Advance care planning discussions with geriatric patients

BACKGROUND Advance care planning discussions are conversations with patients about future treatment to ensure that the patients' wishes are known if their decision-making capacity fails. Many doctors fear that such conversations represent a strain on patients. We wished to test systematic advance care planning discussions on an acute geriatric ward and to investigate how patients felt about such discussions.

MATERIAL AND METHOD All patients who were admitted were continuously assessed with regard to their capacity for reflection on their future illness. An internationally tested tool was used as a basis for discussion with willing patients.

RESULTS Of 96 patients who were assessed, a total of 34 were found to be unsuitable and four declined. Of the 58 interviewed, 54 wanted complete transparency of information and 47 wanted their families to participate when important information was to be imparted and crucial decisions on treatment were to be made. A total of 11 wanted no involvement of their families in these processes. All of them wanted their doctor to participate in important decisions. The majority took a very positive view of an advance care planning discussion of this type. Only one had a negative attitude.

INTERPRETATION The patients were overwhelmingly positive with regard to advance care planning discussions. They have important messages to convey about information, the involvement of their families and the intensity of end-of-life treatment.

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MAIN MESSAGE

An offer of advance care planning discussions was well received by geriatric patients during their hospitalisation

All those who took part in the discussions wanted their doctor to participate in important decisions

Not all patients wanted their next of kin to be involved in the decision-making processes

The right to refuse treatment at the end of life is explicitly expressed in Section 4–9 of the Patients' and Users' Rights Act. To fulfil this right, a conversation must take place with patients while they are still capable of it. Advance directives by patients in the form of living wills – written declarations which they have drawn up – are not legally binding in Norway, and there is no clear obligation to elucidate patients' wishes in advance. However, in Section 4–6 of the Norwegian Patients' and Users' Rights Act, the duty to take account of what the patient would have presumably given permission for is made explicit.

Studies have not always been able to demonstrate that living wills have an impact on the treatment the patient receives (1–4). A controlled study on improved advance communication to patients found no improvement in the quality of end of life care. The process of dying was mechanically supported, painful and prolonged to an equal extent for the intervention group as for the control group (5).

Other studies have nevertheless demonstrated an association between the treatment that patients had said they wanted at the end of life and the treatment they received (6). This applies to dementia patients (7), hospice patients (8) and patients aged 80 years or more who were hospitalised on medical wards (9). In these studies, advance care planning discussions resulted in fewer hospitalisations and better quality of life at the end of life. One of the studies also showed an association between advance care planning discussions and reduced stress, anxiety and depression among next of kin (9). The planning process is valuable in itself for patients and their next of kin (10).

The Norwegian Directorate of Health guidelines *Decision-making processes in the limitation of life-prolonging treatment* recommend preparatory discussions in situations in which there is a risk of serious complications or at the end of life. In a large meta-analysis, Mullick et al. recommend advance planning in such situations, but also in early stages of dementia (11). The guidelines were issued in 2009 and revised in 2013. It is nonetheless our impression that advance care planning discussions have not yet become an institutionalised part of the Norwegian health services. One reason may be that health personnel are hesitant because they find it uncomfortable or believe it to be stressful for patients. In a study of terminally ill patients, however, only 1.9 % perceived it as highly stressful to discuss end of life treatment (12).

A number of tools have been designed to support patients' decisions with regard to treatment (13). Murtagh et al. presented a questionnaire that was evaluated positively by treating doctors and patients when it was used systematically for patients with serious diseases (14).

With regard to elderly patients on the medical ward, it is often difficult to select

BOX 1

Patients' preferences regarding information and decisions on health assistance[1] – questionnaire used in the study

1. Everyone copes with their illness differently. Some like to know all the details of their illness and treatment, some prefer limited information, and some prefer not to know, or to know very little. Do you prefer: not to know / limited information / to know all the details (any comments)
2. Do you feel the information you have had so far has been: too little / about right / too much (any comments)
3. If they ask us, may we talk to your family about your illness? Yes / No
4. Is there anyone in your family whom you would prefer us not to give information to?
5. Do you prefer anyone particular to be with you to hear results or to discuss and make important decisions about your care and treatments?
6. Have you ever written down your wishes about future care or treatment?
7. The staff here will always try and advise what is in your best interests, and will discuss this with you whenever possible. It is helpful, however, to know if you have any particular preferences for or against specific treatments?
8. If there are any major decisions, do you prefer: for the doctors to make the decisions / for the doctors to give you all the information and help you make the decision / for you and your family to discuss and decide together / for you alone to make the decision / other (please indicate)

[1] Reproduced with the permission of Murtagh & Thorns (14).

the correct intensity of treatment. An overview of studies conducted on the elderly and frail showed that between 61 % and 91 % wanted discussions about end of life treatment, but very few had been granted these (15). The acutely hospitalised often have an immediately reduced capacity to participate in decision making themselves (16).

Norwegian studies have been conducted on patient involvement in treatment decisions in nursing homes (17, 18) and in the case of acute hospitalisations from nursing homes in the final stage of life (19), but there are no studies on advance care planning discussions with geriatric hospital patients.

We wished to investigate the following: What proportion of geriatric hospital patients have a preserved capacity to participate in discussions on medical decisions pertaining to them? What proportion respond affirmatively to an invitation to take part in this type of discussion? How do they perceive the discussion? What do they respond to questions about information, involvement of next of kin and the decision-making process with regard to current and future treatment?

Material and method

The Section for Geriatric Medicine at the Department of Internal Medicine, Sorlandet Hospital Kristiansand has seven beds. Altogether 85 % of the patients are admitted as emergency cases. The cause of hospitalisation is most frequently acute functional failure with a wide spectrum of underlying diagnoses. The duty doctors in the accident and emergency department decide whether the patients should be admitted to the section for geriatric medicine. The patients' average age is 82 years and the average period of hospitalisation is four days.

Murtagh & Thorns' questionnaire (14) was completed by the researcher. It contains categories for crossing off response alternatives, and space for comments. The form (Box 1) has been translated into Norwegian. The questions on the form were used as the basis for a discussion. One form with supplementary comments was completed for each patient.

All patients admitted over a period of four months in the autumn of 2012 were assessed with a view to whether they were capable of reflecting on their future wishes for treatment and information. Those who could not participate in a meaningful discussion about these questions due to cognitive failure or somatic disease were excluded.

Doctors on their rounds assessed the patients based on clinical judgement, supported by interdisciplinary geriatric examination. This examination consists of systematic interviews with next of kin and includes questions regarding cognitive function. An occupational therapist carries out testing of patients with suspected cognitive failure. Almost all patients in the section for geriatric medicine are examined using next of kin interviews and most are examined by an occupational therapist.

Suitable patients were informed verbally and in writing by the doctor and were then invited to participate. In the information they were given, it was emphasised that the purpose of the study was to strengthen patients' influence on their treatment, now and in the future. Those who agreed to participate signed a declaration of consent. They were then visited by one of the authors (PF), senior consultant in the department, who held a single conversation with only the patient present. PF was not the treating doctor during that period. The conversations lasted around 20 minutes.

The doctor who had a discussion with the patients on discharge asked what they felt about the interview. The responses were categorised as a negative, neutral or positive experience, and it was possible for them to add supplementary comments.

Approval

The Regional Ethics Committee considered that there was no obligation to submit the study to the committee. It was approved by the Norwegian Social Science Data Services and the Data Protection Official for Research.

Results

Altogether 96 patients were assessed for inclusion, of whom 34 were found to be unsuitable and four declined to participate. A total of 58 patients were interviewed, of whom 54 wanted full information about their health condition and four wanted limited information or a little at a time.

A total of 52 stated that we could inform their next of kin if they requested information. Some indicated persons we were not to inform. Altogether 47 wanted someone in their immediate family with them when they were to receive important information and when they were to make treatment choices. Eleven wanted to be alone with the doctor during such discussions. It was important for some of them that their next of kin were not included. All of them wanted their doctor with them when decisions had to be made, but none responded that the doctor alone should decide.

Altogether 42 patients stated afterwards that it had been a positive experience to discuss these topics, but only one of the 58 responded that she found the conversation stressful and a burden. Fifteen said that they had had a «reasonable» experience.

Only one had already put their particular wishes for future treatment in writing. The person concerned did not want to be resuscitated. One half formulated their wishes for future treatment during the discussion. Six made specific statements with regard to treatment, for example that they did not want surgery, respirator treatment or chemotherapy. A total of 23 expressed attitudes such as a desire for reluctance on the part of the hospital to provide life-prolonging treatment if they were to become demented, in need of nursing home care or at the end of life – and that quality of life meant more than length of life.

Discussion

In all, 60 % of the geriatric patients who were hospitalised in the study period were assessed as suitable for advance care planning discussions, and almost all were willing to have such discussions. Almost 80 % said afterwards that these discussions had been a positive experience. This may have been influenced by the fact that it was the treating doctor who invited them to have the discussion, and who asked them how they felt about it in retrospect.

The findings are nevertheless interesting. Both the authors participated in the working group for the national guidelines on limiting life-prolonging treatment. When working on these guidelines, several group members thought that a preparatory discussion could be unpalatable for many patients. As it transpired, this was not the case for these patients, which tallies with what others have found (15).

It is worth drawing attention to the patients' views on information and family involvement. Nearly all of them want full and transparent information. By far the majority would like a family member with them when they are given important information and significant decisions are to be made. However, several clearly wish to limit their families' influence and access to information. The patients must therefore be asked what they want. None wanted the doctor alone to decide without their involvement in the discussion.

Do these discussions provide information that is helpful for future decisions if the patients lose their capacity to be involved? A minority expressed specific wishes with regard to treatment or non-treatment. None of them stated that they would want treatment in any situation.

In this study one single conversation was held. Most of the patients had never discussed these issues before. In studies of advanced care planning discussions, several conversations are generally used, often conducted by specially trained nurses who bring in next of kin and doctors during the process (9). Such thorough processes over time certainly provide the patients with better opportunities to develop the standpoints that are important to them.

The literature indicates that the best entry point for good advance processes are questions about the patients' goals and values, rather than discussing this or that treatment (20). Some are of the opinion that the essence of future planning lies in two questions: If you cannot, or choose not to participate in decision making about what treatment you should have, what should we consider and with whom can we speak (21)?

Conclusion

Patients admitted to an acute geriatric ward have a positive attitude to advance care planning discussions. They have important messages to convey about the extent of involvement of their next of kin and how decisions should be made about the treatment they should receive.

In the course of a brief conversation without preparation, only a minority express clear wishes with regard to specific treatment or non-treatment. Perhaps more patients would arrive at clearer conclusions regarding their wishes if further follow-up discussions took place and if next of kin were involved, should this be the patients' wish.

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