using questionnaires with open-ended questions is that it is not possible to pose follow-up questions.
CONCLUSIONS

The overall conclusions from this thesis are:

- Palliative care as defined by WHO (132) is a most useful philosophy of care that can also be applied to end-stage dementia care, and a general palliative approach is also useful in earlier stages of the disease (89). This philosophy of care can improve the quality of life for the dementia patient and for the family.

Paper I  
- Organisation and leadership need to be improved and better defined within dementia care. There is a lack of distinct leadership with respect to affirming the staff and introducing a clear philosophy of care. Teamwork involving physicians – registered nurses – other staff must be improved. Further education for the staff must be a normal routine and a leadership instrument for improving the quality of care.

Paper II  
- There is a lack of focus on existential issues in dementia care, both as regards patients and family members. Staff members need more education within this area. There must be routines for follow-up of family members after the patient has died.

Paper III  
- There are many similarities, but also differences, in optimal support to families in dementia care and families in palliative cancer care. Forming support groups, providing knowledge and education, providing respite care, and relieving feelings of guilt were specially stressed by the staff in dementia care as being of importance for dementia family members.

Paper IV  
- The existential crisis for the family member of a dementia patient could be analysed in the existential terms of freedom, responsibility, isolation, death and meaning. The leadership and staff in dementia care must try to identify and understand this crisis experienced by family members and how it is expressed. Staff members can naturally not resolve this crisis, but need to have appropriate knowledge about it and dare to listen and hopefully contribute to a dialogue.
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