

Original Article

Dying in the Hospital: What Happens and What Matters, According to Bereaved Relatives

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Abstract

Context. Most deaths in Western countries occur in hospital, but little is known about factors determining the quality of dying (QOD).

Objectives. The aim was to assess the QOD in hospital as experienced by relatives and identify factors related to QOD.

Methods. A cross-sectional study on 18 wards of a university hospital in The Netherlands was conducted, including relatives of patients who died after an admission of more than six hours, from June 2009 to March 2011. Relatives' perceptions of QOD and quality of care and the relation between dimensions of QOD and overall QOD scores were assessed.

Results. Two hundred forty-nine relatives participated (51%) and rated overall QOD at 6.3 (SD 2.7; range 0–10). According to relatives, patients suffered from 7.0 (SD 5.8) of 22 symptoms and were at peace with imminent death in 37%. Patients had been aware of imminent death in 26%, and relatives were aware in 49%. Furthermore, 39% of patients and 50% of relatives had said good-bye, and 77% of patients died in the presence of a relative. Symptom alleviation was sufficient in 53%, and in 75%, sufficient efforts had been made to relieve symptoms. Characteristics of QOD and quality of care could be summarized in nine domains, explaining 34% of the variation of QOD scores. Medical, personalized, and supportive care were most strongly related to QOD.

Conclusion. Relatives rated QOD as sufficient. A majority of patients and relatives were not sufficiently prepared for imminent death, and relatives experienced many problems. QOD appears to be a multidimensional construct, strongly affected by medical care and staff attentiveness. *J Pain Symptom Manage* 2015;49:203–213. © 2015 American Academy of Hospice and Palliative Medicine. Published by Elsevier Inc. All rights reserved.

Key Words

Hospitals, palliative care, quality of dying, relatives, terminal care

Introduction

In most Western countries, more than 50% of deaths occur in hospital.^{1,2} Some studies have reported on the satisfaction of health care professionals and relatives with end-of-life (EOL) care in the hospital;^{3,4} others have found deficiencies and unmet needs of patients and relatives.^{5–14} These deficiencies often relate to a lack of awareness that a patient is imminently dying, insufficient alleviation of symptoms,

inadequate communication, and the use of invasive procedures shortly before death.^{5–14}

Research on the quality of dying (QOD) in hospitals involves conceptual, methodological, and ethical difficulties.^{15–22} As a result, studies strongly differ in their conceptualization of QOD (e.g., with respect to the constituent factors and the time frame), research methodology (e.g., epidemiologic surveys, in-depth interviews), the populations studied (e.g., cancer patients, the elderly, intensive care patients), and

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sources of information (e.g., patients, medical records, relatives, health care professionals).

QOD has been found to be a multidimensional construct, including physical, psychological, social, and spiritual experiences; life closure; death preparation and circumstances of death; and characteristics of health care at the EOL.²¹ Another study showed that health care structures and processes can influence QOD experiences, in addition to patient-related factors.²³ Still, little is known about patients' and relatives' experiences at the very EOL in hospital and factors explaining these experiences.²¹

We aimed to contribute to better understanding of the experiences of patients and relatives in the last days of life and to identify factors that are related to the overall QOD.²¹ We explored what, according to relatives, happens when patients die in hospital, and what matters, by assessing experiences and identifying factors that are related to the experience of either a good or a poor QOD.

Methods

Design

We performed a retrospective cross-sectional questionnaire study among relatives of patients who died in hospital. This study was part of a larger study to explore and understand palliative and terminal care in the hospital (PalTeC-H), which also involved physicians and nurses. More detailed information on the rationale and the study protocol has been published elsewhere.²⁴

Study Population and Data Collection

Erasmus MC, University Medical Center Rotterdam, is a 1300-bed general university hospital in The Netherlands. All adult patients who died between June 2009 and March 2011 on one of 18 wards in this hospital after an admission of at least six hours were eligible for the study. Because in The Netherlands most in-hospital deaths occur on regular wards in which processes of care strongly differ from those in intensive care units, the latter were not included in this study. For each eligible patient, one relative was asked to participate by filling out a written questionnaire. After a patient's death, a ward nurse informed relatives of this study; they could then provide the nurse with an address for sending written information and the questionnaire. In the absence of an address, an invitation was sent to the last address of the patient. Ten to 13 weeks after the patient died, the primary investigator (F. E. W.) invited a relative to complete a questionnaire. In case of no response after four weeks, one reminder was sent. Participants also could ask the investigator to complete the

questionnaire in an interview, for example, in cases of illiteracy or visual impairment.

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 was not required because data were gathered after patients' deaths and the study involves minimal risk to the participants. In case of emotional distress as a result of completion of the questionnaire, participants were given the opportunity to call or meet the nurse investigator.

Assessment

Patient characteristics, such as date of birth, gender, diagnosis, and the duration and ward of the patient's final admission, were derived from the medical file. An extensive questionnaire was developed by an expert group because available instruments did not meet our goals.^{25,26} Our questionnaire included items on multiple dimensions of QOD, including physical, psychological, social, and existential experiences; life closure and death preparation; circumstances of death; and nature of health care.²¹ We added specific items on relatives' satisfaction with EOL care.^{23,27} We included relevant items of the Views Of Informal Carers Evaluation of Services questionnaire, the Leiden Detachment Scale, and the Quality of Dying and Death (QODD) questionnaire.²⁷⁻²⁹ Preliminary versions of the questionnaire were critically reviewed by a representative of the hospital patient council, tested for relevance and face validity among persons who had recently lost a relative, and piloted in the 1st 30 cases. The final version of the questionnaire comprised 93 items, including one item on 14 physical symptoms (i.e., pain, dyspnea, coughing, death rattle, difficulty sleeping, fatigue, dry mouth, lack of appetite, nausea, swallowing problems, constipation, decreased consciousness, confusion, and agitation) and eight psychological symptoms (i.e., anxiety, loneliness, dependency, tenseness, worrying, sadness, feelings of powerlessness, depressed mood).

We used various scales, mostly gradually ascending, to allow for nuance, for example, a four-point scale (none/mild/moderate/severe) to assess the intensity of physical and psychological symptoms and three-point scales (yes, more or less, no) for most other items, which almost all concerned the last 24 hours of life. Overall QOD was assessed on a 0–10 numerical rating scale, asking "How would you evaluate the quality of dying of your relative?" with 0 being very poor and 10 almost perfect. Items evaluating care were explicitly referred to as hospital EOL care.

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