Ethical Reasoning among Experienced Registered Nurses in Relation to Communication with Severely Ill Patients Disclosing Personal Knowledge

by

Lilian Jansson

Umeå 1993
Ethical Reasoning among Experienced Registered Nurses in Relation to Communication with Severely Ill Patients: Disclosing Personal Knowledge

AKADEMISK AVHANDLING

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av

Lilian Jansson

Umeå 1993
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Lilian Jansson, Department of Advanced Nursing, University of Umeå

ABSTRACT
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Through a phenomenological hermeneutic analysis of video recordings of two RNs' interaction with each of four severely demented patients, it was possible to interpret the patients' vague and unclear communicative cues. But observations based on an assessment of facial muscle movements showed that it was very difficult (the FACS).

Group supervision based on a narrative framework was carried out in order to support nurses working in dementia care. Interviews with the fifteen RNs showed that they experienced recognition and reassurance of worth, an increased repertoire of actions, gained new perspectives, an increased awareness of their professional role, and interdependence.

It is proposed that the care of severely ill patients can be improved by the use of a narrative approach both as regards understanding patients and encouraging RNs to develop their clinical knowledge through reflecting on their own and their coworkers' narrations about care.

Key words: Communication, dementia care, ethical reasoning, group-supervision, narrative ethics, oncological care, phenomenological hermeneutics, reflection, video recording
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Umeå 1993
To Lars

Anders, Karin and Maria
Matthew 7:12
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This dissertation is based on the following papers which will be referred to in the text by their roman numerals:


The papers have been reprinted with the kind permission of the respective journal.
INTRODUCTION

This study focuses on the reasoning exercised by experienced registered nurses (RNs) in ethically problematic situations which arise in the care of severely ill patients with cancer and dementia respectively. These two groups of patients are in the final stages of life and the focus of care is palliative rather than curative. Palliative care is seen here as 'the management of physical and emotional symptoms and the provision of social and spiritual support for both patient and family during the course of a progressive illness that is beyond the reach of cure' (New South Wales Palliative Care Association 1983).

Carers when caring for severely ill patients, face situations where they feel uncertain about what is the best and the right thing to do. This uncertainty is often related to difficulties to communicate with patients, patients' family and coworkers.

In caring for the severely ill patient the relationship between patient and carer is of the utmost importance. It is made possible by means of communication. Through communication the patient and caregiver can recognize each other. The ways in which the carer reacts and responds to the patient in thought, feeling and action are important.

Ethical problems in the care of terminally ill cancer patients

Difficulties in communicating with terminally ill cancer patients arise for many reasons. Glaser and Strauss (1965) describe care environments where open communication about dying was not permitted. Benoliel (1988) states that peer pressures against speaking openly and prohibitions by physicians and/or family against conversation with the patient concerning the diagnosis and prognosis create difficulties. Practising nurses rank communication in death-related encounters as among the most problematic they face (Quint 1976, Western Consortium for Cancer Nursing Research
Providing care for terminally ill cancer patients often involves ethical problems associated with withdrawing feeding (Fry 1986). The terminally ill patient may refuse food for several reasons; loss of appetite, mechanical problems when chewing and swallowing, changes in taste, and a wish to die (Gray et al. 1988, Davis et al. accepted). Ruben and coworkers (1988) state that the occurrence of feeding problems can be seen as an indication that the patient is in the terminal stage of life.

Ethical problems experienced by carers in cancer care are often related to personal and job-related factors which create high levels of stress (Gray-Toft 1980, Barstow 1988, Davidson et al. 1990, Cohen and Sarter 1992, Beck-Friis 1993, Kuuppelomäki 1993). RNs experienced in the care of patients with cancer emphasized that whether or not they were able to act in a way they felt was good and right in difficult care situations was dependent on their co-operation with coworkers (Åström et al. 1993).

Ethical problems in the care of severely demented patients

In the care of elderly patients with dementia disease, many of the ethical problems experienced by the carers are connected with the fact that the patients have a reduced ability to communicate connected to dementia symptoms (Levine et al., 1984, Obler and Albert 1984, Arras 1988, Ekman and Norberg 1988, Rapcsak et al. 1989, Reisberg et al. 1989, Abeysinghe et al. 1990, Ekman et al. 1991). In the final stages of the disease the patient is often described as having lost most of her/his verbal and non-verbal communicative ability (Bayles and Kaszniak 1987). The carers have very little solid basis for their interpretations which can lead them regarding the patient as an object (Athlin et al. 1989). There are also carers who interpret the few and unclear cues as revealing some meaning (Farran and Keane-Hagerty 1989, Norberg and Asplund 1990, Bohling 1991).
Patients suffering from severe dementia often have problems with food (Fairburn and Hope 1988, Bucht and Sandman 1990) due to such symptoms as amnesia, apraxia, agnosia and aphasia (Athlin and Norberg 1987, Watson 1993), especially in the terminal stage of life (Sandman et al. 1990). Carers have difficulties in interpreting the demented patient's communicative intention during feeding, and the uncertainty about how to treat the patient gives rise to ethical problems. When the patient is unable to receive food through spoon-feeding, alternative means to feed the patient and withdrawing feeding are considered (Norberg et al. 1987, Volicer et al. 1990, Asplund et al. 1991a). Spoon-feeding then can be used to show the love and concern (Lynn and Childress 1983).

Strain and exhaustion amongst carers of severely demented patients are common (Äström 1990, Hallberg and Norberg accepted). These problems are connected to such as an experience of meaninglessness and powerlessness (Hallberg and Norberg 1990, Åkerlund and Norberg 1990, Asplund and Norberg, accepted). Asplund (1991) states that there is a relationship between the carers' experience of an overall meaning in life, the experience of meaning in the care of a severely demented patient and the experience of meaning in a patient's communicative cues.

Support to RNs in the care of severely ill patients

A deeper understanding of the nurses' experiences of ethical problems can provide a basis for determining how to support the carers so that they come better prepared to meet the patients' needs.

Support groups, clinical group-supervision, and group counselling are often regarded as most valuable when it comes to preventing and decreasing job-related stress, and promoting professional development (Gray-Toft 1980, Bulechek and MacCloskey 1985, Kadushin 1985, Anderson and Riggin 1991, MacKenzie 1992, Johns 1993). The rationale behind these approaches is that if carers are given opportunities, in a regular and organized way, to express and share their problems and possibilities, they can become aware of and work through their care difficulties.
Being in ethically problematic care situations

The word ethics and the word morality are often used as synonyms. When we talk about morals we often refer to norms, customs and/or traditions that guide us in actions (cf. Garfinkel 1967). The word morality is sometimes used to refer to the practice of a person, whereas the word ethics is used to refer to the rules or principles explicitly held or stated by that person (Fox and DeMarco 1990). Kemp (1991) talks about ethics as a fundamental opinion on the right way to live and morality as norms and moral rules with which we try to transform ethics into actions. The connection between moral reasoning, ethics and action is complex (Locke 1983, Kurtines and Gewirtz 1984).

Beauchamp and Childress (1989), suggest the existence of a context-independent moral reasoning. They mean that ethics formulates, describes and defends basic moral principles that govern moral life. When we do not experience ethical problems we may follow principles, without being aware of them, but when we do not know how to automatically apply the principles and thus become aware of them we experience ethical problems. When an ethical problem occurs, it can be analyzed as a conflict between various general ethical principles, e.g. the principles of autonomy, beneficence, and justice. A problem-solving moral reasoning is required (Fox and DeMarco 1990). Kohlberg (1981) has described moral development as a growing ability to reason in accordance with abstract and general ethical principles in a context-independent manner.

A more context-dependent moral reasoning is described by Jonsen and Toulmin (1988). They state the importance of using paradigm cases and maxims based on personal experiences when deciding how to act in ethically problematic situations. This decision occurs through an 'ordering of cases by paradigm and analogy, appeals to maxims and analyses of circumstances, the qualification of opinions, the accumulation of multiple arguments, and the statement of practical resolutions of particular moral problems in the light of all these considerations' (pp. 256-257). Åström and coworkers (submitted) have made explicit the use of paradigm cases and maxims by RNs considered to be experienced and good of cancer care. It was evident that some nurses used paradigm cases with negative outcomes.
and limiting maxims, while others used paradigm cases with positive outcomes and liberating maxims.

The use of paradigm cases and maxims can be seen as a kind of personal knowledge, *i.e.* knowledge traditions interacting with the person's lived experience (Polanyi 1958). Personal moral knowledge has been described by Phenix (1964). Moral action presupposes an active personal commitment, participation and freedom which requires maturation.

Nerheim (1991) emphasizes that there is always a background of tacit knowledge that affects moral reasoning and action, *i.e.* knowledge that functions tacitly (Polanyi 1966) and that we rely on when we focus on something else, or experience that is 'unsayable', *i.e.* can not be said but only shown (Wittgenstein 1922). The outlook on the human situation in which moral actions should be taken is an important tacit knowledge. Nerheim (1991) takes Karl Adolf Eichmann, the Nazi war criminal as an example of a person with a destructive outlook on life. His crime was that he was alienated from the human situation, he had no insight in to what he did (*cf.* Arendt 1977). Burell (1977) describes self-deception as an ethical problem. We choose to stay unaware of what we take part in. His idea is that we not only need to be conscious of what we are doing but also about ourselves doing it.

Ricoeur (1987) says that narration may serve as a link between action and ethics. To narrate an experience is to retell the 'prehistory' that one has been 'entangled in' (Ricoeur 1984) or in other words tell the lived story (Tappan 1990). A story shows a complex interplay amongst cognitive, emotional and conative elements (Tappan and Brown 1989) and can be supposed to disclose personal knowledge. A story can not be narrated without implying ethics of some kind (Kemp 1991). By giving ourselves images in narratives we can prefigure life and make choices about which imagined narratives to live. In narrative ethics the ethical principles express a fundamental ethical attitude and can be disclosed through our narrative competence (Kemp 1988). Ricoeur (1987) claims that there are both good and bad narratives and proposes that narratives that fulfil the criteria implied in the Golden Rule (Matthew 7:12) are good. The Golden Rule demands that we recognize (confirm) the other and avoid violence.
According to Ricoeur (1978) the problem of recognizing the right to freedom in the other person is the central phenomenon of ethics. The actualization of an other's freedom presupposes my freedom and my freedom presupposes the other's freedom (cf. Hegel 1967, Asplund 1991, Ekman 1993). The person finds herself/himself in a situation that is historical and not ethically neutral. Values express what is desirable and norms what is prohibited. Imperatives express what should be done. Vitz (1990) describes moral development as an increasing ability to use narrative thinking in a context-dependent way.

THE AIM OF THE STUDY

The aim of this dissertation was to disclose personal knowledge among experienced RNs in relation to feeding severely ill patients with cancer and dementia, communicating with severely demented patients, and receiving group supervision in dementia care.

MATERIAL AND METHODS

Participants and design of the dissertation

A schematic illustration of the dissertation concerning number of subjects, methods of data collection, types of analysis and context for the different studies is presented in Table 1. The data were collected in different settings in Northern Sweden.
Table 1. Number of subjects, methods of data collection, types of analysis and context for the study.

<table>
<thead>
<tr>
<th>Paper</th>
<th>Number of subjects</th>
<th>Context for the study</th>
<th>Method of data collection</th>
<th>Type of analysis</th>
</tr>
</thead>
<tbody>
<tr>
<td>I</td>
<td>20 RNs</td>
<td>Cancer care</td>
<td>Interviews</td>
<td>Digital</td>
</tr>
<tr>
<td>II</td>
<td>20 RNs</td>
<td>Dementia care</td>
<td>Interviews</td>
<td>Digital</td>
</tr>
<tr>
<td>III</td>
<td>20+20 RNs</td>
<td>Cancer care and dementia care</td>
<td>Interviews</td>
<td>Analogue/digital</td>
</tr>
<tr>
<td>IV</td>
<td>4 patients 2 RNs</td>
<td>Dementia care</td>
<td>Videotaped observations</td>
<td>Analogue/digital</td>
</tr>
<tr>
<td>V</td>
<td>4 patients 2 RNs</td>
<td>Dementia care</td>
<td>Videotaped observations</td>
<td>Analogue/digital</td>
</tr>
<tr>
<td>VI</td>
<td>15 RNs</td>
<td>Dementia care</td>
<td>Interviews</td>
<td>Analogue</td>
</tr>
</tbody>
</table>

A structured interview was conducted with twenty RNs involved in cancer care (I) and dementia care (II) respectively. Characteristics of the RNs are given in Table 2. For a description of nursing education in Sweden see Hjelm-Karlsson (1988). The RNs in I and II were identified by their nurse directors as being 'good and experienced' nurses. The directors used their own criteria for judging 'good and experienced' nurses in accordance with the policies of their clinics.
Table 2. Characteristics of nurses in studies I, II, and III (n=40)

<table>
<thead>
<tr>
<th>Nurses in:</th>
<th>Cancer care (n=20)</th>
<th>Dementia care (n=20)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age (yrs, range)</td>
<td>29-63</td>
<td>32-52</td>
</tr>
<tr>
<td>Sex (female/male)</td>
<td>20/0</td>
<td>16/4</td>
</tr>
<tr>
<td>Head nurses/staff nurses</td>
<td>5/15</td>
<td>8/12</td>
</tr>
<tr>
<td>Years in nursing (range)</td>
<td>8-39</td>
<td>6-30</td>
</tr>
<tr>
<td>Years in dementia care and in cancer care, respectively (range)</td>
<td>4-25</td>
<td>4-30</td>
</tr>
</tbody>
</table>

The questionnaire used in these studies was constructed by Anne Davis, USA, Miriam Hirschfeld, Israel, and Astrid Norberg, Sweden (the interview formulas are shown in I and II) and has been used in a study to investigate the experience of ethical dilemmas among carers when feeding terminally ill cancer patients and severely demented patients in different cultures (Davidsson et al. 1990, Davis et al. in press, Norberg et al. submitted). The interview formula was developed from a model for ethical reasoning based on an analysis of the literature (Beauchamp and Childress, 1979) and interviews with carers experienced in dementia care in Sweden and Israel (Åkerlund and Norberg 1985, Norberg and Hirschfeld 1987).

The RNs experienced in cancer care were asked to make a decision about whether or not a hypothetical case of an elderly female, terminally ill cancer patient who refuses food should be fed. In the same way the RNs experienced in dementia care were asked whether or not they would feed an elderly severely demented woman, who exhibits refusal-like feeding behaviour. The RNs were also asked under what circumstances they could justify active euthanasia and rank order ethical principles. In the following the two groups are referred to as cancer care nurses (CaRNs) and dementia nurses (DeRNs). In a second analysis (III) the above interviews were analyzed in order to illuminate what it meant to these nurses to face a
situation where the patients who refuse food can/can not decide for themselves.

Papers IV and V deal with four patients, two men and two women with Alzheimers' disease (AD) (APA 1987) (Table 3). The care was given for three weeks by a RN and for another three weeks by a nurse teacher (RNT), both experienced in the care of demented patients.

Table 3. Characteristics of the patients in IV and V (the names are fictive).

<table>
<thead>
<tr>
<th></th>
<th>Ann</th>
<th>Benny</th>
<th>Charles</th>
<th>Dorothea</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age</td>
<td>57</td>
<td>76</td>
<td>89</td>
<td>78</td>
</tr>
<tr>
<td>Duration of AD</td>
<td>8</td>
<td>12</td>
<td>5</td>
<td>8</td>
</tr>
<tr>
<td>(yrs)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Duration of hospital-stay (yrs)</td>
<td>5</td>
<td>10</td>
<td>4</td>
<td>4</td>
</tr>
</tbody>
</table>

The four patients were assessed as being in the final stage of AD. With the exception of a few hours a day they were bedridden, incontinent for urine and faeces and had been spoon-fed for two years or more. Their ordinary carers regarded them all as mute and totally dependent.

Ann had worked as a teacher and had been interested in culture, especially music and literature. At the time of the study she could not recognize her relatives. It was very difficult to feed her, her oral mucosa was irritated, she was cachectic and her legs and arms were clearly rigid.

Benny had worked as an industrial worker and had been interested in hunting, fishing and various kinds of sports. He liked folk-music and had often played the accordion. His hearing had been poor for many years.
The farm had been Charles’ main interest. He was fond of all kinds of music and also enjoyed reading the newspaper. He had contractures in his arms and legs.

Dorothea was a farmer's wife. She had been very fond of singing. Her hearing had been poor for many years. She had contractures in her legs and arms.

All the patients are now dead and the diagnosis of AD was confirmed by autopsy.

On the basis of a pilot study (cf. Norberg et al. 1986) and a previous study (Asplund et al. 1991), a program for care was designed which was regarded to be a positive stimulation for the patients. The patients were videotaped during selected activities, morning care, music-listening, rocking in a rocking-chair, having lunch, the carer read aloud to the patient. Between the different activities there were periods of rest. Two cameras were used, one focused on the patient’s face and the other on the patient and the carer together.

In paper V a sample of video sequences judged in paper IV to be emotional facial expressions of anger, disgust, happiness, sadness and surprise were assessed by another researcher using the Facial Action Coding System (FACS) (Ekman and Frisen, 1978).

Paper VI reports group supervision of fifteen DeRNs from four different units at a psychogeriatric clinic over a period of 1 1/2 years and interviews regarding their experiences of being supervised. The characteristics of the DeRNs are shown in Table 4.
Table 4. Description of the supervised and interviewed DeRNs (n=15).

<table>
<thead>
<tr>
<th>Characteristics</th>
<th>N</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sex - male/female</td>
<td>2/13</td>
</tr>
<tr>
<td>RNs working with:</td>
<td></td>
</tr>
<tr>
<td>psychogeriatric in-patients</td>
<td>11</td>
</tr>
<tr>
<td>psychogeriatric out-patients</td>
<td>1</td>
</tr>
<tr>
<td>psychogeriatric daycare-patients</td>
<td>2</td>
</tr>
<tr>
<td>administration</td>
<td>1</td>
</tr>
<tr>
<td>Age (range)</td>
<td>35-55</td>
</tr>
<tr>
<td>Years in psychogeriatric care (range)</td>
<td>2-30</td>
</tr>
</tbody>
</table>

During the period of supervision, the fifteen DeRNs were divided into two groups. Each group was headed by a supervisor and met for one hour, about once a week. At the first meeting each group agreed on a contract which would be valid for one year. To each session each member of the group brought a story from her/his clinical work, which they wanted to share and reflect upon in the group. After each session the supervisor took notes of the stories discussed. In order to illuminate the DeRNs' experience of participating in the group supervision, a personal narrative, tape-recorded interview was carried out with the fifteen DeRNs, focusing on the experience of the supervision (Mishler 1986). The DeRNs were asked to narrate an example of a supervision-session that had been of special importance to them in their work with demented patients and to relate their thoughts and feelings to their experience of being supervised.

Analysis

The interview formulas used in papers I and II were restructured into four different coding schemes. The schemes differed marginally according to
type of care (dementia or cancer care) or whether the patients were fed or not. A scheme for a demented patient who was not fed is shown in Appendix.

The interviews were transcribed and coded independently by two researchers concerning whether or not the interviewees would feed a patient who refused food, under what circumstances they would change their minds, how they rank ordered ethical principles and justified their ranking.

In papers III and VI a phenomenological hermeneutic method inspired by Ricoeur (1976) was used for the analysis of the interviews. The analysis was performed in a series of steps. Firstly, there was a naive reading of the interview text in order to get the sense of it. Secondly, there was a structural analysis of the text in order to identify those parts with meaningful connections relevant to the research questions. Lastly, the texts were seen as a whole again (interpreted whole), taking into consideration the naive reading and the structural analysis. The interpreted whole was then reflected upon.

The phenomenological hermeneutic method described above was also applied when analysing the videotaped activities in IV and V. In accordance with Ricoeur (1971a), patients' and DeRNs' actions were regarded as texts. In order to get a sense of the whole, the first author watched one third of the videotapes focusing on the patients' faces (naive reading). In the next step (structural analysis) all the video sessions were watched and meaningful communication sequences were identified. A written description was made of the observed facial expressions as well as of the vocalisations, single words, and of the DeRNs' actions, such as verbal utterances and care activities. An interpretation of the meaning of each expression was made immediately after the description. In the last step narratives about the patients were written (interpreted whole).

In paper V the same videotapes were used as in IV. An analogous analysis and a digital analysis were compared. Emotional facial expressions that were judged to show anger, disgust, happiness, sadness and surprise, i.e. emotions that can be assessed by means of the FACS-technique (Ekman...
and Friesen 1978) were marked on the videotapes (minute and second) and analyzed by another researcher according to a modified version of the FACS-technique (cf. Oster 1978, Asplund et al. 1991b). The FACS-technique identifies the distinct facial muscle movements that are combined to form facial action units (AUs) that can be related to different emotions. The above-mentioned emotions were marked on the videotape, translated into AUs and analyzed according to the FACS-technique. Only the most significant AUs reported for each of the assessed emotions were required for the interpretation of a certain emotion. To have a baseline, the FACS analyses were firstly performed a few seconds before the selected expression started. Then the judged facial expressions were analyzed into AUs and combinations of AUs. The agreement between the two techniques was calculated for all rated emotions.

FINDINGS

The two groups of RNs in papers I, II and III were asked about their decision to feed or not feed a severely ill, mentally alert, elderly woman with cancer and a severely demented elderly woman, respectively. None of the RNs considered using force or violence against their patients. The RNs' overall attitude was to give priority to the ethical principle of autonomy, but when the situation was complicated the DeRNs tended to change their priority to the ethical principle of beneficence. They all had problems explaining their ethical choices. The CaRNs said that decisions in ethically problematic situations depended on the situation at hand and were context-based. They described difficulties in acting in accordance with their convictions. The DeRNs more than the CaRNs, referred to their own experiences in their work as nurses, but they referred just as often to personal experiences. The question about whether or not to feed the patient was not as urgent as the question of whether or not to accept active euthanasia. Requests from dying patients caused frustration in RNs, since they understood the patient's wish but felt they would not be able to live with the knowledge that they had killed the patient. They gave vague justifications for their opinion.
The DeRNs emphasized the difficulty in understanding the meaning of the behaviour of severely demented patients and saw interpretation of the patient's wish as their prime task. Typically the DeRNs did not see the ethical principles as separate entities, that could be applied one by one. They tried to integrate them into a whole. They saw feeding more as a 'loving relationship' than medical treatment.

When the interviews were analyzed using a phenomenological hermeneutic method, in order to make comparisons of what it means to these RNs in cancer and dementia care to face situations where the patient can/can not decide for her/himself (III), five themes were identified 1) interpretation of their patient's wish and what is best for the patient 2) respecting the patient and oneself 3) transcending experiences and role models 4) imagining oneself in the patient's shoes, and 5) advocating for patients. The main problem for the CaRNs was to defend their own moral integrity. For the DeRNs the main problem was to interpret the patient's communicative cues and understand her/his wishes. The RNs' ethical reasoning in both groups seemed to be closely connected to the Golden Role: 'Whatever you have people do to you, do the same for them' (Matthew 7:12). The CaRNs thought one of their missions was to support patients so that they could better understand their situation and thereby become more able to make their own decisions, i.e. to help the patients to be their own advocates. For DeRNs' understanding the patient seemed to be crucial. They saw themselves as the spokesmen for their patients and had to act as the patients' advocacy.

The phenomenological hermeneutic interpretations of videotaped interactions (IV) between each of two experienced DeRNs and each of four patients in the terminal stage of AD revealed that it was possible to see the patients as capable of having experiences and of communicating them to their carers although their ordinary carers reported that they were more or less unable to communicate. The patients were judged able to express feelings such as happiness, surprise, curiosity, attention and show when they were upset or felt uncomfortable they seemed to listen and show when they were bewildered. The analysis made it possible to put together the observed communicative cues into a narrative for each patient. These
narratives gave a picture of which the patient differed from that described at the onset of the project.

When the results of the unstructured naturalistic analysis (UNM) in IV was compared with the results from an analysis by means of FACS (V), there was in total 48 percent agreement between the two methods. In one of the four patients the agreement for the judgement of happiness was 98 percent. Only in two patients was there a high level of agreement, namely regarding happiness in one of the patients (22/33) and regarding disgust in another patient (6/6). Thus the interpretation of the severely demented patients' facial expressions by means of the UNM showed a more competent patient than those by means of the FACS-technique.

The evaluation of the DeRNs' lived experience of being supported by clinical group supervision, based on a narrative framework (VI) produced the following themes, 1) recognition and reassurance of worth, 2) increased repertoire of actions and/or new perspectives discovered, 3) increased awareness of the professional role of a nurse, and 4) experience of interdependence. The conclusion drawn from the study was that group-supervision can help the RNs to understand themselves and others better, they question things and get new ideas about how to handle situations that occur in their clinical work. The themes found indicated that RNs experienced being confirmed and confirming.

REFLECTIONS

We perform daily activities within a practical mode. Then the awareness of the situation in which we are engaged can not be divided into objects, but is rather a network of interrelated projects (cf. Heidegger 1962). In the practical mode we have a lived experience but are not fully aware of what we feel and think or why we act as we do. We act in the usual way and have a vague feeling that 'this is the right thing to do'. It is only when we get problems, face alternatives and surprises we have to reflect. We may reason in three steps, firstly we narrate, secondly we reflect on the
narration and thirdly we put the reflected whole within a theoretical perspective.

In papers I-III good and experienced RNs were asked to describe their reflections on a hypothetical case and argue in a theoretical context-independent way for their choice of actions. As there is a risk that people are unaware of their normal way of being, i.e. their background (tacit) knowledge is taken for granted, the hypothetical case was made complicated in order to create some disorder so as to make them aware of their reasoning (cf. Garfinkel 1967). The RNs were also confronted with the ethical principles of autonomy, beneficence, sanctity of life and justice. Nilstun (1990) correctly states that the importance of the principle of sanctity of life is difficult to interpret because the interviewers first presented it as a consequence of the principle of autonomy and then as an independent principle.

The RNs had difficulty placing their reasoning within a theoretical principled ethics perspective. Furthermore, they emphasized the situation at hand and reasoned mainly in a narrative context-dependent way. Their reasoning seemed to be in accordance with Gilligan (1982). She describes a context-based and narrative approach rather than an approach based on abstract thinking. The fact that the RNs stressed the importance of the relationship to the patient for their actions in the situation described can be understood in the light of narrative ethics. We perform our moral actions within stories which involve other people. In each situation and relationship we must interpret what is required from us (cf. Arendt 1978).

In paper III the RNs stressed that every situation is unique. This finding is congruent with that of Åström and coworkers (1993) that the actions of the same CaRNs as reported here were dependent on the situation at hand. The most important situational factor was whether or not they had a support group where they could share their thoughts. Without a support group they stressed difficulties in acting in accordance with their ethical conviction. This finding shows that Nilstun (1992) was right in criticizing I for not taking the RNs' group of co-actors enough into account.
The fact that the RNs explicitly or implicitly emphasized that they acted in accordance with the Golden Rule (I, II, III) can be seen as an indication of a high level of moral development, i.e. using an abstract principle (Kohlberg 1981) or telling good stories, i.e. stories that embody actions in accordance with the Golden Rule (Ricoeur 1987).

According to Ricoeur (1987) acting in accordance with the Golden Rule means recognizing the other's freedom and preventing violence. The fact that the CaRNs said they encouraged the patient to express her wishes and acted as her advocate by supporting the patient to understand the situation better, and the DeRNs tried so hard to interpret the patient's wish and act as her advocate (III) can be seen as their recognizing the patient's freedom and fighting for it to become posited (cf. Ricoeur 1978). The fact that both groups of RNs so strongly opposed the use of force and violence when feeding a severely ill patient (I, II, III) and their strong objection to active euthanasia (I, II) could be understood by reference to the Golden Rule and to the statement by Levinas (1969) that when you are face to face with the other, you can read a demand not to kill her or him.

The DeRNs especially emphasized the necessity and difficulty of being able to interpret the patient's wishes and what was best for her/him (III). Paper IV illuminates the process of giving meaning to lived experience, or alternatively finding meaning in it. When looking at the videotapes of severely demented patients in interaction with DeRNs, the researcher received a lived experience of the patient's facial expressions that she interpreted. She did this by putting them within a narrative frame, seeing them as a text that was interpreted in a phenomenological hermeneutical way (cf. Ricoeur 1971a, 1976, Klemm 1983). It was possible to see the patients as capable of having experiences, and of communicating them to their DeRNs. The analysis made it possible to put together the observed communication into a narrative for each patient. This narrative gave quite a different picture of the patient than that given by the ordinary carers at the onset of the investigation. This can be seen as a consequence of a narrative preunderstanding, which was strengthened by the nurses who acted towards the patients as if they were people who were able to participate in a lived narrative. In accordance with Ekman and coworkers (1993) and Kihlgren and coworkers (accepteda,b) it was found that the severely
demented patients were much more able to communicate than was expected.

It was difficult to interpret the facial expressions of the severely demented patients by use of the abstract context-independent coding scheme of the FACS regarding the demented patient's face as an object to be recognized (cf. Asplund et al. 1991b) (V). The face, however, can also be approached as disclosing the presence of a person. We enter into a relationship with a partner through looking. When we receive a glance from the patient it calls on us to respond. It seems reasonable to assume that by using the unstructured naturalistic method (IV), the researcher came close to this approach. Thus it seems logical that she responded to the patient as a person (Levinas 1969, Jacques 1991). To understand a text means not only to grasp its meaning but also to understand the claims that it has on us (Freeman 1985). When the carer reads the demented patient's face, the face is not an object that should be interpreted but a means of disclosing a person. This implies a new relationship with the patient. The nurse caring for a severely demented patient needs a close and deep relation to her/his patient to be able to understand her/his communicative cues. However, a close relationship can lead to experiences of strain (Kuremyr et al. manuscript).

The basis of the care is the DeRNs' communication with the severely ill patient. They understand the meaning of the interpreted communication within the whole of their outlook on care and life. This includes their basic ethical attitudes (Kemp 1988), and their philosophy of care (Norberg et al. 1992). They understand their patient within the patient's life story (cf. Arendt 1958). The concrete care of the patient is delivered within the whole of the climate of the wards, and the cooperation with coworkers (Åström et al. 1993). Therefore it seems logical that care should be developed through group supervision based on a narrative perspective (VI). The DeRNs narrate their lived experience to other DeRNs at the same clinic. In this way they are helped to interpret their own lived experience and to acquire a consensus about what good and correct care means. The philosophy of care may become integrated in the RNs and develop parallel with the development of the RNs.
The development through narrations that are reflected on can be understood within the frame of reference of skill acquisition in a practice discipline (cf. Dreyfus and Dreyfus 1986). Being able to act in ethically problematic care situations is only one component of the knowledge needed (Pörn 1990). Because being experienced is not the same as being in possession of something, it is difficult to communicate and can most easily be understood by being put into stories (Gadamer 1988).

In the analysis of interviews (III, VI) and videotaped interactions (IV, V) a phenomenological hermeneutic method was used, inspired by Ricoeur (1976). The reason for this choice is that Ricoeur explicitly tries to develop a strict method for interpretation.

Hermeneutics is a method for the interpretation of texts. It does not seem problematic to regard taped interviews as texts (III, VI). To see videotapes as texts may seem more problematic (IV, V). Ricoeur (1971 a) states that it is possible to see action as analogous with texts, i.e. it is possible to detach the meaning of the action from the event of the action through a fixation. This makes it possible to objectify the action and interpret it. As videotapes are such rich texts a reduction was performed by transforming aspects of the videotape into a written manuscript. Thus there were two fixations of texts.

The phenomenological hermeneutic method combines a phenomenological philosophy, methods from structuralism, and hermeneutics (Bleicher 1980). The naive reading of the text aims at grasping the immediately, intuitively given phenomena. Connecting with methods used by structuralists, Ricoeur stresses the need for objective interpretation (distanciation) prior to existential analysis. The text is regarded as a closed system, elements and their interrelations are described. The aim of the structural analyses is to explain the text, not interpret it. It does not 'say something about something'. The analysis then proceeds 'under the conditions of the hermeneutical circle', i.e. the text is interpreted through a process of seeing the whole in the light of its parts and the parts in the light of the whole. The interpretation reveals multiple meanings and relates them to 'the what' that the text talks about.
The development of the research that this dissertation is based on has led to the use of a combination of both an analogous and a digital communication with the material (cf. Wilden 1980). The phenomenological hermeneutic method can be seen as an alternation between analogous and digital handling of data (Norberg and Norberg, manuscript). During the naive reading the phenomenon is approached in an analogous way; it is seen as a continuous flow that can express 'both - and'. The meaning is intuited. During the structural analysis a digital handling of data is used; they are regarded as discontinuous elements that express 'either-or'. Signification is sought. In the interpreted whole the approach is again analogous. The meaning of the text is appropriated in relation to its reference (Bruns 1992). The interpretation ends in the interpreter understanding herself or himself better (Ricoeur 1971b). When reading the report of the interpretation the reader becomes involved in a similar process (cf. Iser 1978). The assumption is that in the midst of lived experience, we are not fully aware of what we do. Our lives are like a play with players that do not know the plot (Freeman 1985). We understand ourselves in relation to shared symbols (Madison 1988). Applied to the care of severely demented patients it seems important for carers to understand the patient from her or his own world of symbols (cf. Ekman 1993).

The meaning of a text must first be understood within its original context through decontextualising it to grasp its essence towards recontextualising it in a new context (Freeman 1985, Ricoeur 1988). Thus in order to use the interpretations in this dissertation a process of decontextualisation and recontextualisation has to be applied. For example it is an important contextual factor that the RNs investigated were regarded good and experienced in the care of severely ill cancer and demented patients respectively (I, II, III). Furthermore the two DeRNs who cared for the videotaped patients (IV, V) were regarded as good and experienced, and were given the optimal preconditions for providing good care. For example they had the time needed for the patients. Of course, one can not expect novice RNs working in a task assignment care system with a shortage of personnel to provide their patients with the good standard of care presented in this dissertation. The knowledge that it is possible to disclose hidden abilities in severely demented patients is important when deciding about care priorities.
In this dissertation the RNs' personal knowledge about the care of severely ill patients was disclosed, i.e. 'brought to appearance'. As disclosure is also the aim of phenomenological hermeneutics that method was used. Bruns' (1992) idea is that Ricoeur's method is a hermeneutics of praxis and action. In paper VI this hermeneutic disclosure of the DeRNs' personal knowledge was seen as an intervention. It was supposed to change reality for the RNs and thereby also for their patients. This is in accordance with Ricoeurian hermeneutics. The interpretation projects a possible world, and the understanding of a world shows itself only in action (Freeman 1984, Bruns 1992).

As the ultimate aim of this dissertation was to improve the care of severely demented and terminally ill cancer patients by disclosing the RNs' personal knowledge and in the case of DeRNs also to help them improve their reasoning by systematic clinical supervision, it seems important to evaluate whether these kinds of interventions affect the care of the patients. For example video recordings of caregivers' actions would provide valuable new texts to be interpreted and reflected on by the researchers as well as by the carers themselves.

The finding that RNs can achieve understanding of themselves as nurses by listening to and reflecting on their own narratives (VI) and that they can understand their patients by seeing them in the narrative context of the stories they are entangled in (IV, V), make it important to train nurses in narrating good stories about care. It is also important that the organisation of care offers carers the time and opportunity to narrate their experiences with patients, for example in oral reports (cf. Hamran 1991). The leader must be able to detect bad stories about patient care and also know how to bring insight to the carer-narrator about the meaning of their stories, and opening up alternative stories as a possibility to improve care.
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Appendix. Coding scheme concerning feeding a dementia patient. If there was "no feeding".

Justification:
- O autonomy
- O beneficence
- O none
- O other
- O other

Opinion changed under what condition?
- O enjoys being touched
- O aware of her situation
- O previously stressed life is sacred
- O no family or friends
- O husband and children ask you to feed
- O cared for in her own home
- O not enough staff

Active euthanasia - what conditions?
- O none
- O severe suffering
- O patient's wish
- O terminal stage
- O patient's previously expressed wish
- O other

How explain euthanasia to personal?
- O autonomy
- O beneficence
- O none
- O other
- O justice
- O nonmaleficence
- O sanctity of life

Change in law - a difference?
- O no
- O yes

If yes: Why?

Rank order of ethical principles
1st: 2nd: 3rd: 4th:
Extra principle:
Motivation for rank order:
Same rank order in personnel life?
- O Yes
- O No
If no: 1st: 2nd: 3rd: 4th:
Extra principle:
Motivation for rank order: