

Zorg op de grens : palliatieve zorg in ethisch perspectief

Citation for published version (APA):

van Osselen-Riem, J. (2003). *Zorg op de grens : palliatieve zorg in ethisch perspectief*. [Doctoral Thesis, Maastricht University]. Lemma. <https://doi.org/10.26481/dis.20031217jo>

Document status and date:

Published: 01/01/2003

DOI:

[10.26481/dis.20031217jo](https://doi.org/10.26481/dis.20031217jo)

Document Version:

Publisher's PDF, also known as Version of record

Please check the document version of this publication:

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Care on the border, an ethical perspective on Palliative Care

SUMMARY

When he could no longer bear the silence in his room, he would press the alarm button next to his chair. His hearing, like his eyesight, had deteriorated lately. He didn't hear the 'yes, please?' which sounded through the intercom. Again he rang, again ... 'We're on our way!'. The sound reached his ear: they heard him...

He immediately started to talk: a glass of water, he wanted, chilled please. And who was he talking to, he also asked. The intercom remained silent. It was already disconnected. When the nurse came into his room after an hour, he couldn't remember. Why had he rung?

The first paragraph tells the story about the last stages of the life of a dear friend: a period that confronted me with experiences in which physical dependency and the need for care met walls of incomprehension and rancour. Situations in which the path to self-reflection appeared to be blocked, so that the patient, but also the care-giver, found themselves in isolation, a situation that stood in contrast with the philosophy of the palliative care movement, which by that time was developing in the Netherlands and with which I was closely involved. In retrospect, it was that concrete situation which was my motivation, the start of a quest for the practice of palliative care and the place of ethics therein.

This study offers a multidisciplinary sketch of palliative care and ethics from the perspectives of care-givers, patients and family. The research took place at the hospice Rozenheuvel in Rozendaal. Theoretical perspectives have been employed to analyse the practice of care-giving and to clarify the concrete situations which arise. The tension between the system and real-life experiences along with the urgency of making moral values recognisable and topics for ongoing discussion are illustrated by actual cases. The approaches of care-ethics and rule-ethics are placed in the context of this ongoing tension between the real-life experiences and expectations and system rules.

The purpose of this research is to make a contribution to the practice and theory of palliative care through the description and clarification of ethical problems as they arise in the actual practice of care-giving and to search for guidelines for the people involved. The goal was to locate forms of communication and ethical reflection, which could guarantee the continuance and further development of the unique qualities of palliative care.

The summary presents the findings of the research and its methodology. In doing this, it focuses on how the theoretical perspectives – social theory, ethics, and communication as a precondition for ethics – have contributed to the understanding of the practice of care-giving and to the clarification of the tensions confronting the care-givers. The responsive method offers possibilities for an optimal dialogue with all the people involved in the practice, not just with the care-givers, but also the patients and their families.

Theoretical framework

System and real-life situations

The development of science and technology in modern times, coupled with specialisation in knowledge and practice, has led to sub-systems with their own languages and rationales to which the self-evident everyday world has no access. Important and far-reaching life experiences with which people are confronted, such as handicaps, illness and death, disappear from sight in the development of specialised facilities with their own knowledge base, rules and assumptions in order to maintain and develop these facilities. The sharing and exchange of experiences and feelings concerning what it means to be confronted with obstacles to existence are less self-evident and existential meaning is institutionalised. People learn to express these in the language of the care-givers. Solutions are sought in technical possibilities and facilities.

Furthermore, the secularisation and removal of religious references, resulting from the individualisation and rationalisation of modern times, make collective answers to existential and emotional occurrences less extensive or less accessible. While these developments have made a contribution to emancipation and freedom from hierarchical forms of suppression and power, they have also created a vacuum of powerlessness and lack of communal frameworks for reflection in the dimensions of life experience.

The development of palliative care in the Netherlands, but also worldwide, can best be explained as a contra-movement, initiated by people in the healthcare sector or in humanistic or religious organisations who were no longer willing to accept the approach to the care of terminal patients as practiced in hospitals. While the hospital focuses on treatment and cure, palliative care considers care itself and the quality of life as paramount. This type of care is not only directed to physical aspects but encompasses 'total care': emotions, existential questions and social aspects receive equal attention. Such care is offered and developed in small care facilities, such as hospices and 'almost at home' houses.

While palliative care arose from discontent with the limitations of the healthcare system, it cannot function outside that system. Structural financial support is necessary in order for it to be accessible to people who need this care. Rules and procedures are equally crucial for the organisation of palliative care and the guarantee of its continuance. A realisation of the tension which accompanies rationality and how this places pressure on important dimensions of daily life is one of the insights to be gained from the historical development of palliative care. In order to prevent the pressure exerted by the system from reaching excessively high levels, an awareness of the fundamental norms and values and of the necessity for continuous reflection appear to be important tasks.

Knowledge of the motivation and the norms and values of palliative care alone do not result in the ideal practice. This research also corroborates that point. Care-givers are caught in the middle between the system and the real world. They know the case histories of their patients and are involved in their wishes and needs. Simultaneously they belong to an organisation with its own rules, professional assumptions and language. Care-givers, sharing daily life experiences with their patients, often have to follow system rules. Examples of how this tension in real situations becomes apparent and clouds relational concerns were presented regularly in the weekly Internal Care Council (IZO) and in conversations with the care-givers themselves.

One of the tragic aspects of a care-giving practice is the confrontation with conflicting obligations. Conflicting expectations and duties clearly illustrate that rational considerations and rules do not solve all problems. Nussbaum provides further insight, using her concept of an ethics based on everyday experience, convictions, and relational involvement. Neither abstract rules nor theoretical engagement lead to relational involvement in the practice of care-giving.

This is reached through openness to the case histories, emotions and experiences of people involved.

Rule-ethics and care-ethics

The study focuses on two approaches in ethics: *rule-ethics* and *care-ethics*. Rule-ethics comprises a structural approach with clearly defined points of departure. A phased plan assists care-givers step by step to make decisions regarding the principles and treatments valid in ethically difficult situations. Rule-ethics is concerned with the principles of well-doing and avoiding damage, the right to autonomy and the principle of justice. Autonomy is defined as the right of the patient to make their own decisions. The doctor has an obligation to inform the patient as completely as possible.

In care-ethics, relational involvement and reciprocity are more central. Autonomy is not just perceived as independence and self-determination. Vulnerability and finiteness are also viewed as part of human existence. People are involved with each other in the exercise of their autonomy. Support and the eventual actions of others do not automatically constitute an intrusion into this autonomy. The tension between the system and real-life experience is mirrored in the care-giving practice and there is a comparable tension between the ethics of care and the ethics of rules. This is illustrated in myriad examples throughout the study.

Neither care-ethics nor rule-ethics appears to be sufficient by itself to bridge the tension between the everyday world and the system in order to provide a foundation to protect the unique qualities of palliative care. Ethics as a source for thought and action is directly under pressure from the rational rules system. At the same time, however, it serves as a driving force for the emotions and existential questions, which this tension creates for those concerned. In that sense, care-ethics and rule-ethics can be seen as complementary to each other or as vehicles for exchange. Rule-ethics offers clarity and structure in difficult and crisis situations, while care-ethics remains close to experience itself and seeks solutions for the tension and frustration of a too rigorous policy. Such cooperation is only possible in a climate where normative points of departure provide a continuous and clear source for treatment and reflection on both assumptions and their effect on the practice itself. Even though this research is too limited to draw general conclusions, it nevertheless pinpoints factors that play an important role in guaranteeing that palliative care main-

tains its uniqueness, even when it becomes integrated into the regular health-care system.

Communication as condition for the practice of care-giving

The conflict between the experiences of daily life and the demands of the system limits the discussion of moral and existential experiences. Communication is essential for the practice of palliative care. Ethics in a care-giving practice requires space for the organisation of communication and reflection. According to Verkerk, the social context is important, as moral questions do not arise of themselves. People in a given social reality, often coloured by power relationships, pose these ethical questions from their own diverse perspectives. Moral beliefs are closely allied with the identity of people and consequently the resulting actions are frequently emotionally charged. This represents a strong contradiction to the rationality of the system. Moral questions do not mesh well with the concepts of objectivity and feasibility, which are inherent in the system. The tension sometimes makes it so difficult that it limits the space for communication and the posing of existential and moral questions. This does not mean, however, that the question cannot be raised. Kunneman employs the term 'slowly arising' or 'delayed questions', to describe problems, classified as existential matters, which lie outside the logic of modern technological development but which will eventually surface and call for reflection.

The hospice Internal Caregiving Council (IZO) offers one possibility for regular discussion of ethical questions. Such a council provides space for life experience and the emotions and questions that play a role in real-life situations. Policy meetings, on the other hand, address more procedural issues such as general treatment and sedation policy. The real-life situation, which was the original cause for the meeting, disappears into the background. A moral decision-making board requires not only a communication climate wherein diverse perspectives receive space for reflection and negotiation in the search for what is right and good in difficult situations but, equally important, ensures that those situations remain central to the discussion. The climate is enhanced by the presence of diverse points of view. Therefore, it is important that the complete multidisciplinary team be present. The opportunity offered by the IZO for ethical questions and experiences to be spontaneously brought into the discussion meets that need. Space is created for emotions and vulnerability, space for empathy with the real-life story and experience being related, and its

effects on the individuals concerned.

A responsive methodology: furthering dialogue between participants

The hermeneutic dialogue, whereby people interpret their existence through interaction with each other, has an important role in this approach. A broad dialogue was initiated with care-givers and personnel as far as scheduling permitted. Discussions addressed both the researcher's and care-givers' questions. A rigid structure as in quantitative research was not sought. There needed to be space for the questions, expectations, and norms and values that play a role in the practice. Researcher and practitioners set up a joint process to uncover tensions in the practice and clarify the problems present.

Research activities undertaken included: participatory observation, preparatory discussions with the management, introductory meetings to clarify the purpose and methodology of the study, and the use of case studies of care-giving practice to initiate a dialogue with those working in the hospice. Interviews were held not only with doctors and nurses who participated in the different situations but also with pastoral and social workers and others involved with the hospice work. The weekly care-giving council (IZO) was attended to monitor the decision-making on ethical questions posed by the care-givers. Multidisciplinary meetings were organised to discuss relevant issues which arose in the interviews, e.g. expectations about good care, ethics and autonomy.

In the responsive method, the researcher is not an independent expert but rather a participant involved in the process along with other participants. The researcher's contribution is the capacity to interpret and to create a climate wherein a learning process through dialogue is initiated, and desirable change processes are possible. In this study, a process unfolded which, after being set in motion by the researcher, was adopted and worked out further by the care-givers themselves. Instead of group meetings on topics chosen by the researcher from the interviews, a choice was made to initiate a process of policy development on sedation.

This approach delivered a number of surprises, as the most pressing problem for study in the council could not be predetermined. Generally, people associate ethics and palliative care directly with issues such as euthanasia, discontinuation of medicine and abstinence policy. The conversations with the care-givers brought other issues to the forefront. These included: the transfer of patients

to other types of facilities against their will, patient privacy, the effects of the current care policy on the quality of life (the palliative aspect of the care) and issues concerning the knowledge of care-givers and family and the care-givers' own feelings of powerlessness.

The voices of the patient and family were not sufficiently audible in this study. Only one patient and one relative were interviewed, and they did not participate in the policy forum. The views and wishes of the patient and their family were primarily expressed in the council discussion by the nurses. The researcher gained additional understanding of the situation of the patient and their family during a twelve-month period as a volunteer in the study. The realisation of the patient's vulnerability inhibited the researcher from large-scale interviewing. This is however an area that warrants more attention. The patients' questions, expectations and norms and values would result in a more balanced overall picture for consideration and could contribute to better insight and understanding.

The research methodology followed resulted in sufficient opportunities for dialogue with hospice practitioners. It was, however, not sufficient for an evaluation of the implementation of the learning process that took place or of its future viability. The same tension was noticeable between the system and daily life experience. In the responsive method the dimension of daily life, the (hospice) practice and the experiences of the people involved with each other are key. For that reason the responsive method is especially suitable for palliative care, which focuses on the daily life and experience of the patient rather than only on the treatment of physical problems. This synergy also extends to the ethics of care. That explains why it was the nurses who frequently brought up ethical questions of that nature along with specific aspects of the patient's life experience. The responsive method, palliative care and the ethics of care all consider daily life and relational involvement as their central focus.

The research has made the ambivalence of the current hospice practice evident. Emphasis on aspects of experience in palliative care in a care-ethics approach alone creates vulnerability and isolation. Rules and protocols in rule-ethics limit critical reflection and communication. In order to make the tension between these two bearable and to be able to continue to offer the quality of care, it is necessary to remain aware of the life histories of people and the real-life situations in which they occur while continuing to reflect on the normative assumptions of palliative care. The research noted a tendency towards dominance of rule-ethics. This study with all its questions and clarifications

should be seen as a small contribution to the dialogue needed to assist caregivers, patients and families and all those involved with palliative care practices in their own process of discovery and learning.

Doorn, May 2003