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Decision-making in palliative care practice and the need for moral deliberation: a qualitative study

Maaike Hermsen*, Henk ten Have

Department of Ethics, Philosophy, and History of Medicine, University Medical Centre Nijmegen,
232 EFG, P.O. Box 9101, 6500 HB Nijmegen, The Netherlands

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Abstract

The development of palliative care is increasing the interest in the moral problems that arise in the practice of palliative care. It is not clear how caregivers deal with these moral problems. In this article, we focus on the decision whether to continue treatment or to withhold it, and discuss the way caregivers deal with this question amongst themselves and in communication or consultation with the patient. We look at moral deliberation, the process of identifying the crucial arguments for this decision in palliative care.

Keywords: Palliative care; Decision-making; Moral deliberation

1. Introduction

The development of palliative care is increasing the interest in the moral problems that arise in the practice of palliative care [1,2]. The multi-professional nature of palliative care, the difficulties of caring for the terminally ill, and the complicated medical and nursing problems involved, combine to foster a particular sensitivity to moral problems in many palliative care professionals [3,4]. Earlier studies [5,6] have identified and explored these moral problems in palliative care. These studies have not made it clear how caregivers deal with the moral problems that arise in health care practice, nor is it known if the decisive arguments differ between health care environments, and—if they do differ—how they differ. In this article, we compare various palliative care environments.

We focus on two aspects of the decision to (dis)continue treatment, and discuss the ways in which caregivers deal with these problems. We analyse the considerations and arguments relevant to the (dis)continuation of a treatment. Then, we discuss the way in which the palliative patient is informed about, and takes part in, this discussion. Finally, we analyse the value of, and the need for, moral deliberation, that identifies the arguments that are crucial for each such decision in palliative care.

2. Methods

There are a variety of research methods available to investigate the specific moral considerations and arguments that are crucial to action and decision when palliative caregivers are confronted with moral problems. This contribution describes the results of 15 qualitative, semi-structured interviews with caregivers working in five different environments: the medical oncology ward of a general hospital, the medical oncology ward of a university hospital, a hospice, a nursing home and a general practice. The moral problems mentioned earlier are encountered in all five environments. To get a broad overview of these topics, we not only looked at different environments, but also interviewed a range of professionals (doctors, nurses and attendants). The interviews took place in February and March 2002. The lengths of the interviews varied from 1 to 1.5 h.

We constructed a list of relevant topics that were to be covered during the interviews, based on earlier systematic studies [5,6]. In this sort of qualitative research, such a list is called an interview guide [7]. Because this was an open investigation (the sort of data that was going to be necessary to allow us to answer the purpose of the interviews was not clear beforehand), the guide was useful in structuring the interview.

The interviews have been analysed as follows. First, the 'moral reality' was extracted and reconstructed from the perspectives of the interviewees, expressed in their own language ('the actor's point of view' or 'the inner perspective')

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* Corresponding author. Tel.: +31-24-3615320; fax: +31-24-3540254.
E-mail address: m.hermsen@efg.umcn.nl (M. Hermsen).

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[7,8]. This involved transcribing the interviews and subsequently attaching specific codes to various segments of the text. The basic question was, what phrases and concepts did the interviewees use to identify ways of dealing with moral problems? This sort of 'moral reality' can be unfolded and conceptualized in so called 'sensitizing concepts' [9,10]. Meaningful concepts identified by the interviewees had to be classified in terms of the researchers' (authors') ideas of morally relevant considerations and arguments. This required repeated analyses of, and reflection about, the research material [8,11,12].

The results of the interviews are described further. Three caregivers per palliative care setting are not enough to allow us to draw reliable and general conclusions about the settings *individually.* Thus, we first focus on *general* morally relevant arguments, valid for all environments. Next, we highlight *differences* between environments. The two hospital environments turned out to be nearly identical, and we have lumped them together.

We will first consider the arguments bearing on the (dis)continuation of treatment and proceed to the question of communication with the palliative patient. The discussion is illustrated with quotations from the interviews.

3. Results

3.1. (Dis)continuation of treatment

The interviewees mentioned the following general moral arguments as involved in the (dis)continuation of treatment.

All the caregivers working in the five different environments thought that it was important to recognise the autonomy of the patients and of their relatives. Access to detailed and clear information is a precondition for the patients and their relatives to be able to make an autonomous decision about the benefit of a certain treatment. After all

> "the quality of the information available determines the quality of the choice the patient is able to make", a hospice nurse explained.

The interviews made it clear that the autonomy of patients is becoming an increasingly important factor in decision-making in palliative care. Patients are becoming less inhibited about expressing their wishes and preferences, and doctors are paying more attention to the wishes of patients than they did in the past. A general practitioner gave an example where he'd acted as an advocate for a patient with a particular demand. He argues that caregivers should focus on finding out what are crucial values for the patient:

> [a patient, authors] "was very freedom-loving, he wouldn't be tied down. I'd mentioned to the internist that the patient was planning to go on holiday and that he wouldn't accept a regular schedule of visits to the hospital. The internist could bear this in mind."

All caregivers working in the five different environments mentioned that the autonomous wishes of patients and their relatives are relevant in decision-making in palliative care. Caregivers working in the nursing home—where patients are more likely to be totally or partially incompetent, tend to lay the emphasis on the wishes the patient would have had when competent.

In the next sections, we will focus on the questions about decisions about the futility of a treatment, raised *specifically* in the various environments.

3.1.1. Hospitals

In the hospitals, the crucial factors are the assessment of the medical feasibility of a treatment and the social and psychological capacity of patients on the other hand. The balance of these factors determines whether a treatment will be continued or abandoned. The aims and consequences of a treatment have to be made clear, and it has to be decided what is medically–technically achievable. Then a judgement has to be made about whether the patient will be able to tolerate the treatment; the psychosocial aspects of the patient's situation have to be clarified.

> Consequently, "we have to judge whether the patient and their relatives will be able to tolerate a treatment of this intensity. [. . .]. It is important to regularly evaluate this social and psychological capacity", a doctor of the general hospital states.

Part of this judgement involves regular evaluation of the quality of life of the patient. Patients push out the frontiers all the time because their will to live can be very strong, but eventually further treatment is going to start degrading their quality of life and at that point further treatment is contra-indicated.

The interviews made it clear that the question of whether to offer a patient a futile treatment, or the continuation of a futile treatment is an issue for doctors and nurses working in the hospitals. It is also clear that non-medical considerations might motivate specific (non-)treatment decisions. In general, when the treatment is futile—when the probability of remission is minimal—the doctors felt that it should not be offered to the patient as a real possibility. However, sometimes when a treatment is futile the doctors will still offer their patients a last chance. In these cases the motivation is psychological rather than medical; the decision to discontinue the treatment is being postponed in order to give the patient the time to get used to the fact that the treatment is useless. Patients need that last chance because they are clutching at straws. When the patient eventually realises that the treatment is ineffective, they take the initiative in bringing it to an end.

> In that case "the decision to stop the treatment becomes their own decision and that is an advantage", as a nurse indicated.