Advance care planning in Norwegian nursing homes

BACKGROUND Nursing home patients are often frail and have a number of chronic conditions. Increased risk of critical events, hospitalisations and death indicates the need for dialogue with patients and their next of kin about the future, how to agree on sound decisions and what should happen if the patient's health condition deteriorates. Previous studies have shown that only a minority of nursing homes practise this type of advance care planning.

MATERIAL AND METHOD In early summer 2014, a questionnaire was sent to all Norwegian nursing homes, containing questions about the prevalence and content of advance care planning.

RESULTS A total of 57 % (486 nursing homes) responded to the survey. Approximately two-thirds reported that they «always' or «usually' undertook advance care planning and around one-third of them had written guidelines. The conversations primarily took place when the patient's health condition deteriorated, when the patient entered the last phase of life, or in connection with the admission interview. Hospitalisation, pain relief and cardiopulmonary resuscitation (CPR) were the most frequent topics. Next of kin and the nursing home doctor participated most often in the interviews, while the patients participated more seldom.

INTERPRETATION There were large variations between the nursing homes with regard to advance care planning. This may partly be explained by the lack of national guidelines, and partly by the fact that this is a relatively recent discussion in Norway. The infrequent participation by patients in the conversations is probably associated with the fact that among them a high proportion are cognitively impaired, the availability of medical resources is low, and a culture of patient participation is insufficiently developed.

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The questionnaire is available at tidsskriftet.no/gjerbergengappendiks

MAIN MESSAGE

A large number of nursing homes practised some form of advance care planning, but there were major variations in terms of its timing, content and participants

A minority of the nursing homes had established guidelines for advance care planning

Participants mainly included the next of kin and the nursing home doctor, the nursing home patients participated more seldom

Patient participation increased in proportion to the availability of doctors in the nursing home

In 2013, approximately 47 % of all deaths in Norway occurred in nursing homes (1). An increasing proportion of nursing home patients with cognitive failure (2) and a high number of critical events, such as acute deterioration in the health condition, represent challenges in terms of providing care and treatment in line with the patient's wishes and values. To ensure that the medical decisions that are made comply with ethical guidelines and legislation, it is crucial that the patients are able to express their wishes in time. Are they fearful of something, how much information do they want, how do they want their next of kin to be involved in decisions? Moreover, are there some kinds of health care they do not want to receive?

The patient's preferences with regard to care and treatment can be revealed through preparatory conversations (advance care planning, ACP). Such conversations may include hospitalisations, life-prolonging treatment, alleviation of symptoms and the final stage of life, as well as more existential questions (3, 4).

During the last decade, registering the use of various forms of advance care planning has become common in a number of Western countries (3, 4). The Directorate of Health manual for decision-making processes for life-prolonging treatment emphasises appropriate routines for promotion of patient self-determination, and a preparatory conversation is recommended when the patient's life is coming to an end (5).

A study from 2007 revealed, however, that very few Norwegian nursing homes practised this type of advance care planning (6). A qualitative study undertaken among nursing home patients and their next of kin a few years later found that some patients wanted such conversations, while other found it unnecessary. Nearly all of the 33 next of kin included in the study wanted such discussions (7). A study of advance care planning of future health assistance and information in an acute geriatrics ward showed that approximately four-fifths of the patients took a positive view of discussing such matters (8).

In the period 1990–2015, a number of systematic reviews focusing on advance care planning in nursing homes were published (9–16). Sharp and collaborators found that 60–80 % of the elderly wished to discuss these matters themselves (12). Van der Steen and collaborators investigated what conditions are conducive to conversations of this type among dementia patients and their next of kin, and concluded that health personnel ought to take the initiative (13). The use of advance care planning requires sensitivity regarding the timing, and openness to responses from patients and

Table 1 Topics raised in advance care planning. Based on questionnaire responses from 486 nursing homes

Topic	Proportion in per cent
Hospitalisation	87
Pain relief	83
CPR status	79
Use of antibiotics	75
Artificial feeding	63
Other questions linked to the final stage of life and death	47

their next of kin. The advantages of engaging in advance care planning include better documentation of the patient's preferences, provision of care that is more in line with the patient's wishes, a reduction in the number of hospitalisations and a more appropriate use of hospices and palliative care (9–16).

In this study, we wished to map the prevalence and implementation of advance care planning in all Norwegian nursing homes.

Material and method

The questionnaire was first sent to ten nursing homes and subsequently adjusted through the addition of further response categories. The questionnaire included 19 questions about matters such as the prevalence and content of advance care planning, the participants, the availability of written guidelines for the sessions and how often these were documented (see gjerbegappendiks).

«Advance care planning» was defined as «a conversation in which the patient and/or their next of kin in cooperation with staff members seek to elicit the patient's wishes for future treatment, care and nursing should his or her health condition deteriorate». Further questions included implementation of conversations upon admission and the topics discussed in these.

The questionnaire was sent to all Norwegian nursing homes in the spring of 2014, addressed to the head of institution/unit. Only nursing homes with long-term wards were included, amounting to 848. The results are described in simple statistical analyses undertaken in SPSS, version 22. Differences between groups are described in bivariate analyses using the chi-square test.

Table 2 Participants in advance care planning. Based on questionnaire responses from 486 nursing homes

Participants	Mostly (%)	Occasionally (%)	Rarely/never (%)	Don't know (%)	Number of nursing homes[1] (n)
Patient	37.7	42.2	20	0.2	446
Next of kin	93.2	6.6	–	0.2	456
Head of department	44.4	34.4	20.9	0.2	401
Nursing home doctor	79.1	17.3	3.2	0.5	444
Primary contact person	64.4	28.4	6.4	0.7	419

[1] Figures in the column refer to the number of nursing homes that ticked one of the alternatives for the different participants

Table 3 When does the advance care planning take place? Based on questionnaire responses from 486 nursing homes

Time	Proportion (%)
When the patient's health deteriorates	75.7
When it is assumed that the patient is entering the final stage of life	58.6
Shortly after admission	44.4
At annual check-ups	42.4
Repeatedly, as part of a process	28.8

The study does not involve personally identifiable information and is therefore exempt from notification to the Norwegian Centre for Research Data (NSD), formerly the Norwegian Social Science Data Services, and to the Regional Committee for Medical and Health Research Ethics.

Results

After having sent out two reminders we received responses from a total of 486 nursing homes (57.3 %). All counties were represented. The questionnaire had been addressed to the managers of the nursing homes, with a request to obtain information from others if they had insufficient knowledge themselves. Those who responded were either head of the nursing home (48 %), head of department (35 %), educational nurse or a registered nurse (13 %), or a nursing home doctor (8 %).

On average, the nursing homes had 47.5 beds (range: 6–182 beds). The average number of doctor-hours per week amounted to 0.37 hours per bed (median: 0.31 hours; range: 0.01–1.94 hours).

Advance care planning – prevalence and guidelines

One-fifth of the nursing homes (20 %) reported that they «always» practise advance care planning, whereas 44 % reported doing this «usually». Altogether 28 % responded «occasionally» and 7 % answered «rarely/never».

Of those who practised advance care planning «always»/«usually»/«occasionally», altogether 34 % responded that they had written guidelines for this type of conversations. Those who «always» practised such discussions more often responded that they had guidelines (67 %) when compared to those who practised this «usually» (33 %) or «occasionally» (13 %) ($p < 0.05$). In nursing homes with a good availability of doctors significantly more such conversations were undertaken when compared to nursing homes with fewer medical resources available ($p < 0.05$).

We asked to be supplied with the guidelines from approximately 20 % of the institutions that reported to have such documents (28 nursing homes), and received 11 answers. Five of them contained guidelines that included the patient's wishes for future health assistance.

Content of the advance care planning conversations

Table 1 shows that a large majority address questions such as hospitalisation, pain relief and cardiopulmonary resuscitation (CPR). Somewhat less than half (47 %) also reported that «other questions associated with the final stage of life and death» are addressed.

The respondents provided detail in free text, and the responses were grouped into three main categories: the role of the next of kin, spiritual/existential questions, and honouring the patient's wishes and interests. More rarely, reference was made to administration of fluids, expected course of dementia development and what happens at the terminal stage.

Who participates and when?

Table 2 shows that the participants mainly encompass the next of kin and the nursing home doctor; patients participate more rarely. Patients in nursing homes with high availability of nursing home doctors participate significantly more often than patients in nursing homes with fewer medical resources available ($p < 0.001$).

A deterioration in the patient's health condition (76 %) and the assumption that the patient is entering the end-of-life stage (59 %) are the most frequent occasions for such conversations. In addition, the advance care planning sessions are occasionally combined with the annual check-ups (Table 3).

Somewhat less than 30 % answered that the conversations were undertaken repeatedly as part of a process. This took place significantly more often in nursing homes that reported to have written guidelines for such discussions available, when compared to other nursing homes; 40 % and 25 % respectively ($p < 0.005$).

Documentation

Nearly all respondents (96 %) reported that the patient's wishes «usually» are documented in the patient records. Altogether 30 % reported that this is also noted elsewhere, for example in the palliative care plan or the user participation form.

Advance care planning and admission interview

A large majority of the nursing homes (93 %) carried out an admission interview with the patient and/or the next of kin upon admission. These interviews mostly tended to focus on practical issues and the patient's life story.

Two-thirds of the respondents also reported to address questions regarding treatment in the event of a deterioration in the patient's health condition, i.e. a topic which is central to what we designate as advance care planning. Furthermore, in an open response alternative, some referred to clarification of expectations and clarification of treatment options respectively.

Discussion

To sum up briefly, the results indicate that «advance care planning» was undertaken in more nursing homes in 2014 than in 2007 (6), but these conversations were undertaken in very varying ways and rarely in conformity with international recommendations.

In the following we will discuss three topics that are of importance to nursing homes that intend to conduct advance care planning appropriately: variations in practices, patient participation and the importance of the availability of doctors in the nursing home.

Variations in practices

The frequency of advance care planning varies considerably between nursing homes. Moreover, the results indicate differences in terms of their content, timing, participants and form of documentation.

The most likely explanation is perhaps that in the absence of national recommendations from the health authorities, the nursing homes have developed their own practices. The variations may also be a result of a varying desire among the patients or their next of kin to participate in this type of conversations (7).

The study also indicated differences in terms of what is understood to constitute «advance care planning». The results indicate that these conversations are generally undertaken when the patient's condition deteriorates or when his or her life is approaching its end, alternatively in the admission interview.

Two-thirds of the respondents reported that issues related to treatment if the patient's health condition deteriorates are addressed in the admission interview, when the patient is generally new to the nursing home. Although they had ticked this box in the questionnaire, we obtained the impression that they would undertake individual assessments of the appropriate timing, for example by considering whether such an interview would be too stressful for a patient immediately after admission. Such interviews must be offered at a time that feels appropriate for those concerned.

One study found that most next of kin felt that it was too early to discuss such matters in the admission interview (7). For some, the transfer to a nursing home was so emotionally stressful that discussing the final stage of life was seen as an excessive burden. Others found it more appropriate to delay such a conversation until the patient's health had deteriorated (7). The «right» time to have such a discussion is debatable, but several studies underscore the importance of sensitivity on the part of health personnel regarding the wishes of the patients and their next of kin, and the crucial significance of good communication skills (3, 13).

Patient participation

In Norway there are no national guidelines for advance care planning, but the Directorate of Health recommends that the nursing home invite the patients and their next of kin to this type of conversation (5). Internationally, emphasis tends to be placed on the following: establishing familiarity with the patient before it is too late, the importance of eliciting the patient's wishes regarding treatment and care in the time to come, clarifying the role of the next of kin, and not exclusively focusing on death or the final stage of life (12, 16).

Our findings are corroborated by other recent studies confirming that nursing home patients participate in such sessions only in exceptional cases (7), even when they are able to give informed consent (17). This gives reason to question how the patient's right to co-determination is ensured, and the basis for the decisions made by health personnel.

The observation that the patients only participate in the conversations to a limited extent can partly be ascribed to the fact that a large proportion of the nursing home patients suffer from cognitive failure. We also know that the capacity to give informed consent is variable; even though the patient may be incapacitated in certain respects, he or she may be able to provide consent in others. We may also envisage that patients with reduced capacity to give informed consent in some cases should be permitted to participate in the sessions accompanied by their closest relatives.

Our study indicated that the next of kin participated in advance care planning far more frequently than the patients themselves. This concurs with findings made by other studies (18, 19). When the patient is no longer able to provide consent, the next of kin should be consulted regarding what the patient would have wanted in terms of treatment (20). One precondition for basing decisions on the assessments made by the next of kin, however, is that they are aware of the patient's wishes and preferences, which in fact is often not the case (21–23). It is therefore crucial to ask directly what they actually know when it comes to the patient's wishes and preferences.

We know that health personnel occasionally let themselves be pressured by next of kin to make decisions, often tending towards maintaining life-prolonging treatment, contrary to medical assessments of the patient's best interests as well as their own opinion regarding the patient's wishes (19, 24).

Availability of nursing home doctors

There were major variations between the nursing homes in terms of the availability of doctors, a finding which concurs with public statistics (25). In line with health-policy intentions, there has been some degree of growth in such resources during the last decade (26). Our study showed a somewhat lower figure for hours of availability than what is stated in the database referred to above, where the number of hours amounted to 0.49 hours per resident per week in 2014 (25).

Good availability of medical resources seems to increase the frequency of advance care planning as well as patient participation. We have previously found that increased availability of nursing home doctors co-varies with less use of coercion, and that the doctors fulfil a key function in assessments of capacity to give informed consent and the use of coercion (24, 27). The nursing home doctor appears to have a key role in reaffirming the patient's voice when difficult questions are discussed and decisions made. The doctor is also charged with making the final decision – in line with the patient's values and wishes.

A review article that investigated the patients' and their relatives' experiences of the doctor's contribution to appropriate treatment, nursing and care at the final stage of life found that they often felt the lack of an available and competent doctor who could actively participate in conversations and decisions pertaining to the end of life (28).

In their study of collaboration pertaining to dying patients, Dreyer and collaborators (29) found that in nursing homes with good availability of doctors there was better collaboration with the nurses regarding treatment issues, as well as a better basis for entering into appropriate processes with the patients and their relatives than in nursing homes with fewer doctors available.

Internationally as well, unsatisfactory availability of doctors in nursing homes is regarded as a persistent problem, associated with issues such as unnecessary hospitalisations, problems in communication and decision-making and dissatisfaction on the part of patients and their next of kin (30).

Weaknesses of the study

A response rate of 57% was somewhat less than desirable and gives rise to uncertainty regarding the responses. The limitation lies in the generalisability to all Norwegian nursing homes. We may assume that the nursing homes that practise advance care planning may be overrepresented among the respondents.

The questionnaire was addressed to the nursing home's management, but with a request to obtain information from others, for example a head nurse, should they be uncertain of what to answer. The head of institution/unit is responsible for the entire nursing home and is rarely in daily contact with the patients. Our failure to specify that those who are most knowledgeable should be the ones to respond to the questionnaire represents a weakness of this study.

We should probably have included questions regarding the ways in which decisions are documented. Despite these weaknesses, we believe that the present study provides valuable information on the use of advance care planning in Norwegian nursing homes.

Conclusion

The results indicate that some form of advance care planning is undertaken in a growing number of nursing homes, although the timing and content of such conversations and the identity of the participants tend to vary. The patients rarely participate in these conversations.

In light of the fact that the discussion on the importance of advance care planning to better ensure the wishes and values of the patients is relatively new in Norway, this variation in practices is not surprising. It also shows the necessity of raising this topic in the health policy debate. In addition, studies ought to be undertaken to elucidate the implementation of advance care planning and its importance for the patients, their next of kin and nursing home employees.

The results also indicate a need for competence enhancement and national guidelines.

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