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A European multicenter study on systematic ethics work in nursing homes

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Background: There are many existing ethical challenges in nursing homes. Although different methods and approaches to discussing the ethical challenges have been established, systematic ethics work is not yet a standard in all nursing homes. The aim of the present study was to explore ethical challenges and approaches to implementing systematic ethics work in nursing homes.
Methods: Data from five institutions in Austria, Germany and Norway were collected, and a mixed-methods two-tiered study approach was chosen. Documentation of ethics discussions was combined with qualitative focus group interviews with staff members regarding the implementation of systematic ethics work in nursing homes.
Results: One hundred and five ethics meetings were documented. The main topics were advance care planning, ethical challenges associated with artificial nutrition, hospitalisation and end-of-life decision-making. Of the meetings, 33% focused mainly on everyday ethical challenges. In 76% of prospective case discussions, agreements about a solution were reached; however, in 29% of these no residents or relatives participated. The advantages of systematic ethics work described by the staff were enhanced openness and dialogue, overall, and a greater ethical awareness. Many voiced a need for structure and support from the administration.
Conclusions: Systematic ethics work is greatly appreciated by the staff and helps to reach a consensus in the majority of case discussions. It should be implemented in all nursing homes. Attention to everyday ethical challenges is important. The participation of relatives and physicians could be improved. The participation of the residents' in ethics discussions should be encouraged to strengthen their autonomy and dignity.

Keywords: ethics, elder care, nursing home care, palliative care, decision-making, autonomy.

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Introduction

In elderly care and the 'nursing home world', many ethical challenges and dilemmas have to be faced. Both 'everyday ethical issues' and 'big ethical issues' have been described in the literature (1–11). The typical ethical challenges in nursing homes are lack of resources (3–5), resident autonomy issues, such as the use of coercion or restraints (4–8), and decision-making surrounding end-of-life care (3, 5, 9–11).

More than 90% of the staff at a Norwegian nursing home experienced ethical problems as a burden (12). A main barrier to the use of ethics discussions and ethics committees in nursing homes seems to be a lack of awareness (9). The Norwegian Association of Local and Regional Authorities started the 'Cooperation for building ethics competence' in order to improve competence in ethics through ethics education and reflection on ethics in nursing homes and primary care in 2007 (13). The project showed that the sustainability of ethics work depends on an assignment from the administration, ethics competence and methods for structuring ethical reflection (14).

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There is a need for systematic ethics work including ethics education and ethics reflection (4, 5, 9), but it is not yet standard in all nursing homes. Systematic ethics work 'includes the organisation's 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' (12). Different approaches to discussing ethics in nursing homes have been established in the USA (9), Germany (15, 16), Austria (16, 17) and Norway (4, 18). At present, theses approaches include, for example, informal discussions, reflection groups, moral case deliberation, ethics consultant, ethics committee, ethics café, ethics rounds or role play (19, 20). Ethics support has become more diverse and adapted to local needs and everyday ethical issues are important topics (1, 19, 20). So far there is no international gold standard or a state of the art for systematic ethics work other than that the need to discuss and handle ethical challenges in nursing homes is widely recognised.

The theoretical background and perspective of this study are the principles of biomedical ethics as proposed by Beauchamp and Childress with autonomy as a central concept in modern bioethics (21, 22), as well as palliative care ethics and hospice philosophy where the patients and their relatives' wishes and needs are paramount (23, 24). Although the principlism that is based on the four moral principles respect for autonomy, nonmaleficence, beneficence and justice (21) is not a classical ethical theory, it is a frequently used ethical framework of moral norms in modern bioethics (22). The four principles approach is widely used in medical ethics to discuss ethical dilemmas in ethics committees and ethics consultations in hospitals. Due to its importance in modern bioethics, the principle of respect for autonomy has even been referred to as being 'first among equals' (25). In order to respect the residents' autonomy in nursing homes, the inclusion of residents and relatives in the discussion about ethical challenges and decision-making is needed (26).

Aims of the study

The main aims of the study were to investigate which types of ethical challenges are discussed and to study approaches to implementing systematic ethics work that have already been incorporated into the daily practices in nursing homes.

The research questions were as follows:

1 Which ethical challenges are discussed in nursing homes?
2 What are the staff's experiences with the implementation of systematic ethics work?
3 Were residents and relatives included in ethics discussions?

Ethical considerations and ethical approval

The documentation of the resident cases from the ethics meetings was confidential. The cases were documented using a questionnaire with a description of the case discussed, but without personal data concerning the resident, relatives or other participants. No resident data other than gender and age were documented. The participants of the focus group interviews were informed about the study and invited to participate by the nursing home management. All participants had the opportunity to ask clarifying questions prior to their participation in the interview and gave informed consent. The Regional Ethics Committee (REK Sør-Øst A) in Oslo, Norway, approved the study protocol (reference 2009/1339a).

Methods

The study used a mixed-methods approach (27) combining quantitative data from questionnaires on ethics discussions in nursing homes and qualitative data from focus group interviews about systematic ethics work. Mixed methods were used in order to provide a richer picture (27) of systematic ethics work in nursing homes. In part one of the study, a questionnaire about ethics meetings in nursing homes was used to collect data on the types of ethical challenges and ethics discussions. In part two, nursing home staff with experience in the implementation of systematic ethics work and members of nursing home ethics groups or ethics committees were interviewed in focus groups about the implementation and practice of systematic ethics work.

Part 1: Ethics discussions in nursing homes

As there is no existing gold standard for systematic ethics work in nursing homes, we chose to use purposeful sampling (28) and included centres that have introduced programmes to increase the staff's ethical competence as models of good practice.

Informants and recruitment. Five centres from three different countries (Austria, Germany and Norway) participated. Three models of good practice from different countries and two nursing homes were included in the study. These were as follows:

1 The CS Caritas Socialis GmbH (CS) in Vienna, Austria, runs three nursing homes and two special units for people with dementia in Vienna, altogether housing a total of 333 residents. Since 2007, the CS has used four different arenas for ethics discussions throughout the organisation (12, 17). The most frequently used arenas

are the resident ethics meeting (REM) and an institutional ethics committee.

2 The clinical ethics committee in primary care in Oslo, Norway (klinisk etikk-komité i kommunehelsetjenesten, KEKK), serves as a joint ethics committee for 25 nursing homes in Oslo with 2 350 care places (29, 30). It is organised by the administration of the Department of Nursing Home Care, City of Oslo. KEKK's aim is to focus on ethical dilemmas through ethics case discussions, education, counselling and establishing ethics guidelines (29, 30).

3 The network for ethics in elderly care 'Frankfurter Netzwerk Ethik in der Altenpflege' (31, 32) includes two joint ethics committees for nursing homes in Frankfurt and an open ethics discussion arena for staff from elderly care, the so-called Netzwerk NAEHE where ethical challenges can be discussed. In a 'NAEHE' meeting, usually 8–12 participants (mostly nursing home staff) discuss ethical challenges or cases aided by a moderator/ethicist (31, 32).

4 and 5. In addition to these three models, two nursing homes, one from Norway (with 100 long-term care places) and one from Germany (with 88 long-term care places) which were in the starting phase of establishing ethics discussions in their long-term care facilities, were included.

The management at all the facilities were asked to participate in the study by documenting ethics meetings from their ethics discussion arenas.

Data collection. A questionnaire was used to document all ethics discussions from the five participating centres (Table 1). The questionnaire had been used in a previous study from one centre in Austria (12). The moderators of the ethics discussions were asked to document each ethics meeting by filling out the questionnaire within a period of one year. The type of ethics meeting, the total number of cases, the ethical challenges and questions, the conclusions, and the consequences were documented.

Data analysis. For the analysis of the data obtained in the questionnaires, descriptive statistics were used. The results from the questionnaires were compared with data collected from a previous study using CS Vienna as the only location (12) and findings from the literature. Important outcome measures were as follows:

- Was a consensus reached?
- Did residents or relatives participate in ethics discussions?

Table 1 Questionnaire about ethics consultation in nursing homes

1. Place and institution:
2. Date:
3. Number of participants:
4. Type of ethics consultation (tick off):
   - ☐ Non-formal discussion between colleagues
   - ☐ Ethics-reflection group
   - ☐ Ethics committee
5. Participants profession (tick off):
   - ☐ Nurse
   - ☐ Auxiliary nurse
   - ☐ Physician
   - ☐ Physiotherapist
   - ☐ Ergonomist
   - ☐ Social worker
   - ☐ Priest
   - ☐ Others (describe here):_____
6. Has the patient attended the meeting himself? (tick off):
   - ☐ The patient himself
   - ☐ Next of kin, evtl. number
7. Has the patient written advance directives?
8. Was a patient case discussed? (tick off):
   - ☐ Actual patient where a decision has to be made
   - ☐ Retrospective; after a decision had been made and the patient is not in the nursing home anymore
   - ☐ Discussion and general ethical challenges or problems, e.g. use of restraints, withdrawing of life-sustaining treatment, etc.
9. What was the reason for the meeting?
10. Who took the initiative to the meeting?
11. What was the ethical problem/were the ethical problems?
12. Was there consensus about one solution?
    - Has the suggestion been put into practice?

Part 2: Focus group interviews of nursing home staff

Focus group interviews were used to investigate staff experience with systematic ethics work in nursing homes. Qualitative description was used in order to provide a straight description of the issue in everyday terms (33).

Informants and recruitment. Nursing home staff members or nursing home ethics committee members with experience in the implementation of systematic ethics work or ethics discussions were informed by their leaders at staff meetings about the study and were invited to participate. The five focus group interviews comprised of 43 participants from Austria, Germany and Norway. All participants were engaged in work with the implementation of systematic ethics work in nursing homes and 23 of them were members of nursing home ethics committees. Table 2 provides an overview of the focus group participants' characteristics. The informants received written information and had the opportunity to contact the researcher in order to ask questions about the study. They were able to participate within their usual working hours.

Data collection. The focus group discussions were led by the first author using opening questions (Table 3). An open-ended interview technique with follow-up

Table 2 Focus group participants (n=43)

Focus group nr.	*1*	*2*	*3*	*4*	*5*
Number of participants	11	9	10	4	9
Nursing staff	5		4	3	3
Spiritual care	2			1	2
Management (incl. nursing managers)	2	9	3		
Physician	2				1
Ethicist			3		1
Researcher					2
Ethics committee member	4		10		9

*Some of the participants had more than one profession/function.

Table 3 Opening questions for the focus group interviews

- What are your experiences with systematic ethics discussions in the nursing home?
- What are the advantages or disadvantages of the model of ethics discussion that is used in your institution?
- How do you assure that the residents will is taken into account?
- How can systematic ethics work be improved further within your organisation?
- What are signs of success of the implementation of systematic ethics work in your organisation?

questions related to the participants' answers and responses was used. The interviews were recorded digitally.

Transcription and data analysis. The first author (GB) and three trained assistants performed a verbatim transcription of the digital interview recordings using the transcription software f4, from Audiotranskription (34). The software QSR NVIVO 9 (35) was used to aid the systematic coding and analysis of the interview transcripts. Data analysis was based on qualitative description and qualitative content analysis with data-derived themes (33, 36–38). During the analysis, the text was coded and similar codes were merged to themes. A description of the analysis process is provided in Table 4. Repeated reading of the interview transcripts and repeated discussions with the co-authors were used as a measure to validate the findings through the whole process of analysis. Repeated comparisons of the researchers' presuppositions with the results, using critical reflection and meta-positions (36) as well as repeated discussions with the co-authors about alternative interpretations of the results, were used to ensure reflexivity.

Results

Part 1: Ethics discussions in nursing homes

A total of 105 ethics meetings were documented. Table 5 provides an overview of all ethics meetings, including the meeting type, the participants and the ethical challenges

Table 4 Description of the analysis process

1. GB and all co-authors read the transcripts and familiarised themselves with the data
2. GB and EG independently identified preliminary codes and themes
3. GB and all co-authors compared and discussed the preliminary codes and themes
4. GB and EG revised the preliminary codes and themes
5. GB and all co-authors discussed the revised codes and themes and agreed on the final codes and themes
6. GB and EG checked the transcripts in order to question the findings
7. GB and all co-authors discussed the findings and themes and agreed about the interpretation of the data

discussed. Table 6 shows a summary of the most important results. The main topics were advance care planning (ACP), insertion of a percutaneous endoscopic gastrostomy tube (PEG) or ethical challenges associated with PEG use, hospitalisation and end-of-life decision-making. Many meetings focused on decision-making for residents with dementia (Table 5). Of the ethics meetings, 87 were prospective, where decisions for a resident had to be made. Agreement on a solution was reached in 76% of these cases. Relatives participated in most prospective ethics meetings, whereas residents did not participate in any of the meetings. In 29% of these meetings, neither residents nor relatives participated, even though prospective decisions for a resident were to be made. In 97 ethics meetings, the professions of the participants were documented. Nurses participated in 100% of these meetings, physicians in 76%. Meetings that focused mainly on everyday ethical challenges covered a third of all cases. Common ethical challenges presented were about residents' behaviour, coercion, autonomy, sexual abuse, refusal of care or treatment, level of care, the nurses' duty to care, etc. Only two of the documented ethics meetings consisted of informal discussions on ethical challenges.

Part 2: Focus group interviews of nursing home staff

The process of analysis of the interview data (Table 4) led to three main themes and eleven subthemes (Fig. 1), which are presented below.

1. *Ethical challenges – one should listen to the resident's wishes and needs*

This main theme was about ethical challenges with practical consequences for the residents living in the nursing home. These included issues about autonomy, conflicts between residents and relatives, lack of resources, and a change of focus from big end-of-life issues to everyday ethics.

Respecting the residents' dignity and autonomy. Many informants described the need to protect and maintain the

Table 5 Overview over 105 ethics meetings from 5 centres in 3 countries

Nr.	*Type of meeting*	*Profession of participants**	*Discussion type prospective = 1 retrospective = 2 common challenges = 3*	*Topic for the meeting*
1	EC	N, PC, P	3	Education planning, participation in research projects, palliative medicine and multiple sclerosis, end-of-life care in dementia
2	EC	N, PC, P	3	Guideline pain treatment, education planning, participation in research projects, end-of-life care in dementia
3	REM	N, PC	1	Artificial nutrition and PEG
4	REM	N, PC	1	Hospitalisation vs. palliative care in the nursing home
5	REM	N, PC	1	Artificial nutrition and PEG, Do not resuscitate (DNR)-order, hospitalisation and moving to another nursing home ward
6	REM	N, P, PC, AN	1	Death of the residents wife
7	REM	N, P, PC, AN	1	Resident refuses food, drink and medication
8	REM	N, P	1	ACP, DNR? No communication possible
9	REM	N, PC, P	1	Resident refuses nutrition, ACP
10	REM	N, PC, P	1	ACP, PEG use in the future
11	REM	N, PC, P, PSY	1	Refusal of food and drink
12	REM	N, P, PC, AN	1	Hospitalisation vs Palliative Care in the nursing home
13	REM	N, P	1	ACP, hospitalisation?, assumed will
14	REM	N, P, AN	1	Assumed will, ACP
15	REM	N, P	1	ACP, PEG?
16	REM	N, P, SW	1	Daily care adequate?
17	REM	N, AN, P	1	Resident with dementia, ACP?
18	REM	N, P	1	Artificial nutrition and PEG?
19	REM	N, P	2	Limitation of therapy as documented in another nursing home/residents condition improved
20	REM	N, P	1	ACP, hospitalisation?
21	REM	N, P	1	Overweight in a resident with dementia
22	REM	N, P	1	Nutrition, weight loss
23	REM	N, P	1	Coercion to enable pacemaker control in a patient with dementia?
24	REM	N	1	Place of care, ACP, life-prolonging treatment
25	REM	N, AN, P	1	Hospitalisation, PEG-insertion?
26	REM	N, P	1	PEG-insertion in the hospital against the residents written will. Afterwards removal of the PEG by the resident
27	REM	N, P	1	ACP, Palliative Care planning
2e	REM	N, P	1	Medical diagnostic or treatment
20	REM	N, P	1	Life-prolonging treatment, PEG
30	REM	N, P	1	ACP
31	REM	N, P, PC, AN	1	ACP, PEG, resuscitation
32	REM	N, P	1	Nutrition, weightloss, PEG-insertion?
33	REM	N, P	1	Wish to die, ACP, Palliative Care
34	REM	N, P	1	Resident with dementia and PEG-insertion after hospitalisation
35	REM	N, AN, P	1	Resident with dementia and partial refusion of nutrition, ACP
36	REM	N, P	1	Resident with dementia, ACP?
37	REM	N, P	1	Resident with dementia, ACP?
36	REM	N, AN, P	1	Resident with dementia, ACP?
39	REM	N, AN, P	1	Resident with dementia and refusing of nutrition, ACP
40	REM	N, P	1	Resident with dementia, ACP?
41	REM	N, P	1	Resident with dementia, ACP?
42	REM	N, P	1	Resident with cancer, hospitalisation. Palliative Care
43	REM	N, P	1	Resident with dementia, ACP?
44	REM	N, P	1	Resident with dementia, ACP, hospitalisation, PEG?
45	REM	N, P	1	ACP, PEG, Palliative Care planning

Table 5 (Continued)

Nr.	Type of meeting	Profession of participants*	Discussion type prospective = 1 retrospective = 2 common challenges = 3	Topic for the meeting
46	REM	N, P	1	ACP, PEG, DNR, Palliative Care planning
47	REM	N, P	1	Resident with dementia, ACP?
48	REM	N, PC, P	1	Resident with dementia, ACP?
49	REM	N, P	1	Resident with dementia, ACP?
50	REM	N, AN, PC, P, PSY	1	Resident refuses food, weight loss
51	REM	N, P	1	Nutrition, depression
52	REM	N, AN, P	1	Nutrition, PEG, ACP
53	REM	N, P	1	ACP, PEG, Palliative Care planning
54	REM	N, P	1	PEG, life-prolonging treatment
55	REM	N, AN, PC, P	1	Resident with dementia, ACP?
56	REM	N, P	1	ACP, PEG, DNR, hospitalisation?
57	REM	N, P	1	ACP, PEG, DNR, Palliative Care planning
58	REM	N, P	1	Nutrition, weight loss, PEG-insertion?, ACP
59	REM	N, P	1	Resident with cancer, hospitalisation, PEG-insertion, Palliative Care
60	REM	N, AN, P	1	Resident with dementia, ACP?
61	REM	N, P	1	Resident with dementia, ACP?
62	REM	N, P	1	Nutrition, weight loss, PEG-insertion?, ACP
63	EC	N, AN, P, O, PC, ET	3	Economical challenges and risk for ethical dilemmas
64	EC	N, AN, P, O, PC, ET	3	Educational efforts, ethical challenges of political reforms
65	EC	N, AN, P, O, PC, ET	3	Alcohol in nursing homes, confidentiality
66	EC	N, AN. P, O, PC, ET	3	Documentation of cases discussed in the ethics committee, documentation of the residents will in the journal in the nursing home
67	EC	N, AN, P, O, PC, ET	3	Celebration of feasts in nursing homes in a multicultural society
68	EC	N, P, PC, ET	1	Future PEG use in a resident with multiple sclerosis
69	EC	N, AN, P, O, PC, ET	1	Resident bad removed a peg several times, PEG-insertion?
70	EC	N, AN, P, O, PC, ET	2	Coercion, withdrawal of life-prolonging therapy
71	EC	N, AN, P, O, PC, ET	2	Young resident with small children who needed a lot of resources for Palliative Care within the holiday period, extra personnel was hired, adequate use of resources?
72	ECS	N	1	Medical condition, lack of cooperation
73	ECS	N	1	Resident with dementia and fear, ACP
74	ECS	N	3	Relatives complain about insufficient care
75	ECS	N, SW	1	Resident with dementia and depression. How to improve quality of life"?
76	INF	N	1	Resident with diabetes mellitus and lack of compliance to medical treatment, autonomy
77	ECS	no info	2	Sexual abuse of a resident by a staff member
78	ECS	no info	1	resident with dementia who believes to be able to move home
79	ECS	no info	1	Resident suicidal?
80	ECS	no info	3	Autonomy, non-compliance of a resident
81	ECS	no info	1	Resident with PEG and written advance directive that states no life-prolonging treatment
82	ECS	no info	1	Resident in a vegetative state, parents and husband have different opinions about the residents will
83	ECS	no info	1	Relative with extreme high expectations of the care of the resident
84	ECS	no info	1	Optimal care for a chronic wound

Table 5 (Continued)

Nr.	*Type of meeting*	*Profession of participants**	*Discussion type prospective = 1 retrospective = 2 common challenges = 3*	*Topic for the meeting*
85	EC	N, P, SW, PC, ET	1	Resident refuses palliative care after being moved from the hospital
86	EC	N, P, SW, PC, ET	1	Aggressive behaviour of a resident
87	EC	N, P, SW, PC, ET	1	Residents will? Inadequate nutrition
88	EC	N, P, SW, PC, ET	1	Resident has financial problems and problems with his insurance company, oxygen equipment
89	EC	N, P, SW, PC, ET	1	Resident shall receive palliative care at the end-of-life, nutrition via PEG?
90	EC	N, P, SW, PC, ET	1	Resident refuses hospitalisation although urgent medical need (bowel obstruction)
91	EC	N, PC	2	Staff sees a decision made but the residents guardian as not appropriate
92	EC	N, PC	1	Residents guardian alcoholic? Residents autonomy and will?
93	EC	N, PC, SW	2	Resident with the need for amputation and shifting will
94	EC	N, PC	2	Death of a resident due to inadequate medical care
95	EC	N, PC	1	Sexual abuse of a resident by a staff member
96	EC	N, PC	1	Problems with advance care planning, recommendation from a judge to write a new ACP
97	EC	N, PC, SW	1	Decision to hospitalise a resident by the guardian
98	EC	N, PC, SW	1	Treatment withdrawal, conflict between physician and nurses
99	EC	N, PC	1	To withhold or withdraw artificial nutrition, resident was not asked about his opinion although he was able to communicate
100	INF	N	2	Placement of a young resident in a closed area
101	EC	N, PC, SW	1	Lacking information of the resident by a physician concerning palliative surgery, informed consent?
102	EC	N, PC, SW	1	Physicians behaviour: the resident was not included in a conversation about the treatment [although this might have been possible), hospitalisation?
103	EC	N, PC, SW, ET	2	Hospitalisation of a resident, the written living will was not send to the hospital with the patient, therefore he received maximal acute therapy in the hospital
104	EC	N, P, SW, PC, ET	1	Insufficient care of a resident by his wife
105	EC	N, PC	1	Residents consent to artificial nutrition?

*Profession of participants N, nurse; AN, assistant nurse; P, physician; PC, pastoral care; SW, social worker; O, occupational therapist; PSY, psychologist; ET, ethicist.
EC, ethics committee; REM, resident ethics meeting; ECD, ethics case discussion; INF, informal discussion.

residents' dignity and autonomy and stated that residents should be treated as autonomous individuals.

> The residents are dependent on our goodwill. . .to strive for a feeling of equal power so that it becomes almost a balance of powers. . .and respect for borders. (group 4/2)
>
> . . .you should not treat all persons the same, but you should treat them with the same (respect and) dignity. (group 4/3)

In order to respect the wishes of the residents, some nursing homes have already implemented regular conversations about the residents' preferences.

> And we do have regular conversations with the residents. . .About everything from how long they want their egg boiled and their living situation to the end of life. . .And of course there has to happen something with the demands they utter. (group 5/7)

To enable autonomy in end-of-life care, it is important to listen to the resident's wishes that often may not be stated directly but are embedded in stories that show their attitudes. There is a need to prepare for the end of life over time.

Table 6 Summary of the main results from 105 documented ethics discussions

	Nr. of cases	*Percentage of cases*
Of all ethics meetings	105	
Advance care planning (ACP)	48	46
PEG insertion or ethical challenges associated to PEG use	45	43
Hospitalisation	35	33
Everyday ethical challenges	35	33
End-of-life decision-making	27	26
Of all prospective case discussions	87	
No resident or relative present	25	29
Agreement about a solution reached	66	76

> I think it is important to have a dialogue with the patient and the relatives right from the first day. . .I think this can prevent many conflicts. . .if you dare to talk about it. (group 5/9)

The end of life has to be seen in connection with the resident's former life and his views and attitudes. Sometimes a conversation in everyday life can lead to an EOL conversation where the resident describes their wishes regarding care.

> . . .the theme opera ball has led to the theme dying. On the day of the opera ball a resident told a nurse: she had her dress that she once wore at the opera ball in her wardrobe. . .and then the resident told the nurse – I want to wear that dress when I am dead. That conversation lead to documentation of the residents wishes in the notes. (group 1/10)

Conflicts between the residents and relatives. There are differing views between residents, relatives and staff members about everyday matters and many ethical challenges are about decision-making in EOL care. Our informants frequently mentioned that the residents and relatives had different opinions.

> A resident says one thing and the relative another. This is often difficult for the staff. (group 5/3)

Often nobody seems to ask the residents or tries to include them in the discussion about what is best for them.

> I think this is the most difficult thing, how many relatives listen to the wishes of their parents, or who tries to. . .Everybody wants to do the best, but if that is the best, the really good for the resident, I sometimes really doubt it. . .because often 10 people talk, but nobody asks (the resident). (group 2/3)

Lack of resources. Several informants mentioned there being a lack of resources, which will reduce the amount

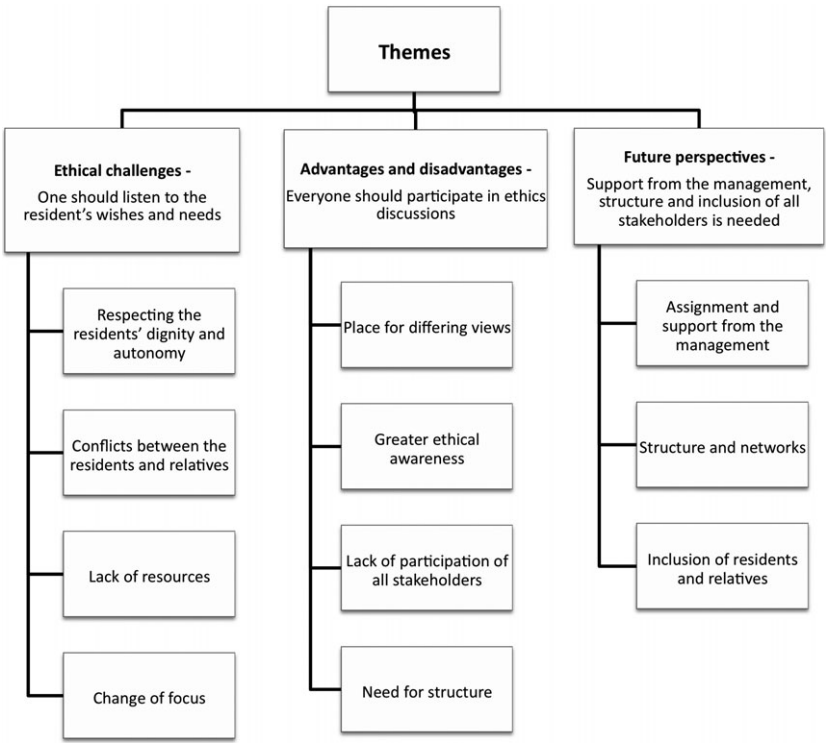

Figure 1 Themes from the focus group interviews of nursing home staff.

of help available to the residents and may thus endanger their feeling of dignity.

> It is also about financial means from the county administration. It is called to enhance effectiveness with nice words. But it is ethics, an ethical dilemma to reduce staff on the wards and to expect optimal care at the same time. (group 4/1)

More resources are needed for palliative care in nursing homes. One informant described the lack of resources for end-of-life care as ageism.

> And I have said: Only because the people in a hospice are younger they do have a total different claim. That topic concerns me very much, if you could balance it...or organise it in another way... (group 2/4)

Change of focus. Many informants perceived a change in the main focus of the discussions from end-of-life care issues to everyday ethical challenges over time. Everyday ethical challenges are frequent and of great importance for the residents, but seem to appear secondary after focussing on ethics in general and big ethical issues such as end-of-life decisions. This is illustrated with the tipping ethics iceberg (Fig. 2).

> ...and there is a never ending story about nutrition at the end-of-life and all questions about withholding or withdrawing therapy...but questions about everyday life in the nursing home are increasing...Our ethics committee has discussed intense difficult behaviour....sexuality...privacy and intimacy in the nursing home...we just have begun to excavate the tip...and every day new topics arise. (group 3/2)

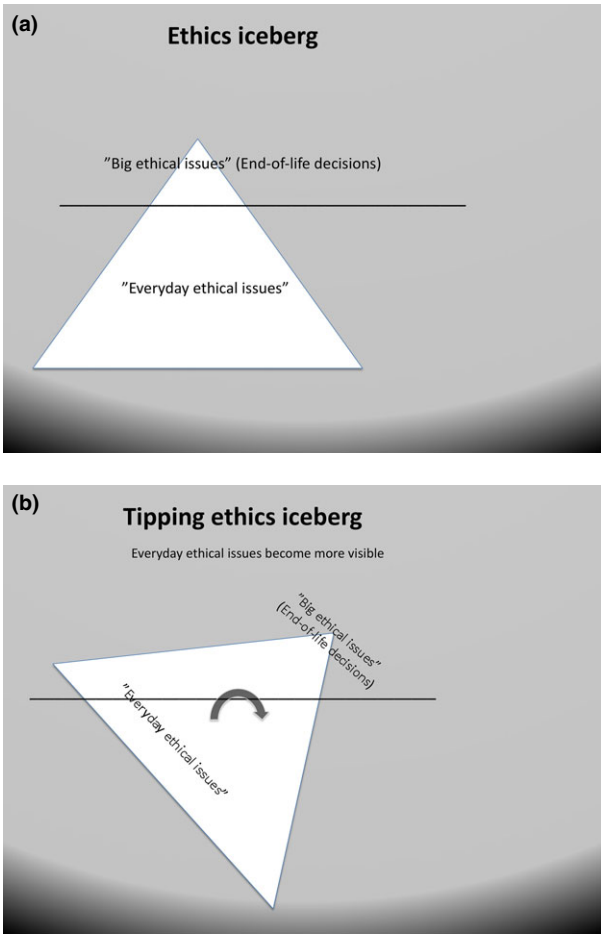

Figure 2 (a) The ethics iceberg. (b) The tipping ethics iceberg.

2. *Advantages and disadvantages – everyone should participate in ethics discussions*

The informants experienced many advantages with systematic ethics work. Different perspectives helped them to view dilemmas from different angles. Discussions became more open and people mentioned having a raised ethical awareness in general. A main disadvantage described was the general lack of participating residents.

Place for differing views. Many informants mentioned that there was respect for others' views.

> ...it was a great relief both for the relatives and the staff...that the problem really could be looked at from different angles...and that we came to a conclusion that everyone could accept. (group 3/6)

The whole staff is allowed to participate, even non-medical personnel.

> And I think that it is an advantage that I have experienced that enormous important information came from the cleaning personnel...They know more about (the residents) life-story than others...and they have a different role. To view things from different role perspectives is very interesting. (group 5/3)

A basic precondition for ethics work is an organisational culture that permits questions to be asked.

> What I experience as very positive is that ethics is possible at every level...that asking questions is appreciated. (group 1/10)

More openness was also viewed as sign of the success of the implementation of ethics work.

> That you recognise (people) to be quite frank in the meetings. That they dare to say more... (group 4/2)

Nevertheless sometimes one has to face the fact that there is not always an answer and to share a sort of common uncertainty.

> And there is the conscience which is basic in ethics reflection that there is no answer...That is what we have learnt. (group 5/3)

Greater ethical awareness. Ethics became part of everyday work.

> I think this is a process, and now it (ethical reflection) is part of everyday work. (group 5/3)

Ethical awareness also includes the relatives.

> For me it was a milestone for creating a (ethics) culture in the institution when a relative demanded an ethics consultation for the first time. (group 3/3)

Lack of participation of all stakeholders. The participation of residents in ethics discussions is rare, although many residents are able to express their wishes.

> They (the residents) are pretty certain how they want it…at the end-of-life. But we as relatives and staff do not listen. (group 5/9)

While many informants are used to discussing ethical challenges with a physician, others miss the physician's participation.

> Probably one should pay the physician for attending ethics discussions…Then they would have an incentive to participate in our institution. (group 2/6)

Need for structure. There is a need for structured systematic ethics work.

> I think ethics work has two sides. One side is the ethics work we do everyday during our usual meetings…we do have discussions in everyday work about the difficult cases…But to be able to raise things in structured forms (for ethics consultation)… this is complicated…it is continued that we feel a bit uncomfortable to raise things…That we have an ethics committee where we can raise cases, I think that is a good option…I appreciate it. (group 5/8)

There are different types of arenas needed. In addition to time to reflect on ethics, some informants want an option to discuss ethics in a nursing home ethics committee.

> I think one advantage with our model is that (ethics) reflection is on-going everywhere. And if you raise (a case) it can provide a kind of meta-perspective. (group 5/1)

3. *Future perspectives – support from management, structure and inclusion of all stakeholders is needed*

Many participants have concrete wishes for the future. These included:

Assignment and support from management. Many informants wanted support from management.

> And we do need an assignment from the administration… (so far) we do not have an assignment or order… (group 4/3)

Time needed for ethical reflection should be seen as part of the usual working hours.

> Ethics consultation is work and should belong to the usual tasks of the staff. None of our staff would participate if it (the time for ethics consultation and the NAEHE-meetings) would not count as working time. (group 3/3)

Structure and networks. Many informants appreciated a structured approach to systematic ethics work, including time for reflection, the possibility to talk to an ethics contact person and an ethics committee.

> We need to structure ethics work, everybody is allowed to say something…it is important to be heard…(group 4/4)
>
> Some things can be solved on the wards and some in the institution…And some have to be raised further. (group 3/8)

Some wanted to form a network to discuss ethical challenges in elderly care with others, such as, for example, hospital staff.

> A network with the collaborating hospitals to discuss ethical questions. (group 2/3)

Inclusion of residents and relatives. The participants wanted relatives and residents to participate in ethics discussions and to have the possibility to ask for an ethics meeting.

> I think that cases from relatives should be raised into the ethics committee. (group 5/1)
>
> If the staff and the relative do not agree and stand against each other…probably one should hear what the patient himself wants. (group 4/1)

Discussion

The main findings of the study are as follows: ethics meetings were often about end-of-life care and life-sustaining measures, but a third of the cases dealt mainly with everyday ethical challenges. The advantages of systematic ethics work described by the participants were as follows: a place for differing views, more dialogue and a greater ethical awareness. Many stated that there was a need for structure and support from administration. The lack of participation of residents and too few participating relatives and physicians were mentioned as disadvantages. Suggestions for future ethics work were as follows: support from management, to establish ethics networks with hospitals, and more inclusion of residents, relatives and physicians in ethics discussions. The results and experiences from the three participating countries were similar.

In combination, the results from both parts of the study suggest that systematic ethics work in nursing homes in the beginning focuses mostly on big ethical issues like withholding or withdrawing life-prolonging treatment and end-of-life decision-making. Everyday ethics first arises as an issue when ethical discussions have become common. This change in the focus is illustrated in Fig. 2: the tipping ethics iceberg.

The results are discussed based on the theoretical background of our study consisting of the principle of autonomy and its importance in principlism and palliative care ethics.

Ethical challenges in nursing homes

Compared with other studies (3, 5, 9–12, 15), our results support previous findings that frequently the ethical challenges discussed in nursing homes are about end-of-life care and decision-making. As end-of-life issues are a major concern, the implementation of hospice and palliative care philosophy with patient-centred care models, including ethics discussions, might help people cope with these challenges. In Germany, a new law to enhance palliative care in nursing homes has passed the 'Bundestag' in 2015 (39).

Some of the participants from our study suggested that palliative care and end-of-life care have to be discussed earlier. ACP is paramount in nursing homes and may help to avoid ethical dilemmas in end-of-life care, leading to better quality of end-of-life care, and it may even save costs (40–43). Interestingly, our data indicate that information about wishes for end-of-life care can be drawn from everyday communication and the resident's attitude, in addition to written advance directives.

A change of focus in ethics discussions, from end-of-life themes to everyday ethical challenges, was observed. This is visualised with the tipping ethics iceberg (Fig. 2). The discussion of the more prominent ethical challenges with respect to end-of-life care probably raises awareness of everyday ethics in general. The increasing visibility of everyday ethics, in general, is reflected in an increased number of publications, often dealing with autonomy, dignity, residents behaviour, coercion, but also, for example, with gender and sexuality issues (2, 4–8, 19, 44–54). From the residents' viewpoint, everyday issues, including different 'small' things and, for example, sexuality, are of great importance (2, 55, 56).

Ethical challenges with respect to decision-making and the everyday life of residents with dementia were frequent topics in the documented ethics meetings (Table 5). The ethical challenges connected to dementia in nursing homes concern, for example, patient participation (57), sexual expression as aspect of well-being (51) and the flexible use of time in the care for these persons (58). Older patients who resist help may cause moral distress for healthcare personnel (59). This may be one explanation for the fact that many nursing home staff members perceive ethical challenges as a burden in their everyday work (12).

The principle of autonomy is paramount in medical bioethics and palliative care. Unfortunately, many nursing home residents do have dementia and cannot express their wishes verbally. In such cases, care ethics and relational ethics have to be taken into account. Care ethics as described, for example, by Conradi (60) and Gilligan (61) is based on relation and the reflection of nursing practice (62). The logic of care is quite different from the way of thinking in mainstream ethics. In contrast to prevailing modern ethical theory, care ethics (60–62) does not focus on autonomous rational individuals who subsequently cooperate in the form of contract relations. Care ethics (60–62) reminds us that through many phases of life we are anything but reasonable, autonomous or independent individuals: in childhood, old age, sickness and weakness. In the contrary, from a care ethics perspective, it is indispensable to understand ourselves as fundamentally connected beings.

In summary, the subjects of ethics discussions are not just dilemma situations but meaningful situations in general, which concern the fundamental questions of human life.

Experience with systematic ethics work

Our data show that experiences with ethics consultation were in general very positive, and several participants described developing a greater ethical awareness. Ethics reflection may improve practice (63). Key factors for the implementation of systematic ethics work are as follows: support from administration, ethics education and structures regarding places and times for ethical reflection. Our findings support similar findings from the literature (14, 63, 64). In contrast to previous studies (4, 5), a lack of resources was not as prominent in our data. A main concern described in our data was a lack of participation of residents and, partially, relatives and physicians. As resident wishes may be uncertain, this may hinder the residents from exercising their autonomy and may cause moral distress for the relatives (42).

Data from our study support the idea of using different approaches, such as, for example, ethical reflection and an ethics committee within the same institution. This suggestion is similar to the three-step approach with different levels for ethics consultation in nursing homes as, for example, ethics reflection groups and ethics committees (1, 20).

Systematic ethics work involves reflections around everyday issues on the basis of paradigmatic narratives and connecting with other people by making an effort to understand and to feel with others.

Inclusion of residents and relatives

It is remarkable that the participation of residents is totally absent in the present findings. This is in conflict

with the importance of autonomy in principlism. Recent studies have shown that only a few nursing home residents had preparatory conversations about ACP and end-of-life care (42, 65). These findings are in stark contrast to the importance of autonomy in modern bioethics, palliative care and patient-centred care (21–25). Nursing home residents do care about 'small' things and everyday ethical challenges (2, 55) and want to be informed about their medical condition (55, 66). Unfortunately, many residents do not experience that they are autonomous or that their free will is respected (2, 63). Nursing home staff should engage in ACP and active planning for end-of-life care, and offer conversations with residents and relatives about their views and preferences regularly (42, 65, 67, 68). Assessing the residents' preferences leads to more appropriate decisions and may enhance the residents' feeling of dignity (57, 66). Preliminary results from on-going work indicate that resident participation in ethics discussions is feasible and that the staff in general might be too reluctant to encourage residents to participate (69).

Limitations and strengths of the study

One limitation of the study was that only two informal discussions were documented in our data. Therefore, the topics of the more informal discussions might be different from those found in our data. One might speculate that everyday ethical issues are more often discussed in informal meetings and that therefore the percentage with respect to these issues might be even higher than found in our data. Nevertheless, everyday ethical challenges are frequent in our data. As we have chosen to include models of good practice and nursing homes with an interest in systematic ethics work, one might speculate that the ethical awareness of the staff from these locations is higher than average and that the results therefore might not be representative for all nursing homes in the three countries. On the contrary, the ethical challenges might be the same, but they are not observed without an ethical awareness.

Conclusions and implications

Ethical reflection is greatly appreciated by the staff and can help in reaching a consensus in most prospective case discussions. Systematic ethics meetings that include the relatives and residents should be implemented in all nursing homes. Everyday ethical issues should be addressed in addition to end-of-life ethical issues. The regular participation of physicians and relatives could be improved further. The participation of residents in ethics meetings should be strongly encouraged.

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Author contributions

Georg Bollig worked out the study design and the questionnaires used in the study. Gerda Schmidt, Jan Henrik Rosland, Arnd T. May, Eva Gjengedal and Andreas Heller reviewed the study design, commented on it and suggested modifications. All authors agreed on the selection of the participating ethics committees and nursing homes. Georg Bollig organised the data collection, the data analysis and the draft process of the first version of the manuscript. Georg Bollig and Gerda Schmidt collected the data. All authors participated in data analysis and reviewed and revised the manuscript critically and participated in the discussion of the results. All authors read and approved the final version of the manuscript.

Ethical approval

The Regional Ethics Committee (REK Sør-Øst A) in Oslo, Norway, approved the study protocol (reference 2009/1339a). The documentation of the resident cases from the ethics meetings was confidential. The cases were documented using a questionnaire with a description of the case discussed, but without personal data concerning the resident, relatives or other participants. No resident data other than gender and age were documented. The participants of the focus group interviews were informed about the study and invited to participate by the nursing home management. All participants had the opportunity to ask clarifying questions prior to their participation in the interview and gave informed consent.

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