



Nothing to complain about? Residents' and relatives' views on a "good life" and ethical challenges in nursing homes

Nursing Ethics
2016, Vol. 23(2) 142–153
© The Author(s) 2014
Reprints and permission:
sagepub.co.uk/journalsPermissions.nav
10.1177/0969733014557719
nej.sagepub.com
 SAGE

Georg Bollig

University of Bergen, Norway; Haraldsplass Deaconess Hospital Bergen, Norway;
HELIOS Klinikum Schleswig, Germany

Eva Gjengedal

University of Bergen, Norway; Molde University College, Norway

Jan Henrik Rosland

University of Bergen, Norway; Haraldsplass Deaconess Hospital Bergen, Norway;
Haukeland University Hospital, Norway

Abstract

Background: Nursing home residents are a vulnerable population. Most of them suffer from multi-morbidity, while many have cognitive impairment or dementia and need care around the clock. Several ethical challenges in nursing homes have been described in the scientific literature. Most studies have used staff members as informants, some have focused on the relatives' view, but substantial knowledge about the residents' perspective is lacking.

Objective: To study what nursing home residents and their relatives perceive as ethical challenges in Norwegian nursing homes.

Research design: A qualitative design with in-depth interviews with nursing home residents, and focus-group interviews with relatives of nursing home residents. The digitally recorded interviews were transcribed verbatim. Analysis was based on Interpretive Description.

Participants and research context: A total of 25 nursing home residents from nine nursing homes in Norway, and 18 relatives of nursing home residents from three of these nursing homes.

Ethical considerations: This study was reported to and approved by the Regional Ethics Committee in Oslo, Norway.

Findings and discussion: The main ethical challenges in Norwegian nursing homes from the residents' and relatives' perspective were as follows: (a) acceptance and adaptation, (b) well-being and a good life, (c) autonomy and self-determination, and (d) lack of resources. The relationship with the staff was of out-most importance and was experienced as both rewarding and problematic. None of the residents in our study mentioned ethical challenges connected to end-of-life care.

Conclusion: Residents and relatives experience ethical challenges in Norwegian nursing homes, mostly connected to "everyday ethical issues."

Corresponding author: Georg Bollig, Department of Anesthesiology, Intensive Care, Palliative Medicine and Pain Therapy, HELIOS Klinikum Schleswig, Lutherstr. 22, D-24837 Schleswig, Germany.
Email: bollig.georg@gmx.de

Keywords

Older people, ethics, nursing homes, relatives' view, residents' view

Introduction

People living in nursing homes are vulnerable. The term nursing home in this study includes long-term care facilities for older people. In Norway, usually only older people with a high need of care and need for medical assistance are admitted to nursing homes. Many nursing home residents in Norway suffer from multimorbidity; more than 80% have dementia and more than 70% show psychiatric and behavioral symptoms.¹

A review of the literature revealed two major groups of ethical issues in nursing homes. The first group of issues consists of "everyday ethical issues," such as autonomy, privacy, informed consent, use of restraints, offensive behavior, refusal of medication, food, placement of people, and lack of resources. Second, "big ethical issues," mostly in regard to life or death matters including decisions to sustain or withdraw life-sustaining treatment, to hospitalize or not, and other similar matters.²⁻⁹ Most case consultations by nursing home ethics committees in the United States were about end-of-life issues and tube feeding.⁵ In a Norwegian nursing home survey, the most frequently reported ethical challenges were inadequate care due to lack of resources and violation of the patient's autonomy and integrity. Many staff members also described conflicts with relatives and dilemmas concerning end-of-life care.⁷ Conflicts between healthcare personnel and relatives were often mentioned in the literature.^{7,10} Another major ethical problem in nursing homes is the lack of participation of the residents and their next of kin in decision-making. According to Dreyer et al., there are inadequate procedures to include the relatives and to address ethical and legal aspects of patient autonomy in decision-making in Norwegian nursing homes.¹¹

A methodological weakness of research in this field is the fact that most research is based on questionnaires and interviews aimed at the staff or managers. At present, there is a lack of research on ethical challenges from the perspective of residents and their next of kin. The aim of this study was to explore what patients and their relatives perceive as a "good life" and ethical challenges in nursing home care including end-of-life care.

Method

This study had a qualitative design using semi-structured, in-depth interviews with nursing home residents and focus-group interviews with their relatives. The methods used to collect and analyze the data were based on the descriptions by Kvale¹² and Malterud¹³ and especially on Interpretive Description as provided by Thorne.¹⁴ Studies using this method have according to Thorne some common features: they are conducted in a naturalistic context, use subjective and experiential knowledge as a source of clinical insight, acknowledge a socially constructed element to human experience, presume that there is not one true "reality," but that human experiences consist of multiple constructed realities that may even be contradictory. Interpretive Description acknowledges that researcher and participant influence each other by interaction.¹⁴

Participants and research field

Purposive sampling was used to ensure the greatest possible variation of the data. Therefore, sampling aimed for geographical spread and different sizes and locations of the included nursing homes. An overview of the participating residents and relatives and characteristics of the nursing homes, including their size and location (urban vs rural area), is given in Tables 1 and 2. A total of 25 nursing home residents participated in in-depth interviews. All residents were living on long-term wards, and older people with short-time or

Table 1. Informants—nursing home residents.

No.	Age (years)	Gender	Interview duration in minutes	Number of nursinghome residents in the nursing home	Community size—inhabitants	Comment
1	66	Male	20	50–100	>50,000	
2	70	Male	71	100–150	>600,000	
3	74	Female	43	100–150	>250,000	
4	75	Male	22	100–150	>250,000	
5	77	Female	43	100–150	>600,000	
6	79	Male	36	<50	<1500	
7	81	Male	47	100–150	>250,000	
8	81	Female	41	100–150	>600,000	
9	83	Male	12	<50	<1500	
10	87	Female	30	<50	<1500	
11	88	Female	30	50–100	>600,000	
12	89	Female	18	100–150	>250,000	
13	89	Female	38	50–100	>50,000	
14	89	Female	33	150–200	>600,000	
15	91	Female	44	100–150	>100,000	
16	92	Female	10	100–150	>250,000	Excluded during the interview because of cognitive impairment
17	92	Male	49	100–150	>100,000	
18	93	Male	16	100–150	>250,000	
19	94	Female	15	50–100	>600,000	
20	94	Female	46	100–150	>600,000	
21	95	Female	22	100–150	>600,000	
22	96	Female	39	100–150	>250,000	
23	97	Male	23	50–100	>50,000	
24	99	Female	18	50–100	>50,000	
25	100	Female	33	100–150	>250,000	

In order to protect the residents' privacy and to ensure that they can stay anonymous, the resident numbers in the table do not correspond with the numbers of the citations.

rehabilitation residence were excluded from the study. The residents came from nine Norwegian nursing homes in five regions, public and private owners and communities with a varying number of inhabitants. In addition, three focus-group interviews were undertaken with a total number of 18 relatives of nursing home residents from three different nursing homes. Both participating residents and relatives were selected by nursing home staff or nursing home physicians. All participants received written information about the study and had the opportunity to ask questions prior to signing written informed consent.

Data collection

All interviews were undertaken by the first author (G.B.) in the patient's room or another private room. The focus-group interviews with relatives were conducted in a suitable room within the nursing home. In order to enable open communication and discussion of critique, staff members were not permitted.

The individual interviews started with two opening questions: "How can you live a good life in the nursing home?" and "Can you please describe a usual day in the nursing home?" in order to open up for the patients' own descriptions. Most of the interviews were open, with follow-up questions related to the

Table 2. Informants—relatives of nursing home residents.

No.	Age (years)	Gender	Number of nursing home residents in the nursing home	Community size—inhabitants
1	41	Female	<50	<1500
2	45	Male	100–150	>250,000
3	53	Female	<50	<1500
4	58	Female	<50	<1500
5	59	Female	100–150	>250,000
6	60	Female	100–150	>250,000
7	66	Female	<50	<1500
8	67	Female	100–150	>250,000
9	67	Female	100–150	>250,000
10	71	Female	100–150	>250,000
11	72	Female	100–150	>250,000
12	73	Female	100–150	>250,000
13	74	Female	100–150	>250,000
14	77	Male	100–150	>250,000
15	77	Female	100–150	>250,000
16	80	Male	100–150	>250,000
17	86	Male	100–150	>250,000
18	91	Male	100–150	>250,000

In order to protect the relatives' privacy and to ensure that they can stay anonymous, the resident numbers in the table do not correspond with the numbers of the citations.

patient's answers and responses. If no ethical challenges were mentioned, the interviewer asked about ethical challenges, which were reported to exist in nursing homes in the literature.^{2–9} Key themes in the interview guide were as follows: a good life in the nursing home, daily life in the nursing home, and ethical challenges in daily life as well as in end-of-life care.

The focus groups were based on preliminary results from the analysis of the individual interviews. The interviews began with questions about a good life and ethical challenges in the nursing home, followed by an open group discussion, where the interviewer asked clarifying questions. All interviews were digitally recorded and transcribed verbatim by the first author and two trained assistants. Transcription was aided by the software f4 from Audiotranskription.¹⁵

Analysis

The analysis of the transcripts was conducted in multiple phases.^{12,14} Analysis and coding were supported by the computer program NVivo 9.^{16,17} The text was read several times, and meaning units and preliminary themes were coded by different researchers (G.B. and E.G.). To control the analysis, all authors reviewed the data material on their own. Coding was then discussed, revised, and approved repeatedly to ensure agreement on the main themes and meanings. After a preliminary coding of the first 11 participant transcripts, an interview guide for the focus-group discussions was prepared based on the initial results from these interviews. Source triangulation was used to discover different perspectives or agreement on the topic from different angles. Therefore, the preliminary results from the individual interviews could be questioned and deepened in the group interviews in addition to investigating the relative's views. Further analysis of the themes found in the data material and the coded text was done repeatedly and was supplemented by the interviewer's (G.B.) field notes. Validation of the results was sought by repeated reading of the interviews

in order to question the findings in the interview transcripts and repeated discussions with the co-workers of the study. The analysis of both the individual and focus-group interviews led to four main themes that are presented in the “Results” section.

Research ethics

This study was reported to and approved by the Regional Ethics Committee (REK Sør-Øst A) in Oslo, Norway, reference 2009/1339a. Written informed consent was obtained from all participants. All participants were informed of their right to end the interview at any time without reason or consequence. Participants were informed that they did not have to answer any question if they did not feel comfortable doing so. Patients with signs of cognitive impairment or dementia were excluded from the study. Only one patient had to be excluded, and no interview had to be ended upon the patient’s request. In few cases, patients did not answer a question and the interviewer changed the topic.

Results and interpretations

Many of the informants from the individual interviews began by saying that they had no complaints. In contrast to that statement, the findings revealed that there were several ethical issues in nursing homes, and four main themes were defined. Each theme is illustrated with one describing sentence and will be described and discussed further. Most themes have both positive and negative aspects. The main findings from the group discussions, which will be described at the end of each section, were similar to the findings from the residents’ interviews.

Acceptance and adaptation: “To become a nursing home resident”

There are profound ethical challenges when people have to move into a nursing home. One major challenge is to preserve dignity. For most people, it will be their last place of residence until they die. The informants told the interviewer about the process of acceptance of their own situation and seeing death as a normal part of life, but they also told about hope. This showed the ambiguity of living in the nursing home in an ambivalent situation between life and death. Most informants did not want to complain and said that they were offered good care and that they were grateful to receive care in the nursing home:

I think it is very good like it is at present. (Resident 8)

Although many residents experience the transition as troublesome, some reported a homelike feeling after living in the nursing home for a while:

I think differently [about being in the nursing home] than I did in the beginning when I came here . . . because I now feel more connected [to the nursing home] than I did when I came here. I do feel more at home. (Resident 5)

Acceptance and adaptation play a role for both residents and relatives. The relatives have to accept the fact that they have to move their loved-ones into the nursing home. Some relatives described a feeling of guilt or failure because of the fact that they could not take care of their loved-ones at home anymore:

Relative 2: Yes it is hard to be a relative.

Relative 4: We probably all have the same feelings about it. That we should have endured it a little bit longer, we should have endured [caring for relatives at home]. And the most difficult [part] was to sign the papers [for

admittance to the nursing home]. But, on the other hand, we do know that we could not have managed [caring for relatives at home] much longer. (Focus group 1)

Well-being and a good life: “To participate instead of sitting in a chair”

Participation in daily life and social contact are the two main dimensions of well-being from the residents’ perspective. Interestingly, to sit in a room and watch people on the street and at a nearby supermarket through a window was described as taking part in the lives of other people. Well-being was not just created by the surroundings, contact with the staff and the other residents alone, but was described to be achievable by active behavior of the residents themselves. It is the resident’s own attitude that mattered. To think positively and to do something on one’s own seemed to be important:

And I do as much as I can. I do the cleaning and make my bed myself. And I do what I am able to participate in life. You can participate in life and not just sit on your butt . . . (Resident 17)

Dimensions of a good life and well-being described by the informants were often about normal aspects of everyday life, such as participating in activities (including training with a physiotherapist), eating, and communicating with others. As there are many patients suffering from dementia in nursing homes, the residents without cognitive impairment only have a few people with which to communicate:

I usually sit together with a nice lady, she is old, more than 90. But she is quite clear in her head. We talk together and eat together . . . otherwise, most people in here are in bad condition in their heads. (Resident 15)

Food was often described as being important. Mealtimes were the main structure of the day. A bad meal could lead to the experience of a bad day overall:

And you know, you just sit and wait for mealtime. Lunch at one o’ clock, coffee at four and so on. This is what happens during the day. There is nothing else going on. (Resident 20)

From the interviews, it was evident that to be seen as a human being and to be engaged in some kinds of social interaction were crucial factors for well-being and the preservation of their dignity as described by the residents. Ethical problems could arise from lack of contact. For the relatives, activities and participation were the most important dimensions of well-being. Often, relatives participated in the daily life in the nursing home by feeding the residents, singing, or reading for them.

From the residents’ point of view, the relationship to the nurses is crucial to live a good life in the nursing home:

Everything depends on how the nurses are. Their way to behave, their face . . . counts very much, their attitude. (Resident 3)

The relatives shared the resident’s opinion that the relationship to the nurses is a very important factor for well-being. They defined a good nurse as somebody who would *see the resident and show that she cares*, which illustrated the two dimensions of well-being described above. To be a good caregiver is, according to the relatives, not connected to formal training but depends on attitude:

Relative 4: They sit down and seem to be interested [in the residents]. They have to look at them and to show that they have time.

Relative 3: These are not just professionals but also unskilled care givers. The ones who have an inborn radar . . . I must admit they are caring. “Care” or “thoughtfulness” might be the right words for it. (Focus group 2)

Autonomy and self-determination: “Striving to keep one’s own autonomy”

The opinions of the nursing home residents on the extent of autonomy and self-determination that they experienced in daily life varied greatly between different residents and different wards, even within the same nursing home. Many participants mentioned this theme embedded in stories of the relationship to the nurses. While some felt that they could decide most things (e.g. having breakfast in bed at the time they wanted), the majority of informants reported that they did not have much to decide at all and did not feel autonomous or self-determinant. Informants talked about problems inviting guests to share their meal, obstacles to smoke, being controlled around the clock, and that daily routines were in deep contrast to their desired level of self-determination. The following examples focus on the informants who mentioned problems with autonomy:

You lose a big part of your freedom. Everybody who comes into a nursing home will discover that. For example, you cannot just take your bag and tell them that you will go shopping. You can not do that. (Resident 22)

A problem can be the lack of respect that can influence the feeling of dignity. One resident spoke about a young assistant who was watching TV while feeding her:

I have told them These are young girls who are not used to this . . . and if the television is on . . . they concentrate on the film and forget to feed me. (Resident 3)

To be respected is of great importance in order to be able to practice self-determination:

When they (the nurses) enter the room . . . they shall knock on the door. This is my room! Sometimes I choose to be quiet and not to say anything. (Resident 3)

The relatives stated that lack of resources could also be experienced as an offense and, thus, endanger autonomy. For example, some residents have to go to bed at six o’ clock in the evening because there are too few nurses on duty in the evening.

Another important finding was the description of a problematic relationship to the nurses. The relatives often had to complain about things because the residents themselves were afraid to face consequences if they would complain themselves. The relatives could be labeled as troublemakers by the staff. Therefore, many relatives do not complain “too much”:

It is not always easy to be a relative [of a nursing home resident] . . . I have always let them know, from the very first day. I had to talk about it . . . then you are labeled as a relative who . . . [is difficult to deal with]. When I came in, I felt someone [the nurses] saying—“There she is.” When they were in the corridor, I just saw them stepping away into a room. (Relative 6, focus group 1)

Locked doors were acceptable for most relatives in order to prevent demented residents from leaving the nursing home. Otherwise, the relatives refused coercion (e.g. in order to give medication or food). As mentioned above, some stated that early bedtime due to lack of personnel was unacceptable coercion.

Lack of resources: “More hands and more time for social contact are needed”

The residents believed that they received too little help from the staff and had little social contact with the staff:

They are too few staff members . . . they do not have enough staff. They cannot be everywhere, these ladies. So, I understand their situation. (Resident 3)

Most of the residents did not want to complain, and many stated that they did not have anything about which to complain. However, stories from their daily life showed that lack of resources was a problem:

We do have much waiting time . . . if there is something [you need] . . . they tell you that you just have to call, just call . . . so everything will be done, but it is not like that . . . it takes time. For example, if I sit here and eat breakfast, I just need to call when I am done. Then you may sit a long time . . . a very long time before they think that I am done, and I have to wait for them to come . . . (Resident 5)

Many residents would appreciate more activities, and some would like to have the possibility to train regularly with a physiotherapist:

The only thing that I miss, which I think they can do something about . . . is a physiotherapist. This would be good to have here . . . but they do not have money. When I was in the hospital we had physiotherapists . . . I had to take medicine, but when the physiotherapist came . . . he managed to make my limbs move again . . . (Resident 7)

You know, they [the other residents] are placed in a chair and then they sit there. With more personnel, we could come out more often . . . and not just sit in a chair in the living room and be half asleep. (Resident 12)

Activity options, such as a sewing room, had been closed down in some places due to lack of resources:

It has been there before, they told me it has. A sewing room and other things which one could work with, but this offer does not exist anymore. They cannot afford it anymore. It has been removed from all nursing homes: there is nothing. We just sit in the chair . . . that is what we do. There is not a set of cards to play with. I believe this has to do with the local government, costs and payments. (Resident 20)

Some of the residents would like to have better, healthier food, or simply more options when dining:

There is one thing I do miss very much, that is fresh fruit. (Resident 15)

The relatives see the lack of resources as being a serious problem. According to their description, this deficiency leads to lack of contact with the residents. Too few staff members were also named as cause of coercion.

Relative 4: We do need more hands.

Relative 1: They don't have time. There are at least too many residents per staff member. (Focus group 3)

Discussion

The informants in our study described factors associated with a good life and the preservation of their dignity and several ethical challenges in Norwegian nursing homes that could be categorized as everyday ethical issues. The main findings of the study were that residents and relatives experienced challenges with acceptance and adaptation, well-being and a good life, autonomy and self-determination, and lack of resources. Adaptation to living in the nursing home often led to feeling as though complaining was inappropriate. Preserving their dignity is important for the residents. Many residents were aware that they would die in the nursing home, but none of them specified ethical challenges connected to end-of-life care.

Our findings were contrary to another Norwegian qualitative study on quality of life of nursing home residents published by Sørbye et al.¹⁸ in 2011, which concluded that most residents enjoyed themselves in the nursing home and were satisfied with the offered care. Nevertheless, most of the 20 residents in that study that was performed as quality assurance measure wanted more time to talk to the staff about

challenges in daily life and more serious themes.¹⁸ In order to preserve the residents' dignity, time for dialogue and communication is crucial. It has been emphasized that the assessment of the nursing home residents' satisfaction was difficult due to cognitive impairment and vulnerability and that qualitative and ethnographic methods could help to provide a more balanced picture than using surveys.¹⁹ Our informants did not want to complain too much, probably because of the fear of consequences. The balance between ensuring autonomy and dignity has been described to be an ethical challenge for nursing home staff because they have had to use weak restraints. Such a behavior disrespected patients' autonomy.²⁰ The term "total institution" was introduced by Goffman and has also been applied to the nursing home world where vulnerable residents were dependent upon the nurses.^{9,21} This term seems to cover the views of some of our informants who felt that there was no autonomy in a nursing home because residents were under observation at all hours. Kindness, humanity, and respect are core values of medical professionalism and dignity conserving care.²² Respecting the residents' autonomy could enhance their satisfaction, although shortcomings of self-determination were often mentioned by the residents.²³ In order to enhance self-determination, the staff could help the resident understand that certain areas could be controlled by the residents themselves.²⁴

Brandburg et al.²⁴ described 21 facilitative resident strategies for "making a life in a nursing home." The main strategies were to take one day at a time, to seek supportive relationships, to be patient, and to make the best out of it. "To take one day at a time" seems to be a frequently used strategy in our material. Our informants told the interviewer about the process of acceptance and adaptation, which was similar to the facilitative strategy "learn the nursing home system and how to get what you need."²⁴ The relation to and the behavior of the nursing home staff influenced the feeling of dignity. Our results showed that the relationship to the staff was of utmost importance and that dignity could be protected or endangered by the staff's behavior. Nursing home residents are highly vulnerable with regard to dignity, and their dignity is challenged by illness and care needs.²⁵ In order to be able to live a good life in the nursing home, a safe surrounding with enough space, nursing care around the clock, enjoyable food, self-determination, regular activity, and social contact were necessary. Interestingly, both residents' and staff members' attitudes and behaviors could help to create a good life and preserve dignity. The description of a good nurse in our material was similar to a recent literature review: good nurses were understanding, caring, and recognized the patients' needs promptly. Good nurses built trust-based relationships with the residents.²⁶ Our material showed that trust-based relationships between the staff and relatives were important for the relatives as well. Inactivity and too little contact were major challenges in nursing homes at present. The residents need to communicate with other people; talking had been described to be the most important activity for them.²³ To meet communication needs means to show respect and can thus strengthen the feeling of dignity. According to Kojer and Schmidl,²⁷ to receive contact and empathic communication should be a human right for nursing home residents. Therefore, basic care should include taking care of communicational needs, in addition to the need of being dry, clean, and fed.

A qualitative review on living well in care homes discussed the lack of autonomy and difficulties in forming relationships with others and summed up four key themes: acceptance, adaptation, connectedness with others, and a homelike environment.²⁸ The authors concluded that a relationship-centered approach was wanted by the residents but "requires the well-being of both staff and residents, and an examination of the philosophy and values of the administration as these will undoubtedly affect the psychological milieu (or well-being) of all who live and work there."²⁸ It seems that well-being regularly included both residents and staff, and that the well-being of both groups was influenced by their behavior. Therefore, the well-being of the staff should be taken into account when aiming for enhancement of the residents' well-being, but must not be prioritized at the expense of the residents.

The residents want both physical and psychosocial care; being able to receive help when needed was important.²⁹ Unfortunately, lack of resources in terms of too few staff was crucial because there was too little time for social contact. In Norwegian primary healthcare, inadequate attention, the need for social

contact, and physical activity or self-determination were ethical challenges experienced most frequently by healthcare workers.³⁰ Staff working closest with the patients reported ethical challenges more often than those working further away.³⁰ Although lack of resources did not necessarily cause lack of contact with the nurses, it restricts the time frame in which nurses could use their spare time for contact with the residents. Lack of resources has been named an ethical challenge in many studies from the literature.^{2,6-9,30-32} That lack of resources and staffing could result in inadequate care had been observed in one of the participating nursing homes and was recorded in the researcher's field notes. In that situation, there was one nurse who had to feed four residents. The nurse felt that this was an ethical dilemma because she did not know whom to feed first or whether it was appropriate to feed four people at the same time. Lack of resources and the frequent use of "suboptimal staffing" may be the cause of avoidable coercion in nursing homes.³² For the residents in our study, lack of resources was almost synonymous with lack of time to get help from or to have contact with the staff. Dignity and quality of life are endangered by both lack of resources and disrespect of the residents' autonomy. Early bedtime because of too few nurses is not only lack of resources but a violation of the residents' autonomy and an offense to dignity. Sufficient resources and nursing home staff seem to be the crucial factor in order to meet the residents' and relatives' communication and care needs and to preserve their dignity. These findings were in accordance with research where nursing home staff have been informants.^{6,7,30}

This study addressed the views of nursing home residents and relatives on ethical challenges in nursing homes in addition to former knowledge of the views of nursing home staff. The views of the residents and relatives from our study agreed on most aforementioned themes. Many informants from both groups mentioned problems with self-determination, lack of factors associated well-being (e.g. food and staffing), lack of resources, and the importance of the relationship to the staff. The interaction with the care givers was of utmost importance because the staff needed to know the residents and to be sensitive to the residents' needs in order to ensure their autonomy and dignity.³³ Residents and relatives were found to have different strategies when complaining. It seems that the relatives often complained about certain issues to the staff because some residents were afraid to complain due to fear of consequences.

Limitations and strengths of the study

One possible limitation is the selection of participants. Due to ethical concerns, all nursing home residents with cognitive impairment or dementia were excluded from the study. Another possible limitation of the study could be that the nursing home staff selected the participants. However, our results show that there were both positive and negative comments, and the informants defined several areas with ethical challenges and the need for improvement. The experience of the first author (G.B.) as a physician from working in a nursing home and palliative medicine may be considered both strength and weakness of the study. Being able to talk to nursing home residents about their losses, diseases, and death enabled the interviewer to ensure empathic communication. To avoid "going blind" by own presumptions and the researcher's own point of view from working as a nursing home physician and the danger to try to verify own hypotheses about possible results, the interviewer reflected his preconceptions during the whole process. This was done using meta-positions and team reflections with the coauthors and supervisors.

It could probably be seen as a weakness that our study did not identify ethical challenges in end-of-life care from the residents' point of view. Although the residents were especially asked about end-of-life care, they did not report ethical challenges in this area. It seems that everyday ethical issues are most important for the residents. It could be considered to be the strength of the study that the interview atmosphere was open enough to talk about problems and negative aspects as well as death and dying. Although most participants stated in the beginning that they had nothing to complain about, they allowed themselves to utter critiques during the interview. Most of the informants in our study were grateful and thanked the interviewer

for the talk and the time spent together. Some of the informants stated that they never before had talked to another person about some of the issues mentioned during the interview. For the relatives, the group discussion seemed to be a place where they could share their feelings and problems related to being a relative of a nursing home resident with others in the same situation.

Conclusion and implications

Residents and relatives did experience ethical challenges in Norwegian nursing homes, mostly connected to “everyday ethical issues” including lack of resources to meet their basic communication and care needs. None of the residents did mention ethical issues in end-of-life care. Social contact, participation in daily life, and self-determination were important factors for a good life for the residents.

Implications of the study for practice are as follows: the results of our study suggest that daily routines in nursing homes should be adapted to these challenges, and that one should strive to meet the residents’ wishes as far as possible in order to strengthen their feeling of autonomy and dignity. Ethics education and systematic ethics work in nursing homes should probably focus more on everyday ethical issues instead of focusing solely on end-of-life care and decision-making conflicts.

Further research could focus on how to improve the resident’s autonomy in nursing homes and to include them in decision-making in everyday life. Research on the views of residents with cognitive impairment and dementia is interesting though methodologically and ethically problematic.

Acknowledgments

The authors would like to thank Ole Frithjof Norheim for his review of, and valuable comments on, this article.

Conflict of interest

All authors declare that there is no conflict of interest.

Funding

This research project has been financially supported by the Norwegian Extra Foundation for Health and Rehabilitation through EXTRA funds.

References

1. Selbæk G, Kirkevold Ø and Engedal K. The prevalence of psychiatric symptoms and behavioural disturbances and the use of psychotropic drugs in Norwegian nursing homes. *Int J Geriatr Psychiatry* 2007; 22: 843–849.
2. Olson E, Chichin ER, Libow LS, et al. A center on ethics in long-term care. *Gerontologist* 1993; 33(2): 269–274.
3. Glasser G, Zweibel NR and Cassel CK. The ethics committee in the nursing home: results of a national survey. *J Am Geriatr Soc* 1988; 36: 150–156.
4. Hayley D, Cassel CK, Snyder L, et al. Ethical and legal issues in nursing home care. *Arch Intern Med* 1996; 156: 249–256.
5. Weston CM, O’Brien LA, Goldfarb NI, et al. The NJ SEED Project: evaluation of an innovative initiative for ethics training in nursing homes. *J Am Med Dir Assoc* 2005; 6: 68–75.
6. Bollig G, Pedersen R and Førde R. Etik i sykehjem og hjemmetjenester [Ethics in nursing homes and home health care]. *Sykepleien forskning* 2009; 4: 186–196.
7. Gjerberg E, Førde R, Pedersen R, et al. Ethical challenges in the provision of end-of-life care in Norwegian nursing homes. *Soc Sci Med* 2010; 71(4): 677–684.
8. Bollig G. Ethical decision-making in nursing homes—a literature study. In: Schildmann J, Gordon JS and Vollmann J (eds) *Clinical ethics consultation—theories and methods, implementation, evaluation*. 1st ed. Farnham: Ashgate, 2010, pp. 189–201.

9. Bockenheimer-Lucius G, Dansou R and Sauer T. *Ethikkomitee im Altenpflegeheim* [Ethics committee in the nursing home]. Frankfurt am Main: Campus, 2012, pp. 46–51, 149–225.
10. Dreyer A, Forde R and Nortvedt P. Life-prolonging treatment in nursing homes: how do physicians and nurses describe and justify their own practice? *J Med Ethics* 2010; 36: 396–400.
11. Dreyer A, Forde R and Nortvedt P. Autonomy at the end of life: life-prolonging treatment in nursing homes—relatives role in the decision-making process. *J Med Ethics* 2009; 35: 672–677.
12. Kvale S. *Interviews—an introduction to qualitative research interviewing*. 1st ed. Thousand Oaks, CA: Sage, 1996, pp. 124–209.
13. Malterud K. *Kvalitative metoder i medisinsk forskning* [Qualitative methods in medical research]. 2nd ed. Oslo: Universitetsforlaget, 2003, pp. 129–137.
14. Thorne S. *Interpretive description*. 1st ed. Walnut Creek, CA: Left Coast Press, 2008, pp. 11–262.
15. Dresing T and Pehl T. *Praxisbuch Interview und Transkription* [Practice handbook of interview and transcription]. 4th ed. Marburg, 2012, <http://www.audiotranskription.de/download/Handbuch-f4.pdf> (accessed 5 May 2014).
16. NVIVO. *NVivo 9-getting-started-guide*, <http://download.qsrinternational.com/Document/NVivo9/NVivo9-Getting-Started-Guide.pdf> (2011, accessed 5 May 2014).
17. Bazeley P and Jackson K. *Qualitative data analysis with NVIVO*. 2nd ed. Los Angeles, CA: Sage, 2013, pp. 68–153.
18. Sørbye LW, Grue EV and Vibe O. Trives på sykehjem [Enjoying themselves in the nursing home]. *Sykepleien* 2011; 8: 68–71.
19. Newerla A. Ein Schein von Qualität [A pretence of quality]. *Praxis Palliat Care* 2013; 18: 36–37.
20. Jakobsen R and Sørli V. Dignity of older people in a nursing home: narratives of care providers. *Nurs Ethics* 2010; 17: 289–300.
21. Goffman E. *Asylums: essays on the social situation of mental patients and other inmates*. 1st ed. New York: Anchor Books, 1961.
22. Chochinov HM. Dignity and the essence of medicine: the A, B, C, and D of dignity conserving care. *BMJ* 2007; 335: 184–187.
23. Andersson I, Pettersson E and Sidenvall B. Daily life after moving into a care home—experiences from older people, relatives and contact persons. *J Clin Nurs* 2007; 16: 1712–1718.
24. Brandenburg GL, Symes L, Mastel-Smith B, et al. Resident strategies for making a life in a nursing home: a qualitative study. *J Adv Nurs* 2013; 69: 862–874.
25. Pleschberger S. Dignity and the challenge of dying in nursing homes: the residents' view. *Age Ageing* 2007; 36: 197–202.
26. Van der Elst E, Dierckx de Casterlé B and Gastmans C. Elderly patients' and residents' perceptions of “the good nurse”: a literature review. *J Med Ethics* 2012; 38: 93–97.
27. Kojer M and Schmidl M. *Demenz und palliative Geriatrie in der Praxis* [Dementia and palliative geriatrics in practice]. 1st ed. Vienna: Springer, 2011, pp. 199–205.
28. Bradshaw SA, Playford ED and Riazi A. Living well in care homes: a systematic review of qualitative studies. *Age Ageing* 2012; 41: 429–440.
29. Dybvik TK, Gjengedal E and Lykkeslet E. At the mercy of others—for better or worse. *Scand J Caring Sci* 2014; 28(3): 537–543.
30. Lillemoen L and Pedersen R. Ethical challenges and how to develop ethics support in primary health care. *Nurs Ethics* 2012; 20: 96–108.
31. Kayser-Jones J, Schell E, Lyons W, et al. Factors that influence end-of-life care in nursing homes: the physical environment, inadequate staffing and lack of supervision. *Gerontologist* 2003; 43: 76–84.
32. Gjerberg E, Hem MH, Førde R, et al. How to avoid and prevent coercion in nursing homes: a qualitative study. *Nurs Ethics* 2013; 20: 632–644.
33. Moser A, Houtepen R and Widdershoven G. Patient autonomy in nurse-led shared care: a review of theoretical and empirical literature. *J Adv Nurs* 2007; 57: 357–365.