Dementia Care in an Ethical Perspective:

An exploratory study of caregivers' experiences of ethical conflicts when feeding severely demented patients.

by

Britt Mari Åkerlund
DEMENTIA CARE IN AN ETHICAL PERSPECTIVE:

An exploratory study of caregivers' experiences of ethical conflicts when feeding severely demented patients.

AKADEMISK AVHANDLING
som med vederbörligt tillstånd av Rektorsämbetet vid Umeå Universitet för avläggande av doktorsexamen i medicinsk vetenskap kommer att offentligen försvaras i Humanisthusets hörsal E, i Umeå lördagen den 15 december 1990 kl 9.00.

av

Britt Mari Åkerlund

Umeå 1990
ABSTRACT

DEMENTIA CARE IN AN ETHICAL PERSPECTIVE:

An exploratory study of caregivers' experiences of ethical conflicts when feeding severely demented patients.

Britt Mari Åkerlund, Departments of Geriatric Medicine and Advanced Nursing

The aim of this study was to explore how caregivers caring for severely demented patients experience ethical conflict situations. Feeding patients in a late state of dementia was chosen as focus. Special attention was paid to analyses of the caregivers' experiences with regard to their feelings, use of force, interpretations of the patients' behaviour and their ethical reasoning.

The study was carried out in five separate parts, presented as five papers. A phenomenological - hermeneutic approach was consistent. Personal interviews, a projective defence mechanism test, the Meta Contrast Technique and an analysis of patient/caregiver behaviour as shown in video taped feeding sessions were the methods used.

Study participants were forty-one caregivers in psychogeriatric care, registered nurses, licensed practical nurses and nurses' assistants.

The result indicated that, when facing ethical decisions the caregivers were caught in a double bind conflict due to the contradicting ethical demands "Keep the patient alive!" and "Don't cause the patient suffering!". The difficulty to interpret what the patients experienced and the impossibility to know for sure what actions would be right or wrong were sources of anxiety. They defined force feeding individually, yet a pattern was found. Some caregivers defined force feeding according to the amount of persuasiveness or violence they had to perform. Some regarded force feeding from a patient wish perspective. A majority combined the two dimensions.

The caregivers' ethical reasoning showed that their decision making was to be regarded as a process grounded on ethical rules. Interdependence in the relation caregiver/patient made them develop their reasoning in a direction of existential reasoning.

Key words: ethics, nursing, feeding behaviour, dementia
To

Gerd Backman and Karin Ljungqvist
ABSTRACT

DEMENTIA CARE IN AN ETHICAL PERSPECTIVE:

An exploratory study of caregivers' experiences of ethical conflicts when feeding severely demented patients.

Britt Mari Åkerlund, Departments of Geriatric Medicine and Advanced Nursing

The aim of this study was to explore how caregivers caring for severely demented patients experience ethical conflict situations. Feeding patients in a late state of dementia was chosen as focus. Special attention was paid to analyses of the caregivers' experiences with regard to their feelings, use of force, interpretations of the patients' behaviour and their ethical reasoning.

The study was carried out in five separate parts, presented as five papers. A phenomenological - hermeneutic approach was consistent. Personal interviews, a projective defence mechanism test, the Meta Contrast Technique and an analysis of patient/caregiver behaviour as shown in video taped feeding sessions were the methods used.

Study participants were forty-one caregivers in psychogeriatric care, registered nurses, licensed practical nurses and nurses' assistants.

The result indicated that, when facing ethical decisions the caregivers were caught in a double bind conflict due to the contradicting ethical demands "Keep the patient alive!" and "Don't cause the patient suffering!". The difficulty to interpret what the patients experienced and the impossibility to know for sure what actions would be right or wrong were sources of anxiety. They defined force feeding individually, yet a pattern was found. Some caregivers defined force feeding according to the amount of persuasiveness or violence they had to perform. Some regarded force feeding from a patient wish perspective. A majority combined the two dimensions.

The caregivers' ethical reasoning showed that their decision making was to be regarded as a process grounded on ethical rules. Interdependence in the relation caregiver/patient made them develop their reasoning in a direction of existential reasoning.

Key words: ethics, nursing, feeding behaviour, dementia
This thesis is based on the following studies:


V Åkerlund B.M. and Norberg A. Intuition: Two caregivers' descriptions of how they provide severely demented patients with loving care. Submitted to Omega 1990.

These papers will be referred to in the text by their Roman numerals.
INTRODUCTION

There was a time when caring for sick fellow-beings was a vocation. From time immemorial, women, sometimes female relatives sometimes nuns, have taken care of the diseased. Times have changed, caring is in our days regarded as a profession rather than a vocation, but still there are the women, young women, old women, warm-hearted women and professional women, providing care for children, old people, disabled and diseased. Even if a few men are to be found in health care today, caring is still principally of female concern. Trying to describe how caregivers experience their work, for better or for worse, their hope and despair, their concern for the patients and their anxiety and satisfaction thus at the same time becomes a portrayal of contemporary women.

Caring is a heavy task. Caring for incurably ill patients is especially arduous and may give the caregivers a feeling of powerlessness, insufficiency or cause anxiety (Menzies, 1970). Patients with dementia diseases are incurably ill. Caring for patients with severe dementia is maybe the most trying task to be found in nursing. There are also discussions of "burnout" and tedium as common problems among caregivers in geriatric and psychogeriatric care (Åström, 1990). Still there are many care-givers in dementia care who seem to feel job satisfaction over the years and possess remarkable enthusiasm and engagement in their patients' well-being.

Due to their cognitive deficits, patients with severe dementia can not guide or direct their own care. They can not express their wishes neither complain (Dyck, 1984; Ekman & Norberg, 1988). The responsibility for their care as being human and loving lies in the hands of the caregivers, hopefully in cooperation with relatives.

A demented patient is subjected to serious progressive cognitive decline, with memory loss, disorientation, agnosia, apraxia and aphasia as symptoms (Sulkava & Amberla, 1982; Brâne, 1989). In late states of dementia diseases, behavioural and emotional disturbances frequently occur in
addition to the cognitive deficits. When patients have reached a state of cognitive deterioration, where the ability to communicate verbally has ceased, it is the task of the caregiver to interpret nonverbal behaviour and find a context for caring according to the patients' needs (Lo and Dornbrand, 1984). There are several studies focusing on the caregivers' interpretations of severely demented patients' behaviour in feeding situations as means to improve the quality of their care (Athlin & Norberg, 1987; Athlin et al., 1990; Hallberg et al., 1990; Norberg et al., 1987;). Studies of patients' signs of hunger and thirst (Michaelsson et al., 1987) and reactions to sensory stimulation (Norberg et al., 1986) are other important contributions indicating that severely demented patients are dependent upon the caregiver as an interpreter of their needs.

When a patient neither accepts treatment nor verbally and consciously motivates a refusal, the caregiver is in a dilemma. Is the patient's refusal to be respected or should the caregiver force him to accept? This problem becomes obvious when patients in a late state of dementia do not take food or fluid voluntarily any longer. Again there is the question of the caregivers' ability to interpret the patients' cues. Interviews with caregivers have illustrated how they interpreted food refusal (Norberg et al., 1980b; Norberg et al., 1987; Athlin et al., 1998). Poor relations between patient and caregiver, as well as poor taste of the food, also nausea, agnosia and apraxia were at times regarded as the cause of food refusal (Norberg et al., 1988). Severe depression was also brought up as possible interpretations and even death wishes, however with some hesitance (Norberg & Asplund, 1990).

Should a caregiver ever give up the efforts to feed? Should tube feeding be used? When does feeding become force feeding? Are coaxing and prizing with a spoon to be regarded as using force? Competent patients' right to autonomy is generally accepted as an important ethical principle (Beauchamp & Childress, 1979). If a patient has not been adjudicated to be incompetent the principle of autonomy and the criteria of uselessness and grave burden must prevail (Veatch, 1984). Still there are situations when the competent patient's wish to discontinue treatment or refuse attempts of
nutritional support is experienced as a severe ethical conflict, even if his decision is unambiguous and informed and would cause no harm to others (Fry, 1986; Lo & Jonsen, 1980). Should nurses and physicians be guided by what they think is in the patient's best interest or should they respect the patient's autonomy? Furthermore patients with diminished competence due to serious mental disorders (Dresser & Boisabuin, 1986) and demented patients with dangerous behaviour (Watts et al., 1989) elicit conflicting values and highlight ethically as well as legally the complexity of autonomy. There is also the question if a demented patient's life history, his past autonomy with values and beliefs, should be taken into consideration and be given priority to medical responsibilities grounded in his best interest (McCullogh, 1984). Patient autonomy is always a complicated issue (Jackson & Youngner, 1979) and determining competency in the case of dementia is especially difficult (Watts & Cassel, 1984).

In the case of Claire Conroy (Braithwaite & Thomasma, 1986; Lo & Dornbrand, 1986; Mariner, 1984; Olins, 1986) the patient's presumed wish to avoid life sustaining treatment was regarded as legally justifying withdrawing of artificial nutritional support. There are the arguments that natural or artificial nourishment may be given or withheld, depending on the patient's comfort (Ramsey, 1976; Wanzer et al., 1984) or that artificial feeding increases the risks of complications as pressure sores and pneumonia (Lynn and Childress, 1983).

One basis for decision making is to be found in ethical principles and their corresponding rules. Beside the principle of autonomy, there are the principles of nonmaleficence and beneficence. The principles correspond to the moral rules: Do not deprive anyone of his freedom! Do not cause harm or inflict pain or disability! Do promote good! (Beachamps & Childress, 1979). For patients in terminal states of dementia the principle of nonmaleficence becomes operative if there are no other advance directives (Nelson & Bernat, 1989; Sachs & Cassel, 1989). Ethics is part of the human situation. No one can run away from his responsibility (Lögstrup, 1971). Even if a senior physician is legally liable for decisions,
the prime caregiver is the person who carries them out in the daily contact and close relation to the patient (Watts, et al., 1986). To know how to act when a patient compresses his lips and refuses to take the offered food or fluid is a problem for the caregiver (Howell, 1984). There and then ethical theories, principles and rules seem highly abstract while the caregiver's anxiety, concern and love for the patient seem concrete.

Ethical decisions can be taken on the basis of different models for ethical reasoning (Hof, 1970; Beauchamp & Childress, 1979). According to the teleological model, the consequence or effect of an act determines if it is right or wrong (Bexell et al., 1980). The deontological model refers to each act as having an internal quality of right or wrong independent of the result of the act, c.f. the case of Clare Conroy earlier mentioned. With an ontological ethical model, reasoning starts from a description and interpretation of phenomena of the situation. The interdependence of the interacting individuals is emphasized (Armgard, 1971; Bexell et al., 1985).

Feeding can be regarded both as life saving medical treatment (Kleinman, 1986) and basic care (Dresser, 1985). But feeding can also be regarded as caring in a deeper sense, as equivalent to touching and speaking (Miles, 1985; 1987) and as symbolization for love (Lynn & Childress, 1983). Without evidence of reciprocation and some minimal personal relatedness caring becomes worthless (Ramsey, 1970). Thus feeding a severely demented patient may be regarded as a reciprocal changing of gifts, with the caregiver giving the patient food or fluid as a symbol of her human love and the patient returning the gift by receiving. When a patient has reached the state of dementia where he can not communicate any longer the act of feeding becomes the care situation, where the caregiver most clearly can experience an intrinsic value and meaning.

Because feeding is so pregnant in caring, it is also the situation where the caregiver most often is faced with ethical decision making and exposed to conflicting ethical demands. When it is difficult to feed a patient the caregiver may feel
that she must keep him alive, yet not inflict pain or otherwise cause pointless suffering (Norberg et al., 1980a). The caregiver in that case is exposed to conflicting demands of a character that fulfils the criteria of a double bind situation (Bateson et al., 1956; Erickson, 1974) i.e. contains contradictory messages, on different logical levels, has long duration, is of importance for the parties involved, who are interdependent. The conflict is insoluble as long as the parties are prohibited to metacommunicate. The double bind hypothesis is useful when aiming at an analysis of conflict situations in social systems as well as between individuals or small groups (Watzlawick et al., 1967; Watzlawick, 1974).

Miller (1971) wanted to highlight the clinical observation that nutrition of the ill aged reflected unresolved problems in the feeding process. He pointed to the nurse-patient relationship in the feeding process as having been inadequately studied and in need for fundamental research for resolution. Since then much has been contributed but much is still left to inquire.

AIM

The aim of this study was to explore how caregivers caring for severely demented patients experience ethical conflict situations. Feeding patients in a late state of dementia was chosen as focus. Special attention was paid to analyses of the caregivers' experiences with regard to their feelings, use of force, interpretations of the patients' behaviour and their ethical reasoning.
METHOD

Study participants

Forty caregivers from the large psychogeriatric clinic at Umedalen's Hospital and five from Sidsjön's Hospital participated in the study. Both hospitals had a history of old mental hospitals why licensed practical nurses (mental) were in majority in the nursing staffs. The study participants from Umedalen were selected by stratified random sampling with number of years in health care as stratified variable i.e. twenty caregivers with more than twenty years in health care and twenty with less than five years were selected. The caregivers from Sidsjön were chosen because they made the nursing team for one special patient. The participants varied in education. Registered nurses (RA), licensed practical nurses (LPN) and nurse's assistants (NA) were all represented in the sample. Two caregivers were asked to participate as they were renowned as outstanding in their occupational roles, thus possessing a high degree of expertise. The majority of participants were females, only four were males. Characteristics of the caregivers are described in each paper.

Design, methods and results

The study was carried out in five separate parts, presented as five papers, referred to with their Roman numerals I-V. The phenomenological-hermeneutic approach was consistent. Personal interviews (I,II & V), a projective defence mechanism test, The Meta Contrast Technique (III) and an analysis of patient-caregiver behaviour shown in video taped feeding sessions (IV) were the methods used.

In paper I forty caregivers from Umedalen were asked to participate in deep interviews about their thoughts and feelings towards feeding, when patients in a late state of dementia did not take food or fluid voluntarily any longer. All accepted to participate but one young LPN. Unfortunately she did not even want to give an answer to why she refused.
The interviews were developed with special attention paid to the concepts force, double bind conflicts and anxiety. The caregivers reported that they often felt anxious when patients refused to take food or fluid. They were caught in a double bind situation guided by two strong contradictory ethical demands: "Keep the patient alive" and "Don't cause the patient suffering". They had difficulties in knowing what was right and what was wrong. Force feeding did all of them turn down. But they defined force individually. Some of them had a perspective proceeding from the patient's wish and some of them defined force according to how much persuasion or strength they had to use while others integrated both dimensions in their definition.

In paper II five caregivers from Sidsjön were interviewed about their problems feeding a patient in the terminal state of Alzheimer's disease. They made the nursing team for this patient and had asked for advice in their ethical quandary if they should continue to feed the patient per os or feed by nasogastric tube. They were ambivalent and worried and expressed a desperate need for ethical guidance.

During the interviews they verbally developed their own ethical reasoning. They all reached the conclusion that even if spoon feeding was arduous and risky with a patient nearly choking, they preferred spoon feeding to tube feeding as spoon feeding gave better conditions for practicing human and loving care. They regarded feeding as a basic constituent of a relationship and as the relationship is a basic constituent of loving care, spoon feeding turned out to be the instrument through which the caregivers could express their empathy.

In paper III thirteen caregivers from Umedalen participated. They had earlier (I) expressed themselves clearly about how they reasoned in ethical conflict situations. They were tested with a projective defence mechanism test, The Meta Contrast Technique (Smith et al., 1982) and their use of psychological defence mechanisms was studied.

Isolation turned out to be the most conspicuous defence in this group. At first this seemed as a surprising finding, as isolation is a defence mechanism usually associated with
emotional indifference. On second thoughts, it seemed likely to assume that isolation is the kind of defence that enhance the caregivers’ possibility to be sensitive to their patients’ needs without being overwhelmed by their misery. Furthermore patients with severe dementia may transfer their own isolation to their caregivers (cf. Hallberg & Norberg, 1990).

In paper IV thirty-six caregivers from Umedalen watched four video taped feeding sessions where a nurse tried to feed patients in very late states of dementia. After each film sequence they responded to four-graded Likert-scales about what they thought the patients and their nurse experienced.

Main findings were that the caregivers tried to interpret i.e. were sensitive to the patients' vague cues and imputed meaning into their behaviour. Through the caregivers' ratings each patient was pictured as an individual with her own characteristics. The nurse was rated as someone who answered to the patients' cues, in a manner that indicated relatedness.

In paper V two mental nurses from Umedalen with more than thirty years in health care and a high recognition as excellent, expert caregivers were interviewed about their thoughts and feelings with regard to dementia care. One of them was recently retired and the other one had another couple of months left to her retirement. They were asked about their thoughts and feelings when caring for severely demented patients and what they thought made a good caregiver. Through the interviews there was the opportunity to follow their ethical reasoning.

When developing the interviews relatedness, dignity, integrity, human love, patience and intuition were revealed. Their ethical reasoning bore a close resemblance to existential perspectives on nursing ethics. To be a loving caregiver for patients with severe dementia calls for deep personal commitment.
Paradigms determining the study design

This study developed by gradually stages during the years as a clinical psychologist at the psychogeriatric clinic at Umedalen's Hospital. The clinic, with nearly one hundred and fifty patients and a nursing staff of nearly two hundred and fifty, offered an incessant flow of relations, situations and problems to philosophize upon. The ethical dilemma to keep the patient alive without causing him suffering was always implicitly present even if not explicitly expressed by the caregivers. How the caregivers experienced this dilemma was the first problem that occurred as important to elucidate. Psychodynamic psychology, Bateson’s et al. (1953) double bind theory, Kohlberg's (1974) model for moral reasoning and principled ethics as presented by Beauchamps and Childress (1979) belonged to previous knowledge forming the underlying frames of reference for preassumptions. The hermeneutic circle was familiar as a way of reasoning, when trying to understand contexts.

A phenomenological approach (Bogdan & Taylor, 1975; Oiler, 1982) was chosen as the purpose was to describe as truthfully as possible what the caregivers experienced when caring for severely demented patients. Interpretation of their descriptions would contribute to an understanding of how they related to Quality of life ethics and Sanctity of life ethics. Thus the first part of the study (I) was developed on the basis of the preassumption that caring for patients in a late state of dementia could cause the caregivers anxiety as a consequence of permanent exposure to conflicting ethical demands.

The results of the first study (I) had indicated that the caregivers were caught in a double bind conflict, when facing ethical decisions, due to the difficulty to interpret what the patients experienced and the impossibility to know for sure what actions would be right or wrong. They described their work as mainly satisfying at the same time as they described their serious struggling with difficult decisions in ethical conflict situations as anxiety provoking. Thus two new questions had arisen, first how the caregivers coped with their anxiety and second how they interpreted the patients'
cues. The psychodynamic paradigm was used as means to understand both the caregivers' defence strategies (III) and how they interpreted severely demented patients non verbal cues (IV).

There was still the aim to get a deeper an even more comprehensive understanding of the caregivers' ethical reasoning. With principled ethics as frame of reference, where the question of right or wrong is focused, five caregivers were interviewed about their dilemma to decide whether or not to tube-feed a patient in a terminal state of Alzheimer's disease (II). At last two recognized expert caregivers were interviewed with the aim to try to follow their process of ethical reasoning, which led to an existential perspective on care ethics (V). The hermeneutic circle served to develop an understanding of text and context in those interview series.
INTERPRETATIONS OF RESULTS

When the five parts of this study were completed, paper V came to enlighten the entire study. Thus this paper has determined the choice of main themes for interpretations of results.

Power

The patient described in paper II, was in a terminal state of Alzheimer's disease. She lay curled up like a fetus, had epileptic spasms and showed no reactions. The food had to be inserted deep into her throat in order to elicit swallowing reflexes. She was as powerless as a human being can be and still be alive. The caregivers felt powerless. They could not get into contact with their patient. They did not know if she sensed their efforts to give tender care or if she experienced pain. They took eventually stands against tube-feeding and continued spoon-feeding as means to maintain at least the feeling to preserve some kind of minimal relatedness and interaction.

In paper IV, the caregivers were asked to rate if they thought a nurse, feeding severely demented patients experienced himself as afraid of having too much power over the patients (item 5, Tables 4 and 5), and if they thought the nurse experienced himself as powerless (item 19, Tables 4 and 5). Likewise they rated if they thought the patient felt helpless (item 7, Tables 2 and 3). There was a high degree of consensus with regard to the patients as experiencing themselves as helpless, i.e. without power. There were also strong tendencies to agreement about the nurse as experiencing himself as powerless and consequently the caregivers did mostly deny that the nurse could feel afraid of having too much power over the patient.

Fromm (1973) points to the ambiguity of the concept power. There is the good power, the power to do good things, the power to accomplish. But there is also the sadist aspect of power, as the power over another fellow-being, someone weaker. The caregivers regarded the severely demented patients as powerless in the sense that they had no control
over their situation. They regarded at the same time themselves as without power, as the patients' diseases were incurable. What they could accomplish was giving loving care, provided that they at least succeeded to create a minimal relatedness by making the patients take some food and fluid. When the patients could not receive what the caregivers wanted to provide their feelings of powerlessness increased, yet there were no signs indicating that they would be inclined to a sadist use of power. This was in fact also confirmed during interviews (I) where the interviewees reported that social control among the staff was fairly strict, and there would hardly be the possibility for a caregiver to show sadistic tendencies towards patients without someone intervening. It seems as if the study participants, due to high moral standards regarded power as the power to accomplish good and not to be used as control over the patients.

However, power over someone is not altogether a bad thing. Courage to control sadists, i. e. power over those who want to do harm is at the same time a power to do good.

If returning again to the five caregivers (II) who eventually decided not to tube-feed their patient because they preferred relatedness, there is still a question. They agreed on the spoon-feeding as risky and strenuous for the patient. They could not know if she experienced pain or not. They could neither know if she was able to experience relatedness or not. At first, their decision to continue spoon-feeding seemed as a decision for the benefice of the patient. On second thought, there could be the possibility that their judgement was dimmed by their own needs for relatedness with the patient as means to make their job worth while, i. e. meaningful. There is maybe a faint fragrance of mingled motives to be sensed. Consideration for the patient could have been confused with the caregivers' own needs for relatedness. There is apparently important to take Fromm's call, for awareness of the ambiguity of power, seriously.

**Force**

When a patient has reached the phase of dementia where he is not able to eat by himself any longer, he has to be fed by his
caregiver. As long as he can communicate verbally and show his likes and dislikes, the caregiver does not experience feeding as a problem (I, V). But when the disease has progressed to a state where the patient’s ability to speak has ceased, the caregiver experience the situation as difficult. To have to interpret a patient’s wishes from his nonverbal behaviour without getting clear responses in return was described by the caregivers as anxiety-provoking (I, II, V). The caregiver who feels required to feed the patient has to face the problem of force feeding.

In paper IV, the caregivers were asked to rate if they thought the patients and the nurse experienced the feeding situation as one of force feeding. According to the ratings, one of the patients, patient No 2 was regarded as being force fed (item 8, Tables 4 and 5; item 20, Tables 2 and 3). She compressed her lips and screwed up her eyes all the time, and the nurse had to coax with the spoon to feed. The result indicated that the caregivers could point out this specific patient as one being forced, but the study design gave no room for explanations as to why that was the case.

In papers II and V a definition of violence never was brought up as a subject as it did not represent any problem in the situations referred. In paper II, because the patient opened her mouth and swallowed without coaxing and in paper V because the interviewees had reached a level of ethical reasoning beyond defining force as the crucial question.

In paper I, the interviewees defined force feeding as being anything between mild persuasion and physical violence. There were as many definitions of force as there were interviewees. First, this seemed confusing, but after a while there was a pattern to be seen. The pattern contained two dimensions along which force seemed to be defined. The first dimension was connected to the amount of physical violence, i.e. coaxing and prizing, the caregivers had to perform to make the patient eat. The second dimension was their impression of the patient’s wish, i.e. a patient wish perspective. Some caregivers defined force according to the violence dimension, while some had the patient wish
perspective. Yet many interviewees had an approach where both dimensions seemed to be integrated.

In a teleological perspective force-feeding may be justifiable, if the desirable consequence e.g. is, to keep the patient alive, no matter how. Analysed in a deontological perspective force-feeding may also be justified, if regarded as the act of feeding i.e. the basic constituent of survival, where feeding per se has its own intrinsic value. In an ontological perspective force-feeding may be judged as abuse or not dependent upon interrelatedness in the care situation.

The caregivers who defined force-feeding according to the amount of violence they had to use to make the patient eat, simultaneously denied they practiced force feeding. They justified their coaxing and prizing by referring to their duty to keep the patient alive. They evaluated their actions as right or wrong due to effect, thus using a teleological model for ethical reasoning.

Those who defined force feeding according to a patient wish perspective also used an ontological model when evaluating their actions as right or wrong. Their relatedness to their patients was important and they regarded feeding as one part of the total care situation. They expressed deep concern for the patient's assumed experience of his situation and pointed to the difficulty in knowing what would be right or wrong from the patient's perspective. They stressed the importance to consider the patient's wish when making decisions. At the same time several caregivers expressed a wish for some kind of basis in a deontological set of rules, to safeguard themselves and the patients against decisions at discretion.

A deontologic model for reasoning was not easily discovered among the study participants. Yet one young licensed practical nurse came fairly close, when she described the situation as a choice between two evils (I). She justified her efforts to feed, even so unpleasant for the patient, with the argument that the patient must be hungry and hunger is painful.
Those who saw the world through teleological glasses were rather convinced that their actions were morally justifiable, while those who had an ontological outlook on ethics were prone to vacillate and experience patients' food refusal as a source of anxiety.

**Anxiety**

In papers I and II the caregivers described how they experienced the two ethical demands "Keep the patient alive!" and "Don't cause the patient suffering!" as conflicting, when patients refused to receive food and fluid. The conflict was of double bind character thus insoluble. Whatever stand they took or action they performed there was the risk that their decisions were to be regarded as wrong. This uncertainty in ethical dilemmas caused feelings of anxiety.

Paper III indicates that the caregivers' level of psychological defence against anxiety was connected to how they related to the two conflicting demands. Those who had taken an unambiguous stand and regarded "Keep the patient alive!" as their rule for guidance exhibited higher levels of psychological defence than those who declared themselves ambivalent to the moral dilemma.

It seems contradictory that caregivers, who declared themselves as largely certain, that their duty was to keep the patient alive, showed higher levels of defence against anxiety than those, who described themselves as uncertain and often exposed to feelings of anxiety because of moral quandary. The question of cause and effect is not easily answered, but calls for inquiring.

In a teleological model for ethical reasoning the consequence determines if an action is to be regarded as morally right or wrong. This means that there are answers. If the caregiver has succeeded to make the patient take food or fluid she has been acting correctly, provided the aim was to keep the patient alive. The answer is to be found in the effect of the action. If on the other hand, the caregiver reasons according to an ontological model there are so many different aspects to
be taken into consideration that the caregiver never can receive a conclusive answer. She is left alone with her own judgement and life philosophy as guidance (cf. Lögstrup, 1971).

A teleological model for ethical reasoning, where guiding rules are explicit, offers lesser personal challenging than an ontological, where evaluation of the total situation is required all the time. Thus persons with lower tolerance limits for anxiety and consequently higher levels of psychological defences mobilized, would be the ones prone to adopt a teleological model. This may also be used as protection against too close a relation to patients. Hence persons with higher tolerance for anxiety would be prepared to endure uncertainty and anxiety without mobilizing as much defence. A high tolerance for anxiety is required when performing the task of coming close to miserable patients. The choice of an ontological model for ethical reasoning may be suitable for caregivers with capacity for containing and holding and lesser need for protecting themselves by means of using psychological defences. A caregiver's choice of an ontological model for ethical reasoning may be connected to her ability for empathy and autonomy.

**Empathy**

In paper V one of the interviewees referred to one of the most important characteristics of a good caregiver as the power to live a patient's part. She described how she imagined a severely demented, aggressive and disruptive patient as the kind and human person he had been earlier. She had thoughts about his family and what his life would have been like. With help of her imagination she painted a picture of a person and could feel warmth and human love. Empathy expressed as relatedness to the patients was often mentioned (I, II, V) as basic in the care situation.

Paper IV illustrates how the caregivers tried to interpret severely demented patients' non verbal cues and impute meaning into their behaviour. The four patients were given characteristics that made them appear as four separate individuals. There was also consensus among the caregivers
that they regarded the patients as persons who seemed to want tenderness. Paper IV is an illustration of the caregivers' ability to regard their patients as subjects, thus avoiding objectification and alienation.

In paper III, isolation used as psychological defence is interpreted as one of the essentials when aiming at close relatedness with a severely demented patient. Isolation may function as a filter, through which the caregiver can perceive reality without introjecting the whole range of disgust, sorrow and depression a severely demented patient's suffering may transfer. Thus isolation used as defence gives the caregiver an opportunity to perceive the patient's needs without being overwhelmed by anxiety.

Prerequisites for empathy were, when trying to synthesize the results of the five papers, the caregivers' containing and holding function, relatedness between the caregiver and her patient and an ability and willingness to interpret and impute meaning into the patients' vague nonverbal cues. The caregivers' instruments for practicing empathy were their ability to listen, use their imagination and patience.

Implicitly the caregivers described empathy as the power to live the others' part, the ability to understand the other person, consider his needs and wishes and feel related to him, yet maintaining a distance and respect for the other's integrity and dignity.

**Dignity**

Dignity was often mentioned in papers I, II and V as an important aspect of care for the severely demented patient. For the dying patient peace and quiet and a hand to hold illustrated what the caregivers meant by dignity. With the expression dignified treatment of patients, the caregivers also referred to their duty to protect patients against humiliating themselves through unworthy behaviour. To help the patients to cover themselves and to maintain privacy in the bathroom were examples of dignified treatment, as well as efforts to keep up table manners. The caregivers' attention to
tidiness with regard to the patients' clothing and surrounding may also be interpreted as a sign of their feeling for the importance of dignified treatment.

The word dignity was mostly used by the caregivers in the same context as integrity. The concepts were strongly connected. However, dignity was to be understood as the patient's worth as a human being, seen through the eyes of others, while integrity referred to the patient's image of himself as a person experiencing wholeness and meaning.

When patients have lost their capacity for intellectual reasoning, their memory, language and judgement, they are dependent upon their caregiver who can make use of her empathy to help them continue their lives in dignity with maintained integrity. To analyse the meaning of the concepts dignity and integrity they must be understood in a larger context of care ethics.

**Ethical reasoning**

In papers I and II ethical reasoning was centred around ethical dilemmas. The contradiction "Keep the patient alive" and "Don't cause the patient suffering" represented one insoluble dilemma. Questions about ethical limits with regard to feeding as force-feeding were raised. The interviewed caregivers' ethical reasoning was to a large extent expressions of seeking the truth in terms of answers. To know if their actions would be judged as right or wrong was the focus of their quandaries. When there were no clear answers to be found, they experienced ethical decision making as a source of anxiety. To quite a large extent they seemed to reason in a teleological frame of reference. But when given the opportunity to develop their thoughts verbally, they gradually came closer to an ontological model for reasoning (II). The quality of the relation to the patient became more important in their reasoning than seeking the truth in answers (V). Yet with the reservation that the legal rights of the individual always must be considered and euthanasia never used.
Even if paper IV does not offer the opportunity to follow the process of ethical reasoning, it illustrates how the caregivers imputed meaning into the patients' nonverbal cues and took individualized stands after having interpreted their behaviour. Yet there was consensus that the patients wanted more tenderness, were helpless and not without feelings. The caregivers expressed that they could see the patients as separate individuals and take different stands according to what they presumed was adequate for each of them. At the same time they referred to a basis of moral standards including all human beings' need for tenderness and all human beings as having feelings.

In paper V, interviews with two recognized expert caregivers, gave an illustration of how two mature persons have developed to a level beyond a teleological model. They expressed that they did not feel the importance of judgement of their actions as morally right or wrong any longer. Their concern was centred around their possibility to act for the benefice of the patient. "Do good" was given priority to "Do right". Yet, one of the interviewees when explaining her process of ethical reasoning gave a wonderful description of her parents' and especially her father's influence on her moral development, by teaching rules about right and wrong.

The caregivers' ethical reasoning could be followed along two different paths. One path was the teleological, where answers and judgements about right or wrong were focused. This path seemed fairly straight, if the walker had a map and compass in her equipment. Sometimes the map was not clear, sometimes the variation of the compass had to be considered, but largely the walker felt convinced she would find her way. The other path, the ontological, the ethic of understanding was more complicated. The maps were not complete with white spots and the compass varied due to fields of magnetism.

The real walkers, not necessarily the oldest or most experienced with regard to amount of walking they had performed, but most passionate, did not find enough adventure in the straight paths after a while. They had heard about mountain paths leading to great experiences
and were prepared to endure hardships, with the hope to reach an understanding of the meaning of life. But however adventurous and courageous, even the most experienced walker never neglected the primary safety rules or forgot to bring a map and compass when starting off. The caregivers showed that ethical reasoning is something beyond dichotomizing ethics in teleology versus ontology. Principled ethics were not to be understood as opposing an existential perspective on care ethics.

Caring for patients as the severely demented, who can not express their wishes and needs, is in many respects to be compared to an expedition with the aim to gain a deeper understanding of the meaning of life and death by getting a mountain view over the numinous.

Death

Ambivalence is frightening. Death is frightening (III). Maybe there are the reasons why not that much was said about death in this study. In papers I, II and V the caregivers described their feelings when faced with the death of a patient. Death was not seldom seen as a rescuer from pains and indignity and for the best of the patient when he had reached a state of severe dementia. Nonetheless they mourned over patients with whom they had felt related.

In paper IV there are illustrations of reluctance to admit that severely demented patients may have a death wish. The caregivers also showed large hesitance with regard to admit that a nurse would be able to wish that a patient, even so demented, would die.

Thoughts about admitting euthanasia were strictly rejected with emphasis and abhorrence, referring to every human being's right to fulfil his life time (I).

In paper V, the caregivers philosophized upon death as something peace and quiet, the moment when pain and indignity have come to an end, the feeling of coming close to something beyond and a touch of the numinous.
Ramsey's (1974) reasoning about the indignity of "Death in dignity" did not appeal to the caregivers participating in this study. Even if they showed reluctance to speak up loudly about their thoughts of death and dying, they expressed themselves clearly enough. Death may be the rescuer.
DISCUSSION

The aim of this study was to explore how caregivers caring for severely demented patients experienced ethical conflict situations and how they reasoned. The phenomenological approach proved profitable to gain information and understanding of what caregivers actually experience and how they reason when they are engaged in their everyday practical tasks of life (cf. Oiler, 1982; Tanner, 1897). Hermeneutic inquiry (cf. Benner, 1984; Reeder, 1989) did really enlighten the caregivers' thoughts and feelings in the context of ethical theories and contributed to a deepened understanding of the process of their ethical reasoning.

Yet, one of the methods used (III) may be questioned. The Meta Contrast Technique (Smith et al., 1982) is interesting as a clinical method for studying psychological defence mechanisms, but has the disadvantage of not being widely used. This led to an extreme caution regarding the interpretation of the result. The perceptgenetic model (Kragh & Smith, 1970) on which the test is based is interesting enough and with a more outspoken interpretation, the test results had been of greater value. Still the test functioned well as means to raise interesting questions about the caregivers' strategies when faced with ethical dilemmas.

The majority of study participants (I) were selected by stratified sampling. Five were selected because they were the nursing team for one special patient (II) and two because they were recognized as expert caregivers. There are reasons to question if the stratified sampling had any function. A study choice of recognized experts and novices as participants could have contributed even more to an understanding of caregivers ethical reasoning (cf. Benner, 1984).

Did this study reveal a feminine way of reasoning different from what would have been a masculine? Yes (cf. Gilligan, 1982; Cooper, 1989), if their way of relating to ethical dilemmas was compared to cognitive theories on moral development (cf. Kohlberg, 1981). No, if taken into
consideration the men who have contributed to care ethics from a psychodynamic perspective (Gaylin, 1979), a theological perspective (Ramsey, 1970; 1974; 1976; Lögstrup, 1971; Thomasma, 1980a; 1980b; 1984a; 1984b; Thomasma & Pellegrino 1981) and an existential perspective (Marcel, 1963; Mayeroff, 1971). If it is true that women dislike dichotomies and take efforts to unite them, this study gives an example of feminine reasoning.

There are discussions about the possibility to apply general principles normatively (Twomey, 1989) and to which extent each concrete situation needs an individualized judgement (Fletcher, 1969). There is also the question if existential approaches should ground ethical reasoning in care (cf. Huggins & Scalzi, 1988; Bishop & Shudder, 1987). This study gave many examples of how caregivers wanted to get a total picture within which as well their questions of right and wrong could be answered, as whether they were doing good.

In this study the participants' age, years in health care and education did not seem to influence the result. Moral development and ethical reasoning seemed to be mostly determined by the individual's personality structure. Also other studies (Ketefian, 1981; 1987; 1988; Woodruff, 1985) have pointed to the need to explore relevant personality characteristics as determinants for moral reasoning. They did not find connections between caregivers' educational level and their level of reasoning on ethical nursing matters. There is no answer to what the relevant characteristics would be, without taking the risk of sounding self-evident. A strong ego with well adapted defences (III), good containing and holding function and a development beyond the need for omnipotence (V) could be some of the important characteristics. Maturity as described by Jung (Jaffé, 1962; V) and the virtues care and wisdom as described by Erikson (1982) are qualities hardly measurable, but intuitively obvious, when looking for someone to trust as caregiver.

Life as the opposite to death is the most manifest dichotomy. Ramsey (1974) objects with emphasis to the possibility of a death in dignity. In this study death was described as peace and quite, a possibility of ending life in dignity. When the
patient had reached the state of disease where there was only pain and indignity left death was sometimes regarded as the rescuer. (I, II, V). To face that life always has an end and that the end sometimes is the rescue from pain is one way of getting reconciliation and perhaps a way to endure the frightening power of the dichotomy. Yet did the study participants hesitate to admit that they could wish that a severely demented patient would die or that patients might possess death wishes. They expressed great abhorrence when asked about the possibility to use euthanasia (I). This was contradictory to findings by Norberg and Asplund (1990). A large majority of their interviewees admitted that they felt relief for the sake of the severely demented patient when he died. Several of their interviewees also admitted that they in some cases could accept the thought of euthanasia, yet with the reservation that judgement must be very comprehensive and skilled. The study population was very similar to the one of this study, with regard to educational level and years in health care. Why, the difference in outcome? The study by Norberg and Asplund was carried out at nursing homes, while the present study mainly took part at a university hospital. Can hopelessness and meaninglessness be experienced by the staff in nursing homes due to lack of dialogues, support, supervision and educational programs? Can this lack be projected on to the patients as feelings of meaninglessness and death wishes (II)? If so, systematic dialogues on care ethics, further education and supervision would be possible cures!

Respect and freedom for oneself and for other persons are keywords for Thomasma (1980a; 1980b; 1981; 1984a; 1984b). A caregiver experiencing freedom and respect in her own life has the prerequisites to treat her patients with dignity thus respecting his freedom to fulfil his life, even if the meaning is not spontaneously obvious. In this study the caregivers demonstrated a wish to understand more, not only about their demented patients, but about life. When they perceived the tension between the dichotomies power-powerlessness, force-freedom, anxiety-trust, empathy-objectification, dignity-indignity and life-death they also expressed their yearn to know more about life in a total context. Questions of right and wrong were developed to a
new level of abstraction as questions of getting the grasp of total situations (cf. Benner, 1984).

There on the caregivers' adventurous journey, principled ethics, the map and compass, proved to be essential equipment, but not enough. The travelling companions, the patients, had brought a lot of luggage to be taken care of by their caregivers. The expectations were high. Hopefully the journey would enrich all participants. Food and fluid, plaster and pills were stored in the caregivers' bags. But the most experienced caregivers had also prepared themselves with stories to tell, songs to be sung and one had brought her bible. The journey could be long or short, no one knew in advance. High mountains and deep valleys had to be crossed. Rain, hot sun and snow storms could come. But if all went well, there was the possibility that the company would reach their goal and get the grace (cf. Marcel, 1963) of experiencing the midnight sun together.

In that moment of peace and fulfilment we remember with gratefulness Jung and his cherries (V; Jaffé, 1962), the Greek nun Lanara (1981) who described caring in the context of philosophy and the French dramatist and existentialist (Marcel, 1963). They had already told how adventurous travelling could be and that it should be a continuous process. The earth is round and the universe seems infinite. The reasoning on care ethics can never come to an end.
ACKNOWLEDGEMENTS

This work was eventually completed, although so much happened in between. My fellow-beings helped me to keep warm through the longest and coldest winter night. Thank you, all of you!

The study participants, the caregivers, my work-mates, generously shared their knowledge, reasoning thoughts and feelings.

Professor Astrid Norberg, Head of Department of Advanced Nursing, shared her deep knowledge, incessant flow of ideas, creativity and sincere comradeship. What a supervisor!

Professor Gösta Bucht, Head of Department of Geriatric Medicine, shared his knowledge and brought me up in geriatrics.

Associated Professor Sture Eriksson, my much appreciated boss, always challenging and demanding logical thinking, eventually convinced me that a word-processor can replace pencils and erasers.

Dr P O Sandman, warm friend and colleague, always required connection between concrete and abstract reasoning.

Professor Bengt Winblad, thought I used too few tables and diagrams, but introduced my to Astrid!

The fellow-doctoral students in Geriatric Medicine and Advanced Nursing, accepted me although an outsider.

Mrs Inga-Greta Nilsson and Mrs Karin Stenmark, helped me when I was lost in the jungle of bureaucracy.

My circle of friends, and my sister Eva, you were always there!

Dr Karin Enzell and Dr Lars Olov Wahlund, St Göran's Hospital, offered finally generous support.

Börje Hellner, provided intellectual challenging for breakfast as well as late night suppers and a cosy study with a CD. Without his love and care this work would neither have been resumed nor completed. If he proposed, I would accept.

This study was supported by grants from the Swedish Work Environmental Fund and Stiftelsen för Gamla Tjänarinnor.
REFERENCES


Brâne, G. (1989). The GBS Scale. A Geriatric Rating Scale and its Clinical Application. Reports from the Department of Psychiatry and Neurochemistry, St, Jörgen’s Hospital, Gothenburg.


Norberg, A., Melin, E. & Asplund, K. (1986). Reactions to music, touch and object presentation in the final stage of dementia. An


