Long-Term Nursing Care of Elderly People: identifying ethically problematic experiences among patients, relatives and nurses in Finland

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Key words: ethics; elderly people; integrity; long-term care

The aim of this study was to explore ethically problematic situations in the long-term nursing care of elderly people. It was assumed that greater awareness of ethical problems in caring for elderly people helps to ensure ethically high standards of nursing care. To obtain a broad perspective on the current situation, the data for this study were collected among elderly patients, their relatives and nurses in one long-term care institution in Finland. The patients ($n = 10$) were interviewed, while the relatives ($n = 17$) and nurses ($n = 9$) wrote an essay. Interpretation of the data was based on qualitative content analysis. Problematic experiences were divided into three categories concerning patients' psychological, physical and social integrity. In the case of psychological integrity, the problems were seen as being related to treatment, self-determination and obtaining information; for physical integrity, they were related to physical abuse and lack of individualized care; and for social integrity, to loneliness and social isolation. This study provided no information on the prevalence of ethical problems. However, it is clear from the results that patient integrity warrants more attention in the nursing care of elderly patients.

Introduction

The growth of the elderly population looks set to continue over the next few decades. Forecasts for the Organization for Economic Cooperation and Development countries indicate that, by 2050, the proportion of persons aged 65 years or over may more than double.[1] In Europe, a life expectancy of 85 years or more could well become normal.[2] In the development of social welfare and health care services, the main

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emphasis is on enabling older individuals to live in their own homes for as long as possible.[3] The elderly persons admitted to institutions today are older, have more illnesses, are in poorer condition and are more dependent on others than before.[4] Most of them have functional limitations,[5] suffer from dementia,[4,6] and have a diminished capacity to make independent decisions,[7] which in turn increase their vulnerability.

Nurses are responsible for the ethical quality of the nursing care provided to long-term patients. In Finland the main legal principles related to the treatment and care of patients are set out in the Act on the Status and Rights of Patients.[8] A national framework for ensuring the highest possible standards of care for elderly people has been laid down by the Ministry of Social Affairs and Health;[9] this stresses the importance of safeguarding the quality of life and the right to self-determination and independence for all older people.

Many everyday ethical problems in long-term care have to do with the concepts of autonomy,[10–13] privacy[14,15] and integrity.[16,17] The realization of autonomy, when this refers to decisions and activities based on an individual's own choices, involves both conceptual and practical problems.[12,18] These problems are due, first, to the external characteristics of long-term care and its routines,[19] and to its paternalistic nature.[10,11] Secondly, there are also internal, ageing-related factors (e.g. impaired vision and hearing) that restrict an individual's autonomy. In addition, reduced strength, illnesses and cognitive changes may undermine autonomy.[18]

Institutionalization may in itself contribute to a sense of reduced autonomy,[20] especially in cases where patients strongly object to the idea of living in an institution for the rest of their lives, even at the cost of their health and security.[21] There are various other everyday problems such as the extent to which patients are able to influence their own daily programme,[19,22] including eating,[10,22] taking care of personal hygiene, clothing[10] and freedom of movement.[10,23] In this context the roles of relatives[7,8,20] and nurses[20] as the patient's advocates are crucial.

Privacy is known to be extremely important to the elderly people who live in institutions.[14,15] Personal space or territory is a key aspect of privacy.[15] The loss of privacy is particularly significant when elderly people become permanent, and often dependent, residents,[24] and need more help with very personal activities.[14] Patients feel offended if a nurse intrudes into their personal space[16,17] by touching or exposing them[14,16] without asking permission.[25] It has been shown that such intrusions are associated with submission. Patients whose personal space is violated during treatment may consent to procedures without asking questions, feeling very much like passive recipients of care.[26]

Some studies have approached this issue from the vantage point of integrity.[16,17] Ethical problems have been described by reference to the importance of respecting the patient's dignity, self-determination, personal views, personal space and property, and giving consideration to culture and the patient's family. Violations of the patient's physical integrity, for instance, failure to provide adequate clothing, may also have adverse effects on patient integrity. Especially in situations where patients are defenceless and highly dependent on others for care, violations of integrity tend to give rise to ethical problems in nursing.[16,17]

In spite of the growing awareness of ethical issues in long-term care, there is still a lack of research addressing the problems concerned from patients', relatives' and nurses' points of view. In order to gain an adequate understanding of these ethical issues, we need to explore the views of all these groups, including the relatives of patients with dementia. In Finland, over half of all institutionalized elderly long-term patients have dementia.[27]

The purpose of this article is to identify and describe the ethically problematic care-related experiences of patients, relatives and nurses. The information provided by this investigation will help professionals working in the field of health care to tackle more effectively the questions and problems that are of current concern in the care of elderly persons in Finland.

Method

The data were collected in open interviews with patients and from essays written by relatives and nurses. The patients were interviewed because most of them were in such a poor physical condition they would not have been able to write.

Ethical considerations

The study protocol was submitted for approval to the ethics committee of the community health centre in question. All participants received a letter that described the purpose of the study and the research process. It was also made clear in this letter that participation was entirely voluntary and that all the information collected would be handled anonymously and in confidence. The nurses discussed the content of the letter with the patients and written consent was obtained from those willing to take part. At the beginning of the interviews, the course of the study was once more explained. The interviewees were free to withdraw their participation at any time.[28] The nurses and relatives who volunteered to participate received a similar letter and an envelope in which they were asked to return their essays anonymously. The writing of an essay was considered as an indication of informed consent.

Participants

The patients interviewed were selected by the nursing staff on the participating wards using the following criteria: (1) aged over 65 years; (2) length of stay in hospital at least three months; (3) able to discuss everyday matters in a comprehensive way; (4) orientated in time and place; and (5) willing to take part. The patients were asked by the nurses to give their written informed consent and also to consent to their relatives participating in the study. On the wards concerned, 13 patients both met these criteria and gave their written informed consent. Two interviews were discontinued owing to patients' inability to answer, and one patient decided not to participate after all; these three cases were excluded from the analysis.

Relatives visiting the chosen wards during a specified period were contacted to ask whether they would be interested in taking part in the study. In the case of patients

with severe dementia, the decision was made independently by family members. All nurses working on the same wards during this period were also asked to participate. The final sample consisted of 10 patients, 17 relatives, and 9 nurses from four similar long-term care wards of one randomly selected community health centre in southern Finland. In the Finnish health care system, community health centres are primary health care facilities funded by local governments. They have several satellite clinics and inpatient wards for people needing long-term institutional care.[29] On the inpatient wards, the patients are more often bed-ridden than is the case in geriatric institutions, such as homes for the care of elderly people. On average, less than one-third of the nursing personnel are registered nurses, about half are staff nurses and the rest are auxiliary staff.[4]

The health centre in our study cared for 180 inpatients on six long-term wards at the time of data collection. The patients who took part in this study were aged from 71 to 84 years (mean 79, standard deviation = 4.27); there were four women and six men. The duration of their most recent continuous stay in hospital ranged from nine months to six years (mean 1 year 8 months). All the patients needed help from nursing staff with their daily activities. Only one was sufficiently ambulant to move short distances using a walking aid.

The average age of the 17 relatives was 62 years (range 32–78); only one was male. Eleven were relatives of patients suffering from dementia who were unable to communicate everyday matters in a comprehensible way and were not orientated in time and place. The nurses' ages ranged from 35 to 52 years; one was male. Their mean work experience was 17 years (range 7–25). Five were registered nurses and four were enrolled nurses.

Data collection

In both the interviews and the essays, the respondents were asked the same question: 'What kind of ethically problematic experiences have you had?' The interviews began with a broader, explorative open-ended question: 'What is your daily life like in this institution?' Additional questions were asked when the researcher wanted the informants to elaborate on their story.

The background information collected from the patients included age, length of stay on the long-term ward and the amount of help they needed with their daily activities. Relatives and nurses were asked to state their age and gender. The nurses were additionally asked questions about their work history and current job.

The interviews were conducted by the researcher (ST) in the patients' rooms. Eight of the 10 patients were in their own beds and two were in wheelchairs. The interviews lasted for 15 minutes to 2 hours (mean 38 minutes). Nine interviews were tape-recorded. One patient did not give permission to have the interview tape-recorded, so detailed notes were taken instead.

The relatives and nurses who volunteered to participate were given written instructions on how to write the essays and return them. The instructions were given to 30 relatives, 17 of whom wrote an essay, and to 30 nurses, only nine of whom returned an essay. The essays were hand-written and their length ranged from half a page to two pages.

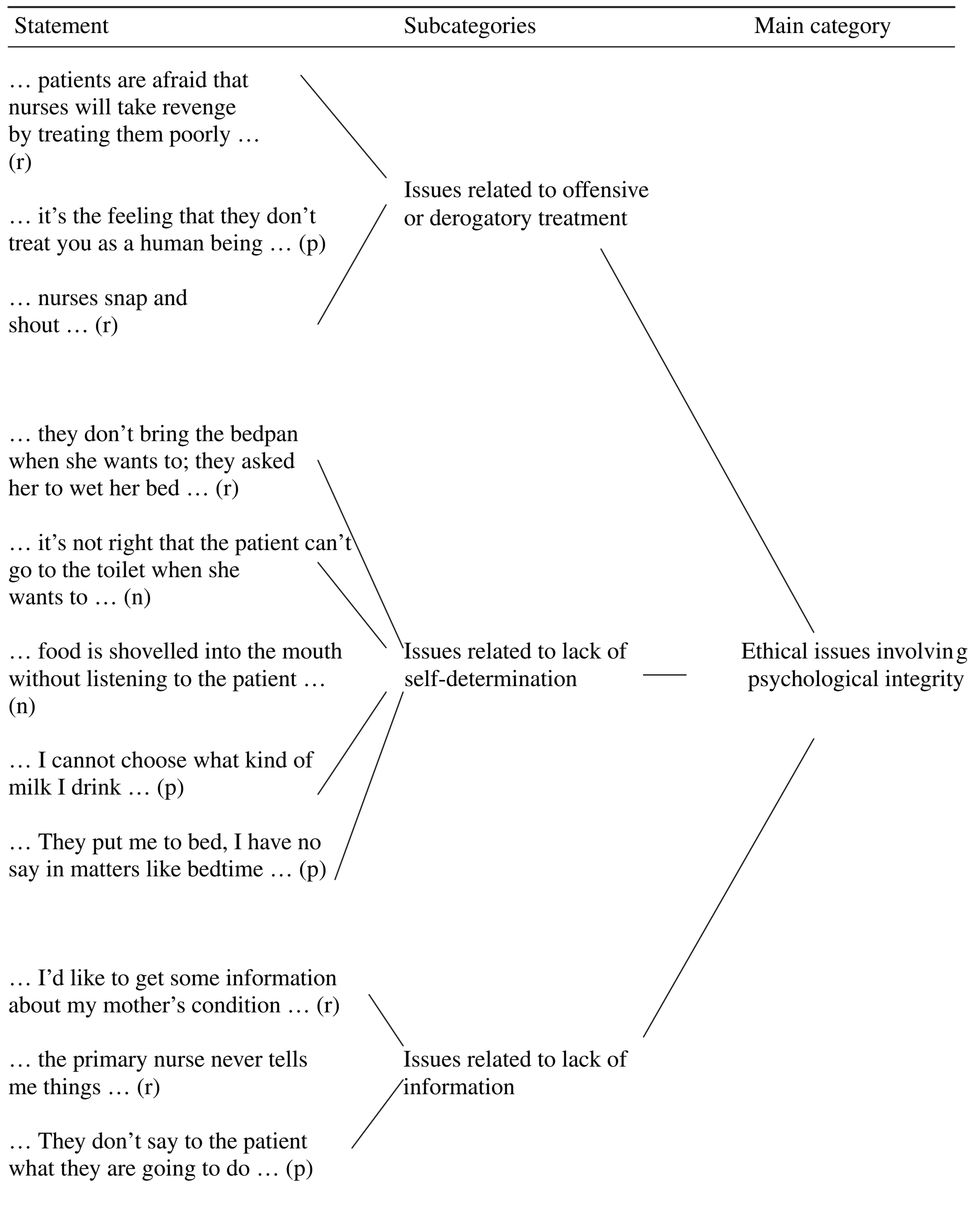

Figure 1 An example of deriving a category from data (r, relative; p, patient; n, nurse)

Analysis

Data interpretation was based on qualitative content analysis.[30] First, the interviews were transcribed verbatim. Then authentic expressions with a similar content were coded. These codes constituted the subcategory headings reflecting the content of the respective expression (eg issues related to self-determination). Main categories were

derived from these subcategories by reference to the literature,[30] based on the specifications of respect for patients' integrity.[16,17,31,32]

Excerpts are used in presenting the results. Some minor revisions have been made to their wording for reasons of confidentiality. Figure 1 gives an example of deriving a category from the data.

Results

Based on the data obtained from the patients, relatives and nurses (Table 1), three main categories of ethical issues were extracted by the analysis: problems relating to the patient's psychological integrity, physical integrity and social integrity. On the basis of the literature these main categories were taken to include the following aspects: psychological integrity comprises the right to self-determination[17,31] and respect for human dignity;[16,17,31] physical integrity the inviolability of the physical environment and responding to physical needs;[16,17,31] and social integrity the requirement that older patients are not isolated from other people inside the institution or indeed from the outside world.[17]

Most patients started the interviews with a general statement about their experiences, which were primarily positive. They said they felt the nurses at the health centre were doing their very best under conditions of great time pressure. Any references to distressing situations they had experienced would usually come later on during the discussion; in the course of the interview they reverted to these incidents on several occasions.

Table 1 presents the occurrence of ethical problems.

Ethical problems relating to psychological integrity

This main category comprises the ethical problems faced by patients, relatives and nurses that seem to be related to patients' psychological integrity. They can be further

Table 1 Occurrence of ethical problems

Ethical problem	Patients ($n = 10$)	Relatives 1[a] ($n = 6$)	Relatives 2[b] ($n = 11$)	Nurses ($n = 9$)
Psychological integrity				
Offensive or derogatory treatment	Yes	Yes	Yes	Yes
Lack of respect for patients' self-determination	Yes	Yes	Yes	Yes
Lack of information	Yes	No	Yes	No
Physical integrity				
Physical abuse	Yes	Yes	Yes	No
Lack of individualized care	No	Yes	Yes	Yes
Social integrity				
Loneliness in institution	Yes	Yes	Yes	No
Isolation from outside world	No	No	Yes	No

[a]Relatives of patients able to communicate.
[b]Relatives of patients unable to communicate and not orientated in time and place.

divided into three subcategories: offensive or derogatory treatment, lack of respect for patients' self-determination and lack of information. The first two were identified by all groups of respondents; the latter was not mentioned by the nurses. Each of these subcategories is briefly described below.

Offensive or derogatory treatment

Reference by the patients to offensive or derogatory treatment usually involved descriptions of rude or angry behaviour on the part of staff members. In some cases it was thought this was prompted by the patients expressing their own wishes about nursing care. According to the patients, the nurses had a set routine they followed on the ward; any deviation from that routine would be liable to cause problems. In the words of one patient:

> They don't really look very favourably on your special wishes. If I've said I would like to go to sleep a bit earlier, they're a bit angry.

According to the relatives, patients undergoing long-term care were not always treated very well by staff members: this was manifested as a sense of indifference, which caused the patients to feel like 'outsiders', or speechless or angry. Lack of humane treatment was regarded as a problem most particularly with short-term temporary staff, younger nurses and untrained staff, as illustrated by the following excerpt:

> Older nurses have the time to show empathy for the aged even when they are in a hurry. Younger nurses tend to lack this skill to some extent; it is replaced by a drive for efficiency and a sense of impatience.

Nurses described the lack of humanity as routinized care. Some said they did not follow a patient-orientated approach in their work. This was described by one nurse:

> Patients are sometimes turned and changed by two nurses as if they were objects on a shelf and not approached as human beings.

Nurses also described their own sense of discomfort when they observed each other's activities in situations where a patient's human dignity was not respected. Strapping a patient to a wheelchair, for instance, was described by some as degrading.

Lack of respect for patients' self-determination

Some patients made the point that they were unable to express their own wishes because everything on the ward was strictly organized according to set routines to which they had to submit. One patient reported:

> You have to be content here and not go against anyone; they won't listen.

Some also drew attention to the reasons why nursing staff were not in a position to respond to individual needs, such as a shortage of staff and their time pressures. They were particularly annoyed not to have any say in decisions concerning daily routines, such as choosing what bread to eat and what to drink, and when to go to bed and wake up or go to the toilet and wash themselves (eg how damp a washcloth they want to use). According to the relatives, the patients had to wait in order to obtain help:

> It's depressing to hear an elderly person say she wants to go to the toilet: 'I need to do number two.' The answer they get is, 'We'll help you as soon as it's pad-changing time.'

The nurses reported that they sometimes forgot their patients' wishes and made decisions on their behalf. They also acknowledged that patients who were unable to express themselves received inferior care, especially when there were no strong-minded relatives to stand up for them. According to the nurses' essays, nursing care is not necessarily tailored to meet individual needs, but provided according to schedules. This gives rise to a sense of inadequacy among staff members. They also find it difficult to cope with situations where patients refuse to eat or take their medicine. Patients who refuse all help and whose wishes are obscure or contradictory are particularly difficult. Rejecting help may manifest itself in rejecting everything.

According to the nurses, situations where a patient and a relative disagree can be highly problematic. Nurses can respect a patient's decision not to eat, but relatives do not always accept this and feed the patient by force or insist on having a nasogastric tube inserted. Relatives were also prepared to accept drastic treatments even if these caused patients' suffering. The desire of relatives to intervene in patients' care was also seen as problematic.

Lack of information

Some patients said they lacked information about daily nursing activities. Nurses did not always explain what they were doing. One patient with severe visual impairment expected to be informed about who and what was involved in his daily nursing interventions. Friendly nurses gave information without being asked.

Relatives also complained about a lack of information. They were not kept informed about the patients' health status, nor did they ask. The relatives wanted the primary nurses and doctors to introduce themselves. They said they would have wanted to talk more often with the nurses, and for the nurses to show greater initiative in giving information.

> One of the nurses could talk with relatives at least once a month.

Issues that worried relatives, and which they would have liked to discuss with nurses, were sometimes experienced as negative by staff.

Ethical problems relating to physical integrity

This main category comprises ethical problems experienced by patients, relatives and nurses that seem to be related to patients' physical integrity. There are two subcategories: physical abuse and lack of individual care. The former was identified by patients and relatives, the latter by nurses and relatives.

Physical abuse

The issues in this subcategory were related to touching. In the words of one patient:

> It's like getting hurt, wrenching I mean; they won't listen to you.

The lack of respectful touching leads to an experience of loss of human dignity:

> It hurts and the feeling that you're not treated as a human being, that it doesn't matter, you're an object.

One relative reported a patient being pinched and wrenched by a nurse.

Lack of individualized care

Both relatives and nurses referred to the lack of individualized care. According to the relatives, patients' individual needs do not always receive due consideration. Nurses do not respond to requests because everything is done according to fixed routines and schedules. Eating, washing and toileting all have to be done according to a strict timetable. The problems in this subcategory were seen by the relatives as being due to staff shortages, routines, schedules of nursing interventions and disregard for patients' individual habits and manners, as illustrated in the following excerpt:

> The nurses won't take the trouble to read the patient records. Everyone is cared for according to the same routine. They should speak with relatives more often.

Patients with dementia in particular were seen as being left on their own if there were no relatives to stand up for them.

> Not everyone is capable of complaining and informing others of their ailments. Not all patients have a relative who could look after them.

Restless patients caused problems to their relatives, who did not know how to cope with the situation. Some relatives thought that patients were not given enough sedative medication; others considered it a problem that the patient was so heavily sedated that they could not even move.

Nurses shared the view that long-term patients' care needs were occasionally neglected. As one nurse stated:

> You often forget long-term patients' physical needs concerning elimination. It's much easier to take care of them with enemas and incontinence pads.

Ethical problems relating to social integrity

This main category comprises ethical problems experienced by patients and relatives that seem to be related to patients' social integrity. There are two subcategories: loneliness in the institution and isolation from life outside the institution. The former was identified by patients and relatives, and the latter by only one relative.

Loneliness in the institution

For patients, the time they spend in an institution is boring and depressing; all they do is to lie there and wait. The nurses are fully occupied and have no time for conversation. The nursing interventions are carried out in a hurry:

> You have to wait, there are very few staff and they're all fully occupied. They do talk to you during treatments, but they can't stay for long because they're so busy.

Adding to the sense of loneliness, room-mates are often unable to speak and relatives may live far away. One patient said he tried to use his imagination to help him cope with the boredom:

> My thoughts wander about very swiftly and I spend a lot of time daydreaming.

Another patient said that everything feels bad in the institution and that one just has to put up with the circumstances because there is no alternative.

One of the relatives thought that patients spend too much time alone, just sitting and waiting in their wheelchairs.

Isolation from the outside world

Isolation from the outside world was associated with the nurses' time pressures. As one relative wrote:

> Nobody has the time to take them out to the park, for example. It would be really nice for my mother and for others if there were part-time assistants who, especially in the summer, could take these older people out.

Discussion

The purpose of this qualitative study was to describe the kind of ethical problems experienced by patients, relatives and nurses in long-term care institutions. All three groups of respondents reported experiences of ethically problematic situations.

These were ordered into three main categories that illustrate the focal meaning of the participants' experiences of ethically problematic situations. The results of this study indicate that ethical problems concerning psychological integrity have to do with offensive or derogatory treatment and with lack of self-determination and information. Forms of offensive treatment included inappropriate or rude behaviour and neglect. As in previous studies,[33] the results here indicated that this kind of conduct was shown particularly by short-term temporary and untrained staff. Relatives thought this behaviour was revenge for their interference in matters concerning the patients' care. According to the patients, inappropriate treatment gave rise to the experience of a loss of human dignity.

Problems related to self-determination were reported by all three groups of respondents. Nurses are quite well aware of this aspect of patients' rights and have higher expectations in this respect[13] because self-determination is a fundamental legal principle[8] that is emphasized in Finnish recommendations concerning quality of care for elderly people[9] and in ethical guidelines for health care workers.[34] However, institutionalized elderly patients have only very limited opportunities to influence their own care. On average, such opportunities are less readily available than patients would want and expect.[4] Patients' wishes concerning their daily lives frequently involve issues unrelated to the schedules of the ward. Wishes concerning meals, for instance, have often been discussed in previous articles.[10,16,22] Patients who are unable to communicate presented a particular problem in this respect,[35] as was the case with those with no relatives to stand up for them.[7]

The right to self-determination in personal matters is closely connected with the right to obtain information.[8] According to patients and their relatives, however, there are some major problems here. Nurses, on the other hand, did not report problems related to information. In a previous study,[13] nurses were found to have a consistently more positive view of the frequency of information giving than patients. One possible reason for their failure to recognize these unmet needs is that they feel that they are in

fact providing enough information, whereas relatives assess the amount of information received against the amount of information requested.

As for violations of physical integrity, those related to physical abuse were raised by both patients themselves and their relatives. Indeed, it seems that these problems may well pass unnoticed if patients are unable to express themselves. These difficulties of expression may also be conducive to caring for patients with little regard for their individual needs. Nursing procedures are carried out according to set schedules and routines, which runs counter to the needs of individuality. These have also been addressed in previous studies.[10,16] Failure to attend to individual needs and the lack of human touch are regarded as forms of patient abuse,[33] which, according to previous research is relatively uncommon in Finland.[36] In an earlier study, about 2% of relatives ($n = 642$) reported more or less weekly incidents of rough handling in association with care activities or thought that nurses addressed elderly patients like children. Neglect of care, on the other hand, is somewhat more common.[36]

As to social integrity, patient experiences included loneliness and social isolation. This result is in line with earlier findings.[17] Patients rarely have room-mates with whom they can speak, and nurses have very little time to spare for patients beyond their routines. Furthermore, patients have no chance to maintain contact with life outside the institution because nobody is available to take them out.

Limitations

This study had some limitations that need to be briefly discussed. The first of these concerns the method of sampling. In qualitative research, participants need to have personal experience of the events under study. They should also be able and willing to take part.[30] In the present study, the patients who met the inclusion criteria were recruited by the nursing staff, which involved some risk of selection bias. The same applies in some measure to the relatives, although in their case the letters requesting descriptions about problems they had experienced were given only to those who expressed their willingness to contribute. The nurses, too, were recruited from among those indicating their willingness to participate. The data provided by the participants show that patients, relatives and nurses do indeed have experiences that involve ethical issues and that they have the courage to raise sensitive issues such as abuse.

The essay format of data collection that was applied to relatives and nurses may have made it easier for these participants more openly to describe difficult and sensitive issues. Previous research has shown that, although relatives are for the main part satisfied with the care provided in institutions,[4] they are not always able to specify the factors with which they are satisfied. It is easier for them to describe in detail the factors with which they are dissatisfied.[37] A deductive approach in content analysis may be counterproductive in terms of contributing new knowledge to the subject area.

Results obtained from a relatively small sample are, however, always bound to the context and, when set in another context, should be viewed with caution. Nonetheless our findings are consistent with previous research results and are therefore likely to have wider relevance.

Conclusion and recommendations

We may conclude that our three groups of respondents had fairly similar views on the nature of ethical problems in long-term care. Such problems were identified least often by nursing staff. It is clear that nursing care with ethically high standards must always be based on sound professional ethics. Patients have the right to be treated with respect and regard for their integrity. In the care of elderly patients undergoing long-term care this means that: (1) their wishes are attended to; (2) they are given information about their own care; (3) offending behaviour does not occur under any circumstances; (4) patients' basic human needs are met; (5) there is no physical abuse; and (6) patients are not isolated from their social environment. Andersson[31] has three criteria for a good health care professional: someone who is willing and able to respect patients' integrity and to assess relevant facts, who has knowledge of the relevant legislation and professional ethics, and takes responsibility for his or her own actions in situations involving ethical problems.

Older people receiving long-term care are usually in a relatively poor condition and thus almost totally dependent on the care provided. As far as the ethical quality of care is concerned, the most crucial issue is the interaction between nurse and patient, in terms of both how to act and what is done. The measurement of interaction is highly problematic, however, and various approaches are needed in order properly to research the topic.

The aspects of psychological, physical and social integrity in the nursing care of long-term elderly patients warrant further research. First, there is a need for generalizable data on the frequency of ethical problems and associated factors in clinical practice, considered from nurses', patients' and relatives' perspectives. As the present study was concerned only with identifying problematic areas, it was unable to shed any light on the prevalence of these problems. Second, more information is needed on the occurrence of ethical problems in the care of older people who are unable to express themselves. Third, more work is needed to discover how staff training can improve nurses' skills and their ability to recognize and deal with ethical issues related to patient integrity.

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