

# What Happens & What Matters

*A study on Palliative and Terminal  
Care in the Hospital (PalTeC-H)*

*Erica Witkamp*

## Acknowledgements

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# **What Happens and What Matters**

A study on Palliative and Terminal care in the Hospital (PalTeC-H)

## **Wat er gebeurt en Wat er toe doet**

Onderzoek naar Palliatieve en Terminale zorg in het Ziekenhuis (PalTeC-H)

### **PROEFSCHRIFT**

ter verkrijging van de graad van doctor  
aan de Erasmus Universiteit Rotterdam,  
op gezag van de rector magnificus  
Prof.dr. H.A.P. Pols  
en volgens besluit van het College voor Promoties.

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*Frederika Elisabeth Witkamp*  
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# 1

## General Introduction



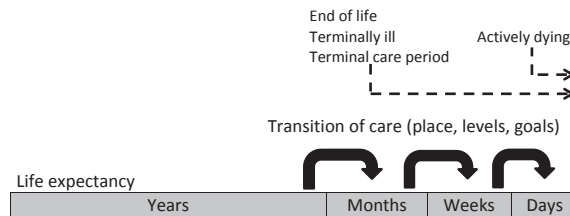


## BACKGROUND

### Palliative and terminal care

In 2002 the World Health Organization redefined palliative care as “an approach that improves the quality of life of patients and their family facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual”<sup>1</sup>.

Palliative care can be provided at any time during a patient’s incurable illness, and may be combined with disease-modifying and life-prolonging treatment<sup>2</sup>. Although there is no consensus, neither in clinical practice, nor in scientific literature, on definitions of ‘terminal phase’, ‘terminally ill’ and ‘end of life’, or on similar terms used to describe the care at the end of life, these terms mostly are used for patients whose life expectancy is three months or less<sup>3</sup>. The dying phase is mostly described as the final hours or days of life, when the patient is “actively dying”, and care for the dying as care provided during these final moments<sup>3</sup> (fig. 1).



**Figure 1:** Conceptual framework toward understanding “actively dying,” “end of life,” “terminally ill,” “terminal care,” and “transition of care.” from Hui et al, *Journal of Pain and Symptom Management*, 2014

Demographic changes, especially the risen life expectancy, have contributed to an increase in the number of elderly persons in our Western society<sup>4</sup>. Since the last decade, this results in a slowly increasing number of deaths each year in the Netherlands, i.e. from 136.000 in 2005 to 141.000 in 2012. Of these deaths, 73.000 to 108.000 occur after a period of decline in health, and of palliative care, depending on how this is defined<sup>5</sup>.

### Research in end-of-life care

Research in end-of-life care, particularly experimental research, involves many conceptual, methodological and ethical challenges<sup>6-13</sup>. Conceptual difficulties include, for example, variance and disagreement on concepts and definitions, and on the multidimensionality of the quality of dying<sup>3</sup>. Methodological and ethical challenges concern a variety of issues, such as the inclusion in research of patients at the end of their lives, uncertainty regard-

ing the value of proxy assessments, and loss to follow up of patients with limiting life expectancy in prospective experimental studies<sup>11,12</sup>. Furthermore, experimental research in end-of-life care often requires the use of new procedures and behaviors in clinical practice, addressing structures and processes of care, which in general are complex to implement and to evaluate<sup>14-16</sup>. Finally, only few validated measurement instruments in end-of-life care have been developed, most of which for use in specific populations, or to assess specific problems<sup>17-19</sup>.

### Shortcomings in quality of care for the dying in the hospital

In most Western countries more than 50% of all patients die in the hospital<sup>20,21</sup>. However, in the Netherlands this percentage is relatively low and it even decreased from 32% of all deaths in 2005 to 26% in 2012<sup>22</sup>. Hospital care is typically focused on cure and life prolongation and not on care in the dying phase. Throughout the hospital patients may need care in their last days of life, on wards that lack palliative care expertise<sup>23</sup>. Some studies have reported about satisfaction of health care professionals and relatives with end-of-life care in the hospital<sup>24,25</sup>. However, studies much more frequently report on deficiencies in the quality of care and unmet needs of patients dying in the hospital, including poor symptom control, insufficient communication, a lack of awareness of approaching death, the use of invasive procedures shortly before death, and shortcomings in health care professionals' knowledge, skills and attitudes<sup>23,26-41</sup>.

### Quality of dying and quality of care for the dying

Although "quality of dying" is not well defined, many investigators have studied the multidimensionality of the concept<sup>42-47</sup>. Based on a literature review, Hales et al (2008) extracted seven domains of quality of dying, including physical, psychological, social and spiritual experiences, the nature of health care, life closure and death preparation, and the circumstances of death<sup>6</sup>. These domains include, for example, physical and psychological symptoms such as pain, dyspnoea, lack of appetite, fatigue, anxiety, tenseness, and sadness; the feeling of being a burden to the social network; acceptance of imminent death; being cared for at the preferred site in the dying phase; awareness of imminent death and saying goodbye; and dying in the presence of a close relative. In order to achieve a good quality of dying, end-of-life care should address various needs in different domains of patients and their relatives. Several factors have been found to affect the quality of dying, such as structures and processes of health care (e.g. organization, environment, communication), individual patient factors (e.g. diagnosis and psychological characteristics), as well as factors in the social network of the patient (e.g. family or friends involved in informal care)<sup>44</sup>. However, it remains unclear to what extent these factors determine a poor or good deathbed.

Taking into account the nature of shortcomings in hospital end-of-life care, improvement efforts should include numerous and various measures<sup>48</sup>. In a literature review, Al-Qurainy et al (2009) proposed several improvement strategies: integration of palliative care services in the hospital to enhance caregivers' attention for the transition of treatment goals; increase of palliative care knowledge among health care professionals; and improvement of prognostication, advanced care planning and communication<sup>23</sup>.

As mentioned previously, deaths may occur throughout the hospital in various wards. In the Erasmus MC, for example, each year 350-400 adult patients die in one of the 21, non-intensive care wards; half of them die in four wards (neurology, medical oncology and geriatrics, lung diseases and palliative oncology care), and the other half in one of the 17 other wards. Therefore, most physicians and nurses are only rarely confronted with dying patients. Building expertise and improving and maintaining good quality of such complex care is not obvious.

### Nursing care for the dying

When the end of life approaches, patients often have increased needs for assistance in activities of daily life, comfort care, and coping with advanced disease. In this phase, nurses' contact with patients and relatives gets more intensive. Nurses assess what is happening and what is important for patients and relatives, and aim to meet these needs. However, they also increasingly have to deal with the complexity of the patient's situation, such as severe suffering, ethical problems, and difficulties in communication with patients, relatives and other health care professionals<sup>49,50</sup>. Although nurses are generally dedicated to provide high-quality end-of-life care, they experience many difficulties, such as lack of involvement in care planning, unrealistic expectations of the family, uncertainty on their role, and a lack of experience, knowledge and skills<sup>51-55</sup>. Some studies indeed found that nurses have insufficient knowledge and competencies to provide adequate palliative and end-of-life care<sup>56-60</sup>.

### Nurse champions

To address the complexity of palliative and end-of-life care throughout the hospital, and to meet the nurses' needs for increased knowledge and skills, hospitals increasingly start working with 'palliative care nurse champions'. These nurse champions are staff nurses of the wards, who collaborate in a palliative care network. They improve their own knowledge and skills on palliative care and care for the dying, by education and networking. Subsequently they aim to disseminate their knowledge and experience to their colleagues and the multidisciplinary team in their wards. Although this method of quality improvement has been used in various ward-overarching care problems in other fields, such as wound and tissue problems and infection prevention, the effectiveness of such networks has rarely been evaluated. Moreover, problems have been reported on

the sustainability, due to difficulties to participate in network meetings and in lack of self-confidence to take up the role of being an ambassador in a specific field<sup>61-64</sup>.

## ABOUT THIS THESIS

The objective of this thesis is to better understand quality of dying in the hospital, and to assess the effect of an intervention with palliative care nurse champions in the hospital.

The main research questions are:

- What is the quality of dying in the hospital and which are its determinants?
- What is the effect of a network of palliative care nurse champions on quality of dying in the hospital?

We performed a study in the Erasmus MC University Medical Centre in Rotterdam, The Netherlands. Data were collected between June 2009 and July 2012, among nurses, physicians and bereaved relatives, on patients who had died on one of the participating non-intensive care wards.

In short this thesis includes chapters on the preparation of the study (Part 1), on the quality of dying in the hospital (Part 2) and on the effect of nurse champions (Part 3).

### Part 1: Preparation of the study

Chapter 2 describes the development and validation of a questionnaire aimed at assessing the knowledge and opinions of nurses regarding palliative care, the Rotterdam MOVE2PC Questionnaire.

Primary goal of this questionnaire was to evaluate differences in knowledge of nurse champions, before the start of the network and 1,5 year after the start. To validate whether the instrument was appropriate to assess differences in this group, the knowledge and opinions of randomly selected hospital nurses were assessed, as well as the knowledge and opinions of nurses attending an advanced course on palliative care, before and after the program.

Chapter 3 describes the study protocol of the three-phased study on quality of dying in the hospital, including its methodology and the intervention. Phase 1 of this study involves the assessment of the characteristics of end-of-life care and quality of dying before the intervention (16 months); phase 2 is the intervention-implementation period and was regarded as a running-up period for the nurse champions (5 months); phase 3 is the period of post-intervention assessments (16 months).

## Part 2: Quality of dying in the hospital

Chapter 4 describes what happens and what matters regarding quality of dying in the hospital, according to bereaved relatives. In this study, experiences of bereaved relatives of patients who died during phase 1 and phase 2 are described. Furthermore, factors determining the variance in experiences are identified.

Chapter 5 analyses the concordance between experiences of bereaved relatives, physicians and nurses, regarding the patient's quality of dying, their awareness of imminent death and communicational aspects. Furthermore, the association between health care professional's communication and preparation and circumstances of death were analyzed.

Chapter 6 describes the experiences of relatives related to the quality of dying of patients, from a medical-ethical perspective on patient autonomy and care ethics. The question was whether the widely used concept of individual autonomy sufficiently addresses the needs of patients and their relatives. Therefore we analyzed the additional comments relatives made in the questionnaire.

Chapter 7 describes the awareness of physicians of patient's impending death and the impact of this awareness on medical care and communication. We analyzed the data of physicians, involved in the care for patients who died during phase 1 and 2 of the study.

## Part 3: The effect of palliative care nurse champions

Chapter 8 builds on the identification of domains of quality of dying and describes whether the intervention with nurse champions has an effect on the experiences of bereaved relatives regarding these domains of quality of dying of patients. We compared the outcomes between phase 1 and 3 in intervention wards and subsequently compared the results to those in the control wards, assessed during the same periods.

Chapter 9 finally analyses the effects of the intervention of nurse champions on nursing care in the last days of life, such as instrumental interventions and communication. In a secondary analysis of patients who died after a hospitalization of at least 24 hours, we compared nursing care provided during phase 1 and 3 in the intervention wards, and subsequently compared the results to the findings in the control wards, assessed during the same periods.

## Discussion

Chapter 10 concludes this thesis with a general discussion on the findings and the methods, and with implications for the future.

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# PART 1

PREPARATION



# 2

## Validation of the Rotterdam MOVE2PC Questionnaire for Assessment of Nurses' Knowledge and Opinions on Palliative Care

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Carin C.D. van der Rijt, Agnes van der Heide.

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## ABSTRACT

### Aim

The purpose of this study was the psychometric testing of a questionnaire to assess nurses' opinions, subjective norms, perceived difficulties, and knowledge related to palliative care.

### Methods

The 63-item questionnaire was tested among 219 nurses in groups differing in education and experience.

### Results

The intra-rater agreement was moderate to good ( $\kappa > 0.5 \kappa_{\max}$ ), and internal consistency was good ( $\alpha = .77$ ). Construct validity was demonstrated by between-groups differences in knowledge, opinions, and perceived difficulties, and responsiveness was shown by improved scores after an education program. Time of completion was 20 minutes and 99% missed at most 5 items, demonstrating feasibility.

### Conclusion

Findings support the usefulness of the instrument for assessing nurses' opinions, subjective norms, perceived difficulties, and knowledge related to palliative care.

## INTRODUCTION

Nurses increasingly provide palliative and terminal care to patients suffering from cancer or other chronic diseases. The percentage of all deaths in the world due to chronic diseases is expected to increase from 63% in 2010 to 72% in 2020<sup>1</sup>, and patients with chronic diseases are frequently admitted to a hospital during the last 3 months of life<sup>2</sup>. When death is approaching, goals of care need to change, from modifying the disease to optimizing quality of life by providing palliative and end-of-life care. The increasing number of patients in need of palliative care makes it urgent for nurses to improve their competence in providing this care. The purpose of this study was to develop and test an instrument to assess nurses' knowledge, opinions, subjective norms, perceived difficulties, and educational needs related to palliative care.

Palliative care requires specific knowledge, attitudes, and skills<sup>3</sup>. Providing adequate palliative care is challenging, due to many factors, for example, the fact that communication with patients at the end of life is difficult<sup>4,5</sup>. Espinosa and colleagues<sup>6</sup> identified various other barriers nurses experience when providing end-of-life care, including lack of involvement in care planning, disagreement among physicians, unrealistic expectations of the family, and a lack of experience and education. Nurses' knowledge and competence for providing adequate palliative and end-of-life care have frequently been found to be insufficient<sup>7-10</sup>. Furthermore, nurses themselves report a gap in their education in palliative care<sup>10,11</sup>. Some investigators also suggest that without specific education, nurses might have negative attitudes towards care for the dying<sup>12</sup>, although others have found more positive attitudes<sup>9</sup>.

Many education programs have been developed to improve nurses' competence in palliative care, but their effects have rarely been adequately assessed<sup>13</sup>. The measurement of competence has been the subject of much debate in the literature, in part due to differences in definitions of competence and differences in opinions about whether competency should be assessed in terms of knowledge, attitudes, and / or skills, and about the influence of subjective norms<sup>14-18</sup>. In the last decades, several instruments to assess these different aspects of nurses' competence in palliative care have been developed, such as the Frommelt Attitude toward Care of the Dying Scale (FATCOD)<sup>19-21</sup>, the Palliative Care Quiz for Nurses (PCQN)<sup>22,23</sup>, the C-PCQN, an expanded version of the PCQN<sup>24</sup>, the Palliative Care Knowledge Test (PCKT)<sup>25</sup>, and the assessment instrument for intensive care nurses on experiences, attitudes, and beliefs towards end-of-life care<sup>26</sup>. Limitations of these instruments are that they assess either knowledge, or opinions, or attitudes, but not all three, or that they have been developed for inexperienced nurses and will therefore not demonstrate the shortages in competence of nurses experienced in palliative care. Furthermore, they only address cancer care, intensive care, or care for the dying, but

do not address issues for the various patient groups requiring palliative care with which general nurses are confronted.

Our goals were to assess the competence of both experienced and inexperienced general hospital nurses related to palliative care and the effects of a palliative care education program on measures of competence. To this end we developed a new instrument, the Rotterdam MOVE2PC Questionnaire, Dutch abbreviation of Assessment of Knowledge and Opinions of Nurses Regarding to Palliative Care. The aim of this study was to validate the Dutch MOVE2PC as an instrument appropriate to meet our goals.

## METHODS

### Sample and Setting

From February 2010 to September 2012, 219 nurses and 4 other healthcare professionals,  $N=223$  in total, participated in this study. At the start, 21 nurses working at an affiliated cancer center, 3 nurse consultants in palliative care, and 4 other professionals, that is, experts in palliative medicine, palliative care research, and nursing education, contributed to the development and assessments of content and face validity of the questionnaire. All other tests were performed in two groups of nurses. One group was a sample of 119 hospital nurses, working on 17 in-patient wards (nursing students, registered nurses, team coordinators, and nurse specialists), who were randomly selected by computer from the hospital database. The other group consisted of 76 nurses, mostly working in nursing homes, hospices, and home care, who were enrolled in an education program on palliative care. These nurses filled in the questionnaire before and after their education program.

### The Education Program

The 25-day education program consists of plenary meetings and working groups, and a study load of 600 hours completed over 12 months. The program aims at improving nurses' knowledge, attitudes, and skills regarding palliative care, including symptom management, psycho-social and spiritual care, communication skills, consultation skills, evidence based care, and organization of palliative care. Throughout the program, nurses have to pass several exams and complete various assignments before receiving a certificate.

### The Rotterdam MOVE2PC Questionnaire

#### *Background*

A 66-item questionnaire was developed, based on evidence that a variety of factors, such as knowledge, attitudes, values, and skills, contribute to nurses' competence and performance in various situations<sup>15,16,27</sup>. According to Bandura's<sup>27</sup> social cognitive theory,

people's perceived capabilities are predictive of their efforts in practice, and people tend to avoid situations and activities which, they believe, exceed their capabilities. Self-efficacy beliefs affect many human processes, including motivational and affective processes. When people believe they can not manage a perceived difficult situation, they experience stress and anxiety arousal<sup>27</sup>. For understanding perceived difficult situations in palliative nursing, we included items on hypothetical clinical situations, and on the imaginary situation of a nurse suffering from a terminal disease and facing imminent death. We described these situations in vignettes, based on evidence that experiential knowledge is an important predictor for practice and decision-making in nursing<sup>28</sup>. The questions and vignettes were mostly based upon real patient cases and clinical situations. Previously developed instruments were taken into account when choosing themes and items. One example is a situation that was assessed as potentially difficult (a patient is asking "I will get better, won't I?"), which was based on the item "Nurse, am I dying?" from the FATCOD (Frommelt, 1991). The statement "Palliative care and intensive life prolonging treatment can be combined", that was used in the opinion section, was based on the statement "the philosophy of palliative care is compatible with that of aggressive treatment" from the PCQN (Ross et al. 1996). Knowledge statements were derived from the Dutch national guidelines for palliative care and the Dutch version of the Pain Knowledge Questionnaire (PKQ-DLV)<sup>29</sup>.

### *Content*

Part 1 of the questionnaire assesses nurses' characteristics, such as gender, age, working environment, actual experience with palliative care, and time spent on education in palliative care (8 items). In Part 2, respondents score on a 5-point scale, with the anchors "*strongly disagree*" and "*strongly agree*", to what extent they agree with 11 statements regarding opinions and 5 statements regarding subjective norms in palliative care, incorporated in a vignette. In Part 3, 20 potentially difficult situations are presented in three clinical vignettes describing patients in the last weeks or days of their lives. Nurses are asked to score the extent to which they perceive these situations to be difficult, using a 5-point Likert-type scale, anchored at "*very difficult*" and "*certainly not difficult*" and a category "I have not been exposed to this situation". In Part 4, knowledge is assessed using 22 statements regarding symptoms, symptom treatment, and care, using three answer categories: "*true*", "*false*", and "*I don't know*".

The self-administered questionnaire is available in Dutch as hard copy and in a computerized version. It was translated into English for the purpose of international publication.

### Validation of the Rotterdam MOVE2PC Questionnaire – Parts 2-4

On the second to fourth parts of the questionnaire we performed six psychometric tests to validate the MOVE2PC, according to the COSMIN checklist, which was originally de-

veloped for health-related patient-reported outcomes<sup>30</sup>. The questionnaire was adapted based on test results. All the data were analyzed using SPSS 15 and 19 and VasserStats.

### *Content and face validity*

To assess the degree to which the MOVE2PC adequately assesses knowledge and opinions related to palliative care, palliative care experts screened subsequent versions of the questionnaire on comprehensiveness and relevance (content validity). Remarks of the first three experts were addressed in a second version, which was reviewed by two new experts. Their comments were addressed in a third version that was again reviewed by two new experts. Subsequently, seven nurses from the cancer center completed the questionnaire to assess whether the MOVE2PC was comprehensive and unambiguous for the target population (face validity). They were explicitly asked to comment critically on the content and the text of the instrument and to register their time spent on the completion of the questionnaire.

### *Reliability*

The intra-rater reliability, i.e., the degree to which the outcome of the questionnaire was based on constant and 'true' scores (real opinions or knowledge) instead of error scores or guesses, was tested with 14 nurses from the cancer center, excluding the 7 previously involved nurses, who completed the questionnaire twice with an interval of 2 weeks. These nurses did not know in advance that they would be asked twice. We used Cohen's Kappa to test for agreement between the first and second assessment<sup>31</sup>. A weighted Kappa was calculated because we used nominal scales with three or more categories<sup>32</sup>. Items with a 5- and 6-point scale were analyzed using the quadratic weighted Kappa and the linear Kappa was used for items with a 3-point scale. Altman (2000) described guidelines to interpret the Kappa values as  $< 0.20 = \text{Poor}$ ;  $0.21-0.40 = \text{Fair}$ ;  $0.41 - 0.60 = \text{Moderate}$ ;  $0.61-0.80 = \text{Good}$  and  $0.81 - 1.00 = \text{Very Good}$ . We set the cut-off point at an observed agreement of at least  $\kappa \geq 0.35$  of the maximum ( $\kappa_{\max}$ ) and we aimed for 90% of the score to be at least  $\kappa \geq 0.50\kappa_{\max}$ . After the intra-rater reliability test, 5- and 6-point scales were merged to 3-point scales because of inconsistency in responses in the answer category "I have not been exposed to this situation", and imprecise discrimination between several other answer categories. Items still being  $< 0.35 \kappa_{\max}$  were deleted or changed before the next psychometric test.

The internal consistency of the Rotterdam MOVE2PC was tested using data from the sample of 119 hospital nurses. We used Cronbachs' alpha for the whole questionnaire as well as for the parts with enough items to calculate separately, i.e., the knowledge statements and the perceived difficulties, to test the degree of the interrelatedness among the items<sup>33</sup>.



### *Construct validity*

The ability of the questionnaire to distinguish nurses with different levels of competence was tested by comparing the group of hospital nurses with the group of nurses starting the education program on palliative care. We hypothesized these two groups to be different from each other. Due to the selection criteria and the intensity of this education program, we expected that nurses intending to complete this extensive program would already be more dedicated, more experienced, and more skilled in palliative care in advance of the program, compared to the general hospital nurses.

Similarities and differences between the groups were tested two sided, using ANOVA, Pearsons' Chi square test, and students' *t*- test. Level of significance was set at  $p < .05$ .

### *Responsiveness*

The questionnaire's sensitivity to change was determined by comparing nurses' scores before and after completion of the education program on palliative care. A positive change after the intensive education program was hypothesized.

Similarities and differences between measurements before and after the education program were tested unpaired and two-sided using ANOVA, Pearsons' Chi square test, and students' *t*- test. Level of significance was set at  $p < .05$ .

### *Feasibility*

We tested both a hard copy and a computerized version of the questionnaire; the hard copy was used in the education group and the computerized version in the other group. Based on the time of completion during face validity testing, participants in the education group were given 20 minutes to complete, because we wanted to develop an instrument that does not take too much time. Missing values in parts 2-4 of the completed questionnaires were counted in the education groups and in the hospital sample.

### Human Subjects Protection

Under Dutch law, no specific ethical approval was required for this study because consent was inferred from participation, and the respondents were informed that their answers would be used for research purposes.

## RESULTS

### Content and Face validity

The experts' comments, for example concerning unclear knowledge statements or unclear formulations of items, were used to optimize preliminary versions of the MOVE2PC. If at least one expert had doubts about an item, it was deleted or changed. After three

series of comments only minor textual changes were proposed. Seven oncology nurses who subsequently completed the last adapted version of the questionnaire needed 20 minutes for completion and made 43 remarks on the content concerning formulations, the structure of questions, and the relevance of some items. These remarks were used to further improve comprehensiveness and reduce ambiguity of items.

### Reliability

Using Cohen's Kappa, we found 8 of 58 items with  $\kappa < 0.35 \kappa_{\max}$  (insufficient). After merging the 5- and 6-point scales to 3-point scales, 3 items were deleted because a large proportion of participants changed their response from one extreme of the scale to the other, and wording for 4 items was changed. Of the remaining items, 96% achieved a score of at least  $0.5 \kappa_{\max}$  of which 33% were  $> 0.8 \kappa_{\max}$ . The final questionnaire had a Cronbach's  $\alpha$  of .77. For perceived difficulties, Cronbach's  $\alpha$  was .79 and for knowledge statements it was .65.

### Construct validity

As expected, hospital nurses' characteristics differed significantly from those of nurses in the education group (Table 1). Nurses attending the education program had a higher age, were more experienced as a nurse, and had more often attended advanced courses on palliative care. Of them, 59% were working in a non-hospital setting and 82% spent more than 25% of their time on providing palliative care, in contrast to 18% of the hospital nurses. The two groups responded differently to 5 of the 11 opinion statements, but no differences were found in the subjective norms (Table 2). The hospital nurses perceived 5 of 18 described situations more often as difficult compared with nurses in the education program (Table 3), and the latter more often gave a correct answer to six knowledge items (Table 4). In the sum score for potential difficulties no difference between the groups was found, and of the total 20 knowledge statements, nurses in the education program answered 12.0 (*SD* 2.4) items correctly versus 10.3 (*SD* 3.0) in the hospital group ( $p < .01$ ) (Table 5).

### Responsiveness

Sixty-three nurses completed the questionnaires before and after the education program. Nurses changed their opinion on one item: after the education more nurses thought that life prolonging treatment is usually continued for too long in the hospital (Table 2). After the education program six potentially difficult situations were significantly less often perceived as difficult, whereas one situation was more often perceived as difficult (Table 3). The sum score of situations perceived as difficult decreased significantly from 7.8 (*SD* 2.6) to 6.3 (*SD* 2.5) ( $p < .01$ ) (Table 5). Four knowledge statements were more often assessed correctly after the education program compared with before (Table 4). The sum score of correct answers increased significantly from 12.0 (*SD* 2.4) to 13.7 (*SD* 2.2) ( $p < .01$ ) (Table 5).

**Table 1** General Characteristics of Hospital Nurses and Nurses in the Education Program (N=195)

Characteristics of participants	Hospital n = 119 n (%)	Pre-education n=76 n (%)	Difference Hospital/ Pre-education (p-value) <sup>a</sup>
Gender			.01
female	104 (87)	74 (97)	
Age			< .01
< 30 years	67 (56)	6 (8)	
30-49 years	41 (34)	49 (64)	
≥ 50 years	11 (9)	21(28)	
Status			< .01
Student	7 (6)	-	
Staff nurse	66 (56)	47 (62)	
Nurse specialist	24 (20)	26 (34)	
Senior staff nurse	4 (3)	-	
Nurse coordinator/ manager	13 (11)	-	
Nursing experience			< .01
as student	7 (6)	-	
0-1 year	17 (14)	-	
2-4 year	31 (26)	7 (9)	
5-10 year	29 (24)	22 (29)	
≥ 11 year	35 (29)	47 (62)	
Advanced education on palliative care			< .01
< 1 day	77 (65)	7 (9)	
1-7 days	33 (28)	28 (37)	
8-14 days	4 (3)	11 (15)	
> 14 days	5 (4)	29 (38)	
Percentage of work time = palliative care			< .01
0-25%	97 (82)	14 (18)	
25-50%	18 (15)	17 (22)	
50-75%	4 (3)	18 (24)	
>75%	0	26 (34)	
Setting <sup>b</sup>			< .01
University or general hospital	119 (100)	31 (41)	
Nursing home	-	9 (12)	
Home care	-	19 (25)	
Hospice	-	20 (26)	
Other	-	1 (1)	

<sup>a</sup> t-test or one way ANOVA <sup>b</sup> respondents could answer > 1 institution

Table 2 Opinions and Subjective Norms on Palliative Care of Hospital Nurses and Post- Education Program (N=195)

	Agree with statement				Difference Pre-education / Post-education (p-value) <sup>a</sup>
	Hospital n=119 n (%)	Pre-education n=76 n (%)	Post-education n=63 n (%)	Hospital/ Pre-education (p-value) <sup>a</sup>	
<b>Opinions on palliative care</b>					
1	The aim of palliative care is treatment of pain only.	1 (1)	0	1 (2)	.27
2	Palliative care starts in the last weeks of life.	25 (21)	0	1 (2)	< .01
3	Palliative care and intensive life prolonging treatment can be combined.	50 (42)	45 (59)	45 (71)	< .01
4	Palliative care includes spiritual care.	100 (84)	74 (97)	62 (99)	.01
5	Palliative care includes care for patients' family/ relatives .	116 (98)	76 (100)	63 (100)	n.m.
6	The acute care hospital is an appropriate place to die.	17 (14)	9 (12)	9 (14)	.76
7	To arrange any kind of hospice or terminal care deprives patients of all hope.	7 (6)	4 (5)	0	.64
8	Visits of a relative should be permitted all day.	102 (86)	66 (87)	54 (86)	.35
9	Patients should be clearly informed about imminent death.	97 (82)	48 (63)	38 (60)	.01
10	A patient having a prognosis of only a few days to live should not be transported to home or hospice.	4 (3)	5 (7)	1 (2)	.42
11	Usually life prolonging treatment in the hospital is continued too long	61 (51)	31 (41)	36 (57)	.04
<b>Subjective norms on palliative care</b>					
<b>Vignette: When I am terminally ill and am about to die ...</b>					
1	I wish the nurse would not start a discussion of approaching death with me, but respond only when I initiate it.	16 (13)	7 (9)	3 (5)	.61
2	I do not wish to foresee my death.	10 (8)	1 (2) <sup>b</sup>	1 (2)	.10
3	I prefer that a nurse refers me to a spiritual advisor (e.g. chaplain, vicar, humanistic counselor, imam) or a social worker.	112 (94)	73 (96)	62 (98)	.83
4	I wish to prepare myself and my family and friends.	116 (98)	74 (97)	62 (98)	.39
5	I wish I could die at home.	97 (82)	49 (78) <sup>b</sup>	46 (73)	.82

<sup>a</sup> Pearson Chi-Square test, 2 degrees of freedom

<sup>b</sup> n=63; item changed/ added after pre education measurement of one group of 13 nurses  
n.m. = not measurable

**Table 3** Perceived Difficulties in Palliative Care of Hospital Nurses and Nurses Pre- and Post - Education Program (N=195)

	Based on described vignettes: Do you think the following situations are difficult or not difficult?	Situation perceived as difficult				Difference Hospital / Pre-education Post-education (p-value) <sup>a</sup>	Difference Pre-education / Post-education (p-value) <sup>a</sup>
		Hospital n=119 N (%)	Pre- education n=76 N (%)	Post- education n=63 N (%)	Difference Hospital / Pre-education (p-value) <sup>a</sup>		
Vignette 1: Bad news							
After several diagnostics it has become clear that there are no opportunities for recovery or prolonging life for a patient on your ward. The staff expects the patient's prognosis to be a few weeks only. In the presence of a colleague nurse the physician has discussed this poor prognosis with the patient.							
1	You arrive at patient's room and find him very upset, due to the meeting with the physician.	37 (31)	12 (16)	5 (8)	<.01	.33	
2	After 2 days the patient asks you: "I will get better, won't I?"	71 (60)	39 (51)	20 (32)	.36	.07	
3	The patient feels very sad because he has to say goodbye to his young children soon.	87 (73)	64 (84)	40 (64)	.06	.01	
4	Relatives of the patient are angry at everyone and no one can do well in their opinion.	61 (51)	38 (50)	29 (46)	.38	.82	
5	The patient and his spouse want to talk with you about the end of patient's life.	25 (21)	8 (11)	1 (2)	.02	.05	
Vignette 2: Treatment yes or no?							
A patient on your ward is expected to live no longer than 2-3 weeks							
6	The patient no longer wants any kind of treatment, even when his symptoms can be treated well.	37 (31)	19 (25)	13 (21)	.56	.10	
7	The family definitely does not want the bad prognosis to be discussed with the patient.	106 (89)	69 (91)	48 (76)	.23	.02	
8	The antibiotics prescribed for the patient no longer have any results. You have to stop the medication and remove the syringe driver.	7 (6)	6 (8)	1 (2)	.86	.19	
9	The patient has a cardiac arrest and you have to resuscitate him, because there is no decision on DNR policy.	93 (78)	70 (92)	59 (94)	.08	.70	
10	The patient suffers from severe breathlessness. The attending junior physician does not know how to relieve this suffering, but refuses to consult a senior staff member.	89 (75)	57 (75)	40 (64)	.96	.39	
11	The patient feels very anxious about what will happen and asks you for support.	23 (19)	12 (16)	4 (6)	.75	.01	
12	The physician made the decision to start tube feeding.	45 (38)	40 (53)	45 (71)	.10	.04	
13	The patient becomes delirious and may suddenly become aggressive.	32 (27)	32 (42)	11 (18)	.08	.01	
14	The physician gave directives for several diagnostic procedures.	84 (71)	58 (76)	47 (75)	.63	.72	

**Table 3** Perceived Difficulties in Palliative Care of Hospital Nurses and Nurses Pre- and Post - Education Program (N=195) (continued)

	Based on described vignettes: Do you think the following situations are difficult or not difficult?	Situation perceived as difficult				Difference Hospital / Pre-education (p-value) <sup>a</sup>	Difference Post-education (p-value) <sup>a</sup>
		Hospital n=119 N (%)	Pre-education n=76 N (%)	Post-education n=63 N (%)	Difference Hospital / Pre-education (p-value) <sup>a</sup>		
Vignette 3: Terminal care							
A patient on your ward is in terminal condition and his prognosis is only about 24 -48 hours.							
15	You are assigned to care for this patient and know that he may die at the moment you enter his room.	29 (24)	1 (1)	1 (2)	< .01	.96	
16	The physician has decided to withdraw the patient's tube feeding. You have to remove the tube.	4 (3)	0	1(2)	.05	.09	
17	The family does not agree with the decision to stop the tube feeding.	77 (65)	44 (58)	27 (43)	.62	.14	
18	You have to say goodbye to the patient because palliative sedation has started.	53 (45)	21 (28)	6 (10)	.01	.02	

<sup>a</sup> Pearson Chi-Square test, 2 degrees of freedom

**Table 4** Statements on Knowledge of Symptom Management and Palliative Care of Hospital Nurses and Nurses Pre- and Post - Education Program (N=195)

	Palliative care knowledge statements	True or False (T/F)	Answered correctly				Difference Hospital / Pre-education (p-value) <sup>a</sup>	Difference Post-education (p-value) <sup>a</sup>
			Hospital n=119 N (%)	Pre-education n=76 N (%)	Post-education n=63 N (%)	Difference Hospital / Pre-education (p-value) <sup>a</sup>		
1	The prevalence of constipation in cancer patients in the palliative phase is higher than in patients in the final stage of chronic heart failure.	F	15 (13)	17 (22)	17 (27)	.02	.65	
2	When constipation, caused by opioids (e.g., morphine) has been relieved, laxans can be stopped.	F	115 (97)	76 (100)	63 (100)	.27	n.m.	
3	When artificial hydration is withheld, the patient is likely to have more symptoms in the dying phase.	F	53 (45)	72 (95)	61 (97)	< .01	.80	
4	The prescription of fortifying drinks is almost always worthwhile for patients with a prognosis of 2-3 weeks when they no longer have enough intake of nutrients.	F	69 (58)	58 (76)	56 (89)	.01	.09	

**Table 4** Statements on Knowledge of Symptom Management and Palliative Care of Hospital Nurses and Nurses Pre- and Post - Education Program (N=195) (continued)

Palliative care knowledge statements	True or False (T/F)	Answered correctly				Difference	
		Hospital n=19 N (%)	Pre-education n=76 N (%)	Post-education n=63 N (%)	Hospital / Pre-education (p-value) <sup>a</sup>	Pre-education/ Post-education (p-value) <sup>a</sup>	
5 Pain in the legs in patients with chronic heart failure is best treated by opioids like morphine, when paracetamol is no longer sufficient.	T	30 (25)	16(21)	24 (38)	.11	.06	
6 The prevalence of depression in patients with advanced chronic heart failure is about 60%.	T	39 (33)	24 (32)	36 (60)	.76	<.01	
7 Anxiety and restlessness are more prevalent in the terminal phase of cancer than of other chronic terminal diseases.	F	43 (36)	35 (46)	32 (51)	.35	.20	
8 One of the characteristics of a delirium is that it develops in a short time.	T	104 (87)	59 (77)	56 (89)	.20	.07	
9 When palliative sedation is started, the treatment of pain can be withdrawn.	F	97 (82)	69 (91)	38 (92)	.21	.42	
10 Oxygen is the most appropriate treatment to start with in case of shortness of breath in the terminal phase.	F	39 (33)	39 (51)	43 (68)	.07	.21	
11 Treatment of depression in the terminal phase is not worthwhile.	F	105 (88)	74 (98)	63 (100)	.08	.43	
12 The most appropriate treatment for death rattle is suction of secretion.	F	83 (70)	75 (99)	63 (100)	<.01	.36	
13 Problems of a dry mouth due to reduced saliva production in the palliative phase can be solved by sugar free chewing gum as well as by artificial saliva.	T	24 (20)	23 (30)	36 (57)	.24	<.01	
14 When nausea is a problem in the palliative phase it is appropriate to do an extensive history and monitor daily.	T	61 (51)	53 (70)	46 (73)	.04	.17	
15 The prevalence of pain in advanced chronic heart failure is comparable to that in advanced cancer.	T	22 (19)	8 (11)	10 (16)	.06	0.01	
16 The adherence to prescribed pain medication of patients in pain is quite good.	F	73 (61)	43 (57)	38 (60)	.97	.40	
17 Patients mostly are prescribed too little pain medication.	T	48 (40)	33 (43)	34 (54)	.34	.41	
18 It is important to wait as long as possible to start strong pain medication, to save this for worsening pain.	F	99 (83)	65 (86)	60 (95)	.16	.35	
19 Vivid dreams might be a signal of a delirium.	T	84 (71)	53 (70)	56 (89)	.90	<.01	
20 A patient in the last phase of life always has the right to receive 24 hours per day homecare.	F	21 (18)	20 (26)	11 (18)	.27	.15	

<sup>a</sup> Pearson Chi-Square test, 2 degrees of freedom

**Table 5** Sum Score of Perceived Difficulties and Correct Answers to Knowledge Statements of Hospital Nurses and Nurses Pre- and Post - Education (N=195)

	Hospital <i>n</i> =119 Mean (SD)	Pre-education <i>n</i> =76 Mean (SD)	Post- education <i>n</i> =63 Mean (SD)	Difference Hospital / Pre-education ( <i>p</i> -value) <sup>a</sup>	Difference Pre-education / Post-education ( <i>p</i> -value) <sup>a</sup>
<b>Perceived difficulties on palliative care</b>					
Answer "difficult" in total of all 18 described situations <sup>b</sup> .	8.1 (3.0)	7.8 (2.6)	6.3 (2.5)	.47	< .01
<b>Knowledge statements on palliative care</b>					
Correct answers on total of all 20 statements <sup>b</sup> .	10.3 (3.0)	12.0 (2.4)	13.7 (2.2)	< .01	< .01

<sup>a</sup> Students' t-test

<sup>b</sup> All items given the same weight. The 18 items on perceived difficulties were combined by ranking the answer "difficult" as 1 and others as 0. The 20 knowledge statements were combined by ranking the correct answer as 1 and others as 0.

## Feasibility

Nurses in the education group filled in the paper version twice (before and after the program); at both times they finished it within 20 minutes (*N*=139). Seventy percent fully completed all parts, 23% missed one or two items, and one missed more than five items. Of the 119 hospital nurses, 90% fully completed all parts, 8% missed one or two items, and one had more than five missing items.

## DISCUSSION

To minimize the risk of measurement error of this self-administered questionnaire, six measurement properties were evaluated, using a sample of 223 professionals that included experts on palliative care, experts on education, and nurses of the target population. We tested all items for relevance, and the content validity, face validity, consistency, and construct validity of the instrument<sup>34,35</sup>. The Rotterdam MOVE2PC questionnaire proved to be a valid instrument for assessing nurses' knowledge, opinions, subjective norms, and perceived difficulties related to palliative care, and for measuring the effects of an education program on palliative care.

Criteria on sample size were met according to the COSMIN checklist, which is at this moment the best available checklist to evaluate the methodological quality of studies on measurement properties in a standardized way. This checklist, based on expert opinions and extensive validation considers a sample size of > 50 as good and > 100 as excellent. A factor analysis could not be performed because this would have required a sample size of five to seven times the number of items<sup>30</sup>.



Tests of reproducibility and internal consistency of the questionnaire demonstrated its reliability. An important assumption when using Kappa to test for reproducibility is that errors in rating occur independently<sup>32</sup>. To maximize independence we used an interval of 2 to 4 weeks to avoid nurses recalling their previous answers, based on the recommendations of Steiner and Norman (2003). Because Kappa will be reduced by chance agreement, e.g., due to high or low prevalence of certain answers, the interpretation of the magnitude of Kappa was reported as the Kappa  $\kappa_{\max}$ , reflecting the maximum extent of the ability to agree<sup>32</sup>. Almost all items showed an agreement of  $\kappa > 0.5 \kappa_{\max}$ , of which 33% were  $> 0.8 \kappa_{\max}$ , indicating moderate to very good agreement in the test-retest analysis<sup>36,37</sup>.

For internal consistency, Cronbach's alpha coefficient was acceptable, with values between .70 and .90<sup>31</sup>. The internal consistency of the total questionnaire as well as of the separate parts was good and comparable with other instruments, such as the C-PCQN (.71) and the PCKT (.81)<sup>13,25</sup>. The magnitude of the Cronbach's alpha coefficient is not solely influenced by homogeneity of the items, but also by the number of items and their multidimensionality<sup>31</sup>. The MOVE2PC contains multiple dimensions (e.g., knowledge and opinions) that together form a construct, and therefore, as expected, the alpha remained standing when individual items were deleted<sup>34,35</sup>.

The MOVE2PC showed good construct validity and responsiveness. The scores for the questionnaire varied in the anticipated direction between hospital nurses and nurses attending an education program, as expected due to more experience and previously derived knowledge in the education group.

Within the group of hospital nurses the sum scores of correctly answered knowledge statements and perceived difficult situations showed more variation compared to the education group (*SD* 3.0 vs 2.4 and 3.0 vs 2.6, respectively). This might be explained by the larger variation in age, experience, and involvement in palliative care of the hospital nurses, but the impact of these determinants should be investigated in a larger sample. The MOVE2PC nevertheless resulted in a 2-point difference in correctly answered knowledge statements between the hospital group and education group.

After the education program, nurses had an increased level of knowledge and perceived fewer situations as being difficult. This shows that the questionnaire is sufficiently sensitive to detect change. With a standard deviation of 2.2 in the sum score of correctly answered knowledge statements, the results show decreased variation between nurses after the education program, while the instrument still distinguished high and very high levels of knowledge.

Unfortunately, there is no gold standard against which to compare these findings, thus whether this is an adequate level of knowledge cannot be determined until norms are developed.

We detected only one change in opinions and no change in subjective norms. This might be due to common and strong norms related to end-of-life care among nurses,

norms which are not easily changed. These opinions and norms might predict practice and decision-making in nursing, e.g., with regard to referring patients to a spiritual advisor or social worker, and communication with patients and relatives. To confirm this hypothesis, further research is needed.

Finally the questionnaire was shown to be feasible, even though it contains 63 items. Participants managed to complete the paper version in 20 minutes, and only 1% of the respondents missed more than 5 items.

Though the MOVE2PC was developed for use in the Netherlands, the items assessed in the MOVE2PC are of relevance for nurses throughout the world. According to the WHO palliative care requires an integrative approach of prevention, early identification of physical, psychosocial and spiritual problems, and care of both the patient and his relatives in all health care settings<sup>38</sup>. The position and role of nurses as health care professionals throughout the world provide them with the opportunity of having intensive contact with patients and relatives, to assess what is happening and what is important to them, and to assist them in coping with advanced disease<sup>39</sup>. Nurses everywhere get confronted with the complexity of palliative care too, e.g., with severe suffering of patients, ethical problems, and difficulties in communication with patients, relatives and other health care professionals<sup>45</sup>Espinosa, Young & Walsh,<sup>6</sup>. The MOVE2PC assessment of perceived difficulties is therefore expected to be applicable in many other countries. In addition, opinions and knowledge statements in the MOVE2PC are based on Dutch guidelines on palliative care, which are in turn based on WHO<sup>40</sup>. Specific items, such as the item on organization of palliative care, might need a country specific answer, and if the MOVE2PC is translated into other languages and used in other countries, validation would be needed.

### Limitations

For this validation study, some methodological considerations should be taken into account. We did not use a validated inter-rater agreement index, such as the content validity index (CVI), to structure the evaluation by the experts of the content of the first version of the questionnaire<sup>41</sup>. Instead, we used a strong but slightly less transparent method of improvement by first using the verbal comments of three experts. Thereafter, twice two new experts successively assessed improved versions of the questionnaire. Another limitation may be that we tested the hard copy in one group and the computerized version in the other group, which might have influenced the results. This might also explain the differences in levels of completion between groups (70% in hardcopy vs 90% in the computerized version). Although the questionnaire was sensitive to change over time, this was tested in only 76 nurses. Further testing in larger samples is needed to confirm results.

## CONCLUSION

The Rotterdam MOVE2PC questionnaire assesses nurses' knowledge, opinions, subjective norms, and perceived difficulties related to providing palliative care. This questionnaire is particularly appropriate for studying the competence and educational needs of general nurses providing palliative care to various patients, and for evaluating education programs aimed at improving nurses' knowledge and competence in palliative end-of-life care. It proved to be an instrument with good feasibility, validity, reliability, and responsiveness, which is expected to be relevant for nurses throughout the world.

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# 3

## Improving the quality of Palliative and Terminal Care in the Hospital by a network of palliative care nurse champions: the study protocol of the PalTeC-H project.

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## ABSTRACT

### Background

The quality of care of patients dying in the hospital is often judged as insufficient. This article describes the protocol of a study to assess the quality of care of the dying patient and the contribution of an educational and networking programme for staff nurses assigned to be palliative care nurse champions on inpatient wards of a large university hospital in the Netherlands.

### Design

We designed a controlled before and after study. Assessments are performed among bereaved relatives, nurses and physicians on seven wards before and after introduction of the intervention and on 11 control wards where the intervention is not applied. We focus on care provided during the last three days of life, covered in global ratings of the quality of life in the last three days of life and the quality of dying, and various secondary endpoints of treatment and care affecting quality of life and dying.

### Discussion

With this study we will improve the understanding of and attention for patients' needs, and the quality of care in the dying phase in the hospital and measure the impact of a quality improvement intervention targeted at nurses.



## BACKGROUND

Providing end-of-life care in a hospital is challenging, because hospital care is typically focussed on prolonging life. Several studies have described the unmet needs of patients dying in hospitals, such as poor symptom control and insufficient communication<sup>1-5</sup>. Gaps in end-of-life care have been identified, e.g. the lack of awareness of approaching death and shortcomings in healthcare professionals' knowledge of and skills in palliative care<sup>1-6</sup>. To date research on end-of-life care in hospitals has been mainly descriptive, focussing on the characteristics of care, identifying problems and suggesting possibilities for improvement. In a literature review, Al-Qurainy et al (2009) proposed improvement strategies: integration of palliative care services in the hospital to enhance caregivers' attention for the transition of treatment goals<sup>7</sup>; increase of palliative care knowledge among healthcare professionals; and improvement of prognostication, advanced care planning and communication. However, experimental studies on quality improvement interventions in end-of-life care in the hospital are scarce, partly due to methodological challenges in health services research in general and in the field of palliative care in particular. Many results of studies on quality improvement interventions are thus affected by concerns about the validity and reliability of data, due to e.g. limitations of the design, selection bias, inaccurate measurements and confounding<sup>6, 8-12</sup>. To evaluate the effects of changes in palliative care structures and processes on patient outcomes, innovative experimental research is needed<sup>6, 13-19</sup>.

In the Netherlands most in-hospital deaths occur on wards that lack specific palliative care expertise. Innovations to improve the quality of end-of-life care in the hospital have to be disseminated to all these wards and to be integrated in the whole hospital care system<sup>7</sup>. This process of quality improvement seems to be comparable to innovations in other fields of hospital health care, such as infection prevention, and tissue and wound care. To address these problems, networks of specialized nurses, such as infection control link nurses have been implemented in many hospitals. Only few studies have evaluated the effects of these link nurses' networks, but the results were promising<sup>20-22</sup>. Some work has been done on networks of palliative care nurse champions in the UK<sup>23,24</sup>. In the Netherlands a few hospitals have recently started such a network. The empowerment of hospital nurses in being an ambassador of palliative and end-of-life care and in the dissemination of palliative care knowledge and skills could contribute to the quality of care of patients dying in the hospital<sup>25-27</sup>. However, rigorous evaluation of the effects on the outcome of care is necessary. In this article we describe the study protocol of the PalTeC-H project: a study on understanding and improving Palliative and Terminal Care in the Hospital.

## METHODS AND DESIGN

### Objectives

Objectives of this study are (1) to explore and understand the impact of the quality of care on the quality of life at the end of life and the quality of dying in a hospital and (2) to investigate the contribution of a quality improvement intervention which consists of the implementation of a network of palliative care nurse champions. We define end-of-life care as care provided during the last three days of life (at most). We hypothesize the implementation of the network to result in more attention for palliative care, in improved and timely recognition of patients' palliative care needs, in more involvement of palliative care experts and, eventually, in improved quality of life during the last three days of life, improved quality of dying and increased satisfaction of bereaved relatives.

### The intervention

The intervention is a change in the organizational structure, targeted at nurses, which indirectly affects care by three main components: education, knowledge dissemination and support, plus several organizational elements (table 1). On intervention wards two staff nurses are appointed to be palliative care nurse champions – further referred to as champions. Together they form a palliative care network coordinated by the multidisciplinary consultation team for pain and palliative care. They participate in monthly educational meetings of the network and in a targeted education programme of two days annually. The education programme includes palliative care knowledge and skills as well as organizational knowledge and skills, e.g. on planning dissemination of knowledge, in order to teach the champions to be an ambassador of palliative care on the wards. Champions need to identify gaps in knowledge on and quality of palliative care on their ward and to raise health care givers' awareness on patients' palliative care needs. They have to organize educational activities, implement protocols on palliative and terminal care, and evaluate these activities at the end of each year. A senior nurse consultant, member of the multidisciplinary consultation team, is assigned to be the network coordinator, supported by the medical oncologist of the team. This network coordinator organizes the meetings and education programmes and supports champions individually in developing plans and performing activities.

Assuming that 14 champions each spend eight hours per month on network activities, and that the coordinator spends 24 hours per month, the intervention costs are estimated at € 50.000 per year.

**Table 1** The intervention

Phase	Activities	Method
Preparation	Ward selection	Registration multidisciplinary consultation team Literature review Consent of 7 ward managers
	Organization	Selection of 14 palliative care nurse champions Appointment of a coordinator Development and planning network and education programme
Introduction and follow-up	Composition network	Contact coordinator, ward manager and nurse champions on intervention wards
	Meetings	Every month 90 minutes (9 meetings per year)
	Education	Targeted education programme 2 days yearly and at every network meeting
	Mission/ champions' activities	Dissemination of knowledge Planned activities on each ward Promotion of consulting multidisciplinary consultation team on pain and palliative care Implementation of problem based care pathways or protocols on wards
	Support	Coaching nurse champions in plans and activities Information in organizational journal, information in newsletters Discuss compliance with unit managers

## Study population

All wards in a large general university hospital in the Netherlands participate in this study, including a specialized unit for palliative cancer care, but excluding the department of psychiatry and the Intensive Care departments.

We collect data on adult patients who died at one of the 18 participating wards after having been admitted at least 6 hours prior to death.

## Design

We designed a controlled before and after study with three phases: 1) pre-intervention phase (16 months); 2) phase in which the intervention is introduced (5 months); and 3) post-intervention phase (16 months). The intervention, i.e the appointment of two champions joining the network, is introduced in seven wards that regularly admit cancer patients or patients with other chronic and life threatening diseases, such as chronic cardiac diseases and COPD. Although there is not much evidence on the time needed to effectively disseminate expertise and knowledge into clinical practice (25-27), we decided that the introduction phase lasts five months, as a run-up period(13). In the 11 wards where the intervention is not introduced, the same measurements are performed to control for changes that are not due to the intervention, for example changes in hospital policy (table 2). These control wards are expected to have a similar number of deaths as the intervention wards.

**Table 2** Participating wards

Intervention group	Control group
Cardiology	Haematology
Ear Nose Throat surgery	Internal medicine - gastro intestinal diseases
Gastro-intestinal surgery	Internal medicine – renal diseases
Gynaecology and urology	Neurology
Internal medicine – infectious diseases and endocrinology	Neurosurgery and brain surgery
Lung diseases	Liver and kidney transplant and vascular surgery
Medical oncology and geriatrics	Orthopaedics
	Plastic surgery and dermatology
	Medical Oncology - palliative care
	Trauma surgery
	Thorax surgery

## Endpoints

Primary endpoints to reflect the outcomes of care of the dying are global assessments of patients' quality of life during the last three days of life and patients' quality of dying on a 0-10 numeric rating scale, comparable to the global ratings in the Quality of Dying and Death questionnaire<sup>28</sup>. The quality of dying has been suggested to encompass seven domains: physical, psychological, social and spiritual experiences, the nature of health care, life closure and death preparation, and the circumstances of death<sup>29</sup>. Secondary endpoints therefore include symptoms, recognition of approaching death, satisfaction of bereaved relatives with health care (e.g. communication, decision making and care) and presence of relatives at the moment of death. Changes in the process of care, such as nursing interventions, treatment goals and the number of referrals to the multidisciplinary consultation team are also secondary endpoints (table 3). In addition, we assess champion nurses' knowledge on palliative care before and after the intervention and monitor the developing process of the network.

## DATA COLLECTION

On every participating ward, one or two nurses are assigned to distribute questionnaires to a nurse and a physician involved in each dying patient's care, within one week after the patient has deceased. Completed questionnaires are sent to the principal investigator (FEW). Three months after a patients' death a relative is sent a written invitation to complete a questionnaire. In case of non-response this invitation is resent after one month. Data on patient and care characteristics such as diagnosis and do not resuscitate agreements are derived from the patient record, when not available from physicians.

**Table 3** Endpoints

QUALITY OF LIFE DURING THE LAST 3 DAYS OF LIFE AND QUALITY OF DYING	PROCESS OF CARE	SATISFACTION WITH HEALTH CARE IN THE LAST 3 DAYS OF LIFE
<i>Quality of life</i> : Perceptions by relatives and health care providers of quality of life during last 3 days of life: Global rate (0-10) Physical comfort Psychological well-being Social functioning and well-being Spiritual well-being, being in peace  <i>Quality of dying of patient</i> Perceptions by family and health care providers of quality of dying of patient: Global rate (0-10) Life closure and death preparation Circumstances of death  <i>Quality of life of family</i> Health status Grief resolution	<i>Technical process</i> Appropriate use of nursing interventions Changes in treatment policy / NTBR Symptom management Recognition of imminent death Referrals to multidisciplinary consultation team	<i>Patient satisfaction with care:</i> Perceptions by relatives: Preferences honoured regarding way of dying Satisfaction with: - technical process - decision making process - interpersonal and communication style  <i>Relatives' satisfaction with care</i> Satisfaction with: - technical process - decision making process - timeliness and usefulness of information and counselling - interpersonal and communication style - extent to which patient/ family preferences honoured - extent to which opportunities provided to patient to complete life meaningfully - present at patients' death

Derived and adapted from Stewart et al (1999) Conceptual model of factors affecting quality and length of life of dying patients and their families

We use three different questionnaires: for physicians (35 items), nurses (55 items) and bereaved relatives (94 items). The questionnaires were developed by a group of experts and criticized by a representative of the hospital patients' council. Then they were tested on relevance and face validity among members of all targeted groups, and piloted in the first 30 cases. Bereaved relatives are asked to answer questions as patients' proxy and as unit of care themselves.

Champions' knowledge and opinions are assessed using the Rotterdam MOVE2PC questionnaire, developed and validated for use among general nurses by our research team (publication in manuscript; FEW, LZ, CR, AH). The network process is investigated by counting the champions' presence at network meetings and education programmes, assessing their activities on the wards, and assessing the coaching activities of the coordinator.

### Data analysis

To address the first objective, i.e. to explore and understand the impact of the quality of care on the quality of life at the end of life and the quality of dying in the hospital, we will analyze primary and secondary endpoints, their interrelatedness, and possible

determinants. We will use data from all participating wards during the pre-intervention phase and the intervention-introduction phase (21 months). To address the second objective, i.e. to investigate the influence of the network of nurse champions, we will compare primary and secondary endpoints between the pre- and post-intervention phase (2 x 16 months). Significant changes in the intervention group that are not found in the control group will be interpreted as differences due to the intervention. To measure a difference of one unit on a 0-10 numeric rating scale for global quality of life during the last three days and global quality of dying between the pre-intervention and post-intervention measurement (phase 1 and phase 3), with an assumed standard deviation of 2.5, we need data on 400 patients: 100 patients before as well as after the intervention on both the intervention and the control wards (Lehr's formula  $16 / (1/2.5)^2 = 100$ )<sup>30</sup>. Expecting a participation rate of 50% among nurses, physicians and relatives we aim to include 400 cases in the pre-intervention phase and 400 in the post-intervention phase. Data will be analyzed using descriptive analyses, univariate and multivariate regression analyses, t-tests, ANOVA and Chi square tests.

### Ethical considerations

Approval for this study was given by the Medical Ethical Research Committee of the Erasmus MC. The intervention was assigned to seven wards and randomisation of individual patients was not needed. According to the Dutch legislation informed consent was not required because data is gathered after patients' death and the study involves no more than minimal risk to the participants.

## DISCUSSION

### Measurement of quality of end-of-life care

The multidimensionality and evolution of care at the end of life have been subject of many studies in the last decades<sup>17,19,31-35</sup>. Quality of life, quality of dying and quality of care are overlapping constructs but can be distinguished<sup>29-36</sup>. Quality of life (at the end of life) involves physical, psychological, social and spiritual experiences, and quality of dying additionally includes the domains of nature of health care, life closure and death preparation, and the circumstances of death<sup>29</sup>. Quality of care at the end of life addresses the extent to which these domains are affected by health care.

We study the quality of care of dying patients and their families, as suggested by Stewart et al (1999). Stewart's model suggests that health care structures and processes, such as organization, physical environment, communication and decision making, as well as individual patient factors, e.g. diagnosis, psychological characteristics and religious background, determine the quality of dying. According to this model we study to which extent

the structure and process of care and patient factors affect the quality of life during the last days of life and quality of dying in the hospital<sup>29,31</sup>.

In consequence of the uncertainty of prognostication, ethical concerns and methodological considerations of prospective measurement in dying patients<sup>37,38</sup>, we perform retrospective assessments. We invite relatives to participate 3-4 months after the patient's death and incorporate overlap in items asked to relatives and healthcare providers, to address potential recall bias and differences in the reporting of subjective states, such as pain and anxiety, between patients, relatives and healthcare providers<sup>19,39</sup>.

A literature search for instruments investigating different aspects of end-of-life care showed that quality of life instruments do not capture experiences unique to the dying process and focus on physical domains mainly<sup>36,40,41</sup>. In 2008 and 2010, reviews were published on quality of life instruments for use in palliative care<sup>40</sup>, quality of dying instruments<sup>42</sup> and instruments for the assessment of care of the dying<sup>41</sup>, respectively. It was concluded that the QODD, a measure of Quality of Dying and Death developed by Curtis et al (2002) is the best tested measure of quality of dying to date, although the developers themselves judged it to be suboptimal<sup>28,43</sup>. The QODD did not meet our goals precisely, because of e.g. the extent of assessing symptoms at the end of life (two physical symptoms only) and the timeframe of reference (one week to one month before death). In addition, it has not been used as a self-completion questionnaire by relatives<sup>41</sup>. More recently Mayland (2011) published on the ECHO-D questionnaire (Evaluating Care and Health Outcomes – for the Dying), developed to evaluate the impact of the Liverpool Care Pathway for the Dying Patient among bereaved relatives<sup>44</sup>. We specifically aim to investigate preferences and experiences in the last three days of life, the inter-relationship of the different domains of quality of life during the last days of life and quality of dying, and their association with bereaved relatives' overall satisfaction with the quality of care<sup>19,42,45</sup>. Therefore, we developed three new questionnaires, taking into account the content of previous questionnaires, to include the perspectives of relatives and health care providers.

### Evaluation of the intervention

According to the Medical Research Council (MRC) Framework for Development and Evaluation of RCT's for Complex Interventions to improve health, the intervention with a network of champions is complex<sup>13,46</sup>. Many ingredients contribute to the effects, such as the individual champions' knowledge and skills and interdisciplinary collaboration, and "it is not easy precisely to define the "active ingredients" of the intervention"<sup>46</sup>. The performance depends on the activities of the champions in the context of their ward, and the "dose" to which professionals and patients are exposed to the intervention may differ among the wards. A principal element of the intervention is the transfer of knowledge. Knowledge transfer is an interpersonal and cognitive process that can promote change

strategies and the utilization of this knowledge<sup>25,26</sup>. Coaching the champions to adapt various approaches for the implementation of their newly acquired knowledge is an important tool in our study, in consequence of the need for simultaneous strategies in health care innovations<sup>27</sup>. To date reported effects of champions' networks are limited to increased knowledge and confidence of the champions themselves<sup>10,23,47,48</sup>. This study will add information on changes in health carers' behaviour and eventually on the impact on the quality of life at the end of life, the quality of dying and proxies' satisfaction with care.

## CONCLUSION

This study will improve the understanding of and attention for patients' needs, and the quality of care in the dying phase in the hospital. To our knowledge no studies have investigated this topic to the same extent, from the perspective of both healthcare providers and relatives, or measured the effects of an intervention with nurse champions on the quality of care at the end of life.

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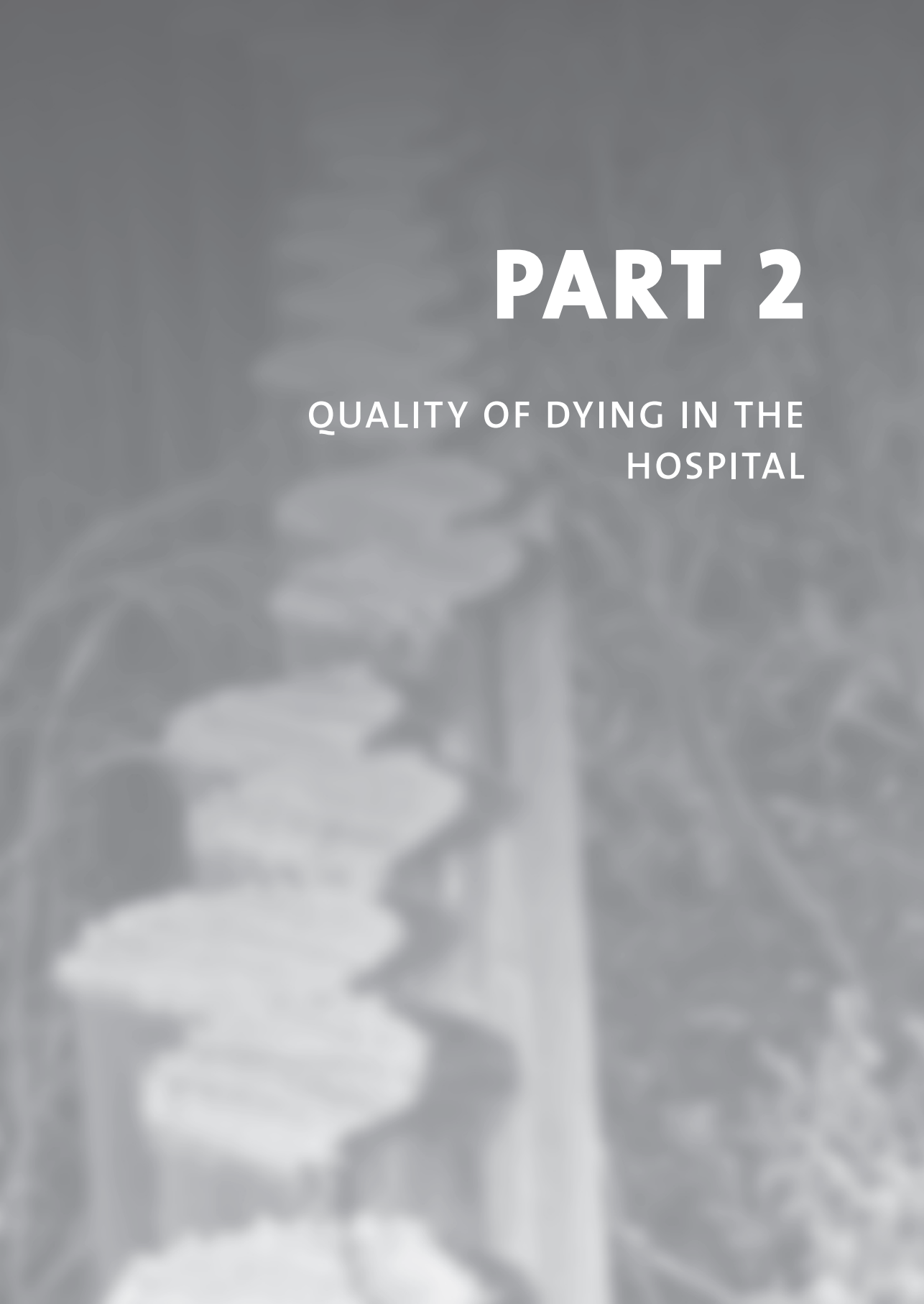
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# PART 2

## QUALITY OF DYING IN THE HOSPITAL





# 4

## 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)

### Objective

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 admission of more than six hours, from June 2009 to March 2011. Relatives' perception 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%. Further, 39% of patients and 50% of relatives had said goodbye, and 77% of patients died in presence of a relative. Symptoms 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 on imminent death and relatives experienced many problems. QOD appears to be a multidimensional construct, strongly affected by medical care and staff attentiveness.



## INTRODUCTION

In most western countries, over 50% of deaths occur in hospital<sup>1,2</sup>. Some studies have reported on the satisfaction of healthcare professionals and relatives with end-of-life (EOL) care in the hospital,<sup>3,4</sup> others have found deficiencies and unmet needs of patients and relatives.<sup>5-14</sup> 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.<sup>5-14</sup>

Research on the quality of dying (QOD) in hospitals involves conceptual, methodological and ethical difficulties.<sup>15-22</sup> As a result, studies strongly differ in their conceptualization of QOD (e.g. with respect to the constituent factors and the timeframe), research methodology (e.g. epidemiological surveys, in-depth interviews), the populations studied (e.g., cancer patients, elderly, intensive care patients), and 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 end of life.<sup>21</sup> Another study showed that health care structures and processes can influence QOD experiences, in addition to patient-related factors.<sup>23</sup> Still little is known about patients' and relatives' experiences at the very end of life in hospital, and factors explaining these experiences.<sup>21</sup> 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 experience of QOD.<sup>21</sup> 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 is part of a larger study to explore and understand palliative and terminal care in the hospital (PaTeC-H), which also involved physicians and nurses. More detailed information on the rationale and the study protocol has been published elsewhere.<sup>24</sup>

### 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

at one of 18 wards in this hospital after an admission of at least 6 hours were eligible for the study. Because in the Netherlands most in-hospital deaths occur on regular wards where 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, who 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 thirteen weeks after the patient died, the primary investigator (FEW) invited a relative to complete a questionnaire. In case of no response after four weeks, one reminder was sent. Participants could also ask the investigator to complete the questionnaire in an interview, e.g. in case 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' death and the study involves minimal risk to the participants. In case of emotional distress due to 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.<sup>25,26</sup> 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.<sup>21</sup> We added specific items on relatives' satisfaction with EOL care.<sup>23,27</sup> We included relevant items of the Views Of Informal Carers Evaluation of Services questionnaire (VOICES), the Leiden Detachment Scale (LSD), and the Quality of Dying and Death (QODD) questionnaire.<sup>27-29</sup> Preliminary versions of the questionnaire were criticized by a representative of the hospital patient council, tested on relevance and face validity among persons who had recently lost a relative, and piloted in the first 30 cases. The final version of the questionnaire comprised 93 items, including 1 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 8 psychological symptoms (i.e. anxiety, loneliness, dependency, tenseness, worrying, sadness, feelings of powerlessness, depressed mood).

We used various scales, mostly gradually ascending, to give room for nuance, e.g. 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 to hospital EOL care.

### Data-analysis

All three and four point variables were recoded into dichotomous variables; yes vs. more or less/no, and none/mild vs. moderate/severe, to summarize the findings. The association between QOD scores and characteristics of care was analyzed in a six step procedure: 1) Linear regression analyses, to test the relation of variables to the overall QOD score, while controlling for case characteristics; 2) Selection of variables that were statistically significantly related to the QOD score with a p-value < 0.10; 3) Principal Component Analyses of selected variables, to identify domains of the factors related to the QOD; 4) Multiple imputation of missing values; we followed the formal adjustments of 'multiple imputation, then deletion',<sup>30</sup> and set the number of replications at 22, being the highest percentage of missing values. Seventeen cases (3%) were deleted afterwards due to a missing score on the outcome variable; 5) Multivariate regression analysis, to analyse the association between domains and QOD scores; and 6) Multivariate regression analysis combining all domains, by forced entry of pooled parameters of each domain. Analyses were performed using SPSS 20.

## RESULTS

During the study period, 524 cases were eligible for inclusion. Of these 524 cases, relatives of 32 patients (6%) could not be traced; in two cases healthcare staff had objections against asking the relative to participate. Two hundred forty-nine relatives responded (response rate 51%). One participant requested a face-to-face interview to fill out the questionnaire.

The mean time from the patient's death until completion of the questionnaire was 15.5 weeks (sd 3.4; range 10-31 weeks). No differences between responders and non-responders were found for patients' gender, age, duration of last admission and ward of last admission. Fifty nine of the 241 nonparticipating relatives reported to have objections against participation in this study ( $n=30$ ), to have emotional problems ( $n=19$ ) or to have other reasons for not responding ( $n=10$ ).

## Characteristics of patients and relatives

Mean age of the patients was 69 years (SD 14), and most patients were male (57%; table 1). Fifty-nine per cent had lived in partnership until the last admission, and 78% had children.

**Table 1** Characteristics of deceased patients and relatives

Patients		Total (n=249) n <sup>a</sup>	%	Median/ min-max
Age	Mean (SD)	68.6 (13.9)		70/ 26-95
Gender	Male	142	57	
<i>Marital status</i>	Married / living with a partner	146	59	
	Widowed / Divorced / Living alone / Other	102	41	
Children	One or more children < 19 years	21	8	
	Only children ≥ 19 years	173	70	
	No	50	20	
Education	Low (ISCED level 1-2)	78	31	
	Intermediate (ISCED 3-4)	90	36	
	High (ISCED 5-6)	48	19	
	Other/ unknown	33	13	
Religious	Yes	115	48	
Diagnosis <sup>b</sup>	Cancer	123	49	
	Non-cancer	126	51	
Duration of severe illness	≤ 6 months	101	41	
	> 6 months	144	58	
Wards	Non-surgical wards	191	77	
	Surgical wards	58	23	
Relatives involved in informal care, last 24 hrs	0 relatives	9	4	
	1 relative	39	16	
	2 relatives	85	34	
	3 relatives	78	31	
	> 3 relatives	38	15	
Duration last admission	Mean (SD)	15.0 (21.3)		8/ 0-146
<b>Relatives</b>				
Age	Mean (SD)	55.6 (12.9)		55/ 20-89
Gender	Female	159	64	
Relation	Partner / spouse	105	42	
	Child (in law)	93	37	
	Other	51	21	

ISCED=International Standard Classification of Education. Variables related to QOD score in the univariate analysis are given in italics.

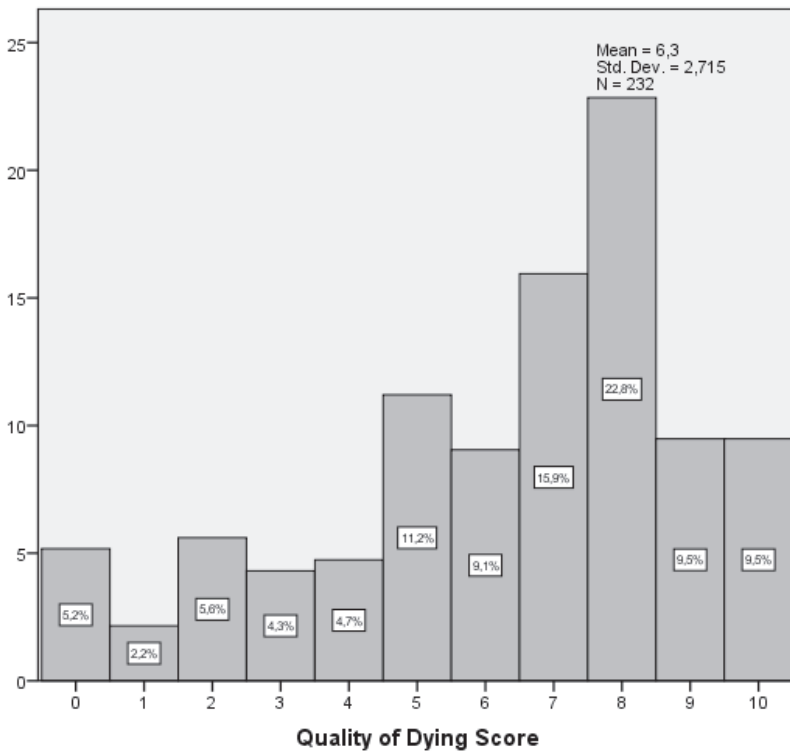
<sup>a</sup> n may not add up to the total because of missing values

<sup>b</sup> derived from patient records

Of all patients, 48% were religious, of whom the large majority were Christian. Half of the patients were diagnosed with cancer. According to the relatives, 59% of the patients had been severely ill for more than six months, whereas 15% had been severely ill for less than one month. Most patients died on a non-surgical ward (77%); the mean final in-hospital stay was 15 days (SD 21); 20% died within two days of admission. Most patients (65%) had two or three family members involved in informal care during the last 24 hours. The relatives participating in the study had a mean age of 56 years (SD 13) and 94% reported to be in moderate to (very) good health. Most of them were female (64%), and were the patient's spouse (42%) or child (in law) (37%). In 88% of the cases, they had been involved in informal care of the patient during the last 24 hours.

**Quality of dying**

The mean overall quality of dying (QOD) score was 6.3 (SD 2.7; range 0-10; fig.1).



**Fig. 1** Distribution of QOD scores

**Table 2** Physical, psychological, social and spiritual experiences: Prevalence in the last 24 hours before death (N=249)

<b>Physical Symptoms</b>	<b>Moderate - Severe n %</b>	<b>None- Mild n %</b>	<b>Don't know n %</b>	<b>Missing n %</b>
<i>Pain</i>	92 37	76 31	47 19	34 14
Dyspnea	113 45	72 29	24 10	40 16
Coughing	64 26	113 45	26 10	46 19
Death rattle	89 36	90 36	26 10	44 18
<i>Difficulty sleeping</i>	57 23	99 40	45 18	48 19
<i>Fatigue</i>	115 46	48 19	46 19	40 16
<i>Dry mouth</i>	128 51	38 15	44 18	39 16
Lack of appetite	105 42	36 15	55 22	53 21
<i>Nausea</i>	39 16	83 33	73 29	54 22
Swallowing problems	97 39	56 23	46 19	50 20
Constipation	63 25	55 22	82 33	49 20
Decreased consciousness	120 48	71 29	17 7	41 17
Confusion	74 30	84 34	43 17	48 19
<i>Agitation</i>	95 38	76 31	32 13	49 20
<b>Total number of physical symptoms, mean (SD)</b>	5.0 (3.9)			
<b>Psychological Symptoms</b>				
<i>Anxiety</i>	69 28	60 24	71 29	49 20
<i>Loneliness</i>	39 16	76 31	84 34	50 20
Dependency	54 22	85 34	58 23	52 21
<i>Tense ness</i>	56 23	68 27	72 29	53 21
Worrying	65 26	58 23	76 31	50 20
<i>Sadness</i>	75 30	54 22	72 29	48 19
<i>Feelings of powerlessness</i>	81 33	47 19	70 28	50 20
Depressed mood	52 21	54 22	92 37	51 21
<b>Total number of psychological symptoms, mean (SD)</b>	2.0 (2.6)			
<b>Total number of physical and psychological symptoms, mean (SD)</b>	7.0 (5.8)			
<b>Social and spiritual experiences</b>	<b>Yes n %</b>	<b>No n %</b>	<b>Don't know n %</b>	<b>Missing n %</b>
<i>Patient was at peace with imminent death</i>	93 37	51 21	7 39	8 3
Patient had practical problems during last days of life (e.g. on finances or care for family)	43 17	187 75	15 6	4 2
Patient needed relatives' attendance or support	140 56	46 19	57 23	6 2
Need of attendance or support was fulfilled	133 53	6 2	15 6	95 40

No = no and more or less / sometimes .

Variables related to QOD score in the univariate analysis are given in italics, adjusted for patient marital status and relative age

**Table 3** Life closure / death preparation and circumstances of death (*n*=249)

<b>Patients</b>	<b><i>n</i><sup>a</sup></b>	<b>%</b>
<i>Patient had discussed preferences for medical treatment at EOL</i>		
Yes	129	52
No	110	44
<i>Patient had discussed preferences for medical treatment at the EOL with a physician</i>		
Yes	77	31
No	172	69
<i>Patient had discussed preferences for place of death</i>		
Yes, preference for hospital	16	6
Yes, other preference	61	25
No, not discussed	159	64
Don't know	7	3
<i>Patient was aware of imminent death</i>		
Yes	65	26
No	135	54
Don't know	43	17
<i>Patient was able to say goodbye</i>		
Yes	96	39
No	132	53
Don't know	16	6
<i>Relative was aware of imminent death</i>		
Yes	121	49
No	119	48
Don't know	4	2
<i>Relative was informed of imminent death</i>		
Yes	160	64
No	81	33
Don't know	0	0
<i>Relative said goodbye to patient</i>		
Yes	125	50
No	121	49
Don't know	0	0
<i>Relative was present at moment of death</i>		
Yes	190	77
No	57	23
<i>In hindsight, the hospital was right place of death</i>		
Yes	131	53
No	98	39
Don't know	11	4
<i>Sufficient attention for preferred rituals at moment of death</i>		
Yes	110	44
No	23	9
Don't know	73	29

No = no and more or less / sometimes .

Variables related to QOD score in the univariate analysis are given in italics, adjusted for patient marital status and relative age

<sup>a</sup> *n* may not add up to the total and percentages may not add up to 100 because of missing values.

## Symptoms and death preparation

Relatives reported that patients had suffered from a mean of 5 out of 14 physical symptoms (SD 3.9) with moderate-severe intensity in the last 24 hours (table 2). Most prevalent were a dry mouth, decreased consciousness, fatigue, and dyspnea. Of patients with decreased consciousness in the final 24 hours ( $n=120$ ), 80% already had decreased consciousness 3 days prior to death. Of the eight psychological symptoms studied, patients had suffered from a mean of 2 (SD 2.6) symptoms with moderate-severe intensity, of which feelings of powerlessness, sadness, anxiety and worrying were most prevalent. In 23% - 37%, relatives did not have insight into the patient's psychological symptoms, which was partly related to patients' decreased consciousness. In 37%, relatives reported that patients had been at peace with their imminent death. During the last month of life, 52% of all patients were reported to have discussed their preferences for medical treatment at the end of life (table 3). In 31%, patients had discussed preferences with a physician, mostly a general practitioner. Thirty one per cent of the patients had indicated their preferred place of death: 20% preferred to die at home, 6% in hospital and 5% in another setting.

In 26%, relatives reported that patients had known that their death was imminent, that is, likely to occur within a few days, and 39% of the patients had been able to say goodbye to their family. Of the relatives, 49% had been aware of patients' imminent death. Two-thirds (64%) of the relatives reported that they had been informed by a physician on the

**Table 4** Nature of health care and evaluation of processes of hospital EOL care ( $n=249$ )

Patients	<i>n</i> <sup>a</sup>	%
<i>In the last 24 hours, patient participated sufficiently in decision making on medical treatment</i>		
Yes	105	42
No	70	28
Don't know	49	20
<i>In the last 24 hours, patient participated sufficiently in decision making on nursing care</i>		
Yes	107	43
No	61	25
Don't know	50	20
<i>In the last 24 hours, relative participated sufficiently in decision making on medical treatment</i>		
Yes	175	70
No	44	18
Don't know	15	6
<i>In the last 24 hours, relative participated sufficiently in decision making on nursing care</i>		
Yes	170	68
No	32	13
Don't know	22	9



**Table 4** Nature of health care and evaluation of processes of hospital EOL care (*n*=249) (continued)

<b>Patients</b>	<b><i>n</i><sup>a</sup></b>	<b>%</b>
<i>Relative was informed sufficiently about situation, condition and care</i>		
Yes	194	78
No (too little)	41	17
No (too much)	3	1
<i>Efforts to alleviate symptoms and problems last 24 hours before death were sufficient</i>		
Yes	187	75
No	40	16
Don't know	9	4
<i>Nursing care last 24 hours before death was sufficient</i>		
Yes	200	80
No	30	12
Don't know	5	2
<i>Social and spiritual support last 24 hours before death was sufficient</i>		
Yes	146	59
No	69	28
Don't know	16	6
<i>Symptoms were sufficiently alleviated in last 24 hours</i>		
Yes	131	53
No	59	24
Don't know	42	17
<i>Opportunity to discuss personal or religious preferences was sufficient</i>		
Yes	138	55
No	36	15
Don't know	54	22
<i>Attention to preferred rituals at the moment of death was sufficient</i>		
Yes	133	53
No	28	11
Don't know	69	28
<i>Affirmation of the patient as a whole person was sufficient</i>		
Yes	156	63
No	53	21
Don't know	25	10
<i>Attention to hospital facilities and wishes of patient and relative was sufficient</i>		
Yes	174	70
No	41	16
Don't know	19	8
<i>Effort to make last days of life tolerable for the patient was sufficient</i>		
Yes	140	56
No	44	18
Don't know	53	21
<i>Effort to make the last days tolerable for relatives was sufficient</i>		
Yes	154	62
No	39	16
Don't know	39	16

No = no and more or less / sometimes .

Variables related to QOD score in the univariate analysis are given in italics, adjusted for patient marital status and relative age

<sup>a</sup> *n* may not add up to the total and percentages may not add up to 100 because of missing values.

patient's approaching death. In cases of decreased consciousness, relatives were more likely to be aware of imminent death and to be informed by the physician. Half of the relatives (50%) had said goodbye to the patient and in 77%, at least one relative had been present at the moment of death.

### Experiences with care

According to relatives, 42% of the patients had been sufficiently involved in medical decision making (table 4). Relatives evaluated their own participation in medical decision making as sufficient in 70%, and 78% had received enough information about the patient's disease status and treatment options.

In 53% of cases, patient's symptoms and problems in the last 24 hours had been sufficiently alleviated according to relatives, and in 75%, they felt physicians had made enough efforts trying to control symptoms. In 59%, the level of social and emotional support was sufficient, such as support in resolving practical problems, accepting the imminence of death, and in preparing to say goodbye. In 63%, relatives felt that the patient had sufficiently been regarded as a human being and in 70% that enough attention had been paid to hospital facilities, such as privacy and opportunities for having meals for the relatives.

### Explaining overall QOD

Univariate analysis showed that of all general characteristics of patients and relatives, living alone until final admission, and a higher age of the relative were significantly associated with a higher QOD score. All simple regression analyses were controlled for these two characteristics.

Of all symptoms and problems, agitation, anxiety and not being in peace with imminent death were most strongly related to QOD scores ( $R^2$  0.09, 0.11, and 0.08 respectively). Relatives being informed about patients' impending death ( $R^2$  0.11), and about patients' condition ( $R^2$  0.08), as well as relatives' opportunity to participate in decision making ( $R^2$  0.11) were also related to the QOD scores. The degree to which relatives felt that physicians had made sufficient efforts to alleviate problems and symptoms in the last 24 hours was most strongly related to QOD ( $R^2$  0.14). In total, 37 variables were identified explaining part of the variation in QOD scores, and these are all presented in *italic* in the tables.

### Identification of relevant domains affecting QOD

All 37 variables, except the two case characteristics, were analyzed in two principal component analyses. Thirteen physical and psychological symptoms were combined in the first analysis. The Kaiser-Meyer-Olkin (KMO) measure of sample adequacy was 0.88 ( $p=0.00$ ) which is considered high. The resulting rotated component matrix (Varimax) had two components, that could be labelled as physical and psychological experiences ( $R^2$  0.54; table 5; domain 2 and 3),

**Table 5** Domains of dying and care explaining variance of Quality of Dying score

Theme variables	B <sup>a</sup> (se)	p-value	R <sup>2</sup> <sup>b</sup>	Theme variables	B <sup>a</sup> (se)	p-value	R <sup>2</sup> <sup>b</sup>
<b>1. General characteristics</b>				<b>2. Physical experiences</b>			
Marital status	1.13 (.35)	0.00		Pain	-0.24 (.41)	0.55	
Age relative	0.04 (.01)	0.00		Trouble sleeping	-0.74 (.46)	0.11	
<i>General characteristics</i>	1.01 (.25)	0.00	0.06	Dry mouth	-0.01 (.42)	0.99	
<b>3. Psychological experiences</b>				<b>4. Acceptance of imminent death</b>			
Anxiety	-0.48 (.59)	0.42		Nausea	-0.39 (.49)	0.42	
Loneliness	-0.28 (.60)	0.64		Fatigue	-0.24 (.44)	0.58	
Tenseness	-0.89 (.57)	0.12		Agitation	-0.93 (.41)	0.03	
Sadness	-0.98 (.62)	0.12		<i>Physical experiences</i>	1.00 (.23)	0.00	0.09
Powerlessness	0.52 (.61)	0.39		<b>5. Medical care/ symptom management</b>			
Worrying	-0.14 (.51)	0.78		In peace with imminent death	1.22 (.38)	0.00	
Depressive mood	0.41 (.67)	0.54		Patient was aware of imminent death	0.17 (.43)	0.70	
<i>Psychological experiences</i>	1.00 (.25)	0.00	0.08	<i>Acceptance</i>	1.00 (.28)		0.05
<b>6. Preparation on/ circumstances of death</b>				<b>7. Shared decision making</b>			
Relative was aware of imminent death	0.09 (.36)	0.81		Symptoms alleviated	0.51 (.37)	0.17	
Attention to hospital facilities and wishes of patient and relatives	1.37 (.41)	0.00		Efforts to alleviate symptoms and problems final 24 hours	1.67 (.43)	0.00	
Relative was present at moment of death	-0.01 (.44)	0.98		Relative was informed on imminence of death	1.25 (.36)	0.00	
Relative said goodbye	0.88 (.45)	0.05		Hospital right place of death in hindsight	0.63 (.33)	0.06	
Patient said goodbyes	0.14 (.44)	0.72		<i>Medical care/ symptom management</i>	1.00 (.12)	0.01	0.22
<i>Circumstances of death</i>	1.00 (.19)	0.00	0.11	<b>8. Personalized care</b>			
<b>8. Personalized care</b>				<b>9. Supportive care/ care for relatives</b>			
Affirmation of the patient as a person	1.27 (.41)	0.00		Relative participated in nursing care decisions	0.11 (.66)	0.86	
Attention to preferred rituals at moment of death	0.30 (.37)	0.42		Relative informed about condition and care	1.42 (.58)	0.01	
Opportunities to discuss personal or religious preferences	0.69 (.38)	0.07		Relative participated in medical decisions	1.16 (.59)	0.05	
Discussed preferences on EoL treatment	0.25 (.34)	0.46		Nursing care final 24 h.	0.38 (.52)	0.46	
Social and spiritual support last 24 h.	0.75 (.39)	0.06		<i>Supportive care/ care for relatives</i>	1.00 (.16)	0.00	0.15
<i>Personalized care</i>	1.00 (.15)	0.00	0.16	<b>Total of domains</b>			
<b>Total of domains</b>				<b>Total of domains</b>			
	0.35 (.03)	0.00	0.34				

EOL = End of Life

<sup>a</sup> B = unstandardized regression coefficient, expressing the strength of the association relation between a variable and QOD

Total domains on QOD score = Sum of (domains\*unstandardized coefficient [B]): (general characteristics \* 1.01) + (physical exp\* 1.00) + (psychological exp\* 1.00) + etc. etc.etc.

<sup>b</sup> Adjusted R<sup>2</sup>

The remaining 22 variables were combined in the second analysis, with a KMO of 0.78 ( $p=0.00$ ), which is considered as good. This rotated component matrix had 6 components, that could be labelled as “acceptance of imminent death”, “medical care/ symptom management”, “preparation on and circumstances of dying”, “shared decision making”, “personalized care” and “supportive care/ care for relatives” ( $R^2$  0.62; table 5; domains 4–9).

For each domain, parameters were entered in multivariate linear regression models to assess the association between the identified domains and overall QOD (table 5). All domains were significantly associated with QOD, with  $R^2$  being 0.02 for shared decision making, up to 0.22 for medical care. When we combined all domains in one regression analysis, the model explained 34% of the variation in QOD scores.

## DISCUSSION

This study provides a comprehensive and detailed insight into what happens and what matters for patients dying in the hospital, according to bereaved relatives. Bereaved relatives rated QOD, in non-intensive care wards of a large university hospital on average 6.3, which might be considered as sufficient, according to a widely used score system in the Netherlands, but their scores largely varied. The multidimensionality of quality of dying was confirmed, and we found a crucial impact of several characteristics of EOL care. When caring for terminally ill patients, health care professionals need skills to relieve symptoms, and to recognize worsening of patients’ condition. This needs to be combined with demonstration of awareness and attentiveness regarding individual patient and relative needs, and adequate communication about prognosis, medical decisions, and patient and relative preferences.

### Strengths and weaknesses of the study

A major strength of this study is the comprehensive assessment of multiple dimensions of QOD and the thorough analysis of relationships between these dimensions and the overall score of QOD. As a result, to our knowledge, this study is the first study explaining one-third of the aspects determining the QOD in the hospital. QOD appeared to be strongly affected by medical care and staff attentiveness, and these results may contribute to the debate on QOD and quality of care for the dying, in scientific literature and in society.<sup>31-34</sup>

One limitation of the study is that it was performed in one hospital, and although it was a large hospital with 18 different participating wards, this might diminish the generalizability of our results. The response rate of 51% however was fair when compared to the response rate of 35% in a comparable postal self-administered questionnaire study among bereaved relatives in the UK,<sup>35</sup> and patients’ age, gender, duration of last admission, and type of wards were similarly distributed among included and non-included

cases. A second limitation is that we did not assess QOD using a previously studied questionnaire, such as the QODD, which might decrease the opportunity of comparison with other studies. We performed a retrospective study among all in-hospital deaths during 21 months, which decreases possible selection bias, but implies the impossibility of interviewing patients, and the risk of recall bias.<sup>19,20</sup> The information on QOD was provided by relatives, and as such, our results do not reflect care as provided but care as perceived and remembered by relatives.

### Main findings and comparisons with other studies

In a randomized controlled trial on the Liverpool Care Pathway, Costantini et al recently described EOL care for cancer patients in Italian hospitals, and found some similarities.<sup>36</sup> The mean score for the quality of care in control wards in Italy was 63 on a 0-100 scale, which might be considered comparable to the mean score of 6.3 on a 0-10 scale we found for QOD. Findings on the presence of pain, dyspnea and nausea in the dying phase also seem to be comparable. Further, in both studies relatives were relatively dissatisfied about the emotional support they had received. In our study many patients suffered from multiple symptoms during the last 24 hours. In 53% of all cases relatives indicated that symptoms were sufficiently alleviated. These findings are comparable to those reported elsewhere.<sup>8,36-41</sup> Relatives frequently reported not to know whether the patient suffered from psychological problems, which could partly be explained by patients' decreased consciousness. We did not find social experiences that were related to QOD scores.

Six physical symptoms explained 9% of the variation in QOD scores, whereas efforts made by staff to alleviate these symptoms explained 14%. Relatives probably tend to accept unrelieved symptoms, as long as physicians demonstrate that they are consciously addressing the patient's problems and needs. Relatives' trust that the physician does his utmost in EOL care has previously been found to be an important attribute of a good QOD.<sup>42,43</sup>

Although almost all participating relatives were involved in care of the patient during the last days of life, and 64% had been told that the patient's death was imminent, only half of them had foreseen that the patient would die at short notice. Patient's decreased consciousness during the last days of life increased the likelihood that relatives had foreseen death. The relatively common lack of awareness of the imminence of death might be influenced by the fact that in the Netherlands, patients are in general only admitted to the hospital when they have a chance of recovery or prolonging life; only one-third of all deaths occur in the hospital. For patients who are expected to die within weeks or days, care is preferably provided by home care organizations or hospices. In the hospital setting, where care is typically focused on prolonging life, it is often difficult to identify in advance patients who are unlikely to recover from a worsening condition.<sup>44</sup> However, in a parallel study in the same population, physicians had been aware of patient's imminent death in 79% of cases.<sup>45</sup> The difference between physician's awareness

and relative's and patient's awareness might be correlated to problematic communication, but also to variation in the interpretation of what 'imminent death' entails.<sup>46,47</sup> Whether and how physicians actually informed relatives about the patient's imminent death was not assessed and might differ from relatives' reports.<sup>48</sup> It has previously been shown that communication between physicians and patients or relatives about a poor prognosis and imminent death is often problematic.<sup>7,12,49,50</sup> Nevertheless, families of severely ill patients have been shown to need prognostic information, especially if the prognosis is poor. Respect, sensitivity, compassion and frequent communication have been identified as important conditions to support such communication.<sup>51-53</sup> Relatives in our study reported that only 26% of the patients had been fully aware of imminent death. Patient awareness of and being in peace with approaching death were correlated with higher QOD scores, which has also been found elsewhere.<sup>46</sup>

In 77% of all studied cases, patients died in the presence of family, which was more than reported in studies in hospitals in New Zealand and France, where 60% and 34% of deceased patients, respectively, died with family being present.<sup>3,9</sup> Presence at the moment of death was not strongly related to QOD; relatives gave more weight to saying goodbye.

We found that attentiveness to relatives affected QOD experiences. In EOL care, collaboration between relatives and professional staff is crucial, for example, regarding recognition of and communication about patient problems, decision making and the organization of care.

Our study confirmed the multidimensionality of QOD. We found an impact of symptom burden, staff attentiveness to the needs of patients and their relatives, adequate information and communication, and acceptance of imminent death. The explained variation of 34% of the QOD scores still leaves us with a large proportion of unexplained variance. It is likely that factors such as personality traits of patients and relatives, cultural and ethnic factors, patients' quality of life during the phase preceding the dying phase, and perceptions of what a good death entails may also contribute to the explanation of QOD ratings.<sup>13,23,42,54</sup> Our findings confirmed the results of Zhang et al.,<sup>13</sup> who could explain 19% of the variation in quality of life scores of cancer patients and demonstrated the importance of religious care, and of the formation of a 'therapeutic alliance' between the oncologist and the patient.<sup>13</sup>

Nevertheless, for a better understanding of factors explaining the variance in QOD, more observational research is needed, in addition to experimental studies on interventions to improve EOL care in the hospital.

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# 5

## Concordance between experiences of bereaved relatives, physicians and nurses with hospital end-of-life care: everyone his “own truth”

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## ABSTRACT

### Background

When patients die relatives and healthcare professionals may appreciate the quality of the dying phase differently, but comparisons are rare.

### Objective

Comparison of the experiences of bereaved relatives, physicians and nurses concerning the quality of dying, and exploring the relation to communication.

### Design

A cross-sectional study, from June 2009 – July 2012.

### Setting

A large Dutch university hospital.

### Participants

Relatives, physicians and nurses of patients dying in the hospital.

### Measurements

Concordance on the quality of dying (QOD) (0-10 scale), awareness of impending death, and end-of-life communication.

### Results

Data on all three perspectives were available for 200 patients (mean age of 69 years, 59% male and 54% dying from cancer). Concordance between the experiences of relatives, physicians and nurses in general was poor. Relatives' scores for QOD (median 7; IQR 5-8) were lower than physicians' and nurses' (both median 7; IQR 6-8) ( $p = 0.002$ ). 48% of the relatives, 77% of the physicians and 73% of the nurses had been aware of the patient's impending death. Physicians more often reported to have informed patients and relatives of end-of-life issues than relatives indicated. When both physicians and relatives reported that physicians had discussed the patient's prognosis, relatives' awareness of impending death and presence at patient's deathbed were more likely.

### Conclusion

Relatives, physicians and nurses seem to have their "own truth" about the quality of dying. Professionals should put more emphasis on the collaboration with relatives, on their willingness of timely communication about impending death, and on verification of relative's understanding.

## INTRODUCTION

As death comes to us all and most people die after a period of declining health and a significant symptom burden, knowledge on how end-of-life care can contribute to a good deathbed is highly needed. Research on patient reported outcomes and the effectiveness of interventions at the end of life is complex, e.g. because of methodological and ethical considerations.<sup>1-3</sup> Furthermore, perspectives vary on what good quality of dying is, and how this should be achieved, as was recently shown in the debate on the Liverpool Care Pathway of the dying patient.<sup>4-9</sup> A major limiting factor is that the main person involved, i.e. the dying patient cannot participate in the debate on outcome measures and in the evaluation of experiences in the dying phase.<sup>2</sup> Proxy assessments are needed, including those of relatives and healthcare professionals (HCPs) who may have various perspectives and values.<sup>3,10-13</sup>

Studies have shown that relatives and patients share important priorities, such as honest and clear communication, involvement in medical decisions, relief of symptom burden, and having the opportunity of completing life and saying goodbye;<sup>10,14-18</sup> therefore relatives might be able to represent some of the patient's interests. Most studies on proxy evaluation of end-of-life care compare symptom scores of patients and relatives or HCPs. These studies show a tendency of relatives to overestimate the severity of symptoms in comparison to patients' self-reports, whereas nurses and physicians tend to underestimate them.<sup>10,12,16,19-21</sup> Only a few small studies have compared the experiences of the dying phase of relatives and HCPs, showing low to moderate concordance between these groups.<sup>13,22</sup> In the National audit of end-of-life care in Irish hospitals physicians evaluated care more positively than relatives, whereas nurses reported intermediate opinions.<sup>23</sup> More insight is needed into the appreciation of relatives of the care and communication in the last days of life and how this is related to the perspectives of HCPs.

The purpose of this study was to better understand evaluation of the dying experience from different perspectives, and how end-of-life communication may affect the quality of dying. Therefore we compared bereaved relatives', and physicians' and nurses' assessments of dying patients' quality of life and quality of dying, their awareness of impending death, and their communication; furthermore, we analyzed how communication was related to relatives' appreciation of aspects of the quality of dying and the quality of care, such as preparation for death, and satisfaction with care.

## METHODS

The study was embedded in a larger study on the quality of palliative and terminal care in the hospital (the PalTeC-H study). We included cases of patients who died in 18

non-intensive care wards of a 1300-bed university hospital in The Netherlands (i.e. 951 consecutive deaths), between June 2009 and July 2012, after a hospitalization of at least 6 hours. The protocol of this study is described elsewhere.<sup>24</sup> Physicians and nurses who had closely been involved in daily care for a dying patient were asked by the team coordinator of the ward to complete a questionnaire within at most two weeks after the patient's death. Ten to thirteen weeks after the death of a patient a relative was invited by post by the primary investigator (FW) to complete a questionnaire. When needed, a written reminder was sent after four weeks.

### 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 because data were gathered after patients' death and the study involved minimal risk or burden to the respondents.

### Questionnaires

Previous research provided us with a multidimensional framework to understand the quality of dying.<sup>25,26</sup> Based on this framework we developed three complementary questionnaires for relatives, physicians and nurses including physical, psycho-social, and spiritual experiences, preparedness to and circumstances of death, and nature of care in the last phase of life.<sup>24</sup> Some topics were assessed from all perspectives, including two summarizing items, in which the respondents were asked to rate the patient's quality of life during the final three days (further referred to as QOL3) and his quality of dying (QOD), both on a 0-10 scale with zero being "very poor" and ten "almost perfect". Further, all were asked whether HCPs had discussed patient's impending death with relatives and patients (no or yes), and whether they had been aware of the patient's impending death, (no, more or less, yes). 'Being aware' was defined as being aware that death was likely to occur within hours or days, and "being more or less aware" as knowing that the patient would die, but not expecting that death would occur so soon. We also asked when the respondents had become aware of the patient's impending death (< 24 hrs, between 24 to 48, or 48 to 72 hrs and > 72 hrs in advance). Finally, we assessed aspects of the quality of dying and the quality of care according to relatives, including opportunities to prepare for death, satisfaction with care, saying goodbye (no, more or less, yes) and presence at the moment of death (yes, no).

### Data analysis

We analyzed data on all patients for whom respondents from all three groups (relatives, physicians and nurses) had completed a questionnaire. Linear regression analyses were performed to study the effect of patient characteristics (i.e. age, gender, diagnosis cancer

or no cancer, duration of the final hospitalization) on QOL3 or QOD scores. Differences of QOL3 and QOD scores between the groups were estimated using multilevel regression analysis. The multilevel model included random effects for the intercepts of the regression model to allow for the multiple measurements per patient, and fixed effects for the three perspectives. Correlations between participants' awareness of the patient's impending death and the moment of their awareness were tested using cross tables with Chi<sup>2</sup> tests and Spearman correlation coefficients, respectively. Agreement between physicians and relatives on whether physicians had informed relatives of the patient's impending death was tested using Cohen's Kappa ( $\kappa$ ): values were interpreted as <0.20 = poor; 0.21-0.40 = fair; 0.41 – 0.60 = moderate; 0.61 -0.80 = good and 0.81 – 1.0 = very good concordance.<sup>27</sup> Furthermore we analyzed the relation of the communication of HCPs about a patient's impending death with patients' and relatives' awareness and death preparation, relatives' presence at the moment of death, and their satisfaction with care, using Chi<sup>2</sup> tests. Level of significance was set at  $p < 0.05$  for all analyses. All data were analyzed with statistical packages SPSS 21 and R version 2.13.

## RESULTS

### General characteristics

During the study period 951 patients died. All invited participants responded independently; the response rates per group were 52% for relatives, 45% for physicians, and 54% for nurses. For 200 patients all three questionnaires were completed. At the time of death, the mean age of these patients was 69 years and the mean duration of the final hospitalization was 14 days; 54% died of cancer; at the time of admission to the hospital the treatment goal was symptom control for 61%, and terminal care for 5% (table 1). Relatives were mostly the spouse (50%) or a child (34%) of the patient, and 88% were involved in patient care during final days; their mean age was 57 years. Participating physicians were mostly interns, and 37% had cared for more than five dying patients during the previous 12 months. Of the participating nurses 28% had cared for more than five dying patients during the previous 12 months. In 61% of the cases, nurses had cared for the patient during at least 2 shifts. Characteristics and outcomes were similar to those of the total study populations.<sup>28,29</sup>

### Quality of life and quality of dying

Both the QOL3 and the QOD were scored with a range from 0-10, in all three groups of participants. The median QOL3 score of the relatives was 3 (Inter Quartile Range (IQR) 1-6), whereas physicians and nurses scored QOL3 significantly higher (both median 5; IQR 3-6) (F 12.76;  $p < 0.001$ ) (table 2). The median QOD score was 7 in all three groups, with a IQR

**Table 1:** General characteristics of patients, relatives, physicians and nurses

		<b>N=200</b>	
		<b>n (%)</b>	<b>Mean (SD)</b>
<b>Patients</b>			
Sex	Male	117 (59)	
	Female	83 (41)	
Age (years)			69.0 (12.6)
Duration final hospitalization (days)			13.7 (15.8)
Marital status	Married/living in partnership	129 (65)	
	Widowed/divorced/alone	71 (35)	
Diagnosis of cancer		108 (54)	
Ward	Acute palliative care (cancer center)	38 (19)	
	Neurology	31 (16)	
	Ear, nose & throat diseases	20 (10)	
	Lung diseases	21 (11)	
	Medical oncology / geriatrics	18 (9)	
	Other	72 (36)	
Treatment goal(s) at admission <sup>a</sup>	Symptom control	121 (61)	
	Recovery or life prolongation	63 (32)	
	Diagnostics	7 (4)	
	Terminal care	10 (5)	
	Other	17 (9)	
<b>Relatives</b>			
Sex	Male	74 (37)	
	Female	124 (63)	
Age (years)			57 (14.1)
Relation to patient	Spouse	99 (50)	
	Child	68 (34)	
	Other	28 (14)	
Involved in care final days prior to death	Yes	176 (88)	
	No	24 (12)	
Time between patient passing away and completion of questionnaire (weeks)			15.5 (4.0)
<b>Physicians</b>			
Sex	Male	86 (37)	
	Female	112 (62)	
Age (years)			30 (6.0)
Function	Attending physician on the ward	136 (68)	
	Attending physician (out of office hours)	38 (19)	
	Other	23 (12)	



**Table 1:** General characteristics of patients, relatives, physicians and nurses (continued)

		N=200	
		n (%)	Mean (SD)
Number of dying patients cared for during previous 12 months			
	≤ 2	70 (35)	
	3-5	54 (27)	
	> 5	74 (37)	
<b>Nurses</b>			
Sex	Male	18 (9)	
	Female	179 (90)	
Age (yrs)			35 (12.3)
Number of dying patients cared for during previous 12 months			
	≤ 2	77 (39)	
	3-5	64 (32)	
	>5	55 (28)	

<sup>a</sup> More than one goal possible, percentage may be added up to > 100%

**Table 2:** Quality of life during final 3 days (QOL<sub>3</sub>) and quality of dying (QOD) (N=200)

	Relatives	Physicians	Nurses	Analysis of variance <sup>b</sup>	
	Median (IQR)	Median (IQR)	Median (IQR)	F- value	p- value
Quality of life during last 3 days (QOL <sub>3</sub> ) <sup>a</sup>	3 (1-6)	5 (3-6)	5 (3-6)	12.755	< 0.001
Quality of Dying (QOD) <sup>a</sup>	7 (5-8)	7 (6-8)	7 (6-8)	6.47	0.002

IQR = Inter Quartile Range

<sup>a</sup> Scale 0-10

<sup>b</sup> Multilevel analyses to compare outcomes in 3 groups

of 5-8 in relatives, and 6-8 in HCP's, the latter being significantly higher than relatives' scores (F 6.47; p=0.002). QOL<sub>3</sub> and QOD scores were not related to patients' diagnosis, age or gender. Relatives' and physicians' QOL<sub>3</sub> scores were slightly lower if the duration of the hospitalization had been longer (F5.63, B-0.03; p=0.02, and F4.56, B-0.02; p=0.03, respectively).

### Awareness of impending death

Relatives reported to have been aware of the patient's impending death in 48% of all cases. Physicians and nurses had been aware in 77% and 73%, respectively (table 3). There was no correlation in the awareness between relatives and physicians (Rho = 0.10; p=0.17) and poor correlation between relatives and nurses (Rho = 0.26; p=0.000), and nurses and physicians (Rho = 0.20; p=0.004). Of all cases, 29% of relatives had not been aware of patient's impending death and in another 29% they became aware during the final 24 hours. In 38% of cases physicians and nurses became aware of the patient's impending death in the final 24 hours and correlation between physician and nurses moments of

awareness was moderate ( $Rho = 0.41$ ;  $p = 0.000$ ). Correlation between relative's and HCPs' moments of awareness was poor and in the opposite direction ( $Rho = -0.25$ ;  $p = 0.003$  and  $Rho = -0.26$ ;  $p = 0.001$ , respectively).

**Table 3:** Awareness of impending death ( $N=200$ )

		Physicians <i>n</i> (%)	Nurses <i>n</i> (%)	Relatives <i>n</i> (%)
Awareness of impending death	Yes	154 (77)	145 (73)	95 (48)
	More or less	27 (14)	22 (11)	40 (20)
	No	16 (8)	30 (15)	57 (29)
	Missing values	3 (1)	3 (1)	8 (3)
Correlation Rho ( <i>p</i> )	P-N <sup>a</sup>	0.20 (0.004)		
	N-R	0.26 (<0.001)		
	P-R	0.10 (0.17)		
Moment of awareness of impending death	< 24 hrs	77 (38)	82 (41)	58 (29)
	24-72 hrs	65 (32)	59 (30)	46 (23)
	> 72 hrs	42 (21)	38 (19)	31 (16)
	Missing values	16 (9)	21 (10)	64 (32)
Correlation Rho ( <i>p</i> )	P-N <sup>a</sup>	0.41 (<0.001)		
	N-R	-0.26 (0.001)		
	P-R	-0.25 (0.003)		

Rho = Spearmans' correlation coefficient

<sup>a</sup> P-N = Physician and Nurse; N-R = Nurse and Relative; P-R = Physician and Relative

## Communication

Physicians more often reported to have informed patients and relatives of end-of-life issues than relatives and nurses indicated (table 4). In 57% physicians reported that they (32%) or a colleague (25%) had informed patients about their impending death. In 27%, this had been impossible, due to unconsciousness of the patient. Physicians reported to have informed 90% of relatives of the patient's impending death, whereas 64% of the relatives reported to have been informed ( $\kappa = 0.18$ ,  $p = 0.001$ ).

Compared to cases in which only the physician reported that the relative was informed about impending death, relatives who had confirmed this communication were more likely to have been aware of the patient's impending death (63% vs 27%), to have said goodbye (64% vs 36%), to be satisfied about symptom management (82% vs 69%) and about emotional and social support (76% vs 53%), and to have been present at the moment of death (92% vs 75%) (table 5). Discussion between relatives and physicians about impending death did not affect patient's preparedness. When the physician reported to have discussed impending death with the patient relatives more often reported that the patient had been aware of impending death (41% vs 14%) and had said goodbye (58% vs

27%), and that relatives themselves had said goodbye (59% vs 40%). When nurses had discussed the end of life with patient this was also associated with increased percentages of patients' awareness, patients' and relatives' goodbyes, and relatives' presence at the moment of death.

**Table 4:** Communication about end of life, end-of-life decisions or impending death (N=200)

Perspectives:		With patient n (%)	With relative n (%)
Physician reported	To have discussed the patient's impending death	114 (57)	180 (90)
Relative reported	That the physician had discussed the patient's impending death	n.a.	127 (64)
Nurse reported	That the physician had discussed the patient's impending death	83 (42)	131 (66)
	To have discussed the patient's impending death	72 (36)	n.a.

n.a. = not assessed

**Table 5:** Communication about impending death and its relation to patients' and relatives' awareness, their death preparation, and satisfaction with care (N=200)

	Patient (according to relative)					Relative			
	n	was aware of impending death n (%) <sup>a</sup>	was in peace n (%) <sup>a</sup>	said goodbye n (%) <sup>a</sup>	was aware of impending death n (%) <sup>a</sup>	was satisfied about symptom management during final 24 h. n (%) <sup>a</sup>	was satisfied about social and emotional support final 24 h. n (%) <sup>a</sup>	said goodbye n (%) <sup>a</sup>	was present at deathbed n (%) <sup>a</sup>
Physician reported to have informed relative about patient's impending death (n=174) and relative reported to have been informed									
Yes	119	43 (36)	50 (42)	62 (52)	75 (63)	98 (82)	90 (76)	76 (64)	110 (92)
No	55	16 (29)	23 (42)	22 (40)	15 (27)	38 (69)	29 (53)	20 (36)	41 (75)
Physician reported to have discussed impending death with patient									
Yes	114	47 (41)	52 (46)	66 (58)	61 (54)	85 (71)	71 (62)	67 (59)	98 (86)
No	86	12 (14)	25 (29)	23 (27)	35 (41)	62 (72)	57 (66)	34 (40)	66 (77)
Nurse reported to have discussed impending death with patient									
Yes	72	35 (49)	39 (54)	50 (69)	39 (54)	56 (77)	52 (72)	48 (67)	68 (94)
No	128	26 (20)	39 (30)	40 (31)	58 (45)	93 (73)	78 (61)	55 (43)	99 (77)

<sup>a</sup> = row percentages

*Italic* = p<0.05 in 2x2 table (Pearson's Chi square)

## DISCUSSION

In the acute hospital setting, bereaved relatives and HCPs rated the QOL<sub>3</sub> as poor and the QOD as moderate; HCPs scored QOL<sub>3</sub> and QOD significantly higher than relatives. The concordance of their evaluation of QOL<sub>3</sub> and QOD, their awareness of the impending

death of the patient, and of discussions about impending death was poor. However, communication between HCPs, patients and relatives about impending death was associated with better awareness of and preparedness for the end of life, and with more satisfaction with care.

A poor concordance of perspectives on end-of-life care was also found in a few other studies.<sup>13,22,23</sup> Different stakeholders seem to experience their “own truth” and probably there is not “one truth”. This finding has important implications regarding the development and use of quality indicators and outcome measures in end-of-life care. The use of such indicators in palliative care is in its infancy and the effects of their implementation have not yet been assessed.<sup>30,31</sup> Our study shows that outcomes are likely to be affected by the type of assessor.

Relatives had been fully aware of the impending death of the patient in 48% of the cases, whereas physicians and nurses had been aware in 77% and 73% of all cases. However, in four out of ten cases HCPs only became aware of the nearness of death during the final 24 hours. The awareness and moment of awareness of relatives and HCPs were not or even negatively correlated. Awareness of impending death is often seen as an important condition for a good death<sup>32-35</sup>, however it is known to frequently occur late in the hospital.<sup>35-37</sup> Hospital care is typically aimed at improving patients’ health and subsequently discharge them to go home. Only in 5% the treatment goal at admission was providing care in the dying phase. This practice affects the expectations of patients, relatives and HCPs. Most participants in our study might have expected the patient to be discharged to go home after the hospitalization, which instead turned out to end with the patient’s death. Recognition of the irreversibility of a worsening health condition and, subsequently, refocusing care to enable the patient and his relatives to have a good death bed, is difficult.<sup>36,38</sup> Our finding that relatives and HCPs evaluated the dying phase differently and recognized the imminence of death at various moments underlines the need for frequent and adequate communication between patients, physicians, nurses and relatives, during the final days of life and also after death. Every party involved brings his own expertise and jointly they are probably best able to assess the patient’s needs and prospects: physicians have biomedical knowledge and skills, nurses have expertise in personal care and daily observations, and relatives probably best know how to interpret patients’ appearance and behavior.

One-third of the relatively young participating physicians had discussed imminent death with the patient themselves. The provision of clinical care in the learning environment of a teaching hospital is challenging; junior doctors need adequate supervision to learn more about end-of-life care, truth telling and breaking bad news.<sup>39,40</sup>

This study also showed that being informed about patient’s impending death did not obviously result in awareness of the nearness of death. Nevertheless, communication of HCPs with relatives and patients clearly affected the awareness of impending death and

the preparation for the end of life, especially when the relative confirmed to have been informed by the physician, which was not always the case. Taking into account physicians' late awareness and the number of cases in which patients could not be informed because they were unconscious, communication about impending death might often have taken place late in the process.<sup>41,42</sup> Communication at the end of life is one of the most difficult tasks of doctors and concerns deliberations on *if* bad news should be broken, *when*, and *how*.<sup>36,38,41</sup> When being confronted with a fatal prognosis, relatives might experience tension between wanting to know what to expect and needing to remain hopeful. This tension might lead to ignoring prognostic information, relying on one's own beliefs, and focusing on positive details.<sup>43</sup> To support relatives in "preparing for the worst and hoping for the best", sensitive and frequent communication is needed, about the patient's prognosis, and about the physician's expectations of the effects of treatment.<sup>43,44</sup> When end-of-life communication is regarded as a continuous process, disclosure of an impending death might be less difficult, for the physician and for the patient and relative, which in turn might yield higher levels of satisfaction with care.<sup>44,45</sup>

Nurses discussed the impending death with patients in only one-third of all cases, but when they did, this was associated with increased awareness of patients of their impending death, with the extent to which patients and relatives had been able to say goodbye and with relatives' presence at the moment of death. Nurses are known to experience many difficulties in end-of-life communication, such as uncertainty about their role, and their knowledge and skills. They also need to wait for the physician to disclose bad news and then often hesitate in initiating difficult conversations with patients and relatives.<sup>38,46,47</sup> Although nurses are generally dedicated to provide the best end-of-life care, they may in practice often continue to provide care as usual, until the physician explicitly and openly states that the patient is dying.<sup>48,49</sup>

### Strengths and weaknesses

To our knowledge this is the first study to examine QOL3 and QOD from the perspectives of relatives, physicians and nurses, in a large number of cases, without restrictions regarding diagnoses or duration of illness. We comprehensively assessed experiences with end-of-life communication, and their relation to death preparation and circumstances of death. The response rates were similar to response rates in comparable studies and groups of participants,<sup>50-52</sup> and the characteristics and results in the 200 common cases were similar to those in the separate groups. Still, some selection bias cannot be ruled out, which might result into more positive experiences of physicians and relatives.<sup>53</sup> Our findings provide concrete opportunities to improve care, instead of satisfaction rates, which are often high in evaluation studies in healthcare<sup>54</sup>.

Due to the cross-sectional design we cannot draw firm conclusions about causality. Although 84% of participating relatives were close relatives of the patient, and 88% were

involved in the care of the patient during his final days, physicians might have informed other family members, who again might not have informed the participating relative. The moment after death at which relatives and HCPs filled in questionnaires differed. HCPs were asked to fill in a questionnaire as soon as possible after patient's death, to restrict recall bias. Relatives were asked later, to diminish disturbance of their bereavement, but their perspectives might have changed in this period, and recall bias cannot be ruled out. However, emotional events, such as the death of a beloved person, are known to be recalled better compared to less moving events. Finally, we used newly developed questionnaires and as a result our findings cannot easily be compared to those of other studies using other instruments.

## CONCLUSION

Relatives, physicians and nurses had different perspectives on the quality of the final days of patients' lives, on their quality of dying, and on communication about impending death. Everyone seems to experience his "own truth". To achieve improvements in care in the dying phase, more emphasis should be put on the collaboration between HCPs and relatives in the therapeutic alliance with patients. Furthermore, physicians should be more willing to timely discuss a poor prognosis, and to check whether patient's and relative's understanding align with physicians'.

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# 6

## How to deal with autonomy in hospital end-of life care? Exploring the experiences of relatives

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*Submitted for publication*

## ABSTRACT

### Background

Hospital care and communication tend to be focused on the individual patient and the 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.

### Aim

Our aim was to investigate the experiences of relatives concerning their role and position during the last days of the patient's life in the hospital.

### Design/ setting

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.

### Participants

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 'comprehensible, timely and sensitive information and communication', 'involvement in decision-making', 'acknowledgement of their position', 'being able to trust healthcare staff', and for 'rest and privacy'. When relatives felt that their role had sufficiently been acknowledged by healthcare professionals (HCPs), their experiences were more positive.

### Interpretation

Relatives have an important role in care of dying patients in the hospital. An approach to care of HCPs 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 collaborate with relatives in providing care that optimally addresses the needs of patients.

## 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<sup>1-4</sup>. 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<sup>5,6</sup>. In Western healthcare decision-making is mainly based on the principle of individual autonomy<sup>7,8</sup>, which in philosophy is described as self-rule or independence and in legislation as the individual right to decide on medical treatment<sup>9-11</sup>. In the hospital setting healthcare professionals (HCPs) usually focus on the patient when making decisions on treatment and care, assuming that the patient is competent and able to decide for himself. They will involve relatives only when needed<sup>12</sup>. Relatives' involvement becomes more important when the end of life approaches. Many patients want their close relative to be informed about their illness and to involve them in major decisions at the end of life<sup>13,14</sup>. Furthermore, when patient's physical and psychosocial condition deteriorates, patients often are no longer able to optimally participate in the decision-making without the support of relatives.

The role and needs of relatives should be addressed within palliative care, both for their own wellbeing and to support them in caring for the patient<sup>6</sup>. Many studies showed that timely information and communication enable the patient and the 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<sup>4,13,15-19</sup>. It can therefore be questioned whether individual patient needs and individual autonomy are the most appropriate base for end-of-life care. In this study we aim to explore relatives' experiences regarding their position and role in the hospital during the patient's last phase of life.

## METHODS

### Design / Setting

This study was embedded in a retrospective questionnaire study on palliative and terminal care in the hospital (PalTeC-H)<sup>20</sup>. 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. For this paper, 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 non-intensive care wards (table 1). Ten to thirteen 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. Of 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.

**Table 1.** Characteristics of patients and relatives

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

## Data analysis

A qualitative inductive content method was used to systematically analyze the texts<sup>21,22</sup>. After selection of the relevant questions, all comments were read by two researchers (FEW, SMD). The data were coded across all questions using the open coding method<sup>22,23</sup>. Two researchers (FEW, SMD) coded the data independently. The codes were discussed until consensus was reached. Twenty-one different codes were distracted, and discussed

and agreed upon with two other researchers (AH, RJ). Subsequently the codes were categorized into overarching themes.

### 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 because data were gathered after patients' death and the study involved minimal risk or burden to the respondents. Participants were informed that all data would be anonymously analysed.

## RESULTS

451 relatives gave 2730 comments and answers to the 10 questions, with a range of 149 – 397 per question. The experiences of relatives concerning their position and role could be summarized in five categories, i.e. 'information and communication', 'involvement in decision-making', 'acknowledgement', 'trust', and 'rest and privacy'.

### Information and communication

Experiences with information and communication concerned comprehensibility, timeliness and sensitivity (box 1).

#### *Comprehensibility.*

Relatives reported that they had felt a need for comprehensible information about the patient's situation and prospects, in order to accompany the patient and to participate in decision-making when needed. Physicians were expected to explain the patient's situation accurately and in an understandable way. Relatives experienced contradictive information from the multidisciplinary team as confusing. They critically reported about situations in which they were not informed, or it had been difficult to get in touch with the physician, or where the physician had discussed the patient's impending death with the patient only. Relatives' need for information also concerned procedures after death.

#### *Timeliness and sensitivity.*

Timeliness, with an emphasis on 'in time' and 'pro-active', was related to positive experiences concerning information and communication. Being informed and called in time enabled relatives, or would have enabled them, to prepare for imminent death, and to arrive in time at the ward to be with the patient in his final moments. When relatives were informed pro-actively, they were satisfied, whereas they critically appraised situations in which they repeatedly had to ask for information. Furthermore, relatives reported about

their preferences for being informed clearly and decisively, as well as in a sensitive way. Information after the patient's death had been helpful to get more clarity about what had happened in the final phase.

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**Box 1: Information and communication**

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Quotes

Various doctors told us different things; this was very confusing. (R 914, wife, 55y)

Physicians and nurses informed us adequately (R74, husband, 89y)

I was called in the morning when I was at my office, and they asked whether I could come that day, because her saturation was decreasing. Being a lay person I cannot be expected to understand that; I would have wanted them to be more clear, more pressing.' (R 104, sister, 54y)

Only on the last day we realized that she was dying; we were only told that she was not doing well. (R 264, daughter, 60y)

In the morning we were invited to meet with the physician at 4.30 PM; when we arrived at 4.15 PM he had just died (R 50, father, 73y)

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### Involvement in decision-making

Many relatives reported about their involvement in making medical decisions, either together with the patient or as representative when the patient was unable to communicate; whether they had been given options to choose from on behalf of the patient, what these options were and what information they had received (box 2). Relatives who were satisfied concerning their role as patient's representative in the decision-making, had been clearly informed about the options and felt that they had made decisions together with the physician. Relatives who stayed all day with the patient reported about sufficient opportunities to be involved in all decisions, while others had experienced difficulties in getting an appointment with the physician. Relatives who had not been involved in the decisions making process reported that they felt neglected, that they could not agree with the decisions made, or did not understand these decisions.

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**Box 2: involvement in decision-making**

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Quotes

I really had difficulty to convince them of his preferences (to die smoothly, without choking) (R 220, sister, 55y)

Every option was explained and decisions were shared (R185, wife, 77y)

We were present all the time, so we could continuously interfere and discuss everything (R503, daughter, 46 y)

Medical examinations etc. were communicated, but not discussed (R815, wife, 69y)

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## Acknowledgement

Relatives' need for 'acknowledgement' refers to the experience that HCPs should do their best to affirm the patient as a person and the relative in his position and relation to the patient (box 3). Relatives were satisfied when they were treated with respect, and reported about easy, honest and open communication with the medical and nursing staff; they were dissatisfied when they lacked such experiences. It was important for relatives that HCPs acknowledged their close involvement with and specific knowledge of the patient, his situation, and his values, and their significance to the patient. Relatives reported that being able to visit the patient every hour of the day was important, so that they could express their love and affection, support the patient in his last phase of life and meaningfully contribute to the patient's well-being. Therefore the opportunity to stay during the nights and to have a meal and beverage at the bedside was important. Furthermore, relatives needed acknowledgement of their feelings of uncertainty regarding their position in the hospital. For example, it was seen as helpful to have a conversation with the nurse after the patient's death to be affirmed in the adequacy of their role and care. Acknowledgement of and respect for relatives also was important after the patient's death, e.g. when confirming the patient's death, discussing organ donation, offering condolences, and providing relatives time to say goodbye.

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### Box 3: Acknowledgment

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#### Quotes

They asked only him for information, but his answers were confusing and the staff did not understand him. I did, but they did not listen to me. (R724, wife, 42y)

They did not ask me once about how she should be cared for. (R263, husband, 47y)

..... he had been hospitalized shortly, and they supported him by allowing me, after his admission at night, to stay as long as I wanted to (R336, wife, 64y)

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## Trust

Trust concerned experiences about whether HCPs provided good care, or what relatives believed to encompass good care, whether HCPs did what they promised to do, and whether they did all they could to relieve the patient's suffering (box 4). Relatives reported about feeling stressed when they felt that the quality of care was insufficient. Others felt confident when they left the patient knowing that he was in good hands. These experiences were often related to relatives' experienced knowledge and skills of the HCPs, e.g. regarding symptom control and communication, attitudes towards the patient, such as showing respect and loving care, and to the availability of enough medical and nursing staff. Disagreement about medical decisions, both within the medical team and between the physician and the patient or relatives, affected relatives' feelings of confidence.

**Box 4: trust**

## Quotes

'We were asked to give her food and drinks. thereafter we had left, the food just stood there, even though she could not reach it.' (R 940, personal coach, 28y)

'If we wanted to go out for a while, we could leave him behind in good hands' (R 7, daughter, 32 y)

'Five days before he died he asked for extra pain medication because he couldn't take it anymore. The physician refused, because he did not consider him to suffer "hopelessly". Who decides on that? The physician? Or the patient who feels that life is slipping away while he almost literally dies of his pain? (R 56, daughter, 40y )

**Rest and privacy**

Experiences concerning rest and privacy were related to having a private room for the patient, silence and privacy when receiving visitors, being able to share time and emotions and to be oneself (box 5). Rest also involved avoiding futile medical examinations, which were a burden for the patient. When having a private room, relatives reported about 'being on their own' with the patient, which could either be experienced as being abandoned or as being respected in their privacy. This seemed to be related to undisclosed expectations about whether HCPs should pro-actively enter the patient's room or on the patient's or relatives' initiative.

**Box 5: rest and privacy**

The final 24 hours, especially the very last hours, our "being together" was a positive experience. The nurses from the night shift were totally unaware of approaching death. (593, husband, 56 y)

'There was not enough rest. Too much noise on the corridor and much agitation in the room of the patient!!!' (R 549 wife, 50y)

'Even though we requested to bother him as little as possible, they were still carrying out many burdensome examinations.' (R 542, wife, 60y)

The evening before he died we had a very good conversation (R 116 , daughter, 47y)

**INTERPRETATION**

Bereaved relatives felt better able to represent the patient when they were acknowledged in their role as caregiver, representative and close relative, and as such to be timely informed and involved in making decisions about treatment and care. Experiences were more positive when the patient was provided with optimal care and felt as comfortable as possible and when there was sufficient trust, privacy and rest in end-of-life care.

## Explanation of findings

Our findings are in line with those of Heyland et al (2006), who described the priorities for end-of-life care of patients with advanced diseases and their relatives, such as trust and confidence, clear information, and being involved in decisions<sup>13</sup>. To represent the patient's interests in decision-making when needed, relatives require timely information about the illness and options for treatment, to enable them to discuss preferences for treatment and care with the patient<sup>17,18,24</sup>. Not all patients can be expected to completely inform their relatives. Therefore HCPs should timely ask patients to designate a relative to receive medical information. Furthermore, HCPs' attitude should support relative's confidence in maintaining their caregiver role in an unknown place with unknown routines<sup>4,7</sup>.

These findings suggest that relatives have two distinguishable roles during the last phase of life of the patient. Firstly, HCPs should acknowledge that the patient's illness is also a problem of relatives<sup>8,25</sup>. It is not an isolated, nor a temporary event, but a highly stressful non-reversible situation that deeply affects the relative's life and future [8]. Because of this, relatives need care and attention of hospital staff themselves, which extends to the period after the patients' death, when relatives realize that the patient has died and might need support in their bereavement process and in moving forward with their lives<sup>19</sup>. Secondly, relatives have the role of caregiver and of advisor in complex decisions, and eventually may need to act as the patient's representative. During the last days of life the physical and mental health of patients and their decision-making capacity may fluctuate and gradually diminish, which demands flexibility of relatives to the role of representative. Palliative care should therefore also support relatives in their role as an intermediate between the patient and HCPs, with the end-goal of improving the quality of life and quality of dying of the patient.

In addition, the identity of severely ill patients shifts dramatically in the hospital, as compared to when they were still at home. Care in the hospital is often impersonal and fragmented and tends to reduce patients with full histories and relational identities into diseased body parts that are described and approached in medical jargon<sup>8</sup>. Patients are connected to their relatives and these relationships shape their identity. Relatives are reminders that the patient is not merely a collection of dysfunctional body parts that require professional intervention, but a moral agent with a history and important relationships. Relatives are the constant factors in a changing plethora of HCPs<sup>8</sup>. They enable the patient to maintain his identity, to live his personal life till the end and to die in accordance with his values. Because relatives know the patient best and want to ensure that his interests are respected as well as possible, relatives want to have an intermediate role between the patient and healthcare staff.

HCPs' acknowledgement of relatives' role and expertise towards patients at the end of life might be a prerequisite for other positive experiences. When HCPs acknowledge this role, comprehensive and timely information, involving relatives in decision-making, and

facilitate rest, privacy, and practical facilities might be a natural consequence. Structural attention to relatives seems to be in contrast with current clinical practice in the hospital, e.g. in attitudes of HCPs and in the organization of care<sup>12</sup>. The focus in Western health-care is on the individual patient, to the exclusion of the interests of others<sup>8</sup>. Especially in North-Western countries, HCPs in hospitals do not prioritize attention to a patient's social network and structures of care might not be appropriate to do so<sup>10</sup>. Hospital care is primarily focused on the individual autonomous patient, considering him to be rational and independent<sup>9</sup>, and respecting his rights on information, confidentiality and privacy<sup>25</sup>. In this context the concept of individual autonomy as one of the main principles in healthcare might fail. It is important to acknowledge that interdependence is inextricably tied to the human condition<sup>26</sup>. People are connected and involved with each other<sup>27</sup>. The concept of relational autonomy, in which the patient and the relatives are seen as interdependent, is more appropriate in end-of-life care<sup>28</sup>, where the involvement of relatives is important in preserving or restoring an overall sense of patients' identity, agency and selfhood<sup>29</sup>.

### Limitations and strengths

A limitation is that this study was conducted in one hospital, which may limit the generalizability of the findings. The research questions of the original study were focused on the patient, and not primarily on the experiences of relatives. Furthermore, the study originally was not performed as a qualitative study; the qualitative design of this study however allowed for an in-depth analysis of all the comments. We found many similar comments within the 451 completed questionnaires, suggesting that we have reached saturation of data.

### Conclusion

This study shows that relatives of patients dying in the hospital need to be acknowledged in their role of caregiver and representative of the patient and to be informed and involved in decision-making. In addition, relatives need to be able to trust HCPs in providing good care. They also need practical support. Such acknowledgement and support enables them to take care of the patient and represent his interests at the end of life. This may conflict with an approach that is based on the principle of individual autonomy. Relational autonomy, considering patient and relative to be connected and interdependent, is probably a more appropriate concept in end-of-life care.

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# 7

## Is physician awareness of impending death in hospital related to better communication and medical care?

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## ABSTRACT

### Background

In hospitals, where care is focussed on cure and life prolongation, impending death is often recognized too late. Physician awareness of impending death is a prerequisite for communication with patients and relatives about dying in hospital and providing care that adequately addresses patients' needs.

### Objective

To examine to what extent physicians are aware of the impending death of their dying patients and if awareness is related with communication and medical care at the end of life, with quality of life in the last three days and quality of dying.

### Design

Retrospective survey among hospital physicians after patient deaths.

### Setting/Subjects

Patients who died between June 2009 and February 2011 at Erasmus University Medical Center (Rotterdam, the Netherlands).

### Measurements

Physician self-reported awareness of impending death, communication with patients and relatives, medical care, quality of life in the last three days and quality of dying.

### Results

The response rate was 44% (N=228). Physicians reported that they had been aware of the impending death in 67% of their dying patients. If they had been aware, discussing death with patients and relatives was more likely, as well as changing the treatment goal into comfort care or withholding treatment and prescribing opioids in the last three days of life. When physicians had been aware of impending death, they rated the quality of dying higher.

### Conclusions

In two-thirds of deaths, hospital physicians had been aware of impending death of their dying patients. Physician awareness was related with more communication and more appropriate care in the last days of life.

## INTRODUCTION

In the Netherlands hospital mortality is lower than in most other European countries and worldwide, but still 30% of all deaths occur in hospital<sup>1,2</sup>. Previous research has indicated that the quality of care at the end of life in hospitals may sometimes be unsatisfactory<sup>3-6</sup>. In general, several barriers that prevent physicians from providing appropriate care and communication with both patients and their family caregivers at the end of life were reported. One barrier was a feeling of discomfort with discussing death and dying<sup>7,8</sup>. A prerequisite for providing appropriate care at the end of life is physician awareness of impending death<sup>9</sup>. In hospitals, where care is typically focused on cure and prolongation of life, recognition of impending death is known to occur late<sup>6</sup>, possibly impeding appropriate care at the end of life<sup>10</sup>. Still, awareness of impending death may not automatically result in adequate end-of-life care.

Few studies examined physician awareness of impending death in hospital and whether this is associated with better communication, medical care and quality of dying and death<sup>9</sup>. The aim of this study was to examine to what extent physicians in a hospital were aware of the impending death of their dying patients, and if this was related with physician communication with patients and relatives, medical care at the end of life, quality of life in the last three days and quality of dying.

The research questions were:

1. To what extent are hospital physicians aware of the impending death of their dying patients in hospital?
2. To what extent is physician awareness of impending death related to physician communication and medical care?
3. To what extent is physician awareness of impending death related to the quality of life in the final three days and to the quality of dying?

## METHODS

For this study we used data collected with a retrospective survey among physicians after patient deaths at Erasmus University Medical Center (Erasmus MC), a 1300-beds university hospital in Rotterdam, The Netherlands. This is part of the PalTec-H-study on understanding and improving palliative and terminal care in the hospital<sup>11</sup>.

### Participants

Physicians were surveyed about patients who died at one of 18 participating wards between June 2009 and February 2011, if the patient had been admitted at least six

hours prior to death. The participating wards were all wards of Erasmus MC, including a specialised unit for palliative cancer care, but excluding the department of psychiatry and the intensive care departments.

### Data collection

For each deceased patient at the participating wards, a coordinating nurse provided a questionnaire (in Dutch) to a physician involved in that patient's care within one week after death. The questionnaire was anonymous. Responding physicians sent their completed questionnaires to the principal investigator of the PalTec-H-study (F.E. Witkamp). Missing information about patient and care characteristics such as diagnosis and do-not-resuscitate agreements were derived from the patients' hospital records, when not provided by the surveyed physician.

### The questionnaire

A 35-item survey instrument was used. Physicians were asked if they had been aware of the impending death of the patient, and if so, how long before death: less than six hours; between 6 and 12 hours; 12-24 hours, 24-48 hours, 48-72 hours before death or more than three days before death. The physicians were also asked to rate patients' quality of life during the final three days and quality of dying, using a 0-10 numerical rating scale (10 is best), which is comparable to the global ratings in the Quality of Dying and Death questionnaire<sup>12</sup>. Other items in the questionnaire concerned patient characteristics (sex, age, cause of death, duration of final admission); physician characteristics (sex, age, experience as a physician, number of dying patients cared for in the last 12 months); physician communication about impending death with the patients, their relatives and their family physicians; changes in treatment goals during the last days of life; prescription of opioids and sedatives.

### Analysis

When a physician reported that impending death was not recognized until less than six hours before the patient's death, we considered it to be a death of which the physician had not been aware in advance. Bivariate associations between awareness of impending death, and physician communication and medical care in the last days of life were analyzed using contingency tables and Pearson's  $\chi^2$ -tests. Bivariate associations between awareness of impending death and quality of life during the three final days and quality of dying were examined using t-tests. IBM SPSS statistics (version 20) was used for all computations.

### Ethical considerations

Approval for this study was given by the medical ethical research committee of the Erasmus MC. According to Dutch legislation, informed consent of patients was not required because the data were gathered after patients' death and the study involves no risk for the patients.

## RESULTS

Physicians completed the questionnaire for 228 of 524 patients who died during the study period, resulting in a response rate of 44%. Of those 228 patients, 60% were male; mean age was 67 years (standard deviation [SD]: 14 years); 45% died of cancer, 51.4 % of other conditions, and 3.6% of a combination of the above. Mean duration of the final hospital stay was 17 days (SD: 24 days) and 35% died within 4 days after admission. No differences were found in gender, age, cause of death, and duration of final admission between patients for whom physicians did and did not respond. Of the responding physicians 58% were female, 45% were younger than 30 years and 64% had less than 5 years of experience as a physician. Almost one third (31%) had cared for 2 or fewer dying patients in the previous 12 months.

### Awareness of impending death

Physicians reported that they had been aware of impending death in 67% of dying patients and 'more or less' aware in another 12%; in 21% of deaths, the imminence of

**Table 1** Physician awareness of impending death of patients dying in hospital (N=228)

	<i>n</i> <sup>a</sup> (%) <sup>b</sup>
Had it prior to death been clear that the patient would die within hours or days?	
Yes	152 (67)
More or less	27 (12)
No	47 (21)
If it had been clear, when did it become clear?	
Longer than 3 days before death	47 (32)
On day 3 (72 - 48 hours) before death	22 (15)
On day 2 (48 - 24 hours) before death	31 (21)
24 - 12 hours before death	34 (23)
12 - 6 hours before death	12 (8)
If it had <u>not</u> been clear that the patient would die within hours or days, what was the cause of such non-awareness?	
Medically there was no reason to expect death within a few days	24 (83)
The patient had only recently been admitted to the ward and the first investigations were still ongoing	2 (7)
The health situation of the patient was unclear	0 (0.0)
Other	3 (10)
If it had <u>not</u> been clear in advance that the patient would die within hours or days, could the physician, have recognized it in retrospect?	
Yes	4 (14)
More or less	7 (25)
No	17 (61)

<sup>a</sup> Numbers may not add up to *n* because of missing values

<sup>b</sup> Presented percentages are column percentages

death had not been recognized (Table 1). In 68% of cases in which physicians had been aware that death was impending, it became apparent in the last three days before death. In 83% of the cases in which physicians had not been aware of impending death, they reported there was no medical reason to expect death within a few days; in 61% of the cases in which physicians had not been aware of impending death physicians reported that in their opinion they could not have recognized the imminence of death. Awareness of impending death was similar at the palliative cancer care unit (67.5%) compared to the other participating wards (67.2%) (data not shown in table).

Physician awareness of impending death was not related to patient characteristics (age, sex, cause of death, length of stay), or physician characteristics (age, sex, staff position, number of dying patients attended in the last 12 months).

### Awareness of impending death and physician communication in the last three days of life

According to physicians, they or a colleague physician discussed the patient's death with 51% of patients and with 87% of relatives (Table 2). The patient's family physician was informed about the patient's impending death in 22% of cases. When comparing cases in which physicians had not been aware to cases in which physicians had been aware of patient's impending death, it was more likely in the latter that they had discussed death with patients (in 57% vs. 39%;  $p$ -value 0.01) and with relatives (95% vs. 72%;  $p < 0.01$ ). Physician awareness of impending death was only weakly associated with informing the

**Table 2** Physician awareness of impending death of patients dying in hospital and physician communication ( $N=228$ )

	Physician had been aware of impending death			$p$ -value <sup>c</sup>
	Total	Yes	No/ More or less	
	$n^a$ (%) <sup>b</sup>	%		
Did the physician discuss death with the patient?				0.01
Yes, or a colleague (physician) did	114 (51)	57	39	
No	108 (49)	43	61	
Did the physician discuss death with relatives?				<0.01
Yes, or a colleague (physician) did	194 (87)	95	72	
No	29 (13)	5	28	
Was the family physician informed about the patient's death?				0.06
Yes	40 (22)	26	14	
No	139 (78)	74	86	

<sup>a</sup> Numbers may not add up to N because of missing values

<sup>b</sup> All percentages are column percentages

<sup>c</sup> Pearson  $\chi^2$

patient's family physician about the patient's death (in 26% of cases when impending death had been recognized vs. in 14% when it had not been recognized;  $p=0.06$ ).

Awareness of impending death and medical care in the last three days of liAt the time of admission, in 56% of cases the treatment goal was diagnosis, cure, life prolongation, or recovery and in 44% of cases it was symptom treatment, comfort care or withholding treatment. In the last three days of life, in 58% of deceased patients the treatment goal had not been changed, in 34% it was changed into comfort care or withholding treatment, and in 8% into cure, life prolongation or recovery (Table 3). The decision to change the treatment goal was discussed with the patient in 61% of the cases, and with relatives in 94% of cases. If the physician had been aware of impending death, changing the treat-

**Table 3** Physician awareness of impending death of patients dying in hospital and medical care at the end of life ( $N=228$ )

	Physician had been aware of impending death			<i>p</i> -value <sup>c</sup>
	Total	Yes	No/More or less	
	<i>n</i> <sup>a</sup> (%) <sup>b</sup>	% <sup>b</sup>		
Was the treatment goal changed during the last days of life?				<0.01
No	127 (58)	48	78	
Yes, into comfort care or withholding treatment	76 (34)	45	13	
Yes, into cure, life prolonging, recovery or other	18 (8)	7	10	
Was the patient involved in the decision to change the treatment goal? <sup>d</sup>				0.77
Decision was discussed with patient	54 (61)	61	57	
Decision was not discussed with patient	35 (39)	39	43	
Was the relative(s) involved in the decision to change the treatment goal? <sup>e</sup>				0.30
Decision was discussed with relative	85 (94)	93	100	
Decision was not discussed with relative	5 (6)	7	0	
Were opioids prescribed to the patient during the last days of life?				<0.01
Yes	156 (76)	84	59	
No	50 (24)	16	41	
Were sedatives prescribed to the patient during the last days of life?				0.81
Yes	70 (33)	34	32	
No	142 (67)	66	68	
Did the patient receive palliative sedation therapy?				0.23
Yes	60 (27)	30	22	
No	162 (73)	71	78	

<sup>a</sup> Numbers may not add up to N because of missing values

<sup>b</sup> All presented percentages are column percentages

<sup>c</sup> Pearson  $\chi^2$

<sup>d</sup>  $n=89$

<sup>e</sup>  $n=90$

ment goal into comfort care or withholding treatment was more likely as compared to cases in which the physician had not been aware (45% vs. in 13%;  $p$ -value  $< 0.01$ ). In 76% of patients opioids were prescribed during the last three days. Prescription of opioids was more likely when the physician had been aware of impending death, compared to non-awareness (84% vs. 59%;  $p$ -value  $< 0.01$ ). In 33% of patients sedatives were prescribed during the last three days. Prescription of sedatives was not more likely when the physician had been aware of impending death compared to non-awareness (34% vs. 32%,  $p$ -value: 0.81). Palliative sedation therapy was used in 27% of all deceased patients and its use was not related to the awareness of impending death.

### Awareness of impending death and quality of life in the last three days and quality of dying

The overall score for quality of life in the last three days was 4.7 (SD: 2.0); for quality of dying it was 6.9 (SD: 1.6). When they had been aware of impending death, the physicians rated the quality of dying of their patients as better than when they had not been aware (mean: 7.0 vs. 6.4;  $p$ -value=0.02) (Table 4). Whether or not physicians had been aware of impending death was not related to quality of life in the last three days.

**Table 4** Physician awareness of impending death and quality of life during the last three days and quality of dying of patients dying in hospital according to the hospital physician (**N=228**)

	Physician awareness of impending death			$p$ -value <sup>a</sup>
	Total	Yes	No/ More or less	
	Mean (SD)			
Quality of life during the last three days of life, according to the physician? <sup>b</sup>	4.7 (2.0)	4.6 (2.2)	4.9 (1.6)	0.29
Quality of dying, according to the physician? <sup>b</sup>	6.9 (1.6)	7.0 (1.4)	6.4 (1.7)	0.02

<sup>a</sup> t-test

<sup>b</sup> Missing values:  $n=50$   
SD: standard deviation

## DISCUSSION

In this study hospital physicians had been aware of impending death in two-thirds of their dying patients. If they had been aware, physicians were more likely to discuss death with patients and their relatives, to change the treatment goal into comfort care or withholding treatment, and to prescribe opioids in the last three days of life. Physicians rated the quality of dying higher in patients for whom they had been aware of impending death.

Our response rate was rather low, although it was comparable to the response rates in other surveys among physicians<sup>13</sup>. Non-response bias is a risk, although on all wards physicians participated and patients for whom physicians responded did not differ in



demographic characteristics, diagnosis or duration of final admission from patients not included. Responding physicians might have been more dedicated to palliative and terminal care and therefore more likely to be aware of their patients' impending death, possibly resulting in an overestimation of the awareness rate. The latter may also be a result of self-report bias. The self-reporting by physicians about their own clinical practice in end-of-life care may result in answers not always reflecting the real behaviour of physicians, but what is considered desirable in caring for people at the end of life<sup>14</sup>. Recall bias cannot be completely ruled out, though it may be limited because the questionnaires were distributed within a week after the patients' death. Further, only physicians' perspectives are reported in this study, which most probably differ from the perspectives of relatives and other healthcare professionals<sup>15</sup>. Comparing the perspective of physicians, relatives and nurses may result in a more nuanced description of communication and care at the end of life for people dying in hospitals. Our study was performed with physicians of patients of a large teaching hospital, which may limit the generalizability of our findings to other hospitals<sup>16</sup>, healthcare settings<sup>17</sup>, or other countries<sup>1</sup>.

In a majority of deaths, hospital physicians reported that they had been aware that death would occur within days or hours; in one-third of deaths physicians were not or only more or less aware of impending death. Our findings regarding physician awareness are comparable to the results of a post-mortem survey among hospital physicians in the US<sup>9</sup>, but substantially higher than what was found in a retrospective chart review in a German teaching hospital, where for only 38% of hospital deaths evidence was found that medical staff was aware of impending death<sup>6</sup>. The high self-reported awareness rate of impending death we found is also surprising in the context of previous research, in which physicians tended to systematically overestimate the life expectancy of their terminally ill patients<sup>18</sup>. In our study, life expectancy may still have been overestimated until the moment at which the imminence of death was recognized. Our finding may be partly explained by the attention for the needs of terminally ill patients and the establishment of palliative care consultation teams in many healthcare settings in the Dutch healthcare system, including hospitals<sup>19-22</sup>. At Erasmus MC, a specialist palliative care consultation team is available to support doctors and nurses in providing palliative and terminal care<sup>23</sup>. The number of consultations of the Erasmus MC palliative consultation team has increased over the past years, indicating the embedding of the team in the hospital<sup>24</sup>. We hypothesize that since the palliative care team does not take over the care of the usual caregivers in the hospital, the availability of the team may result in a learning effect, more attention and better skills regarding recognition of impending death.

In more than half of the patients, the attending physician or a colleague physician personally discussed the impending death with the patient; in a similar US-study only 11% of physicians reported personally speaking with patients about dying<sup>9</sup>. Open awareness and communication about dying may be more common in the Netherlands, as suggested

by higher prevalences of advance care planning and patient preferences for place of death known by general practitioners, as compared to other countries<sup>25-27</sup>. However, in 39% of cases in which the treatment goal was changed in the final days of life this was not discussed with the patient, which may indicate that such decisions were made late in the disease process and could no longer be discussed with the patient. Communication about treatment options and patient's preferences at the end of life should therefore not be postponed to the final days of life.

Moreover, when deaths were recognized, communication with patients and relatives about death, changing the treatment goal into comfort care or withholding treatment and prescribing opioids became more likely, suggesting that hospital physicians consider end-of-life care of their patients as part of their professional responsibility, despite the focus of hospitals on curative and life-prolonging care. Palliative sedation therapy was not related to awareness of impending death, which may partly be explained by our limitation of physician awareness of at least 6 hours prior to death. The use of palliative sedation therapy, in 27% of cases, was remarkably high compared to the incidence of continuous deep sedation of 12.3% found in all deaths in the Netherlands in 2010<sup>28</sup>. Nevertheless, it was found before that people dying in hospitals were about twice as likely to receive continuous deep sedation compared to those dying at home or in long-term care settings, which may be explained by the higher chance of people with severe refractory symptoms, in whom palliative sedation is indicated, to die in hospitals<sup>29</sup>.

Identification of key points in the course of chronic life-limiting illnesses, such as the diagnosis, the transition from mainly curative to palliative care and the start of the dying phase, is of major importance to assess palliative needs and provide adequate palliative care. Professional caregivers in all health care settings, hereby assisted by palliative care specialists, should be trained to recognize those key points, to discuss options with patients and family caregivers, and to provide adequate palliative care. It has been shown that patient awareness of impending death is related with better care at the end of life and better quality of dying<sup>30,31</sup>. In particular, skills to timely recognize impending death should be an important topic in the training of hospital physicians, as well as developing the attitude that providing adequate terminal care to the dying and their relatives is an integral part of hospital care.

## CONCLUSION

This study shows that physician awareness of impending death of hospital patients was associated to anticipating care, yielding better communication and appropriate medical care at the end of life.

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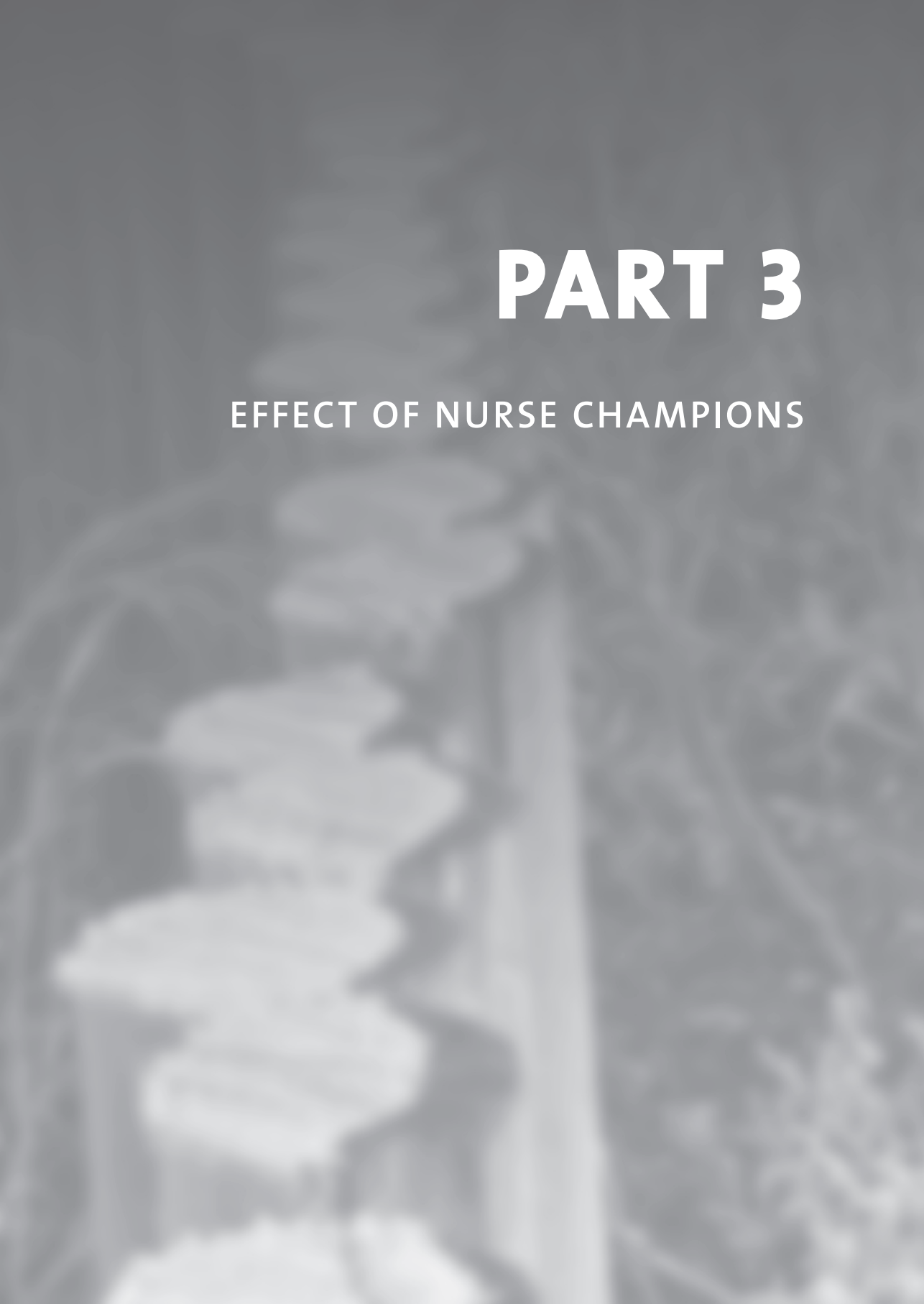
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# PART 3

## EFFECT OF NURSE CHAMPIONS







# 8

## Effect of palliative care nurse champions on the quality of dying in the hospital according to bereaved relatives: a controlled before and after study

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## ABSTRACT

### Background

To improve the quality of end-of-life care, hospitals increasingly appoint palliative care nurse champions. We investigated the effect of nurse champions on the quality of life during the last three days of life (QOL3) and the quality of dying (QOD) as experienced by bereaved relatives.

### Methods

In a controlled before and after study (June 2009-July 2012), each death at non-intensive care units in a university hospital was followed by an invitation to relatives (10-13 weeks later) to answer a questionnaire. Halfway through the study, two nurse champions were appointed in each of 7 intervention wards; 11 wards served as control wards. The QOL3, QOD, and multiple dimensions of QOD, were compared before and after the introduction of nurse champions. Data were analysed with t-tests, Mann Whitney-U and Pearson's Chi<sup>2</sup> tests.

### Results

For the two periods, data were collected on 86 and 84 patients, respectively, in intervention wards, and on 108 and 118 patients, respectively, in control wards (overall response 52%). In the intervention wards, no differences were found in QOL3 and QOD scores pre- and post-intervention: in both periods, median score for QOL3 was 3.0 and for QOD 7.0. No differences were found in multiple QOD dimensions. In control wards the median QOD score was 7.0 pre-intervention and 6.0 post-intervention ( $p=0.04$ ). Other scores were comparable with those in intervention wards.

### Discussion

After introduction of nurse champions, no improvements were found in experiences of bereaved relatives concerning the QOL3 and the QOD of patients dying in hospital.

## BACKGROUND

In Western countries many patients die in the hospital<sup>1,2</sup>. As hospital care focuses on cure and prolonging life, staff competence regarding palliative and terminal care in hospital is not necessarily a matter of course<sup>3-5</sup>. Studies have reported unmet needs of patients dying in the hospital, e.g. regarding symptom control, communication, and awareness of approaching death<sup>6-11</sup>. However, improving the quality of hospital end-of-life care is complex. Shortcomings in processes and structures of care, as well as in staff competence, have to be addressed. Therefore, multiple strategies are needed which have to be disseminated throughout the hospital in various wards<sup>12</sup>.

In many healthcare settings, networks of nurse champions are set up, primarily aimed to support the dissemination of specific knowledge and, finally, to improve the quality of care. The effects of palliative care nurse champions in hospitals have rarely been evaluated. Studies in the UK reported that nurse champions themselves experienced increased knowledge on palliative care and felt more confident in collaborating with physicians and experts<sup>13-16</sup>. To our knowledge no study has evaluated the effects of palliative care nurse champions on the quality of care as experienced by patients or their relatives. In general, experimental studies on quality improvement interventions in end-of-life care in the hospital are scarce<sup>12</sup>. Health services research in palliative care involves methodological and ethical challenges related to the complex nature of most interventions, ethical limitations of doing research among dying patients, and the risk of selection bias and confounding<sup>9,17-20</sup>. Innovative experimental study designs are needed to evaluate whether changes in structures, processes and competencies in palliative care affect patient outcomes<sup>9,19,20</sup>. An intervention with nurse champions in the hospital setting is such a complex intervention, aimed at changing processes and competencies in care<sup>19,21</sup>. Many factors may contribute to the effects, such as individual champions' knowledge and skills, the ward staff's attitude towards end-of-life care, and interdisciplinary collaboration. Furthermore, effective processes of dissemination of knowledge and skills, and changed behaviour, are a prerequisite for improving the quality of care as experienced by patients or their relatives. This study investigates the effect of palliative care nurse champions on the quality of dying (QOD) in the hospital, as experienced by bereaved relatives.

## METHODS

This study is part of a large study on understanding Palliative and Terminal Care in the Hospital (PalTeC-H); the study protocol and rationale are extensively described elsewhere<sup>22</sup>.

## Design

We performed a controlled before-after study in 18 non-intensive care wards of a 1300-bed Dutch university hospital. Halfway through the study, in 7 intervention wards (i.e. medical oncology and geriatrics, internal medicine, Ear, Nose & Throat surgery, gastrointestinal surgery, gynaecology and urology, lung diseases, and cardiology) two nurses were appointed to become a palliative care nurse champion (hereafter referred to as: nurse champion). Data were compared before and after the introduction of nurse champions, and results were compared to outcomes in the same periods in 11 control wards in which the intervention was not applied. The pre-intervention phase lasted from June 2009 to October 2010 and the post-intervention phase from March 2011 to July 2012 (both periods 16 months each).

## The intervention

In October 2010, the nurses who were appointed to the position of nurse champion became a member of a palliative care nursing network. At least one nurse champion per ward was expected to participate in the monthly network meetings. Furthermore, they all attended a yearly two-day education program on palliative care, including symptom management, communication skills, and terminal care. Our main goal was to enable the nurse champions to identify gaps in knowledge and quality regarding palliative care on their ward, to raise ward staff's awareness of palliative care needs and to initiate care improvement programs, e.g. on the management of pain or delirium. A senior nurse-specialist on palliative care coordinated the network; she organised the meetings and education programs, and supported the nurse champions in their individual activities.

## Study population

For each adult patient who had died in the hospital after a hospitalisation of at least 6 h, we included one close relative. An invitation was sent to the former address of the patient, or to the address of the close relative in case this was earlier provided to the ward nurse.

## Ethical considerations

The study was approved by the Medical Ethical Research Committee of the hospital. According to Dutch regulation, written informed consent of patients was not required because we only collected observational data after the patient's death and the study involved minimal risk to the participants. In case of emotional distress due to participation, participants were given the opportunity to call or meet the nurse investigator.

## Questionnaire

We hypothesised that QOD in the hospital would be multidimensional including, e.g., physical, psycho-social and spiritual experiences, life closure and death preparation, and care processes<sup>22-24</sup>. End-of-life care was defined as care provided during the last three days of life. Palliative care experts developed a questionnaire that comprehensively assessed the experiences of bereaved relatives with regard to QOD, QOL3 and end-of-life care. Preliminary versions were critically evaluated by a representative of the hospital patient council, tested on relevance and face validity among persons who had recently lost a relative, and piloted in the first 30 cases. The final version of the questionnaire contained 93 items. Patient characteristics, such as date of birth, gender, and the duration and ward of final hospitalisation were derived from the hospital administration, and the diagnosis cancer or non-cancer from the medical file. In a study among 249 relatives we previously analysed which dimensions and items most determined the QOD according to relatives, i.e. the dimensions of physical symptom burden (7 items), psychological symptom burden (7 items), acceptance of death (2 items), medical care and symptom management (4 items), shared decision-making (2 items), preparation on and circumstances of death (5 items), personalised care (5 items), and supportive care and care for relatives (4 items) (see Box 1)<sup>25</sup>.

## Data collection

The relative was invited by the primary investigator (FEW), 10-13 weeks after the death, to participate in the study and complete the questionnaire. In cases of non-response, one reminder was sent after 4 weeks. Participants could also ask the investigator to complete the questionnaire during an interview, e.g. in case of illiteracy or visual impairment. Participants were informed about the general aim of the study (i.e. to assess the quality of dying and end-of-life care in the hospital) but not about the intervention and the assignment of the study groups.

## Endpoints

Primary endpoints were relatives' global numerical scores (0-10) on QOL3 and QOD, asking "How would you evaluate the quality of life during the last 3 days of life of your relative?", and "How would you evaluate the quality of dying of your relative?", with 0 indicating "very poor" and 10 indicating "almost perfect". Secondary endpoints were scores of previously mentioned domains<sup>25</sup>.

## Data analysis

To measure a difference of one unit on the QOL3 and the QOD scales between the pre- and post-intervention phase, with an assumed standard deviation of 2.5, we needed data on 400 patients: i.e. 100 patients both before and after the intervention, on both the

<b>Box 1: Domains of Quality of Dying</b>	
Domains	Topics
Physical symptom burden	Pain
	Dyspnoea
	Dry mouth
	Trouble sleeping
	Fatigue
	Nausea
	Agitation
Psychological symptom burden	Anxiety
	Loneliness
	Tenseness
	Sadness
	Powerlessness
	Worrying
	Depressive mood
Acceptance of imminent death	Patient being in peace with imminent death
	Patient being aware of imminent death
Medical treatment and symptom management	Alleviation of symptoms
	Staff's efforts to alleviate symptoms and problems
	Relative being informed on imminence of death
	In hindsight, evaluation of hospital as right place of death
Preparation on and circumstances of death	Relative being aware of imminent death
	Attention to hospital facilities and wishes of patient and relatives
	Relative being present at moment of death
	Relative saying goodbye
	Patient saying goodbye
Shared decision-making	Patient participation in nursing care decisions
	Patient participation in medical decisions
Personalised care	Affirmation of the patient as a person
	Attention to preferred rituals at moment of death
	Opportunities to discuss personal or religious preferences
	Patient having discussed preferences on EoL treatment
Supportive care and care for relatives	Social and spiritual support last 24 h.
	Relative participation in nursing care decisions
	Relative being informed about condition and care
	Relative participation medical decisions
	Nursing care final 24 h.

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intervention and the control wards<sup>22</sup>. Anticipating a participation rate of 50% among the relatives, we aimed to include 800 patients.

Domain-related items were recoded to dichotomous values: physical and psychological symptoms rated by relatives as “moderate” or “severe” were recoded to value 1; the answers “don’t know”, “none” or “mild” were recoded to value 0; For other items that could be answered as yes, no or don’t know, value 1 was used for yes and 0 for the other two possible answers. Per domain we counted the values of the variables. Principal component analyses showed that the different variables per domain were similarly correlated, resulting in the same weight for all values. In the two symptom domains, a higher score indicated a lower QOD, and a higher score in the other domains indicated a higher QOD. The mean value per domain was calculated. We compared outcomes of QOL3, QOD, and the mean domain values, pre- and post-intervention in the intervention wards. Subsequently, the findings were compared to outcomes in the same periods in the control wards. Data were analysed with t-tests, Mann Whitney-U tests, and Pearson’s Chi-square tests, using SPSS data analysis software, version 21.

## RESULTS

During the study period 818 patients (similarly distributed between pre- and post-intervention assessment) died, i.e. 351 in the intervention wards and 467 in the control wards. Relatives of 49 deceased patients (6%) could not be traced and in three cases healthcare staff had objections against asking the relative to participate. A questionnaire was sent to 761 relatives; 396 (52%) participated, i.e. 170 in the intervention wards (86 pre- and 84 post-intervention) and 226 in the control wards (108 pre- and 118 post-intervention). One participant requested a face-to-face interview to fill out the questionnaire. The patients that were reported on were older than patients of whom no relative participated (68.5 vs 65.5 years;  $p=0.006$ ). No differences were found between responders and non-responders for patients’ gender, duration, and ward of last hospitalisation.

### Characteristics of patients and relatives

A majority of patients was male, lived in partnership until last admission, and had been ill for  $\geq 6$  months (Table 1). Relatives were most often the partner or child of the patient and, on average, relatives completed the questionnaire 15.6 weeks (sd 5.8) after the patient’s death. Some of the characteristics differed slightly between the pre- and post-intervention assessment, e.g. regarding patient’s and relative’s age, and the duration of hospitalisation.

Table 1: General characteristics

	Intervention wards <sup>a</sup> (N=167)			Control wards <sup>b</sup> (N=215)		
	Pre-intervention n=86	Post-intervention n=84	Difference pre-post <sup>c</sup> (p-value)	Pre-intervention n=108	Post-intervention n=118	Difference pre-post <sup>c</sup> (p-value)
Patients						
Age in years; mean (SD)	69 (12)	68 / 13	0.81	67 (17)	70 (13)	0.08
Gender						
Male	54 (63)	53 (63)	0.97	60 (56)	65 (55)	0.91
Female	32 (37)	31 (37)		48 (44)	53 (45)	
Marital status	49 (57)	58 (70)	0.10	65 (60)	79 (67)	0.42
Married/living with a partner						
Widowed/Divorced/Living alone/Other	37 (43)	26 (30)		43 (40)	39 (33)	
Children						
One or more children < 19 years	9 (11)	5 (6)	0.21	7 (6)	11 (9)	0.33
Only children ≥ 19 years	63 (73)	57 (68)		69 (64)	83 (71)	
No	14 (16)	22 (26)		32 (30)	24 (20)	
Education						
Low (ISCED level 1-2)	29 (34)	25 (30)	0.79	31 (29)	41 (35)	0.47
Intermediate (ISCED 3-4)	33 (38)	34 (41)		40 (37)	42 (35)	
High (ISCED 5-6)	14 (16)	11 (13)		24 (22)	23 (20)	
Other/ unknown	10 (12)	14 (17)		13 (12)	12 (10)	
Religious						
Yes	42 (49)	41 (50)	0.87	56 (52)	69 (59)	0.13
No/ unknown	44 (51)	43 (50)		52 (48)	59 (41)	
Diagnosis <sup>d</sup>						
Cancer	47 (55)	51 (61)	0.47	42 (39)	57 (48)	0.16
Non-cancer	39 (45)	33 (39)		66 (61)	61 (52)	
Duration of severe illness						
< 1 month	6 (7)	8 (10)	0.83	21 (21)	25 (22)	0.83
≥ 1 and ≤ 6 months	26 (31)	24 (29)		19 (19)	25 (22)	
> 6 months	52 (60)	52 (62)		63 (60)	61 (52)	
Wards						
Non-surgical wards	65 (76)	63 (75)	0.96	83 (77)	90 (76)	0.87
Surgical wards	21 (24)	21 (25)		25 (23)	28 (24)	



Table 1: General characteristics (continued)

	Intervention wards <sup>a</sup> (N=167)		Control wards <sup>b</sup> (N=215)		Difference pre-post <sup>c</sup> (p-value)
	Pre-intervention n=86	Post-intervention n=84	Pre-intervention n=108	Post-intervention n=118	
Duration last admission in days: mean / SD	17.0 / 24.0	14.3 / 14.5	17.8 / 23.4	13.2 / 13.2	0.05
<b>Relatives</b>					
Age in years: mean / SD	55 / 13	58 / 14	55 / 12	58 / 14	0.11
Gender					
Male	26 (30)	29 (35)	39 (36)	47 (40)	0.53
Female	59 (70)	55 (65)	69 (64)	70 (60)	
Relation					
Partner / spouse	38 (44)	46 (55)	44 (41)	66 (56)	0.05
Child (in law)	32 (37)	21 (25)	39 (36)	37 (31)	
Other	16 (19)	17 (20)	25 (23)	15 (13)	

<sup>a</sup> Intervention wards: Cardiology; Ear Nose & Throat surgery; Gastro-intestinal surgery; Gynaecology and urology; Internal Medicine – infectious diseases and endocrinology; Lung diseases; Medical oncology and geriatrics

<sup>b</sup> Control wards: Haematology; Internal medicine- gastro intestinal diseases; Internal medicine- renal diseases; Neurology; Neurosurgery and brain surgery; Liver and kidney transplant and vascular surgery; Orthopaedics; Plastic surgery and dermatology; Trauma surgery; Thorax surgery; Palliative oncology

<sup>c</sup> Pearson's Chi<sup>2</sup> tests

<sup>d</sup> Diagnosis derived from patient record

## Implementation

The seven intervention wards appointed 14 staff nurses to become palliative care nurse champions. They received four days of education and, on average, participated in 8.2 of the 18 network meetings. Five nurse champions prematurely left the network and were replaced by others.

### Effects on quality of life during last 3 days of life and quality of dying

In the intervention wards the median QOL3 score was 3.0 both pre- and post-intervention (mid-80% range 0.2-7.0, and 0.0-7.0, respectively) ( $p=0.92$ ) (Table 2). The median QOD score was 7.0 in both phases (mid-80% range [10<sup>th</sup>-90<sup>th</sup> percentile] 2.0-10.0, and 1.0-9.0 respectively) ( $p=0.57$ ). In the control wards the median QOL3 score also was 3.0 during pre and post-intervention assessment (mid-80% range 0.0-8.0 both) ( $p=0.20$ ). The median QOD pre-intervention was 7.0 (mid-80% range 1.3-9.0) and post-intervention the median was 6.0 (mid-80% range 0.0-9.0) ( $p=0.04$ ).

**Table 2:** Effects of intervention on Quality of Life (QOL3) during last 3 days of life and Quality of Dying (QOD)

QOL3 and QOD	Intervention wards			Control wards		
	Pre-intervention	Post-intervention	Difference pre-post <sup>a</sup> (p-value)	Pre-intervention	Post-intervention	Difference pre-post <sup>a</sup> (p-value)
Quality of life during last 3 days: median (mid-80%)	3 (0.2-7.0)	3 (0.0-7.0)	0.92	3 (0.0-8.8)	3 (0.0-8.0)	0.20
Quality of dying: median (mid-80%)	7 (2.0-10.0)	7 (1.0-9.0)	0.57	7 (1.3-9.0)	6 (0.0-9.0)	0.04

Mid-80% = mid-80% range (10%-90%)

<sup>a</sup> Independent samples Mann-Whitney U-test

### Effects on domains of QOD

Relatives reported that, during the final 24 h, patients had moderately to severely suffered from 2.5 of 7 physical symptoms, and from 2.0 of 7 psychological symptoms; no differences were found between pre and post-intervention assessment (Table 3). Scores in the other domains, i.e. of acceptance of death, medical care and symptom management, shared decision-making, preparation on and circumstances of death, personalised care, and supportive care and care for relatives, did not differ between the pre- and post-intervention period.

**Table 3:** Effects of intervention on domains of QOD

Domains	Intervention wards			Control wards		
	Pre-intervention Mean (SD)	Post-intervention Mean (SD)	Difference ( <i>p</i> -value) <sup>a</sup>	Pre-intervention Mean (SD)	Post-intervention Mean (SD)	Difference ( <i>p</i> -value) <sup>a</sup>
Physical symptoms (0-7) <sup>b</sup>	2.7 (1.8)	2.8 (1.7)	0.86	1.8 (1.7)	1.9 (1.9)	0.91
Psychological symptoms (0-7) <sup>b</sup>	2.5 (2.7)	2.4 (2.7)	0.59	1.4 (2.1)	1.7 (2.4)	0.21
Acceptance of imminent death (0-2) <sup>c</sup>	0.7 (0.7)	0.7 (0.8)	0.92	0.6 (0.8)	0.7 (0.8)	0.26
Medical treatment/ symptom management (0-4) <sup>c</sup>	2.3 (1.3)	2.2 (1.3)	0.86	2.6 (1.3)	2.2 (1.3)	0.15
Preparation on / circumstances of death (0-5) <sup>c</sup>	3.0 (1.6)	2.9 (1.7)	0.27	2.9 (1.5)	2.7 (1.6)	0.41
Shared decision-making (0-2) <sup>c</sup>	0.9 (1.0)	0.9 (0.9)	0.57	0.8 (0.9)	0.9 (0.9)	0.37
Personalised care (0-5) <sup>c</sup>	2.1 (1.4)	2.1 (1.4)	0.94	2.2 (1.4)	2.4 (1.3)	0.75
Supportive care/ care for relatives (0-4) <sup>c</sup>	2.9 (1.4)	2.6 (1.5)	0.33	3.0 (1.3)	3.0 (1.3)	0.94

<sup>a</sup> Pearson's Chi<sup>2</sup> test

<sup>b</sup> Higher score indicates more symptom burden

<sup>c</sup> Higher score indicates more satisfaction

## DISCUSSION

In this controlled before and after study we found no improvements in the QOL<sub>3</sub> and QOD as experienced by bereaved relatives. Patient or relative-reported outcomes of care in the last days of life are seldom investigated. Some experimental studies to improve cancer care are available, but rarely resulted in improved care as evaluated by patients or relatives<sup>26</sup>. We found no studies on the impact of an intervention with palliative care nurse champions on the quality of life at the end of life or the quality of dying, as experienced by relatives or patients.

In the control wards, during post-intervention assessment, relatives more often evaluated the QOD as (very) poor, compared to the pre-intervention assessment. These findings cannot easily be explained. We made no in-depth study of the care processes in the control wards, but relatives reported slightly (but not significantly) increased psychological symptom burden and dissatisfaction on medical treatment and symptom management. Another explanation might be the development in Western societies towards empowerment of the general public and of patients, which might be reflected in increased expressions of dissatisfaction in society in general and in health care in particular<sup>27</sup>. The fact that the median QOD score in the intervention wards post-intervention was similar to the pre-intervention

assessment, might cautiously be interpreted as an effect of nurse champions. Although the questionnaires and assessment procedures differed, our scores on QOD might (to some extent) be comparable to the outcomes of two recent studies assessing the total Quality of Dying and Death (QODD) score (rated on a 0-100 scale) among relatives of patients who died in 'acute' hospitals. In Italy, the mean QODD in the control wards of a cluster randomised trial on the Liverpool Care Pathway (LCP) was 63<sup>28</sup>. In Canada the QODD in various settings was on average 65 and hospital deaths were associated with lower scores<sup>29</sup>.

In our study, in all wards relatives scored the QOL3 with a median of 3.0, and the middle 80% scored 0-9. Such a low score might not be surprising, as patients in the last days of life are confronted with suffering from symptoms and deterioration of health, strongly affecting their quality of life. Nevertheless, this score must be cautiously interpreted as it was rated by a relative; relatives may tend to overestimate the severity of symptoms and problems when compared to the evaluation of patients and healthcare professionals<sup>30-34</sup>.

Many factors might have contributed to our equal outcomes pre- and post-intervention. Firstly, many aspects could contribute to the effects of nurse champions, including knowledge, skills and attitudes of the individual nurse champions and team members, and the context of the wards<sup>20,21</sup>. Secondly, a network of nurse champions is an organisational model primarily aimed at enabling and supporting optimal processes of care<sup>35</sup>, the effect of which may not be recognised by patients or relatives<sup>26,28</sup>. Thirdly, the intervention was based on the indirect transfer and dissemination of knowledge of palliative care experts to the wards, i.e. via nurse champions. Such a model has advantages when compared to direct teaching ward teams by palliative care experts, e.g. because the nurse champions might be more motivated than other team members to learn from the experts, and they have better insight into the ward culture and more implementation opportunities than the experts<sup>22,36,37</sup>. To be effective, however, nurse champions needed first to adapt to new knowledge and skills themselves, then to incorporate these in their behaviour and then to disseminate these to the teams, which also implied the need for teaching skills<sup>38,39</sup>. Subsequently, ward staff needed to put newly derived knowledge and skills into practice. Obviously, these processes were at risk for disturbance and barriers. Fourthly, end-of-life care should be multidisciplinary care and the effect of nurse champions in the multidisciplinary team remains unclear. Nurse champions might have had difficulties in assuming their roles and discussing goals of treatment and care with other team members, especially the physicians. Empowerment of nurse champions has been suggested to be essential for good performance<sup>9,17-20</sup>. Fifthly, the performance of the intervention depended strongly on the activities of nurse champions in their ward, who needed to apply multiple strategies<sup>40</sup>. The nurse network facilitated nurse champions to share knowledge, and to capture knowledge and skills from outside their wards. However, they were not used to working in a network and it might have taken additional time to benefit from this model, and to internalise improving strategies. Moreover, the high turnover of

nurse champions implied periods of non-activity and delay. Finally, the design and process of the study might have limited our findings; our study was slightly underpowered in the intervention wards. The education program had to be planned ahead to enable nurse champions to participate and, in hindsight, we received less than the planned number of questionnaires. In addition, we planned a 5-month period for nurse champions to take up their role and assumed further incremental growth after the start of the post-intervention assessment. Nurse champions probably needed more time before generating an effect. Furthermore, we only assessed their effect on care in the last days of life, while the intervention was aimed at improving care during the entire palliative phase.

Despite the equal findings in relatives' experiences, we believe that nurse champions might contribute to the awareness of palliative care needs and of shortcomings in care, and also to the role of nurses in the multidisciplinary team. After the shift from curative to palliative and terminal care, more emphasis is needed on comfort care, which implies a larger role for nurses. Some have also described a role for nurses in end-of-life communication and decision-making, and in the support of relatives in these processes, including being an information broker (towards the physician, family or in mediation), supporter (including supporting trust and empathy) and advocate (to physician and family)<sup>41-44</sup>. Therefore, nurses need to take up this role and improve their knowledge, skills, confidence and performance<sup>4,5,41-43,45,46</sup>. Improving and maintaining competence in end-of-life care in the hospital is challenging, e.g. because of low prevalence, complexity of care, ethical dilemmas and emotional difficulties<sup>4,47,48</sup>. Continued education of all nurses does not seem to be cost-effective; therefore, a model with nurse champions might facilitate nurses to meet the requirements<sup>14,16,35</sup>. However, to enable nurse champions to fulfill their role, they need to be acknowledged, facilitated and supported by, e.g., experts in palliative care and ward management. Furthermore, improvement of end-of-life care requires multiple strategies and has to go beyond the appointment of two nurse champions on the ward<sup>40</sup>.

## CONCLUSION

We found no effect of the introduction of palliative care nurse champions on the experiences of relatives regarding the quality of life in the last three days of life and the quality of dying of patients dying in hospital. However, also no worsening was found, as was seen in the control wards. Moreover, we showed that experimental research in the organisation of end-of-life care is feasible but needs a well-prepared study design and process. Good planning, commitment of management, and the support of palliative care experts are essential elements of the implementation of the intervention. Future research on nurse champions should take into account a longer 'running-up' period to implement the intervention and to empower the nurses to take up their role.

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# 9

## Effect of palliative care nurse champions on nursing care of dying patients in the hospital: a controlled before and after study

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Under review for publication

## ABSTRACT

### Background

Hospitals increasingly appoint nurse champions to improve quality of care. This study investigated the effect of palliative care nurse champions on nursing end-of-life care.

### Methods

In a controlled before after study (June 2009-July 2012) hospital nurses completed questionnaires on end-of-life care within two weeks after the patient's death. Halfway through the study, in 7 intervention wards two nurse champions were appointed. End-of-life care was compared before and after the introduction of the nurse champions. Results were also compared with outcomes from 11 control wards. Data were analyzed with t-tests, Mann Whitney-U and Pearson's Chi<sup>2</sup> tests.

### Results

In the intervention wards, data were collected on 81 patients pre-intervention and on 93 patients post-intervention; in control wards these numbers were 114 and 121, respectively (response 54%). After introduction of the nurse champions, only in the intervention wards did nurses more frequently discuss imminent death with the patients (35% pre-intervention vs 50% post-intervention,  $p=0.05$ ), were more frequently aware of psychological symptoms (57% vs 71%,  $p=0.04$ ), and performed less futile interventions during the final hours (on average 0.8 vs 0.4 out of 4 interventions,  $p=0.00$ ). No effect was found on nurses' awareness of patient's imminent death. Nurses' median score for quality of dying was lower in the post-intervention period (7.5 vs 7.0;  $p=0.02$ ).

### Conclusion

Nurse champions appear to have a beneficial effect on end-of-life nursing care in the hospital. Findings indicate increased communication and more awareness of patients' palliative care needs. Increased awareness made nurses more critical about the quality of dying.

## BACKGROUND

In hospitals, the quality of end-of-life care is often insufficient, e.g. regarding symptom control, communication, and healthcare professionals' awareness of approaching death<sup>1-8</sup>. Deficiencies have also been found in palliative care knowledge and skills of nurses and physicians<sup>9,10</sup>. Interventions to improve end-of-life care should comprise multiple strategies to address shortcomings in the processes and structures of end-of-life care, as well as in knowledge, skills and attitudes on palliative care<sup>11-14</sup>. Furthermore, interventions to improve hospital end-of-life care should be disseminated throughout the hospital wards, many of which lack specific palliative care expertise<sup>10,12</sup>. This might be similar to other ward-overarching fields of care, such as infection control, and wound and tissue care, for which several hospitals have implemented networks of nurse champions or link nurses. Although evaluation of the effects of such nurse champions is scarce the results are promising<sup>15-19</sup>. Also, some UK studies reported that palliative care nurse champions themselves experienced increased knowledge on palliative care, and felt more confident when collaborating with physicians and experts<sup>20-23</sup>.

A network of palliative care nurse champions could address various shortcomings in end-of-life care. Empowerment of nurses to become an ambassador of palliative and end-of-life care may raise medical and nursing staff's awareness of patients' needs in palliative care, and of the shortcomings in their own knowledge. Ward-based palliative care nurse champions could be intermediates between palliative care experts and ward staff. Similar to nurse champions in other fields, they may be a resource and role model for their colleagues e.g. by facilitating the dissemination of knowledge and skills, and the implementation of protocols regarding end-of-life care, while taking into account the context and culture of their ward<sup>11,24-27</sup>. This may improve the recognition of palliative care needs, communication with patients and relatives, and the care delivered to both. Furthermore, the dying phase may be recognized earlier. This study examines the effect of palliative care nurse champions on end-of-life care in hospital in a quasi-experimental study with a controlled before-after design.

## METHODS

This study is part of a larger study on understanding and improving Palliative and Terminal Care in the Hospital (PalTeC-H); the protocol for this is described elsewhere<sup>36</sup>. Primary outcomes in the PalTeC-H study are bereaved relative's experiences (reported in a concomitant manuscript); in this secondary analysis we examined the nurses' experiences and nurses' end-of life care.

## Study design

The effect of palliative care nurse champions (hereafter referred to as: nurse champions) was investigated in a 1300-bed Dutch university hospital using a controlled before-after design. Hospital end-of-life care was defined as care provided during the last three days of life, and included patients who died in one of 18 non-intensive care wards after an in-hospital stay of at least 6 h. In 7 intervention wards (i.e. medical oncology and geriatrics, internal medicine, ear/nose/throat surgery, gastro-intestinal surgery, gynecology and urology, lung diseases and cardiology), two nurses were appointed halfway through the study to become a nurse champion. End-of-life care and the quality of dying in the intervention wards were compared before and after the introduction of nurse champions. Results were also compared to end-of-life care in the same periods in 11 control wards in which the intervention was not applied. The pre-intervention phase lasted from June 2009 to October 2010 and the post-intervention phase from March 2011 to July 2012 (both 16 months each).

## Participants

In a sample of consecutive patients who had died on participating wards during both study periods nurses who had been involved in patient care were asked to participate.

## Ethical considerations

This study was approved by the Medical Ethical Research Committee of the Erasmus MC. According to Dutch regulations, informed consent of patients was not required because only observational data were collected after the patients' death.

## The intervention

The nurse champions participated in a palliative care network that was coordinated by a senior nurse consultant who was a member of the hospital multidisciplinary expert team on pain and palliative care (hereafter referred to as: expert team). Every month an educational network meeting was organised in which at least one nurse champion per ward was expected to participate. Further, all nurse champions participated in annual tailored two-day education programs. Nurse champions were trained to identify gaps in the knowledge on and quality of palliative care in their ward, to raise ward staff's awareness of palliative care needs, and to initiate implementation of end-of-life care protocols, e.g. on management of pain/delirium and on palliative sedation. The coordinator organised the meetings and education programs, and supported nurse champions individually in developing the plans and performing activities.

### Measurement and data collection

We developed a questionnaire to evaluate multiple dimensions of quality of dying and of hospital end-of-life care, including the patient's physical and psychological symptoms, social problems and acceptance of death, nurses' awareness of impending death, and nursing care during the last days. The questionnaire was tested among staff nurses and subsequently piloted in the first 30 cases. We then added two global numerical scores (0-10), asking "*How do you rate the patient's quality of life during the last 3 days of life?*" (QOL3), and "*How do you rate the patient's quality of dying?*" (QOD), with zero indicating "very poor" and 10 indicating "almost perfect". Data of patients included in the pilot study were also used for the current analysis. Within 2 weeks after a patient's death a nurse who was closely involved in the care for this patient was asked by a team coordinator to complete the questionnaire and, subsequently, to send it anonymously to the primary investigator (FEW).

### Endpoints

Endpoints were nurses' awareness of imminent death and of the psychosocial condition of the patient, characteristics of care as provided by nurses during the last days of the patient's life, and nurses' scores on QOL3 and QOD.

### Data analysis

For this analysis we analysed the data of the subgroup of patients who were admitted to hospital at least 24 h prior to death, because we wanted to exclude the assessment of vital functions on hospital admission. To detect selection bias we compared the characteristics of patients for whom nurses did and did not make a report. We compared outcomes pre- and post-intervention in the intervention wards, and in the same periods in the control wards, using t-tests, Mann-Whitney U-tests and Pearson's Chi-square tests. SPSS, version 20, was used for the analyses.

## RESULTS

### Process characteristics of the intervention

Initially, 14 nurses participated in the network of palliative care nurse champions. Five nurse champions prematurely left the network and were replaced by colleagues. During the study period, nurse champions received four days of tailored education and could participate in 18 network meetings; they participated (on average) in 8.2 meetings.

### Characteristics of nurses, patients and nursing care

During the study period 818 patients died: 396 (48%) in the pre-intervention and 422 (52%) in the post-intervention period. Nurses completed a questionnaire on 447 patients (response rates in the intervention and control wards of 54% and 55%, respectively). Of these patients 409 had stayed at least 24 h in the hospital (Table 1). Nurses on all wards completed questionnaires. In 46% of the questionnaires, nurses reported to be aged  $\leq 30$  years whereas in 17% they were aged  $\geq 50$  years. In 59% nurses reported to have  $\geq 5$  years of experience, and in 31% nurses reported to have cared for  $\geq 6$  dying patients during the previous year. The patients nurses reported on were on average aged 66 years, 59% were male, and they had died after a mean in-hospital stay of 16 days. Patients for whom no questionnaire had been completed were older (69 years;  $p=0.01$ ), and had had a shorter final hospital stay (mean 13 days,  $p=0.03$ ).

Response rates per ward differed ( $\chi^2 89.7$ ,  $p=0.00$ ); in three wards the response rate was  $\leq 40\%$  (i.e. thorax surgery [25%], gastro-intestinal surgery [30%], and neurosurgery [37%]), and in four wards it was  $\geq 70\%$  (i.e. palliative oncology [72%], vascular surgery and transplantation [80%], hematology [82%], and ear, nose and throat surgery [94%]).

Most nurses had cared for the patient during at least two shifts (68%), and 78% had had at least two contacts with the patient's relative(s). Post-intervention, more nurses reported on barriers in communication with the patient, e.g. caused by coma, hearing loss or speaking problems, compared to pre-intervention (11% pre vs 24% post;  $p=0.05$ ). Other characteristics remained the same pre- and post-intervention and no differences were found in the control wards.

### Nurses' awareness of imminent death

In the intervention wards, nurses were aware of patients' imminent death in 91% of all cases pre- intervention and this was the same post-intervention (Table 2). Awareness was raised more than 24 h prior to death in about half of all cases. In the control wards, nurses' awareness of imminent death also remained unchanged, albeit at a slightly lower level.

### Communication about imminent death

In the intervention wards, nurses had discussed imminent death with 35% of all patients pre- intervention (Table 2) compared with 50% post-intervention ( $p=0.05$ ). Pre-intervention, 32% of the nurses did not know whether the patient had been informed about their imminent death by the physician; 25% reported that patients had been informed explicitly and 18% implicitly. Although not significant, these percentages were slightly different post-intervention, i.e. 24% of nurses did not know whether the patient had been informed, and in 36% they reported that patients had been informed explicitly and in 12% implicitly. No differences in communication were found in the control wards.



**Table 1:** Characteristics of the patients and nursing care

	Intervention wards <sup>a</sup> N=174			Control wards <sup>b</sup> N=235		
	Pre- Intervention n=81 (%)	Post- Intervention n=93 (%)	P-value difference pre-post <sup>c</sup>	Pre- Intervention n=114 (%)	Post- Intervention n=121 (%)	P-value difference pre-post <sup>c</sup>
<b>Patients</b>						
Age in years: mean (SD)	66 (14)	67 (13)	0.86 <sup>d</sup>	65 (15)	67 (15)	0.21 <sup>d</sup>
Gender						
male	50 (62)	60 (65)	0.70	66 (58)	66 (55)	0.61
female	31 (38)	33 (35)		48 (42)	55 (45)	
Length of hospitalisation in days; mean (SD)	20 (29)	16 (31)	0.42 <sup>d</sup>	16 (17)	17 (26)	0.71 <sup>d</sup>
Ward						
surgical	25 (31)	19 (20)	0.11	22 (19)	33 (28)	0.15
non-surgical	56 (69)	74 (80)		92 (81)	86 (72)	
Diagnosis						
cancer	46 (57)	57 (60)	0.65	53 (46)	58 (48)	0.83
non-cancer	35 (43)	37 (40)		61 (54)	63 (52)	
<b>Nursing care</b>						
Number of shifts cared for patient (%)						
≤1	21 (26)	30 (33)		39 (34)	40 (33)	
2-3	33 (41)	41 (44)	0.36	48 (42)	49 (41)	0.80
≥ 4	26 (32)	20 (22)		27 (24)	32 (26)	
Contact with relatives (%)						
No	5 (6)	8 (9)		6 (5)	11 (9)	
Yes, once	6 (7)	13 (14)	0.27	18 (16)	24 (20)	0.33
Yes, ≥ 2 times	70 (86)	71 (76)		90 (79)	86 (71)	
Barriers in communication <sup>e</sup>						
Yes	9 (11)	22 (24)	0.05	16 (14)	19 (16)	0.94
No	72 (89)	71 (76)		98 (86)	102 (84)	
Barriers in culture <sup>f</sup>						
Yes	5 (6)	10 (11)	0.22	7 (6)	8 (7)	0.97
No	76 (94)	83 (89)		106 (94)	112 (93)	

<sup>a</sup> Intervention wards: Cardiology; Ear Nose & Throat surgery; Gastro-intestinal surgery; Gynaecology and urology; Internal medicine – infectious diseases and endocrinology; Lung diseases; Medical oncology and geriatrics

<sup>b</sup> Control wards: Haematology; Internal medicine- gastro intestinal diseases; Internal medicine-renal diseases; Neurology; Neurosurgery; Liver and kidney transplant and vascular surgery; Orthopaedics; Plastic surgery and dermatology; Trauma surgery; Thorax surgery; Palliative oncology

<sup>c</sup> Pearson's Chi<sup>2</sup> tests

<sup>d</sup> Independent sample t-test

<sup>e</sup> Barriers due to e.g. insomnolence, different language, speaking disorders

<sup>f</sup> Barriers due to different culture and background, values and beliefs

**Table 2:** Awareness of and communication about imminent death

	Intervention wards			Control wards		
	Pre-intervention <i>n</i> =81 (%)	Post-intervention <i>n</i> =93 (%)	P-value difference pre-post <sup>a</sup>	Pre-intervention <i>n</i> =114 (%)	Post-intervention <i>n</i> =121 (%)	P-value difference pre-post <sup>a</sup>
Nurse had been aware of imminent death						
Yes/More or less	74 (91)	78 (86)	0.25	93 (82)	93 (79)	0.60
No	7 (9)	13 (14)		21 (18)	25 (21)	
Moment of awareness: in hours prior to death						
< 6	13 (16)	11 (12)		15 (13)	25 (21)	
6-24	22 (27)	28 (30)	0.70	31 (27)	31 (26)	0.29
> 24	41 (51)	43 (46)		50 (44)	46 (38)	
Nurse(s) had talked with patient about imminent death						
Yes	28 (35)	46 (50)	0.05	37 (33)	32 (26)	0.31
No or don't know	53 (65)	47 (50)		77 (67)	89 (74)	
Patient was informed about their imminent death by the physician						
Yes, explicitly	20 (25)	32 (36)	0.33	30 (26)	31 (26)	0.59
Yes, implicitly	14 (18)	11 (12)		11 (10)	14 (12)	
No	20 (25)	25 (28)		52 (46)	45 (39)	
Don't know	25 (32)	21 (24)		19 (17)	26 (22)	

<sup>a</sup> Pearson's Chi-square test

### Insight in patients' psychosocial condition

For eight psychological symptoms (e.g. anxiety, tenseness, sadness, depressed mood) nurses were asked if they knew whether or not these symptoms had been a burden for the patient. In intervention wards, nurses had this insight for 4 symptoms pre-intervention and for 4.5 symptoms post-intervention (Table 3). This insight increased significantly for 'feelings of anxiety' and 'tenseness' ( $p=0.04$  and  $0.03$ , respectively). Pre-intervention, 70% of nurses had insight in whether patients had been aware of their imminent death and 88% in whether they had been at peace with that. In these specific cases nurses thought that about 50% of the patients had been aware and that almost 60% were at peace with this. These percentages were the same post-intervention. In the control wards, nurses were generally less frequently aware of patients' psychosocial condition and no differences were found between both periods.

### Nursing interventions and diagnostic measurements in the last 24 h before death

In the intervention wards, pre-intervention the nurses provided on average 5.3 of 18 interventions during the last 24 h, such as hygiene care, tube feeding and intravenous fluids, and assessment of blood pressure and temperature; this number was similar post-intervention (Table 4). In-depth analysis showed no differences pre- and post-intervention

**Table 3:** Nurses' insight in patients' psychosocial condition

Nurse knew if patient:	Intervention wards			Control wards		
	Pre-intervention n=81 (%)	Post-intervention n=93 (%)	P-value difference pre-post <sup>a</sup>	Pre-intervention n=114 (%)	Post-intervention n=121(%)	P-value difference pre-post <sup>a</sup>
suffered from anxiety	42 (57)	61 (71)	0.04	60 (57)	68 (61)	0.54
suffered from loneliness	40 (55)	50 (58)	0.40	53 (50)	54 (48)	0.85
suffered from dependency	43 (58)	53 (62)	0.35	55 (51)	52 (47)	0.50
suffered from tenseness	36 (49)	57 (66)	0.03	47 (44)	49 (44)	0.93
suffered from worrying	45 (61)	54 (63)	0.46	44 (41)	43 (39)	0.72
suffered from sadness	41 (56)	51 (59)	0.41	41 (38)	48 (43)	0.49
suffered from feelings of powerlessness	41 (55)	50 (58)	0.46	47 (44)	42 (38)	0.39
suffered from feelings of depression	38 (52)	45 (52)	0.55	37 (35)	41 (37)	0.72
was in peace with imminent death	57 (70)	62 (68)	0.60	60 (53)	70 (58)	0.42
was aware of imminent death	71 (88)	81 (87)	0.91	90 (79)	99 (82)	0.58
had practical or social problems during last days of life	49 (61)	57 (61)	0.91	71 (62)	73 (60)	0.76

<sup>a</sup> Pearson's Chi-square test

in diagnostic measurements (range 0-4), in providing tube feeding and intravenous fluids (range 0-4), and in basic care interventions (range 0-5). Other interventions, i.e. repositioning, wound care, bandaging, and suction of secretion, were applied less often post-intervention ( $p=0.00$ ). No differences were found in the control wards. An association was found between the moment nurses' awareness of imminent death was raised, and diagnostic measurements, tube feeding and intravenous fluids: these interventions were applied less often when nurses had foreseen imminent death  $\geq 24$  h prior to death compared with cases in which nurses' awareness was raised  $\leq 24$  h in advance ( $p<0.00$ ).

### Global score of quality of life during last 3 days of life and quality of dying

In the intervention wards, the median score for QOL<sub>3</sub> was 5.0 during pre- and post-intervention assessment (mid-80% range [10<sup>th</sup>-90<sup>th</sup> percentile] 2-8 pre-, and 2-7 post-intervention, respectively [ $p=0.59$ ]). The median score for QOD was 7.5 (mid-80% range 5-9) pre-intervention and 7.0 (mid-80% range 3-9) post-intervention ( $p=0.03$ ). In control wards the median for QOL<sub>3</sub> was 5.0 during pre-intervention and 4.0 during post-intervention assessment ( $p=0.84$ ); the median for QOD was 7 for both periods ( $p=0.58$ ).

**Table 4:** Nursing interventions and diagnostic measurements in the last 24 hours of life

	Intervention wards			Control wards		
	Pre-intervention n=81	Post-intervention n=93	P-value difference pre-post <sup>a</sup>	Pre-intervention n=114	Post-intervention n=121	P-value difference pre-post <sup>a</sup>
Diagnostic measurements <sup>b</sup> (0-4) Mean (SD)	1.5 (1.6)	1.4 (1.5)	0.81	1.5 (1.6)	1.5 (1.6)	0.86
Artificial nutrition and hydration and blood transfusion <sup>c</sup> (0-4) Mean (SD)	0.7 (0.8)	0.6 (0.7)	0.70	0.8 (0.9)	0.9 (0.8)	0.68
Basic care interventions <sup>d</sup> (0-5) Mean (SD)	2.2 (1.2)	2.3 (1.1)	0.37	2.6 (0.9)	2.5 (0.9)	0.51
Other interventions <sup>e</sup> (0-4) Mean (SD)	0.8 (0.9)	0.4 (0.6)	0.00	0.9 (0.9)	0.7 (0.9)	0.11
Total number of interventions (0-18) Mean (SD)	5.3 (3.2)	5.0 (2.6)	0.47	6.1 (3.0)	5.8 (3.1)	0.49

<sup>a</sup> Independent samples t-test

<sup>b</sup> Measurement of blood pressure, temperature, oxygen saturation and blood glucose

<sup>c</sup> Providing tube feeding, intravenous hydration, intravenous nutrition and blood transfusion

<sup>d</sup> Hygiene (washing or showering), oral care, urinary catheter care, pain assessment

<sup>e</sup> Repositioning, wound care, bandaging, suction of secretion

**Table 5:** Global quality of last three days of life (QOL3) and quality of dying (QOD)

	Intervention wards			Control wards		
	Pre-intervention n=53 <sup>b</sup>	Post-intervention n=88 <sup>b</sup>	P-value difference pre-post <sup>a</sup>	Pre-intervention n=91 <sup>b</sup>	Post-intervention n=118 <sup>b</sup>	P-value difference pre-post <sup>a</sup>
Quality of life during last 3 days: median (mid-80%)	5 (2.0-8.0)	5 (2.0-7.0)	0.59	5 (2.0-7.0)	4 (1.0-7.0)	0.84
Quality of dying: median (mid-80%)	7.5 (5.0-9.0)	7.0 (3.0-9.0)	0.02	7 (2.6-8.0)	7 (3.0-9.0)	0.58

<sup>a</sup>Independent samples Mann-Whitney U-test

<sup>b</sup>These items were added to the questionnaire after the pilot study so that numbers are not equal to the total groups

## DISCUSSION

In this controlled before and after study, nurses working on wards which appointed palliative care nurse champions were more aware of psychological symptom burden in dying patients and more frequently discussed the end of life with patients. Furthermore, non-essential nursing interventions were more frequently discontinued in the last 24 h. Post-intervention, nurses more often - though not significant- knew whether or not the physician had informed the patient about imminent death.

Evaluation of an intervention that consists of the implementation of a network of nurse champions is complex<sup>37,38</sup>. Many aspects which cannot precisely be defined may contribute to the effect of the intervention. The dissemination of knowledge regarding palliative care to colleagues on the ward is uncertain; it remains unclear which healthcare professionals are 'affected' by the intervention, e.g. received education, or experienced nurse champion's increased expertise<sup>37</sup>. Individual characteristics and competences of the nurse champions, and contextual characteristics of the workplace, may influence successful implementation<sup>39</sup>. In addition, implementation of such an intervention faces operational difficulties. The continuation of the network was an intensive process. We noticed the importance of management support, collaboration with the expert team, qualified coordination and coaching of the nurse champions, as well as the intrinsic motivation of nurse champions to continue their work. Problems related to attending meetings during work time, a rapid turnover of nurse champions, and the nomination of junior nurses to the position of nurse champions, have previously been reported<sup>19,39</sup>. Therefore, our finding that, despite these complicating factors, the appointment of nurse champions resulted in beneficial changes in clinical practice was not immediately obvious.

The introduction of nurse champions has contributed to increased attention for communication about the end of life. In the Netherlands, disclosure of a poor prognosis by a physician has to precede nursing communication about imminent death. Pre-intervention, nurses reported that in about one third of the cases it was unknown whether the physician had informed the patient and in only 25% had physicians explicitly informed patients about the imminence of death. Post-intervention, nurses tended to more frequently know whether the patient had been informed and whether this information had been given explicitly. This increased focus on physician communication, as well as the report of more patient-related barriers in communication, might be the result of increased attention paid to communication. This coincided with increased communication about patients' imminent death by the nurses. Increased awareness of whether patients were burdened by psychological symptoms (such as tenseness and anxiety) might be the result of improved communication. Shortcomings and barriers have been reported in communication at the end of life between patients and healthcare professionals, and among the staff<sup>8,40-42</sup>. Nurses consider communication at the end of life, although difficult, to be part of their responsibility; previously, education was found to contribute to the increased confidence in interdisciplinary communication and communication with dying patients<sup>10,20-23,40,43-45</sup>. In our study, increased attention in the intervention wards to palliative care and to physician end-of-life communication might also have contributed to the improved end-of-life communication by nurses.

We also studied nursing interventions and diagnostic measurements during the last 24 h. The implementation of nurse champions had some effect on interventions previously described as 'non-essential care' in the final hours, such as repositioning and bandaging<sup>46</sup>.

However, the same applies to diagnostic measurements in the dying phase, for which we found no effect of nurse champions<sup>46</sup>. We found that continuation of diagnostic measurements, and providing tube feeding and intravenous fluids, was associated with relatively late awareness of impending death; this emphasises the importance of an earlier recognition of approaching death.

Our findings suggest that there was increased attention to end of life care in the intervention wards after the implementation of nurses champions. The decreased median score for quality of dying in the intervention wards might be explained by increased awareness of the shortcomings in care. We believe this is an important finding for further improvements. Awareness of shortcomings and a sense of urgency are prerequisites for successful changes in care<sup>47</sup>.

The effects we found were relatively small and no improvements were found in nurses' awareness of impending death, or awareness of social or existential problems. In addition to the high turnover rate of nurse champions, the 5-month period during which nurses could prepare for their new roles before we started the post-intervention assessment might have been too short. A main element of the intervention is knowledge transfer; this is a complex process that implies that nurse champions first have to improve their own knowledge and then have to learn how to disseminate knowledge and skills among their colleagues<sup>24-26</sup>. It is suggested that nurse champions can only have an effect when they have knowledge of palliative care, teaching capacities, and authority towards managers and colleagues<sup>19,22</sup>. Therefore, the training and individual coaching of nurse champions continued until the end of the study, and their competences and confidence may have grown incrementally. Therefore, the impact of nurse champions might be larger on the long term.

This study has some limitations. First, we investigated the effect of nurse champions in only one hospital. Second, we only studied the effect on care during the last days of the patient's life; the intervention was aimed at improving palliative care during the entire course of terminal illness. Third, intervention wards were not randomly chosen, but assigned based on categories of patients likely to need palliative and terminal care in the end-stage of their disease. These wards (e.g. oncology) might have been more motivated to take measures to improve end-of-life care. Cluster randomisation would have been a stronger design; however, obliging wards to make a commitment for almost two years seemed inefficient and likely to yield a significant risk of preliminary discontinuation.

## CONCLUSION

In this study, palliative care nurse champions appeared to have a relevant beneficial effect on the care of dying patients in the hospital. Post-intervention, nurses more frequently

discussed imminent death with the patients, were more often aware of a patient's psychological condition, and more often discontinued non-essential interventions. Furthermore, nurse's attention to physician end-of-life communication tended to improve, being a prerequisite for their communication. Increased awareness made nurses more critical about the quality of dying in the hospital. Taking into account the ongoing development of nurse champions, these results are promising.

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# 10

General discussion



In this thesis we studied the quality of dying and the quality of care of patients who died in the hospital, in order to explore, to explain, and to improve the quality of dying. We mainly used quantitative methods and administered written questionnaires in three groups, i.e. bereaved relatives, and involved physicians and nurses. In addition we performed a secondary qualitative analysis of data collected among bereaved relatives. This chapter discusses the main findings of the study, methodological considerations, and implications and recommendations for clinical practice and further research.

## MAIN FINDINGS

The objective of this thesis was to better understand quality of dying in the hospital, and to assess the effect of an intervention with palliative care nurse champions in the hospital. We had two main research questions:

- What is the quality of dying in the hospital and what are its determinants?
- What is the effect of a network of palliative care nurse champions on quality of dying in the hospital?

### The quality of dying in the hospital

Several studies have shown that lack of knowledge and skills as well as attitudes regarding palliative and terminal care of health care professionals in the hospital are associated with insufficient quality of care of the dying patient<sup>1-9</sup>. When preparing our study, we developed and validated a tool to assess knowledge and opinions of nurses regarding palliative care (chapter 2). The instrument met various psychometric requirements. We found that in our study site many nurses were not adequately equipped to provide palliative and terminal care. They appeared to have poor knowledge on palliative care, with a mean score of 10.3 out of 20 on knowledge statements, and reported to experience 8 out of 18 described situations in palliative care as “difficult”. These findings supported our idea that improvement in palliative and terminal hospital care at least had to address nurses and nursing care.

Our main study on the quality of dying in the hospital and the effect of palliative care nurse champions included three phases (chapter 3): the pre-intervention phase (16 months), the intervention-introduction phase (5 months), and the post-intervention phase (16 months). To better understand the experiences regarding the quality of dying and the quality of care in the hospital, we developed three different questionnaires, assessing the experiences of relatives, physicians and nurses. Some items were similar in all groups, but many differed, taking into account the different roles and perspectives of these groups<sup>10-16</sup>. Primary endpoints of the study were the experiences of bereaved relatives regarding the quality of dying and the quality of life during the last three days

of life of patients who died in the hospital after an admission of 6 hours or more. Further we studied the experiences of relatives on the quality of hospital care in the last days of life, and the experiences of physicians and nurses on the care for the patient in his last days of life and his quality of dying.

During the first and second phase of the study, 249 bereaved relatives, rated the quality of dying (QOD) of the patient on average at 6.3 on a 0-10 scale (chapter 4): 7% rated the QOD at 0 or 1 and 19% rated it at 9 or 10, showing the broad range of experiences and suggesting a widespread variance of the quality of care. Relatives rated the quality of life during patient's final 3 days of life (QOL<sub>3</sub>) on average at 3.7, also with a range from 0-10. They reported that patients had suffered moderately or severely from 7 out of 22 physical and psychological symptoms. In 53% of cases relatives thought that the symptoms had sufficiently been alleviated during the last 24 hours of life, and in 75% they were satisfied about the efforts of health care professionals to relieve these symptoms. According to relatives only 26% of the patients had been fully aware of their approaching death. Relatives themselves had been fully aware in 49%. Seventy seven per cent of the patients had died in the presence of a relative.

Nine domains comprising various items explained the variance in the QOD scores of relatives for 34%. These domains were patient characteristics (such as marital status, relative's age); physical symptoms (e.g. dry mouth, trouble sleeping); psychological symptoms (e.g. anxiety, loneliness); acceptance of death (being in peace, awareness); medical care/symptom management (e.g. alleviation of symptoms, efforts to alleviate symptoms); shared decision making (in medical and nursing decisions); preparation/circumstances of death (e.g. saying goodbye, relative's presence at moment of death); personalized care (e.g. affirmation of patient as person, attention to preferred rituals); supportive care /care for the relatives (e.g. information about condition, involvement in decision making). Medical care and symptom management were most prominent in explaining QOD scores, explaining 22% of the variance, followed by personalized care (16%) and supportive care/care for the relatives (15%). The domain scores were correlated which suggests that positive experiences in one domain are related to positive experiences in other domains. Although two-thirds of the variance in QOD scores still remain unexplained, our findings clearly demonstrate that end-of-life care has an impact on the quality of dying. Attentiveness to the problems, symptoms and situation of the individual patient and his relatives, and involvement of the relatives in end-of-life care seem to be of crucial importance.

Physicians and nurses rated the QOD and QOL<sub>3</sub> other than relatives. In 200 cases we compared the experiences from relatives, physicians and nurses (chapter 5). The results showed that not only the ratings of QOD and QOL<sub>3</sub> differed significantly between these groups, but also their experiences of awareness of and communication about the patient's approaching death. Everyone seemed to 'have his own truth'. We found that



when (according to relatives) patients had been informed that death was imminent, they were better prepared for their death, and when relatives reported to have been informed themselves, they were also better prepared for patient's death. When relatives felt that health care professionals had acknowledged them in being significant for the patient and in patient care, and had informed and involved them, they were more likely to be satisfied about the hospital end-of-life care, and more likely to have experienced a good closure of patient's life (chapter 5 and 6). Timely and open discussions between patients, relatives, physicians and nurses about their hopes, fears, expectations and doubts, will not only support patients and relatives to prepare for life closure, but may also contribute to earlier awareness of an inevitable short-term death. This might in the end contribute to the withholding of futile diagnostic procedures or treatments at the end of life. Involving relatives in decisions about the treatment and care of patients in the hospital is not standard practice, and might even be seen as controversial, because it may harm the privacy and autonomy of the patient. However, when the patient deteriorates and the end of life is approaching, patients, relatives, and also health care professionals want relatives to become more involved in care and in decision making. This moral dilemma can be addressed, when health care professionals give up the idea that autonomy is strictly individual, and also take into account the principle of relational autonomy, in which the patient's and the relative's autonomy are seen as interrelated and additional to each other (chapter 6).

Awareness and acknowledgement of the inevitability of death is a prerequisite for discussions about life closure and death, and for adapting to terminal care. In our study, physicians in the first two study phases ( $n=228$ ) reported for 31% of all deceased patients that they had become aware of the imminence of death less than 24 hours prior to death (chapter 7). They had discussed the imminence of death with the patient in 51% and with the relatives in 95%. When they had discussed the imminence of death with the patient, they were more likely to rate the QOD higher.

### Effect of palliative care nurse champions

To measure the effect of an organizational intervention on the quality of dying and the quality of care, we compared the experiences of relatives (chapter 8), nurses and nursing end-of-life care (chapter 9) in 7 intervention wards before (phase 1) and after (phase 3) implementation of the intervention. The intervention included the appointment of two palliative care nurse champions per ward and the establishment of a nurse network for palliative care. Results in the intervention wards were compared to results in 11 control wards, where the same data were collected during the same periods, but in which the intervention was not applied. In the intervention wards, we found no differences in relatives' ratings of the QOD (median score 7), the QOL3 (median score 3), and the quality of care before and after the intervention (chapter 8). In the control wards, relatives rated

the QOD lower in the post-intervention phase (median score 6) when compared to pre-intervention phase (median score 7). Although we could not explain these results with any certainty, a preventive effect of the nurse champions cannot be ruled out.

In a subgroup of patients, i.e. those who had been hospitalized for 24 hours or more prior to death, we found some differences in nursing care in the intervention wards before and after the introduction of the palliative care nurse champions (chapter 9). After the intervention, ward nurses more often discussed end-of-life topics with patients, more often knew whether the patient suffered from psychological symptoms, and more often discontinued futile nursing care during the last hours of life. In addition they more often reported about barriers in communication with patients and we found a trend towards increased insight into physician's communication with the patient. After the intervention, nurses in intervention wards rated the QOD of the patient lower (median 7.5 vs 7.0, before and after the intervention, respectively). No differences were found in the control wards. These findings suggest an improved communication by nurses at the end of life and acknowledgement of the nurse's role in end-of-life communication, as well as increased awareness that some nursing interventions might become futile when the patient is dying. Furthermore, nurses seemed to have become more aware of the shortcomings in provided end-of-life care in the ward.

## METHODOLOGICAL CONSIDERATIONS

### Setting

This study was conducted in a large Dutch university medical center, i.e. the Erasmus MC, in Rotterdam. The Erasmus MC is a 1300-beds hospital, including a general hospital, a cancer institute, and a children's' hospital, with 39 medical specialties. In 2012 in total 36.000 hospitalizations were registered and 750 adult patients died in the hospital<sup>17</sup>. During our study, each year 320 - 350 patients died in one out of the 18 participating wards after an admission of at least 6 hours. This single-site study has some limitations regarding the generalizability of the findings. In the Netherlands a relatively low percentage of deaths occur in a hospital when compared to other European countries<sup>18-20</sup>, and a relatively high percentage of in-hospital deaths occur in non-intensive care wards, when compared to the United States. Nevertheless, the needs of patients at the very end of life in Western societies might show more similarities than differences<sup>21,22</sup>. However, generalizing our results to other care settings, such as nursing homes, home care and hospice care is not obvious.

## Study population

When assessing the quality of dying and the quality of care for the dying, the main person involved, i.e. the dying patient, cannot be asked. To replace patient assessment and to get a comprehensive insight into the quality of the dying phase, we assessed detailed experiences from multiple perspectives, i.e. a close relative and an involved physician and nurse. Selection of cases was prevented by including all patients who had died in participating wards, except those with a very short hospitalization, i.e. less than 6 hours. Therefore expected and unexpected deaths could be included. Healthcare professionals were not involved in the selection of relatives, but had the opportunity to refuse contacting a relative, which occurred in only three cases. Besides, we provided relatives with the opportunity to fill out the questionnaire in a face-to-face interview with the researcher, to enable people to participate even if they were not able to read or understand written questionnaires. Only one person requested a personal interview. Nevertheless, relatively well-educated and Dutch speaking relatives might be overrepresented in our sample, which requires caution in generalization to culturally and socio-economically different populations.

## The intervention

As expected, the intervention with palliative care nurse champions was complex. Firstly, the intervention as such was complex, with many ingredients contributing to the intervention (such as the educational programs and various network meetings for nurse champions), and to the effects (e.g. changes in attitudes, increased consultations of experts on palliative care). Secondly, nurse champions do their work in varying teams and contexts, with varying needs regarding palliative care and improvements in care. Thirdly, the implementation of a complex organisational intervention throughout a large university hospital, dealing with many stakeholders having varying priorities in treatment, care and policy, was challenging. During the project the nurse champions had difficulties to fulfill their roles, for example in finding time to attend the network meetings and to disseminate newly acquired knowledge, skills and attitudes and palliative care protocols to the ward staff. Besides, empowerment of the nurse champions and acknowledgement of their role were recurring challenges. Four preconditions significantly contributed to the results of this study: 1) the expertise and efforts of the network coordinator, who constantly strived to make the network succeed; 2) the commitment of all managers of the intervention wards; 3) the support of the expert team on palliative care; and 4) the monthly network meetings and the yearly educational program. Nurse champions themselves reported that the monthly network meetings and the support of physicians and ward managers were very supportive in maintaining their enthusiasm and fulfilling their role. The generalizability of our findings depends on the way the intervention is filled in and implemented in other settings.

## Methods and materials

The research questions in this study required retrospective measurements. We assessed the quality of dying comprehensively using three complementary questionnaires for relatives, physicians and nurses, which were piloted in the three target groups, but not tested on various psychometric properties. Nevertheless, our findings were comparable to the results of some other studies, that e.g. used the validated quality of dying and death questionnaire (QODD), and with studies assessing the prevalence of symptoms in the dying phase<sup>21-24</sup>.

## The controlled before and after design

To assess the effect of nurse champions, we performed a 'before and after study'. The strength of the design was enhanced by using a control group of wards that were similar regarding their specialties (surgical/non-surgical), and the proportion of patients with cancer and of patients in need of terminal care<sup>25-27</sup>. Nevertheless there might have been a selection bias. Managers of the intervention wards were willing to support palliative nursing care, and to spend time and efforts to improve the quality of palliative and terminal care. In these wards, other healthcare professionals also might have been more eager to improve palliative and terminal care. Cluster randomization could have prevented this potential selection, but would also have complicated the intervention. Wards that are unwilling to prioritize palliative and terminal care could have been randomized in the intervention group. Forcing wards to appoint palliative care nurse champions and subsequently allow them to attend monthly meetings during almost 2 years, would have increased the likelihood that the nurse champions would experience difficulties in fulfilling their role. Such wards are not very likely to implement an intervention as the one studied here anyhow. Therefore, we considered a controlled before and after design to be the best design possible.

## The outcomes

Our main outcomes concerned the experiences of relatives regarding quality of life during the last days of life and the quality of dying. We could explain 34% of the variance in the global scores on QOD among relatives. However, we found that the care that was provided to the patient during his final hospitalization was hardly associated to this QOL3-score (unpublished). Half of all relatives rated the QOL3 at 3 or less. This might suggest that relatives relate the quality of patient's life in his final days to the quality of life the patient had before, and from this perspective in-hospital care in the last days of life might not be expected to significantly affect the quality of life. This has implications for defining outcomes of research in end-of-life care. Half of the physicians and nurses rated the QOL3 at 5 or less. This might suggest that healthcare professionals, who usually do

not know the quality of life of the patient before hospitalization, base their QOL3 scores on other factors, such as their own beliefs and comparison to other patients.

## IMPLICATIONS AND RECOMMENDATIONS FOR THE FUTURE

### Structure and processes of end-of-life care

This study showed a wide variety in experiences of different stakeholders of the quality of dying. We could not identify subgroups of patients of whom the relatives rated the QOD high or low, and high and low QOD scores were found across all participating hospital wards. Thus the quality of dying and the quality of care cannot be predicted based on patient or disease characteristics, or structures of healthcare, such as wards or medical departments. The variety in experiences may imply that healthcare professionals, caring for dying patients, did not achieve control over the outcomes. When looking at relatives' experiences, the quality of care for a particular patient seems to depend on coincidences, e.g. regarding the healthcare professional's awareness of the dying phase, the willingness of the physicians to timely discuss a poor prognosis or doubts about the effectiveness of therapies, the confidence of nurses to discuss end-of-life issues with the patient, and the staff's attentiveness to the individual needs of patients and relatives. A similar pattern of coincidences could be identified regarding the introduction of palliative care nurse champions in the wards. We made appointments with all the intervention ward managers to enable the nurse champions to fulfill their role as ambassador of palliative care. However, the quality of introduction and implementation of the nurse champions could not be controlled. Whether the nurse champions would be allowed to attend meetings, to do their job, and were acknowledged in their expertise and role by other disciplines and nurse colleagues, also seemed to a great extent depending on coincidences. These experiences show that various factors might form a barrier for quality improvements in end-of-life care throughout the hospital, such as the organization and culture in the wards, and the attitudes of healthcare professionals regarding end-of-life care. To guarantee good quality of care for all dying patients and their relatives, uniformly structured care is needed, based on the best up-to-date evidence. Healthcare professionals need adequate knowledge, skills, attitude, and confidence, and sufficient facilities to take care of the dying patient and his relatives. Education, protocols and adapted routines on each ward are required, including awareness of each professional's responsibilities and tasks, adequate consultation of experts in palliative or psychosocial care, and measures to improve the process of care, such as use of the Liverpool Care Pathway for the dying patient. The network of nurse champions, in collaboration with the multidisciplinary expert team for palliative care should initiate and organize such processes, facilitated by ward managers. In addition, the use of quality indicators will enable structural evaluation

of processes and outcomes of end-of-life care per ward, and comparison between wards and hospitals.

### Validation of outcome measures

In the Netherlands many efforts are made to assess patient satisfaction and safety in hospital care. To date, experiences of bereaved relatives with care in the dying phase were hardly included. Recently, Claessen et al (2013) studied the newly developed 102-item Consumer Quality Index (CQI) on palliative care, to evaluate palliative care provided to patients in the last week of life in various settings among 204 patients and bereaved relatives.<sup>28</sup> In this study only 1,5 % of the participants reported on hospital end-of-life care. Our study showed the feasibility of evaluating the experiences of relatives regarding the quality of dying and the quality of end-of-life care in the hospital, and the added value when compared to solely evaluation in healthcare professionals. We could identify 37 items, together explaining 34% of the variance in the QOD score. Development of a short form of our extensive questionnaire and additional research to validate this instrument and the outcomes is needed to identify most important patient and relatives reported outcomes of terminal care. This instrument could then be used for continuous evaluation and for benchmarking in hospitals and possibly in other settings.

### Concept of quality of dying in relation to quality of life at the end of life

We found that our respondents consistently rated QOL<sub>3</sub> lower than QOD. This might not be surprising, taking into account the deteriorated condition of most patients just before death. However, the difference between QOL<sub>3</sub> and QOD scores affects the conceptualization of 'quality of dying'. Hui et al (2013) showed that various terms are used for quality of dying, but that they are rarely and inconsistently defined<sup>29</sup>. Quality of life during the last days and quality of dying are often considered to represent similar concepts, that relate to either the last week, the last month or even the last months of life, and quality of dying is sometimes assessed prior to death<sup>29-33</sup>. Apparently, dying can be seen as either a process or an event<sup>34</sup>. Our finding that QOL<sub>3</sub> and QOD were consistently evaluated differently, demonstrates a need for better defining and distinguishing of different phases in the last period of life, both in clinical practice and in the scientific debate<sup>29</sup>.

### Role and position of relatives

The position of relatives of patients at the end of life is complex. Relatives themselves are affected by the serious and life-threatening disease of the patient. They need to prepare for the death of their beloved and to face the future without their partner, parent, child or friend. To meet these needs, the WHO already recognized that relatives should be part of the target group of palliative and terminal care<sup>35</sup>. Our study however showed an additional need of relatives. During hospitalization for a serious illness, patients and

relatives discuss the patient's health status, the treatment options, and preferences. Relatives enable the patient to maintain his identity, to live his personal life until the end, and finally to die in a way that is in accordance with his preferences<sup>36</sup>. Therefore relatives probably know best how to interpret the patient's behavior and what his preferences are. When the patient is no longer capable to look after his own interests, most relatives want and need to represent the patient. To enable them to do so, they need timely information about the patient's condition, to prepare for the end of life and to significantly participate in medical decision making. For healthcare professionals in Western societies, the deeply felt importance of individual autonomy might be an obstacle to involve relatives. The Dutch healthcare law regulates proxy replacement for patients who are mentally incapacitated, which has to be confirmed by a judge. This formal process is not commonly practiced in terminal care, and might be difficult and undesirable to apply. However, informal acknowledgement of the position of relatives might also enable healthcare professionals to adopt the idea that patients and relatives are depending on each other and to have confidence in collaboration with relatives as standard of care<sup>36</sup>. This will ease the process of fully informed decision making for all participants, i.e. patients, relatives and healthcare professionals and of end-of-life care that is truly patient-centered.

The relevance of such collaboration was shown by the finding that relatives and healthcare professionals often have differing information regarding the situation of the patient. For example, awareness of the imminence of death differed: some relatives were earlier aware of the inevitability of death than healthcare professionals. Better and more communication and collaboration between relatives and healthcare professionals could therefore further improve the quality of end-of-life care. Communication should not be seen as flowing only in one direction; it should go beyond just informing relatives at the very end of life and asking them for information to organize care. Acknowledgement of relatives' role in informal care and representation of the patient's interests, and inviting them to participate in a therapeutic alliance with the patient, may contribute to a better quality of care. Timely discussions on the imminence of death between healthcare professionals, patients and relatives might diminish the use of futile diagnostic procedures and interventions at the end of life, yield better evaluation of the quality of care by relatives, and in increased satisfaction of physicians and nurses.

Besides, after the introduction of parental care in pediatric wards and family centered care in the intensive care, structured attentiveness to relatives of adult patients should be implemented in all general hospital wards. Whereas the importance of informal care will probably increase in our society, rooming-in facilities for relatives will be standard. Therefore research, development, and implementation of supportive family care interventions are urgently needed.

### Different perspectives, different opinions, different outcomes

We found various outcomes in the same patients, including varying global scores on QOL3 and the QOD among physicians and relatives. These findings have important implications for the use of quality indicators in palliative and terminal care, and even beyond. The outcomes of quality indicators will be strongly affected by the type of assessor. This should be taken into account when applying quality indicators in benchmarking and setting norms for clinical improvement.

### The role and position of nurses in hospital end-of-life care

In end-of-life care nurses have a crucial role. They spend more time at the bedside than any other healthcare professional, having more opportunity to assess patients' psychosocial needs and to discuss their feelings, doubts and preferences regarding the future. We found that in intervention wards prior to the implementation of nurse champions and in control wards, nurses discussed end-of-life issues in only one third of the cases with the patient. Furthermore, in one third nurses did not know whether the patient suffered from up to half of the assessed psychological symptoms, and in more than 40% nurses' awareness of impending death was only raised during the final 24 hours. Hospital nurses seem not to take advantage of their role as primary professional caregiver, or to take up their role as patient advocate or educator.

In our assessment of palliative care knowledge, opinions and perceived difficulties, we identified many dilemmas for hospital nurses. These dilemmas were previously described in some qualitative studies and concern dealing with conflicting opinions of relatives, dealing with uncertainty regarding prognosis and hope, dealing with overoptimistic physicians and medical futility, and dealing with organizational conflicts<sup>37-40</sup>. In addition, we found that nurses' opinions about good nursing care at the end of life appeared to be in contrast with their activities, their feelings of comfort, and their skills and knowledge. For example, nurses reported that psychosocial care and care of the relatives are important in palliative care, but frequently did not provide that care themselves, and rarely reported on consultation of psychosocial and spiritual professionals; nurses' personal idea of a good death and of initiating the discussion about imminent death frequently did not correspond to the care as provided<sup>37,41</sup>. These dilemmas might cause stress, but also passivity which might result in just providing care according to the medical directives until the physician declares that the patient is dying<sup>42</sup>.

These findings do not only raise a burden for the nurses; our study showed that nurses' end-of-life communication was associated to better awareness and circumstances of dying, and more attentiveness for the significant role of nurses in end-of-life care, as well as increased empowerment of nurses is likely to contribute to better hospital end-of-life care. Continuation of the network of palliative care nurse champions, coordinated by a dedicated senior nurse consultant was found to be supportive for the nurse champions.



In the end, positive effects of nursing care on patients' quality of the last phase of life and quality of dying can only be achieved by the nurses and the nurse champions, in collaboration with the medical staff and hospital management.

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# 11

Summary / Samenvatting





## SUMMARY

In this study we investigated the quality of the dying phase in the hospital from various perspectives and the effect of an intervention with palliative care nurse champions. The study was performed in the Erasmus MC, University Medical Centre in Rotterdam, The Netherlands. Data were collected among nurses, physicians and bereaved relatives between June 2009 and July 2012 in 18 participating non-intensive care wards.

In the background chapter (**Chapter 1**), the main concepts for this study are defined, such as the terminal phase, which is interpreted as the last months of life, and the dying phase, the final hours or days of life. Quality of dying is interpreted as a multidimensional concept, which includes seven dimensions, i.e. physical, psychological, social and spiritual experiences, the nature of healthcare, life closure and death preparation, and the circumstances of death.

To meet the needs of patients at the end of life, a multidisciplinary approach to care is most appropriate. Nurses have an important role in care for the dying. In teaching hospitals with a high turn-over of medical students and interns, nurses are a relatively constant factor. Therefore we particularly focused on nurses and nursing care when developing an intervention to improve care.

In this study we addressed two main topics, i.e.:

- The quality of dying in the hospital and its determinants
- The effect of a network of palliative care nurse champions on quality of dying in the hospital

Part one of this thesis describes the preparation phase of the main study.

In **chapter 2** we present a study on the validation of a newly developed questionnaire aimed at assessing the knowledge and opinions of nurses regarding palliative care: the Rotterdam MOVE2PC Questionnaire. In a sample of 223 professionals, the instrument was evaluated on relevance of the items, content validity, face validity, consistency, and construct validity, and feasibility. We assessed knowledge and opinions of randomly selected hospital nurses, and of nurses attending an advanced course on palliative care, before and after the program. We found that the questionnaire is appropriate for studying the competence and educational needs of general nurses providing palliative care, and for evaluating education programs aimed at improving nurses' knowledge and competence in palliative end-of-life care. The data also showed that general hospital nurses have poor to moderate knowledge on palliative care and may experience many difficulties in providing hospital end-of-life care.

**Chapter 3** describes the study protocol of the main study on the quality of dying in the hospital, including its methodology and the intervention. The intervention included the

establishment, halfway through the study, of a palliative care nursing network in which 14 staff nurses from seven wards participated. These palliative care nurse champions received a targeted educational program of two days annually and had monthly network meetings. The network was coordinated by a senior nurse consultant of the Erasmus MC multidisciplinary expert team for pain and palliative care. We designed a controlled before and after study in 18 non-intensive care wards, i.e. seven intervention wards and 11 control wards where the intervention was not applied. Assessments were performed during three phases: phase 1, before the intervention (16 months); phase 2, during the intervention-implementation period (5 months); phase 3, after the implementation of the intervention (16 months). We developed three complementary questionnaires for bereaved relatives, nurses and physicians who were involved in the care for patients who died at any of the participating wards, after a hospitalisation of at least 6 hours. The quality of life during the last three days of life, the quality of dying and the quality of care were assessed in global numerical ratings (0-10; 0 being very poor and 10 being almost perfect, and in various secondary endpoints.

Part 2 of this thesis describes our findings about the quality of dying in the hospital and its determinants.

In **chapter 4** we studied what happens during the last days of life of patients who die in the hospital and what matters according to bereaved relatives. Data were analyzed for 249 patients who had died during phase 1 and phase 2 of the study, i.e. from June 2009 to March 2011. In the hospital, relatives on average rated the quality of dying as 6.3, with a broad range of experiences. During the final 24 hours of life, patients suffered from various symptoms with moderate to severe intensity. A minority of the patients and half of the relatives were reported having been aware of the imminence of death. One-third of the patients had been in peace with their imminent death. Half of the relatives and 39% of patients were able to say goodbye. In the end, a large majority of the patients died with a relative at their bedside. Various characteristics of patients, the illness, treatment and care were related to the quality of dying. We identified 37 of them, which could be summarized in 9 domains. These domains could explain one-third of the variation of quality of dying scores. Medical, personalized and supportive care are most strongly related to the quality of dying score.

In **chapter 5** we present the analyses of the concordance of the experiences of bereaved relatives, physicians and nurses for 200 out of a total of 951 patients, for whom questionnaires were completed from the three perspectives. Main outcomes were the patient's quality of dying, awareness of imminent death and whether patients and relatives had been informed about the imminence of death. Furthermore, the association between communication and preparation and circumstances of death was analysed. We found that the concordance between the experiences of relatives, physicians and nurses in general was poor: all groups seem to have their "own truth". Relatives' scores for the quality of dying were lower than those of physicians and nurses. Half of the relatives and

three-quarters of the physicians and the nurses were aware of the patient's impending death. Physicians more often reported to have informed patients and relatives about end-of-life issues than relatives indicated. When both physicians and relatives agreed that physicians had discussed the patient's prognosis, relatives' awareness of impending death and presence at patient's deathbed were more likely.

The World Health Organization already stated that patients and relatives together are the target group of palliative care. However, in Western healthcare decision making is mainly based on the principle of individual autonomy. Healthcare professionals usually focus on the patient when making decisions on treatment and care, assuming that the patient will involve relatives when needed. However, relatives' involvement becomes more important at the end of life, when patients are no longer able to optimally participate in the decision-making without the support of relatives. In **chapter 6** we aimed to get more insight into the experiences of relatives concerning their role and position in the hospital during the last days of patient's life. We performed a secondary qualitative analysis of the comments and explanations relatives had added to 10 closed questions. Relatives had completed a questionnaire for 451 out of a total of 951 patients. We found that the experiences relatives reported on mainly concerned their role as caregiver of the patient. Relatives expressed experiences related to 'information and communication', 'involvement in decision-making', 'acknowledgement', 'trust', and 'rest and privacy'. When relatives felt that their role was sufficiently acknowledged by healthcare professionals, who accordingly informed them and involved them in decision-making, their experiences were more positive. These findings suggest that relatives may have an important and potentially underestimated role in care of the dying patient in the hospital. This role might be better addressed by healthcare professionals when they work from the principle of relational autonomy.

In **Chapter 7** we present a study on the experiences of physicians who were involved in the care for dying patients during phase 1 and 2 of the study. We analysed whether the physician's awareness of patient's impending death is related to the provided medical care and communication. Physicians had been fully aware of the impending death in two-thirds of their dying patients. In those cases, they more frequently discussed impending death with patients and relatives, and more often changed the treatment goal into comfort care or withholding treatment. However, physicians' awareness of impending death was raised rather late in the illness process: in about one-third of cases had become aware of the patient's impending death in the final 24 hours and in a similar percentage two or three days before death. The decision to change the treatment goal from, for example, recovery and life prolongation to comfort care, may therefore also have been made late in the process and often could not be discussed anymore with the patient. Physicians themselves evaluated the quality of dying more positively when they had been aware of the patient's impending death as compared to when they had lacked such awareness.

Part 3 of this thesis concerns the effect of nurse champions on the quality of dying.

In this part we present the results of the controlled before and after study, in which the effects of the nurse champions and their network in the seven intervention wards are studied and compared to the outcomes in 11 control wards.

In **chapter 8** the effect of the intervention as experienced by relatives is described. In the intervention wards, no differences were found in the scores on quality of life in the last days of life and quality of dying between the pre- and post-intervention period. No differences were found either in multiple dimensions of quality of dying. In the control wards, the median score for quality of dying was one unit lower in the post-intervention period as compared to the pre-intervention period. Other outcomes were similar in both periods. The lack of effect of the intervention may be explained by various factors, such as the complexity of the intervention, its working mechanism, i.e. via indirect transfer of knowledge, the champion's difficulties to master their roles, and the design of the study. The continuation of a nurse network is challenging and not obvious, e.g. due to difficulties to attend meetings during office hours and to a rapid turnover of nurse champions. Furthermore, improvement and maintenance of competence in end-of-life care in the hospital is also challenging, for example, because of a low prevalence of dying at many wards and the complexity of care. For reasons of cost-effectiveness, a model with nurse champions may therefore be the best practice that is possible and feasible.

In **chapter 9** we present our study on the effects of nurse champions on nursing end-of-life care, in a subgroup of patients, i.e. those who had been hospitalized for at least 24 hours prior to death.

The study shows that palliative care nurse champions had a beneficial effect on end-of-life nursing care in the hospital. In the post-intervention period, staff nurses in intervention wards were more aware of the psychological symptom burden in dying patients and more frequently discussed the end of life with patients. Furthermore, non-essential nursing interventions were more frequently discontinued in the last 24 h. Nurses also knew better whether or not the physician had informed the patient about his imminent death. An additional effect of the intervention seemed to be that nurses were more critical about the quality of dying and quality of care in the hospital. This may be beneficial for feelings of urgency to further improve the quality of care for the dying patient.

Finally, in **chapter 10** (general discussion) the main findings of this thesis are summarized and integrated, methodological considerations are discussed, and recommendations for clinical practice and future research are given. Bereaved relatives report a broad range of experiences, which suggest a widespread variance of the quality of care. When looking at these experiences, the quality of care for a particular patient seems to depend on random variation and healthcare professionals may not have control over the process of care. Furthermore, relatives, physicians and nurses have different perspectives and opinions about the quality and outcomes of care for a particular patient. Intensified collaboration

between healthcare professionals and relatives, including timely discussions on expectations and experiences of the patient's illness, prognosis, treatment and medical decisions, may yield better experiences of the quality of care of relatives and increased satisfaction of physicians and nurses. The role of nurses in hospital end-of-life care needs to be further strengthened. Palliative care nurse champions in the hospital improve the quality of nursing care. Even more impact may be achieved with increased confidence in nurses' role in palliative care of nurses, the medical staff and the managers.

Future research in this field should emphasize interventions to improve the involvement of relatives in care and decision-making in the hospital, the concepts of the quality of life at the very end of life, the quality of dying, and the outcomes of end-of-life care.



## SAMENVATTING

In deze studie is vanuit verschillende invalshoeken onderzoek gedaan naar de kwaliteit van sterven in het ziekenhuis. Tevens is onderzocht wat de invloed is van een interventie met verpleegkundig aandachtsvelders palliatieve zorg op de kwaliteit van sterven. Voor dit onderzoek hebben we gegevens verzameld bij artsen, verpleegkundigen en nabestaanden van patiënten die zijn overleden tussen juni 2009 en juli 2012 op 18 niet-intensive-care afdelingen van het Erasmus MC in Rotterdam (Nederland).

In de inleiding van dit proefschrift (**hoofdstuk 1**) is de context van het onderzoek beschreven. Hoewel er geen consensus bestaat over begrippen als de ‘terminale fase’ en de ‘laatste levensfase’ hebben we deze opgevat als de laatste weken tot maanden van het leven en ‘terminale zorg’ en ‘zorg in de laatste levensfase’ als zorg verleend in deze periode. De ‘stervensfase’ hebben we geïnterpreteerd als de laatste uren tot dagen van het leven; ‘zorg in de stervensfase’ en ‘zorg rond het levenseinde’ als de zorg verleend in deze periode, tot na het overlijden. ‘Kwaliteit van sterven’ is eveneens geen duidelijk gedefinieerd begrip. Het wordt opgevat als een multidimensionaal concept bestaande uit lichamelijke, psychische, sociale en spirituele ervaringen, afronding van het leven en voorbereiding op naderend overlijden, de aard van de zorg rond het levenseinde en de omstandigheden van het overlijden.

Om tegemoet te komen aan de behoeften van patiënten in de terminale fase en stervensfase is een multidisciplinaire aanpak vereist. Verpleegkundigen hebben daarin een belangrijke rol. In universitaire en opleidingsziekenhuizen, waar artsen in opleiding vaak rouleren, vormen verpleegkundigen een relatief constante factor in de zorg. Bij het ontwikkelen van een interventie om de kwaliteit van zorg structureel te verbeteren hebben we ons daarom vooral gericht op de verpleegkundigen.

In dit onderzoek hadden we twee hoofdvragen, namelijk:

- Wat is de kwaliteit van sterven in het ziekenhuis, en wat zijn daarvan de determinanten?
- Wat is de invloed van een netwerk van verpleegkundig aandachtsvelders palliatieve zorg op de kwaliteit van sterven in het ziekenhuis.

De studies in dit proefschrift zijn als volgt ingedeeld: *deel 1* (hfdst. 2 en 3) beschrijft het werk dat is gedaan ter voorbereiding op de hoofdstudie. *Deel 2* (hfdst. 4 t/m 7) gaat over de kwaliteit van sterven in het ziekenhuis en de determinanten daarvan en *deel 3* (hfdst 8 en 9) van dit proefschrift gaat over het effect van de interventie.

In **hoofdstuk 2** presenteren we een onderzoek waarin we een door ons nieuw ontwikkelde vragenlijst valideren. Deze vragenlijst, de Rotterdamse MOVE2PZ-vragenlijst, is bedoeld om kennis en opvattingen van verpleegkundigen inzake palliatieve zorg te

meten. In een onderzoekspopulatie van 223 professionals is de vragenlijst onderzocht op relevantie van de items, de validiteit van de vragenlijst als geheel en van de afzonderlijke items en de samenhang tussen de items. Tevens is de betrouwbaarheid van de antwoorden onderzocht en de haalbaarheid om de MOVE2PZ-vragenlijst te gebruiken in de praktijk. Daarvoor hebben we de vragenlijst verspreid onder een groep willekeurig geselecteerde verpleegkundigen, verspreid over de ziekenhuisafdelingen die deelnamen aan de hoofdstudie. Tevens hebben we bij verpleegkundigen die een gespecialiseerde opleiding voor palliatieve zorg volgden, voor de start en na afsluiting van de opleiding de vragenlijst uitgezet. We vonden dat de MOVE2PZ-vragenlijst valide en betrouwbaar is om de kennis en opvattingen van verpleegkundigen te meten op het gebied van de zorg in de laatste levensfase. De uitkomsten gaven inzicht in de problemen die verpleegkundigen ervaren en in de behoefte aan en effecten van aanvullende scholing. Deze studie liet ook zien dat verpleegkundigen in het ziekenhuis matige kennis hebben van palliatieve zorg en dat ze in de zorg voor patiënten in de laatste levensfase regelmatig met moeilijke situaties worden geconfronteerd.

**Hoofdstuk 3** beschrijft het onderzoeksprotocol van de hoofdstudie, en benoemt de procedure, de onderzoeksmethode en de interventie. De interventie betreft het aanstellen van 14 verpleegkundigen op 7 afdelingen tot verpleegkundig aandachtsvelders palliatieve zorg (kortweg 'aandachtsvelders' genoemd), halverwege de onderzoeksperiode. Deze aandachtsvelders vormden samen een netwerk dat werd gecoördineerd door een senior verpleegkundig consulent van het multidisciplinaire consultatieteam voor pijn en palliatieve zorg van het Erasmus MC. De aandachtsvelders namen jaarlijks deel aan een tweedaagse scholing (de 'kennisdagen') die speciaal voor hen was ontwikkeld en ze participeerden in maandelijkse bijeenkomsten van het netwerk. Voor het onderzoek kozen we een gecontroleerd quasi-experimenteel ontwerp. Achttien niet-intensive-care afdelingen namen deel; daarvan fungeerden zeven afdelingen als interventie-afdelingen en 11 afdelingen, zonder aandachtsvelders, als controle afdelingen. Gedurende 37 maanden werden gegevens verzameld: gedurende fase 1 vond de voormeting plaats (16 maanden); fase 2 was de fase waarin de interventie werd geïmplementeerd (5 maanden) en in fase 3 vond de nameting plaats (16 maanden). Voor het verzamelen van gegevens werden drie elkaar aanvullende vragenlijsten ontwikkeld, namelijk één voor nabestaanden, één voor artsen en één voor verpleegkundigen. Voor elke patiënt die op één van de deelnemende afdelingen was overleden na een opname van tenminste 6 uur, werden een bij de patiënt betrokken naaste, arts en verpleegkundige uitgenodigd voor deelname aan het onderzoek. De primaire uitkomstmaten waren de kwaliteit van leven gedurende de laatste 3 dagen van het leven en de kwaliteit van sterven, beide uitgedrukt in een cijfer tussen 0 en 10 (0 betekende zeer slecht en 10 betekende bijna perfect). Daarnaast waren er diverse secundaire uitkomstmaten, zoals op gebied van prevalentie van symptomen, het voorzien van het naderend overlijden en zorg en communicatie.



In deel 2, **hoofdstuk 4** hebben we bestudeerd wat er volgens nabestaanden gebeurde in de laatste dagen van het leven van de patiënt in het ziekenhuis, en wat volgens hen van invloed was op de kwaliteit van sterven. Daartoe hebben we de vragenlijsten geanalyseerd van nabestaanden over patiënten die waren overleden gedurende fase 1 en 2 van de studie, dus tussen juni 2009 en maart 2011. De ervaringen van nabestaanden liepen wijd uiteen. Ze beschreven dat patiënten in de laatste 24 uur matig tot ernstig last hadden van gemiddeld zeven uit 22 symptomen, en dat een-derde van de patiënten vrede had met het naderend overlijden. Een minderheid van de patiënten en de helft van de nabestaanden had zien aankomen dat de patiënt snel zou overlijden. Negenendertig procent van de patiënten en de helft van de naasten hadden afscheid genomen en bij ruim driekwart van de patiënten was een naaste aanwezig op het moment van overlijden. Gemiddeld gaven nabestaanden een 6.3 voor de kwaliteit van sterven en diverse kenmerken van de patiënt, zijn ziekte, behandeling en zorg hielden verband met dit cijfer. Zevenendertig determinanten konden worden samengevat in 9 domeinen, waarmee we een derde van de variatie in het cijfer voor kwaliteit van sterven konden verklaren. De domeinen medische zorg, aandacht voor de individuele patiënt en ondersteunende zorg beïnvloedden het cijfer voor kwaliteit van sterven het meest.

Over 200 patiënten, uit een totaal van 951 geïnccludeerde patiënten, ontvingen we van alle participanten een vragenlijst, te weten een nabestaande, en een bij de patiënt betrokken arts en verpleegkundige. In **hoofdstuk 5** beschrijven we onze studie naar de overeenkomsten in ervaringen van deze drie groepen. Belangrijkste uitkomstmaten waren de kwaliteit van sterven, of was voorzien dat de patiënt op korte termijn zou overlijden, en of er met patiënt en naaste was gesproken over het naderend overlijden. Daarnaast is onderzocht of er een verband bestond tussen communicatie over het naderend overlijden en de voorbereiding op en omstandigheden van het overlijden. We vonden in het algemeen weinig overeenkomst tussen de ervaringen van nabestaanden, artsen en verpleegkundigen; iedere groep leek zijn “eigen waarheid” te hebben. Nabestaanden gaven vaker een lagere score voor kwaliteit van sterven dan artsen en verpleegkundigen. Van de nabestaanden had de helft het overlijden zien aankomen, tegenover driekwart van de artsen en de verpleegkundigen. Artsen rapporteerden vaker dan nabestaanden dat de arts met de patiënt en de naasten had gesproken over het naderend overlijden. Wanneer zowel de artsen als de nabestaanden hadden aangegeven dat ze met elkaar hadden gesproken over het overlijden, was de kans groter dat nabestaanden hadden zien aankomen dat de patiënt ging sterven en dat een naaste aanwezig was bij het overlijden.

Volgens de Wereld Gezondheid Organisatie richt palliatieve zorg zich niet alleen op de patiënt maar ook op diens naasten. In onze Westerse samenleving zijn de medische zorg en besluitvorming gebaseerd op het principe van individuele autonomie. Bij beslissingen over zorg en behandeling richten zorgverleners zich op de patiënt en gaan er vanuit dat de patiënt zelf zijn naasten informeert en betreft, wanneer hij dat wil. In de stervens-

fase echter, als de patiënt niet meer in staat is om zelf beslissingen te nemen, is de hulp van naasten vaak noodzakelijk. In **hoofdstuk 6** beogen we meer inzicht te krijgen in de ervaringen van naasten met betrekking tot hun eigen rol en positie in het ziekenhuis in de laatste dagen van het leven van de patiënt. Hiervoor hebben we door middel van een kwalitatieve tekstanalyse bestudeerd wat de 451 deelnemende nabestaanden antwoorden op 10 open vragen. Nabestaanden rapporteerden vaak over hun rol als mantelzorgers. Hun ervaringen betroffen vooral “informatie en communicatie”, “betrokkenheid bij de besluitvorming”, “erkenning”, “vertrouwen” en “rust en privacy”. Wanneer zorgverleners naasten voldoende hadden erkend in hun rol als mantelzorgers en hen op basis daarvan voldoende en tijdig hadden geïnformeerd en betrokken in de besluitvorming, waren hun ervaringen positiever. Dit onderzoek laat zien dat naasten een belangrijke rol kunnen hebben in de zorg voor een patiënt die sterft in het ziekenhuis, maar dat de waarde daarvan vaak wordt onderschat. Als zorgverleners hun handelen zouden baseren op het principe van relationele autonomie, zou beter kunnen worden ingespeeld op de rol van naasten.

In **hoofdstuk 7** beschrijven we het onderzoek naar de ervaringen van artsen die betrokken waren bij de zorg voor de patiënten die overleden gedurende fase 1 en 2 van het onderzoek. We bestudeerden of er een verband was tussen het voorzien van het naderend overlijden door artsen en hun medische zorg en communicatie. Bij twee-derde van alle overlijdens gaven artsen aan dat ze hadden voorzien dat de patiënt op korte termijn zou gaan overlijden. In deze gevallen hadden ze vaker met de patiënt en naaste gesproken over het naderend overlijden en was het doel van de opname en behandeling vaker gewijzigd in het bieden van comfort of het stoppen met behandelen. Echter, in veel gevallen zagen artsen pas laat aankomen dat het overlijden onafwendbaar was: in ongeveer een derde van de gevallen gedurende de laatste 24 uur voor overlijden en in een zelfde aantal 2 of 3 dagen voor overlijden. Daardoor werd pas laat in het stervensproces besloten om de behandeling niet langer te richten op herstel of levensverlenging maar op een zo goed mogelijke stervensfase; dit besluit kon dan vaak niet meer met de patiënt worden besproken. Als artsen het overlijden van de patiënt hadden voorzien waren ze positiever over de kwaliteit van sterven, dan wanneer ze dit niet hadden voorzien.

*Deel 3* van dit proefschrift behandelt de vraag of de interventie met verpleegkundig aandachtsvelders palliatieve zorg van invloed was op de kwaliteit van leven in de laatste drie dagen en de kwaliteit van sterven van patiënten die overleden in het ziekenhuis. We hebben dit onderzocht middels een gecontroleerde quasi-experimentele studie met voor- en nameting. In dit deel worden de uitkomsten voor en na de invoering van de aandachtsvelders op de zeven interventieafdelingen vergeleken. Vervolgens vergeleken we dit met de resultaten van de 11 controleafdelingen in dezelfde periodes.

In **hoofdstuk 8** beschrijven we de invloed van de interventie zoals ervaren door nabestaanden. Op de interventieafdelingen vonden we tussen de voor- en nameting geen verschillen in de kwaliteit van leven in de laatste 3 dagen en de kwaliteit van sterven.

Ook werden er geen verschillen gevonden in de eerder gedefinieerde domeinen die van invloed zijn op de kwaliteit van sterven. Op de controleafdelingen was de mediane score voor de kwaliteit van sterven in de nameting een punt lager dan in de voormeting. In de andere uitkomsten vonden we geen significante verschillen. In de discussie worden verscheidene factoren besproken die verband kunnen houden met het ontbreken van een gevonden effect, zoals de complexiteit van de interventie; het werkingsmechanisme van de interventie, namelijk via indirecte overdracht van kennis; de moeite die aandachtsvelders hadden om zich hun nieuwe rol eigen te maken en het ontwerp van de studie. Ook werd duidelijk dat de continuïteit van het netwerk veel aandacht vroeg. Het was bijvoorbeeld voor aandachtsvelders moeilijk om de maandelijkse netwerkbijeenkomsten gedurende hun dienst bij te wonen. Daarnaast kregen verschillende aandachtsvelders een andere functie en moesten worden vervangen. Vanwege de relatief lage prevalentie van patiënten die zorg in de laatste levensfase en in de stervensfase nodig hebben en vanwege de complexiteit van die zorg, is het moeilijk om de benodigde competenties van zorgverleners in het ziekenhuis te verbeteren én te onderhouden. Een zorgmodel met verpleegkundig aandachtsvelders lijkt, om redenen van kosteneffectiviteit derhalve toch het best mogelijke en haalbare model.

In **hoofdstuk 9** beschrijven we de invloed van aandachtsvelders palliatieve zorg op de verpleegkundige zorg in de stervensfase. Omdat we wilden bestuderen welke zorg verpleegkundigen verleenden in de laatste 24 uur hebben we dit onderzoek gedaan in een subgroep van patiënten, namelijk degenen die zijn overleden na een opname van tenminste 24 uur. Het onderzoek laat zien dat de interventie met aandachtsvelders een positief effect had op de verpleegkundige zorg. In de nameting bleek dat verpleegkundigen vaker wisten of patiënten psychische problemen hadden, en dat ze met meer patiënten hadden gesproken over het naderend overlijden. Daarnaast werden minder niet-essentiële verpleegkundige interventies toegepast gedurende de laatste 24 uur. Ook wisten verpleegkundigen vaker of de arts met de patiënt had gesproken over het naderend overlijden. Een bijkomend effect was dat verpleegkundigen op de interventieafdelingen kritischer waren over de kwaliteit van sterven van patiënten op hun afdeling. Dit kan bijdragen aan het erkennen van de noodzaak om de kwaliteit van zorg voor patiënten die gaan overlijden te verbeteren.

In **hoofdstuk 10** (Discussie) worden de belangrijkste bevindingen uit het onderzoek besproken en in breder perspectief geplaatst. Diverse methodologische aspecten worden besproken en er worden aanbevelingen gedaan voor de praktijk en voor verder wetenschappelijk onderzoek. Nabestaanden van patiënten die zijn overleden in het ziekenhuis rapporteerden een grote variëteit aan ervaringen, wat suggereert dat de kwaliteit van zorg in de stervensfase eveneens sterk varieert. De stervensfase is een proces vol onzekerheden; erkenning van deze onzekerheid en begeleiding in het omgaan daarmee kunnen de patiënt en zijn naasten ondersteunen. De inhoud van de zorg voor patiën-

ten in de stervensfase lijkt in het ziekenhuis ook afhankelijk te zijn van de samenloop van omstandigheden; zorgverleners geven onvoldoende sturing aan dit zorgproces, waardoor uitkomsten ook onzeker zijn. Daarnaast beschouwen nabestaanden, artsen en verpleegkundigen de zorg voor individuele patiënten vanuit een ander perspectief en hebben ze verschillende opvattingen over de kwaliteit en de uitkomsten van de verleende zorg. Intensievere samenwerking tussen zorgverleners en naasten, zoals tijdige gesprekken over de ervaringen met en verwachtingen voor het ziektebeloop, over de prognose, behandelingen en medische beslissingen, inclusief de onzekerheden, kunnen bijdragen aan positievere ervaringen van nabestaanden met de kwaliteit van zorg. De rol van verpleegkundigen in de zorg rond het levenseinde moet verder versterkt worden en verpleegkundig aandachtsvelders palliatieve zorg dragen daaraan bij. Dit effect kan verder worden versterkt wanneer verpleegkundigen, artsen en managers het belang van verpleegkundige zorg rond het levenseinde erkennen en daar meer vertrouwen in tonen. Toekomstig onderzoek zou zich met name moeten richten op interventies die leiden tot betere samenwerking met naasten op het gebied van zorg en besluitvorming rond het levenseinde in het ziekenhuis, op de ontwikkeling van de concepten 'kwaliteit van leven in de laatste dagen van het leven' en 'kwaliteit van sterven' en op de gewenste uitkomsten van zorg en behandeling rond het levenseinde.





# 12

Dankwoord

About the author

List of publications and presentations

PhD Portfolio





## DANKWOORD

### *Interdependence is a higher value than independence*

Mooier dan Stephan Covey, in *The 7 habits of highly effective people* (1989) kan ik het niet zeggen. Dit proefschrift kon alleen maar tot stand komen in samenwerking met diverse collega's en experts, en met de ondersteuning en belangstelling van nog meer collega's, familie en vrienden. Tegen jullie allemaal wil ik zeggen: heel erg bedankt!

Tegen sommigen wil ik graag nog iets meer zeggen.

Allereerst wil ik graag alle nabestaanden bedanken die de moeite hebben genomen om een lange en intensieve vragenlijst voor mij in te vullen. Ik realiseer me goed dat dat voor velen moeilijk en emotioneel was; niet iets was wat u "wel even deed". Zonder uw bijdrage zouden we niet weten wat we nu weten, en ik ben ervan overtuigd dat het kan bijdragen aan verbeteringen in de zorg.

Ook wil ik alle artsen en verpleegkundigen bedanken die de moeite hebben genomen om de vragenlijsten in te vullen. In een universiteitsziekenhuis wordt van professionals vaak gevraagd om, naast alle andere werkzaamheden, een bijdrage te leveren aan onderzoek. Jullie aandeel maakt dat we meer inzicht kregen in het zorgverlenersperspectief op de kwaliteit van sterven in het ziekenhuis.

Ik heb op de schouders van reuzen mogen staan! Professor Agnes van der Heide, professor Karin van der Rijt, en Lia van Zuylen; wat heb ik het getroffen met jullie als promotoren en copromotor! Op basis van jullie samenwerking heb ik mogen groeien. Ik kreeg het vertrouwen en de ruimte om het onderzoek op mijn manier uit te voeren, terwijl jullie kaders aangaven en mij met kritische en opbouwende feedback steeds weer verder vooruit hielpen. Lieve Agnes, wat was het fijn om jou te leren kennen en met jou te mogen werken. Zelden heb ik in mijn loopbaan van iemand zoveel geleerd als van jou; niet alleen door je kennis en wijsheid, maar zeker ook door wie je bent. Ik denk met veel warmte terug aan de gesprekken die we hebben gehad. Dank voor alles! Lieve Lia, we herinneren ons beiden nog goed hét gesprek op de fiets, waarin ik mijn idee opperde voor dit promotietraject. Tijdens deze fietstocht werd het "idee" een "plan", en konden we vast gaan wennen aan een veranderende samenwerking. Met dit tot gevolg! Inmiddels hebben we ons koperen samenwerkingsjubileum al achter de rug en wat mij betreft gaan we door tot de 25. Lieve Karin, ook onze samenwerking bestaat al zo lang, hoewel wat minder intensief. Met jouw precisie en aandacht voor detail hielp je me elke keer om geen stappen over te slaan en te proberen alles tot in de finesses te begrijpen. Dat heeft me geholpen om vanuit mijn "manager-stand" in de "onderzoeks-modus" te komen. Wij gaan de komende jaren nog verder samenwerken en ik hoop daarin nog meer van je te kunnen leren!

Professor Paul van der Maas, ook zo'n reus... Dank voor je vertrouwen om als niet-academicus aan dit onderzoek te mogen beginnen. Ik prijs me gelukkig dat ik in de beginfase

van dit project van jouw expertise heb mogen profiteren. Professor Peter Sillevius Smitt, professor Kris Vissers en professor Jan van Busschbach, u wil ik hartelijk danken voor uw inbreng in de finale van dit project: de beoordeling van het manuscript.

Zoals gebruikelijk heeft iedere promovendus paranimfen. Wat ben ik blij met de mijne!

Lieve Angélique, we hebben vroeger in onze lange brieven naar elkaar veel scenario's voor onze toekomst besproken, maar ik kan me niet herinneren dat deze erbij zat. Het leven had wel meer verrassingen voor ons in petto. Zowel de leuke als de minder leuke hebben we altijd gedeeld. Zo nodig stond je naast me om me te steunen; ik ben er ongeloflijk trots op dat je ook nu naast me staat! Lieve Natasja, de mooiste bijkomstigheid van dit promotietraject: ik heb jou leren kennen. We deelden onze kamer, de belangstelling voor onderzoek in dit vakgebied en al snel nog veel meer. Jij bracht me bij de Brocher Foundation, waar ik in februari 2014 een maand mocht verblijven; iets waardoor ik professioneel en persoonlijk gegroeid ben. Twee jaar geleden voelde ik me vereerd dat ik naast jou mocht staan bij jouw promotie. Nu voel ik me vereerd, omdat je naast mij wilt staan!

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Lieve, lieve Edwin; mijn lief, mijn steun en toeverlaat. I would rather go blind. Misschien moet mijn volgend boek gaan over alles wat je voor me betekent....

## ABOUT THE AUTHOR

Erica Witkamp werd geboren op 21 augustus 1964 in Apeldoorn. Ze haalde daar in 1982 haar Atheneum-B diploma aan het Christelijk Lyceum. In 1986 studeerde ze af als verpleegkundige aan de Hogeschool IJsselland in Zwolle. Na haar diplomering werkte ze eerst in verschillende intramurale instellingen in de algemene en geestelijke gezondheidszorg en de langdurige zorg. In 1987 werd ze wijkverpleegkundige bij Thuiszorg West-Brabant in Roosendaal. In 1990/1991 volgde ze de specialistische vervolgopleiding oncologie in Tilburg en in 1992 haalde ze aan de Universiteit Maastricht haar onderwijsbevoegdheid voor het hoger gezondheidszorgonderwijs. Vanaf deze periode was ze ook actief bij de V&VN Oncologie (toen nog Vereniging voor Oncologie Verpleegkundigen); gedurende ruim 12 jaar was ze daar achtereenvolgens lid van de congresredactie, lid en later voorzitter van de symposiumredactie en daarna bestuurslid van de vereniging. Vanaf 1993 tot eind 1998 werkte ze bij Thuiszorg Nieuwe Waterweg-Noord in Schiedam, als stafverpleegkundige en later als meewerkend coördinator van het transmuraal specialistisch team. In januari 1999 maakte Erica de overstap naar het Erasmus MC. Ze ging als verpleegkundig specialist pijn werken bij het Pijnkenniscentrum en de afdeling Neuro-Oncologie. Daar werd de kiem gelegd voor enthousiasme voor onderzoek. Ze implementeerde op enkele afdelingen het Pijn Instructie Programma, een wetenschappelijk bewezen verpleegkundig educatie programma voor patiënten met kanker met chronische pijnklachten. Hoewel het onderzoek uitstekend beviel, ging ze eerst de management-kant op: van 2002 tot 2009 was ze unithoofd palliatieve zorg & symptoomcontrole bij de afdeling Interne Oncologie. In die functie gaf ze leiding aan de gelijknamige unit in het Erasmus MC Kanker Instituut, droeg bij aan de totstandkoming van het multidisciplinaire consultatieteam voor pijn & palliatieve zorg in het Erasmus MC, en aan de ontwikkeling van palliatieve zorg in de regio. In 2009 startte Erica als promovendus bij de afdelingen Maatschappelijke Gezondheidszorg en Interne Oncologie met het PalTec-H project: het onderzoeksproject naar “Palliatieve en Terminal Care in the Hospital”, onderwerp van dit proefschrift. In 2011 voltooide ze de master in health sciences, met als specialisatie Public Health, aan de Erasmus Universiteit Rotterdam. Tevens zette ze in deze periode verpleegkundig onderzoek en Evidence Based Care in het Erasmus MC Kanker Instituut op de kaart.

Vanaf september 2014 werkt Erica bij de Hogeschool Rotterdam. Ze is daar hoofddocent Verpleegkunde bij de HBO-V en het Lectoraat Evidence Based Practice van het Instituut voor Gezondheidszorg. Daarnaast is ze nog een dag per week werkzaam als onderzoeker bij de afdeling Interne Oncologie van het Erasmus MC Kanker Instituut.

Erica is getrouwd met Edwin Herman en is moeder van Freek en Jet.



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Rianne de Wit en **Erica Witkamp** Pijn, bij iedereen anders, *Verpleegkunde Nieuws*, 06/04/2000.

### Oral presentations

Kwaliteit van sterven in het ziekenhuis: ervaringen van naasten in relatie tot de autonomie van de patiënt. Nationaal Congres Palliatieve Zorg, Lunteren, 2014.

Hoe is het met ú? Ondersteuning van naasten in het ziekenhuis. Finale "Voor Goede Zorg", Arnhem/ Utrecht 2014

The impact of a palliative care nursing network on the quality of hospital end-of-life care. Research meeting Dept. Public Health, Rotterdam, 2014.

The first year after allogeneic stem cell transplantation: what we need to know and what we can do. Invited speaker European Bone and Marrow Transplantation Conference, Milan, 2014.

End-of-life research: Quality of dying in the hospital. Brocher Foundation, Geneva-Hermance, 2014

Kwaliteit van sterven in het ziekenhuis: ervaringen van nabestaanden. V&VN Oncologiedagen, Ede, 2013.

Aandachtvelders palliatieve zorg in het ziekenhuis; heeft het effect? V&VN Oncologiedagen, Ede, 2013.

Impact dissemination Strategy ACTION. International Collaboration on End-of-Life Research conference, Rotterdam, 2013

Understanding the quality of dying in a hospital. Poster discussion European Cancer Congress, Amsterdam, 2013.

Aftercare following allogeneic stem cell transplantation: adjustment to individual needs. European Cancer Congress, Amsterdam, 2013.

Een netwerk van verpleegkundig aandachtvelders palliatieve zorg: heeft het effect? Genodigd spreker op Nationaal Congres Palliatieve Zorg "in en om Ziekenhuis op orde?" Arnhem, 2013.

Evidence Based Care: in 10 weken schakelen naar vooruitgang. Oncologiedagen V&VN, Ede, 2012.

Quality of care of patients dying in the hospital: relatives' perspectives. Research seminar Dept. Medical Oncology, Rotterdam, 2012.

Hospital nurses: what do they know and what do they think of palliative care? 7<sup>th</sup> world research congress of the European Association for Palliative Care, Trondheim, 2012.

MOVE2PC: Kennis en opvattingen van verpleegkundigen over palliatieve zorg. Ned. Vlaams Onderzoeksforum, Rotterdam, 2012.

Project Verpleegkundig Onderzoek: fundering voor de toekomst. Oncologiedagen V&VN, Ede, 2011.

Terminale zorg in het ziekenhuis. Nederlands-Vlaams Onderzoeksforum, Antwerpen, 2010.

Nursing care in the last days of life as reported by hospital nurses. European Nursing Congress, Rotterdam, 2010.

Dying in the hospital. Research meeting Dept. Public Health, Rotterdam, 2009.

De verpleegkundige carrière. Leider debat congres Vereniging van Oncologie Verpleegkundigen, Utrecht, 2005.

The Pain Education Program: results of an implementation process on nursing ward. European Cancer Congress 11, Lissabon, 2001.

## PHD PORTFOLIO

Name: Frederika Elisabeth Witkamp

PhD period: 2009 – 2014

Erasmus MC Departments: Public Health and Medical Oncology

Promotores: Prof. Dr. A. van der Heide and Prof. Dr. C.C.D. van der Rijt

Supervisor: Dr. C. van Zuylen

## 1. PHD TRAINING

	Year	Workload	
		Hours	ECTS
<b>General academic skills</b>			
- Scientific writing skills – Prof. Dr. A. van der Heide	2011	12	
- Qualitative Analysis, Theory and Practice – dept. Methodology and Statistics, University Utrecht,	2012		1,5
<b>Research skills</b>			
- Master Health Sciences, specialisation Public Health, NIHES			70
<i>In-depth courses (e.g. Research school, Medical Training)</i>			
- Suffering, Death & palliative Care, Nijmegen	2010		1
<i>Oral Presentations:</i>			
<i>International conferences</i>			
- European Nursing Congress, Rotterdam	2010		1
- Flemish-Dutch Research Forum Palliative Care, Antwerp, Belgium	2010		1
- Flemish-Dutch Research Forum Palliative Care, Rotterdam	2012		1
- European Association of Palliative Care, Trondheim, Norway	2012		1
- European Cancer Congress, Amsterdam	2013		1
- International Collaboration on End-of-life Research (ICER), Rotterdam	2013		1
- Brocher-Foundation, Geneva, Switzerland	2014		1
- European Bone and Marrow transplantation Conference, Milan, Italy	2014		1
<i>National conferences</i>			
- Dutch Oncology Nursing Society (V&VN Oncology), Utrecht	2011		1
- Dutch Oncology Nursing Society (V&VN Oncology), Utrecht	2012		1
- Nationaal congres palliatieve zorg in ziekenhuizen, Arnhem	2013		1
- Dutch Oncology Nursing Society (V&VN Oncology), Utrecht	2013		2
- Presentations Seminars depts. Public health, Medical Oncology	2010-2014		2
- Finale Voor Goede Zorg, VGZ, Arnhem/Utrecht	2014		1
- Nationaal congres palliatieve zorg, Lunteren	2014		1

*Abstracts/ poster presentations (first author - international conferences)*

- Medical Association on Symptom Care in Cancer, Rome, Italy	2009	0,5
- European Oncology Nursing Society, The Hague	2010	0,5
- European Association of Palliative Care, Glasgow, Scotland	2010	1
- European Association of Palliative Care, Lisbon, Portugal	2011	1
- Society of Medical Decision Making, Chigaco, USA	2011	1
- European Association of Palliative Care, Trontheim, Norway.	2012	0,5
- European Association of Palliative Care, Lleida, Spain.	2014	0,5

*Seminars and workshops*

- Workshop Research Proposal Writing – Grant European Oncology Nursing Society; June, 6-8, London,	2011	3
- Seminars department of Public health	2009-2014	2
- Seminars department Medical Oncology	2009-2012	12
- PhD-days	2009, 2011	12

## Didactic skills

- On teaching Evidence Based Care	2010	12
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## Other

- Interim coordinator of two projects on advance care planning (ZonMW, European Union), November – April (6 months)	2013-2014	
- Internal researcher Brocher Foundation, February (1 month), Geneva, Switzerland	2014	

## 2. TEACHING ACTIVITIES

## Lecturing

- Care for the dying patient (Zorgacademie Erasmus MC)	2010-2014	3
- Evidence Based Care (Zorgacademie Erasmus MC)	2011-2013	1
- Quantitative research (Zorgacademie Erasmus MC)	2012-2013	16
- Quality of dying in the hospital (training nurse champions, Erasmus MC)	2011-2013	9
- ACTION project, Kick-off meeting, Florence, Italy	2014	1

## Supervising

- Bachelor student Biomedical Science (L. ten Broecke) (Jan/Sept)	2010	1
- Medical students, theme 3.C.4 (Community projects)	2010-2014	1
- Bachelor student Philosophy and Biomedical Ethics (M. Droger) (april-aug)	2014	1
- Master Student Advanced Nursing Practice (H. van Dijk)	2009; 2014	2







