

Original Article

How to Deal With Relatives of Patients Dying in the Hospital? Qualitative Content Analysis of Relatives' Experiences



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Abstract

Context. Hospital care and communication tend to be focused on the individual patient, and decision making is typically based on the principle of individual autonomy. It can be questioned whether this approach is adequate when a patient is terminally ill.

Objectives. Our aim was to explore the involvement and experiences of relatives in the hospital during the patient's last phase of life.

Methods. This study was embedded in a retrospective questionnaire study on the quality of dying of a consecutive sample of patients who died in a general university hospital in The Netherlands. We performed a secondary qualitative analysis of relatives' comments and answers to open questions. Relatives of 951 deceased adult patients were asked to complete a questionnaire; 451 questionnaires were returned and analyzed for this study.

Results. Relatives expressed a need for 1) comprehensible, timely, and sensitive information and communication, 2) involvement in decision making, 3) acknowledgment of their position, 4) being able to trust health care staff, and 5) rest and privacy. When relatives felt that their role had sufficiently been acknowledged by health care professionals (HCPs), their experiences were more positive.

Conclusion. Relatives emphasized their relation with the patient and their involvement in care of the patient dying in the hospital. An approach of HCPs to care based on the concept of individual autonomy seems inadequate. The role of relatives might be better addressed by the concept of relational autonomy, which provides HCPs with opportunities to create a relationship with relatives in care that optimally addresses the needs of patients. *J Pain Symptom Manage* 2016;52:235–242. © 2016 American Academy of Hospice and Palliative Medicine. Published by Elsevier Inc. All rights reserved.

Key Words

Relatives, family, experiences, hospital, end-of-life care, autonomy

Introduction

In The Netherlands, about one-third of all deaths occur in the hospital, a percentage that is lower than in many other European countries.^{1–4} Many of these deaths are caused by a chronic illness and are

preceded by a period in which the patient is in need of palliative care, including end-of-life decision making.^{5,6} In Western health care, decision making is mainly based on the principle of individual autonomy,^{7,8} which in philosophy is described as self-rule or independence and in legislation as the individual's

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Accepted for publication: February 18, 2016.

right to decide on medical treatment.^{9–11} Although the Institute of Medicine in 2001 already stated that involving the patient's family and friends is a matter of course when providing patient-centered care,¹² health care professionals (HCPs) in the hospital usually only address the patient when making decisions on treatment and care. They assume that the patient is competent and able to decide for himself and will involve relatives only when needed.¹³ According to Quinlan,¹⁴ patients in hospital have a comprised autonomy, as they accommodate to the ethical, legal, and organizational context of the hospital. This is particularly the case at the end of life, when the physical and psychosocial condition deteriorates and patients are no longer able to optimally participate in decision making without the support of relatives.¹⁴ Many patients want their close relative to be informed about their illness and to involve them in major decisions at the end of life.^{15,16} Relatives in palliative care should be supported in caring for the patient and for their own well-being.⁶ Many studies have shown that timely information and communication enable patients and their relatives to prepare together for death and to strengthen their relationship. Furthermore, information and communication can help relatives prepare for surrogate decision making if needed.^{4,15,17–21} Particularly at the end of life, patients tend to think and act in relation to close family and friends.¹⁴ Therefore, it can be questioned whether the patient's individual autonomy is the most appropriate base for end-of-life care. To update, there is a gap in empirical research on patient and relative involvement at the end of life and the implications for HCPs.^{14,22} In this study, we aim to explore the involvement of relatives in the hospital during the patient's last phase of life as experienced by relatives.

Methods

Design and Setting

This study was embedded in a retrospective questionnaire study on palliative and terminal care in the hospital.²³ The original study was carried out in the Erasmus University Medical Center in The Netherlands. The questionnaire we used contained 93 closed- and open-ended questions, the latter being merely questions for clarification. For this article, we used a qualitative approach to study the answers and comments to 10 open questions about hospital care in the last days of life.

Participants

The study population included relatives of 951 consecutive adult patients who died between June 2009 and July 2012, after a hospitalization of at least 6 hours at 18 nonintensive care wards (Table 1). Ten to

Table 1
Characteristics of Patients and Relatives

Characteristics of Participants	N = 451
Patients	
Age: mean (SD)	69 (14)
Sex	
Male	58%
Female	42%
Marital state	
Shared household	63%
Living alone	37%
Diagnosis	
Cancer	51%
Noncancer	49%
Length hospitalization: mean (SD)	15 days (19)
Relatives	
Age: mean (SD)	57 (13)
Sex	
Male	30%
Female	69%
Relation to patient	
Partner/spouse	44%
Child (in law)	37%
Other	19%

13 weeks after the patient had died, the relatives were invited to participate in the study by completion of a questionnaire on the quality of dying in the hospital. For 68 (7%) patients, no relative could be traced. We received 451 completed questionnaires (response 51%). We assumed that by including all participants, the number and content of the comments would be sufficient to cover the full range of experiences.

Data Analysis

A qualitative inductive content method was used to systematically analyze the texts.^{24,25} After selection of the relevant questions, all comments were read by two researchers (F. E. W., S. M. D.). Because the comments of relatives often related to different questions, data were coded across all questions using the open coding method.^{25,26} Two researchers (F. E. W., S. M. D.) coded the data independently. The codes were discussed until consensus was reached. Twenty-six different codes were extracted and discussed and agreed on with two other researchers (A. H., R. J.). The codes were reassembled and restructured into categories (axial coding) and subsequently we discussed and decided on integrating and refining the categories into overarching themes (selective coding) (Table 2). In addition, we summarized the answers to the associated closed questions and counted the number of explanatory comments per question, using SPSS, version 21 (IBM Corp., Armonk, NY).

Ethical Considerations

Approval for this study was given by the Medical Ethical Research Committee of the Erasmus MC. According to Dutch legislation, written informed consent of the patients or respondents was not required

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