Ethical challenges in nursing homes – staff's opinions and experiences with systematic ethics meetings with participation of residents' relatives

Georg Bollig MD, MAS (PhD Candidate, Consultant)[1,2,3], **Gerda Schmidt** RN, MAS (Ward Manager, Nursing Manager Representative)[4], **Jan Henrik Rosland** MD, PhD (Professor, Director, Chief Physician)[1,2,5] and **Andreas Heller** PhD, MA (Professor)[6]

[1]Department of Clinical Medicine, University of Bergen, Bergen, Norway, [2]Sunniva Centre for Palliative Care, Haraldsplass Deaconess Hospital, Bergen, Norway, [3]Department of Anesthesiology, Intensive Care, Palliative Medicine and Pain Therapy, HELIOS Klinikum Schleswig, Schleswig, Germany, [4]Caritas Socialis Vienna, Nursing Home Pramergasse, Vienna, Austria, [5]Centre for Pain Management and Palliative Care, Haukeland University Hospital, Bergen, Norway and [6]Institute of Palliative Care and Organizational Ethics, IFF (Faculty for Interdisciplinary Research and Further Education), Faculty of University Klagenfurt, Vienna, Graz, Austria

Scand J Caring Sci; 2015

Ethical challenges in nursing homes – staff's opinions and experiences with systematic ethics meetings with participation of residents' relatives

Background: Many ethical problems exist in nursing homes. These include, for example, decision-making in end-of-life care, use of restraints and a lack of resources.
Aims: The aim of the present study was to investigate nursing home staffs' opinions and experiences with ethical challenges and to find out which types of ethical challenges and dilemmas occur and are being discussed in nursing homes.
Methods: The study used a two-tiered approach, using a questionnaire on ethical challenges and systematic ethics work, given to all employees of a Norwegian nursing home including nonmedical personnel, and a registration of systematic ethics discussions from an Austrian model of good clinical practice.
Results: Ninety-one per cent of the nursing home staff described ethical problems as a burden. Ninety per cent experienced ethical problems in their daily work. The top three ethical challenges reported by the nursing home staff were as follows: lack of resources (79%), end-of-life issues (39%) and coercion (33%). To improve systematic ethics work, most employees suggested ethics education (86%) and time for ethics discussion (82%). Of 33 documented ethics meetings from Austria during a 1-year period, 29 were prospective resident ethics meetings where decisions for a resident had to be made. Agreement about a solution was reached in all 29 cases, and this consensus was put into practice in all cases. Residents did not participate in the meetings, while relatives participated in a majority of case discussions. In many cases, the main topic was end-of-life care and life-prolonging treatment.
Conclusions: Lack of resources, end-of-life issues and coercion were ethical challenges most often reported by nursing home staff. The staff would appreciate systematic ethics work to aid decision-making. Resident ethics meetings can help to reach consensus in decision-making for nursing home patients. In the future, residents' participation should be encouraged whenever possible.

Keywords: ethics, ethical problems, nursing home, nursing home staff, residents, relatives, ethical deliberation, ethics consultation, ethics committee.

Submitted 13 July 2014, Accepted 9 December 2014

Introduction

Many ethical challenges in the care of the elderly and in nursing homes have been reported in the literature. These include, for example, decision-making and other challenges in end-of-life care (1–3), use of restraints (4, 5), lack of resources (1, 5), autonomy and decision-making capacity (1, 6), communication and cooperation between healthcare workers and the patients' next of kin (5, 6) and the resident's privacy and behaviour (7–9). It seems useful to distinguish between ethical challenges and ethical dilemmas in nursing home care. Ethical challenges include all types of ethical issues, whereas an ethical dilemma is a special type of ethical challenge where one has to choose between different options with no discernible good choice.

Correspondence to:
Georg Bollig, Department of Anesthesiology, Intensive Care, Palliative Medicine and Pain Therapy, HELIOS Klinikum Schleswig, Lutherstr. 22, 24837 Schleswig, Germany
E-mail: bollig.georg@gmx.de

A survey of ethical challenges in the provision of end-of-life care in Norwegian nursing homes showed that nursing home staff most often reported a lack of resources and breaches of patients' autonomy (10). The respondents suggested handling of ethical challenges through more ethics education and time for reflection (10). Based on a review of the literature, ethical challenges in nursing homes can be divided in two major groups: 'everyday ethical issues' such as informed consent, use of restraints, autonomy, refusal of medication or food and offensive behaviour, and 'big ethical issues' which mainly are about end-of-life care and decision-making, for example withholding or withdrawing life-sustaining treatments and the question to hospitalise or not (11).

In 2006, the Norwegian government presented a national plan for better care for the elderly, including care in nursing homes (Storting report nr. 25, 2005–2006) (12). Based on this report, cooperation between the Ministry of Health and Care Services and the Norwegian Association of Local and Regional Authorities (KS) was carried out. As a consequence of this cooperation, educational courses on ethics and different tools to enhance ethics reflection in nursing homes and primary care have been established (13). When the first plans were made and the first measures were undertaken, systematic ethics consultation and ethics support were relatively rare in community care and nursing homes in Norway, whereas Norwegian hospitals already had ethics committees. One exception was the Bergen Red Cross Nursing Home, which had both ethics guidelines and an ethics committee (14). A Norwegian pilot study and literature review performed in 2007–2008 showed that a lack of resources and ethical challenges in end-of-life care are frequently mentioned challenges in Norway. It was concluded that ethics support in nursing homes and home health care should be strengthened, and further evaluation of systematic ethics work and its implementation in primary care and nursing homes was needed (5). The term systematic ethics work as used in this study includes the organisations systematic use of different measures, tools and places to enhance ethics discussions and ways to handle ethically difficult situations and choices in nursing homes, for example ethics education, ethical deliberation, different arenas for ethics discussions, ethics consultants and ethics committees.

Aims of the study

1 To explore the opinions and experiences with ethical challenges of the staff of a large Norwegian nursing home including both healthcare personnel and non-medical personnel.
2 To find out which types of ethical challenges and dilemmas occur and are being discussed in nursing home ethics meetings arenas.
3 To investigate whether results from ethics meetings were put into practice. The inclusion of the residents' view by participation of the residents themselves or their next of kin was of special interest.

Ethical considerations and ethical approval

The participants were informed about the study and were given the opportunity to ask clarifying questions before participating. They were informed about the possibility to withdraw from the study at any time. All informants gave their informed consent to participate. Nursing home staff participating in part 1 of the study was asked to fill out a questionnaire once. In order to assure confidentiality, the questionnaire was anonymous. To document ethics meetings in part 2 of the study, all ethics meetings were reported by using a questionnaire with description of the case discussed, but without personal data of the patient, relatives or the other participants. The study protocol was reported to and approved by the Regional Ethics Committee (REK Sør-Øst A) in Oslo, Norway, reference 2009/1339a.

Methods

The study was based on a mixed-methods approach (15) combining quantitative and qualitative data from surveys with nursing home staff as informants. The reason for using mixed methods in this study was to provide a bigger and richer picture of ethical challenges and ethics consultation in nursing homes. The open qualitative question was also used as additional measure to open up for new themes that probably were not covered by the questionnaire.

Part 1: Questionnaire on ethical challenges in a nursing home

To explore the opinions and experiences of the staff, a 'spotlight approach' (16) was used to get insight from the staff in a typical Norwegian nursing home. A questionnaire, which had been used in a previous pilot study with leaders and ward head nurses as informants (5), was modified and given to all employees of a large Norwegian nursing home including staff from nonmedical professions. The nursing home had 154 beds including beds for rehabilitation and short-term beds. The original questionnaire in Norwegian was shortened and some questions were reframed according to the experiences from the pilot study (5). In addition to the multiple choice questions, the informants were asked to describe a recent ethical challenge or ethical dilemma in their own words. A qualitative question in the questionnaire for nursing home staff was used to emphasise the concerns of the staff members and to open up for descriptions of other challenges or dilemmas that probably were not covered by the questionnaires multiple

choice questions. Detailed information on the question-naire is available on request to the first author.

Informants and recruitment. All staff members were informed by their leaders on staff meetings about the study and were given the possibility to contact the researcher in order to ask questions about the study. They were encouraged to participate and were able to participate within their usual working hours. Table 1 provides an overview of the informants' characteristics.

Data collection. The participants were asked to fill in the anonymous questionnaire that could be sent directly to the researcher. In addition, there was the possibility to fill out the questionnaire within the usual working hours with the researcher present in order to answer questions and to ensure confidentiality by collecting the question-naires directly.

Data analysis. Analyses of the results from the question-naire are described by descriptive statistics to summarise the answers and views of the participants from our sam-ple. The results from the survey were compared to those found in a Norwegian pilot study by Bollig, Pedersen and Førde (5). Qualitative analysis of the informants' written communications of a recent ethical dilemma was per-formed by qualitative description (17–19). The aim of qualitative description according to Neergaard was a 'rich and straight description of an experience or an event', and it is especially useful in mixed-method research (19).

Table 1 Characteristics of participating nursing home staff from Nor-way (n = 93)

Gender
Female (n = 81)
Male (n = 12)
Age
<20 years old (n = 2)
20–29 years old (n = 18)
30–39 years old (n = 22)
40–49 years old (n = 17)
50–59 years old (n = 27)
60–69 years old (n = 7)
80 participants worked with health care, 13 in other professions
Participants' profession
Nurse (n = 19)
Nurse assistant (n = 34)
Physician (n = 2)
Other professions (n = 38) as, for example priest, economist, assistant, occupational therapist, technical and cleaning personnel
Of the participants working in health care, 58 worked on long-term wards, 28 on short-term wards, 3 on palliative wards; some of them worked on more than one ward or part-time in different nursing homes

Part 2: Ethics discussions in nursing homes

In order to give an overview of the types of ethical chal-lenges and dilemmas that occur in nursing homes, a model of good practice for systematic ethics work was sought by the researchers. When the study was planned and started, ethics consultation in nursing homes in Nor-way was developing; however, it was not possible to find a suitable model of good practice for systematic ethics work in Norway to use in the study. Therefore, a model of good clinical practice with already implemented sys-tematic ethics work from Austria was used instead. Ethics discussions were documented in a cooperation of nursing homes of Caritas Socialis (CS) in Vienna.

Informants and recruitment. The management of the CS was asked to allow a documentation of all types of sys-tematic ethics discussions throughout the organisation. CS had three nursing homes and two special units for people with dementia living in flats within the city of Vienna, altogether a total of 333 residents. The nursing homes have used systematic ethics meetings since 2007. CS in Vienna has established systematic ethics work in four combined arenas for discussing ethical challenges and problems. These arenas include the following: (i) assessment and documentation of the resident's will in everyday work which means that the nursing staff of the Caritas Socialis, Vienna, tries to document relevant wishes or expressed values of the residents. They do that by writing residents statements that could be important in the residents' electronic chart; (ii) a palliative care round table which is a scheduled meeting where chal-lenges in palliative care, in general, ethical challenges and residents cases are discussed; (iii) the resident ethics meeting (REM) which is an ethics consultation at a nurs-ing home ward where a moderator uses Socratic dialogue in order to explore the residents will; and (iv) one ethics committee for all institutions belonging to CS which is responsible to establish ethics guidelines and to coordi-nate ethics education and whose six to eight members are nurses, physicians, managers and pastoral carers appointed by the management (20). Care throughout CS is based on the Maieutic Model of Nursing Care accord-ing to Cora van der Kooij (20). Maieutic means 'assis-tance at birth' in greek. The term is connected to the Socratic dialogue where the moderator has the role of a midwife in order to give birth to new knowledge and to aid reasoning. Socratic dialogue is the preferred method to discuss ethical problems in the CS. It is a method that is grounded on values and virtues that are accepted as ethically good. Usually, a moderator asks a serious of questions that help the other participants to reach a con-clusion. CS received the Teleios Award in 2011, a national Austrian award for innovation and sustainability in elderly care, for their efforts to implement systematic

ethics work throughout the organisation (21). The CS model of ethics consultation has been recommended as a model of good practice for respectfulness of human rights and dignity by the European project 'European Partnership for the Wellbeing and Dignity of Older people' in cooperation with the European Commission (22).

Data collection. A questionnaire in German was used to document all ethics discussions on the four different levels that are used by Caritas Socialis in Vienna. The moderators of the ethics discussions were asked to document each meeting. Detailed information on the questionnaire is available on request to the first author.

Data analysis. The analysis of the data from the questionnaire in part 2 was performed in the same way as described under part 1.

Results

Part 1: Questionnaire on ethics from a Norwegian nursing home

The Norwegian nursing home in our study had 140 full-time positions and a total of 238 employees: 115 work directly with health care and nursing. Ninety-three informants answered the questionnaire, representing 66% of the full-time positions or 39% of the total number of employees. Eighty-five of the 93 participants (91%) described ethical challenges as a burden, at least to a minor degree. Eighty-four of the 93 informants (90%) experienced ethical challenges in their daily work. 92.5% of the healthcare workers and 77% of the employees from other professions experienced ethical challenges in their daily work. Figure 1 shows details on the burden of ethical challenges experienced by the informants. The three most common ethical challenges reported by the informants were lack of resources (79%), end-of-life issues (39%) and coercion (33%). Ethical challenges reported by the staff are shown in more detail in Table 2. It highlights that there are differences between the healthcare workers and the other professions. Ethical challenges as end-of-life issues, coercion, lack of professional competence and autonomy issues are more frequently mentioned by healthcare workers, whereas communication issues and other ethical challenges are stated more often by staff members from other professions. Table 3 gives an overview of the nursing home staff's opinions and wishes for the implementation of systematic ethics work. Most of the participants preferred to use informal discussions to handle ethical challenges in everyday work. Ninety per cent of the informants felt that more systematic ethics work was needed in nursing homes. Seventy-three per cent saw a need for more research on the topic. Wishes for the implementation of systematic ethics work were ethics education for the whole staff (86%), time for discussion (82%), meeting places (63%) and the possibility to ask someone with special ethics knowledge (78%). The possibility to consult an ethics committee was expressed by 27% of informants and only 6% wanted to consult a lawyer.

Forty-three participants chose to describe recent ethical challenges in their own words. Recent ethical challenges described by the participants most often included end-of-life issues (e.g. issues about nutrition and treatment), treatment options and medication, especially the practice of covert medication by mixing medication in food without informing the resident, but also coercion, lack of resources and the dilemma of not having enough time to
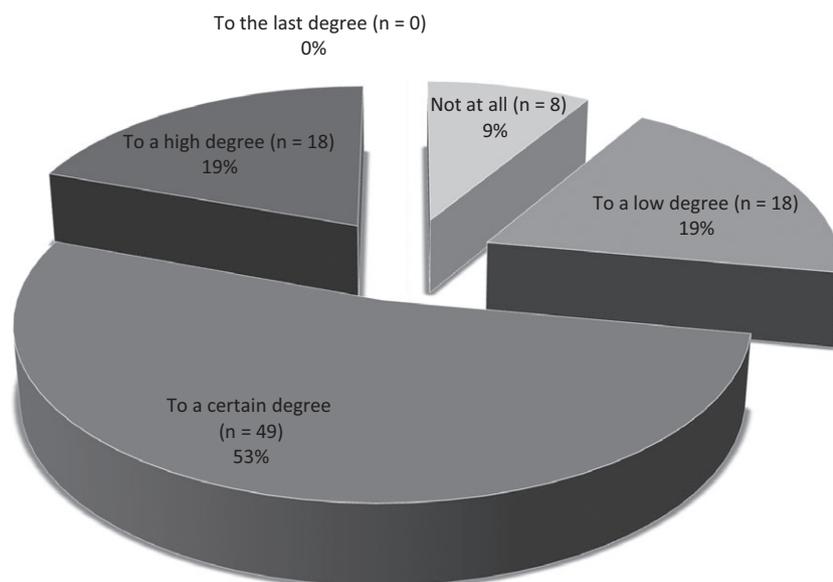

Figure 1 Ethical challenges as burden.

Table 2 Ethical challenges reported by nursing home staff

Type of ethical challenge	Healthcare personnel (n = 80)	Other professions (n = 13)	Total (n = 93)
Resources	(63) 79%	(10) 77%	(73) 79%
End-of-life issues	(34) 43%	(2) 15%	(36) 39%
Coercion	(30) 38%	(1) 8%	(31) 33%
Communication	(24) 30%	(5) 38%	(29) 31%
Lack of professional competence	(26) 33%	(3) 23%	(29) 31%
Autonomy	(24) 30%	(3) 23%	(27) 29%
Others	(1) 1.3%	(1) 8%	(1) 1%

Table 3 Nursing home staffs opinions and wishes for systematic ethics work

	Healthcare personnel (n = 80)	Other professions (n = 13)	Total (n = 93)
Method currently used for discussion of ethical challenges			
Discussion with colleagues	(70) 88%	(9) 69%	(79) 85%
Discussion with nurse, physician, patient/relatives	(67) 84%	(4) 31%	(71) 76%
Reflection group	(7) 9%	(1) 8%	(8) 9%
Ethics committee	(5) 6%	(1) 8%	(6) 6%
Do not know	(1) 1%	(1) 8%	(2) 2%
More systematic ethics work needed	(72) 90%	(12) 92%	(84) 90%
Research on ethics needed	(56) 70%	(12) 92%	(68) 73%
Preferred method for future systematic ethics work			
Education	(65) 81%	(10) 77%	(75) 81%
Education for resource persons	(40) 50%	(5) 38%	(45) 47%
Education for leaders	(48) 60%	(7) 54%	(55) 59%
Education for the whole staff	(68) 85%	(12) 92%	(80) 86%
Internet-based education	(17) 21%	0	(17) 18%
Reflection tools	(43) 54%	(10) 77%	(56) 60%
Ethics guidelines	(54) 68%	(6) 46%	(60) 65%
Core values	(47) 59%	(12) 92%	(59) 63%
Meeting places	(50) 63%	(9) 69%	(59) 63%
Someone to ask	(61) 76%	(12) 92%	(73) 78%
Staff with ethics knowledge	(51) 64%	(9) 69%	(60) 65%
Ethics committee	(22) 38%	(3) 23%	(25) 27%
Lawyer	(6) 8%	0	(6) 6%
Time to discuss ethics	(65) 81%	(11) 85%	(76) 82%
Community meeting places	(45) 56%	(11) 85%	(56) 60%
University education	(53) 66%	(11) 85%	(64) 69%

provide good care to the patients. Respect and privacy have been described as ethical challenges by some of the informants. Three typical examples from these descriptions are as follows:

Lack of time

> In my opinion lack of time for every patient is a big problem because of lack of resources. Some patients do get too little stimulation. Just to be with them more often and to take the patients to some activities can give them a better quality of life. (Staff member 12)

Covert medication

> To mix medication in the jam (without informing the resident). (Staff member 5)

End-of-life issues

> It is not right that a patient has to die alone. We had a patient where the relatives were not there when he came close to death. When the patient died, he was alone. Afterwards the relatives were in despair and became very sad because of that. (Staff member 21)

Part 2: Ethics meetings (from an Austrian model of good clinical practice)

Thirty-three ethics meetings were documented using a structured questionnaire for each meeting within the 1-year study period. Table 4 shows an overview of all documented ethics meetings including participants and topic. Twenty-nine of these were prospective resident ethics meetings (REMs) where decisions for a resident had to be made. Participants in the REM are staff members and representatives of the resident or the resident himself (20). In all 29 cases, the participants agreed on a conclusion that later was put into practice. Relatives in 26 of 29 REMs represented the residents' views. No resident participated in the meetings; thus, in three cases, neither the resident nor relatives were represented. The number of participating next of kin varied from 0 to 3 (mean 1.5). Ethical challenges discussed in prospective resident ethics meetings were mostly about withholding or withdrawing of life-prolonging treatment, for example artificial nutrition, dialysis and advance care planning, do-not-resuscitate orders, or to hospitalise or not. In one case, measures to enhance the patient's quality of life were the main topic of the meeting. The other four ethics meetings were regularly scheduled meetings of the ethics committee of Caritas Socialis. These were used to discuss common ethical challenges, planning educational efforts and work on own ethical guidelines for use in the organisation. Residents' cases were not discussed in any of these four meetings.

The findings from both parts of the study suggest that there is a difference between the type of ethical problems that the nursing home staff experience in their daily work and those discussed in ethics discussion meetings (REM and ethics committee). In daily work, everyday ethical issues seem to play a major role, whereas big ethical problems are more often discussed in official arenas for ethics discussion. Grounded on the findings from our study and a review of the literature, a model of 'the ethics iceberg' was created. The 'ethics iceberg' shown in Fig. 2 illustrates that ethics work and ethics discussions in nursing homes seem to focus on end-of-life issues. Everyday ethical issues, on the other hand, which occur much more frequent, are often hidden under the surface and thus are not properly addressed and therefore receive less attention, although occurring more frequently.

Discussion

Main findings of part 1 of the present study were that most nursing home staff members experienced ethical challenges in their daily work and that many felt these as a burden. Measures to improve systematic ethics work wanted by most employees were ethics education (86%) and time for ethics discussion (82%). Findings from part

2 showed that 29 of 33 documented ethics discussions were prospective resident ethics meetings where decisions for a resident had to be made. In all 29 cases, consensus was reached and put into practice. Relatives participated in a majority of case discussions, but residents did not participate in any meeting. The main topic of the ethics meetings was end-of-life care and life-prolonging treatment.

In our data, 90% of all employees of a large Norwegian nursing home experienced ethical challenges in their daily work. This included 93% of the healthcare workers vs. 77% of employees from other professions. It is thus obvious that ethical issues are frequent and important for most people working in nursing homes. Compared with studies from other countries, ethical challenges in Norwegian nursing homes in general are not very different from those reported in the literature (1–11). But it is striking that the lack of resources is the most frequently mentioned ethical challenge in a wealthy country such as Norway. Our findings highlight the frequency and importance of everyday ethical issues for the staff and add support to the idea that everyday issues are troubling to many nurses (see Fig. 2). The importance of everyday ethical issues and dignity in nursing homes has also been described different authors (9, 23–26). By respecting the residents' dignity, nursing home staff can probably avoid that nursing homes become 'undignifying institutions' (27–29). For all participants from our study, a lack of resources was the most common concern (79%), followed by end-of-life issues (39% in total; 43% for healthcare personnel and 15% for the other professions) and coercion (33%). Interestingly, there was no difference between healthcare workers and employees from other professions regarding a lack of resources as an ethical challenge (79% vs. 77%). The extent of experiencing ethical challenges seems to vary between professions as shown for end-of-life issues. This difference is illustrated in Table 2. Our findings suggest that closeness to residents seems to increase the percentage of ethical challenges experienced by the informants. Lillemoen and Pedersen have described similar findings for primary healthcare workers (30). Nevertheless, more than three-fourths of other professions from our study experience ethical challenges in their daily work indicating that this is an important and universal topic that should be addressed. Probably ethical sensitivity or ethical awareness can be enhanced by ethics education that helps to recognise especially everyday ethical challenges (31, 32). The first step to deal with ethical challenges and dilemmas is to perceive it (32). We found that more than 90% of the participants experienced ethical challenges as a burden in everyday work and 19% experienced ethical challenges as a high degree burden (Fig. 1). The experience of ethical dilemmas without the possibility to solve them can cause moral distress (33). It is thus important both to discuss ethical challenges and find solutions to relieve the staff's burden. Awareness of ethical

Table 4 Results from documented ethics discussions – Caritas Socialis, Vienna

Nr.	Part.	Type of meeting	Profession of participants[a]	Number of next of kin	Discussion prospective = 1 retrospective = 2 common challenges = 3	Reason for the meeting	Who asked for the meeting?	Ethical problem as stated by the group	Comment
1	9	Resident Ethics Meeting (REM)	N, P, AN, PC,	1	1	Withholding of dialysis as life-prolonging treatment	Relatives and nurses	Withholding of dialysis as life-prolonging treatment: benefit vs. Burden for the patient	
2	6	REM	N, AN, P	0	1	Mobilisation and/or surgical therapy of an decubitus	Nurses	Mobilisation and/or surgical treatment vs. No treatment	
3	7	REM	N, AN, P	2	1	Conflict about nutritional treatment of a diabetic patient between the nurses and the patients wife	Nurses	Benefit or burden of nutrition via PEG	
4	6	REM	N, P	2	1	Patients refuses blood sugar control	Head nurse	Benefit or burden of blood sugar control	
5	6	REM	N, P	2	1	Refusal of nutrition and fluids	Physician	Artificial nutrition or acceptance of the patients wish not to eat and drink	
6	7	REM	N, P, PC	2	1	Refusal of nutrition and fluids	Head nurse	Acceptance of the refusal or artificial nutrition?	
7	6	REM	N, P	2	1	Hospitalisation or not?	Relatives	Benefit and burden of hospitalisation for a patient who is temporarily confused?	
8	4	REM	N, P	0	1	Amputation of a foot because of pain or not?	Head nurse	Benefit and burden of amputation. Has the patient the right to refuse amputation?	

[a]Profession of participants: N, Nurse; AN, Assistant nurse; P, Physician; PC, Pastoral Care; SW, Socialworker; O, Occupational therapist.

Table 4 (Continued)

Nr.	Part.	Type of meeting	Profession of participants[a]	Number of next of kin	Discussion prospective = 1 retrospective = 2 common challenges = 3	Reason for the meeting	Who asked for the meeting?	Ethical problem as stated by the group	Comment
9	4	REM	N, P	1	1	DNR-order? Hospitalisation?	Head nurse	Benefit and burden of resuscitation and hospitalisation.	
10	3	REM	AN, P	1	1	Patient dying? Palliative Care?	Physician	DNR-order? Hospitalisation? Artificial nutrition	
11	6	REM	N, P	3	1	Patient falls often. Hospitalisation in case of every fall?	Physician, head nurse	Frequent hospitalisation after every fall?	
12	4	REM	N, P	1	1	Frail patient who dies not want to live anymore	Physician	Life-prolonging treatment? Hospitalisation?	
13	4	REM	N,P	1	1	Hospitalisation or not?	Physician	Frequent hospitalisation because of anaemia?	
14	6	REM	N, P, PS	3	1	Minimal intake of fluid and food	Head nurse	Benefit and burden of starting artificial nutrition via PEG	
15	4	REM	N, P, PC	2	1	Dying process and treatment options	Nurses, Physician	DNR-order? Hospitalisation?	Patient died on the same day
16	8	REM	N, PS	0	1	To people with dementia are attracted to each other and search for body contact (one of them is married)	Head nurse	The patient's behaviour disturbs the others. Should they have the option to use an own room.	
17	5	REM	N, P	3	1	Frail patient. Hospitalisation? Options?	Head nurse	Benefit and burden of hospitalisation or other treatment options.	
18	8	REM	N, AN, O	2	1	Patient with dementia and minimal intake of food and fluids.	Nurse	Artificial nutrition and PEG in the patient's interest?	Patient died on the same day

[a]Profession of participants: N, Nurse; AN, Assistant nurse; P, Physician; PC, Pastoral Care; SW, Socialworker; O, Occupational therapist.

Table 4 (Continued)

Nr.	Part.	Type of meeting	Profession of participants[a]	Number of next of kin	Discussion prospective = 1 retrospective = 2 common challenges = 3	Reason for the meeting	Who asked for the meeting?	Ethical problem as stated by the group	Comment
19	6	REM	N, P, PC	2	1	Patient with dementia and minimal intake of food and fluids.	Physician, head nurse	Benefit and burden of starting artificial nutrition via PEG. Is the decision the same as 6 months ago?	Same discussion had been done 6 months ago. This meeting should decide if the same decision is still applicable.
20	4	REM	N, P	1	1	Frail patient. DNR-order? Advance Care planning in general. Presumed will?	Head nurse	Care at the end of life. Resuscitation? Plan for food and fluid intake.	
21	6	REM	N, AN, P	2	1	Minimal intake of fluid and food. Refusal of feeding.	Head nurse	Artificial nutrition and PEG in the patient's interest? Hospitalisation?	
22	6	REM	N, AN, P, SW	2	1	Patient's condition is deteriorating. Does he have to move into the nursing home?	Nurse	Benefit and burden of moving to the nursing home.	
23	4	REM	N, A	2	1	Patient does not want to live anymore. How to deal with this statement?	Nurse	DNR-order? Hospitalisation? Artificial nutrition	
24	3	REM	N, A	1	1	Patient with dementia and minimal intake of food and fluids. Advance care planning.	Head nurse	Care at the end of life. Resuscitation? Artificial nutrition/hydration?	
25	6	REM	N, A, PC	2	1	Patient with dementia and minimal intake of food and fluids. Care at the end of life. Dying?	Head nurse	Care at the end of life. Resuscitation? Artificial nutrition/hydration?	Intravenous fluids were withdrawn
26	4	REM	N, A	2	1	Patient with dementia and cancer. Advance Care planning.	Nurse	Care at the end of life. Resuscitation? Hospitalisation? Artificial nutrition/hydration?	

[a]Profession of participants: N, Nurse; AN, Assistant nurse; P, Physician; PC, Pastoral Care; SW, Socialworker; O, Occupational therapist.

Table 4 (Continued)

Nr.	Part.	Type of meeting	Profession of participants[a]	Number of next of kin	Discussion prospective = 1 retrospective = 2 common challenges = 3	Reason for the meeting	Who asked for the meeting?	Ethical problem as stated by the group	Comment
27	5	REM	N, P, PC	1	1	How to enhance quality of life for the patient? What is the patient's will? Pain treatment ineffective.	Nurse	Measures to enhance the patient's quality of life.	
28	4	REM	N, A, SW	1	1	Frail patient. DNR-order? Hospitalisation? Artificial nutrition? Advance Care planning in general.	Nurse	Care at the end of life. Resuscitation? Hospitalisation? Artificial nutrition/hydration?	
29	6	REM	N, AN, PC	1	1	Patient's condition (heart insufficiency) is deteriorating. Advance Care planning in general.	Head nurse, Physician	Advance Care planning. Specialist consultation concerning treatment options. Benefit and burden of mobilisation and extended treatment.	
30	7	EC	N,PC,P	0	3	Fluid treatment at the end of life, education planning, participation in research projects	Regular meeting		Discussion of common ethical challenges, no case discussion
31	6	EC	N,PC,P	0	3	Education planning, participation in research projects, guideline home care	Regular meeting		Discussion of common ethical challenges, no case discussion
32	7	EC	N,PC,P	0	3	Guideline fluid treatment at the end of life, education planning, participation in research projects	Regular meeting		Discussion of common ethical challenges, no case discussion
33	8	EC	N,PC,P	0	3	Guideline fluid treatment at the end of life, education planning, participation in research projects	Regular meeting		Discussion of common ethical challenges, no case discussion

[a]Profession of participants: N, Nurse; AN, Assistant nurse; P, Physician; PC, Pastoral Care; SW, Socialworker; O, Occupational therapist.
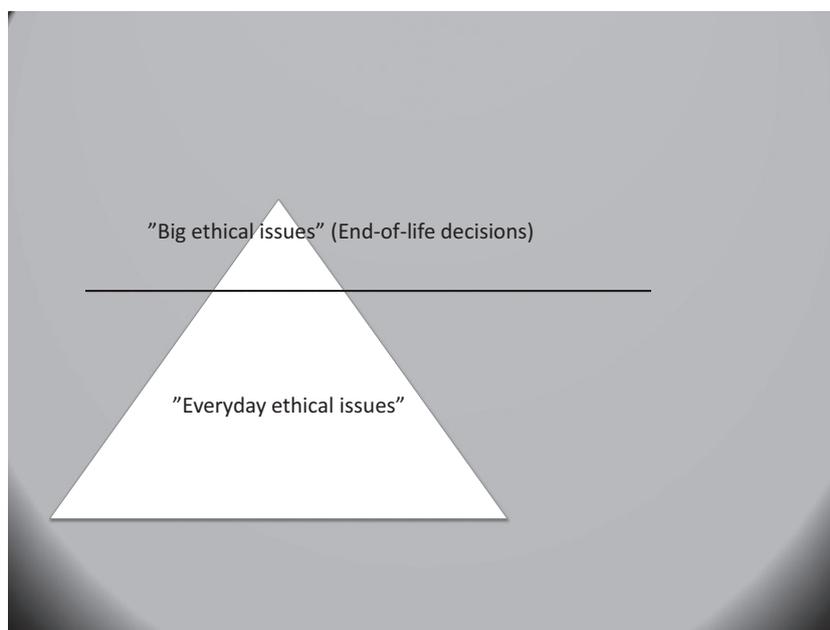
Figure 2 The ethics iceberg.

challenges and time to address these issues therefore seems to have a protective role for the psychological health of the staff. This underlines the necessity of regular ethics discussions in nursing homes.

There is a demand for systematic ethics work in nursing homes. In order to establish a culture of care in nursing homes, the attention for everyday ethical issues and the inclusion of ethics in everyday meetings and discussions have to be more focused in the future. The implementation of special structures or places for systematic ethics work must be based on sensitisation and awareness of ethical aspects in everyday work and communication (32, 34).

Ninety per cent of the healthcare workers and 92% of the employees from other professions expressed that more systematic ethics work is needed. This finding is similar to findings from other studies (5, 10, 30). Most suggested methods to improve ethics work based on our data were ethics education for the whole staff (86%), time for ethical discussions (82%) and to have someone to consult (78%). These findings support previous findings from other studies in Norway where staff management and heads of wards were informants (5, 10). One major benefit for all participants in ethics consultation might be to be heard and to be able to express their concerns. This is important for healthcare personnel, patients and relatives (35). But ethics education alone is not enough. It is also important that managers, policymakers and politicians participate when lack of resources is addressed and discussed. In our findings, 27% of all informants (38% of health personnel vs. 23% of other professions) suggested establishing ethics committees in nursing homes. This confirms the results

of Gjerberg et al. (10) where 30% of participants suggested establishing ethics committees. Only 6% of our informants expressed a wish to collaborate with a lawyer compared to 19% in Gjerberg et al. (10) and nine of 19 participants in Bollig et al.'s research (5). In both studies, most of the respondents were managers, head nurses and people with leading positions, whereas the informants from the present study were employees from all professions, many of them working in direct patient care, assuming a closer relationship to the residents. A reason for the difference could be that staff managers and head nurses more often feel that they have to defend their judgements in public and therefore would appreciate consulting a lawyer. Nevertheless, most informants seem to recognise that ethical challenges cannot be solved by consulting a lawyer, but rather through ethics discussions.

Lack of resources and breaches of autonomy were most often reported by Gjerberg et al., (10) whereas end-of-life care issues were often reported when asked to outline a recent ethical challenge. Covert medication has been described by some of our informants as their most recent ethical dilemma. Between 1.5 and 17% of nursing, home residents do receive covert medication, often without documentation and discussion with relevant parties (36, 37). Covert medication in nursing homes thus seems to be a challenge that should be addressed more openly.

Ethics meetings in nursing homes at present seem to focus mostly on big ethical issues such as end-of-life decision-making, whereas many nursing home staff members experience everyday ethical issues such as a lack of

resources and coercion more frequently. This finding is shown in Fig. 2: the ethics iceberg. The prominence of end-of-life issues in both ethics discussions and the descriptions of recent ethical dilemmas is truly related to the fact that this theme is connected to the nurses 'advocacy role' and therefore is experienced as more distressing (31).

The results of our study show that systematic ethics discussions including relatives of the residents frequently can lead to consent on acceptable decisions for both staff and relatives, and thus can enhance the decision-making process for frail elderly nursing home residents. In the present study, consent was obtained and action taken according to 100% of the registered cases (Table 4). Dialogue and discussion can thus lead to agreement that is acceptable for all involved parties. Important factors seem to be participation in the discussion, to be heard and an open process of decision-making. Although consensus is reached, it is not sure that this consensus always is a good solution from the residents' point of view. Nevertheless, it enables the staff and relatives to decide and to act when needed. In Vienna, the ethics committee did not have any case discussions but worked on ethics guidelines based on the discussion from minor groups. The ethics project of the Norwegian Association of Local and Regional Authorities (13) was based on participation of employees with limited ethics training as ethics consultants, combined with ethics discussions in peer groups (13). This strategy is in accordance with the findings of our study and of Gjerberg et al. (10).

Resident autonomy and participation seems to be limited at present. For nursing home residents, it is important to experience both choice and control over everyday matters (38). It has been suggested to improve participation in decision-making for nursing home residents, even including persons with dementia (39). So far, the residents' involvement in medical decision-making seems to be limited (40). It is astonishing that no resident participated in any of the 29 prospective resident ethics meetings in our study. It was not possible from our recordings to determine the reasons why no residents were involved; thus, we could only speculate. It might be that the residents were considered to be in too poor condition to participate or that the staff members feared involving residents in difficult ethical decision-making. We suppose that there is a lack of creativity arranging verbal and non-verbal communication to support a person-oriented way of participation. This has to be explored in further studies. In 26 of 29 meetings, the relatives represented the residents' views. One might speculate that a relative may be able to express the resident's true wishes, or decide on behalf of the resident if they have not been appointed to do so on a legal basis. Autonomy to make a decision must be based on both capacity to make decisions and having enough information to be able to decide and to get caring support. In a previous study from the USA, 40% of nursing home residents reported being told nothing about their medical condition at all (40). It seems that informing residents of their medical condition and their right to participate in decision-making has to be improved. Nursing homes should therefore implement strategies to enhance residents' involvement and participation in decision-making (41).

Limitations and strengths of the study

One limitation of the study is the use of a 'spotlight approach' where two nursing homes in two different countries have been chosen to study the topic. The nursing homes were selected on purpose. In Norway, a typical large nursing home with many residents was chosen based on the presupposition that this might uncover a larger variety of ethical challenges. Compared with the results from other studies in Norway, it seems to be similar with other Norwegian nursing homes, indicating that the results may induce future practice. The model of good practice from Austria was chosen because of their long experience with systematic ethics work. A strength of the study was that the results from Austria are built on an established tradition in CS for handling ethical challenges, and therefore, a higher awareness for ethical challenges would be found than in other nursing homes.

Conclusions

In the present study, ethical challenges most often reported were related to lack of resources, end-of-life issues and coercion. Resident ethics meetings may help to discuss ethical challenges and may lead to acceptable decisions for all included parties. Besides the often more prominent and obvious ethical challenges in end-of-life care in nursing homes, everyday ethical challenges such as a lack of resources and coercion have to be dealt with. In the public, as well as in systematic ethics discussions, ethical challenges in end-of-life care are more visible than everyday ethical challenges. Thus, ethics meetings should focus more on everyday ethical challenges. The results of the study support the value of a systematic approach to resolve ethical dilemmas in nursing homes. Systematic ethics work in nursing homes needs to be improved and to be implemented in all nursing homes. Both residents and relatives should be invited to participate in discussions concerning ethical challenges and in ethics meetings. To enable residents to use their autonomy as much as possible, participation of the residents in the resident ethics meetings should be encouraged.

Acknowledgements

consultations. The authors greatly appreciate their contribution to make this study possible.

Author contributions

GB designed the study protocol and the questionnaires used. GS, JH and AH commented on these and suggested modifications. All authors agreed to use Caritas Socialis in Vienna as a model of good practice for systematic ethics work. GB organized data collection, data analysis and drafted the first version of the manuscript. GB and GS collected the data. All authors critically revised the manuscript and took part in the discussion of the results. All authors read and approved the final version of the manuscript.

Ethical approval

The study protocol was reported to and approved by the Regional Ethics Committee (REK Sør-Øst A) in Oslo, Norway, reference 2009/1339a. The participants were informed about the study and were given the opportunity to ask clarifying questions before participating. They were informed about the possibility to withdraw from the study at any time. All informants gave their informed consent to participate.

Funding

References

1 Olson E, Chichin ER, Libow LS, Martico-Greenfield T, Neufeld RR, Mulvihill M. A center on ethics in long-term care. *Gerontologist* 1993; 33: 269–74.

2 Weston CM, O'Brien LA, Goldfarb NI, Roumm AR, Isele WP, Hirschfeld K. The NJ SEED Project: evaluation of an innovative initiative for ethics training in nursing homes. *J Am Med Dir Assoc* 2005; 6: 68–75.

3 Schaffer MA. Ethical problems in end-of-life decisions for elderly Norwegians. *Nurs Ethics* 2007; 14: 242–57.

4 Slettebo A, Bunch EH. Solving ethically difficult care situations in nursing homes. *Nurs Ethics* 2004; 11: 543–52.

5 Bollig G, Pedersen R, Førde R. Etikk i sykehjem og hjemmetjenester. (Ethics in nursing homes and home health care) *Sykepleien Forskning* 2009; 4: 186–96.

6 Aroskar MA. Community health nurses. Their most significant ethical decision-making problems. *Nurs Clin North Am* 1989; 24: 967–75.

7 Reitinger E, Heller A, Heimerl K. Ethische Entscheidungen in der Altenpflege. (Ethical decisions in elderly care) *BtPrax* 2007; 2: 58–62.

8 Sansone P. The evolution of a long-term care ethics committee. *HEC Forum* 1996; 8: 44–51.

9 Powers BA. Ethnographic analysis of everyday ethics in the care of nursing home residents with dementia: a taxonomy. *Nurs Res* 2001; 50: 332–9.

10 Gjerberg E, Førde R, Pedersen R, Bollig G. Ethical challenges in the provision of end of life care in Norwegian nursing homes. *Soc Sci Med* 2010; 71: 677–84.

11 Bollig G. Ethical decision-making in nursing homes – a literature study. In *Clinical Ethics Consultation – Theories and Methods, Implementation, Evaluation* (Schildmann J, Gordon JS, Vollmann J eds), 2010, Ashgate, Farnham, 189–201.

12 Storting report St.meld. nr. 25 (2005–2006). *Mestring, muligheter og mening. Framtidas omsorgsutfordringer.* (Parliament report. Coping, possibilities and meaning. Future care challenges.) http://www.regjeringen.no/en/dep/hod/dok/regpubl/stmeld/2005 2006/stmeld-nr-25-2005-2006-.html?id=200879 (last accessed 13 July 2014).

13 Kommunesektorens organisasjon – Samarbeid om etisk kompetanseheving. (Communities organization – cooperation on ethics education) http://www.ks.no/tema/Helse-og-velferd/Samarbeid-for-etisk-kompetanse heving/ (last accessed 13 July 2014).

14 Husebø S. De døende gamle: retningslinjer for etiske avgjørelser om avslutning av livsforlengende behandlingstiltak. (The dying old: guidelines for ethical decisions about withdrawal of life-sustaining treatments) *Omsorg* 2006; 4: 43–45.

15 O'Cathain A, Thomas K. Combining qualitative and quantitative methods. In *Qualitative Research in Health Care*, 3rd edn (Pope C, Mays N eds), 2006, Blackwell Publishing, Oxford, 102–11.

16 Völker TM, Stefan CD, Hauer H, Schreiber W. Projekt "Spotlight Erste-Hilfe" eine Standortbestimmung der Erste Hilfe Kenntnisse österreichischer Autofahrer. (Spotlight first aid – definition of the position of first aid knowledge of Austrian drivers) *Notfall Rettungsmed* 2010; 13: 125–30.

17 Sandelowski M. Whatever happened to qualitative description? *Res Nurs Health* 2000; 23: 334–40.

18 Sandelowski M. What's in a name? Qualitative description revisited *Res Nurs Health* 2010; 33: 77–84.

19 Neergaard MA, Olesen F, Andersen RS, Sondergaard J. Qualitative description – the poor cousin of health research? *BMC Med Res Methodol* 2009; 9: 52.

20 Hallwirth-Spörk C, Heller A, Weiler K (eds). *Hospizkultur und Mäeutik – Offen sein für Leben und Sterben.* 2009 Lambertus, Freiburg im Breisgau. (Hospice culture and maeutics – to be open for living and dying).

21 Teleios 2011. http://www.cs.or.at/deutsch/caritas-socialis/presse-und-kampagnen/presse/caritas-socialis-gewinnt-den-teleios-2011—1-platz-fuer-das-projekt-der-ethischen-bewohnerinnen-besprechung.html (last accessed 13 July 2014).

22 WEDO. *European Quality Framework for long-term care services – Principles and guidelines for the wellbeing and dignity of older people in need of care and assistance.* http://www.nhi.ie/zuploads/page_docs/european%20quality%20framework%20for%20long%20term%20care%20services%20principles%20and%20guidelines.pdf (last accessed 13 July 2014).

23 Powers BA. Everyday ethics in assisted living facilities: a framework for assessing resident-focused issues. *J Gerontol Nurs* 2005; 31: 31–37.

24 Bolmsjø IA, Sandman L, Andersson E. Everyday ethics in the care of elderly people. *Nurs Ethics* 2006; 13: 249–63.

25 Van der Dam S, Abma TA, Kardol MJM, Widdershoven GAM. "Here's my dilemma". Moral case deliberation as a platform for discussing everyday ethics in elderly care. *Health Care Anal* 2012; 20: 250–67.

26 Brodtkorb K, Skisland AV, Slettebø A, Skaar R. Ethical challenges in care for older patients who resist help. *Nurs Ethics* 2014; Aug. 21. pii: 0969733014542672.

27 Shotton L, Seedhouse D. Practical dignity in caring. *Nurs Ethics* 1998; 5: 246–55.

28 Seedhouse D, Gallagher A. Undignifying institutions. *J Med Ethics* 2002; 28: 368–72.

29 Rehnsfeldt A, Lindwall L, Lohne V, Lillestø B, Slettebø Å, Heggestad AKT, Aasgaard T, Råholm MB, Høy B, Sæteren B, Nåden D. The meaning of dignity in nursing home care as seen by relatives. *Nurs Ethics* 2014; 21: 507–17.

30 Lillemoen L, Pedersen R. Ethical challenges and how to develop ethics support in primary health care. *Nurs Ethics* 2012; 20: 96–108.

31 Grace PJ, Fra ST, Schultz GS. Ethics and human rights issues experienced by psychiatric-mental health and substance abuse registered nurses. *J Am Psychiatr Nurses Assoc* 2003; 9: 17–23.

32 Peile E. Supporting primary care with ethics advice and education. *BMJ* 2001; 323: 3–4.

33 Forde R, Aasland OG. Moral distress among Norwegian doctors. *J Med Ethics* 2008; 34: 521–5.

34 Reitinger E, Heller A. Ethik im Sorgebereich der Altenhilfe. (Ethics in the area of eldely care) In *Handbuch der Organisationsethik* (Krobath T, Heller A eds), 2010, Lambertus, Freiburg, 737–65.

35 Howe EG. All care providers need more opportunities to share their ethical concerns with others. *J Clin Ethics* 2010; 21: 179–88.

36 Kirkevold O, Engedal K. Is covert medication in Norwegian nursing homes still a problem? A cross-sectional study *Drugs Aging* 2009; 26: 333–44.

37 Haw C, Stubbs J. Covert administration of medication in older adults: a review of the literature and published studies. *J Psychiatr Ment Health Nurs* 2010; 17: 761–8.

38 Kane RA, Caplan AL, Urv-Wong EK, Freeman IC, Aroskar MA, Finch M. Everyday matters in the lives of nursing home residents: wish for and perception of choice and control. *J Am Geriatr Soc* 1997; 45: 1086–93.

39 Helgesen AK, Larsson M, Athlin E. Patient participation in special care units for persons with dementia: a losing principle? *Nurs Ethics* 2014; 21: 108–18.

40 Wetle T, Levkoff S, Cwikel J, Rosen A. Nursing home resident participation in medical decisions: perceptions and preferences. *Gerontologist* 1988; 22(Suppl): 32–38.

41 Hughes CM, Goldie R. "I just take what I am given": adherence and resident involvement in decision making on medicines in nursing homes for older people: a qualitative survey. *Drugs Aging* 2009; 26: 505–17.