

Who cares?

*An ethical study of the moral attitude of professionals
in palliative care practice*

Acknowledgements

The studies in this thesis were performed at the Department of Ethics, Philosophy and History of Medicine, Radboud University Nijmegen Medical Centre, which participates in the Netherlands School of Primary Care Research (CaRe), acknowledged by the Royal Netherlands Academy of Science (KNAW).

This thesis was carried out within the framework of the Incentive Programme Ethics and Political Issues, which is supported by the Netherlands Organisation for Scientific Research (NWO).

I am grateful to the following institutions for giving me the opportunity to conduct the empirical part of this study:

- Nursing home Regina Pacis, Arnhem
- Nursing home Vrijthof / Hospice Tiel, Tiel
- Home care Zuid-Gelderland, Nijmegen
- Hospice Bethlehem, Nijmegen

Publication of this thesis was financially supported by Integraal Kankercentrum Oost (Nijmegen), Radboudstichting Wetenschappelijk Onderwijsfonds (Vught), J.E. Jurriaanse Stichting (Rotterdam).

© 2007, Gert Olthuis

ISBN 978-90-9021770-3

NUR 883

Cover design: Marije van der Laan, Amsterdam

Graphic design: Bartswerk Grafisch Ontwerp, Nijmegen

Printed by: PrintPartners Ipskamp, Enschede

Who cares?

*An ethical study of the moral attitude of professionals
in palliative care practice*

Een wetenschappelijke proeve op het gebied van de
Medische Wetenschappen

Proefschrift

ter verkrijging van de graad van doctor
aan de Radboud Universiteit Nijmegen
op gezag van de rector magnificus prof. mr. S.C.J.J. Kortmann,
volgens besluit van het College van Decanen
in het openbaar te verdedigen op maandag 25 juni 2007
om 15.30 uur precies
door

Gerrit Jan Olthuis
geboren op 16 maart 1971
te Almelo

Promotor

Prof. dr. H.A.M.J. ten Have

Copromotores

Dr. W.J.M. Dekkers

Dr. C.J.W. Leget

Manuscriptcommissie

Prof. dr. K.C.P. Vissers

Prof. dr. R.S.G. Holdrinet

Prof. dr. B.A.W. Musschenga (Vrije Universiteit Amsterdam)

Contents

<i>Chapter 1</i>	Introduction	1
<i>Chapter 2</i>	Professional competence and palliative care <i>An ethical perspective</i>	19
<i>Chapter 3</i>	Quality of life considered as well-being <i>Views from philosophy and</i> <i>palliative care practice</i>	35
<i>Chapter 4</i>	The caring relationship in hospice care <i>An analysis based on the ethics</i> <i>of the caring conversation</i>	69
<i>Chapter 5</i>	Why hospice nurses need high self-esteem	89
<i>Chapter 6</i>	What kind of caregiver should I be? <i>Moral attitude and reflection in palliative practice</i>	105
<i>Chapter 7</i>	Medical education, palliative care and moral attitude <i>Some objectives and future perspectives</i>	119
<i>Chapter 8</i>	Discussion and conclusion	133
	<i>Summary</i>	157
	<i>Samenvatting</i>	163
	<i>Curriculum vitae</i>	171
	<i>Publications</i>	173

Chapter 1

Introduction

Introduction

What induces people to devote their active working life to the care of patients who are seriously ill with a life-threatening condition which is usually going to kill them? Why do professional carers want a career in palliative care? What motivates them and what sort of qualities do they need to be good at providing such care? How should they relate to their patients? In this thesis it is taken as given that health care professionals who are involved in palliative care on a daily basis act – implicitly or explicitly – from a specific moral attitude. This moral attitude – which is defined in general terms as ‘the motivation and commitment to act in the interest of other people’¹ – of professional palliative caregivers is the subject of this thesis. The moral attitude will be explored from various ethical angles, on the basis of empirical data that have been collected in several palliative care settings. The thesis includes discussion of how this specific moral attitude can be maintained and further developed while working in palliative care. In order to be more specific about the objectives of the study, we now describe the environment in which these questions arise. We define palliative care, the patients that receive such care, and the carers that provide it.

Palliative care

The emergence of modern palliative care as a specific field of care can best be understood as part of the general history of care, which cannot be detached from its societal context.² Four aspects of medicine and society have contributed to the growth of palliative care in Western countries.³ First, medical technology has increasingly blurred the line between life and death, which evoked a search for more comfortable alternatives to an increasingly technological and invasive medical environment. Second, a lack of attention to symptom control in medical education and practice has produced a narrow focus on the pathophysiology and cure of disease rather than on the experiences of the patient. Unfortunately, suffering is not merely physical, but can

also be social, psychological and existential. Third, the loss of community ties and the reduction of the extended family to a more isolated nuclear family leads people to turn to professionals for support in the emotionally loaded task of caring for a seriously ill family member. Fourth, strained and evasive relationships, caused by the stresses involved in dying and bereavement, frequently increase loneliness and suffering at the end of life. These all make a philosophy of care that emphasises human contact more attractive.

'Palliative' is derived from the Latin word 'pallium', which means cloak. In the past four decades, 'pallium' has become a symbol for the warm and compassionate care patients receive at their last stages of life. However, it would be a mistake to reduce palliative care to 'tender loving care' – or TLC as medical specialists used to abbreviate it – entailing a high level of sympathy, and time and inclination to sit by the bedside holding the patient's hand.^{4,5} Palliative care is much more than that as can be seen in the words of Robert Twycross, one of the pioneers in the field, in which the influential definition of the World Health Organisation (see box) can easily be recognised:

*"Palliative care is patient-centered, rather than disease-focused; accepts the inevitability of death while simultaneously is life-affirming; addresses psychological, social, and spiritual concerns as well as physical ones; and is best delivered by a multiprofessional team working in partnership with patients and their families. Palliative care stresses the importance of 'appropriate treatment' and the need for doctors not to prescribe a lingering death. Even though there is no chance of cure, there is much scope for psychosocial and spiritual healing, and often some scope for physical rehabilitation. Palliative care is emotionally demanding for professional carers, and strategies for personal support are necessary."*⁶

Interestingly, the emergence of palliative care in the 1960s coincided with a new medical ethic.⁸ The increasing technical possibilities in medicine, their consequences for the care for the dying and accompanying demographic and societal developments not only stimulated the growth of palliative care but were also crucial to the birth of modern medical ethics.^{8,9} The focus shifted from the preservation of life wherever technically possible to the preservation of life when meaningful. The 'patient as a person' became a central issue. As Twycross says,

palliative care is centred on the patient, rather than on the disease. The editors of the Oxford Textbook of Palliative Medicine point out that palliative care is concerned with three things (p.4): the quality of life as experienced by the patient, the value that is attached to life irrespective of its (economic) contribution to society, and the meaning of life, where existential questions prevail.⁵ This view on the care for those who cannot be cured seems to be acknowledged by the results of a survey among palliative caregivers from 32 European countries.¹⁰ The survey determined that the moral notions that are deemed most important by palliative caregivers are quality of life, human dignity, acceptance of mortality, and total care (physical, psychosocial, and spiritual).

*WHO definition of palliative care*⁷

Palliative care is an approach which improves the quality of life of patients and families facing life-threatening illness, by providing pain and symptom relief, spiritual and psychosocial support from diagnosis to the end of life and bereavement.

Palliative care:

- Provides relief from pain and other distressing symptoms;
 - Affirms life and regards dying as a normal process;
 - Intends neither to hasten nor postpone death;
 - Integrates the psychosocial and spiritual aspects of patient care;
 - Offers a support system to help patients live as actively as possible until death;
 - Offers a support system to help the family cope during the patient's illness and in their own bereavement;
 - Uses a team approach to address the needs of patients and their families, including bereavement counselling, if indicated;
 - Will enhance quality of life, and may also positively influence the course of illness;
 - Is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications.
-
-

Demarcation confusion

Despite the clear contrasts set out in Twycross' description of palliative care, the scope of palliative care remains controversial. A first aspect of controversy is the demarcation within palliative care. Is palliative care in fact terminal care or does it merely involve all care for incurably ill patients? There are several notions in circulation that feed the confusion concerning the scope of palliative care: *supportive care* (which is a part of palliative care aiming at the support of patients undergoing chemotherapy), *palliative medicine* (which has a medical specialist status in the UK and "is the study and management of patients with active, progressive, far-advanced disease, for whom the prognosis is limited and the focus of care is the quality of life"⁵), *hospice care* (which refers to a specific setting, the hospice) or *terminal care* (which concerns care in the last part of the palliative phase when dying is inevitable).¹¹ Research suggests that the majority of the palliative care professionals holds that palliative care starts from the time of diagnosis of an incurable illness.¹² The WHO-definition supports this by emphasising that palliative care is "applicable early in the course of illness".⁷ The provision of palliative care is not limited to the last weeks of a patient's life. Furthermore, it is important to note that the 'illness' is not specified, which makes it wrong to consider palliative care as restricted to the care of cancer patients.

This brings us to a second aspect of the scope of palliative care, involving the demarcation between palliative care and other medical practices. Besides the narrower notions of palliative care mentioned above, there exists the notion *palliative approach*.¹¹ This term is much broader and refers to the philosophy of care that underlies palliative care practices. Central to this approach is dealing with (experiencing) loss and providing care for the whole person. Some confusion does arise because this approach is not restricted to the practice of palliative care; several features of the palliative approach can be recovered in other fields of care, i.e. paediatrics, geriatrics, nursing home care, home care or general practice.¹¹ From this broad perspective the demarcation of palliative care is problematic; how can it be considered as separate from other medical practices if it is an integral part of those practices? It is argued that what demarcates palliative care from other medical practices is a specific moral dimension that is expressed in the way care is given.^{12,13} Pal-

liative care requires virtuous practitioners who are able to provide emotionally involved care. This moral specificity relates to the fact that at the heart of palliative care is the care for the quality of life of patients and their relatives from a physical, psychosocial, and spiritual point of view.¹² The assumed virtuousness and the personal involvement of health care professionals with palliative care are the subject of the current study, but both aspects need to be set in context.

The professionals interviewed for our study work in various caring environments: a hospice, a palliative unit in a nursing home, a palliative department in a hospital, and in patients' homes. The focus of this study is on the broad notion of the palliative approach as expressed in the moral attitude of palliative care professionals. Why do professionals find their niche in palliative care? Why do they chose to adopt the palliative approach? How should palliative care be provided? The discussion in the current study centres around these questions. It is, however, *not* the intention of this thesis to consider the palliative approach as restricted to professionals working in palliative care settings. The intention is rather to obtain insight in the moral attitude that underlies that approach. These insights can be beneficial in both palliative care settings and in other branches of health care where the palliative approach is practiced. The question whether or not palliative carers are 'morally superior' – as sometimes is suggested – when compared with carers working in other medical practices is unjust, since it would imply that non-palliative carers act from a less valued moral attitude. Care actions always acquire their moral significance from the moral attitude expressed by these care activities.¹⁴ This implies that it is undesirable to consider one health care worker, e.g. a hospice nurse, as morally better than another, e.g. a paediatric nurse.

The starting-point of this thesis is to explore the moral attitude from which palliative care professionals care for their patients. As mentioned above, a better understanding of this moral attitude can be beneficial to other medical practices as well, because practicing care from a 'whole person' palliative approach is not limited to practicing care in a palliative setting.

Patients in palliative care

It is argued that a limited life prospect, an expectation of continuous decline and a future that is characterised by the certainty of death, distinguishes patients in the palliative phase from other sick persons.^{11,15} The process cancer patients go through, for example, is marked by a series of critical events.¹⁶ The disclosure of the original diagnosis can be taken as a first critical event. The knowledge of living with a life-threatening illness raises questions about one's death, about suffering, et cetera. Ideally, the provision of palliative care should start from this moment. After treatment is started, most patients experience a curative period where they are able to resume activities from the time before they fell ill. The recurrence of cancer defines the beginning of a new palliative period. In the early stages of this period, the central issue is 'living with an incurable disease'. 'Death' is still regarded as something in the future. This changes in the late palliative care period of terminal care. Most patients experience a point at which they understand that death is imminent. This awareness encourages most of them to work at bringing closure to their lives. Fear (of death, of losing control, of social exclusion, for example) and hope (of a good last period, of a good death, of life after death) often go hand in hand during this process.

The elements of care that may contribute to a quality end-of-life can be sketched roughly on the basis of a recent German study of personal values and patients' individual quality of life in palliative care.¹⁷ Benevolence, self-direction, and universalism are identified as the most important personal values ("emotionally and cognitively relevant principles guiding people's lives") regarding the quality of life of 75 patients who suffered from advanced cancer or ALS. While *self-direction* ("independent thought and action-choosing, creating, exploring") refers to the patients' own life, *universalism* ("understanding, appreciation, tolerance, and protection for the welfare of all people") and *benevolence* ("preservation and enhancement of the welfare of people with whom one is in frequent personal contact") express their concern with others.¹⁷ The researchers suggest that the importance of self-direction may indicate "a more active coping style" (p.158), and that palliative care patients "appear to seek preservation and enhancement of the welfare of friends, relatives, and all people" (p.158) as well.¹⁷

Notably self-direction and benevolence can be retrieved in four of the five domains that characterise quality end-of-life care from the perspective of patients as identified by Singer et al.¹⁸ A first, more general, domain comprehends 'an adequate pain and symptom management', without which an adequate quality of care in the palliative phase would be impossible. The personal value of self-direction is advanced in two domains: the patients' desire to 'avoid inappropriate prolongation of dying' and to 'achieve a sense of control'. Patients made it clear that they preferred to die naturally and that they did not want to be kept alive if they could not enjoy the life they could live. They were afraid of a lingering death. Furthermore, patients deemed it important to retain control when possible and have a proxy of their choice to take over if they became incapable. Benevolence – the value patients attach to the welfare of people close to them – is expressed in two other domains: 'relieving the burden which their dying process imposes on loved ones' and 'the strengthening of relationships with loved ones'. On the one hand, patients were worried about the difficulties their friends and family might experience with their physical care, while witnessing their death, and when involved in substitute decision-making. On the other hand, patients felt that the involvement of loved ones in their dying process was very important. When a certain intimacy was achieved, patients found their relationships strengthened. Quality end-of-life care is therefore considered as a dynamic process that takes place among patients, families, and health care professionals, and which is moderated by individual values, knowledge, and preferences for care.¹⁹

While palliative care is defined by the quality of life of patients, the current study concentrates on professional palliative caregivers. In the following section the environment in which these professionals provide care will be further specified.

Carers in palliative care

Informal carers – like a patient's relatives or volunteers – perhaps play a more emphatic role in palliative care than in other fields of care.¹¹ Because the current study focuses on professional carers, the role these informal carers play in the practice of palliative care is ignored. It is, however, important to note that it is not always simple to bring formal and informal carers into line.

Relatives, who often act as co-carers and sometimes as decision-makers, may also need the support of professional carers. Actually, family support is an explicit aim of palliative care (see WHO-definition). This can raise dilemmas in daily care because paying a proper attention to relatives may distract the carer from the patient, who should be the primary focus of palliative care.²⁰ Therefore professionals are required to divide their attention in a balanced manner. Volunteers on the other hand, should be considered as an integral part of palliative care giving. In daily practice however, the cooperation between voluntary and professional carers is not always trouble-free. Connecting both is regarded a responsibility of the institution they are affiliated with. Furthermore, integration and appropriate cooperation does not only depend on the benevolent dedication of volunteers; it demands adjustments from professionals as well.²¹

The value of teamwork is one of the strengths of palliative care.^{4,5,20} As is pointed out in Twycross' description quoted above, palliative care is best provided by a multiprofessional team. From the patient's perspective, the team comprises all those involved in their care.²⁰ Apart from physicians, nurses and certified nursing assistants (cna's), this means that informal carers and paramedics like social workers, psychologists, physiotherapists, dieticians, and clergy all have to work together to provide good care. Perhaps the teamwork in palliative care can best be described as a dynamic 'professional partnership' since the composition of the team will vary depending on the needs of the patient. Team members are responsible for their own input and formal leadership is not really necessary. It must be noted however, that characterising teamwork as 'professional partnership' involves a (theoretical) model reflecting an ideal. In practice, cooperation and decision-making can be difficult. It is argued, for example, that palliative care teams' handling of moral problems in practice can be much improved.²² Be that as it may, palliative care professionals do not act alone and are dependent on each other. The team bears a collective, multiprofessional responsibility, which is in fact the responsibility for the patient's total good or overall well-being. Palliative carers attempt to achieve the total good of a patient by providing *whole person care*.

F. Randall and R.S. Downie offer an interesting framework in which the commitment of palliative care professionals to provide 'whole person care'

can be examined.²⁰ This framework provides a good starting-point for a first exploration of the moral attitude of palliative care professionals because it offers a comprehensive ethical outlook on whole person care and the role of caregivers who intend to provide such care. Using Randall and Downie's outlook as a point of departure for this thesis is the more interesting since – as their work is considered as an ethical companion to the Oxford textbook⁵ – it sets a standard for palliative care ethics. In the paragraphs that follow, their point of view will be briefly presented. This subsection will be closed with the orientation of the moral attitude of caregivers within the framework of whole person care. However, the framework will not be adopted without any question. In the final chapter of the thesis, Randall and Downie's claims will be reviewed on the basis of the findings of the current study.

Providing whole person care

Randall and Downie argue that palliative care is an integral part of effective health care. They distinguish a threefold aim of health care. First, health care workers – including those in palliative care – will have *personal aims* that are not necessarily connected to their field of work, e.g. earning a living, job security or expressing idealism. These aims could easily be satisfied by other occupations. Second, anyone practicing health care must endorse its *intrinsic aim*, i.e. to bring about the 'medical good'. This aim is intrinsic to palliative care as well. It is concerned with medical treatments as the use of drugs or technical procedures, which can lead for example to amelioration, relief of suffering or prolongation of life. A prerequisite for the success of such treatments – whether they concern patients in general or palliative patients – is dedicated nursing care. The patient's good is more than the patient's medical good. In the third place, dealing with emotional problems or spiritual anxieties involves more than bringing about the medical good and belongs to the *extrinsic aim* of health care. "To ask about the extrinsic aim of palliative care is to ask about what doctors and nurses may be able to do as a result of their standing in the special relationships with their patients which is the condition of fulfilling the intrinsic aim" (p.18).²⁰

The promotion of a patient's emotional, relational and spiritual goods are extrinsic to palliative care's primary aim to bring about the medical good. The

connection of these goods to this primary aim is what makes them a second target of health care. Randall and Downie argue that two reasons underpin this distinction. First, psychological, social or spiritual problems constitute the background or consequences of the patient's primary problems, which are of a medical nature. Second, "there are no skills which professionally qualify a carer for dealing with [...] the range and complexity of people's emotional, relational, or social problems" (p.18).²⁰ It is claimed that it is an illusion to consider a total professional approach consisting of medical, nursing, and counselling skills sufficient to deal with the broad range of human problems that can arise in the last stages of life-threatening illness. In other words, the expertise and skills required to provide the whole person care that palliative care aims at, cannot all be acquired by merely going on a course.

According to Randall and Downie palliative care, like other forms of health care, has two different components.²⁰ Its intrinsic aim demands *professional skills*, which are derived from the knowledge bases of medicine, nursing, social work, psychology and allied health care professions. Dealing with broader human issues – the extrinsic aim of palliative care – requires *practical wisdom*, or *phronesis* as Aristotle described it. Although every person has this ability to some extent, it is cultivated and moulded through experience through the course of life. Palliative caregivers, some more than others, develop this practical wisdom as a consequence of their professional experience, of life in general, and under the influence of their own personalities. This practical wisdom can assist in dealing with the relationship troubles, the regrets, or the anxieties that can occur in a patient's life. Being able to deal with these issues is not a result of some kind of training, but has to do with the manner in which a treatment is given and the manner in which a professional approaches a patient.

Personal involvement

Although palliative care professionals are likely to be motivated to act for the patient's good, Randall and Downie argue that one should be modest about the range of 'whole person care' that can be provided.²⁰ The professional expertise in dealing with psychological, social and spiritual distress is limited; the practical wisdom with which the professional approaches the patient prevails

here. Furthermore, a palliative care team cannot bear the sole responsibility for a patient's overall well-being, because professionals can influence the state of a patient only *in partnership* with that patient. Both carer and patient are actively involved. "Whole person care implies responsibility for influencing physical and mental illness states and minimizing distress from them, in partnership with the patient. It also implies a willingness to assist the patient to overcome psychological, social, and spiritual barriers to well-being, by using our relationship with them as fellow members of community" (p.24).²⁰ The 'willingness to assist the patient to overcome psychological, social, and spiritual barriers to well-being' means that palliative care requires a personal involvement of the professional.

The relationship between patient and professional forms the basis of whole person care. Of course there are many factors that contribute to the success of that relationship, i.e. professional competence, a patient's honesty, et cetera. The unequal nature of the relationship, however, makes two moral conditions a necessity for this relationship to meet its aim: the carer's *commitment* to the patient's good and the patient's *trust* in that commitment.²⁰ Since a patient is dependent on the carer's knowledge, skills and resources, patients have little choice but to trust his carer. But, as Randall and Downie argue, "if patients are to be able to place this trust in their carers, then they must have some grounds for doing so. The best grounds for doing so are that the commitment to act for the patient's *total good* must be part of what it means to be a carer" (p.39).²⁰ This 'ideal of beneficence' must be more than a practical guiding principle for professionals; it must be intrinsic and therefore essential to being a carer.

It is this 'ideal of beneficence', which is expressed in the moral attitude that is central to the current study. In the following chapters palliative carers' moral attitude, defined as 'motivation and commitment to act in the interest of other people', will be explored from several ethical points of view. Professionals from four palliative care settings were interviewed in order to provide practical component in these ethical explorations. The concluding chapter will discuss the most important findings. Here, Randall and Downie's distinction between the intrinsic and extrinsic aim of health – and palliative – care will be discussed as well. Although this distinction is very clear, we doubt

whether making such a sharp distinction between the intrinsic and extrinsic aim and the related 'professional skills' and 'phronesis' is tenable in the light of the findings of the present study.

Objectives & Outline of the thesis

The objectives of the current study can now be formulated. The first objective is to further explore and analyse normative views with regard to the moral attitude of professional caregivers in palliative care. Chapters 2-5 of this thesis examine the moral attitude of palliative care professionals from various ethical angles. The notions of professional competence, phronesis, well-being, the caring relationship, self-esteem, personal identity and professional identity play a central role in these chapters. Semi-structured interviews that were conducted with professionals from a variety of palliative care settings provide the link to practice.²³ After this broad empirical-ethical exploration of the normative views of the moral attitude of palliative caregivers, the focus of the study is shifted. The second objective of this thesis is to explore how the moral attitude of care professionals can be stimulated, preserved and maintained. This objective will be dealt with in the chapters 6 and 7. Finally, the thesis concludes with a chapter that discusses the most important findings of the study.

Chapter 2 examines the moral basis of professional competence in palliative care. On the basis of clinical vignettes, four dimensions (cognitive, technical, relational, affective/moral) of professional competence are discussed. It is argued that another dimension – 'habits of mind' – cannot be detached from these aspects of professional competence. This observation is discussed from the perspective of the *ethics of care* and *virtue ethics*. The notion of *phronesis* is an important element in this discussion.

Chapter 3 concentrates on *quality of life*, which is one of the central values of palliative care practice. Currently, well-being is considered the main indicator of quality of life. The aim of this chapter is to compare insights about well-being from contemporary philosophy with the practice-related opinions of palliative care professionals. These opinions are derived from 19 interviews with palliative care professionals from various settings. Two questions are central to the empirical part of this chapter: 1) Which aspects of well-being

emerge from the views the interviewed professionals have on (their contribution to) the well-being of their patients?, and 2) What does providing palliative care mean for the well-being of the professionals themselves? Subsequently, the empirical results are discussed in the light of two philosophical theories on well-being and the attention is shifted to a more normative question: what should professionals do to help these patients? It will be argued that good palliative care concerns not only the fulfilment of a patient's preferences, but that good care also implies a professional approach that can be characterised as covenantal.

In chapter 4 the caring relationship between palliative care patients and the nurses who care for them will be further explored. A 'sustained partnership based on mutual participation' is supposed to be the most appropriate characterisation of this relationship. This assumption is analysed from a specific ethical point of view using 'the ethics of the caring conversation', which is based on the ethics of Paul Ricoeur. The discussion then concentrates on the perspective of the palliative care professional and will explore the way person, role and the caring relationship are interwoven in hospice care. Two questions are answered: 1) What kind of person should the hospice nurse be?, and 2) How should the hospice nurse engage in caring conversations? A profile of an exemplary hospice nurse will provide the empirical input. This profile is based on statements derived from the analysis of interviews with five hospice nurses and forms the theme of the chapter.

Chapter 5 elaborates on the preceding one and further examines the notion of self-esteem in the personal and professional identity of the hospice nurse. The story of the exemplary hospice nurse once again serves as the empirical theme of the chapter. This chapter also focuses on two questions: 1) What is self-esteem and how is it related to personal identity and its moral dimension?, and 2) How do self-esteem and personal identity relate to the professional identity of the nurse? The discussion demonstrates the importance of the coinciding of moral and personal goals in the life of the palliative care nurse.

A recent report of the European Association for Palliative Care (EAPC) recommends the promotion of reflective practice in palliative nurse education. Chapter 6 explores the moral attitude that professionals bring to such

reflective practice from a virtue-ethical perspective. Quotations from interviews with palliative care professionals provide the practical substance of this exploration. The chapter also explores the way this attitude can be maintained and further developed. The argument concentrates on the question 'what kind of palliative caregiver should I be?' and the role this question should play in reflective practice. It will be argued that portfolio learning offers opportunities to make reflection on that question an integral part of palliative care practice.

Chapter 7 covers the development of the moral attitude of medical students and the role palliative care can play in developing such an attitude. It makes a case that incorporating palliative care into basic medical education will improve the balance between knowledge, skills and attitude in medical training. Structural integration of palliative care into medical education will transform the so called 'hidden curriculum' into a more governed and explicit enculturation of doctors-to-be into the medical community. Two practical means of using palliative care practice to refine medical students' moral attitude are proposed.

Chapter 8 concludes this thesis. This chapter provides a resumé of the thesis' most important findings concerning the moral attitude of palliative care professionals on the basis of three notions: phronesis, the caring conversation, and the covenant of care. Then Randall and Downie's framework of 'whole person care' is briefly evaluated in the context of this study. This chapter closes by advancing some suggestions for future research on moral attitude and professional development in palliative care.

References

1. Olthuis G, Dekkers W. Medical education, palliative care and moral attitude: some objectives and future perspectives. *Med Educ* 2003; 37: 928-33. [Chapter 7 of this thesis]
2. Gracia D. Palliative care and the historical background. In: Ten Have H & Clark D, eds. *The ethics of palliative care: European perspectives*. Buckingham: Open University Press, 2002: 18-33.
3. Barnard D, Towers A, Boston P, Lambrinidou Y, eds. *Crossing over. Narratives of palliative care*. Oxford: Oxford University Press, 2000.
4. Spreeuwenberg C, Bakker DJ, Dillmann RJM, Blijham GH, Teunissen, Zylicz Z, eds. *Handboek palliatieve zorg*. Maarssen: Elsevier Gezondheidszorg, 2002.
5. Doyle D, Hanks G, Cherny N, Calman K, eds. *Oxford textbook of palliative medicine* (3rd ed). Oxford: Oxford University Press, 2003.
6. Twycross RG. The challenge of palliative care. *Int J Clin Oncol* 2002; 7: 271-78.
7. World Health Organization. Palliative care. <http://www.who.int/cancer/palliative/en> (accessed 29 June 2006).
8. Barnard D. The coevolution of bioethics and the medical humanities with palliative medicine, 1967-97. In: Fulford KWM, Dickenson DL, Murray TH, eds. *Healthcare ethics and human values*. Oxford: Blackwell Publishers, 2002: 461-67.
9. Ten Have H, Ter Meulen R, Van Leeuwen E, eds. *Medische ethiek* (2de druk). Houten: Bohn Stafleu Van Loghum, 2003.
10. Janssens R, Ten Have H, Clark D, Broeckaert B, Gracia D, Illhardt J, Lantz G, et al. Palliative care in Europe: Towards a more comprehensive understanding. *Eur J Palliat Care* 2001; 8; 20-23.
11. Teunissen S, Willems D. Het eigene van de palliatieve zorg. In: Spreeuwenberg C, Bakker DJ, Dillmann RJM, Blijham GH, Teunissen, Zylicz Z, eds. *Handboek palliatieve zorg*. Maarssen: Elsevier Gezondheidszorg, 2002: 29-71.
12. Janssens R. *Palliative care. Ethics and concepts*. Nijmegen: Thesis Radboud University Nijmegen, 2001.

13. Ten Have H, Janssens R. *Palliative care in Europe. Concepts and policies*. Amsterdam: IOS Press, 2001.
14. Gastmans C. Care as a moral attitude in nursing. *Nurs Ethics* 1999; 6: 214-23.
15. However, note that – in the light of the foregoing demarcation discussion – this characterisation concerns patients at the end of their lives, not specifically patients who receive care from a palliative approach.
16. McCormick TR, Conley BJ. Patients' perspectives on dying and on the care of dying patients. *West J Med* 1995; 163: 236-43.
17. Fegg MJ, Wasner M, Neudert C, Borasio GD. Personal values and individual quality in life in palliative care patients. *J Pain Symptom Manage* 2005; 30: 154-59.
18. Singer PA, Martin DK, Kelner M. Quality end-of-life care. Patients' perspectives. *JAMA* 1999; 281: 163-68.
19. Steinhäuser KE, Christakis NA, Clipp EC, McNeilly M, McIntyre L, Tulsky JA. Factors considered important at the end of life by patients, family, physicians, and other care providers. *JAMA* 2000; 284: 2476-84.
20. Randall F, Downie RS. *Palliative care ethics. A companion for all specialties* (2nd ed). Oxford: Oxford University Press, 1999.
21. Müller M. The volunteer in palliative care – a clearly defined role. *Eur J Palliat Care* 2005; 12 (suppl.): 24-27.
22. Hermsen M. *Ethics of palliative care in practice*. Nijmegen: Thesis Radboud University Nijmegen, 2005.
23. For methodological details see chapters 3 and 4.

Chapter 2

Professional competence and palliative care

An ethical perspective

Gert Olthuis

Wim Dekkers

Abstract

The aim of this article is to explore an ethical view of professional competence by examining the professional competence of physicians in the context of palliative care. A discussion of the four dimensions of professional competence – knowledge, technical skills, relationships, and affective and moral attitude – leads us to the conclusion that ‘habits of mind’ are important in every aspect of professional competence. This observation is then considered in the context of virtue ethics and ethics of care. Virtue ethics focuses on personal qualities and moral attitudes, while the ethics of care concentrates on the way these qualities are lived out in specific care relationships. Our conclusion points up the importance of education in ethics in the development of professional competence, and argues that because palliative care involves intense human interactions, integrating palliative care into the medical curriculum may improve the ethical culture of health care as a whole.

Journal of Palliative Care 2003; 19: 192-197,

with permission of the Centre for Bioethics, Clinical Research Institute of Montreal, Canada

Professional competence and palliative care

An ethical perspective

Introduction

Medical professionalism and the competence of professionals is the central concern in recent discussions about the future of health care.¹⁻⁵ These discussions include very little systematic reflection on the moral aspects of professionalism from a broader ethical perspective, even though these moral aspects are crucial. In this paper we will use palliative care as a specific example to illustrate the importance of such a broader view of professional competence in the education of physicians. The extensive curriculum for the Education of Physicians in End-of-life Care (EPEC),^{6,7} for example, intends to equip physicians with “a core base of knowledge which, in its application, will help physicians to improve their competence and confidence, strengthen physician-patient relationship, and enhance personal satisfaction with end-of-life care”. According to the EPEC handbook, applying this knowledge in day-to-day practice should “push physicians to rediscover some of the core values of our profession”. This asserts that being a competent professional is more than applying the right knowledge and skills; it also means a commitment to a set of ‘core values’. Despite this the EPEC-curriculum does not systematically look at these values in a wider ethical context. Several authors do go further and suggest that many elements of palliative care can be directly linked to philosophical insights.^{8,9} Schotsmans for instance argues: “Greater awareness of these philosophical foundations therefore has considerable potential to enhance the ethical culture of palliative care” (p.126).⁸ He claims that although specific expertise is a prerequisite for palliative care, “fundamentally one is dealing with an inter-human event, involving both the attendant and the dying person” (p.134).⁸ Schotsmans’ remarks emphasise the significance of a broader moral view in the education of professionals in palliative care, a view that goes beyond ‘a core base of knowledge’ which the EPEC handbook is intended to provide.

This article advances such a broader view of professional competence. Before we can examine the professional competence of physicians in the context of palliative care or reflect on its moral basis, we have to go more deeply into ethics and professional competence and discuss palliative care's 'ethical culture'. What does it mean to say that palliative care has an ethical culture? Does palliative care's ethical culture differ from the culture in other health care disciplines? The goals of medicine can be a useful guide. A recent research project specified four goals of medicine: 1) the prevention of disease and injury and the promotion and maintenance of health, 2) the relief of pain and suffering caused by maladies, 3) the care and cure of those with a malady, and the care of those who cannot be cured, and 4) the avoidance of premature death and the pursuit of a peaceful death.¹⁰ This makes palliative care an integral part of medicine. Three of the four goals refer to palliative care: relief of pain and suffering, care for incurable patients, and the pursuit of a peaceful death. However, modern medical ideology puts an emphasis on the cure aspect of "care and cure", and while there is no inherent contradiction between care and cure in medicine, the emphasis on cure is evident even in day-to-day practice and sometimes distracts from the need for care.¹⁰ Medicine conceived in terms of fighting illness and developing campaigns of treatment to cure disease devalues the caring elements of medicine, such as compassion and attention.

Balancing technical intervention with a humanistic, caring approach to patients lies at the heart of palliative care, as it does elsewhere in medicine. Because palliative care deals with patients who cannot be cured, it necessarily places more emphasis on care than other branches of medicine. This leads to a specific ethical culture that is displayed more clearly in a discipline like palliative care than in other parts of medicine. The increasingly technical approach to care does influence the care of dying patients and several authors have commented on medicalising tendencies in palliative care.¹¹⁻¹³ A comparative survey across 768 palliative care professionals in 32 European countries revealed out that 92% of the respondents held that medical, psychological, social and spiritual care were of equal importance within this field.¹⁴ More than 90% of the respondents considered the following moral notions as central in palliative care: quality of life, human dignity, acceptance of human mortality,

and total care. Obviously, the ethical culture of palliative care is a subset of the ethical culture of medicine as a whole, and these moral notions are also specific ethical elements of medicine in general, but their relevance is more frequently and more dramatically obvious in palliative care. Practicing palliative care can enhance the quality of physicians in general because it exposes the physician to unusually frequent and intense human interactions illustrating these moral notions.

As in medicine in general, the goal of palliative care is the good of the patient.⁹ Palliative care aims “to enable the dying person to live until he dies, at his own maximum potential, performing to the limit of his physical activity and mental capacity with control and independence wherever possible” (p.viii).¹⁵ This aim imposes specific requirements on palliative care professionals. In the next section we will outline these requirements in terms of a recent definition of professional competence. We will illustrate some basic tenets of this definition with some clinical vignettes derived from interviews with palliative care professionals (these interviews form part of a larger research project, titled *Moral attitude in palliative care*). Subsequently, we will turn to ethics and consider professional competence in palliative care from the perspective of virtue ethics and care ethics. Virtue ethics focuses on personal qualities and moral attitudes, care ethics on the way these qualities are lived out in specific care relationships.¹⁶

Professional competence in the context of palliative care

The professional competence of physicians has recently been described by Epstein and Hundert as “the habitual and judicious use of communication, knowledge, technical skills, clinical reasoning, emotions, values, and reflection in daily practice for the benefit of the individual and the community being served” (p.226).⁵ This definition, which is based on several prior definitions, consists of seven dimensions: cognition, technical expertise, integration, context, relationship, affective/moral attitude, and habits of mind.⁵ We will examine the cognitive, technical, relational and affective/moral dimensions in the context of palliative care. The dimension ‘habits of mind’ will be discussed in the next section because it is exactly in this dimension that virtue ethics and care ethics converge.

The cognitive dimension

Box 1

'What we learn at medical school, what is in our heads, that is no practice. You have to learn to apply knowledge in practice. What gives a positive effect in one patient, and a negative effect in another is a difference that you have to learn through experience.'

'As a health care professional you want to do something for patients. You tend to go to people with a lot of baggage. You have to learn to carry the baggage on your back, not in front of you. You have to examine the possibilities for this individual patient and learn what you have to offer. What are the limitations? Where is some space? That is the baggage with which you go to a patient. You need colleagues for that. You have to know the team very well, you have to know what skills you can deploy, what tricks you can use, and what kind of personality you have.'

Core medical knowledge learned at medical school lays the foundation of the *cognitive* dimension of professional competence. Nevertheless, the quotation from a palliative care physician in box 1 is an example that indicates the importance of another kind of knowledge: tacit knowledge. "Tacit knowledge is that which we know but cannot normally easily explain, including the informed use of heuristics (rules of thumb), intuition, and pattern recognition" (p.227).⁵ Practicing palliative care is not just applying knowledge and skills. It requires experience to get a feel for contributing to the quality of life of a seriously ill patient, to get to understand the different possibilities for different patients, to get to recognise gaps in knowledge, and to get to know when to ask for assistance of other team members.

The technical dimension

Box 2

I asked my colleagues about pain treatment: 'Someone has pain and you give them something for it. How long do you wait before there is any result?'

'Well,' they say, 'it depends on what kind of pain.'

'Okay,' I say, 'apart from that, how long do you think somebody may have pain before there is any result?'

'Three quarters of an hour, two hours.'

'And if it happens to you. You're suffering a terrible pain and the doctor prescribes something. What do you think now?'

'Well, preferably five minutes.'

'Why do you apply double standards? Have you ever checked if the drugs you prescribed did work?'

'No, that's a nurse's job.'

'And? Did they ever call you to say whether or not the drugs worked?'

'Never.'

'Do you know whether or not you gave your patient adequate medication?'

'No.'

'And you think we are doing effective pain relief?'

'If you say it like this...'

Without relief from pain and from other distressing symptoms like nausea, vomiting and dyspnoea, it is hard 'to enable dying persons to live until they die,' as Cicely Saunders expressed the aim of palliative care.¹⁵ The technical demands on palliative care practitioners should not be underestimated. A brief discussion between a palliative care physician and his non-palliative colleagues (box 2) shows that technical intervention in palliative care is more than just applying learned skills. Relief of pain for instance, should take place in close deliberation with the patient to find out whether or not the intervention is adequate. Because palliative care's aim is to improve the quality of life for patients who have a limited amount of time left, the urgency of adequate pain relief and the relief of other symptoms often seems to be higher than in other disciplines of medicine. Moreover, the discussion in box 2 also suggests that because of their broad experience in pain relief, palliative care physicians may have an unusually good understanding of the complexities of effective pain relief.

The relational dimension

Box 3

'A palliative care professional has to be good in communication. Not only in communication with patients, but also with the multidisciplinary team. You have to understand patients as well as colleagues. At the moment we don't have a team like we used to have. We're in a weaker position right now, I should say.'

'Our original team had members who complemented each other very well. We had creative people who could not organize accurately, but we also had organizers who picked up things others overlooked. And the rest of the team, the doctor, the social worker, the pastor... if you don't get on well together, it works against the team. And you need each other very much in palliative care. You cannot avoid each other, and if you don't complement, or at least understand one another, you have got a big problem.'

The remarks of the head of a palliative care unit in box 3 indicate that the relational dimension of professional competence applies to communication both with patients and with colleagues. Patients at the close of life expect their caregivers to be there for them, to show personal commitment and to listen attentively to their stories.¹⁷ Communication in palliative care often deals with difficult questions about life and death that evoke emotional reactions in both patient and caregiver.¹⁸ Furthermore, palliative care requires teamwork. A palliative care team may not only involve professionals, but can also include the family, friends, and neighbours of the patient, as well as other volunteers who may contribute to the provision of care.^{19,20} The quotation in box 3 refers to a team of professionals. This emphasises the importance of a balanced team that includes at least nurses, attendants, a physician, a social worker, and a pastor. Such a team can only function well if the professionals involved respect one another, are open-minded, listen well, and find ways to deal with divisions of leadership and responsibility.⁹ Research shows that while working with dying patients and their families can be stressful, close co-operation with others, conflicts with colleagues, difficulties with one's occupational role, and other work-environment related matters are also a major source of stress for those working in palliative care.²¹⁻²³

The affective and moral dimension

Box 4

Up until the last moments I had to convince her that without morphine I could not do anything. She had no tablets, we injected her.

'O no, there we go again,' she used to say.

'No,' I said, 'did you trust me so far?'

'Yes,' she said.

'You can trust that I give you a small amount of 5 mg, it has effect in about 15 minutes, it works for three hours. After two hours I'll ask you how you feel.

And so I did: 'How do you feel?'

'Fine,' she said.

'What were you afraid of?,' I asked.

'That I would go insane, and nauseous.'

'And?'

'Nothing.'

'Can we continue?'

'Yes.'

The affective and moral attitude makes up an important dimension of professional competence in palliative care. Caring requires motivated people who are committed to act for the benefit of other people. The tacit, but essential obligation of caring is to be there when another person needs it, in the way he or she needs it. Caring is helping in such a way that one gives personal attention to the cared-for. As the conversation in box 4 shows, trust, respect and receptivity to the concern of the patient are essential in this dimension. Professionals in palliative care have to be able to tolerate a certain degree of ambiguity and anxiety on the part of the patient when it comes to, for instance, the use of morphine. Some emotional intelligence can be required to get a patient's consent to the administration of a particular drug. Emotional intelligence is also necessary to manage one's own emotions when working with dying patients. Even for professionals, unexamined emotions like feelings of powerlessness, fear of death, grief, cynicism or frustration, can have

unintended consequences that detract from good patient care.^{24,25} Developing self-knowledge and the ability to face up to personal emotions is an important part of the education of physicians. "Excess attachment and avoidance or disengagement are forms of abandonment of the physician's primary mission, caring for the patient" (p.3008).²⁵

From the discussion of these four dimensions of professional competence in the context of palliative care, it appears that scientific knowledge, clinical skills and moral attitude cannot be considered as separate entities in the practice of care. The common thread running through these dimensions is 'the habitual and judicious use' mentioned in the definition of professional competence given above. Our discussion of the cognitive and technical dimension demonstrates that there is no direct relationship between knowledge and skills on the one hand and their application on the other. Experience is necessary to assess the individual patient's needs and to deal with them judiciously. Experience is also required to develop the tacit knowledge that is the basis of the habitual use of the physician's armoury. The discussion of the relational and affective/moral dimensions of professional competence demonstrates the importance of a habitual and judicious use of communication, values and emotions in the day-to-day practice of palliative care. Obviously, the seventh dimension of professional competence mentioned by Epstein and Hundert, 'habits of mind', cannot be detached from the other dimensions.⁵ It plays a part in all the four dimensions that we have discussed. "Competence depends on habits of mind that allow the practitioner to be attentive, curious, self-aware, and willing to recognise and correct errors" (p.228).⁵ In the next section, we consider professional competence from a specific ethical perspective, that of ethics of care and virtue ethics.

The moral basis of professional competence

The ethics of care presumes that caring adequately "is a quality of the morally good person or society" (p.126).²⁶ This does not mean that providing care automatically makes someone morally good. It rather emphasises the central role of caring in human life. The ethics of care considers care as a practice that involves both particular acts of caring, and a general 'habit of mind', involving care, that should inform all aspects of a practitioners life. There

is no intention to overthrow moral rules or ethical principles, but a desire to give a broader account of morality. Tronto identifies four elements of care that form a good starting-point to describe the moral basis of professional competence.²⁶

The first moral aspect of caring is the recognition of a need for care ('caring about'). This requires an attention to needs at various levels. In palliative care, caregivers should first of all recognise the need for care of the dying patient. As discussed above, caregivers also have to be attentive to their colleagues and to their own emotions if they are to provide good palliative care. The second moral aspect of care is 'taking care of', which presupposes a responsibility for care. This means the responsibility of society in general, and health care in particular, to organize palliative care. It also refers to the responsibility of individual caregivers working in palliative care to put palliative care into practice as best they can. The third moral aspect of care is the need for competent care ('care-giving') because the responsibility to provide care can only be met when the caring work is competently performed. The competence of care-giving, Tronto notes, "should centrally inform professional ethics" (p.134), because "intending to provide care, even accepting responsibility for it, but then failing to provide good care, means that in the end the need for care is not met" (p.133).²⁶ The fourth moral aspect of care – 'care-receiving' – involves the response of the care receiver to the care being offered. The vulnerable position of patients in palliative care compromises their status as independent and autonomous individuals. Assessing responsiveness to care "requires that we remain alert to the possibilities for abuse that arise with vulnerability" (p.135).²⁶

Tronto's point of view underscores the importance of a broader ethical view of professional competence. It shows that the various ethical elements of care are inextricably intertwined. Attentiveness for instance, is a central moral element in caring about patients, but the competent performance of caregivers and the responsiveness of care receivers also involve attention. Care ethics also shows that merely professionally competent care, whether it is palliative or not, time and again departs from the needs of the patient.

In fact, the ethics of care has deep historical roots. It dates back to Aristotle's virtue ethics in which *phronesis*, or practical wisdom is the key virtue.

Virtue ethics focuses on someone's inner qualities or character.^{16,27} Aristotle describes the practical wisdom that is required to make the best decision in particular circumstances as "a true state, reasoned, and capable of action with regard to things that are good or bad for man".²⁸ Phronesis should be considered as a capacity that motivates appropriate action in particular situations. It is a quality that enables someone to deliberate about what is good or bad for a human being in a particular situation and as a consequence enables the deliberator to act appropriately.²⁹ The emphasis on phronesis in virtue ethics is connected with the moral aspect of responsibility in care ethics: we are responsible for our intentions as well as for the consequences of our actions, in as far as we can predict them. When we intend to care for the dying, we accept a responsibility to provide professionally competent palliative care. This requires more than just applying knowledge and skills. Whether it concerns knowledge, technical skills, relationships or emotions, practical wisdom is required to judiciously choose appropriate actions. Phronesis is not a feeling about what is good, nor just a capacity to make a good choice, it is rather a habitual disposition to act well.³⁰ As our discussion of professional competence points out, taking good care of the patient starts with the 'habitual and judicious use' of the abilities that a physician has at his or her disposal. Deploying these abilities requires a physician to be able to predict the consequences of his or her actions. After all, palliative intervention aims at the relief of pain and suffering and at improving the quality of life of seriously ill patients.

Conclusion

On the basis of a dialogue between virtue ethics and care ethics, Benner argues that health care can be understood as "a caring practice carried out by practitioners of trustworthy character" (p.50).¹⁶ Looking at professional competence in the context of palliative care from the perspective of the ethics of care and virtue ethics emphasises the importance of the practitioners' trustworthy character or 'practical wisdom' in clinical practice. A review of four of the dimensions of professional competence (the cognitive, technical, relational and affective/moral dimensions) indicates that this wisdom should not be seen as a separate entity supporting a professional's competence, it rather plays a role throughout the provision of care. Ethics cannot be considered as a separate

part of medicine. "Medicine is, at its center, a moral enterprise grounded in a covenant of trust. This covenant obliges physicians to be competent and to use their competence in the patient's best interests" (p.1042).³¹ Since medical education lays the foundation of a physician's professional competence, it should explicitly pay attention to its moral origin. Although practical wisdom, in large part, depends on experience in practice, an education in ethics that sets professional competence in a wider context seems to be a prerequisite for the development of some initial awareness of medicine's moral basis.³²⁻³⁴ As pointed out in Schotsmans's remarks, quoted in the introduction, a greater awareness of the philosophical and moral basis of palliative care makes it possible to improve its ethical culture. Moreover, our discussion of professional competence shows that the qualities that make a good physician also make a good palliative care physician. Because palliative care involves intense human interactions, the basic ethical culture of medicine seems to be more evident in palliative care practice. That is why we argue that integrating palliative care into the medical curriculum may well improve the ethical culture of medicine as a whole.

References

1. Medical Professionalism Project. Medical professionalism in the new millennium: a physicians' charter. *Lancet* 2002; 359: 520-22.
2. Cruess RL, Cruess SR, Johnston SE. Renewing professionalism: an opportunity for medicine. *Acad Med* 1999; 74: 878-84.
3. Cruess RL, Cruess SR, Johnston SE. Professionalism: an ideal to be sustained. *Lancet* 2000; 356: 156-59.
4. Irvine D. The performance of doctors: the new professionalism. *Lancet* 1999; 353: 1174-77.
5. Epstein RM, Hundert EM. Defining and assessing professional competence. *JAMA* 2002; 287: 226-35.
6. The EPEC project. *Participant's handbook*. Chicago: American Medical Association, 1999.
7. The EPEC project. *Trainer's guide*. Chicago: American Medical Association, 1999.
8. Schotsmans P. Palliative care: a relational approach. In: Ten Have H, Clark D, eds. *The ethics of palliative care. European perspectives*. Buckingham: Open University Press, 2002: 126-40.
9. Randall F, Downie RS. *Palliative care ethics. A companion to all specialties* (2nd ed). Oxford: Oxford University Press, 1999.
10. Hanson MJ, Callahan D, eds. *The goals of medicine. The forgotten issue in health care reform*. Washington D.C.: Georgetown University Press, 1999: 1-55.
11. Bradshaw A. The spiritual dimension of hospice: the secularization of an ideal. *Soc Sci Med* 1996; 43: 409-19.
12. Clark D. Between hope and acceptance: the medicalisation of dying. *Br Med J* 2002; 324: 905-07.
13. Georges JJ, Grypdonk M, Dierckx de Casterle B. Being a palliative care nurse in an academic hospital: a qualitative study about nurses' perceptions of palliative care nursing. *J Clin Nurs* 2002; 11: 785-93.
14. Janssens R, Ten Have H, Clark D, Broeckaert B, Gracia D, Illhardt J, Lantz G, et al. Palliative care in Europe: towards a more comprehensive understanding. *Eur J Palliat Care* 2001; 8: 20-23.

15. Saunders C. Foreword. In: Doyle D, Hanks GWC, MacDonald N, eds. *The Oxford textbook of palliative medicine* (2nd ed). Oxford: Oxford University Press, 1998: v-ix.
16. Benner P. A dialogue between virtue ethics and care ethics. *Theoret Med* 1997; 18: 47-61.
17. MacLeod RD. On reflection: doctors learning to care for people who are dying. *Soc Sci Med* 2001; 52: 1719-27.
18. Faulkner A. ABC of palliative care. Communication with patients, families and other professionals. *Br Med J* 1998; 316: 130-32.
19. Latimer EJ. Ethical care at the end of life. *CMAJ* 1998; 158: 1741-47.
20. Ten Have H, Janssens R. *Palliative care in Europe*. Amsterdam: IOS Press, 2001.
21. Vachon MLS. Team stress in palliative/hospice care. *Hosp J* 1987; 3: 75-103.
22. Ramirez A, Addington-Hall J, Richards M. ABC of palliative care. The carers. *Br Med J* 1998; 316: 208-11.
23. Radziewicz RM. Self-care for the caregiver. *Nurs Clin North Am* 2001; 36: 855-69.
24. Harper BC. Growing in caring and professional ethics in hospice. *Hosp J* 1997; 12: 65-70.
25. Meier DE, Back AL, Morrison RS. The inner life of physicians and care of the seriously ill. *JAMA* 2001; 286: 3007-14.
26. Tronto JC. *Moral boundaries. A political argument for an ethic of care*. New York/London: Routledge, 1993: 125-37.
27. Drane JF. Character and the moral life. A virtue approach to biomedical ethics. In: DuBose ER, Hamel RP, O'Connell LJ, eds. *A matter of principles?* Valley Forge, Pennsylvania: Trinity Press International, 1994: 284-309.
28. Aristotle. *Ethics*. London: Penguin Books, 1976: VI.5 1140 b 5.
29. Comte-Sponville A. *A small treatise on the great virtues*. New York: Metropolitan Books, 2001.
30. Pellegrino MD, Thomasma DC. *The virtues in medical practice*. New York: Oxford University Press, 1993.

31. Thompson JN. Moral imperatives for academic medicine. *Acad Med* 1997; 72: 1037-42.
32. Andre J. Learning to see: moral growth during medical training. *J Med Eth* 1992; 18: 148-52.
33. Self DJ, Schrader DE, Baldwin Jr. DC, Wolinsky FD. The moral development of medical students: a pilot study of the possible influence of medical education. *Med Educ* 1993; 27: 26-34.
34. Gross ML. Ethics education and physician morality. *Soc Sci Med* 1999; 49: 329-42.

Quality of life considered as well-being

Views from philosophy and palliative care practice

Gert Olthuis

Wim Dekkers

Abstract

The main measure of quality of life is well-being. The aim of this article is to compare insights about well-being from contemporary philosophy with the practice-related opinions of palliative care professionals. In the first part of the paper two philosophical theories on well-being are introduced: Sumner's theory of authentic happiness and Griffin's theory of prudential perfectionism. The second part presents opinions derived from interviews with nineteen professional palliative caregivers. Both the well-being of patients and the well-being of the carers themselves are considered in this empirical exploration. In the third part the attention shifts from the description of "well-being" to prescriptions for the promotion of well-being. Our interview data are analysed in light of the theories of Sumner and Griffin for clues to the promotion of "well-being". The analysis (1) underscores the subject-relativity of well-being, (2) points out that values that are considered important in every life still seem to be relevant (at least in palliative care practice), and (3) shows the importance of living a certain sort of life when aiming to enhance dying patients' well-being.

Theoretical Medicine & Bioethics 2005; 26: 307-337,

with permission of Springer, Dordrecht, the Netherlands

Quality of life considered as well-being

Views from philosophy and palliative care practice

Introduction

Although the concept of quality of life is well established within contemporary health care, there is little consensus about the nature of this concept.¹ “Quality of life” was introduced into medicine as an additional measure of the effect of an intervention, over and above the basic biomedical information that had been used to judge people’s health, to serve as a supplement to these ‘objective’ medical measures. The underlying idea was that medicine should care about a person as an integrated, feeling and active being and not just focus on the person as a biological organism.² A person’s own assessment of their life was added to the objective measures of health. Nowadays, a person’s well-being is considered the main indication of quality of life. The first part of the current paper is an outline of how the nature of well-being is interpreted in contemporary philosophy. Two recent views on well-being will be introduced in this section: Griffin’s prudential perfectionism and Sumner’s theory of authentic happiness.³

The second part of this paper presents the results of empirical research into the way palliative care professionals perceive well-being. Palliative care aims explicitly at achieving the best possible quality of life for patients who cannot be cured and for their families.⁴ There is a recent trend to pay attention to the well-being of the professionals and informal care-givers of patients with a life-threatening illness as well.⁵ We asked nineteen palliative care workers about their views on (their contribution to) patient well-being and about the impact that providing end-of-life care had on their own well-being.

In the third part of the paper the practice-related views of palliative care professionals on well-being are compared with the insights offered by contemporary philosophy. How do the different aspects of well-being discussed in philosophy relate to professional caregivers’ opinions and their experiences concerning well-being? What does this comparison tell us about how well-being should be promoted?

Contemporary philosophy on well-being

Reflections on quality of life have a long tradition in philosophy. In the classic Greco-Roman period, philosophers reflected on the notion of 'a good life'.⁶ Contemporary philosophy sees a good life or a good quality of life largely in terms of subject-related personal well-being. Well-being here refers to the prudential value of a life. Instead of a general question ('What makes a person's life go well?'), the question is rephrased as asking about the good life of a particular person, with their own biography and characteristics ('What makes life go well for the individual whose life it is?'). The focal point is not what makes a life good compared to other lives, but how outer and inner events in the life of a specific person affect the well-being of that person. One of the main issues in contemporary philosophical discussion about well-being is whether or not prudential values exist independent of a person's desires and experiences of being well. Griffin's prudential perfectionism acknowledges the independent existence of prudential values and argues that there are some things that are valuable in every life. Sumner's theory of authentic happiness denies the independent existence of prudential values and argues that they are valued only in terms of the subject's attitude towards the world.

Sumner: authentic happiness

According to Sumner, well-being involves the experience of "authentic happiness" by which he means that well-being is the happiness as it is experienced by an informed and autonomous person.⁷ In fact his account of well-being is something in between hedonism and desire theory. Classical hedonism, which perceives well-being as a mental state, provides Sumner's theory with the experience requirement: "a necessary condition of a state of affairs making me better off (directly or intrinsically) is that it enter into my experience" (p.175).⁷ Desire theory, as a state-of-the-world theory, adds an information requirement. A person's authentic happiness, which Sumner considers to be a personal satisfaction of desires, is interpreted as an endorsement of the conditions of his or her life. People have to assess their well-being, the fact that life is going well for them, on the basis of a clear and correct perception of their life conditions.

This subjective account of well-being is grounded in an individual's view of the world which "is made up of the values or standards which a subject uses in determining whether their life is satisfying or fulfilling" (p.175).⁷ Their life conditions have to satisfy their own basic values to contribute to their well-being. The affirmation of their life circumstances ('I prefer this state-of-the-world') should be truly theirs (autonomous: 'It is my preference and I determined it independent of others') and should do justice to their lived experience of being well ('I feel well'). For Sumner, well-being is a purely subjective matter that is dependent on personal attitudes of favour and disfavour. Well-being is 'subject-relative': assessments of a person's well-being involve the state-of-affairs of that particular person. The question, however, is whether Sumner has confused subject-relativity and subjectivism about prudential values.⁸ Does the fact that someone's well-being is being assessed from the perspective of their particular life mean that well-being is subjective and that objective features of well-being are ruled out? As Varelius concludes there is no reason to exclude objective theories of well-being on the basis of the subject-relativity of prudential value.⁸ A theory that considers the prudential value of well-being from such an objective perspective is Griffin's prudential perfectionism.⁹

Griffin: prudential perfectionism

Griffin's theory should be seen as 'something in between' desire theory and objective theory. Like Sumner's theory, the basis of Griffin's account is made up of 'informed desires'. Desires can be faulty because of a lack of information, mistaken facts, or because of logical or conceptual errors. In other words, people have to be fully informed about their inner and outer circumstances before they can assess their lives as going well. Griffin's account of informed desires implies that these desires are structured in such a way that their final aim is the good life. Informed desires value the content of the good life. "According to Griffin, things or states of affairs are valuable because we have informed desires for them, but at the same time we have those informed desires because there is something in their nature that we can recognise and appreciate as valuable" (p.120).¹⁰ Desirability is based on more than just being rationally informed. Rational understanding of what is perceived as favourable

is interconnected with a desire that somehow pulls someone towards that favourable object. The appeal that is inherent in the nature of an object that is required for well-being, makes a person knowledgeable about its desirability. Griffin argues that without such an appeal and a subsequent movement to acquire the desirable features of that object, there is no adequate explanation for the fact that features are desirable. It is emphasised that informed desires are considered a response to the features sought because these features are generally intelligible as desirable; one should be able to explain the desirability and others must be able to understand the value of the object.

Griffin moves from informed desires to a perfectionist account of well-being, from the focus on individuals to an objective account which focuses on an index of values that are good for everyone. To put content into his theory, he lists five prudential values that could be endorsed by every well informed person: (1) accomplishment¹¹, (2) the components of human existence (here Griffin explicitly mentions three components of human agency: choosing one's own course through life/autonomy, having the basic capabilities that enable one to act, and liberty), (3) understanding (knowing about oneself and one's world, or being in touch with reality), (4) enjoyment, and (5) deep personal relationships. This list "provides us with an important standard for judging most (ordinary) human lives" (p.70).⁹

In sum, according to both Sumner and Griffin the nature of well-being has to do with the fulfilment of informed desires about personal life circumstances. Sumner emphasises that people's well-being is based on their subjective view on the world and that endorsement of the conditions of their life ('my life goes well') is a reflection of their basic values. Griffin on the contrary, takes informed desires to be both personal and impersonal. The latter appear as prudential values that should be considered necessary conditions for the well-being of every well-informed person. "Well-being is achieved by the realization of the values on the list, but in different ways, in different combinations and to different degrees for each individual" (p.123).¹⁰

Palliative care professionals on well-being

This section empirically examines well-being in the practice of palliative care as it was presented in interviews with professional palliative caregivers. The

aim was to formulate answers to two questions. The first question asks how palliative care professionals see the well-being of dying patients: Which aspects of well-being emerge from the views professional palliative caregivers have on (their contribution to) the well-being of their patients? The second question focuses on the well-being of the caregivers themselves: What does providing palliative care mean for the well-being of these professionals? After a description of the methods used to collect and analyse the data, an overview of our findings will be presented.

Methods

Respondents and data collection

Nineteen palliative care professionals from three different settings participated in a larger study of which this paper is a part (see table 1).¹² A semi-structured list of topics was used to guide the interviews with the participants. This list included a basic set of questions that had to be covered in the course of the interview. The advantage of the semi-structured interview guide was that it ensured that the same general topics were covered in all the interviews, while leaving room for the interviewer to ask follow-up questions based on specific answers of interviewees.¹³

The opening questions were aimed at mapping the respondents' history in (palliative) care: why did they work in health care in general and palliative care in particular, and what motivated or inspired them? Then the interview moved on to focus on the respondents' views on the ideals of palliative care: what is it and what enables palliative caregivers to provide such care in practice? In this section of the interview, we also asked them for their opinion concerning education: can one learn palliative care in training, and – more specifically – is every health care professional suited to provide palliative care? The third part of the interview focused on well-being. The respondents were invited to give their view on the well-being of patients, and we asked them what their contribution to patient well-being would be. We also brought up the concepts of a good life and a good death. The final question concerned the well-being of the interviewees themselves: in what respect did providing palliative care contribute to their own quality of life?

Table 1 - Respondents

Palliative care unit in a nursing home (founded in 1997; 4 beds):			
<i>Position</i>	<i>Age category</i>	<i>Sex</i>	<i>Experience</i>
CNA*	30-39	F	5 years
Dept. head	30-39	F	6 years
Pastor	50-59	M	6 years
CNA*	20-29	F	3 years
Physician	50-59	M	6 years
Social worker	40-49	F	6 years
Activity-facilitator	40-49	F	6 years
Palliative care department located in a hospital (founded in 1997; 6 beds):			
Physiotherapist	40-49	F	6 years
Physician	40-49	M	6 years
Physician	40-49	M	4 years
Nurse	50-59	F	2 years
Nurse	30-39	M	6 years
CNA*	20-29	F	3 years
Home care (the nurses are part of a palliative care expertise project that started in 2002):			
Nurse	20-29	F	2 years
Nurse	50-59	F	2 years
Nurse	30-39	F	2 years
Nurse	30-39	M	1 year
CNA*	40-49	F	24 years
Consultancy team:			
Physician	30-39	F	3 years

* *Certified Nursing Assistant*

Data analysis

In most qualitative analyses three basic steps are followed: immersion, data reduction, and synthesis.^{13,14} Unlike quantitative research, qualitative research requires the researcher to become immersed in the data during the analysis. By frequently reviewing the data during the collection phase, the researcher decides whether or not additional data are needed. As the collection process proceeds the researcher eventually observes that no new information is emerging from the data (theoretical saturation). In this study saturation occurred during the third series of interviews (home care nurses). After completing the home care interviews, only the interview with the consultant was added to the data to increase the variety of the group of respondents. The next step involved data reduction. This process divides the data into more manageable units. To carry out the reduction of the data we used Kwalitan, which is a computer programme for arranging qualitative data.¹⁵ Before entering the data into the programme, the interviews were divided in a total of 178 segments. A segment is a part of an interview that is marked with one or more codes. After importing the data into Kwalitan, a first round of coding took place (by GO). Codes are defined as “tags or labels for assigning units of meaning to the descriptive [...] information compiled during a study” (p.56).¹⁴ Some of the codes were generated from the questions included in the interview while others emerged from the data itself. The analysis produced a list of 29 different codes. Further interpretation and clustering of inter-related codes revealed six categories that synthesised the data into a more coherent whole. We will describe the process of data analysis in more detail elsewhere; four categories are to be discussed in a report on the moral attitude of palliative care professionals. The last two categories – concerning well-being – are discussed below (see box 1).

Limitations of the study

The larger project of which the current study is a part focuses on (the views of) professionals in palliative care. Experiences, opinions and beliefs of volunteers, patients, family and friends are not included in the analysis. Systematic fieldwork observations were not made, nor did we carry out a survey to address a larger group of respondents. Our findings are based upon nineteen

Box 1

1. The well-being of patients
 - (1) The nature of well-being
 - (2) Emphasising life
 - (3) Trying to meet patient preferences
 - (4) Treating the patient as a person
 - (5) Completing life
 - (6) Dying well
 2. The well-being of professionals
 - (7) Satisfaction & enrichment
-
-

interviews with nineteen professionals from various professional roles and from three palliative care settings located in a specific region of one country. Therefore, a certain modesty concerning the empirical findings is called for; one should comply with caution generalizing the results to a larger population. The value of the study mainly consists of the insights it provides concerning both the meaning of well-being for palliative care professionals and the relationship between well-being as it is discussed in philosophy and well-being as it is experienced by palliative carers.

Results 1: The well-being of patients

This category contains six codes. The following six subheadings concern a presentation of the results belonging to these codes (see box 1). The first code reflects what respondents considered to be the nature of well-being. The other five codes deal with what they consider to be valuable aspects of the well-being of palliative care patients. These are the matters that the respondents concentrated on when they explained the opportunities to be well at the end-of-life and their attempts to provide these opportunities. It is important to note here that we do not intend to give a complete overview of what palliative care professionals consider valuable for the well-being of their patients. Our results should be understood as a qualitative exploration of what our respondents thought mattered most for well-being at the end of life.

(1) The nature of well-being

Most participants remarked that they intended to contribute to their patients' well-being. The majority of the respondents answered the question on what they mean by the "well-being" of a palliative patient, by saying that it concerns a judgement of the patient about his or her current situation. "Well-being is when someone tells: 'I feel well considering the situation I'm in.'" [home care nurse] or "I think the well-being of patients is what they experience as well-being. When they enjoy themselves as they want it, then it's okay" [CNA]. Another respondent explained:

"In the terminal phase, the patient's convenience or well-being is most important. It is not about whether a small wound will heal or not. The wound will not heal. It is rather: that this patient accepts the wound and it does not bother her, she's satisfied, considering her condition." [home care CNA]

Apparently, in addition to a patient's individual preferences, well-being is bound to a specific condition. An important aspect of patient well-being seems to be a certain acceptance of the changing living conditions. As the interviewed consultant pointed out: "You strive for a situation as optimal as possible, doing justice to that particular person and to what quality of life is for him", but "you can never expect a terminal patient to feel entirely well." It seems necessary that patients somehow come to terms with being ill and should allow for their illness in their judgements of the quality of their lives.

(2) Emphasising life

A number of participants emphasised the fact that palliative care is concerned with life rather than death. "As long as they are here, they belong to life" [activity-facilitator]. End-of-life care tries to enable patients to live their lives as well as possible.

"Palliative care aims at life. It tries to contribute to the last part of life, to the inescapable progress to the end, in such a way that a patient has some energy left to say: 'I live until the end.' That is the best thing there is, that you can recognise that for a number of patients." [nursing home physician]

In daily practice, the focus on life often consists of enabling patients to enjoy small events like listening to music, a nice conversation or attending a birthday or a wedding: "You try to involve people in daily life as much as possible"

[physiotherapist]. The imminence of death often complicates this focus on life events. One of the respondents used a metaphor when a patient concentrates too much on the actual end of life.

“I compare it to a play in the theatre. You know that in the end the curtain is going to fall. As a spectator, you can stare at that curtain, but then you miss what happens on stage. I try to make clear that instead of staring at the curtain, one can try to concentrate on the scenes. People often experience this as an eye-opener.” [pastor]

Two participants – both physicians – critically examined palliative care’s contributions to patients’ quality of life: “Good palliative care often prolongs people’s lives. But do they live better?” And: “Good life in this respect is romanticising dying. You cannot always remove all suffering or the fact that one has to say goodbye.”

(3) Trying to meet patient preferences

Most respondents maintained that it is not procedures or protocols, but what the patient himself wants that is central to daily palliative care.

“We try to determine if someone aims at something. We concentrate on a person’s own preferences, not on what the hospital or health care in general aims at.” [nurse]

“There is a lot of room for people to lead their own lives. Patients can withdraw to their room, but also have the opportunity to make use of what nursing home life offers.” [pastor]

“The ideal of palliative care is that people can spend the last stage of their lives as they want it themselves, in their own way, together with their families that prefer that way as well.” [home care nurse]

There are limitations regarding attempts to meet patient preferences. An example from a home care nurse: “It is very difficult when clients prefer one nurse over another. Of course, a patient’s authority increases when he is at home and he can refuse our help when he considers it a violation of his privacy. But we’re not in the position to honour his request for a specific nurse; we are all professionals. If our work schedule assigns a less preferred nurse to that client, we call to announce this. And if that client does not agree then there’s no nurse that day.” Furthermore, for the professionals, patient preferences can sometimes be rather unclear:

"What I experience as very difficult is a first encounter. How far has someone gone in the process? I realized that people deal with it [the approaching death] very differently. Some prefer to talk about it very openly, others say that they will talk about it, but when you want to talk to them concerning the content it does not work out. Sometimes you get into a kind of quarrel because they blame you for raising problems that were never discussed." [home care nurse]

"I think it is embarrassing to help a patient with the bedpan when the family is still in the room. But if the patient does not mind them being around, I do not make difficulties about it. I had to learn that." [CNA]

On the other hand, several respondents spoke about their efforts in palliative care to try to fulfil specific wishes of patients. "Somebody can ask: I would like to go outside once more. Well, let's go outside in that bed!" [CNA]. Another respondent noticed: "I once cared for a man who very much wanted to see his horse. I am afraid of horses, but we went" [CNA].

(4) Treating the patient as a person

According to the respondents, considering the patient as a person with a life of their own, with a past, with relatives, emotions, doubts, and with interests and concerns of their own is very important. It is not only a condition for contributing to patient well-being. According to some of them, interest in the patient as a person is also considered a motivation to provide palliative care.

"I am interested in more than a backbone that does not rotate well. I believe it is very interesting to see how people feel and how they think, and why they behave in a particular way and why they have those complaints. You listen to people's stories and think: 'What can I mean for that person?'" [physiotherapist]

"When I teach I notice: these are the good ones. They are open to the effect the situation has on somebody's life and well-being and on how someone looks at the end of life. They want to talk to the patient." [nursing home physician]

What this means in day-to-day practice is evident in the following quotation:

"You have to react to a patient in an appropriate and individualized way. If somebody always had difficulties with talking about emotions, then you know you should not force him. Someone's expression gives you clues. Is he almost in tears or not? Does someone tremble? How does the patient touch you or look at you? These are

the things that tell you how a patient feels. You have to connect to these signals and to the experiences of the family.” [social worker]

Several participants pointed out that previous life events determine a patient’s capacity to deal with illness and suffering at the end of life: “When patients and lay carers talk very openly to each other about what they are going through or about the funeral or about one another’s grief, then that involves the joint history of these people. The character of the patient also plays a part” [home care nurse]. The consultant interviewed added that although contact with patients can be very intense, the variety of personal experiences concerning (the end of) life means that palliative care professionals cannot always know what specific patients actually want.

“People carry with them a whole life and I cannot have the illusion that I know them. Sometimes a person can get terrified unexpectedly and you don’t know what you’ve stirred up. You will always have to be sensitive to the fact that situations of loss and interactions about that are not logical.” [consultant]

(5) Completing life

Three quarters of the respondents mentioned that completion of life plays a part in the quality of the last stages of life.

“The last stage ideally should have room for completion, for people to calm down, to trust that it is going to be all right, that life will end decently.” [nurse]

“I think it is ideal when people experience some growth in that last stage. Perhaps they can have a family reunion or look forward to something, and come to a good closing of their life together with their family.” [social worker]

Nevertheless, dying patients are often quite desperate about what lies ahead, which deprives them of the opportunity to close their lives in a calm and decent way. Anxiety and feelings of hopelessness sometimes lead to a euthanasia request. The nursing home physician explained how he attempts to deal with such a patient’s fear:

“I do not leave people in panic and I do try to help them to collect their thoughts. I try not to lose touch with reality, but I do try to decrease the tension that seems to overwhelm them. I try to put my trust in that particular patient and talk about it. This can open up other possibilities and it can turn out that you are able to make a difference.”

The growth that is possible when patients can overcome their agitation mostly manifests itself in relationships. From the perspective of the respondents, this "growth" generally involves an acceptance of the situation and a deepening of relationships: "Illness can be very meaningful in the palliative phase. You can perceive lovely things happening between people" [home care nurse]. However, a closer relationship does not always make a patient feel better.

"Such a process can be both wonderful and painful because it can become obvious that someone had always felt rejected or that a father had a past that he had previously been unwilling to discuss. I often see an intensification of contacts." [consultant]

Yet if patients are able to live through the last stage of life properly that is of importance for themselves as well as their loved one's: "People who consciously deal with their suffering can be a support for their environment" [home care nurse]. Many patients (re) turn to their religion to seek comfort at the close of life. "I notice that there are quite a few people who seek contact with the convictions about life they grew up with. Of course there is a big difference between the one's who are churchgoers and those who are not" [pastor].

(6) Dying well

The last code concentrates on dying well. This code closely corresponds with – and partly overlaps – the previous code 'completing life'. "We aim at both life and death. Most of the time, the lead up to the moment of death determines whether it will be a 'good' death or a 'bad' death" [department head]. However, central to 'dying well' is not the (more active) individual completion of life but the actual process of dying a patient undergoes quite passively. Besides pain and symptom management, people's image of the end of life, the context of dying and its consequences for others play a part here as well. Several respondents had noticed that death and dying might be taboo for patients and their families.

"Often you know that people know they are dying, but they do not want or cannot talk about it. Or they do not want to burden others." [social worker]

"Dying is banished from many people's existence. They do not know what it is and do not realize that it is not something that takes half an hour." [home care nurse]

Many respondents characterised a good death as something that happens when someone is ready for it and “when a patient has come to terms with the end of life” [home care CNA], preferably unburdened by pain, nausea, agitation, shortness of breath, or fear. Several respondents admitted that this was an ideal rather than a regularly achievable target. The presence of family and friends is mentioned as a part of a good death. Several respondents felt that patients should not die alone, while other participants emphasised that dying is a personal and individual event: “Everybody dies his own death. As a caregiver you have to figure out what is a good death for that person, what he fears and definitely does not want. Then you can anticipate that” [consultant].

In spite of this, a good death does not just involve the death of the person in question. Several respondents point out its value for those who witnessed the dying process.

“[It is good] when someone finally accepts it and has the strength to complete his life together with others, and consequently has the strength to let others accept it.

When someone leaves behind a healthy basis for grief.” [physician]

Others point out the distress that can be caused by witnessing a painful death:

“I was very happy that there was no family present this time. If they had seen this, they probably would not have understood it. They were very vulnerable.” [nurse]

Finally, we note that the quality of a patient’s dying process affects the way loved ones perceive their own death. The next section concentrates on the relationship between providing palliative care and the well-being of the professionals who provide such care.

Results 2: The well-being of professionals

(7) Satisfaction and enrichment

As in other occupations, in palliative care being appreciated is a source of job-satisfaction: “It is nice when people indicate that they appreciate what you did” [nurse]. Nonetheless, one respondent explicitly mentioned that she found it difficult when a patient’s family effusively thanked her for her contribution to care: “When people thank you once, I reply: ‘You’re welcome. I enjoyed it and I am glad it ended well.’ But sometimes they thank you six times. Then I feel awkward” [CNA].

However, the answers of the participants indicate that being appreciated is not the most important source of well-being. One physician considered working in palliative care no more satisfying than working in other branches of health care – “When it comes to job-satisfaction, for me doing something good for a patient does not depend on working in palliative care or in a hospital” – but most respondents identified a number of other sources of satisfaction involved in caring for the dying. The feeling that they had the ability to contribute positively to the situation of patients and their families seems to be an important source of satisfaction for most participants.

“Providing palliative care is trying to offer just a little bit more. That gives me a good feeling when I am at home. It brought me to a level where I would not have been otherwise.” [CNA]

“Sometimes you find such a warm atmosphere in families. That is what you would want to have at home. You can get a very good feeling when you are finished there and everything went well for everybody. I get a kick out of it.” [home care nurse]

“I am not an angel, but often caring for these patients is doing me good.” [CNA]

“If you have the feeling that you have done your part and it went well, than that is satisfying.” [pastor]

“It is very nice to see that it helps people. That gives me a lot of satisfaction.” [home care nurse]

It is not surprising that almost all participants considered that providing palliative care was an enrichment of their lives: it gives a feeling of doing something good, it gives the opportunity to develop personally, and it impels a broader view of life and humanity in general.

“What palliative care does for me when I am at home is that I manage my own time more consciously. We should be happy with what we have got. Tomorrow can be very different from today.” [nursing home physician]

“I learned to put things into perspective. Being amazed at what is important for others and what you think of it yourself.” [activity-facilitator]

“I think I became more mild as a person. I learned about the value of life. Sometimes it seems as if in a short period of time you observe a lot of problems very intensively. I believe you are always confronted with your own life and you learn from that.” [physiotherapist]

“It enriches me. Especially because I have the feeling that palliative care gives me the opportunity to actualise myself.” [consultant]

“You show a lot of yourself, but that is in no proportion to what patients show you. In fact, in two or three weeks every aspect of a whole life passes by; sadness, misery, fights, misunderstanding, love. You take part in that. That is the added value of palliative care: what you give is in no proportion to what you receive.” [nurse]

In the next section we will return to the theories of well-being and discuss them in the light of the picture of well-being in palliative care practice presented above. The aim of this section is to investigate the relationship between philosophical theories about well-being and the views of palliative care professionals on this subject. Furthermore, we will shift our attention from a description and analysis to a consideration of how we ought to act to promote well-being.

Discussion

There are several ways in which empirical studies can be important in medical ethics.¹⁶ One is that they provide descriptions of what is considered moral in a particular context. The importance of a study that describes what palliative care professionals believe about a moral question – like contributing to a dying patient’s well-being – is that these descriptions illuminate human responses to a normative question: what should I do to help these patients? The basis of empirical ethics is that the relationship between normative and descriptive research in ethics is interactive: normative theories raise questions that can be studied in practice and empirical data can bring up issues that impel fine-tuning of ethical theories.^{16,17} In this third part we interpret our empirical results in the light of the theories of Sumner and Griffin, in order to search for clues concerning the promotion of well-being.

Well-being as a value without content

According to Sumner, an adequate description of well-being has to be decoupled from its potential role in a normative framework.⁷ Although he admits that his description will inevitably be guided by some normative destination that he has in mind, he is convinced that (descriptive) questions about the nature of well-being should precede (normative) questions about its value.⁷

Subsequently, he argues, descriptive adequacy requires four boundary conditions: fidelity, generality, formality and neutrality.¹⁸ Working from Sumner's starting-point produces a description of the nature of well-being *without content*: the theory of authentic happiness. This description fits with common sense experiences of well-being, is generally acceptable, formally tells us what it is for a life to go well, and is neutral concerning the enormous variety of human attitudes towards life. When it concerns the role of well-being in ethics, Sumner argues for what he calls 'welfarism', which implies that "ethics ultimately has to do with making lives go well, or at least making sure that they do not go badly" (p.191).⁷

According to Sumner, welfarism means that nothing but well-being matters for ethics. Well-being becomes the only foundational value for ethics, which qualifies welfarism as a monistic theory of the good. Furthermore, as explained in the first section, Sumner regards well-being as entirely dependent upon a person's attitudes of favour or disfavour. What is prudentially valuable (what contributes to a person's well-being) is whatever ways of life are found to be fulfilling by an informed and autonomous subject. Sumner's view on the nature of well-being can be recognised in what our respondents consider the nature of well-being. Most of them emphasised that well-being should be considered a judgement by the patient about his or her current situation. This judgement should be informed and autonomous. The patients themselves determine whether or not they are doing well. A consequence of Sumner's monistic and subjective account of well-being is that what promotes someone's well-being cannot be separated from that particular person: "however valuable something may be in itself, it can promote my well-being only if it is also good or beneficial for me" (p.37).¹⁹ But what then should palliative care professionals do to promote the well-being of dying patients? Should their actions be fully and only dependent upon the opinions of the patients in question?

The content of well-being and its promotion in palliative care

Whereas Sumner argues that the ideal life (of being well) is – without referring to any content – whatever a person considers an ideal life in given circumstances, Griffin abandons the criterion of neutrality and suggests that when we are seeking the ideal life, we are looking at its content (p.58).⁹ Be-

cause there are irreducibly many ideal forms of life, Griffin accepts a plurality of values rather than reducing to Sumner's single ultimate value. Promoting these values would lead human beings, today or in the future, to live better lives (p.71).⁹ While the respondents' views on *the nature of well-being* can be seen as conforming to Sumner's account, a closer look at the other five codes concerning the well-being of palliative care patients reveals the important role of Griffin's prudential values in the palliative actions of professionals directed at the enhancement of well-being. A reflection on our results regarding patient well-being on the basis of Griffin's list of prudential values and other studies will demonstrate this (see table 2).

Emphasising life

According to Griffin, 'agency' is at the heart of what it is to lead a human existence (p.67).⁹ He indicates three components that make up the complexity of agency: 1) autonomy, or deciding for oneself, 2) having the basic capabilities that enable one to act (a body that works, freedom from pain and anxiety), and 3) liberty. The data that have been labelled as emphasising life show that the efforts of palliative carers intend to acknowledge human agency as much as possible. Although a patient's mobility often is seriously diminished at the end-of-life, professionals try to focus on what life has to offer to a patient taking a patient's decreased capabilities into account. As the nursing home physician emphasised: the best thing is a patient saying: 'I live until the end'. Other respondents, however, wondered if palliative care indeed is able to cherish a patient's agency while retaining and restoring his quality of life. Research acknowledges these respondents' doubts. Lawton, for instance, critically comments on palliative care's starting-point to enable patients to live until they die and states that contemporary palliative care seems to ignore the tremendous impact bodily deterioration and decline can have on the patient's self.²⁰ She claims that to realise and maintain selfhood, at least two bodily capacities must be possessed: a "bounded, physically sealed, enclosed body", and "the bodily ability to act as the agent of one's embodied actions and intentions" (p.7).²⁰ Lawton concludes that dying patients often fall out of the category of personhood in both their own and other people's evaluations; they experience a diminishment of self. Yet, the statements of the nursing home physician and

Table 2 – Prudential values in codes concerning patient well-being

<i>Respondents on patient well-being</i>	<i>Prudential values (cf. Griffin)</i>
Emphasising life	Components of human existence: human agency (having the basic capabilities that enable one to act) Enjoyment
Trying to meet patient preferences	Enjoyment Components of human existence: human agency (having the basic capabilities that enable one to act; choosing one's own course through life)
Treating the patient as a person	Deep personal relations
Completing life	Accomplishment Understanding: knowing about oneself and the world, being in touch with reality Deep personal relations
Dying well	Components of human existence: human agency (choosing one's own course through life) Deep personal relations

the pastor indicate that Lawton's assertions do not always follow: a number of patients actually seems to be able to experience the last stages of life as a period where 'human existence' prevails, despite their bodily deterioration. We will get back to this below. Lastly, we point out that the prudential value of enjoyment also plays a part when emphasising life, since professionals attempt to promote well-being through focussing on the joy of the "day-to-day textures of life" (p.67).⁹

Trying to meet patient preferences

Two types of therapeutic (nursing) interaction that possibly improve feelings of well-being of palliative patients can be identified: professional interaction addressing the disease and physical problems, and humanistic and egalitarian personal interaction focussing on psychological well-being.²¹ The data coded as trying to meet patient preferences show the importance of the latter type, acknowledging for instance the prudential value of enjoyment. Although the independent mobility of patients may be minimized (as Lawton pointed out), our respondents still consider them persons who value pleasure or appreciate nature. This is expressed in their occasional attempts to fulfil specific wishes of patients. Furthermore, several studies show that patient and family preferences concerning end-of-life care initially focus on pain and symptom management.²² The prudential value that plays a part here is one of the components of human agency: having the basic capabilities that enable one to act, which means freedom of great pain as well (p.67).⁹ Our study makes clear that palliative carers believe that one should not limit oneself to physical care when it concerns dying patients' well-being. Research identified five domains of quality end-of-life care from patients' perspective: (1) receiving adequate pain and symptom management, (2) avoiding inappropriate prolongation of dying, (3) achieving a sense of control, (4) relieving the burden imposed on loved ones, and (5) strengthening relationships with loved ones.²³ An adequate treatment of pain and symptoms does not seem to be sufficient to attain a sense of well-being at the close of life. This code explicitly advances another component of human agency as well: autonomy in the sense of choosing one's own course through life. As mentioned by one home care nurse: people should spend the last stage of their lives as much as possible in the way they themselves want to. This implies approaching them from a professional perspective in an egalitarian, non-paternalistic way. Nevertheless, the results belonging to this code also make clear (as Sumner would argue) that patients must take their life conditions into account when it concerns the evaluation of their well-being. Their precarious situation for instance makes them both dependent upon others for daily care, and upon organizations for the provision of that care. Not accepting this can have negative consequences for their experienced quality of life.

Treating the patient as a person

Emotional support and personalized care from professionals belong to the most important needs of patients at the end of life.²⁴ Emotional support is primarily expressed through compassion, responsiveness to emotional needs, hope and a positive attitude, and comforting touch.²⁴ In the data that are identified as treating the patient as a person these aspects of care are advanced in the fact that the respondents consider their interest in the patient as a person a motivation to provide palliative care. Due to a growing atmosphere of openness and honesty when patients are dying²⁵, contact with them can be very intense as the interviewed consultant affirms. The respondents consider the opportunity to get closely involved in the dying person's (family) life an attractive element of end-of-life care (see also: Results 2: The well-being of professionals, p.50). Furthermore, personalized care is expressed through treating the whole person, not just the disease, making the patient feel unique and special, and considering the patient's social situation.²⁴ It is suggested that getting to know the (uniqueness of the) patient is central to providing quality palliative care.^{25,26} Our respondents indicate that treating the patient as a person also means taking the joint history of the patient and his family into account.

From the perspective of palliative care professionals, the prudential value 'deep personal relations' is of importance in two ways here. On the one hand, this value plays a part in the significance of the professional-patient relationship, i.e. in the professionals' authentic concern for patient and family. On the other hand, professionals have to deal with relations between patients and their families and loved ones. As several respondents indicate, a patient's relational history partly determines the extent to which he is able to deal with his present situation.

Completing life

Research into patients' perspectives on dying has established the importance of having the opportunity to gain a sense of completion.^{27,28} "Life review, saying good-bye, and resolving unfinished business provide both patients and their families with an opportunity for human development at the end of life" (p.2481).²⁸ Patients often admit to having particular tasks to achieve in bringing closure to life as death draws near.²⁷ Several aspects of life completion are

advanced in our respondents' answers. An open communication with friends and especially family is one of them. As the respondents indicate, this openness can be both supportive (relationships can be deepened) and painful (dealing with unfinished business might raise unexpected matters) for those surrounding the patient. Furthermore, completing life might imply (emotional) deliberations: Should I continue palliative chemo treatment or not?, or What about euthanasia when suffering increases?

First of all, the prudential value of accomplishment plays a role here. Accomplishment can be described as "the act of accomplishing or finishing work completely and successfully".²⁹ Accordingly – since our concern is the end of life – it refers to finishing life completely and successfully. Griffin emphasises that accomplishment differs from achieving pre-set goals: accomplishment as a value is valuable independently of its consequences. This is exemplified both in the strengthening of family ties, as the interviewed social worker remarks, and in making painful confessions before death arrives, as the consultant indicates. Those actions are not meant to reach a particular goal, but seem to be worthwhile in the sense that they give life point or substance serving the well-being of patients who finish their life.¹¹ Furthermore, the data categorized as completing life again show the significance of the prudential value of deep personal relations. According to the respondents for instance, growth at the end of life generally involves a valuable deepening of relationships for patients and their family and friends. Simultaneously, matters that disrupt personal (family) relations can seriously degrade well-being in the last stage of life. Finally, the prudential value of understanding can be recognised in the data gathered as completing life. Understanding is explained as: "Simply knowing about oneself and one's world is part of a good life. We value, not as an instrument but for itself, being in touch with reality, being free from muddle, ignorance, and mistake" (p.67).⁹ According to the respondents, acknowledging that life is ending ('being in touch with reality') contributes to a certain well-being while death is imminent. Professionals stress the importance of consciously dealing with suffering when facing death ('knowing about oneself and one's world'). This can be beneficial for the well-being of both patients and their loved ones.

Dying well

As explained in the results-section, dying well differs from completing life in the sense that the former concentrates on death and the actual dying process a patient undergoes relatively passively. Patients first of all preferred adequate pain and symptom management. Without it, dying well seems to be hard, as the respondents' answers suggest. Simultaneously, several respondents postulated that being open about death and dying is still very much a taboo among patients and their families. Interestingly, some studies recently pointed out the emergence of openness about one's own death in contemporary societies due to a prolonged dying process and medical developments to bring pain and symptoms under control.^{30,31} "The rhetoric of palliative care sets great store by the autonomy of the individual patient and the fulfilling of the latter's wishes about how and where (if not when!) she chooses to die" (p.406).³⁰ And it is claimed that the manner in which 'denial' is defined and used in palliative care literature is not so much as an individual defence mechanism, but as an instrument in a larger discourse on dying, which both invites patients to participate in the planning of their death and labels those who do not comply.³¹ This observation can also be recovered in the interviewed consultant's remark on the fact that everybody dies his own death and caregivers have to figure out a patient's preferences, thus supposing a patient has a specific view on his or her end of life. We suggest that in this shift to consider (the good) death more individualized, the prudential value of choosing one's own course through life can be recognised.

Several studies refer to worries patients have about burdening their own family.^{32,33} In our study these worries were not mentioned. This can probably be explained by the fact that respondents focused on patients who already received professional care. However, the respondents mentioned both the value and dangers of witnessing another person's death. Research among seniors who had provided informal end-of-life care for others, who had experienced their deaths, and who had considered their own death and dying, shows that family members are considered a key element of care.³³ While participants of that study did not think of their previous care giving for others as a burden, there was common concern about burdening their own families regarding their own dying process. Nevertheless, they had learned that dy-

ing people typically depend on others and participants therefore preferred informal caregivers to care for them at home. This suggests that experiences with death and dying of others stimulate reflection upon one's own mortality, which will contribute to the content of the (preferred) image of one's own death. This corresponds with our observations concerning the value and dangers of witnessing the death of loved ones. Apparently, close involvement in a loved one's dying process can have both positive (consolation, acceptance) and negative (worries about burden, fear) consequences for the well-being of both patients and family members and friends at the end of life. It seems however, that the prudential value of deep personal relations inevitably plays a part when it concerns the quality of the dying process.

Thus, our data show that Griffin's prudential values conform relatively well to palliative care professionals' views on well-being. Is the fact that these values can be recognised in palliative care practice sufficient to conclude that they should be promoted generally? From the respondents' perspective, Griffin's list of prudential values appears to be relevant if one intends to positively affect the well-being of palliative care patients. But do these prudential values improve life, independent of the situation of one particular person? Perhaps not, because, as the respondents' answers suggest, a significant part of an individual's well-being depends on the fulfilment of that individual's desires. But the data about the well-being of the professionals themselves suggest the importance of a more objective aspect of well-being, one that goes beyond the subjectively oriented preferential interpretation: the significance of living a certain sort of life.

A covenantal approach to end-of-life care

Beyond the appeal ('ethical pull') that according to Griffin is inherent in the five prudential values, he draws on virtue ethics to explain that well-being depends on the additional 'ethical push' of having lived a good life. The external pull that prudential values have ('these values make an individual life good') cannot be detached from an internal motivation that persuades individuals to interact in a specific way (p.63).⁹ This motivation is embedded in living a certain sort of life.³⁴ For example, an ethical analysis of the relationship between personal and professional identity of hospice nurses in the context

of caring conversations with patients demonstrated that their professional efforts should not be seen separate from the way they experience and evaluate their activities in the light of what they consider worth living for.³⁵ This observation indicates close ties between being a person and being a (palliative care) professional.

To attain well-being it is not sufficient for a person to get what he wants: it also depends on the way the preferences are satisfied. In other words, “my happiness must involve my living a good life rather than just having desires filled” (p.19).³⁶ This ‘living a good life’ does not only relate to someone’s personal life, but is also expressed in professional life. As is evident from the respondents’ answers, they experience providing palliative care as very rewarding. But as the data show, the well-being provided by end-of-life care is not the mere satisfaction of subjective desires. It is also a function of close involvement in other people’s lives – as was put forward in the code ‘treating the patient as a person’ – and the opportunity to contribute positively to the quality of their last stage of life. The basis of the sort of life that seems significant here can be seen in the comments of a nurse (last quote in the second part) about giving and receiving in palliative care: “You show a lot of yourself, but that is in no proportion to what patients show you. [...] What you give is in no proportion to what you receive”. The sort of life revealed by the answers of the professionals corresponds closely to what Byock refers to as ‘a covenantal approach’.³⁷ Byock argues that interaction in palliative care is covenantal rather than contractual. Unlike a contract – which is temporary and founded on distrust – a covenant is durable because it is based on trust. “Within a covenantal approach to illness, care-giving, dying, and grief, people respond to others out of a lived sense of mutuality and because they are motivated by a desire to care. In acting covenantally, I make decisions affecting the well-being of another, conscious that their well-being affects my own” (p.S40).³⁷

Conclusion

Drawing a comparison between two philosophical perspectives on well-being and the practice-related views of palliative care professionals on that subject shows both a bridge and a gap between the subjective account of well-being as advanced by Sumner and the opinions of our respondents. While the majority

of the respondents consider a patient's well-being a (subjective) judgement of that patient about his or her current situation – which is in line with Sumner's assertions – a closer examination of the respondents' answers suggests that the content of that judgement corresponds with features that are considered valuable in *every* life. The prudential values as listed by Griffin play a prominent part in the respondents' accounts on how to promote the well-being of patients at the end of their lives. Although respondents acknowledge the subjectivity of patient well-being, they do not seem to be neutral as to how to enhance it in everyday working life. Whereas quality of life – and well-being as its main indicator – is introduced into medicine as a *subjective* measure of the effect of an intervention, our analysis suggests that *objective* features of what it is to be well (still) play a part in the actions of palliative carers.

The actions of our respondents which are aimed at enhancing their patients' well-being both seem to be determined by the 'ethical pull' of the prudential values and by a particular motivation ('ethical push') that can be characterised as covenantal. The accounts of our respondents concerning their own well-being clarified that their actions are also motivated by their commitment to suffering others. Simultaneously, their efforts should not be interpreted as altruistic: 'What you give is in no proportion to what you receive,' one of the interviewees emphasised. According to Byock, both a lived sense of mutuality and a desire to care are central to the covenantal approach to important life events like illness, death and grief.

In sum, our analysis leads to three significant observations. First, it underscores the subject-relativity of well-being. Second, it points out that values that are considered important in every life still seem to be relevant (at least in palliative care practice). Third, it shows the importance of living a certain sort of life when aiming at enhancing dying patients' well-being. The latter observation implies that the attitudes that should be taken to the desires of palliative patients should ideally be rooted in a *moral* attitude, which reflects a *personal* motivation and commitment to act in the interest of others.³⁸ The extent to which a professional's own well-being depends on the provision of palliative care, justifies careful attention to the (future) professional's motives and personal characteristics in training and education. Eventually, palliative care patients will benefit from this.

References

1. Nordenfelt L. Introduction (to thematic issue on Quality of life). *Ethical Theory and Moral Practice* 1999; 2: 3-10.
2. Nordenfelt L. *Quality of Life, Health and Happiness*. Aldershot: Avebury Ashgate, 1993.
3. In the present article we focus on the theories as they were developed in: James Griffin, *Well-being. Its meaning, measurement and moral importance*. Oxford: Clarendon Press, 1986; and L.W. Sumner, *Welfare, happiness, and ethics*. Oxford: Oxford University Press, 1996. The accounts of Sumner and Griffin were selected because they accurately represent the two positions that play the most important part in the philosophical discussion on one of the key issues concerning well-being: is it purely personal and subjective, as Sumner argues, or do ('objective') values exist that are worth promoting independently of their consequences for our well-being, as Griffin's view contains.
4. This aim is emphasised both by the World Health Organization (see for the WHO's definition of palliative care: <http://www.who.int/cancer/palliative/en/>) and in the literature: e.g., Twycross RG. Quality before quantity – a note of caution. *Palliat Med* 1987; 1: 65-72; Sherman DW. End-of-life care: Challenges and opportunities for health care professionals. *Hosp J* 1999; 14: 109-21; Doyle D, Hanks G, Cherny N, Calman K (eds). *Oxford textbook of palliative medicine* (3rd ed). Oxford: Oxford University Press, 2003.
5. This attention usually concentrates on factors associated with known dangers to the well-being of carers: caring for young patients, a close relationship with a patient, several deaths over a brief period of time, and particularly relationships with other professionals, poor management or resource limitations. See, e.g.: Ramirez A, Addington-Hall J, Richards M. ABC of palliative care. The carers. *Br Med J* 1998; 316: 208-11; Meier DE, Back AL, Morrison RS. The inner life of physicians and care of the seriously ill. *JAMA* 2001; 286: 3007-14; Katz RS, Genevay B. Our patients, our families, ourselves. The impact of the professional's emotional responses on end-of-life care. *Am Behav Scient* 2002; 46: 327-39; Buijssen H, Bruntink R, Van der Ploeg H, Baar F, Stoppelenburg A. *A good ending*,

- good for all? Care for carers working in palliative care.* Nijmegen/Tilburg: De Stiel/TRED, 2003; and Deeken JF, Taylor KL, Mangan P, Yabroff KR, Ingham JM. Care for the caregivers: A review of self-report instruments developed to measure the burden, needs, and quality of life of informal caregivers. *J Pain Symp Manage* 2003; 26: 922-53.
6. See for discussion on several philosophical attempts to define the concept of a good life: Nordenfelt, cited in note 1 and 2 above; Griffin, Sumner cited in note 3 above; but also Musschenga AW. The relation between concepts of quality-of-life, health and happiness. *J Med Philos* 1997; 22: 11-28; Sandøe P. Quality of life – three competing views. *Ethical Theory and Moral Practice* 1999; 2: 11-23; Sandman L. *A good death. On the value of death and dying.* Göteborg: Acta Philosophica Gothoburgensia, 2001; Schermer M. In search of 'the good life' for demented elderly. *Med Health Care Philos* 2003; 6: 35-44.
 7. Sumner LW. *Welfare, happiness and ethics.* Oxford: Oxford University Press, 1996.
 8. Varelius J. Autonomy, subject-relativity, and subjective and objective theories of well-being in bioethics. *Theoret Med* 2003; 24: 363-79.
 9. Griffin J. *Well-being: Its meaning, measurement and moral importance.* Oxford: Clarendon Press, 1986.
 10. Schermer M. *The different faces of autonomy. A study on patient autonomy in ethical theory and hospital practice.* Amsterdam: Thesis University of Amsterdam, 2001.
 11. Accomplishment should be kept distinct from achieving goals that are set by one's self or developing particular skills. These goals can lack point or substance. "Accomplishment, as a value, is valuable independently of its consequences, and it is not accomplishment that a person values if what he is after is one or other of what he supposes its consequences to be. [...] what is accomplished has, by definition, to be worthwhile: it has to be the sort of thing that gives life point or substance" (pp.65, 66).⁹
 12. Since the larger study concentrates on the clarification of the underlying moral attitude of palliative care professionals as expressed through their motivation and intentions, patients were not included in the empirical research.

13. Hull SC, Taylor HA, Kass NE. Qualitative methods. In: Sugarman J, Sulmasy D, eds. *Methods in medical ethics*. Washington: Georgetown University Press, 2001: 146-68.
14. Miles MB, Huberman AM. *Qualitative data analysis: An expanded sourcebook*. Thousand Oakes: SAGE Publications, 1994.
15. See: www.kwalitan.net
16. Sulmasy DP, Sugarman J. The many methods of medical ethics (or, thirteen ways of looking at a blackbird). In: Sugarman J, Sulmasy D, eds. *Methods in medical ethics*. Washington: Georgetown University Press, 2001: 3-18.
17. Pearlman RA, Miles SH, Arnold RM. Contributions of empirical research to medical ethics. *Theoret Med* 1993; 14: 197-210.
18. "A descriptively adequate theory will be faithful to our ordinary assessments of well-being, including the role they play in our common-sense psychology, will cover all core cases and provide a principled resolution of peripheral cases, will not confuse welfare with its sources or ingredients, and will be free of distorting bias" (p.18).⁷
19. Sumner LW. Happiness now and then. In: Jost L, Shiner R, eds. *Eudaimonia and well-being*. Kelowna, BC: Academic Printing & Publishing, 2002: 21-39. (This collection of papers is a special issue of *Apeiron: a Journal for Ancient Philosophy and Science* 2002; 35(4).)
20. Lawton J. *The dying process. Patient's experiences of palliative care*. London: Routledge, 2000.
21. Richardson J. Health promotion in palliative care: the patients' perception of therapeutic interaction with the palliative nurse in the primary care setting. *J Adv Nurs* 2002; 40: 432-40.
22. McCormick TR, Conley BJ. Patients' perspectives on dying and on the care of dying patients. *West J Med* 1995; 163 (special issue: Caring for patients at the end of life): 236-43; Singer PA, Martin DK, Kelner M. Quality end-of-life care. Patients' perspectives. *JAMA* 1999; 281: 163-68; Steinhilber KE, Christakis NA, Clipp EC, McNeilly M, McIntyre L, Tulskey JA. Factors considered important at the end of life by patients, family, physicians, and other care providers. *JAMA* 2000; 284: 2476-82; Yurk R, Morgan D, Franey S, Stebner JB, Lansky D. Understanding the continuum

- of palliative care for patients and their caregivers. *J Pain Symp Manage* 2002; 24: 459-70.
23. Singer PA, Martin DK, Kelner M. Quality end-of-life care. Patients' perspectives. *JAMA* 1999; 281: 163-68.
 24. Wenrich MD, Curtis JR, Ambrozy DM, Carline JD, Shannon SE, Ramsey PG. Dying patients' need for emotional support and personalized care from physicians: perspectives of patients with terminal illness, families, and health care providers. *J Pain Symp Manage* 2003; 25: 236-46.
 25. Martin GW. Empowerment of dying patients: the strategies and barriers to patient autonomy. *J Adv Nurs* 1998; 28: 737-44.
 26. Luker KA, Austin L, Caress A, Hallett CE. The importance of 'knowing the patient': community nurses' constructions of quality in providing palliative care. *J Adv Nurs* 2000; 31: 775-82.
 27. McCormick TR, Conley BJ. Patients' perspectives on dying and on the care of dying patients. *West J Med* 1995; 163 (special issue: Caring for patients at the end of life): 236-43.
 28. Steinhauser KE, Christakis NA, Clipp EC, McNeilly M, McIntyre L, Tulsky JA. Factors considered important at the end of life by patients, family, physicians, and other care providers. *JAMA* 2000; 284: 2476-82.
 29. *Longman dictionary of contemporary English*. Harlow, Essex: Longman Group, 1987.
 30. Walters G. Is there such a thing as a good death? *Palliat Med* 2004; 18: 404-08.
 31. Zimmerman C. Denial of impending death: a discourse analysis of the palliative care literature. *Soc Sc Med* 2004; 59: 1769-80.
 32. Emanuel EJ, Emanuel LL. The promise of a good death. *Lancet* 1998; 351 (suppl II): S21-S29; Singer PA, Martin DK, Kelner M. Quality end-of-life care. Patients' perspectives. *JAMA* 1999; 281: 163-68; Vig EK, Pearlman RA. Good and bad dying from the perspective of terminally ill men. *Arch Intern Med* 2004; 164: 977-81.
 33. Wilson DM. End-of-life care preferences of canadian senior citizens with caregiving experience. *J Adv Nurs* 2000; 31: 1416-21.
 34. Interestingly, while the respondents emphasise the importance they attach to the opportunity to contribute to other people's well-being, none of

them mentions that positively affecting other people's well-being could be significant to patients as well. Perhaps this underscores the claim of Julia Lawton that dying patients experience a diminishment of self and seem to fall out of the category of personhood in both their own and other people's evaluations. See also Lawton, cited in note 20, above.

35. See chapters 4 and 5 of this thesis.
36. Annas J. Should virtue make you happy? In: Jost L, Shiner R, eds. *Eudaimonia and well-being*. Kelowna, BC: Academic Printing & Publishing, 2002: 1-19.
37. Byock I. Rediscovering community at the core of the human condition and social covenant. *Hastings Center Rep* 2003; 33 (suppl.): s40-s41.
38. Olthuis G, Dekkers W. Medical education, palliative care and moral attitude: some objectives and future perspectives. *Med Educ* 2003; 37: 928-33. [Chapter 7 of this thesis]

Chapter 4

The caring relationship in hospice care

An analysis based on the ethics of the caring conversation

Gert Olthuis

Wim Dekkers

Carlo Leget

Paul Vogelaar

Abstract

Good nursing is more than exercising a specific set of skills. It involves the personal identity of the nurse. The aim of this article is to answer two questions: (1) What kind of person should the hospice nurse be? and (2) How should the hospice nurse engage in caring conversations? To answer these questions we analyse a nurse's story that is intended to be a profile of an exemplary hospice nurse. This story was constructed from an analysis of five semistructured interviews with hospice nurses, based on the 'ethics of the caring conversation', which is inspired by the ethical perspective of Paul Ricoeur. The research questions concentrate on the norms of respect, responsibility, and reciprocity, which are integral parts of the 'ethics of the caring conversation'.

Nursing Ethics 2006; 13: 29-40,

with permission of SAGE Publications Ltd, London, UK

The caring relationship in hospice care

An analysis based on the ethics of the caring conversation

Introduction

It is well known that the quality of communication can make the difference between the success and failure of health care.¹ Research has established that the dying patient's perception of 'feeling better' largely depends on a humanistic and egalitarian relationship with the nurse.²⁻⁵ Despite this, several authors have assessed communication in the palliative phase as inadequate.⁶⁻¹¹ In palliative nursing practice in hospitals, for example, a biomedical and task-oriented approach^{9,10} aimed at dealing with the patient's physical needs^{6,11} seems to be dominant. It has been suggested that – for the patient – the quality of care improves considerably when the care provided is patient-centred.¹²⁻¹⁴ Thus the relationship between the health care professional and the patient is increasingly regarded as the key to improving communication at the end-of-life. The patient-centred approach can best be described as establishing a relationship between caregiver and patient that works as a sustained partnership based on mutual participation.¹³ This article presents a discussion of the ethics of this sort of partnership in palliative care, as seen from the perspective of the health care professional, i.e. the hospice nurse.

The aim of this article is to answer two questions: (1) What kind of person should the hospice nurse be?, and (2) How should (s)he engage in caring conversations? To answer these questions, we make use of 'the ethics of the caring conversation' as proposed by Fredriksson and Eriksson.¹⁵ This framework is based on the ethics of the French philosopher Paul Ricoeur. Whereas Ricoeur's ethics concentrates on the relationship between the construction of personal identity and ethics in general, 'the ethics of the caring conversation' elaborates on the identity of nurses and the way they (should) relate to patients. Both approaches are philosophical rather than practical. This paper takes the normative frameworks based on these ethical perspectives, and uses them to analyse statements made by hospice nurses when they were interviewed about their involvement in palliative care. Our goal here is not use

empirical research to verify or correct Ricoeur's ethics, nor is it to question the 'ethics of the caring conversation' as proposed by Fredriksson *et al.* We merely apply their normative framework to the practice of palliative care and use it as a tool to analyse the way person, role and the caring relationship may be said to be interwoven in hospice care.

This paper is part of a more comprehensive study. It focuses on the application of the normative framework to empirical findings that are summarised in the story of Susan (box 1). This story gives a profile of a hospice nurse, structured on the basis of Ricoeur's normative framework. The story is based on five interviews (see appendix 1 for methods and analysis). The second part of the study will be published in a later issue and will relate the analysis below to a more extensive examination of recent literature on the personal and professional identity of nurses (see chapter 5).

Box 1 - Susan's story

After having worked in several hospital departments for more than 20 years, Susan (45) decided to apply for a job as a nurse in a hospice. At the time of the interview, she had worked there for 5 years. What induced her to switch to professional palliative care? "The hospital was not quite what I thought it would be. That became very obvious in the oncology ward. All those chemotherapies. I don't have anything against them, but they just don't suit me. Especially because of what happens to the human body. Doctors inform patients rather well, but I wonder if patients realize what they are to undergo. I see how sick they get and how poor the results are. That bothers me. Quality of life decreases so rapidly. What do you gain? Sometimes nothing. I noticed that the patients were disappointed. My persisting question was: Who am I to think that these people should perhaps have died sooner, but with a better quality of life?" "Furthermore," she continues, "you know what upset me in the hospital? It was all curative: physicians are educated to cure people and consider it a failure when a patient dies. I noticed that doctors would wait a long time before telling a patient that nothing could be done, because there was always some new therapy or experimental treatment, especially in an oncology ward with phase II studies. Patients got very sick and I thought: 'Is this really necessary? Three months left and one of those months very sick...'"

Susan's interest in end-of-life care did not appear out of the blue. "The mystery of having to say goodbye. The fact that death is forever and the considerations of the hereafter have always fascinated me. I think it's very personal. It is tied up with who I am. What decided me to take that final step to quit the job at the hospital, was when I wondered: What tires me at work? What gives me energy? When do I come home feeling well? When I can have conversations with patients about the way they perceive their illness and how they deal with it, or when I can comfort the family, explain things to them, give them information."

After five years of hospice experience, Susan knows pretty well why palliative care suits her. "I am easily accessible. People trust me very quickly. I may and I can get very close. I am not scared of intimacy. I dare to ask, I dare to say something, and I dare to name what I see. I noticed that it opens doors. Why I am not afraid? I think I am not afraid of emotions, I am not afraid of tears. And I think I've experienced enough myself. I had a lot of trouble with relationships. I thought a lot about myself." She goes further into her own history and tells: "Palliative care concerns values that I consider important in life. I struggled with them myself. Being allowed to be as you are. I have noticed that the more I do this, the more I invite others to do this as well. I try to pay attention to who somebody is. Respecting a person without judgements. My point of view is: we're here to take good care of each other."

"Palliative care practice," Susan explains, "is very broad and concerns both the somatic, and the psychosocial and the spiritual. This means you have to be attentive. You should concentrate on what a patient wants, and not on what you have to offer a patient. What is important for me is that I, as a nurse, will have the time to provide care. That I will have the time to start a conversation, and that I will have the opportunity to react to a remark by a patient and not have to go to another patient right away. A patient should have the opportunity to bring something up, whatever it is. Time is then condition number one. For instance, sometimes a patient is terrified. Then I ask: 'What are you afraid of?'"

'I actually don't know.'

Then I say: 'Look at it.'

'I do not dare.'

'Why not,' I ask.

'Then I get more terrified.'

I try to reassure someone that nothing can happen if they analyse their anxiety. Often the process of dying or fear of pain or suffocation come up. Then you can discuss that together with the patient. Explain what you do when pain increases.”

During the interview Susan recalls an event that indirectly contributed to her motivation to reorient professionally: the death of a friend, several years ago. He died two weeks after admission to a palliative care unit in a nursing home. Frequently visiting him made her realize what aspect of care was lacking at that unit. “There I met a couple of nurses who could do the care well, but who in my view missed an essential part of that care. They were interested, but still missed some kind of guts. They didn’t dare to present themselves communicating ‘I am in charge here and I am here for you’. I am not saying you should not show your vulnerability, but despite that vulnerability I believe you should stand firm.”

When asked what is special about palliative care, she answers: “Something is initiated in care at the end-of-life, and that is the real, deeper contact between people. It goes deep very quickly. The art is to find out what it is like for this person. Does he want conversation, or does he want to be left in peace, or to watch television, or whatever... That continues to be fascinating; nobody is the same. For example, I once cared for a woman and the night she died I provided the final care together with her three daughters. I came home at six in the morning and was very happy. I thought: ‘wow, this went so well.’ That’s exactly the difference with other kinds of care; you only lose your mother once. At that moment I realise that I am a witness of such a profound and intimate moment. It is very special to me, having the opportunity to be part of that.”

Another attractive aspect of hospice care came up: “Here in the hospice, I have a different feeling that I had in those 20 years in the hospital. My colleagues here all have a particular perspective, they reflect, and deal with things more consciously. Of course there are differences of opinion and conflicts once in while. Still, I have the idea that we can get on with each other in a mature way here. I expect to grow and to get feedback. If it concerns well-being, I think that the team as we have it is extremely important for my own well-being. They are all people I can call on for questions, to tell them something, or to have a cry... I am a person who needs to be able to say: ‘that patient said this, isn’t it nice? What could she mean?’ Getting some feedback. We’re with a team and I really like working in a team.”

The caring conversation

At the end of life, health care interventions and the quality of life of the patients and their families are largely determined by conversations the patients (and members of their families) have with nurses, physicians and other professionals.^{2,3} Because each patient's illness is incurable, many patients struggle with questions of meaning and need a partner who is willing to listen and engage in that struggle. Within the nursing sciences, Fredriksson – elaborating on studies by Eriksson – developed the term 'caring conversation' as a means to explore the meaning of suffering for the patient.^{15,18} This approach takes the caring relationship to be the central issue in caring. Fredriksson distinguishes between two primary modes of relating to a patient in a caring conversation: one aiming at *connection*, the other aiming at *contact*.¹⁸ These modes form a continuum where 'connection' is used to signify a caring relationship, and 'contact' is to be understood as a relationship with limited intensity and intersubjectivity. Three elements are found to be essential for a caring conversation: presence, touch and listening. The modes of connection and contact each imply a specific interpretation of these elements.

In the relational mode *connection*, the nurse is listening, using connective and caring touch, and is present as 'being with' a patient who wants a connection with the nurse. The characterisation that can be applied here is that of invitation and gift. The patients invite the nurse to enter into their world and to share their narratives. The nurse gives the caring or connective touch, silence and attention. In the *contact* mode the nurse is 'listening', using task-oriented touch, and is present as 'being there' for a patient who wants contact. An adequate characterisation here is that of question and answer. The contact begins with a question from a patient, which is answered by the nurse. As noted in the introduction, a task-oriented approach in palliative care, focussed on the patient's physical problems, is less likely to lead to an improvement of well-being in the sense of 'feeling better'. Since the achievement of the best possible quality of life for the patient is the main goal of palliative care, and the emphasis of this paper is on the caring relationship between hospice nurse and patient, we concentrate on caring conversation in the sense of connection.

The caring conversation in palliative care: ethics and morality

Ricoeur frames the goal of ethics as the ethical intention: “to aim at the ‘good life’ with and for others, in just institutions”.^{15,19,20} This ‘formula’ combines both the Aristotelian heritage of *ethics* as the aim of an accomplished life (what is considered to be good) and the Kantian heritage of *morality* as the articulation of that aim in norms (that which imposes itself as an obligation).¹⁹ Two significant features of this point of view are that ethics should be distinguished from morality, and that the first (the good) has primacy over the latter (the obligatory). The ethical intention has three dimensions: the personal, the interpersonal, and the institutional (see appendix 1). Before going on to answer the two questions that are the focus of this paper, we will clarify these dimensions in the story of Susan (box 1).

Personal dimension: self-esteem

Since the goal of palliative care is to alleviate suffering and to improve the quality of life of patients (and their families) who are facing a life-threatening illness,²¹ the professional perspective of the hospice nurse should be directed to that goal. What *motivates* this nurse to commit herself to this goal? Susan remarks that the attractiveness of end-of-life care is very personal to her and that it is tied up with who she is – someone who is fascinated by the finiteness of life. Furthermore, she indicates that her interest and willingness to care for the dying comes from the value she attaches to ‘taking good care of each other’. Ricoeur (p.176) uses the notion *standards of excellence* – which he borrows from MacIntyre’s *After virtue* – to indicate the good that is immanent in a practice.¹⁹ This ‘good’ is inherently present in the goal of palliative care (to alleviate suffering, to enhance well-being), but is also expressed in the words of Susan referring to the emphasis on the socially and historically constructed notion of ‘total care’ (somatic, psychosocial, and spiritual) in palliative care practice.

As Susan indicates, she values the opportunity to act out these standards of excellence. By valuing this, she also values herself as the author of those palliating actions: in the interpretation of her acting as a hospice nurse, Susan interprets herself. On an ethical plane *self-interpretation* leads to self-esteem.¹⁵ Susan’s story contains two passages that show her self-interpretation

and its relation to self-esteem. The first paragraph gives her interpretation of her work in the oncology ward. Although she does not reject chemotherapy as such, her observations of patients and procedures at the ward bothered her and her view of herself as an oncology nurse damaged her self-esteem. She did not interpret herself as a good nurse. Susan's interpretation of herself as a hospice nurse, however, shows a more positive picture. She explains why palliative care suits her and why she is good at it. In the second half of this paragraph Susan further interprets her own history and indicates precisely how her self-esteem was improved by her work in palliative care. This illustrates the second dimension of Ricoeur's ethical aim.

Interpersonal dimension: solicitude

The ethical intention is not only to live a life with esteem for oneself, but to live a life that is lived with and for others. Susan's interpretation of her own background shows the importance of *solicitude*: concern for the other.²⁰ A good life also implies a good life for the other and this is clearly expressed in Susan's words about the value she attaches to allowing others to be as they are. She emphasises: 'we're here to take good care of each other'. Interestingly, Susan's closing remarks show another side of solicitude and point to the importance of providing palliative care in a team together with other professionals. Apparently, teamwork is not only important for patients, but also for carers. As can be concluded from Susan's words, she has the need to consult with colleagues on a regular basis – in the sense of connection, not contact – and she expresses a certain (no less important) need to be appealed to as "other" in the form of getting feedback. As Ricoeur emphasises, self-esteem and solicitude cannot be experienced or reflected upon without the other.²⁰

Solicitude actualises the dialectic of giving and receiving as a fundamental aspect of the ethical relationship between the self and the other.¹⁵ Ricoeur argues that (the problem of) acknowledging freedom in second person is the central phenomenon of ethics (aiming at the good life): if I don't understand what it is for me to be free, I can't want this for the other.²² He introduces an ethical relationship that combines both asymmetry (Levinas) and mutuality (Aristotle).¹⁵ However, contrary to the Levinasian perspective, it is not the moral injunction coming from the other, but the reduced capacity of being-able-to-act

(suffering) of the other that evokes sympathy from the individual. Because of this passive suffering – which Ricoeur conceives as the reverse of the moral injunction coming from the other¹⁹ – the initiative has to come from the *compassionate other* (com passio: the one suffering with). This readiness to act, emerging from the wish to restore freedom (being-able-to-act) for the other, appears in Susan's story when she talks about the nurses she encountered when her friend died. She believes these nurses somehow lacked such initiative and lacked an attitude that communicated the availability: 'I am here for you'.

Ricoeur explains mutuality in the ethical relationship on the basis of Aristotle's notion of virtuous friendship (the common wish to live together). For this he introduces three closely related principles. First, *reversibility* means that in a relationship, roles are reversible: when a person says 'you', the other understands 'I', and vice versa. Susan's prototype conversation with a terrified patient exemplifies this feature of mutuality. Second, *non-substitutability* indicates that persons apart from their roles are irreplaceable. In the story, this is illustrated by Susan's answer to the question about what is special in palliative care: the fact that end-of-life care is very personal and offers the opportunity for deeper human contact in which everybody is a distinct individual. Finally, these two notions lead to *similitude*, which stems from the exchange between self-esteem and solicitude. This means that the other is not solely receiving and the compassionate person is not merely giving.¹⁵ An example of similitude is advanced twice in Susan's story. First when she explains what gave her energy when she was still working in the hospital: conversations with patients and family, and later in Susan's positive experience in providing final care for one of her patients, in cooperation with the three daughters of the patient. Here, she clearly says what it means for her self-esteem when she is caring (acting) out of concern for others.

Institutional dimension: equality

In the third dimension the analysis moves from the interpersonal to the institutional and extends solicitude to justice by adding *equality* to the interpersonal dimension: equality is to life in institutions what solicitude is to interpersonal relations.^{15,20} Institutions refer to structures of living together that extend beyond the interpersonal relationship and thus expand the range of the ethical

intention to all humanity. An institution involves a system of distribution of goods and burdens and exists only to the extent that individuals take part in it.²⁰ Susan's story involves two health care institutions: hospital (oncology) care and hospice care. It can be seen from her story that Susan did not find her niche in the hospital. The tension between Susan's own perspective (the personal and interpersonal dimension) and her experiences in the hospital (the institutional dimension) can be explained within Ricoeur's framework. In the first paragraph, she gives her opinion that hospital patients often don't die well, because chemotherapy impairs the quality of end-of-life. Oncology care did not match her idea of taking good care of patients at the ends of their lives, while she finds that palliative care does offer a better end-of-life.

Susan's changeover to hospice care may be explained by her personal commitment to palliative care – as we have suggested above – but it may also be that she was persuaded to switch by the nature and language of hospice care with its caring approach. *Language* can be considered the most important institution of the caring conversation.¹⁵ First of all, language, either verbal or non-verbal, marks the beginning of a conversational intervention: it enables a patient to invite a caregiver to interact and gives the latter the opportunity to react. However, a conversation involves much more than face-to-face contact between individuals. What is said by individual speakers is inevitably coloured by 'social languages': discourses peculiar to a specific stratum of society (e.g. a professional group) within a given social system at a given time.²³ The social language of palliative care (patient-centred, holistic, see: *standards of excellence* in 'personal dimension') shapes what individual carers say. When Susan has a conversation with a patient who is afraid of pain or suffocation, she is doing so not only as an individual but also as a professional making use of the socially and historically constructed notion of 'total care'. In this way, through social language, anonymous others participate in communication at the micro-level. Apparently, the role of acting out the institutionally structured and prescribed professional-patient relationship in hospice care suits Susan much better than the role of an oncology nurse taking care of patients undergoing chemotherapy.

Discussion

Practical wisdom

According to Fredriksson and Eriksson, the 'ethics of the caring conversation' can be summarised as a "melting pot where the triadic ethos of self-esteem, autonomy and *caritas*, reconsidered as the norms of respect, responsibility and reciprocity, can be spelled out in the conviction of practical wisdom" (p.145).¹⁵ This summary advances the three central ethical notions of the personal and interpersonal dimension – self-esteem, autonomy (ability-to-act), and *caritas* (referred to as a historical standard of excellence for caring and nursing^{15, p.140}) – translated into corresponding norms. This 'triadic ethos' and the norms emanating from it will function as a guide to answer the questions that are the starting point of this article, though we first have to expand on the concept of practical wisdom.

As Ricoeur argues, the good (ethics) has primacy over the obligatory (morality). The transformation of the ethical intention into norms consequently requires practical wisdom (*phronesis*) that allows the application of these norms to particular cases. The Aristotelian term *phronesis* is often considered to be the central concern of professional competence and can be described as a habitual disposition that enables someone to both deliberate about what is good or bad for a human being in a particular situation and to act appropriately.²⁴ This means that in caring conversations in palliative care, the willingness to do good and the demands of moral rules in practice require the practical wisdom that enables the nurse to make the good and the obligatory tangible to dying patients, who often find themselves in complex and disorderly situations. Thus, conversation can be considered as an aspect of practical wisdom in which a 'reflective equilibrium' between the two poles of the dialectic relationship – the conviction of the good and that which imposes itself as obligatory – is to be achieved.²⁰ But what kind of person should the hospice nurse be? And how should (s)he engage in caring conversations?

What kind of person?

The good life of the hospice nurse, as sketched in Susan's story, makes it clear that self-interpretation on an ethical level is *self-esteem*. At the time Susan worked at the oncology ward, her self-evaluation as a practitioner seemed to

generate less self-esteem than her current evaluation of her role as a hospice nurse. As a norm, self-esteem is interpreted as self-respect and consequently esteem for others becomes *respect*.¹⁵ Respecting others comes up on several occasions in the story: both in Susan's remarks on the importance of allowing others to be as they are, and in her need to receive feedback from others. Moreover, evaluating one's actions presupposes *autonomy*: the capacity to judge is based on the ability to act.²⁰ The norm which corresponds to autonomy is *responsibility*. In Susan's story this comes out as initiative, the readiness to act, which she finds very important in the care of dying patients. In other words, knowledgeable and skilled palliative care nurses should respect both themselves and others and should take the responsibility to be active in their own performance and in acting for dying patients, who lack the ability to act for themselves.

This advances the distinction between, and the close relation between, the *person* of the nurse and the *role* of the nurse in palliative care. This can be seen in Susan's story. On the one hand, Susan's self-esteem as a person arises from her valuing herself as a nurse, which is in fact a role, while Susan's use of the 'social language' of palliative care in her approach to dying patients makes it difficult to distinguish the nurse as a person from someone playing the societal role of a hospice nurse. On the other hand, playing the role of the competent hospice nurse seems to demand a specific personal motivation and a specific capacity to bring palliative 'standards of excellence' into practice. As Susan points out: an active attitude to one's own performance and to dying patients is not granted to everybody.

How to engage in conversations?

So far, the kind of person of the hospice nurse is central to the ethical relationship emphasising respect and responsibility. To correct this asymmetry and to eliminate the risk of a relationship where the nurse acts as a dominant figure, the ethos of *caritas*, reconsidered as the norm of *reciprocity*, is indispensable. This third aspect of the 'triadic ethos' also determines *how* hospice nurses should alleviate suffering through caring conversations: accepting the suffering patient as the person he or she is on the basis of mutuality.¹⁵ Reciprocity is expressed through the principles of reversibility, non-substitutability, and

similitude, which ought to safeguard the caring relationship between hospice nurses and dying patients from the danger of abuse of power. From the ethics of the caring conversation, it is argued that the personal and interpersonal dimension are inextricably tied together by Ricoeur's reformulation of Kant's Golden Rule: 'in order to hold others in esteem, I must hold myself in esteem'.¹⁵ In sum, hospice nurses not only give when they provide care. They also receive. Patients not only receive but they also give. Hospice nurses – as is exemplified in the story of Susan – aim to contribute to the quality of life of dying patients. The patients contribute to the quality of life of their nurses through the positive effect of palliative care on the nurses' self-esteem. Our analysis suggests that such an interaction is essential when a good (ethical) relationship – centred on caring conversations in the sense of connection – is considered the corner stone of palliative care.

A closer examination of this analysis of hospice nurses and the way they should engage in caring conversations will be presented in a following paper. In that paper, our results will be set in context with the recent literature on self-esteem, and on personal and professional identity in nursing.

References

1. Bensing J, Van Dulmen S, Tates K. Communication in context: new directions in communication research. *Patient Educ Couns* 2003; 50: 27-32.
2. Larson DG, Tobin DR. End-of-life conversations. Evolving practice and theory. *JAMA* 2000; 284: 1573-78.
3. Wallace PR. Improving palliative care through effective communication. *Int J Palliat Nurs* 2001; 7: 86-90.
4. Richardson J. Health promotion in palliative care: the patients' perception of therapeutic interaction with the palliative nurse in the primary care setting. *J Adv Nurs* 2002; 40: 432-40.
5. Olthuis G, Dekkers W. Quality of life considered as well-being. Views from philosophy and palliative care practice. *Theoret Med & Bioethics* 2005; 26: 307-37. [Chapter 3 of this thesis]
6. Costello J. Nursing older dying patients: findings from an ethnographic study of death and dying in elderly care wards. *J Adv Nurs* 2001; 35: 59-68.
7. The AM. *Palliative care and communication. Experiences in the clinic.* Buckingham: Open University Press, 2002.
8. Kayser-Jones J. The experience of dying: an ethnographic nursing home study. *The Gerontologist* 2002; 42 (special issue III): 11-19.
9. Georges JJ, Grypdonck M, Dierckx de Casterle B. Being a palliative care nurse in an academic hospital: a qualitative study about nurses' perceptions of palliative nursing. *J Clin Nurs* 2002; 11: 785-93.
10. Ragan SL, Wittenberg E, Hall HT. The communication of palliative care for the elderly cancer patient. *Health Com* 2003; 15: 219-26.
11. De Haes H, Koedoot N. Patient centered decision making in palliative cancer treatment: a world of paradoxes. *Patient Educ Couns* 2003; 50: 43-49.
12. Botelho RJ. A negotiation model for the doctor-patient relationship. *Fam Pract* 1992; 9: 210-18.
13. Toop L. Patient centred primary care. *Br Med J* 1998; 316: 1882-83.
14. Little P, Everitt H, Williamson I, Warner G, Moore M, Gould C, Ferrier K, et al. Observational study of effect of patient centredness and positive

- approach on outcomes of general practice consultations. *Br Med J* 2001; 323: 908-11.
15. Fredriksson L, Eriksson K. The ethics of the caring conversation. *Nurs Ethics* 2003; 10: 138-48.
 16. Peters V. *Kwalitan 5.0. Gebruikershandleiding*. Nijmegen: Department of methods, Radboud University Nijmegen, 2000. See also: www.kwalitan.net.
 17. Miles MB, Huberman AM. *Qualitative data analysis: an expanded sourcebook*. Thousand Oakes: SAGE Publications, 1994.
 18. Fredriksson L. Modes of relating in a caring conversation: a research synthesis on presence, touch and listening. *J Adv Nurs* 1999; 30: 1167-76.
 19. Ricoeur P. *Oneself as another*. Chicago: University of Chicago Press, 1994: 172.
 20. Reagan CE. Personal identity. In: Cohen RA, Marsh JL, eds. *Ricoeur as another*. Albany: State University of New York Press, 2002: 3-31.
 21. World Health Organization. Palliative care. www.who.int/cancer/palliative/en/ (accessed 16 august 2004).
 22. Ricoeur P. *Het probleem van de grondslagen van de moraal [The problem of the foundations of morality]*. Kampen: Kok Agora 1995: 33.
 23. Hermans HJM, Kempen HJG. Body, mind and culture: the dialogical nature of mediated action. *Cult & Psych* 1995; 1: 103-14.
 24. Olthuis G, Dekkers W. Professional competence and palliative care: an ethical perspective. *J Palliat Care* 2003; 19: 192-97. [Chapter 2 of this thesis]

Appendix

Appendix 1 - Respondents, methods and analysis

Respondents

The story of Susan (box 1) is a fictitious story which is composed of exemplary statements (those between quotation marks) made by five hospice nurses who were interviewed within the framework of a larger project: Moral attitude in palliative care. This project explores the personal motivation and commitment of palliative professionals to act in the interest of others. One of the settings where data for this research project were collected was a hospice that had just been founded. Two of the respondents (one male, one female) had prior experience in palliative care practice before getting involved in their current position in the hospice. Two (both female) had worked for many years in an oncology wards in an academic hospital, while one of them worked as a palliative care consultant as well. One respondent (male) had had little experienced concerning end-of-life care before he started to work in the hospice. In sum, Susan's story is to be seen as a portrait of an exemplary nurse that is based on the statements derived from the analysis of the five interviews on the basis of 'the ethics of the caring conversation'.

Methods

The semi-structured interview with hospice professionals initially focussed on the respondents' history in palliative care. Why palliative care, and what motivates them? Next, the theme of palliative care itself was raised. What is it, and what is the ideal? Furthermore, is everybody suited to providing such care? Another theme that was brought up was well-being: What is their view on the well-being of patients? In what respect does providing palliative care contribute to their own well-being?

Analysis

The five interviews were imported into Kwalitan, a software package that is designed to be used to analyse and interpret qualitative data.¹⁶ Before entering the data into the program, the five interviews were divided in segments. A segment is a part of an interview that is marked with one or more codes. The actual analysis took place on the basis of 'the ethics of the caring conversation' that incorporates the ethics

of P. Ricoeur.¹⁵ For this analysis, each of the three components that are the fundament of Ricoeur's ethics and of the ethics of the caring conversation – the personal, the interpersonal and the institutional – were translated into several codes (see list below). Codes are labels for assigning units of meaning to (parts of) interview segments as imported into Kwalitan. For example: all text fragments that referred to a respondent's motivation (first code in the list below) were assigned that code. After coding five interviews, a list of statements concerning the respondents' motivation could be compiled (reduction of data). Subsequently, the most characteristic remarks concerning motivation were used to construct the story of Susan (synthesis).¹⁷ Susan's story should be understood as the profile of an exemplary hospice nurse that is structured on the basis of the normative framework of Ricoeur and built out of selected quotations from the five interviews.

Limitations

This is an exploratory study that aims to provide a concrete picture of the ethics of the caring conversation in palliative care practice. Since its empirical part is based on five interviews in which hospice nurses give their view on (the ideals of) palliative care and their role in practice, we have to be modest about the generality of the results. The strength of the study is that it provides – through the normative framework of Ricoeur – an interpretation of the qualities, processes and considerations that enable hospice nurses to relate to dying persons in the sense of connection. Furthermore, it draws a picture of the close relationship between the person and the role he/she plays as a hospice nurse.

What follows are the three components of Ricoeur's ethical aim, the accompanying codes and the descriptions with which the five interviews were interpreted.

The personal – 'Aiming at the good life...'

Motivation: What motivates the nurse to alleviate the suffering of the dying?

Standards of excellence: What are the standards of excellence immanent in palliative care practice?

Self-interpretation: Concerns the interaction between the respondent's idea of the good life and choices in connection to respondent's practice ('What seems to us to be best with regard to our life as a whole').

The interpersonal – ‘...with and for others...’

Solicitude: Concerns the connection of the interpersonal with the individual and actualises the dialectic of giving and receiving as a fundamental aspect of the ethical relationship (‘A good life cannot be a good life only for oneself but it must also be good for the other’)

Compassionate other: Reflects that an ethical relationship is asymmetrical: the initiative comes from the compassionate other, the one suffering-with.

The following three codes are inseparably connected and explain the mutuality of the ethical relationship:

Reversibility: Refers to roles: when I say you, you understand I.

Nonsubstitutability: Refers to personhood: people are irreplaceable apart from their roles.

Similitude: The one suffering is not solely receiving and the compassionate one is not only giving: there is mutuality.

The institutional – ‘...in just institutions’

Equality: When moving from the interpersonal to the institutional, equality replaces solicitude.

Language: Concerns language as an important institution of the caring conversation.

Why hospice nurses need high self-esteem

Gert Olthuis

Carlo Leget

Wim Dekkers

Abstract

This article discusses the relationship between personal and professional qualities in hospice nurses. We examine the notion of self-esteem in personal and professional identity. The focus is on two questions: (1) What is self-esteem, and how is it related to personal identity and its moral dimension?, and (2) How do self-esteem and personal identity relate to the professional identity of the nurse? We demonstrate that it is important that the moral and personal goals in a nurse's life coincide. If the nurse's personal view of the good life is compatible with their experiences and feelings as professionals, this improves their performance as nurses. We also discuss how good nursing depends on the responses that the nurse gets from others (patients, colleagues, family); they make the nurse feel valued as a person and enable them to see the value of the work they do.

Nursing Ethics 2007; 14: 62-71,

with permission of SAGE Publications Ltd, London, UK

Why hospice nurses need high self-esteem

Introduction

Can *every* nurse be a good palliative care nurse? Can palliative care nurses persevere in the continuous care for dying people *without* the support of significant others? Professional caregivers who are involved in practicing palliative care on a daily basis will probably answer “no” to both questions. Why shouldn’t every nurse be able to provide good palliative care? Why should palliative professionals need the support of other people? This article explores these observations and attempts to offer an explanation from an ethical perspective in which the concepts of self-esteem, personal identity and professional identity play a central role.

Background

This article elaborates on the results of a previous analysis of a depiction of an exemplary hospice nurse.¹ This depiction – the story of Susan – is based on statements derived from the analysis of five interviews with hospice nurses (box 1). Table 1 displays the ethical notions and their corresponding norms that were central to our analysis. These notions were taken from the normative framework that we used to analyse Susan’s story: ‘the ethics of the caring conversation’, which is based on the philosophy of Paul Ricoeur.²

Table 1 – Central ethical notions and corresponding norms

<i>Ethical notion</i>	<i>Corresponding norm</i>
Self-esteem	Self-respect
Autonomy	Responsibility
Caritas	Reciprocity

*Box 1: Susan's story – A synopsis**

Susan (45) has worked in a hospice for 5 years now, after having worked in several different hospital departments for more than 20 years. What induced her to switch from oncology to professional hospice care was the impact of chemotherapies on patients. She doesn't have anything against those therapies, but felt that they just didn't suit her: "Quality of life decreases so rapidly. What do you gain? Patients get very sick and I think: 'Is this really necessary? Three months left and one of those months very sick...'" Furthermore, she realised that she came home feeling good when she had had conversations with patients about the way they perceived their illness and how they dealt with it, or when she could comfort the family, explain things to them, and give them information.

Susan already had an interest in end-of-life care: "The mystery of having to say goodbye. The fact that death is forever and the considerations of the hereafter have always fascinated me. I think it's very personal. It is tied up with who I am." She describes herself as easily accessible and as a person who thought a lot about herself. People are quick to trust her: "I may and I can get very close. I am not scared of intimacy. I dare to ask, I dare to say something, and I dare to name what I see. I noticed that it opens up doors. I think I am not afraid of emotions, I am not afraid of tears." Palliative care concerns values that she considers important in life: being allowed to be as you are, respecting a person without judgements. "My point of view is: we're here to take good care of each other."

Susan emphasises that in hospice practice professionals should concentrate on what a patient wants, and not on what you have to offer a patient as a professional. A patient should have the opportunity to bring something up, whatever it is. "The art is to find out what it is like for this person." Time is then the most important constraint. She believes that hospice professionals should be able to show their vulnerability, but despite that should be able to stand firm, to communicate that: 'I am in charge here and I am here for you'. For Susan, two factors indicate what is special about hospice care. First, that end-of-life care can initiate real, deeper contact between humans. It goes in-depth very quickly. Second, she mentions that in the hospice the atmosphere is not the same as it was in the 20 hospital years: "My colleagues here all have a particular perspective, they reflect, and deal with things more consciously. I expect to grow and to get feedback. I think that the team as we have it is extremely important for my own well-being."

**For methodological details on the way this story was assembled see chapter 4 of this thesis.*

The first question in our analysis was: What kind of person should the hospice nurse be? We identified two important characteristics. First, the interpretation of one's performance as a professional closely corresponds to the esteem one has for oneself as a person. As her story shows, Susan felt much better about herself in the role of a hospice nurse than she did in the role of an oncology nurse. In normative terms, *self-esteem* is interpreted as *self-respect*: Susan seemed to respect herself much more as a hospice nurse. In addition the ability to evaluate one's professional performance depends on one's ability to act, which presupposes *autonomy*. Susan could evaluate her actions as a nurse because she is able to act as an autonomous person who is responsible for her own actions. In a caring relationship in the hospice, this *responsibility* – which is a normative interpretation of autonomy – is expressed by the initiatives of the hospice nurses to actively involve themselves in the care of dying persons. Susan's willingness to engage in hospice care stems from her 'concern for the other' as is brought forward by her assertion that "we're here to take good care of each other". This seems to suit her much better than the responsibilities that she had to accept as an oncology nurse.

The second question we attempted to answer in our analysis was: How should hospice nurses engage in caring conversations? Caring conversations are an avenue for exploring the meaning of suffering for patients. Although hospice nurses ideally perform their job with a pro-active attitude, patients in the palliative phase often find themselves in a dependent position. The ethical notion of *caritas* and the corresponding norm of *reciprocity* play a key role in compensating for this asymmetry in the caring relationship. *Caritas* should be conceived of as a historical standard of excellence for caring and nursing, while reciprocity expresses the dialectic of giving and receiving in the caring relationship between the hospice nurse and the dying person. As can be seen in Susan's words about respecting a person without judgements, hospice nurses engaged in a caring conversation should accept the suffering patient as the person they are, on the basis of mutuality. Susan's concern for the other becomes respect for others, in the same way that Susan's esteem for herself becomes self-respect. Although hospice nurses aim to improve the quality of life of dying patients, the patients contribute to the quality of life of

the nurses because the nurses' self-esteem is improved by the palliative care they provide for patients.

This article

Our previous analysis explored the *professional role* hospice nurses are expected to play and the way this is interwoven with the *person* they are. Self-esteem clearly plays a crucial role. This article elaborates on the earlier analysis and takes further the theoretical clarification of the links between personal and professional identity. The story of Susan will serve as a background for this discussion. We offer a more detailed examination of self-esteem in relation to the notions of personal identity (person) and professional identity (role). We focus on two questions: 1) What is self-esteem and how is it related to personal identity and its moral dimension? and 2) How do self-esteem and personal identity relate to the professional identity of the nurse? In the concluding paragraph we will return to the questions that were posed at the beginning of the article.

What is self-esteem and how is it related to personal identity and its moral dimension?

Self-esteem

Self-esteem can briefly be described as "one's good opinion of one's own worth"³ or "worthiness to be loved".⁴ According to Ricoeur, a person's self-esteem results from self-interpretation.⁵ Self-esteem evolves from a hermeneutical circle where people, in interpreting their actions, are interpreting themselves as a specific person. Ricoeur characterises this hermeneutical circle as a "back-and-forth motion" (p.179) between a person's idea of 'the good life' and the most important decisions of that person's existence (i.e. career, love).⁵ In social psychology, in which the concept of self-esteem is widely discussed, a closer examination of the concept appears to display two characteristics that play a crucial role: it is mastery-oriented and self-esteem monitors one's value as a relational partner. Susan's story offers several examples that illustrate these two characteristics.

First, self-esteem is *mastery-oriented* rather than achievement-oriented. This means that the central issue is mastering abilities rather than pursuing

certain goals as effortlessly as possible. According to Dweck, self-esteem is not something that people can acquire via positive reinforcement directing them to achieve particular goals.⁶ It is rather “a way of experiencing yourself when you are using your resources well – to master challenges, to learn, to help others” (p.128).⁶ Self-esteem is developed in interaction with, and is facilitated by, other people such as parents, peers, and teachers. Self-esteem is something that people feel when they are striving wholeheartedly for worthwhile things. As an oncology nurse, Susan returned home feeling fulfilled when she had had the opportunity to talk to patients about what their illness meant to them. Later on, she described the resources that let her exercise her values as a hospice nurse. This illustrates how Susan’s self-esteem was based on her experiences of using her abilities fully in a service that she found important.

Second, self-esteem monitors *a person’s suitability for membership of desired groups and relationships*.⁷ It motivates behaviour that promotes acceptance by other people, even when relational devaluation is not an immediate problem for that person. Leary and Baumeister suggest that people appear to be particularly predisposed to seek and maintain interpersonal relationships that are characterised by stability, affective concern, frequent contact, and the prospect of continuing contact.⁷ This ‘need to belong’ plays a central role in self-esteem. Self-esteem should therefore be seen as a ‘sociometer’: an internal monitor of the degree to which one is valued as a relational partner. Self-esteem is not a simple reflection of other people’s evaluations, but must be viewed as a more dynamic psychological system. It enables individuals to monitor and maintain the quality of their interpersonal relationships by reacting to others’ responses. At its core, self-esteem refers to how one feels about oneself. It is one’s subjective appraisal of how one stands as a valuable, viable, sought-after member of the groups and relationships to which one belongs by choice (p.2).⁷ Susan’s story illustrates this ‘sociometer’ perspective on self-esteem when she talked about what she considered to be special about hospice care. She emphasised the opportunity hospice care offers to both maintain in-depth relationships with patients and their families, and to establish more reflective relationships with colleagues.

Did Susan experience self-esteem as an oncology nurse? Did she use her resources well in that period? Did she receive positive feedback from others?

Although she did do her best, and others – oncology patients, their families, her colleagues – must have valued her as a relational partner, oncology nursing did not offer enough for her to consider it worth while. The oncology ward apparently did not offer her sufficient opportunity to make use of her resources. In her opinion ‘quality of life’ rather than ‘life extension’ should determine health care interventions at the end of life. In Susan’s view of the good life, participating in caring conversations and hospice nursing do more good than delivering chemotherapy and nursing hospital patients. Hospice care gave her the opportunity to bring her resources into action in a way that she valued, that is, by taking good care of others and allowing them to be as they are. It also gave her the opportunity to be a sought-after member of groups to which she aspired to belong: in meaningful relationships with persons facing death and with colleagues who were prepared to reflect on the way they provide end-of-life care.

Self-esteem and personal identity

We presume that people’s appraisal of the way they use their abilities, and of their performance as a relational partners is central to self-esteem. Yet, how is self-esteem related to personal identity? Etymology offers a first indication. The term ‘identity’ is derived from the Latin word for ‘same’, while in contrast ‘person’ is derived from the Latin word for ‘theatrical mask’, which is something that is changeable.⁸ A mask is an impermanent thing that exists only in its role of representing something other than itself. The point of wearing a mask is to communicate. Masks are used to perform in *social situations*, which implies that the various meanings of that mask are all fundamentally *relational*.

Ricoeur offered a further conceptual clarification of personal identity.⁵ He distinguished between identity as sameness (*idem*) and identity as selfhood (*ipse*). *Idem* points to identity as a unity that has certain permanence in time. Susan as a hospice nurse is the same Susan who was an oncology nurse. Identity meaning *ipse*, however, involves a dialectic of self and other than self: “the selfhood of oneself implies otherness to such an intimate degree that one cannot be thought of without the other” (p.3).⁵ Susan the hospice nurse may still be the same (*idem*) Susan as Susan the oncology nurse, but Susan’s view of herself (*ipse*) changed through her interaction with others. Su-

san's personal, reflective concern with her own experience was progressively transformed by her interactions with others and gradually altered her from an oncology nurse into a hospice nurse.

Although self-esteem enables individuals to monitor and to respond to other people's responses, other people also play a crucial part in personal identity. Since, on the one hand, identity as selfhood (*ipse*) involves the dialectical relationship between self and other, and self-esteem is concerned with maintaining the quality of one's interpersonal relationships, it seems reasonable to assume, as Ricoeur did, that they are interwoven and affect each other. On the other hand, identity as sameness (*idem*) is also related to self-esteem. Korsgaard, for instance, gives an account of personal identity, which emphasises agency or authorship.⁹ She argues that the sort of continuity needed by persons to maintain their own personal identity ('same') essentially involves their agency. According to Korsgaard: "We think of living our lives, and even of having our experiences, as something that we *do*" (p.121).⁹ Given the assumption that self-esteem depends on people's competence to maintain relationships and the extent to which they see themselves as socially valuable, it seems reasonable to conclude that it is tied to the sense of authorship that Korsgaard has in mind. Although we see ourselves as authors of our own actions, the response of others to our actions seems to determine, through self-esteem, *how* we appreciate ourselves as such agents. In Susan's story, she learned to value herself more highly as a hospice nurse than she did as an oncology nurse.

The moral dimension

Self-esteem and personal identity have a shared social nature. The perceived response of others seems to connect self-esteem with personal identity. From Ricoeur's analysis it can be concluded that the social nature of personal identity is the basis for morality. From this discussion of self-esteem and personal identity it appears that 'agency', or 'authorship', plays a prominent part in their mutual connection. Experiencing self-esteem is psychologically relevant: "it appears to influence our sense of agency in addition to our sense of well-being" (p.60).¹⁰ However, what does the moral dimension of the relationship between self-esteem and personal identity imply?

Self-esteem is related to morality because it may be understood to arise from a perception of oneself as morally competent.¹⁰ This accords with our view that self-esteem is one's experience of oneself when one uses one's abilities for the benefit of what one considers important in life. The moral dimension of the relationship between self-esteem and personal identity explains why people wish to act morally. The key to answering this question is located in the integration of morality and personality.¹¹ Moral sensibility shapes personal identity, and identification with morality shapes one's sense of personal responsibility and motivates one to act consistently with what one knows and believes. Moral behaviour is closely associated with the kind of person people consider themselves to be and "depends on how the "I" understands itself and its responsibilities" (p.37).¹¹ Morally good behaviour not only depends on moral beliefs, but also on the manner and extent to which individuals' moral concerns are involved in their sense of themselves as persons (i.e. their personal identity). Two observations from a study on 'moral exemplars' can further clarify this relationship.¹² Both observations can be recognised in Susan's story.

First, morally admirable persons who are regarded as 'moral exemplars' define themselves in terms of moral goals; are more likely to interpret events as morally relevant and will be more likely to see themselves implicated in the solution of these problems.¹² This coincidence of moral and personal goals means that there is little divergence between judgement and conduct and that choices for action are made with some confidence. These people feel morally involved in what happens in their environment and do not hesitate to convert this engagement into action. The coincidence of moral and personal goals in Susan's situation can be seen in the way that her providing palliative care involved values that she considered important. Susan also emphasises the importance of a kind of engagement and readiness to act by communicating 'I am in charge here and I am here for you'.

Second, people's moral goals and choices are actively construed in the context of actual interpersonal relationships.¹² In explaining their life decisions, 'moral exemplars' tend to offer justifications based on actions, events or circumstances rather than on abstractions like values or principles. The active construction and transformation of moral goals and choices is exem-

plified in Susan's story by her switch from oncology to hospice care. It was more her dissatisfaction with the specific experiences of patients undergoing chemotherapy that made her decide to switch to hospice care, than any ethical principle.

The experience of self-esteem is therefore related to people's perceptions of themselves as the authors of their own actions, and is also affected by the dialectical relationship between the individual and others. Self-esteem not only involves concern for oneself, but also concern for others. Meeting demanding challenges, using one's resources well and receiving positive responses from other people feed self-esteem in making for a productive and constructive life.⁶ In the course of the development of 'moral exemplars' as people, personal goals are transformed into moral goals, which become more and more central to their sense of self.¹² Some people "care so deeply about *morality* and about the *quality of their relations with other people* – or most simply and fundamentally about other people – that it *shapes who they are at a fundamental level* and thereby consistently motivates them in the right direction, constrains them from exempting themselves from the claims morality makes on all of us, and compels them to ongoing moral self-reflection" (p.41, emphasis added).¹² We believe that the italicized words indicate the inevitable connection between self-esteem and personal identity and its moral dimension.

How do self-esteem and personal identity relate to the professional identity of nurses?

Personal and professional identity

Öhlén and Segesten have conceptually analysed the professional identity of nurses and discern a personal and an interpersonal dimension.¹³ Their study is helpful in clarifying the nature of the links between personal and professional identity.

The *personal dimension* of professional identity implies that personal identity should be considered a prerequisite for the development of professional identity. The relationship between personal and professional identity is specifically expressed in the fact that the latter concerns the individual nurses' perceptions of themselves in the context of nursing, involving the experience and feeling of being a nurse. Professional identity can be described

as “having the feeling of being a person who can practise nursing with skill and responsibility” and “implies awareness of personal resources and limitations” (p.721).¹³ Being a nurse not only requires a personal effort to be open to patients, but also means interpreting professional activities in the light of being a person, which makes professional development a key contributor to increased self-esteem. This observation demonstrates the crucial role self-esteem plays in nursing care, and makes clear its close relationship to personal and professional identity.

The *interpersonal dimension* of professional identity clarifies the part that *others* play in the relationship between personal and professional identity. Professional identity is developed by interaction with other nurses and through internalization of the relevant knowledge, skills, norms, values and the professional nursing culture. This happens by socialization, which is a continuing interactive lifelong process that characterises both general human development and specific professional growth. The subjective part of professional identity (i.e. nurses’ experience and feeling of themselves as nurses) is considered to be the basis for the objective part (i.e. other people’s images of persons as nurses). This general image of the person of the nurse emphasises presence, readiness to act and congruence between feelings and behaviour towards others.¹³ This image seems to resemble the observations in the ethics of the caring conversation, that initiative has to come from nurses who are actively involved in caring for suffering others. A prerequisite for the development of a professional identity as a nurse is a focus on what is best for patients, which characterises the influence of the patient on professional development. Even though patients are dependent and often in distress, they should still be approached as *persons*. The importance of perceiving patients as persons can again be recognised. Another central element of the interpersonal dimension of the ethics of the caring conversation can therefore be recognised as solicitude, or concern for the other.

Moral agency in a professional context

All the mutually connected threads concerning self-esteem, personal identity, and the professional identity of nurses seem to converge in ‘agency’, or what elsewhere is referred to as ‘moral agency in nursing’.¹⁴ Nurses’ view of them-

selves and of their professional identity is intrinsically linked to their capacity to see good in the work they do. In this respect, two kinds of value can be recognised:¹⁴ the value that is intrinsic to the moment (i.e. the significance to nurses of being present in a particular situation, at a particular time, having the unexpected opportunity to experience a reciprocal relationship that is valued by both themselves and the patients) and the value of personally achieving that which one believes a professional nurse ought to achieve. There is more to this than just excellent job performance; “It requires that the goals of nursing are embraced by nurses as a part of their ongoing chosen direction within their life plan” (p.170).¹⁴ This was emphasised by the exemplary hospice nurse who was the subject of our previous analysis: ‘My point of view is: we’re here to take good care of each other’. We outlined above that self-esteem and (the moral dimension of) personal identity are closely interwoven when it concerns someone’s motivation to act for the benefit of other people. Taking good care of other people can be considered an important condition for a nurses’ development as a persons,¹⁵ but this does seem to happen more naturally when nurses’ moral goals coincide with the goals of those nurses’ personal ambitions.

Concluding remarks

We began by wondering whether every nurse could be a good palliative care nurse and if palliative care nurses could do without the support of significant others. We suggested that the majority of the palliative care community would disagree with these propositions. Our article is aimed at clarifying these ‘palliative commonplaces’ from an ethical perspective on the basis of the relation between self-esteem, personal identity and professional identity.

It seems obvious that palliative care nurses cannot do without the support of others, and this can be explained in terms of self-esteem. As self-esteem largely depends on the perceived quality of interpersonal relationships, the appreciation of others seems to be an indispensable support for a practicing nurse. The often intensely experienced reciprocal relationship with patients and with their families let Susan see her value as a relational partner. Having reflective colleagues in the hospice was also very important. They made her feel that she was a member of their group, in which she wanted to remain, and they saw the value of the work she did; indeed, the work they all did.

The network of interpersonal relationships that impacts on hospice nurses' experience of making a difference and may influence their self-esteem can easily be expanded (e.g.: home front, hospice management, nursing profession as a whole, society). The quality of hospice care is not only determined by the quality of the professionals and of the personal relationships involved, it is also determined by the appreciation these professionals receive from the wider world. The embedding of (hospice) nursing in such a wide relational web also implies a risk: it inevitably contributes to a nurses' self-esteem and to their capacity to see value in the work they do, but it also makes them vulnerable and can just as easily make them feel undervalued. A lack of appreciation has not only negative consequences for the well-being of the nurse. It may also discourage them from making caregiving central to their personal values and may consequently degrade the quality of the care they give.

The fact that not every nurse can become a good palliative care nurse, can be explained by what particular nurses consider valuable in their personal and professional lives. The discussion of self-esteem, the moral dimension of personal identity, and moral agency in nursing demonstrates the importance of the coincidence of moral and personal goals. If nurses' personal view of the good life does not include what they experience and feel as professional nurses, it becomes more difficult for them to provide good nursing. For Susan, providing hospice care puts into everyday practice values that concerned her, that is, taking care of each other, quality of life, being allowed to be as one is. Palliative care values are an important part of Susan's personal life: "It is tied up with who I am." This not only made her suitable to work as a hospice nurse, but it also contributed to her quality of life in the sense that it increased her self-esteem.

References

1. Olthuis G, Dekkers W, Leget C, Vogelaar P. The caring relationship in hospice care. An analysis based on the ethics of the caring conversation. *Nurs Ethics* 2006; 13: 29-40. [Chapter 4 of this thesis]
2. Fredriksson L, Eriksson K. The ethics of the caring conversation. *Nurs Ethics* 2003; 10: 138-48.
3. *Longman Dictionary of Contemporary English*. Harlow, Essex: Longman Group, 1987.
4. Meriwether NK. Can self-esteem sanction morality? *J Moral Educ* 2003; 32: 167-81.
5. Ricoeur P. *Oneself as another*. Chicago: University of Chicago Press, 1994.
6. Dweck CS. *Self-theories: their role in motivation, personality, and development*. Philadelphia: Psychology Press, Taylor & Francis Group, 2000.
7. Leary MR, Baumeister RF. The nature and function of self-esteem: sociometer theory. In: Zanna MP, ed. *Advances in experimental social psychology* (vol. 32). New York: Academic Press, 2000: 1-62.
8. Wren T. Cultural identity and personal identity. In: Musschenga AW, Van Haaften W, Spiecker B, Slors M, eds. *Personal and moral identity*. Dordrecht: Kluwer Academic Publishers, 2002: 231-58.
9. Korsgaard CM. Personal identity and the unity of agency: A Kantian response to Parfit. *Phil & Publ Affairs* 1989; 18: 101-32.
10. Power FC. The moral self in community. In: Lapsley DK, Narvaez D, eds. *Moral development, self, and identity*. Mahwah, New Jersey: Lawrence Erlbaum, 2004: 47-64.
11. Bergman R. Identity as motivation: Toward a theory of the moral self. In: Lapsley DK, Narvaez D, eds. *Moral development, self, and identity*. Mahwah, New Jersey: Lawrence Erlbaum, 2004: 21-46.
12. Colby A, Damon W. The uniting of self and morality in the development of extraordinary moral commitment. In: Noam GC, Wren TE, eds. *The moral self*. Cambridge, Mass.: The MIT Press, 1993: 149-74.
13. Öhlén J, Segesten K. The professional identity of the nurse: concept analysis and development. *J Adv Nurs* 1998; 28: 720-27.

14. Pask EJ. Moral agency in nursing: seeing value in the work and believing that I make a difference. *Nurs Ethics* 2003; 10: 165-74.
15. Gastmans C, Dierckx de Casterle B, Schotsmans P. Nursing considered as moral practice: A philosophical-ethical interpretation of nursing. *Kennedy Inst of Ethics J* 1998; 8: 43-69.

What kind of palliative caregiver should I be?

Moral attitude and reflection in palliative practice

Gert Olthuis

Wim Dekkers

Abstract

A recent EAPC-report recommends the promotion of reflective practice in palliative care. The present article explores the moral attitude that professionals bring to such reflective practice. A clear articulation of this moral attitude is required to structure the recommended reflective practice. We examine this moral attitude in terms of four crucial aspects of virtue ethics; practice, motivation, emotion and practical wisdom. The examination is tailored to palliative care with quotations from interviews with several professionals. It is argued that the reflective practice should be persistently focused on the question: What kind of palliative caregiver should I be? While this question plays an important, but often implicit, role in staff support activities we argue that as an educational tool portfolio learning offers opportunities to improve the integration of reflection into the structure of palliative care practice.

Submitted

What kind of palliative caregiver should I be?

Moral attitude and reflection in palliative practice

Introduction

Because good education programmes are considered a necessary condition for the further professionalisation of palliative care, the European Association for Palliative Care (EAPC) recently published *A Guide for the Development of Palliative Nurse Education in Europe*.¹ This report offers guidelines for the development of education in palliative nursing and presents the basic competences that can reasonably be required of the nurse in practice. It proposes a model of the palliative care learning process that links the various aspects of palliative nursing practice. It places the patient at the centre of the interaction and recognises the various factors that affect the patient's life, such as the family, the interdisciplinary team, the health care system and society.² The report emphasises the direct benefit of education to practice and patient, but it also advocates the – less easily quantified – need for palliative nurses to reflect about their own lives. Self-awareness and the capacity for ethical deliberation are considered to be an integral part of the professional equipment of the practicing nurse.

The EAPC-report is relevant and comprehensive, and its recommendations reflect current practice. It represents an essential step in the further development of palliative care. This article focuses on an aspect of palliative care that is underemphasised in the document: the moral attitude of professionals that forms the basis of the reflective aspect of palliative care practice. A clearer understanding of this moral attitude could make for more specific recommendations about reflective practice. We intend to illustrate the moral attitude by quotations from interviews with palliative care professionals.* We

* *These interviews were conducted within the research project 'Moral attitude in palliative care', which is being carried out by the authors. See references 4 and 5 for methodological details. Note that the quotations in the present article serve merely to illustrate the moral attitude of palliative care professionals. The quotations come from a variety of palliative care professionals, although the EAPC-report focuses on palliative nurse education. We believe that the patient-centred moral attitude that is central to our discussion is required of all palliative care professionals. Methods that can improve reflective nursing practice are applicable in palliative care practice as a whole.*

argue that the pivotal question in reflective palliative practice is: 'What kind of palliative caregiver should I be?' We will briefly suggest how reflective practice can be integrated in the educational approach as proposed in the EAPC-report by pointing out the value of portfolio learning.

Moral attitude and virtue ethics in palliative care

As a starting point it is crucial to acknowledge – as the EAPC-report does – that the efforts of palliative care professionals cannot be seen as separate from their own personal view of life.³⁻⁶ One of the obligations of health care professionals “is commitment to an open, truthful, and fully cooperative relationship with patients” (p.23).⁷ We claim that this obligation should be rooted in a specific moral attitude. It is important to note that health (palliative) care workers always have a specific moral attitude, albeit not always developed to the same extent in every practitioner. The key issue is not how to develop such an attitude, but rather how to maintain it and how to develop it further. As the EAPC-guide suggests, personal self-awareness is an important component of this attitude.

Moral attitude

Elsewhere we have described moral attitude as the personal motivation and commitment to act in the interest of other people.⁸ A closer look at the implications of this moral attitude in palliative care demonstrates that providing care is more than just performing an expert activity in order to achieve certain objectives. Care actions acquire their moral significance from the moral attitude expressed by these care activities.⁹ Caring is centred on the response of the carer to the needs of the one being cared for. In palliative care, providing care is the sensitive and supportive response of the professional to the situation and circumstances of a vulnerable human being who is in need of help, who cannot be cured or whose death is imminent. The professional's response actualises a moral attitude that guides the caring activity. Nurses are driven by values, such as respect, responsibility, and courage, which are fundamental to their moral attitude.¹⁰ The moral goals of palliative care should ideally be moral goals that are part of the professional's personal life.⁶ Moral attitude encompasses a *personal* motivation and commitment to help others.

This means that such an attitude cannot be acquired as some sort of expert skill, but “is brought to expression in typically personal characteristics such as lifestyle, character, social skills and relationships with other human beings” (p.220).⁹

Virtue ethics

Since a moral attitude implies an active concern for other’s well-being, patient-centeredness can be considered a central element. Morally speaking, patient-centeredness can be framed from a consequentialist point of view (‘it is a good thing only if it has good consequences’), a deontological perspective (‘it is good in and of itself and therefore ought to be pursued as a matter of duty’) or from a virtue ethical perspective.¹¹ We will consider the patient-centred moral attitude underlying palliative care practice from a virtue-ethical perspective because this perspective (1) relates good behaviour to the kind of person someone is, and (2) offers insight into the way in which the qualities that are a prerequisite for such behaviour can be (further) developed.

A specific moral attitude seems to be indispensable for realizing the values that are inherent in caring practice. Virtues, for their part, can be considered as interiorized values.¹² Virtues are dispositions that determine one’s attitude towards situations that arise in the practice of life. These situations require choices, where one should choose to act as well as possible.¹³ The morality of an act is determined by what a sensible person would do in a particular situation. Virtues reflect the way in which we *are* - and *act as* - humane people, and can be conceived as the extent to which we are able to act well.¹² Virtues are the qualities people need to be able to realise themselves in the roles they perform, with the abilities they have at their disposal and in the situations they fall into.¹³ Moral perception plays a central part; one sees what has to be done in a situation, because one knows how to perform an activity skilfully.¹⁴

In the following sections, the moral attitude required for palliative care will be discussed from a virtue-ethical perspective, assuming an inseparable connection between virtue on the one hand and practice, motivation, emotion and practical wisdom on the other.

Moral attitude and palliative care practice

Practice

Virtues are developed in practice. They are considered to be dispositions that arise from practice and education and make a person likely to perform particular actions as a matter of habit.¹³ Aristotle claimed that to become virtuous, one should act as a virtuous person would do. Virtues like compassion or courage that can be considered to be prerequisites for good palliative care are characteristics of people that develop as they live their lives.

“When I was a student, I got acquainted with an elderly lady with breast cancer. I visited her once a week and I was impressed by the way she dealt with her life and illness. I remember asking her: ‘I know why I like to come here, but what do you get from talking to such an inexperienced person as me?’ She told me that I was one of two people with whom she could talk about her disease and the way she experienced it. I was surprised. She said that most people brought up commonplaces or started to talk about another topic. [...] A certain thread became visible. My parents told me that as a child I could enter the room with a serious question and that I would not be satisfied until it had been answered seriously. I also remember the shock I felt when my biology teacher said: everybody knows that everybody will die, but no one believes that of himself.” [psychologist, hospice]

The development of virtue is not restricted to the individual’s private life. The interest palliative care professionals have in caring for seriously ill patients inevitably affects the way they provide care at the end of life. Values like ‘person-centeredness’, ‘openness’ or ‘availability’, which are advanced in the quotation above, are continuously actualised in daily practice. The motivation and commitment to act in the interest of others can be strengthened in practice, as the following remark from the same respondent indicates.

“I’ve often wondered why I want to do this, to work in palliative care. What I like is that it is easy to have contact about matters that are essential. You come into contact with the essence of people. I realised that I was not growing in the nursing home where I worked, while in palliative care I do grow. Palliative care brings out the best in me. It addresses my own essence.” [psychologist, hospice]

Motivation

According to virtue ethics, it is not sufficient to apply general rules to particular situations: “The virtuous moral agent has a deep desire to behave well” (p.298).¹⁵ A good palliative caregiver is inclined to provide care in accordance with the values that are inherent to care at the end of life. The desire to care for the whole person – a crucial value in palliative care, as mentioned in the EAPC report – and not just manage symptoms is, for example, expressed in the next quotation:

“Treating people in this [palliative] department is not primarily aimed at just the complaint, but at the whole person. That attracted me very much.” [physiotherapist, palliative unit hospital]

“Palliative care is very broad. You have to be a specialist-generalist. That attracts me. Just like the fact that you can mean a lot for the patient, and for the family.” [hospice physician]

Caring for seriously ill patients as a team is another motivating value that is central to palliative care.

“In my previous job I was involved in care for a dying, handicapped person twice. I noticed the enormous mutuality within the team because we were occupied with something very essential; attempting to make the last stages of life as bearable as possible. I was highly moved by what you can mean for others as a human being. When I was invited to apply for a job here I thought: ‘I believe I have to do this!’” [coordinator volunteers, hospice]

The motivation to act in the interest of others is not only of relevance for patients. As can be understood from the quotation above, great significance is attached to mutuality within the team. This implies that good palliative carers are inclined to look after each other. The habit of reflecting on how colleagues experience their work seems to be intrinsic to palliative care, as the following remark acknowledges.

“Sometimes a colleague will expose an issue that concerns them. Persistent questioning often reveals somebody’s experiences and suddenly you realise: ‘ah, that’s how it is and that’s why you reacted so-and-so.’ You get to learn more about each other’s values and norms and eventually understand why someone acts in the way they do.” [head/nurse, palliative unit nursing home]

But before one can be motivated to perform an action, one must perceive the need for that action. Both emotion and practical wisdom play a role in this perceptual process.

Emotion

Emotions contribute to a person's appreciation of circumstances; they illuminate perception.¹⁵ Emotions involve judgements about important things, in which we acknowledge our needs and inadequacies in areas we do not fully control.¹⁶ In palliative care, where the needs of the incurable patients and the uncertainty of both patients and professionals about the process of dying are central issues, emotions cannot be set aside. For many professionals, the emotional and more existential focus of palliative care constitutes the particular attraction of the work.

"As a lung specialist I missed something. I did some research, published, read papers at all kinds of congresses, but it was all too 'pseudo'. It was not real. I always looked for...this is what it is all about." [physician, palliative unit hospital]

"I have always been curious to know about deeper questions people are concerned with. Not for reasons of faith, but rather to find out what affects people in their lives, what made them move, how did they fit certain events into their lives. I always look for that." [pastor, hospice]

Furthermore, the emotional intensity of (care at) the end of life and the intimate relationships with patients and their families force palliative care professionals to continuously observe and examine their own (emotional) well-being.

"A lot of people live very unconsciously, even in their professional lives. People are not aware of the fact that they do something in one situation that they don't in another, similar situation. Palliative care requires one to move into one's own depths, to listen to other people and to get things across to oneself. That can be frightening sometimes, it is much easier to be a superficial doctor." [physician, hospice]

Practical wisdom

Virtuous people see what needs to be done and are appropriately moved by what they see.¹⁴ Ethical perception is not merely emotional; reasoning enables people to act and feel in ways appropriate to specific circumstances.

Good palliative care requires the capacity to know when and how to exhibit the virtues that actualise the values relevant in that situation. The fundamental virtue that functions as a link between the various relevant virtues is 'phronesis', or practical wisdom. Practical wisdom is considered to be the deliberative capacity to reason well; it enables a person to choose the right action at the right moment within the perspective of the whole situation.^{13,17} The following remark illustrates the crucial role of this deliberative capacity in the interaction with patients:

"I try to encounter people and then find out what happens. Together we set out for the direction we want to go. [...] If someone says that he doesn't want morphine, I don't start it for the time being: 'I promise that if it is necessary I will explain it to you.' It is like a permanent game. This means that you have to put time and energy in it, you have to be available at the moments when they need you." [physician, palliative unit nursing home]

The thoughtfulness – or practical wisdom – that is required to recognise the morally pertinent aspects in practice is also relevant for the carers themselves. The emphasis the EAPC-report puts on the self-awareness of professionals is reflected in the following remark:

"When I started working here I believed that a patient, terminal or not, should be washed every day. But who am I to say that somebody should be washed daily? That is about self-reflection. Why do I want that?" [certified nursing assistant, palliative unit nursing home]

Observation of one's own moral attitude seems to be part and parcel of working in palliative care. The intense experiences in the practice both force professionals to grow into their role as attentive caregiver in palliative situations and simultaneously force them to adjust their perception of themselves and of life in general. Virtue in living and caring seems to develop in practice and not in classrooms. This observation is relevant to the promotion of reflective practice in palliative care.

Promoting reflective practice

The above discussion of the moral attitude of palliative care professionals argues that it is rooted in practice and that it is related to motivation, emotion and practical wisdom. The discussion argues that moral attitude cannot be

achieved through theoretical education, but that it requires continuous attention to, and reflection on, the practice of life and palliative care. From this perspective, the focus of reflective practice in palliative care should be the question 'What kind of palliative caregiver should I be?'. The promotion of self-awareness and ethical deliberation in both palliative nursing and in other aspects of palliative care depends on the professionals' readiness to repeatedly reflect on this question.

How can this reflection be made part of daily practice? To some extent, the question 'what kind of palliative caregiver should I be?' already plays a more or less explicit role in the narrative activities like team intervision, clinical supervision and closure conferences that are progressively being introduced into palliative care.¹⁸⁻²⁰ There are, however, possibilities to integrate attention to self-awareness and ethical deliberation into practice in a more structured way. One of the educational tools that can help effectuate this integration is portfolio learning.

From a professional development perspective, a portfolio is described as a collection of material, made by a professional, that records and reflects on key events and processes in that professional's career.²¹ It is a narrative enterprise that can include a variety of material, from a reflective diary to a career plan, and from a critical article review to one's experience of a critical incident. The portfolio reveals an evolution of thought and expression, as well as knowledge and skill, and can become a reference source of permanent value to the student.²² In fact, building a portfolio enables a professional to repeatedly (re)consider the question 'what kind of palliative caregiver should I be?'.

Three arguments underpin the use of portfolios to stimulate and support reflective practice in palliative care. First of all, a portfolio is not just a record of facts, but also a tool that helps people make sense of the multitude of perceptions and experiences that constitute their (professional) lives; it stimulates moral development. A portfolio can be considered as a "narrative of practice" where the learning is in the telling.²³ Reflective learning through story telling improves both a professional's confidence and their ethical decision-making.^{24,25} As such, portfolios function as a 'meaning-making system' where the learning process is central, rather than the outcome. Second, portfolio learning fits comfortably into the adult education approach recom-

mended by the EAPC-report. Self-directed and problem-based learning forms the basis of this approach. Portfolios can be very effective in continuing professional development^{26,27} and function as an instrument of self-evaluation. Third, the usefulness of portfolios has been demonstrated in undergraduate medical education; they were shown to be a continuing source of stimulation for students' professional development and self-knowledge.²⁸⁻³⁰

Portfolio learning seems to fit into the current staff support activities aimed at self-care and self-awareness and would seem to offer the promotion of the reflective practice recommended by the EAPC-report. Adequate use of portfolios enables professionals to become more self-aware, since it offers them ample opportunity to repeatedly deliberate on ethical issues that arise in palliative care practice and to reflect on their own motivation and emotions.

References

1. EAPC Task Force. *A guide for the development of palliative nurse education in Europe*. European Association for Palliative care, 2004. [Cited (2006) Feb 10] Available from URL: www.eapcnet.org/projects/nursing-education.asp
2. De Vlieger M, Gorch N, Larkin PJ, *et al*. Palliative nurse education: towards a common language. *Palliat Med* 2004; 18: 401-03.
3. Pask EJ. Moral agency in nursing: seeing value in the work and believing that I make a difference. *Nurs Ethics* 2003; 10: 165-74.
4. Olthuis G, Dekkers W. Quality of life considered as well-being. Views from philosophy and palliative care practice. *Theoret Med & Bioethics* 2005; 26: 307-37. [Chapter 3 of this thesis]
5. Olthuis G, Dekkers W, Leget C, Vogelaar P. The caring relationship in hospice care. An analysis based on the ethics of the caring conversation. *Nurs Ethics* 2006; 13: 29-40. [Chapter 4 of this thesis]
6. Olthuis G, Leget C, Dekkers W. Why hospice nurses need high self-esteem. On the relation between personal and professional identity. *Nurs Ethics* 2007; 14: 62-71. [Chapter 5 of this thesis]
7. Campbell A, Gillet G, Jones G. *Medical ethics*, 3rd ed. Oxford: Oxford University Press, 2001.
8. Olthuis G, Dekkers W. Medical education, palliative care and moral attitude: some objectives and future perspectives. *Med Educ* 2003; 37: 928-33. [Chapter 7 of this thesis]
9. Gastmans C. Care as a moral attitude in nursing. *Nurs Ethics* 1999; 6: 214-23.
10. Nåden D, Eriksson K. Understanding the importance of values and moral attitudes in nursing care in preserving human dignity. *Nurs Sci Quarterly* 2004; 17: 86-91.
11. Duggan PS, Geller G, Cooper LA, *et al*. The moral nature of patient-centeredness: is it "just the right thing to do"? *Patient Educ Couns* 2006; 62: 271-76.
12. Comte-Sponville A. *A small treatise on the great virtues*. New York: Metropolitan Books, 2001.

13. Van Tongeren P. *Deugdelijk leven. Een inleiding in de deugdethiek*. Amsterdam: SUN, 2003.
14. Jacobson D. Seeing by feeling: virtues, skills, and moral perception. *Ethical Theory and Moral Practice* 2005; 8: 387-407.
15. Gardiner P. A virtue ethics approach to moral dilemmas in medicine. *J Med Ethics* 2003; 29: 297-302.
16. Nussbaum MC. *Upheavals of thought. The intelligence of emotions*. Cambridge University Press, 2001.
17. MacLeod R. Wisdom and the practice of palliative care. *J Palliat Care* 2003; 19: 123-26.
18. Ramirez A, Addington-Hall J, Richards M. ABC of palliative care. The carers. *Br Med J* 1998; 316: 208-11.
19. Wakefield A. Nurses' responses to death and dying: a need for relentless self-care. *Int J Palliat Nurs* 2000; 6: 245-51.
20. Van Staa AL, Visser A, Van der Zouwe N. Caring for caregivers: experiences and evaluation of interventions for a palliative care team. *Patient Educ Couns* 2000; 41: 93-105.
21. Hall D. Professional development portfolios for teachers and lecturers. *Br J In-service Educ* 1992; 18: 81-86.
22. Finlay IG. Portfolio learning: the humanities in medical education. In: Evans M, Finlay IG, eds. *Medical Humanities*. BMJ Books, 2001: 156-66.
23. Woodward H. Portfolios: narratives for learning. *J In-service Educ* 2000; 26: 329-49.
24. Durgahee T. Reflective practice: nursing ethics through story telling. *Nurs Ethics* 1997; 4: 135-46.
25. Skott C. Storied ethics: conversations in nursing care. *Nurs Ethics* 2003; 10: 368-76.
26. Mathers NJ, Challis MC, Howe AC, *et al*. Portfolios in continuing medical education – effective and efficient? *Med Educ* 1999; 33: 521-30.
27. Smith K, Tillema H. Long-term influences of portfolios on professional development. *Scand J Educ Research* 2001; 45: 183-203.
28. Finlay IG, Maughan TS, Webster DJT. A randomised controlled study of portfolio learning in undergraduate cancer education. *Med Educ* 1998; 32: 172-76.

29. Lonka K, Slotte V, Halttunen M, *et al.* Portfolios as a learning tool in obstetrics and gynaecology undergraduate learning. *Med Educ* 2001; 35: 1125-30.
30. Gordon J. Assessing students' personal and professional development using portfolios and interviews. *Med Educ* 2003; 37: 335-40.

Medical education, palliative care and moral attitude

Some objectives and future perspectives

Gert Olthuis

Wim Dekkers

Abstract

Context Adequate medical education has three interrelated aspects: theoretical knowledge, practical skills, and the personal attitude of the physician. The current emphasis on medical science distracts attention from the importance of the attitude aspect of medical education. We argue that the integration of palliative care into the medical curricula can correct this imbalance between knowledge, skills, and attitude. In our view, including palliative care into medical training not only improves the quality of palliative care, but also contributes to the moral quality of the doctors being trained. To support our argument we emphasise the moral aspects of attitude. Moral attitude focuses on the capacity to respond to others in a humane manner and can be compared with the way a virtuous physician acts. We show the crucial role this moral attitude plays in palliative care and the surplus value palliative care education can have in general medical training.

Perspectives We suggest that clinical experience in palliative care, supplemented by reflection on narratives about chronically ill or dying patients, and mourning or aging processes, offer prospects for developing palliative care education. These perspectives can contribute to the transformation of the present 'hidden curriculum' of contemporary medical education which implicitly shapes the student's moral attitude, into a future more explicit enculturation into the medical realm. Ultimately, this will improve health care as a whole.

Medical Education 2003; 37: 928-933,
with permission of Blackwell Publishing, Oxford, UK

Medical education, palliative care and moral attitude

Some objectives and future perspectives

Introduction

Recently, several authors have argued that current education in palliative care in the medical curricula is inadequate.¹⁻⁴ An inventory of the state of affairs of palliative care in the Netherlands revealed that palliative care is hardly a specific part of medical training.³ In our own professional setting, the University Medical Centre in Nijmegen, there is discussion about whether an optional 4 week-module on palliative care that is highly valued by the students should be integrated in the general medical curriculum. In this paper we will discuss the advantages that integrating palliative care into the core curriculum of medical training can offer in educating the attitudes of medical students.

The Oxford Textbook of Palliative Medicine specifies a series of learning objects in 'Education and training in palliative care' (see box 1).⁵ The authors rightly claim that there is wide agreement about what needs to be explored in palliative care medical education. Their list of objectives summarises - inter alia - the basic principles for enhancing palliative care education proposed by Billings and Block.⁶ Other studies discuss learning objectives that largely resemble those of the Oxford Textbook.^{7,8}

The purpose of this article is to argue that structural attention to palliative care in the medical curriculum will enhance the personalities and the moral characters of the doctors being trained. Adequate medical education is generally considered to have three interrelated aspects: theoretical knowledge, practical skills, and the personal attitude of the physician. Contemporary medical education, however, emphasises knowledge and skills and pays little explicit attention to what kind of person the doctor should be.⁹ Although the personal attitude of the physician is of great concern in medicine as a whole, we argue that by putting more emphasis on palliative care in the medical curriculum, the balance between these three areas can be improved. Typically, palliative care is provided as an integral part of the care of all patients¹⁰ and not by palliative care specialists. Although clinical areas like care of the

elderly or primary care might claim to have the potential to educate students' attitudes, palliative care is also likely to enhance the attitude of the physician-in-training. Physicians tend to see palliative care as epitomizing the ideals of patient care, as has been mentioned in several studies of the provision of end-of-life care in general practice.^{11,12} Although caring for dying patients does not obviously differ from patient care in general, Field observed that dying patients were treated differently from other patients in a number of ways.¹² At the end of their lives, patients receive more time and attention, and care seems to be more patient-centred than elsewhere in medical practice.

In the first section of this article, we elaborate on the process of forming the physician's attitude as an aspect of medical education comparable to the inculcation of theoretical knowledge and practical skills. Here we make a distinction between attitude and moral attitude. The next part of the paper concentrates on the contribution that teaching palliative care can make to attitude-education within the medical curriculum. Finally, we will discuss two teaching methods that can enhance both palliative care education and medical training as a whole. These methods are frequently discussed in the literature, but in the Netherlands rarely applied in medical education.

Box 1

Learning objectives should include the exploration of:

1. death as a part of life and transcultural issues concerning death;
 2. issues defining the decision for palliative care in a variety of clinical settings and the impact of that decision on both the patient's quality of life and health-care costs;
 3. the physical, psychological, social, and spiritual impact of dying on patients and their families;
 4. the control of pain and other symptoms;
 5. psychosocial and existential support of patients and their families;
 6. one's own attitude toward death;
 7. communication skills;
 8. strategies enabling a continuum of care across a variety of in-patient and out-patient settings, particularly care in the home.
-
-

Attitude and moral attitude

Two aspects, i.e. theoretical knowledge and practical skills, of the conceptual trinity that makes up an adequate education are rather easy to recognise and describe, if one takes a closer look at medical education. Theoretical knowledge is acquired as (scientific) information that is presented to students in lectures and books. Practical skills are learned in practical courses and during hospital rotations. The education of the students' attitudes is far more difficult to recognise and describe. The problem is that it is difficult to understand what 'attitude' means. Attitude is a complex term. In this paper we primarily focus on the moral aspects of attitude.

The current psychological concept 'attitude' has been defined as: "a learned predisposition to respond in a consistently favorable or unfavorable manner with respect to a given object" (p.6).¹³ This is a broad and rather abstract definition that does not make clear that in the interaction between doctor and patient morality always plays an important role. Reflecting on the painting *The doctor* (Sir Luke Fildes, 1891), Brody argues that "character and virtue are as important as knowledge and skills in describing the ideal family physician" (p.589).¹⁴ The basis of medical practice is more the maintenance of a network of human relationships than the application of scientific knowledge.¹⁴ A virtuous physician "starts always with his commitment to be a certain kind of person, and he approaches clinical quandaries, conflicts of values, and his patients' interest as a good person should" (p.247).¹⁵ In terms of attitude this means that the attitude of a doctor towards a patient is always a moral attitude which reflects the *personal* motivation and commitment of someone to act in the interest of *other people*. In contrast to the current psychological concept of attitude, moral attitude focuses on the capacity of persons to respond to others in a particular situation in a *humane* manner, and it is this moral attitude which is exemplified by the virtuous physician.

Moral attitude is not about *what* people *do*, but about *the way* they act. Gastmans argues that providing good care requires more than just the competent exercise of the various necessary cognitive and technical functions and skill.¹⁶ Providing good care is more than performing expert activity. Good care requires an inner engagement of the professionals involved. "Nurses derive their specific identity not only from the set of tasks that they perform but

also from the way in which they commit themselves to the caring process" (p.215).¹⁶ Moral attitude is thus closely connected with *the kind of person* someone is. By taking a closer look at the goals of medicine we will further illustrate what we mean by moral attitude.

The goals of medicine concern improving health, curing illness, and if this is not possible, caring for patients and helping them to live with the residues of their illness.¹⁷ Health care professionals involve themselves in the lives of patients by offering them help to attain these ends. "The good of the patient provides the architectonic of the relationship" (p.53).¹⁷ Beneficence, as the guide to medical action, is "grounded in the humanity of the persons interacting in the medical relationship" (p.54).¹⁷ For health care professionals humanity appears in their personal capacity to respond to patients in a humane manner. This is what we mean by moral attitude. More than the psychological concept of attitude, the term moral attitude refers to the kind of person someone is. The moral quality of a person largely determines the moral quality of the actions called for in a particular situation with a specific patient. This moral view of medical practice is an essential component of any discussion of the importance of attitudes in medical education.

Moral attitude in medical education and palliative care

Medical education cannot simply be understood as the transmission of medical, biological and epidemiological information and the acquisition of the necessary practical skills. Medical education necessarily influences the moral identity of the student. Medical training is "a process of moral enculturation" (p.861) into the medical community.¹⁸ This process of enculturation is usually not explicitly expressed in the formal curricula of medical schools. It is reflected in what is called the 'hidden curriculum'. During medical education students get socialised. They adopt and internalise new values, attitudes and rationales about what is important in practicing medicine and how to be a good doctor. Medical training makes students reconstruct their former picture of medicine.¹⁹ The reconstruction of the student's view of the medical world is not an explicit objective of the formal curriculum but an implicit result of being part of the medical community. Personal experiences, stories about patients' experiences, casuistry, doctors and teachers functioning as

role models, and the explicit content of the curriculum all mould the students' way of committing themselves to (future) patients. Medical training gradually and covertly cultivates the moral attitude of the doctor *in spe*. A problematic consequence of this more or less unconscious enculturation of medical students is the aforementioned imbalance in the trinity of adequate education. The emphasis on theoretical knowledge and practical skills distracts attention from the physicians' moral attitude. Several authors have pointed out the crucial role of the professional's moral attitude in palliative care.

Randall and Downie for instance, state that palliative caregivers need to be morally developed persons.²⁰ Much of the success of a doctor, nurse or other health care worker depends on their relationship with each patient. The nature of that relationship depends, in part, on the patient's perceptions of the helper. That is why it is important that the judgements made by health care professionals are not just the product of a technical, scientific mind, but also of a humane and compassionate spirit. The success of a caregiver in palliative care depends on his or her perceptiveness about the patient, and reciprocally, the perceptions of the patient are determined by the apparent commitment of the caregiver.

In a similar vein, Bradshaw mentions the dangers of developments such as the rationalisation of care for terminally ill patients in the United Kingdom, and its reduction to a bureaucratic routine.²¹ She asks whether medical science should be the only basis for terminal care. Medicine is an effective tool to control symptoms and pain, but it is not the only weapon in the arsenal of palliative care. Medical science has always been and will continue to be a vital component of palliative care, but it is now becoming an increasingly dominant component. Bradshaw wonders whether the original ethic of humane care for the dying can have a place in preventing the reduction of palliative care to a purely medical treatment. Although she realises that acquiring the necessary knowledge and skill is important, "the quintessential heart of palliative care is the kind of compassionate people involved in it" (p.418).²¹

Our thesis, that explicit education in palliative care offers medical schools a clear and interesting way of directing attention to the physician's moral attitude, is also supported by medical educators. Barnard *et al* point out the importance of the preclinical years of medical education in preparing students to

provide optimal care for patients near the end-of-life, as well as for patients in general: "The foundations for excellence in end-of-life care that are laid in the preclinical years, are also the foundations for excellence in general medical practice" (p.500).²² "A curriculum that optimally prepares students to give excellent care near the end of life will best prepare them to become excellent physicians in all aspects of medical care" (p.503).²² Obviously, palliative care education fits very well with the aims and agenda of general medical education.

Also, from the perspective of the widely accepted WHO-definition (see box 2), it seems reasonable to conclude that adequate performance in palliative care practice requires engaged caregivers who are capable of acting in a personal and attentive way.²³

Box 2 - WHO definition

Palliative care is an approach that improves the quality of life of patients and their families facing the problem 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. Palliative care:

- provides relief from pain and other distressing symptoms;
 - affirms life and regards death as a normal process;
 - neither hastens nor postpones death;
 - integrates the psychological and spiritual aspects of patient care;
 - offers a support system to help patients live as actively as possible until death;
 - offers a support system to help the family cope during the patient's illness and in their own bereavement.
 - uses a team approach to address the needs of patients and their families, including bereavement counselling, if indicated;
 - will enhance quality of life, and may also positively influence the course of illness;
 - is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications.
-
-

In our view, it is imperative to integrate palliative care into the medical curriculum. This is dictated by the fact that every caregiver must be able to provide palliative care. The inclusion of palliative care in medical training will also contribute to the education of the moral attitude of physicians. In the next section we will focus on two ways of including palliative care education in the medical curriculum.

Two means of educating moral attitude

Several experiences with student participation in a hospice during medical training show that students consider experiencing palliative care practice a welcome and very valuable contribution to their education.^{24,25} These empirical studies support a recent plea to integrate clinical experiences in palliative care into the core curricula of medical schools.²⁶ Moreover, according to Block and Billings, gaining some experience in care for the dying can “help young physicians learn to tolerate a degree of intimacy and personal engagement that other aspects of medical training may subvert or undermine” (p.765).²⁶ Consequently, both professionals and patients throughout the health care system can benefit from the integration of experience in palliative care into the medical training program. However, prudence is called for. Working in palliative care can be stressful, and the students have to be well-supervised and given adequate emotional support if this integration is to be successful.

Another method that can contribute to moral attitude in caring is the use of the humanities in medical school. Health care practitioners are daily confronted with the complex interplay of the generality of the disease and the unique, individual and emotional response to it. Narrative art forms like novels and films can help them understand that interplay in three separate, but inter-linked, ways.²⁷ Literary examples give insight into common patterns of response. Narratives can provide insight into individual differences and may help to produce a feeling for ambiguity. Reading literature also can enrich the language and thus the thought processes of health care practitioners.

Beyond these three more or less cognitive and affective characteristics, novels (or narratives in general) also serve as moral guides for living a good life.²⁸ Experiences with humanities-courses in medical education support these suggestions.²⁹⁻³² While Hampshire³⁰ recommends the study of medicine

in literature as an option for those who are interested, Finlay³¹ and Downie³² suggest an integration of the humanities into the medical curriculum. On the basis of anecdotes from final-year students' tutors, Finlay has noticed the emergence of a different type of graduate in Wales.³¹ The tutors remarked on the students' "ability to show compassion and to communicate effectively, their understanding of the gravity of medical decisions and their insight into human suffering" (p.165).³¹ Others have successfully used a humanities course to explore the impact of cancer on the lives of patients, families and professionals.³³ By offering the student the chance to stand back and reflect about their professional task, the humanities module allowed the student "to access the wealth of human experience that is embodied in the arts" and informed and directed them "in their search for the wisdom and the humanity to fulfil their role as clinicians" (p.53).³³ On the basis of these educational experiences it seems reasonable to conclude that using narratives to dramatise the experiences of the chronically ill or dying patients, the loss of a beloved family member or friend, or the inevitability of aging or death, will not only lead to the provision of better palliative care, but will also result in a generally more humane medical practice.

Concluding remarks

A medical student's journey through medical school may be compared with Dante's medieval journey through the *Inferno*.³⁴ This analogy does not mean that medical education is a hell, but rather that attending medical school contains the same tasks which Dante had to accomplish during his trip, as described in the *Divine comedy*. Dante's first task involves learning God's laws. This task is accomplished through studying case histories of sin and occasional lectures from his companion Virgil on their way down through Purgatory. The second task involves the emotional reactions of Dante to the sufferings and mutilations that human souls undergo in hell. He has to learn to deal with the misery he meets on his way down. These two tasks are identical to the double task that confronts medical students: "they must learn about disease and how to treat it, but they must also retain the capacity to feel, deeply, the suffering they encounter without being overwhelmed or incapacitated by it" (p.204).³⁴ 'Learning about disease and how to treat it', refers to knowledge and skills,

and 'the capacity to feel without being overwhelmed', refers to the moral attitude of the student as it is put forward in this article. As we have indicated, the latter seldom forms an explicit part of contemporary medical education, but is embedded in a 'hidden curriculum' that socialises the students during their progression through medical school.

Education in palliative care can transform the 'hidden curriculum' into a more governed and explicit enculturation of future physicians into the medical community. In particular, experience in palliative care for every student, and exposure to the appropriate narratives during medical training offer serious prospects for developing a profound education for a humane, rather than merely technical, palliative care. Ultimately, this will improve health care as a whole. Unfortunately, there is little empirical understanding of the relationship between the education of palliative caregivers, the practice of palliative care and the personal qualities or moral attitudes that are needed in the care for the dying. This relationship should therefore be a topic for future empirical and philosophical research in palliative care.

References

1. Meier DE, Morisson RS, Cassell CK. Improving palliative care. *Ann Intern Med* 1997; 127: 225-30.
2. McDonagh J, Ljungkvist V. Learning empathy: medical school and the care of the dying patient. *J Palliat Med* 1999; 2: 383-89.
3. Francke A, Persoon A, Temmink D, Kerkstra A. *Palliatieve zorg in Nederland; een inventarisatiestudie naar palliatieve zorg, deskundigheidsbevordering en zorg voor zorgenden*. Utrecht: NIVEL, 1997.
4. Janssens, R. *Palliative care. Concepts and ethics*. Nijmegen: Thesis Radboud University Nijmegen, 2001.
5. Scott JF, MacDonald N, Balfour M. Palliative medicine education. In: Doyle D, Hanks G, MacDonald N, eds. *The Oxford Textbook of Palliative Medicine*, 2nd ed. Oxford: Oxford University Press, 1998.
6. Billings JA, Block S. Palliative care in undergraduate medical education. Status report and future directions. *JAMA* 1997; 278: 733-38.
7. Schonwetter RS, Robinson BE. Educational objectives for medical training in the care for terminally ill. *Acad Med* 1994; 69: 688-90.
8. Abele Meeke S, Klein JE, Fleischman AR, Fins JJ. Development of a palliative education assessment tool for medical student education. *Acad Med* 2000; 75: 986-92.
9. Thompson JN. Moral imperatives for academic medicine. *Acad Med* 1997; 72: 1037-42.
10. O'Neill B, Fallon M. ABC of palliative care. Principles of palliative care and pain control. *Br Med J* 1997; 315: 801-04.
11. Brown JB, Sangster S, Swift J. Factors influencing palliative care. Qualitative study of family physicians' practices. *Can Fam Physician* 1998; 44: 1028-34.
12. Field D. Special not different: general practitioners' accounts of their care of dying people. *Soc Sci Med* 1998; 46: 1111-20.
13. Fishbein M, Ajzen I. *Belief, attitude, intention and behavior: an introduction to theory and research*. Reading, Mass.: Addison-Wesley, 1975.
14. Brody H. The family physician: what sort of person? *Fam Med* 1998; 30: 589-93.

15. Pellegrino ED. The virtuous physician, and the ethics of medicine. In: Shelp EE, ed. *Virtue and medicine. Explorations in the character of medicine*. Dordrecht: D. Reidel Publishing Company, 1985.
16. Gastmans C. Care as a moral attitude in nursing. *Nurs Ethics* 1999; 6: 214-23.
17. Pellegrino ED, Thomasma DC. *The virtues in medical practice*. New York: Oxford University Press, 1993.
18. Hafferty FW, Franks R. The hidden curriculum, ethics teaching, and the structure of medical education. *Acad Med* 1994; 69: 861-71.
19. Andre J. Learning to see: moral growth during medical training. *J Med Eth* 1992; 18:148-52.
20. Randall F, Downie RS. *Palliative care ethics. A companion for all specialties*, 2nd ed. Oxford: Oxford University Press, 1999.
21. Bradshaw A. The spiritual dimension of hospice: the secularization of an ideal. *Soc Sci Med* 1996; 43: 409-19.
22. Barnard D, Quill T, Hafferty FW, Arnold R, Plumb J, Bulger R, et al. Preparing the ground: contributions of the preclinical years to medical education for care near the end of life. *Acad Med* 1999; 74: 499-505.
23. Retrieved from the internet (march 11, 2003). Available from URL <http://www5.who.int/cancer/main.cfm?p=0000000427>
24. Ferrini R, Klein JL. The effect of a community hospice rotation on self-reported knowledge, attitudes and skills of third-year medical students. *Med Educ Online* [serial online] 2000; 5: 6. Available from URL <http://www.med-ed-online.org>
25. Plymale MA, Sloan PA, Johnson M, Snapp J, LaFountain P. Junior medical students' perceptions of an introductory hospice experience. *Hosp J* 2001; 15: 41-51.
26. Block S, Billings JA. Nurturing humanism through teaching palliative care. *Acad Med* 1998; 73: 763-65.
27. Scott AP. The relationship between the arts and medicine. *J Med Ethics: Med Hum* 2000; 26: 3-8.
28. Jones AH. Literature and medicine: narrative ethics. *Lancet* 1997; 349: 1243-46.

29. Hunter KM, Charon R, Coulehan JL. The study of literature in medical education. *Acad Med* 1995; 70: 787-94.
30. Hampshire AJ, Avery AJ. What can students learn from studying medicine in literature? *Med Educ* 2001; 35: 687-90.
31. Finlay IG. Portfolio learning: the humanities in medical education. In: Evans M, Finlay IG, eds. *Medical humanities*. London: BMJ Books, 2001.
32. Downie RS, Hendry RA, Macnaughton RJ, Smith BH. Humanizing medicine: a special study module. *Med Educ* 1997; 31: 276-80.
33. Kirklin D, Meakin R, Singh S, Lloyd M. Living with and dying from cancer: a special study module. *J Med Ethics: Med Hum* 2000; 26: 51-54.
34. Hawkins AH. Charting Dante: the *Inferno* and medical education. *Lit Med* 1992; 11: 200-15.

Chapter 8

Discussion and conclusion

Discussion and conclusion

In several places in this thesis, it has been mentioned that the professionals who were being interviewed for the study indicated that their activities as palliative care professionals formed part of their self-image. For example, in chapter 3 the consultant interviewed remarked that palliative care gave her the opportunity to actualise herself. A psychologist in chapter 6 claimed that working in palliative care “brings out the best in me” and that “it addresses my own essence”. Chapter 5 argues that the performance of nurses will be better if the moral goals of palliative care coincide with their personal view of the good life. One of the nurses interviewed – one of the contributors to the story of the exemplary nurse Susan – explained that her interest in the end of life is “tied up with who I am”. These remarks fit the assumption that becoming a member of the nursing profession is more than acquiring the necessary credentials or necessary skills, “it is rather a feeling of fulfillment at a deeply personal level” (p.96).¹ It is assumed that becoming a nurse means developing a self-identity as a nurse: “It’s just who I am”.¹ That the performance of palliative care professionals is closely interwoven with the people that they are, is something that goes – from the perspective of the present thesis – to the heart of the moral attitude of these professionals and is the central issue of this concluding chapter.

The first objective of this thesis was to explore and analyse normative views about the moral attitude of professional caregivers in palliative care. Opinions from palliative care professionals are combined with several ethical points of view in the chapters 2-5. From the perspective of virtue ethics (chapter 2), theories on well-being (chapter 3), and the hermeneutical ethics of P. Ricoeur (chapter 4) the current study attempts to provide insight into the moral attitude of professional palliative caregivers. On the basis of the notions of self-esteem, of personal identity, and of professional identity the discussion has been extended to the interface of ethics and social psychology (chapter 5). Together, these chapters draw a picture of what motivates and

commits health care professionals to get involved in palliative care and to act in the interest of seriously ill patients who suffer from a life-threatening illness. These chapters also discuss – from a moral perspective – what it takes to be good at providing such care.

The chapters 6 and 7 deal with a second objective: to explore how the moral attitude of care professionals can be stimulated, preserved and maintained. The sixth chapter focuses on the preservation and maintenance of the moral attitude of professionals who already work in palliative care practice. The seventh chapter focuses on ways the moral attitude of medical students can be stimulated during medical training.

The bulk of this concluding chapter is devoted to a résumé of three crucial moral notions that run as a common thread through the preceding chapters: phronesis, the caring conversation, and the covenantal relationship with patients. To better understand how these three notions are interrelated, an ethical view on professionalism in health care – emphasising the interrelationship between the professional and the personal – is introduced in the next section. The three notions are then discussed separately. Next, some comments are made on Randall and Downie's view on 'whole person care' that was introduced in the first chapter of the thesis as a point of departure from which to explore the moral attitude of palliative caregivers. The chapter concludes with an argument for reflective practice and some suggestions for future research on moral attitude and professional development in palliative care.

An ethical view on professionalism

What inspires people to devote their professional life to the care of others? This question has not been well covered in recent debates on what may be expected from health care professionals. According to the theologian Annelies van Heijst the dominant view on professionalism in health care concentrates too much on achieving a specific level of knowledge and skills.² A focus on professionalism as a practice where certain 'objective' standards of excellence are collectively endorsed leaves less room for the 'inter-subjective' aspect of professionalism, which emerges in the practice of care itself. Professional care centres on skillfulness *and* on ethically relevant inter-human contact between colleagues, caregivers, and care receivers. The latter, 'inter-subjective' aspect

deserves more attention than it now gets in recently published discussions about health care professionalism. Van Heijst argues that the ultimate aim of caring is not 'to cure' or 'to improve' but 'to support other persons in their misery and need', in a way that contributes to the good life for all. From this perspective, professional (humanising) care is built on two pillars: 1) having compassion for another person's suffering and consequently drawing the conclusion that one should take the initiative to act in the interests of that person, and 2) the interest, enjoyment, and amazement one can experience with other human beings (p.391).²

Caring as an expression of values

Caring is not morally neutral. Van Heijst understands caring as an unmediated act that takes place directly between two persons. A caring act evokes a response which can be considered a new act. This implies that the results of caring are always uncertain and cannot be fully determined by a protocol. Providing physical care inevitably involves an inter-subjective relationship in which caregiver and care receiver act as persons. Caring is, in short, an act where the caregiver is tuned in to another human being who needs help or support (p.122).² Van Heijst claims that caring should express two values: humaneness and the bond between human beings. Superficially, a caring relationship is asymmetric and based on an urgent need which evokes a caring response of another person. But – at a deeper level – Van Heijst argues that there is a need that is present in both caregiver *and* care receiver; both are in need of each other to lead a real human existence. On the one hand, the caring relationship is asymmetric because of the difference between caregiver and care receiver. On the other hand, the caring relationship is reciprocal because it is an inter-subjective relationship in which both participants are human beings who need each other to confirm their mutual humanity. This tension (asymmetry vs. equivalence) is central in Van Heijst's ethical view on professionalism and is also put forward in the three central notions of this thesis.

Palliative caring

Because there is no chance of cure in palliative care, Van Heijst suggests that attempting 'to support patients in their misery and need' is central to pallia-

tive care practice (p.83, p.161).² Professional palliative care does not aim to fight against suffering at the expense of the quality of life of seriously ill patients, nor does it glorify suffering as a kind of purification. Both on an institutional and a personal level, palliative care attempts to express the value of seriously ill, dying persons and their bonds with other people. As can be read from the WHO-definition (see chapter 1), palliative care considers dying as a normal process and as a part of life, and focuses on supporting patients and their families in a broad sense. Thus, suffering is not banned, but integrated in what humanly may be expected of a good life. Van Heijst's suggestion about palliative care accords with the observations made in the chapters 1 and 2 concerning the specific ethical culture of a 'palliative approach'. Furthermore, the three moral notions that are the common thread in the present study fit into the ethical picture of professionalism Van Heijst proposes.

In the first place, an important characteristic of the act of caring is its uncertainty. Time and again professionals have to deliberate about their interaction with patients. Furthermore, in Van Heijst's view caregivers – like care receivers – are considered as valuable and vulnerable. Since care should not be self-sacrificial, it is important to look for an endurable balance while practicing care. Both deliberation and seeking a balance require the virtue of **phronesis**. In the second place, caring is an inter-subjective activity involving a human relationship. Its aim is not so much to control or neutralise differences between persons and to restore autonomy, but to respect uniqueness and to make space for the suffering other. The **caring conversation** attempts to create such space. In the third place, the process of care can involve a reciprocity in which participants acknowledge each other's humanity. Humanising care can be fulfilling for both care receiver and caregiver. Van Heijst argues that professionals who take the responsibility to care for others in an asymmetrical situation may be convinced that they are relating to their patients as fellow human beings. The present thesis acknowledges her argument and draws attention to the notion of **covenant**.

Phronesis

The place of phronesis in virtue ethics

Aristotle considered phronesis – or practical wisdom – as relevant to the good life as a whole.³⁻⁵ In chapter 2 phronesis is described as a quality that enables a person to deliberate about what is good or bad for a human being in a particular situation and as a consequence enables the deliberator to act appropriately. It is emphasised that this is a habitual disposition, which implies that appropriate action is not the mere consequence of a feeling or a rational choice but rather of a developed and durable capacity to make a balanced judgement which takes account of all the aspects that may influence the process of action. A palliative care professional who has practical wisdom knows about the goal of palliative care and the means that are necessary to attain that goal. In chapter 6 it is pointed out that phronesis functions as a link between various other virtues that are relevant in a situation and that it enables a person to know when and how these virtues are to be exhibited.

Usually, two groups of virtues are distinguished: intellectual virtues and virtues of character.⁶⁻⁸ According to Musschenga, character virtues are action oriented and can be further distinguished in first order and second order virtues of character.⁸ First order character virtues are dispositions which are required of a competent practitioner of a particular social role. A palliative care professional may be expected to provide professionally competent palliative care. However, as was argued in chapter 2, just putting the various dimensions of professional competence into practice is not sufficient. The *way* care is provided plays a crucial role. This involves second order character virtues that refer to the manner in which a practitioner provides care and to the quality and the power of his motivation.⁸ Every character virtue assumes the virtue of practical wisdom.⁷ Practical wisdom is considered as the ordering virtue that discerns how the virtues can be used to best effect.⁹ A virtue is a habitual disposition to choose a middle course between two extremes of behaviour (e.g., dedication is the desire to choose the right middle course between being over-involved and being excessively objective). Practical wisdom plays a central role in the practical reasoning that is required to determine that virtuous middle course and it is thus crucial to what is determined to be

excellent in a specific situation. It belongs to the group of intellectual virtues that involves knowledge oriented virtues aimed at the perfection of reason.

Self-awareness, responsibility, and practice

This study looks at three related aspects of a palliative care professional's practical wisdom: 1) self-awareness, 2) responsibility, and 3) professional practice and the practice of life. First, self-awareness – “understanding what your own true thoughts, feelings, and abilities are”¹⁰ – emphasises the relationship of professionals with themselves. Self-awareness is an essential aspect of knowing when and how to use the virtues in practice (see also chapter 6). Since palliative caregivers' readiness to act is a compassionate response of the caregiver to the needs of the patient, the professional-patient relationship is asymmetric. This inequality is the inevitable starting-point of the caring relationship; the patient is dependent on the competence of the caregiver. But giving care is a reciprocal action¹¹, to be carried out by practitioners of trustworthy character.¹² As Van Heijst emphasises, at a deeper level caregiver and care receiver are equivalent, and the care provided confirms their mutual humanity. The crucial role of this mutuality in the caring relationship in palliative care was put forward in the chapters 4 and 5. Wise palliative care professionals have the experience that lets them choose the right action in particular situations while simultaneously understanding that it is their *personal* effort and commitment that determines the quality of the care provided.

Second, in chapter 2 it is argued that phronesis is related to responsibility. This aspect emphasises the relationship of professionals with needy others. A caregiver's intention to care for a palliative care patient implies a responsibility to provide professionally competent palliative care. Competence is more than meeting the responsibility to provide the sort of care that is presupposed in the 'standards of excellence' of palliative care practice. Rather – as is made clear in chapter 4 – the responsibility for providing good care is part of an ethical relationship between caregiver and patient. The caregiver's willingness to do good is initiated by perceiving the suffering of seriously ill or dying patients, which subsequently evokes a caring response. As can be read from Susan's story (chapter 4), the urge to care is accompanied by a predisposition to find human beings fascinating and an inclination to enjoy deeper human

contact. Van Heijst considers these two aspects as the pillars on which professional, humane care is built.

Third, practical wisdom is inseparably interwoven with professional practice and the practice of life. This emphasises a professional's relation to the wider world. In chapter 6 it is emphasised that virtue in living and caring is developed in practice, which implies that practical wisdom in caring is closely interwoven with the kind of person a palliative care professional is. The personal involvement implicit in caring practice means that the people involved share in each other's lives. Van Heijst argues that the practice of care rests on an availability to strangers, an openness to their needs, a caring and competent response, and the proximity of the professional to those who suffer (p.314).² Illustrative in this respect is Susan's switch from oncology to hospice care which literally brought her closer to the patients she preferred to care for.

Detachment

An issue that is not emphasised in this thesis but which is nevertheless a necessary aspect of the balanced professional judgement is 'detachment'. A moral attitude that is over-involved or too self-sacrificial can be harmful to patients and can lead to burn-out in professionals. A crucial aspect of professionalism is knowing when to take a step back. Granting that some detachment is necessary, too much professional detachment also has its dangers.¹³ Detachment from patients can have a desensitising effect. A professional may become unresponsive or even oblivious to a patient's problems and can possibly become alienated from the role itself. Moreover, detachment may damage a professional's capacity for moral judgement leading to an incapacity to distinguish between legitimate and illegitimate role-based actions. Excessive detachment may, in other words, deteriorate the practical wisdom that is necessary to bring good care into practice. How can detachment have a place in the moral attitude of professional palliative caregivers?

Oakley and Cocking argue that an appropriate level of detachment from patients can be reconciled with the "psychic harmony" that is achieved by the integration of personal and professional life.¹³ Sometimes a professional's role implies a requirement to depart from the attitude towards others that

“would be a morally appropriate attitude to take to those people” (p.141).¹³ Detachment from a morally appropriate attitude can be justified and need not be morally defective, if 1) a professional role can be shown to serve the goals of that profession; 2) psychological detachment in carrying out that role helps a professional meet its requirements and so uphold those goals; and 3) these goals, all things considered, serve morally worthwhile ends (p.145).¹³ For palliative care this implies that detachment from patients can be justified if such withdrawal serves the key human goods which form the proper goals of the profession. E.g., departing from the morally appropriate attitude of close involvement with hospice patients, may give that patient the opportunity to concentrate on strengthening his relationships with others and to deal with ‘unfinished business’ (see chapter 3). This may serve the goals of palliative care (i.e., “improve the quality of life of patients and families facing life-threatening illness” according to the WHO) better than a deep personal relationship with a care professional.

It may be inappropriate to always strive for deep emotional and personal attachments as a means to integrate personal and professional life. Professional detachment from patients can be reconciled with such integration: by regulating their level of detachment from patients against their commitment to the goals of palliative care, professionals can retain their capacity to empathise with a patient and remain sensitive to the consequences of their behaviour (p.150).¹³ As Van Heijst underlines, both caregiver and care receiver are valuable and vulnerable. Since care should not be self-sacrificial, it is important to look for a sustainable balance between the need for care and the ability to provide it, which brings us back to the importance of self-awareness as an aspect of practical wisdom.

Caring conversation

A caring conversation is an indispensable part of the care for palliative patients. Hospice nurse Susan, who was at the centre of the chapters 4 and 5, indicated that what gave her energy when she worked as oncology nurse were the conversations with patients and their families. In fact, this observation was one of the reasons she decided to make the move to a hospice.

Caring conversation and care ethics

The starting point of the ethics of care is the question what people need to experience their world as worth living in.^{14,15} A central assumption is the interdependence of human beings; people need others to give meaning to their existence. From this perspective, care giving is 1) an activity which is rooted in concrete practice, and 2) a process to maintain, continue and repair the world so that people can live their lives as well as possible. As mentioned in chapter 2, attentiveness, responsibility, competence, and responsiveness are identified as crucial moral elements of care. Caring is a process of paying attention to what other people need, taking the responsibility to fulfill that need, and having the actual competence to provide the care that is needed. The element of responsiveness incorporates the care receiver's opinion about the care provided. This becomes tricky when the patient is not responsive to the care received. What if patients do not co-operate and are indifferent to a caregiver's skills and concern?

The caring conversation – as a mode of connecting to a patient and as a way of exploring a patient's suffering – is assumed to be a central issue in the caring process (see chapter 4).¹⁶⁻¹⁸ It is argued that the characterisation of invitation and gift best reflects such a relationship. If a suffering patient does not invite caregivers to explore that suffering and rejects approaches made by caregivers, it is important that such patient should not be abandoned. Caring is intended to respect the value of the individual and aims to make room for their suffering. Abandoning an uncooperative patient would undo these intentions in advance and would provide the very opposite of good care. Distancing oneself from uncooperative patients would be disastrous for the caring conversation that is necessary to keep the process of care going, even though 'real' talk is not possible and communication is limited to being present and communicating availability. If the horizon of care is 'to support other persons in their misery and need', as Van Heijst argues, it is essential to preserve some minimal caring relationship. Being present and available, and showing an openness to the patient in question seems to be a crucial aspect of the caregiver's moral attitude when the caring process becomes difficult.

Ideally, both caregivers and care receivers are involved in the caring process and their relationship can be described as a partnership based on

mutual participation (see also chapters 1 and 4). In chapter 3 this mutual participation is extensively explored as an aspect of well-being. According to the palliative professionals who were interviewed, well-being is – in the first place – a judgement by patients about their current situation. Nevertheless, our empirical analysis identified five issues the respondents generally concentrated on when they explained their attempts to contribute to patient well-being: the emphasis on life, a patient's preferences, the person of the patient, completing life, and dying well. Through conversation, professionals attempt to explore these aspects of well-being while taking into account both the individual patient's situation and their personality. From this perspective, the moral attitude from which these professionals provide care is an attitude that is aimed at contributing in a positive and supporting way to a patient's experience of their world as being one worth living in. In palliative care, the care also has to be directed at cultivating the acceptance of death as a part of life. The data that is presented on 'completing life' and 'dying well' suggest that issues like dealing with unfinished business, reviewing life, strengthening family ties, or knowing that physical pain and symptoms can be managed well, can all contribute to a situation in which patients may accept their situation as one in which death is inevitable.

Emotions and care

Often, emotions play a significant part in the relationship between professional and patient in palliative care and the caring conversation that is a part of this relationship. As noticed in chapter 6, the emotional intensity of palliative care seems to stimulate a professional's motivation and commitment to provide such care. Gastmans warns against an emotivist conception of care in which the commitment to act in the interest of others is momentary and the continuity of a caregiver's involvement is unstable. Care should be motivated by the material and existential condition in which the patient finds himself, not by the fact that a carer is attracted to certain personal features of the patient.^{19,20} However, building and sustaining relationships with patients suffering from progressive and far advanced disease is hard emotional work. Such 'emotional labour' is considered to be a key factor in the provision of care.²¹ Emotional labour involves the regulation and management of feeling and is

originally defined as ‘the induction or suppression of feeling in order to sustain the outward appearance that produces the proper state of mind in others – that of being cared for in a safe and a convivial place’.^{22,23}

In care, emotional labour largely consists of day-to-day responses to common situations. It is demanding and skilled work that is about action and reaction, doing and being. The professional is expected to respond to a patient in a way which is *personal* to both of them.²¹ Van Heijst points out that reciprocity in the caring relationship emerges both from the professional’s knowledge that it is good for others to receive care and from a certain personal generosity. Maintaining a bond with patients involves spending time with them and requires personal attention which means that carers must *give* something of themselves.^{22,23} Studies that framed ‘niceness’ and ‘empathy’ as forms of emotional labour show how palliative caregivers and patients collaboratively form reciprocal relationships in daily practice while doing emotion work.²⁴⁻²⁶ Because care ethics considers caring to be a task in which the carer maintains, continues and repairs the world so that people cared for can live their lives as well as possible, emotional labour can be considered indispensable to bring about that process. The moral attitude of palliative care professionals is thus also a motivation and a commitment to act in the interest of others in a way which includes the emotional work of personal involvement.

Covenant

In the introduction of this thesis, it was argued that the professional-patient relationship in palliative care is required to meet two moral conditions: the *commitment* of the caregiver to the total good of the patient and the patient’s *trust* in that commitment. In the conclusion of chapter 2 it is claimed that providing care is at its centre a moral enterprise grounded in a covenant of trust that obliges care professionals to use their competence in a patient’s best interest. Chapter 3 further examines this covenant and shows the importance of a covenantal approach to palliative care when aiming to support a patient’s well-being.

Menace to the covenant

In chapter 3 the covenant between patient and professional is described as a durable bond based on trust. It is contrasted with a contract which is temporary and founded on distrust. Several authors point out that the covenant of trust is in danger of becoming lost.^{27,28} It is argued that considering patients as clients, adopting a business-like approach to health care, and expanding nursing into a more technologically oriented and separate profession, damage the primary responsibility of health care professionals: "to achieve the well-being of those who are vulnerable" (p.479).²⁸ Providing health care is a special kind of human activity, requiring specific virtues (i.e., humility, honesty, integrity, compassion, dedication, self-discipline), and aimed at serving "the good of those persons who seek our help and trust us to provide it" (p.1553).²⁷ Interestingly, in both articles cited above the obligations that belong to the covenant are emphasised, regardless of any reciprocity. Providing care or practicing medicine would be a self-denying and self-sacrificial service in which the person of the caregiver is entirely effaced. The current study casts doubt on the assumed self-denying character of the covenant between patient and practitioner.

A reciprocal element in the covenant of trust

The bond between human beings that is conceived as a covenant, can be understood in at least two senses that complement each other. The first sense is the bond between human beings who recognise each other as valid interlocutors who are embarking on the same dialogue. In the second sense human beings recognise each other as "someone who to a certain extent belongs to me and to whom I belong" (p.115).²⁹ If the bond in the second sense is not recognised, a serious dialogue and serious interest in other human beings can be difficult. It is the discovery of this *tie* between human beings which generates an obligation towards others. But this tie is also a bond of mutual attachment that comprehends a reciprocal recognition between human beings. Van Heijst argues that despite its asymmetric starting-point, care giving may develop into a reciprocal process in which participants mutually confirm their wholeness and worth as a human being (p.210).² The discussion of self-esteem in the chapters 4 and 5 acknowledges this mutuality and defines this reciprocal

element in the bond between caregiver and care receiver in social-psychological terms.

Giving care is motivated by the material and existential condition of another person. As mentioned above, this condition of suffering evokes a commitment to care from 'the one suffering with' (*com passio*). The centrality of another person's well-being in this process requires that the one providing care esteems the person cared for as a fellow human being. The Ricoeurian reformulation of Kant's golden rule, however, reads: 'in order to hold others in esteem, I must hold myself in esteem' (chapter 4). The examination of self-esteem in hospice nurses in chapter 5 brought forward two aspects concerning self-esteem and acting in the interest of others. First, self-esteem arises when professionals use their abilities to provide benefits that they consider important in life. If the values of palliative care practice coincide with the values that are important in a professional's personal life, this will not only lead to a personal engagement to care, but will also acknowledge the life values of that professional and consequently increase their self-esteem. Second, self-esteem arises when professionals find that the effort they make to put the covenant of trust in practice is appreciated by others. If professionals find that they are accepted as partners in relationships with patients, families and colleagues, this leads to the experience of making a difference – as a caregiver, but also as a human being – which can positively affect their self-esteem.

Although the moral attitude of palliative care professionals is ideally rooted in a covenant of trust in which the well-being of the patient is primary, it does not mean that a professional's own well-being is ignored. The opportunity to care for others on the basis of a mutual bond of trust can improve the self-esteem of the caregiver and create a reciprocal element in the obligation to provide competent care in another's interest. As Byock claims (chapter 3): "In acting covenantally, I make decisions affecting the well-being of another, conscious that their well-being affects my own".³⁰ The motivation and commitment to act in the interest of others expresses a caregiver's esteem for others, but accepting the obligation to meet a patient's needs may also help the caregiver's esteem for themselves.

Whole person care revisited

In the introduction of this thesis, Randall and Downie's framework of whole person care was used as a first orientation of the moral attitude of palliative caregivers.³¹ A key aspect of their framework is the distinction between the intrinsic aim and extrinsic aim of palliative care. Randall and Downie claim that the promotion of a patient's emotional, social and spiritual well-being is extrinsic to palliative care's intrinsic aim of bringing about the medical good. Two arguments support this distinction. First, the patient's primary problems are of a medical nature. Second, it is wrong to think that there is a skilled professional approach to the broad range of human problems (emotional, social, spiritual) that may constitute the background of these medical problems. Dealing with those broader problems requires practical wisdom which is moulded by (life) experiences, while medical problems can be dealt with by means of knowledge-based skills that can be instilled by taking courses. Since intrinsic means "relating to the essential qualities or features of something or someone"¹⁰ and extrinsic means "coming from outside a particular person or thing"¹⁰, Randall and Downie's point of view seems to qualify a professional's attempts to deal with emotional, social and spiritual problems of palliative care patients as a side issue. However, they also argue that palliative care requires personal involvement of the caregiver and that "the commitment to act for the patient's total good must be part of what it means to be a carer" (p.39).³¹

This contrast raises the question of whether such personal involvement and commitment on the basis of experiential knowledge and insight into human characters really must be considered an *extrinsic* aim of palliative care. Furthermore, Randall and Downie seem to qualify their distinction by interpreting it from two points of view (pp.20-21).³¹ On the one hand, they argue that the distinction between the intrinsic and extrinsic aim of palliative care should be firm to prevent palliative care falling short of expectation. All health care practitioners can be trained to aim at the medical good, while their dealings with psychological, social and spiritual distress will largely depend on the experience and personality of the caregiver. This makes the intrinsic aim a reasonable target for all health care practitioners. On the other hand, Randall and Downie admit that practical wisdom can be considered the "controlling element in care" (p.20).³¹ To whatever extent professional expertise develops,

every case is a particular case and practical wisdom always plays an important part in a caregiver's judgements about what to do. The technical skills cannot be exercised without a balanced judgement based on practical wisdom. Moreover practical wisdom is crucial when it comes to the *manner* in which care is given. "Humane treatment flows from the carer with practical wisdom" (p.21).³¹ Here, the distinction between intrinsic and extrinsic is blurred.

The current study supports the latter interpretation in not drawing a sharp line between the intrinsic and extrinsic aim of palliative care. Whether it concerns health care practitioners in general or specialised palliative caregivers, good palliative care requires the personal involvement of the practitioner because the relationship between caregiver and care receiver is crucial. This study does agree with Randall and Downie's view on whole person care on one important issue: the responsibility of palliative carers with regard to the psychological, social and spiritual well-being of the patient is closely connected to their *partnership* with that patient. The moral imperative of respect for a patient's personal values and goals limits the scope of professional activity. This respect is integral to whole person care and acts as a safeguard against setting unrealistic goals. Whole person care can only succeed in partnership with the patient, but – as Van Heijst argues – a patient with an uncooperative attitude must not be rejected.

Randall and Downie claim that acting from a willingness to assist patients to overcome psychological, social and spiritual barriers to their well-being is not really a part of a professional role. In overcoming these barriers, caregivers rather act as a 'caring companion' or as a 'fellow member of community' (p.24).³¹ From this perspective, the personal involvement of palliative care practitioners would be largely disconnected from their professional task of bringing about the medical good. From the point of view of the studies that were conducted in this thesis, such a disconnection seems problematic.

This thesis shows how providing palliative care as a professionally skilled caregiver inevitably implies providing care in which professionals feel personally committed to needy others and in which physical aspects of care are closely related to attention to well-being on a psychosocial and spiritual level. In chapter 2 this is put forward in the 'habits of mind' that are the moral basis of professional competence. Chapter 3 advances the importance

in palliative care practice of a particular set of values that are considered important in every life. It also emphasises the role that a covenant of trust – conceived as a mutual bond between human beings – plays when providing palliative care. The chapters 4 and 5 demonstrate what providing palliative care can mean – by affecting self-esteem – for the professional as a person. The chapters 6 and 7 consider providing palliative care as a potential route to personal and professional growth. In short, these findings endorse the following words: “Palliative care is whole person care not only in the sense that the whole person of the patient is the object of attention. Palliative care also demands that the whole person of the caregiver be involved. Palliative care is, par excellence, care that is given through the medium of the human relationship” (p.464).³²

Reflective practice

Throughout this thesis it is argued that the relationship between patient and professional can be considered the cornerstone of palliative care practice. Finding a balance between involvement in patients’ lives and (occasional) detachment from their suffering requires self-knowledge, reflection and self-examination³³ or, in other words, awareness of personal resources and limitations.³⁴ Mindful of the importance of that balance, a recent report of the European Association for Palliative Care (EAPC) – which is discussed in chapter 6 – stresses the need for reflective practice in palliative nursing. Reflective practice involves thoughtfully considering one’s own experiences in applying one’s professional knowledge and skills to practice while being coached by other professionals in the discipline.³⁵ The current thesis supports a plea for reflective practice, not only for palliative nursing, but for palliative care as a whole. Guided reflection offers opportunity to discuss both ‘objective’ (knowledge and skills) and ‘inter-subjective’ (providing care within an ethical relationship) aspects of professional care. On the basis of this thesis it can be argued that such reflection is a prerequisite for watching over and preserving a professional’s motivation and commitment to act in the interest of others.

Experiences in practice trigger two kinds of reflection, that can both be retrieved in chapter 6. First, *reflection in action* can be described as “the ability to learn and develop continually by creatively applying current and past

experiences and reasoning to unfamiliar events while they are occurring” (p.214).³⁶ It is advanced in chapter 6, for example, in the quotation of the certified nursing assistant who – after having worked in palliative practice for a while – adjusted her belief that a patient should be washed every day. Second, *reflection on action* is “a process of thinking back on what happened in a past situation, what may have contributed to the unexpected event, whether the actions taken were appropriate, and how this situation may affect future practice” (p.214).³⁶ A striking case in this point was the remark of the head/nurse in chapter 6 who emphasised the importance of mutuality within the caring team and the regular sharing of each others’ experiences. Through the process of reflecting ‘in practice’ and ‘on practice’, practitioners continually reshape their approaches and develop the way they practice their profession.³⁶ Since a professional’s moral attitude is closely intertwined with that practice, the process of reflection with which a professional scrutinises experiences in practice also provides the opportunity to scrutinise their moral attitude. In chapter 6 it is argued that portfolio learning may be an effective educational tool to structurally integrate such a process of reflection in practice.

Whereas chapter 6 focuses on the further development and preservation of the moral attitude of professionals who work in palliative care, chapter 7 suggests that palliative care itself can function as a source of reflection on moral attitude. Education is considered a key to ‘good work’.³⁷ The chapter suggests that reflection on experiences in palliative practice should be a part of the formal education of medical students. It is argued that such experiences support a more explicit enculturation into the medical realm and in that way contribute to a less implicit formation of medical students’ moral attitude, and their way of committing themselves to patients. Several authors argue that experiencing intimate and caring situations, e.g. in first clinical encounters, lead to a process of personal reflection and moral reasoning that seriously affected students’ moral awareness.^{38,39} Other studies support this point of view and demonstrate the benefits of a course that brings future doctors into contact with palliative care practice.⁴⁰⁻⁴³ For example, one course immerses students as participant observers in a palliative care setting to counteract the influence of the informal and hidden curricula upon medical education.⁴² Observation of others is supposed to lead to a critical evaluation of the students’

own practices. This acquaintance with palliative care and the consequent discussions and reflection not only demonstrated the fact that each person brings his or her own perspective to the clinical encounter, it also clarified the part human qualities play in medicine. Furthermore, in chapter 7 it is argued that gaining experience in palliative care may be supplemented by reflection on narratives that describe serious illness, death or grief. This focus on palliative care experiences and narratives will help medical students to recognise the human dimensions that form the moral starting point of health care and will thus offer them an opportunity to refine their moral attitude – their motivation and commitment to act in the interest of others.

Future research into ‘Who cares?’

The central message of this study is that moral development as a professional inevitably goes hand in hand with moral development as a person. The professional practice and the personal life of palliative caregivers seem to be so closely related that it is difficult to separate palliative care’s aim to bring about the medical good from professionals’ commitment to both their own well-being and the patient’s total good. In palliative care practice, the question ‘What care should be provided?’ is inseparably related to the question ‘Who cares?’. On the basis of the present study, at least three issues concerning the development and maintenance of the moral attitude of health care professionals deserve attention in future research.

First, from a virtue ethical perspective, future research should take the opportunity to seriously examine the position of role models in the development of professionals. In short, a role model is a person with whom we can identify, who has qualities we would like to have, and who is in a position we would like to reach.⁴⁴ But role models are not unproblematic; they are serendipitous (it is not fixed what a good role model is) and can be silent (the learning is assumed, not explicit).^{44,45} It can be argued that reflection can play an important part in coping with these barriers.⁴⁶ Reflection on actual role models can contribute to a more explicit enculturation into health care and can thus counteract the undesirable effects of the hidden curriculum. Explicit reflection on role model behaviour however, has rarely been studied in health care practice, even less in palliative care practice.

Second, an underemphasised aspect of the ethics of care deserves a more fundamental study: self-care. This issue strongly relates to the development and preservation of the moral attitude of professionals. What kind of care is competent 'care for caregivers'? At first sight, this issue seems to be linked to the reflective practice that was brought up in chapter 6. Research is needed to better understand the self-care of professionals and its relationship with reflection. All the more because this thesis demonstrates that the well-being of the care receiver and the well-being of the caregiver are both involved in providing care.

Third, from a hermeneutical point of view it seems worthwhile to study the relationship between moral attitude and moral competence. It is argued that someone's identity, or having an integrated personality, means changing in the right way; one has to continue to interpret one's actions in one's biography in an understandable and defensible way, which requires a specific moral competence.^{8,47} This process of reinterpreting one's actions in one's biography shows similarities to the argument made in chapter 6 concerning moral attitude and reflective practice in palliative care, in which the central question was 'What kind of palliative caregiver should I be?'. Furthermore, changing in the right way, and developing and maintaining oneself as a person and a professional seems to be closely connected to care ethics' aim of recovering and maintaining a world worth living in. Future (empirical-) ethical research will have to provide further insight into how moral attitude, moral competence and care ethics are connected to each other. The present thesis demonstrates that palliative care and the caregivers that put it into daily practice, are a particularly fertile field for such research on the interface of ethics, empirics, and health care.

References

1. Flaming D. Becoming a nurse: "It's just who I am". *J Med Ethics: Med Hum* 2005; 31: 95-100.
2. Van Heijst A. *Menslievende zorg. Een ethische kijk op professionaliteit*. Kampen: Klement, 2005.
3. Aristoteles. *Ethica*. Groningen: Historische Uitgeverij, 1999.
4. Wils JP. Verstandigheid – een kernbegrip van de hermeneutische ethiek. In: Wils JP, ed. *Ethiek en hermeneutiek*. Leende: Damon, 1999: 111-138.
5. Lovibond S. *Ethical formation*. Cambridge, Mass: Harvard University Press, 2002.
6. Pellegrino MD, Thomasma DC. *The virtues in medical practice*. New York: Oxford University Press, 1993.
7. Van Tongeren P. *Deugdelijk leven. Een inleiding in de deugdethiek*. Amsterdam: SUN, 2003.
8. Musschenga B. *Integriteit. Over de eenheid en heilheid van de persoon*. Utrecht: Lemma, 2004.
9. Doukas DJ. Where is the virtue in professionalism? *Cambr Quart Healthc Ethics* 2003; 12: 147-54.
10. *Macmillan English dictionary for advanced learners*. Oxford: Macmillan Education, 2002.
11. Lindemann K. The ethics of receiving. *Theoret Med* 2003; 24: 501-09.
12. Benner P. A dialogue between virtue ethics and care ethics. *Theoret Med* 1997; 18: 47-61.
13. Oakley J, Cocking D. *Virtue ethics and professional roles*. Cambridge: Cambridge University Press, 2001.
14. Tronto JC. *Moral boundaries. A political argument for an ethic of care*. New York: Routledge, 1993.
15. Smits MJ. *Zorgen voor een draaglijk bestaan. Morele ervaringen van verpleegkundigen*. Maastricht: Thesis University Maastricht, 2004.
16. Fredriksson L. Modes of relating in a caring conversation: a research synthesis on presence, touch and listening. *J Adv Nurs* 1999; 30: 1167-76.
17. Fredriksson L, Eriksson K. The ethics of the caring conversation. *Nurs Ethics* 2003; 10: 138-48.

18. Larson DG, Tobin DR. End-of-life conversations. Evolving practice and theory. *JAMA* 2000; 284: 1573-78.
19. Gastmans C, Dierckx de Casterle B, Schotsmans P. Nursing considered as moral practice: A philosophical-ethical interpretation of nursing. *Kennedy Inst of Ethics J* 1998; 8: 43-69.
20. Gastmans C. Care as a moral attitude in nursing. *Nurs Ethics* 1999; 6: 214-23.
21. James N. Care = organization + physical labour + emotional labour. *Sociol Health & Illn* 1992; 14: 488-509.
22. Staden H. Alertness to the needs of others: a study of the emotional labour of caring. *J Adv Nurs* 1998; 27: 147-56.
23. Skilbeck J, Payne S. Emotional support and the role of the clinical nurse specialist in palliative care. *J Adv Nurs* 2003; 43: 521-30.
24. Li S. 'Symbiotic niceness': constructing a therapeutic relationship in psychosocial palliative care. *Soc Sci Med* 2004; 58: 2571-83.
25. Li S. Doing criticism in 'symbiotic niceness': a study of palliative care nurses' talk. *Soc Sci Med* 2005; 60: 1949-59.
26. Larson EB, Yao X. Clinical empathy as emotional labour in the patient-physician relationship. *JAMA* 2005; 293: 1100-06.
27. Crawshaw R, Rogers DE, Pellegrino ED, Bulger RJ, *et al.* Patient-physician covenant. *JAMA* 1995; 273: 1553.
28. Bradshaw A. The virtue of nursing: the covenant of care. *J Med Ethics* 1999; 25: 477-81.
29. Cortina A. *Covenant and contract: politics, ethics, and religion*. Leuven: Peeters, 2003.
30. Byock I. Rediscovering community at the core of the human condition and social covenant. *Hastings Center Rep* 2003; 33 (suppl.): s40-s41.
31. Randall F, Downie RS. *Palliative care ethics. A companion for all specialties* (2nd ed). Oxford: Oxford University Press, 1999.
32. Barnard D. The coevolution of bioethics and the medical humanities with palliative medicine, 1967-97. In: Fulford KWM, Dickenson DL, Murray TH, eds. *Healthcare ethics and human values*. Oxford: Blackwell Publishers, 2002: 461-67.

33. Montello M. Narrative competence. In: Lindemann Nelson H, ed. *Stories and their limits. Narrative approaches to bioethics*. New York: Routledge, 1997: 185-197.
34. Öhlén J, Segesten K. The professional identity of the nurse: concept analysis and development. *J Adv Nurs* 1998; 28: 720-27.
35. Schön DA. *Educating the reflective practitioner: Toward a new design for teaching and learning in the professions*. San Francisco: Jossey-Bass, 1996.
36. Kaufman DM. Applying educational theory in practice. *Br Med J* 2003; 326: 213-16.
37. Gardner H, Csikszentmihalyi M, Damon W. *Good work. When excellence and ethics meet*. New York: Basic Books, 2001.
38. Lemonidou C, Papathanassoglou E, Giannakopoulou M, Patiraki E, et al. Moral professional personhood: ethical reflections during initial clinical encounters in nursing education. *Nurs Ethics* 2004; 11: 122-37.
39. MacLeod RD. On reflection: doctors learning to care for people who are dying. *Soc Sci Med* 2001; 52: 1719-27.
40. Block S, Billings JA. Nurturing humanism through teaching palliative care. *Acad Med* 1998; 73: 763-65.
41. Maxwell TL, Passow ES, Plumb J, Sifri RD. Experience with hospice: reflections from third-year medical students. *J Palliat Med* 2002; 5: 721-27.
42. Fins JJ, Gentileco BJ, Carver A, Lister P, et al. Reflective practice and palliative care education: a clerkship responds to the informal and hidden curricula. *Acad Med* 2003; 78: 307-12.
43. MacLeod RD, Parkin C, Pullon S, Robertson G. Early clinical exposure to people who are dying: learning to care at the end of life. *Med Educ* 2003; 37: 51-58.
44. Paice E, Heard S, Moss F. How important are role models in making good doctors? *Br Med J* 2002; 325: 707-10.
45. Erde EL. The inadequacy of role models for educating medical students in ethics with some reflections on virtue theory. *Theoret Med* 1997; 18: 31-45.
46. Olthuis G. Role models and moral attitude in palliative care. *Eur J Palliat Care* 2005; 12 (suppl., abstracts of EAPC-congress, 2005): 38.
47. Bransen J. *Jezelf blijven*. Nijmegen: Inaugural speech Radboud University Nijmegen, Sept. 26th 2003.

Summary

The central concern of this thesis is the moral attitude of professionals who work in palliative care. This attitude is described in general terms as ‘the motivation and commitment to act in the interest of others’. The subsequent chapters 2-5 attempt to draw a picture of what kind of professionals provide palliative care on a daily basis. What motivates them? What does it take to be good at such care? How should they engage in their relationships with patients? These questions are part of the first objective of the present study: to explore and analyse normative views with regard to the moral attitude of professionals caregivers in palliative care. The second objective of the study is to explore how the moral attitude of (palliative) care professionals can be stimulated, preserved and maintained. How can professional palliative carers persevere in their motivation and commitment to help patients who suffer from a life-threatening illness (chapter 6)? How can the development of medical students’ moral attitude be stimulated (chapter 7)?

The introductory chapter provides the background against which the above mentioned objectives emerge. It briefly sketches what can be understood as palliative care and what characterises patients who receive such care. It also offers a first orientation on the moral attitude of palliative carers on the basis of a framework of ‘whole person care’ which is taken from Randall and Downie’s standard work on palliative care ethics.

Chapter 2 revolves around professional competence. The aim of the chapter is to explore an ethical view of professional competence by examining the professional competence of physicians in the context of palliative care. Point of departure is the definition of professional competence as ‘the habitual and judicious use of communication, knowledge, technical skills, clinical reasoning, emotions, values, and reflection in daily practice for the benefit of the individual and the community being served’. Four dimensions of this definition – the cognitive, technical, relational and affective/moral dimension – are examined more closely on the basis of clinical vignettes derived from interviews with

palliative care professionals. It is concluded that another dimension – ‘habits of mind’ – plays a crucial role in every aspect of professional competence. This observation is discussed from the perspective of virtue ethics and care ethics. Our conclusion points up the importance of education in ethics in the development of professional competence, and argues that because palliative care involves intense human interactions, integrating palliative care into the medical curriculum may improve the ethical culture of health care as a whole.

In chapter 3 quality of life is considered as well-being. The aim is to compare insights about well-being from contemporary philosophy with the practice-related opinions on well-being of palliative care professionals. In the first part of the chapter it is outlined how the nature of well-being is interpreted in contemporary philosophy. It focuses on two recent views: ‘prudential perfectionism’ and ‘authentic happiness’. The first theory acknowledges the independent existence of prudential values and argues that there are some things that are valuable in every life, the latter denies the independent existence of prudential values and argues that they are valued only in terms of the subject’s attitude towards the world. In the second part opinions on well-being are presented that are derived from interviews with nineteen professional palliative caregivers. Both their views on the well-being of patients and the well-being of the carers themselves are considered. Seven elements are discussed: 1) the nature of well-being, 2) emphasizing life, 3) trying to meet the patient’s preferences, 4) treating the patient as a person, 5) completing life, 6) dying well, 7) the professionals’ satisfaction and enrichment. The third part of the chapter further discusses these elements and focuses on the question how well-being ought to be promoted. A threefold conclusion is presented. First, the analysis underscores the subject-relativity of well-being that is central in ‘authentic happiness’. Second, it seems that values that are considered relevant in every life as presented in the theory of ‘prudential perfectionism’ are relevant in palliative care practice. Third, the analysis points out the importance of a covenantal approach to care when aiming to enhance the well-being of patients in palliative care.

Chapter 4 concentrates on two questions: 1) What kind of person should the hospice nurse be?, and 2) How should (s)he engage in caring conversations? Central in the analysis to answer these questions is the story of Su-

san, a hospice nurse. This story is composed of exemplary statements made by five hospice nurse who were interviewed for this study. The normative framework that is used as a tool to analyse these statements is the 'ethics of the caring conversation' which incorporates the ethics of Paul Ricoeur. It is explored how the professional role a hospice nurse is expected to play is interwoven with the person (s)he is. The ethical notions of self-esteem, autonomy, and caritas and the corresponding norms of self-respect, responsibility, and reciprocity play a key role in answering the two questions that were the starting point of the chapter.

Chapter 5 elaborates on the analysis that was made in the preceding chapter. It offers a more detailed examination of self-esteem in relation to the notions of personal identity (person) and professional identity (role). Again, the story of hospice nurse Susan serves as the background for the discussion. The focus is on examining two questions: 1) What is self-esteem, and how is it related to personal identity and its moral dimension?, and 2) How do self-esteem and personal identity relate to the professional identity of the nurse? It is argued that if the nurse's personal view of the good life is compatible with their experiences and feelings as professionals, this improves their performance as nurses. Furthermore, it is discussed how good nursing depends on the responses that the nurse gets from others (patients, colleagues, family); they make the nurse feel valued as a person and enables them to see the value of the work they do.

The next two chapters serve the second objective of the present thesis. In chapter 6 a recent report of the European Association for Palliative Care is discussed. The report recommends the promotion of reflective practice in palliative care. The moral attitude that professionals bring to such reflective practice is examined in terms of four crucial aspects of virtue ethics: practice, motivation, emotion, and practical wisdom. The examination is tailored to palliative care with quotations from interviews with several professionals. It is argued that the reflective practice should be persistently focused on the question: What kind of palliative caregiver should I be? While this question plays an important, but often implicit, role in staff support activities, it is argued that as an educational tool portfolio learning offers opportunities to improve the integration of reflection into the structure of palliative care practice.

Chapter 7 focuses on the development of the moral attitude of medical students. It is frequently observed that the current emphasis on theoretical knowledge and practical skills in medical education distracts attention from the moral attitude of future doctors. It is argued that including palliative care into medical training not only improves the quality of palliative care in general, but also stimulates the development of the moral attitude of the doctors being trained. Clinical experience in palliative care, supplemented by reflection on narratives about chronically ill or dying patients, and mourning or aging processes, offer prospects for such development. In conclusion, it is suggested that inclusion of palliative care can contribute to the transformation of the present 'hidden curriculum' of contemporary medical education – which implicitly shapes the student's moral attitude – into a more explicit enculturation into the medical realm.

Chapter 8 is largely devoted to a résumé of three crucial moral notions that run like a common thread through the preceding chapters. First, the virtue ethical notion of *phronesis* – or practical wisdom – is discussed. After situating *phronesis* within the whole of virtue ethics, three aspects that relate it to the moral attitude of palliative carers are discussed: 1) self-awareness, 2) responsibility, 3) professional practice and the practice of life. The issue of professional detachment from patients is discussed here as well. Second, the notion of the *caring conversation* is further discussed. It is considered from the perspective of the ethics of care. Subsequently, the role emotional labour plays in the relationship between professional and patient are discussed. The caring conversation does not follow a predetermined formula; personal involvement of the professional through emotion work seems inevitable. Third, the moral notion of the *covenant of care* is further examined. It is argued that the covenantal approach to caregiving is a crucial element of the moral attitude of palliative caregivers. However, the often assumed absence of reciprocity this approach would imply is questioned. The opportunity to care for others from a mutual bond of trust may lead to self-esteem on behalf of the carer and thus shows that a reciprocal element can well be a part of the obligation to provide competent care in another's interest. Chapter 8 is completed with a comment on the framework of 'whole person care' that served as the starting point for the current explorations. It is argued that from the perspec-

tive of the present study palliative care involves both the whole person of the patient and the whole person of the caregiver. It is difficult to separate a palliative care professional's task to skillfully deal with a patient's physical good from the humane interventions that aim at a patient's psychological, social, and spiritual good. This is underlined by both the importance of getting to know the patient as a person and the consequences the commitment to act in the patient's interest can have for the professional as a person, as is repeatedly advanced in this study. The explorations in this thesis support a plea for reflective practice in palliative care. Guided reflection seems to be a prerequisite for watching over and preserving a professional's motivation and commitment to act in the interest of others. Finally, role models, self-care, and moral competence are regarded as issues concerning the development and maintenance of the moral attitude of health care professionals that deserve attention in future research.

Samenvatting

Wat beweegt mensen om hun werkzame leven te wijden aan de zorg voor patiënten die lijden aan een levensbedreigende ziekte en die soms zelfs de dood al in de ogen zien? Wat motiveert hen een professional in de palliatieve zorg te zijn? Hoe zouden palliatieve zorgverleners moeten staan in de relatie met de patiënten waarvoor ze zorgen? Hoe kunnen zorgverleners hun engagement met betrekking tot dit soort intensieve zorg volhouden? In dit proefschrift wordt zichtbaar gemaakt dat de zorgverleners die palliatieve zorg dagelijks in de praktijk brengen, dit werk doen vanuit een bepaalde morele houding. Deze houding wordt in algemene termen omschreven als ‘de motivatie en betrokkenheid om in het belang van anderen te handelen’ en wordt in de voorliggende studie vanuit diverse ethische invalshoeken verkend. Hierbij passeren de deugdeethiek, de hermeneutische ethiek van Paul Ricoeur en welzijnstheorieën uit de hedendaagse filosofie de revue. Tegelijkertijd wordt de morele houding van palliatieve zorgverleners ook vanuit een empirische invalshoek verkend. Een dertigtal interviews met diverse palliatieve zorgverleners die werkzaam zijn in verschillende settings speelt een belangrijke rol in de analyses. De doelstelling van dit proefschrift is tweeledig. Allereerst beoogt deze studie normatieve zienswijzen van zorgverleners ten aanzien van een morele houding in de praktijk van de palliatieve zorg te verkennen en te analyseren. Dit doel staat centraal in de hoofdstukken 2 tot en met 5. Op de tweede plaats wil de studie ook verkennen hoe de morele houding van palliatieve zorgverleners gehandhaafd en gestimuleerd kan worden. Dit gebeurt in de hoofdstukken 6 en 7.

In het inleidende hoofdstuk 1 wordt beknopt geschetst wat verstaan wordt onder palliatieve zorg en wat patiënten karakteriseert die dergelijke zorg ontvangen. Zo verschijnt de achtergrond waartegen de hierboven genoemde vragen en doelen zich aandienen. Bovendien biedt dit hoofdstuk een eerste oriëntatie op de morele houding van palliatieve zorgverleners op basis van een kader van *whole person care* (‘zorg voor de hele mens’) dat is ontleend

aan Randall en Downie's standaardwerk op het gebied van de ethiek van de palliatieve zorg.

De achtergrond voor hoofdstuk 2 wordt gevormd door recente discussies over medisch professionalisme. Een breder, ethisch perspectief ontbreekt daarin veelal. In dit hoofdstuk wordt het begrip professionele competentie nader onderzocht in de context van de palliatieve zorg met als doel nader in te gaan op de morele basis van professioneel competente zorg. Het vertrekpunt is een definitie van professionele competentie als 'het vanzelfsprekend en oordeelkundig gebruik van communicatie, kennis, technische vaardigheden, klinisch redeneren, emoties, waarden en reflectie in de dagelijkse praktijk van de zorg ten bate van het individu en de gemeenschap' (Epstein et al, 2002). Vier dimensies van deze definitie – de cognitieve, technische, relationele en affectief-morele – worden bediscussieerd aan de hand van een aantal interviewfragmenten, afkomstig uit interviews met palliatieve zorgprofessionals. Er wordt geconcludeerd dat een vijfde dimensie – *habits of mind* ('tweede natuur') – een cruciale rol speelt in elke dimensie van professionele competentie. Competent handelen hangt, met andere woorden, nauw samen met een vanzelfsprekende, morele houding die een zorgverlener in staat stelt zich aandachtig, nieuwsgierig en zelfbewust op te stellen jegens patiënten. Dat geldt voor zowel de technische en cognitieve aspecten, als de morele, emotionele en relationele aspecten van het handelen. Deze constatering wordt vervolgens besproken vanuit het perspectief van de deugdethiek – die zich richt op morele kwaliteiten en houdingen – en de zorgethiek – waarin de nadruk ligt op de wijze waarop die kwaliteiten vorm krijgen in zorgrelaties. In de conclusie wordt gewezen op het belang van ethiekonderwijs als het gaat om het ontwikkelen van professionele competentie. Ook wordt beargumenteerd dat, omdat intense menselijke interacties er zo centraal in staan, de palliatieve zorg goede aanknopingspunten biedt om over de morele basis van geneeskunde na te denken; het vertrouwen dat patiënten stellen in de competentie van dokters en de plicht van de dokter die kundigheid in te zetten in het belang van de patiënt. Daarom zou het integreren van palliatieve zorg in het geneeskunde curriculum de ethische cultuur van de gezondheidszorg als geheel mogelijk kunnen verbeteren.

Palliatieve zorg, en daarmee ook het handelen van palliatieve zorgverleners, richt zich op het verbeteren van de kwaliteit van leven van patiënten met een levensbedreigende ziekte en hun familie. Een belangrijke maat voor kwaliteit van leven is welzijn. Het doel van hoofdstuk 3 is om inzichten over het begrip welzijn uit de hedendaagse filosofie te vergelijken met de praktijkgerelateerde opvattingen over welzijn van palliatieve zorgprofessionals. In het eerste deel van het hoofdstuk wordt geschetst hoe in de filosofie de essentie van welzijn wordt geïnterpreteerd. Twee gezichtspunten staan centraal: 'authentic happiness' en 'prudential perfectionism'. Beide visies vertrekken vanuit de vraag: Wat maakt het leven goed voor degene wiens leven het is? Een heikel punt is vervolgens de kwestie of er waardevolle zaken zijn aan te duiden, los van individuele wensen en verlangens, die richtinggevend zijn voor het welzijn van iemand. De eerste theorie ontkent dit en stelt dat zaken met betrekking tot welzijn alleen gewaardeerd kunnen worden in termen van iemands (subjectieve) houding jegens de wereld. De tweede theorie daarentegen, erkent het bestaan van waarden die van belang zijn voor elk leven, onafhankelijk van het individuele perspectief. In het tweede deel van het hoofdstuk worden de opvattingen over welzijn gepresenteerd zoals die naar voren komen uit interviews met negentien palliatieve zorgverleners. Zowel hun visie op het welzijn van de patiënt als die op het welzijn van de zorgverlener komen aan bod. Zeven punten worden besproken: 1) de essentie van welzijn, 2) de nadruk op het leven, 3) proberen tegemoet te komen aan de voorkeuren van de patiënt, 4) omgaan met de patiënt als persoon, 5) afronden van het leven, 6) goed sterven, 7) voldoening en verrijking van de professional als persoon. Het derde deel van het hoofdstuk gaat dieper in op deze zeven punten en concentreert zich op de vraag hoe welzijn dan verbeterd kan worden. De conclusie is drievoudig. Allereerst onderstreept de analyse de subjectgerelateerdheid van welzijn die centraal staat in de theorie van 'authentic happiness'. De geïnterviewde zorgverleners maken duidelijk dat het welzijn van de patiënt een oordeel is van die patiënt over zijn of haar eigen situatie. Op de tweede plaats maakt de analyse duidelijk dat, hoewel zij het welzijn van de patiënt als een *individueel* oordeel opvatten, palliatieve zorgverleners zich in de praktijk in belangrijke mate laten leiden door de waarden die de theorie van 'prudential perfectionism' als relevant beschouwt in *elk* leven. Een derde

punt wijst vervolgens op het belang van een benadering van zorg vanuit de 'menselijke verbondenheid' (*covenant*). Zoals een geïnterviewde verpleegkundige benadrukte: 'Wat je geeft, staat in geen verhouding tot wat je ontvangt.' Vanuit een dergelijke verbondenheid wordt gehandeld met de bedoeling het welzijn van de ander te beïnvloeden, wetend dat het welzijn van de ander een rol speelt bij dat van zichzelf.

In hoofdstuk 4 wordt één specifieke palliatieve zorgprofessional onder de loep genomen: de hospice verpleegkundige. De 'ethiek van het zorggesprek', gebaseerd op de hermeneutische ethiek van Paul Ricoeur, wordt in dit hoofdstuk ingezet om het op basis van interviews samengestelde verhaal van hospice verpleegkundige Susan nader te duiden. Centraal in deze analyse staat de wijze waarop persoon, professionele rol en zorgrelatie met elkaar verweven zijn in de hospice zorg. In het hoofdstuk wordt geprobeerd antwoord te geven op twee vragen: 1) Wat voor persoon moet de hospice verpleegkundige zijn? en 2) Hoe moet hij/zij participeren in gesprekken waarin de betekenis van het lijden voor de patiënt verkend wordt? Met betrekking tot de eerste vraag komt het belang naar voren van de wijze waarop de verpleegkundige zichzelf acht (*self-esteem*) en de achting die hij of zij heeft voor anderen. In meer normatieve termen wordt dan gesproken van zelfrespect en respect. Daarnaast speelt de notie van autonomie een rol. Het evalueren van het eigen handelen (wat kan leiden tot zelfachting) veronderstelt de mogelijkheid tot handelen te hebben (autonomie). In normatieve zin brengt deze mogelijkheid een verantwoordelijkheid met zich mee. In het geval van een hospice verpleegkundige is dat de verantwoordelijkheid te handelen in het belang van doodzieke patiënten die niet de mogelijkheid hebben zelf te handelen. Het antwoord op de tweede vraag benadrukt het belang de lijdende patiënt als persoon, vanuit een houding van wederkerigheid, te benaderen. Hiermee wordt allereerst het gevaar van een puur asymmetrische relatie bezworen; de relatie tussen hospice verpleegkundige en patiënt is idealiter ook een relatie van medemenselijkheid. Bovendien, en hierop aansluitend, maakt het ethische perspectief van Ricoeur duidelijk dat het persoonlijke en interpersoonlijke nauw verbonden zijn. Of zoals Ricoeurs herformulering van Kants gulden regel luidt: 'teneinde anderen te kunnen achten, moet ik mezelf achten'.

In hoofdstuk 5 wordt de analyse van het vierde hoofdstuk verder uitgewerkt en wordt de notie van zelffaching (*self-esteem*) in relatie tot persoonlijke en professionele identiteit bestudeerd. Ook hier dient het verhaal van hospice verpleegkundige Susan als achtergrond voor de discussie. Twee vragen staan centraal: 1) Wat is *self-esteem*, en hoe is het gerelateerd aan de morele dimensie van persoonlijke identiteit?, en 2) Hoe zijn *self-esteem* en persoonlijke identiteit gerelateerd aan de professionele identiteit van de verpleegkundige? Er wordt betoogd dat de begrippen zelffaching, persoonlijke identiteit en professionele identiteit zich verenigen in wat wordt genoemd 'moreel actorschap'. Het beeld dat verpleegkundigen van zichzelf als persoon hebben en het beeld dat ze hebben van zichzelf als professional is intrinsiek verbonden met hun vermogen het goede te zien in het werk dat ze doen. Zowel de waarde van het verpleegkundige werk *op zich*, als de waarde die het heeft voor de verpleegkundige *zelf* – dat deze doet wat hij of zij vindt dat een professionele verpleegkundige zou moeten doen – spelen hierbij een rol. Met andere woorden, goede verpleegkundige zorg vereist idealiter dat de ervaringen en gevoelens die een professional in de praktijk van de zorg heeft, aansluiten bij het beeld van het goede leven dat deze professional als persoon voor ogen staat. Tot slot wordt besproken hoe 'goed verplegen' samenhangt met de respons die verpleegkundigen krijgen van anderen (patiënten, collega's, familie); deze respons zorgt er voor dat zij zich gewaardeerd voelen als persoon en laat hen de waarde van het verpleegkundige werk zien. Het draagt, kortom, bij aan hun zelffaching.

De volgende twee hoofdstukken staan in het teken van het tweede doel van het proefschrift: het verkennen van de wijze waarop de morele houding van palliatieve zorgverleners gehandhaafd en gestimuleerd kan worden. In hoofdstuk 6 vormt een recent rapport van de *European Association of Palliative Care* (EAPC) de aanleiding voor de discussie. Het rapport beveelt de bevordering van 'reflective practice' in de palliatieve zorg aan, waarmee de noodzaak van zelfbewustzijn en het vermogen van het maken van ethische afwegingen wordt bedoeld. De morele houding van waaruit professionals deelnemen aan een dergelijke reflexieve praktijk wordt in dit hoofdstuk besproken aan de hand van vier cruciale aspecten van de deugdethiek: praktijk, motivatie, emotie en praktische wijsheid. Deze bespreking wordt op de maat

van de palliatieve zorg gesneden aan de hand van citaten uit interviews met verscheidene professionals. Er wordt betoogd dat een reflexieve praktijk zich voortdurend zou moeten richten op de vraag Wat voor palliatieve zorgverlener zou ik willen zijn? Deze vraag speelt een belangrijke, maar vaak impliciete, rol in activiteiten die professionals ondersteunen in hun werk (zoals bijvoorbeeld intervisie). Er wordt beargumenteerd dat ‘portfolio leren’ kansen biedt de integratie van reflectie in de praktijk van de palliatieve zorg te verbeteren.

In hoofdstuk 7 staat de ontwikkeling van de morele houding van medisch studenten centraal. Er wordt vaak beweerd dat de nadruk op theoretische kennis en praktische vaardigheden in het medisch onderwijs de aandacht afleidt van de morele houding van toekomstige dokters. In dit hoofdstuk wordt betoogd dat het opnemen van palliatieve zorg in de medische training niet alleen de kwaliteit van de palliatieve zorg in het algemeen verbetert, maar ook de ontwikkeling van de morele houding van de dokters in spe zal verbeteren. Het opdoen van enige klinische ervaring in de palliatieve zorg, aangevuld met reflectie op verhalen over chronisch zieke of stervende patiënten, en over rouw of veroudering, biedt kansen om de ontwikkeling van een morele houding te stimuleren. In de conclusie wordt opgemerkt dat het structureel opnemen van palliatieve zorg in de geneeskunde opleiding kan bijdragen aan het omvormen van het *hidden curriculum* in het hedendaagse medisch onderwijs – dat de morele houding van studenten impliciet vormt – tot een meer expliciete inwijding in de medische gemeenschap. Het reflecteren op ervaringen in en verhalen over zorg rond het levenseinde kan studenten in een vroeg stadium gevoelig maken voor de morele onderneming die de praktijk van de geneeskunde in feite is.

Hoofdstuk 8 is grotendeels gewijd aan het samen nemen en verder doordenken van drie cruciale morele noties die als een rode draad door het proefschrift lopen. Allereerst wordt de deugdethische notie *phronesis*, of praktische wijsheid, besproken. Na *phronesis* gesitueerd te hebben in het geheel van de deugdethiek, worden drie aspecten die gerelateerd zijn aan de morele houding van palliatieve zorgverleners nader bediscussieerd: 1) zelfbewustzijn, 2) verantwoordelijkheid en 3) praktijk. Het spanningsveld tussen nabijheid en afstand houden van de patiënt wordt hier ook besproken. Ten tweede wordt de notie van de *caring conversation* uitgewerkt. Dit begrip wordt bediscussieerd

vanuit het perspectief van de zorgethiek, waarin de nadruk ligt op de vraag wat mensen van anderen nodig hebben om hun leefwereld als waardevol te ervaren. Bovendien wordt de rol die 'emotionele arbeid' speelt in de relatie tussen professional en patiënt besproken. Een gesprek dat de betekenis van het lijden voor de patiënt verkent, volgt geen van tevoren vastgestelde formule; persoonlijke betrokkenheid van de professional en omgaan met emoties lijken onvermijdelijk. Ten derde wordt het begrip *covenant* ('verbondenheid') verder onderzocht. Er wordt betoogd dat dit een cruciaal element is in de morele houding van palliatieve zorgverleners. De door sommigen veronderstelde afwezigheid van wederkerigheid in dit verband wordt echter in twijfel getrokken. De kans om voor anderen te zorgen vanuit een onderlinge band van vertrouwen kan leiden tot zelfachting aan de kant van de zorgverlener. Dit laat zien dat een wederkerig element goed een onderdeel kan vormen van de morele verplichting competente zorg te verlenen in het belang van de ander. Hoofdstuk 8 wordt afgesloten met een beknopt commentaar op Randall en Downie's visie op *whole person care* die diende als uitgangspunt van het onderzoek in dit proefschrift. Er wordt betoogd dat vanuit het perspectief van dit onderzoek het verlenen van palliatieve zorg zowel 'de hele persoon van de patiënt' als 'de hele persoon van de zorgverlener' aangaat. De professionele taak om vaardig om te gaan met de fysieke aspecten van de zorg, kan moeilijk los worden gezien van het handelen van professionals op het vlak van de psychosociale en spirituele zorg. Deze bewering en de observatie dat de relatie tussen de professional en de patiënt de hoeksteen vormt van de palliatieve zorgpraktijk, ondersteunen een pleidooi voor een meer reflexieve praktijk in de palliatieve zorg. Het onder begeleiding reflecteren op praktijkervaringen lijkt een noodzakelijke voorwaarde te zijn om de morele houding van zorgprofessionals te bewaken en te handhaven.

Curriculum vitae

Hoewel in dit proefschrift een groep zorgverleners van voornamelijk vrouwen centraal staat (zoals verbeeld op het omslag), ben ik een man. Ik ben in 1971 in een ziekenhuis in Almelo geboren. Twee jaar daarvoor, in 1969, publiceerde J.H. van den Berg *Medische macht en medische ethiek*. Dit boekje wordt over het algemeen aangemerkt als het begin van de 'nieuwe' medische ethiek in Nederland. De paternalistische medische macht brokkelde sindsdien af en de openheid jegens patiënten nam toe. De stem van de patiënt won aan belang bij het nemen van beslissingen. Deze verschuiving had zich nog niet helemaal voltrokken in het ziekenhuis waar ik ter wereld kwam. Mijn vader was bijna de kans ontnomen om de geboorte van zijn eerste kind bij te wonen. Ik lag namelijk in stuit en de hoofdzuster achtte het verstandiger dat hij in de wachtkamer bleef. Hij weigerde. De zuster hield voet bij stuk, maar de dienstdoende gynaecoloog schoot te hulp: "Deze man is zo rustig, laat hem er toch bij." En zo geschiedde. Na dit, naar huidige medisch-ethische maatstaven gemeten, tumultueuze begin van mijn leven, groeide ik in alle rust op in Hellendoorn. Vervolgens verhuisde ik, na het behalen van het VWO-examen (College Noetsele, Nijverdal) in 1989, naar Nijmegen voor de studie Bestuurs- en beleidswetenschappen. Deze studie beviel maar matig. In de loop van het studiejaar besloot ik te stoppen en het jaar daarop psychologie te gaan studeren. In januari 1996 studeerde ik af in de richting Cultuur- en godsdienstpsychologie (thans Cultuur- en persoonlijkheidspsychologie). Er volgde een periode van vrijwilligerswerk bij de Wetenschapswinkel (inmiddels opgeheven) van de Radboud Universiteit en enkele korte aanstellingen bij Cultuur- en godsdienstpsychologie. In 1998 verwierf ik een beurs van de Radboudstichting Wetenschappelijk Onderwijsfonds waarmee ik in de gelegenheid werd gesteld om een aanvullend jaar Ethiek te gaan studeren aan de universiteiten van Tilburg en Nijmegen. Aan het einde van dat studiejaar, in het voorjaar van 1999, kwam ik een vacature tegen voor een onderzoeker bij de afdeling Ethiek, Filosofie en Geschiedenis van de Geneeskunde (EFG) van het UMC St Radboud. Het project

was getiteld 'Gezondheidszorg in een multiculturele samenleving' en werd gefinancierd door de Wetenschapswinkel. Ik solliciteerde, werd aangenomen en zette mijn eerste schreden in de medische ethiek. Eind 2000 werd het project afgerond met de publicatie van het rapport *Colourful care*. In het daarop volgende jaar kreeg ik de gelegenheid uitvoerend onderzoeker te worden van het onderzoeksproject 'Morele attitudevorming in de palliatieve zorgverlening', dat volop in de race was voor een subsidie van NWO. Het project zou eveneens uitgevoerd worden bij de afdeling EFG. De subsidie werd toegekend en het onderzoek ging in de zomer van 2001 van start. Inmiddels is ook dat project afgerond. Het resultaat heeft u nu in handen.

Gert Olthuis

Nijmegen, maart 2007

Publications

- Olthuis G. Gezondheidszorg in een multiculturele samenleving. *Ethische Perspectieven* 2000; 10(2): 141-143.
- Olthuis G. *Colourful Care. Multiculturele zorg: tussen beleid en mentaliteit*. Nijmegen: Wetenschapswinkel KUN, 2000.
- Olthuis G. Multiculturele gezondheidszorg. Een kwestie van beleid en vaardigheid. *Tijdschrift voor Geneeskunde en Ethiek* 2001; 11: 3-8.
- Olthuis G. Kleurrijke zorg. *Versie. Tijdschrift voor gezondheid, burgerschap en politiek* 2001; 19(2): 4-9.
- Olthuis G. Morele attitudevorming in de palliatieve zorgverlening. *Ethische Perspectieven* 2001; 11(3): 188-190.
- Olthuis G. De toekomst zal het leren. Narrativiteit, morele vorming en medisch onderwijs. *Tijdschrift voor Geneeskunde en Ethiek* 2002; 12: 96-98.
- Olthuis G. Geen leven zonder lijden. *Pallium. Tijdschrift voor palliatieve zorg* 2002; 4(3): 18-21.
- Olthuis G. Zoeken naar globale moraal. *Ethiek & Maatschappij* 2002; 5(3): 25-31.
- Olthuis G. De juiste toon. De houding van hulpverleners in de palliatieve zorg. *Pallium. Tijdschrift voor palliatieve zorg* 2002; 4(5): 28-31.
- Olthuis G. 'De beul is bij je'. Symposium over de actualiteit van ondraaglijk lijden. *Tijdschrift voor Geneeskunde en Ethiek* 2002; 12: 124-125.
- Olthuis G, Van Heteren G. Multicultural health care in practice: an empirical exploration of multicultural care in the Netherlands. *Health Care Analysis* 2003; 11: 199-206.
- Olthuis G, Dekkers W. Medical education, palliative care and moral attitude: some objectives and future perspectives. *Medical Education* 2003; 37: 928-933.
- Olthuis G, Dekkers W. Professional competence and palliative care: an ethical perspective. *Journal of Palliative Care* 2003; 19: 192-197.

- Olthuis G. Persoon en professional. Professionele competentie in de palliatieve zorg in ethisch perspectief. In: Verkerk M, Hartoungh R, red. *Ethiek en palliatieve zorg*. Assen: Van Gorcum, 2003: 93-107.
- Olthuis G. Ondraaglijk lijden. Impressie van een congres. *Algemeen Nederlands Tijdschrift voor Wijsbegeerte* 2003; 95: 141-143.
- Olthuis G. Palliatieve zorg en de computer. *Pallium. Tijdschrift voor palliatieve zorg* 2003; 5(3): 9.
- Olthuis G. De eed in de praktijk. Aankomend artsen zouden ervaring moeten opdoen in de palliatieve zorg. *Medisch Contact* 2003; 58: 1266-1267.
- Olthuis G. Evidence Based Medicine: richtinggevende poolster of oude wijn? *Tijdschrift voor Gezondheidszorg en Ethiek* 2003; 13: 119-120.
- Olthuis G, Dekkers W. Quality of life considered as well-being. Views from philosophy and palliative care practice. *Theoretical Medicine & Bioethics* 2005; 26: 307-337.
- Janssens MJPA, Olthuis G, Dekkers W. Terminal sedation and dehydration go hand in hand. *International Journal of Palliative Nursing* 2005; 11: 334-35.
- Dekkers W, Olthuis G. Sterilisatie is geen juridisch wapen. *De Gelderlander*, 11 juni 2005.
- Leget C, Olthuis G. Compassie & co. Medelijden als basis van morele vorming en de kansen van portfolio onderwijs. *Tijdschrift voor Gezondheidszorg en Ethiek* 2005; 15: 106-111.
- Olthuis G, Dekkers W, Leget C, Vogelaar P. The caring relationship in hospice care. An analysis based on the ethics of the caring conversation. *Nursing Ethics* 2006; 13: 29-40.
- Olthuis G, Leget C, Dekkers W. Why hospice nurses need high self-esteem. *Nursing Ethics* 2007; 14: 62-71.
- Leget C, Olthuis G. Compassion as a basis for ethics in medical education. *Journal of Medical Ethics*. Accepted for publication.

- advertentie-

Vindt u dit proefschrift mooi vormgegeven?

Voor de inhoud bent u natuurlijk zelf verantwoordelijk ...

... maar voor een goede vormgeving en drukwerkbegeleiding kunt u terecht bij

Bart Roelofs van Bartswerk Grafisch Ontwerp.

De vormgeving van een proefschrift is aan allerlei regels gebonden. Ik kan u helpen om tot een mooi en goed resultaat te komen door:

- een ontwerp te maken dat er aantrekkelijk uit ziet en aan de regels voldoet;
- de lay-out tot in de puntjes consequent uit te voeren;
- als contactpersoon met drukkerijen op te treden.

Vraag vrijblijvend informatie of een offerte aan:



Bartswerk Grafisch Ontwerp
Dommer van Poldersveldtweg 138
6523 DD Nijmegen
024-3602633
info@bartswerk.nl
www.bartswerk.nl