Living till the End:
Cancer Patients in the Last Phase of Life

Elsbeth de Vogel-Voogt

Living till the End:
Cancer Patients in the Last Phase of Life

Leven tot het einde:
Kankerpatiënten in de laatste levensfase

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LORD, our Lord,
how majestic is your name in all the earth!
You have set your glory
above the heavens.
When I consider your heavens,
the work of your fingers,
the moon and the stars,
which you have set in place,
what are mere mortals that you are mindful of them,
human beings that you care for them?
You have made them a little lower than the heavenly beings
and crowned them with glory and honor.
You made them rulers over the works of your hands;
you put everything under their feet.

Part of Psalm 8

Scripture taken from the Holy Bible, Today's New International® Version TNIV©.

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Introduction

1.1 Background

Death comes to us all and is a socially and culturally embedded biological phenomenon. In almost all Western countries, approximately 1% of the population dies annually. At the beginning of the 20th century, death was regarded as a natural and inevitable event with a limited role for medicine and health care. Most people died from infectious diseases and the duration of the terminal disease process was usually limited. Since then, a shift has occurred in causes of death. This shift is partly the result of advances in medicine that have greatly improved the possibilities to treat seriously ill patients and to prolong life or postpone death. Infectious diseases have to a great extent been replaced by degenerative and man-made diseases, such as cardiovascular disease and cancer (Seale 2000; Wolleswinkel-van den Bosch *et al.* 1997). As a result, chronic illness with an associated prolonged period of decline is now a common trajectory of dying (Byock 2000). Such a period of decline is characterized by various symptoms and restrictions in functioning. Therefore, patients dying from chronic illnesses are often in need of symptom management and other kinds of palliative care in the last phase of life. Thus, the traditional focus of medicine on interventions and technologies aimed at prevention, cure or life-prolongation, has nowadays been completed with the recognition that symptom management and improvement of patients' quality of life are also important and worthy health care goals (Sepulveda *et al.* 2002).

1.2 Aging

The shift in causes of death has resulted in a substantial increase in life expectancy in the Netherlands, from about 71 years for men and 75 years for women in 1960, to 77 years for men and 81 years for women in 2004 (Statistics Netherlands (a)). Together with the temporary post-war rise in birth rates, the increased life expectancy has resulted in the ageing of the population in all developed countries. People over 65 are, for example, expected to represent about 24% of the population in The Netherlands in the year 2040, as compared to 14% in 2005 (Statistics Netherlands (b)). Thus, elderly people account for a large part of health care expenditures. Further, they account for the large majority of deaths nowadays (Polder *et al.* 2002; Spillman and Lubitz 2000).

During the 20th century, living arrangements have changed as a consequence of prosperity and individualisation. In developed countries, family size has decreased and a growing proportion of elderly people has been living in households separate from their children (Grundy *et al.* 2004). In the 1980s about 30% of people aged 65 and older lived alone in private households, in the UK as well as in the US (Seale 2000). Because of gender differences in life expectancy and marriage patterns (older men marrying younger women), many elderly widows are living alone toward the end of their life (Seale 2000). This also holds for cancer patients, as was shown in a study among older people with cancer in the UK (Grundy *et al.* 2004). Between 1981 and 1991, their household circumstances were very similar to those of the rest of the population of the same age, and both showed a large increase in living alone. The changing living arrangements of people have important implications for planning and provision of care for patients in the last phase of life.

1.3 Palliative care and end-of-life decision making

The origin of palliative care lies in the early 1980s, when the World Health Organization (WHO) Cancer Unit began the development of a global initiative to advocate pain relief and opioid availability worldwide (Sepulveda *et al.* 2002). The management of cancer pain was conceived as the spearhead for a comprehensive and integrated palliative care approach to be developed in the medium term. Nowadays, the WHO approach to palliative care has been extended, such that the physical, emotional and spiritual needs of the patient are all considered important concerns for palliative care (Peretti-Watel *et al.* 2005; Sepulveda *et al.* 2002). Traditionally, palliative care was perceived as being only relevant to patients not responsive to curative treatment, but in the latest WHO definition of palliative care, it is stated that the principles of palliative care should be applied as early as possible in the course of chronic, ultimately fatal disease (Sepulveda *et al.* 2002). As a patient's disease advances and there is proportionately less to offer in terms of life prolongation, the focus of care should progressively shift towards comfort and quality of life (Byock 2000).

An important issue in palliative care is the principle of proportionality. Care planning and decision-making would be guided by weighing the potential benefits of an available intervention against the risks. The values and self-defined goals of the patient, as well as his or her current quality of life form the fulcrum for this ongoing planning and decision-making process (Byock 2000).

Another important issue in palliative care is patient autonomy. In recent decades physicians' attitudes and practices have shifted towards promoting greater patient autonomy, control and participation in the medical decision-making process (Peretti-Watel *et al.* 2005). Seale (2000) has argued that this shift is closely connected with a broader tendency of late modern societies, in which individuals tend to plan and control major life events by developing a calculative attitude to the available options for action. According to Seale, the will to control one's life has also extended to the dying process, especially in developed Anglophone countries.

In the Netherlands, medical care for patients who are in the last phase of life has received much attention during the past decade. The organisation of health care services for terminally ill patients has greatly expanded during a 5-year period from 1998 through 2003, during which the government financially supported 6 university-based centres for the further development of end-of-life care (Gordijn and Janssens 2000). Several initiatives were taken to enable the fine-tuning in end-of-life care, such as developing interdisciplinary consultation facilities, case discussions for caregivers, and co-operation within regional networks of health care providers. After this 5-year period, the government took the position that, whereas death and dying are common events in human life, the provision of end-of-life care should be part of the professional skills of all physicians, including general practitioners providing end-of-life care to patients who are staying at home (Francke and Kerkstra 2000; Smeenk *et al.* 2000)

1.4 Coping with incurable disease

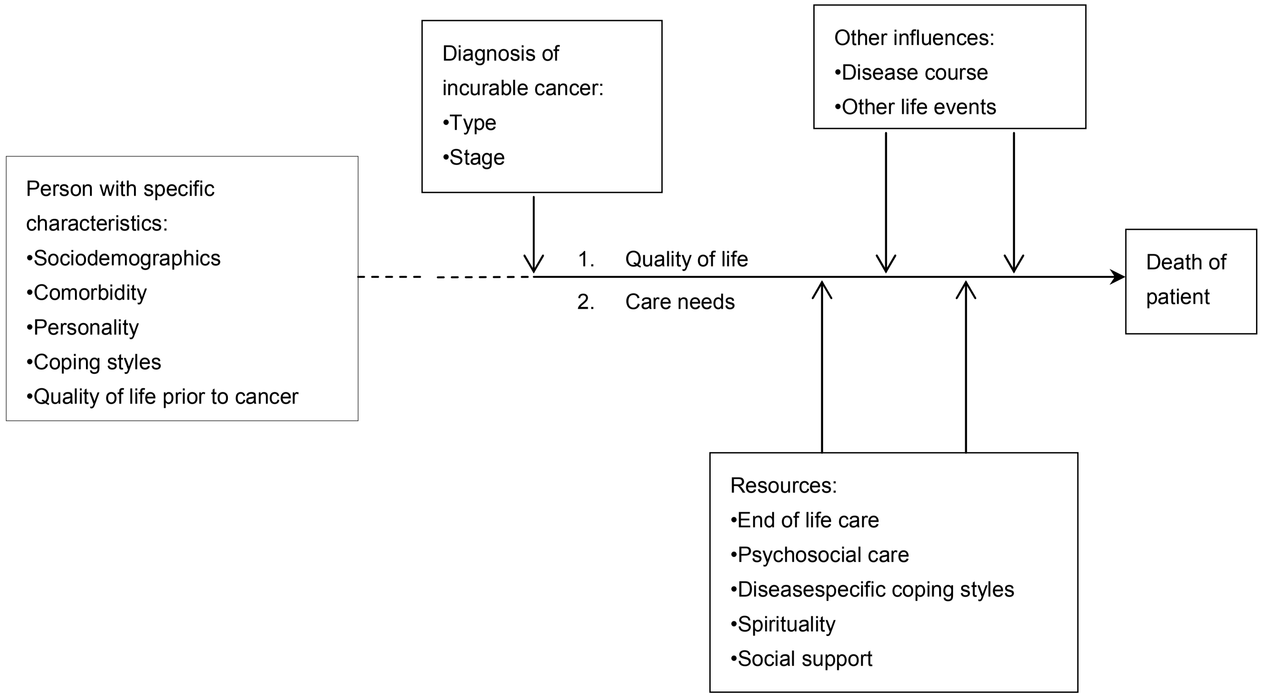
As for all types of care, palliative care is provided in interaction between caregiver and consumer of this care, that is the patient. Therefore, personal characteristics of patients should be taken into account, and need to be studied. Carl Rogers assumed that each person responds as an organised whole to reality as he or she perceives it. He emphasized self-actualisation, which he describes as an innate tendency toward growth that motivates all human behaviour (Bernstein *et al.* 1997; Rogers 1961). Many other definitions of man are available, but they have in common that individuals can be characterised by factors in which they differ, such as demographic characteristics, identity, feelings of self-efficacy and autonomy, personality, and coping styles.

Until now, no theoretical model exists that explains the impact of life-threatening diseases on people. When people are confronted with a life-threatening disease such as cancer, their situation can be described as in figure 1-1. A person with individual characteristics, personal wishes and goals is confronted with a stress-evoking event (incurable cancer). Lazarus and Folkman argue that it is important how a person perceives the stressor and that the reaction on the stressor is determined by individual characteristics and specific resources (DeLongis *et al.* 1988; Folkman *et al.* 1986). Resources, such as social support, financial resources, and medical care, can be used to cope with a life-threatening event. The characteristics of the person, the disease, and the available resources together determine the impact of the disease on a specific person, which results in specific problems and needs on physical, social, psychological and spiritual dimensions. Furthermore, the course of the disease and life events, such as the death of a spouse, influence how patients are doing in the last phase of life. In figure 1-1 the horizontal line represents a patient's quality of life and care needs over time, after he or she is diagnosed with incurable cancer and until death.

1.5 Research questions

In this thesis, we explored cancer patients' last phase of life by measuring their quality of life, their care needs, and their evaluation of medical care.

Figure 1.1 Schematic representation of the last phase of life after diagnosis of incurable cancer.



1.5.1 Quality of life of cancer patients in the last phase of life

The first part of the thesis focuses on quality of life of cancer patients in their last phase of life:

1. What are the levels of positive and negative affect in patients with incurable cancer and which psychological problems do these patients report?
2. What is the quality of life of cancer patients during their last year of life?

1.5.2 End-of-life care and medical decision making

In the second part of the thesis, four aspects of end-of-care and medical decision making will be addressed:

3. What kind of health care is provided to patients with cancer in the last phase of life in different settings, and how do patients appreciate this care?
4. What are the attitudes of cancer patients toward medical treatment, and how are these attitudes related to advance initiatives to participate in medical decision-making concerning their own end of life?
5. What are the care needs of cancer patients in their last phase of life?
6. Which patients are dying in an institution and which patients are dying at home, and is the place of death related to patients' symptoms, characteristics of the dying process, and satisfaction with care?

1.6 Method of the study

To answer these research questions we followed a cohort of 128 patients with incurable breast cancer, colorectal cancer, ovary cancer, lung cancer or prostate cancer, during the last stage of their lives. Oncologists, pulmonologists, urologists and radiotherapists in the south and south-western part of the Netherlands invited outpatients to participate in the study. Patients were included within two months of being informed that their cancer was probably incurable. All participants have given their written informed consent.

The patients filled out a written questionnaire that addressed demographic factors, problems and care needs in several domains, and psychological status. Patients were also interviewed personally at home. The interview addressed cancer therapy, contacts with health care professionals, satisfaction with care, and patients' attitudes toward treatment and initiatives to anticipate medical decision-making at the end of life. Further, several factors that might be related to health care and quality of life in the last phase of life were addressed, such as coping styles, social support, and meaningfulness. During follow-up, patients filled out a written questionnaire every 3 months. Most topics that were addressed at inclusion were repeated every 3 or every 6 months.

Shortly after inclusion of a patient, a relative of the patient was asked to participate in the study and fill out a short questionnaire about socio-demographic characteristics and quality of life. When patients died during the research period, we asked these bereaved relatives to participate in a personal interview at home 3 months after the death of the patient. Personal characteristics of the bereaved relatives, such as age, and relationship with the patient were included in the interview. Further, contacts with health care professionals, cancer therapy, patient's satisfaction with care, and problems in end-of-life care during the 3 months before death were assessed. Additional data on the medical treatment of the patients who died were collected in written questionnaires that were sent to the attending clinical specialist and the patient's general practitioner.

1.7 Outline of this thesis

In chapters 2 and 3 we address the first subject of the thesis, the quality of life of incurable cancer patients. **Chapter 2** focuses on the psychological status and affect of cancer patients after they have heard a diagnosis of incurable cancer. Further, the provision of and need for psychosocial care are addressed. **Chapter 3** describes the quality of life of cancer patients during their last year of life. Chapters 4, 5, 6 and 7 concern the second subject of this thesis, end-of-life care and medical decision making. **Chapter 4** reviews which health care interventions are provided to cancer patients in the last phase of life, their evaluation of care, and their additional care needs. **Chapter 5** presents the attitudes of cancer patients toward medical treatment and the engagement in advance initiatives to participate in medical decision-making concerning their own end of life. **Chapter 6** describes the need for information of cancer patients in their last phase of life. Finally, **chapter 7** explores whether patients' symptoms, characteristics of the dying process, and satisfaction with care are related to the place of death. The final part of the thesis consists of a general discussion of the findings of the study (**chapter 8**) and a summary of these findings.

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2

Positive and negative affect after diagnosis of advanced cancer

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Abstract

Anxiety and depression are studied thoroughly in patients with advanced cancer. However, little is known about the nature of mood disorders in this stage of the disease. We studied positive and negative affect in patients who have heard a diagnosis of advanced cancer, and examined how these are related to anxiety and depression, and to other patient and care factors. One hundred and five patients filled out a written questionnaire and were interviewed personally. The PANAS positive affect scores were lower than those in the general population, but the negative affect scores were fairly similar. We found a rather low prevalence of depression (13%) and anxiety (8%) as measured by the HADS. The emotional problems patients mentioned most frequently were anxiety about metastases (26%), the unpredictability of the future (18%) and anxiety about physical suffering (15%). Both positive and negative affect were most strongly related to patient's sense of meaning and peace. We conclude that distinguishing positive and negative affect enhances the understanding of psychological distress of patients with advanced cancer, that seems to be mainly caused by low levels of positive affect. Several theories are discussed to explain this finding, that may contribute to efforts to improve care for these patients.

Introduction

The psychological distress experienced by cancer patients has been studied thoroughly in various stages of the disease (Hagedoorn *et al.* 2000; Northouse *et al.* 2002; Ritterband and Spielberger 2001; Schnoll *et al.* 1998; Van't Spijker *et al.* 1997). For example, while meta-analysis showed that cancer patients were more depressed than the general population, there were no differences between cancer patients and the general population with respect to anxiety and psychological distress (Van't Spijker *et al.* 1997). In patients with a prognosis of six months or less, the prevalence of depression according to the International Classification of Diseases 10 criteria was 22% (Lloyd-Williams and Friedman 2001). Some studies focused on psychological distress during the course of the disease (Hanson Frost *et al.* 2000; Hwang *et al.* 2003; Kurtz *et al.* 2002; Northouse *et al.* 2002; Tattersall *et al.* 2002). Hwang *et al.* (2003) have shown that the psychological distress increases significantly in the last two or three months before death, especially in the last month of life. A longitudinal study in geriatric patients with lung cancer showed lower social functioning and more severe physical symptoms to be predictors of depression (Kurtz *et al.* 2002). Furthermore, patients who had received radiotherapy in the last 40 days were less depressed than those who had not received it.

Most studies have focused on measuring psychological distress in terms of anxiety, depression, or psychological distress in general; less attention has been paid to the levels of negative or positive feelings. In psychological theory, positive and negative affect have been recognized as separate axes of psychological well-being, a fact that has led to the development of new instruments such as the Positive and Negative Affect Schedule (PANAS) (Peeters *et al.* 1996; Watson *et al.* 1988). These axes are independent, and they are related to personality characteristics (Watson *et al.* 1988). In recent theories and physioneurological research the concept of positive and negative affect appeared fruitful as well (Carver *et al.* 1999; Zelenski and Larsen 1999).

Anxiety and depression on the one hand, and positive and negative affect on the other are correlated. Negative affectivity has been found to be related to both anxiety and depression, while the absence of positive affect is related more strongly to depression (Boon and Peeters 1999). However, whereas depression in psychiatric patients was found to be associated both with higher scores on negative feelings and lower scores on positive feelings, Ritterband showed that cancer patients had a lower level of positive feelings than healthy controls, while no differences were found for negative feelings (Boon and Peeters 1999; Ritterband and Spielberger 2001). It is unknown whether the diagnosis of depression in patients with advanced cancer is also predominantly related to a low positive affect, and not to a high negative affect.

The aim of this article is to assess the levels of positive and negative affect in patients with advanced cancer. Furthermore, we examined how affect is related to other psychological distress measures, such as anxiety and depression. To identify the factors related to positive and negative affect, we studied the relationships between positive and negative affect on the one hand, and the type of cancer, patient characteristics and care factors on the other.

Methods

Sample

Thirty-six oncologists, pulmonologists and urologists in the south-western Netherlands asked outpatients with breast cancer, colorectal cancer, ovarian cancer, lung cancer or prostate cancer to participate in the study. Patients were included within two months of being informed that their cancer was at an advanced stage. We defined criteria for each type of cancer in order to include an unselected group in whom the survival was expected to be less than one year in the majority of cases (see Box 1) (Tumorregistry Munich). Patients were included only after they had given their written informed consent.

The questionnaire

The patients filled out a written questionnaire that addressed demographic factors (age, sex, marital status, education, religion, net (family) income and type of health insurance), and psychological status. Affect was measured by the Positive and Negative Affect

Box 2-1. Inclusion criteria

Type of cancer	This disease stage had been established for at most 2 months ago
Breast cancer	– metastases at a distance at the first appearance of the disease – or metastases at a distance in at least two organ sites after primary treatment
Colorectal cancer	– the primary tumor could not be removed by surgery – or metastases at a distance (without options of curative surgery) – or local recurrence of the tumor
Ovarian cancer	– recurrence
Lung cancer	– metastases at a distance – or local extension of the disease without curative options
Prostate cancer	– the level of prostate specific antigen (PSA) was higher than 20 ng/ml and increasing

Schedule (PANAS) (Peeters *et al.* 1996; Watson *et al.* 1988). The PANAS contains two subscales, each consisting of ten items: Positive Affect (PA) and Negative Affect (NA). PA reflects the extent to which a person feels enthusiastic, active, and alert. A high PA score reflects a state of high energy, full concentration, and pleasurable engagement. In contrast, NA is a general dimension of subjective distress subsuming a variety of aversive mood states, and a high NA score indicates more distress. Patients were instructed to indicate how they had been feeling during the last two weeks. Patients' scores were compared to scores of a Dutch normative sample for the PANAS (Peeters *et al.* 1996). This sample consisted of 382 healthy persons aged between 24-82 years (mean age: 53 years). While PA and NA were not related to age or education level, women scored higher on NA than men, whereas no difference on PA was found for sex. Therefore, separate NA norm scores were calculated for men and women.

We used four instruments to assess other measures of psychological distress: 1. the Problems and Needs in Palliative Care (PNPC) questionnaire, which measures how often patients experience various emotional problems and problems with relationships (Osse *et al.* 2002); 2. the emotional functioning scale of EORTC QLQ C30 (Aaronson *et al.* 1993; Kaasa *et al.* 1995) consisting of four items, in which a high score indicates better emotional functioning; 3. the Hospital Anxiety and Depression Scale (HADS) (Zigmond and Snaith 1983; Spinhoven *et al.* 1997), which assesses Anxiety and Depression; and, 4. one item of Euroqol-5D measuring mental health problems (The EuroQol Group, 1990). The three latter instruments are often used in cancer research, and were included to allow comparison of our patient group with other populations (Fayers *et al.* 1998; Hotopf *et al.* 2002).

The interview

Patients were also interviewed personally at home. The interviewers were prepared for interviewing patients with advanced cancer during a two-day course in interview techniques. Validated instruments were used in the interview whenever possible. The interview addressed the use of psychosocial care, including informal care received from relatives or friends, and formal care received from health care professionals: several types of psychosocial care were listed and patients had to indicate whether they had received those types of care. Psychosocial care needs were measured by asking the patients whether they needed (additional) care for the emotional problems or problems with relationships that were assessed in the PNPC questionnaire. The need for information was also investigated.

The interview also addressed factors that might be related to positive and negative affect. Both the anti-tumor treatment the patient had received and planned anti-tumor treatment, including surgery, chemotherapy and radiotherapy, were registered. The EORTC QLQ C30 (Aaronson *et al.* 1993; Kaasa *et al.* 1995) was used to measure quality of life. Spiritual well being was measured by the FACIT-Sp, which consists of two scales, one measuring 'sense of meaning and peace', and the other assessing the role of faith in illness (Brady *et al.* 1999; Peterman *et al.* 2002). Disease-specific coping was operationalized by the adapted Utrecht Coping Checklist (Sanderman and Ormel 1992; Schreurs *et al.* 1993), in which we reformulated the introduction to the items to focus more on patient's current style of dealing with (advanced) cancer and disease related problems (Oldehinkel *et al.* 1992). Social support was measured on a four-point Likert scale by asking how much support patients received from relatives and friends (De Haes, 1988). The reliabilities of the questionnaires mentioned above ranged from moderate to good; Cronbach's alpha's ranged from 0.58 to 0.90.

Statistical analysis

The research protocol was approved by the Medical Ethical Committee of Erasmus MC University Medical Center Rotterdam. To analyze the data we used the Statistical Package for the Social Sciences (SPSS) version 10.0. The occurrence of psychological problems, use of health care and care needs are presented in frequency tables. Pearson's correlations, student's t-test and analysis of variances were used to test the statistical significance of relationships between psychological status and type of cancer, patient and care factors. Sequential linear regression analysis was used to determine the contribution of different factors to the level of positive and negative affect. Firstly, demographic factors were entered, followed by type of cancer and treatment. Thirdly, symptoms and functioning were entered, followed by coping style and support. Finally, the spirituality-scales were entered in the regression analyses.

Results

Patients characteristics

Of 165 identified subjects, 6 had died before an interview could take place. Of the 159 eligible patients, 105 agreed to participate (response rate: 66%). Reasons not to participate were: participation was expected to be too burdensome (n=28), patients had a poor physical condition or comorbidity (n=11). In 15 cases the reason was unknown.

Compared to those who did not participate, patients who participated were younger (mean age was 63.0 vs. 66.4 years; p= 0.04) and had received chemotherapy more often (70% vs. 55%; p= 0.03). There were no statistically significant differences between the participants and non-participants regarding sex, primary diagnosis, metastases, comorbidity, radiotherapy or surgery.

Biographical and disease-specific characteristics of patients with different types of cancer are described in table 2-1. The mean age of participating patients was 63.0 years; the mean length of disease was 21.6 months. Women with breast cancer were relatively

Table 2-1. Characteristics of the patient (N=105)

	Breast cancer (N= 30)	Lung cancer (N= 34)	Other type of cancer[a] (N= 41)	Total (N= 105)	p-value
Biographical characteristics					
Age (years)					
Mean (SD)	56.4 (1.2)	64.0 (9.5)	66.9 (9.1)	63.0 (10.7)	0.000
Length of disease (months)					
Mean (SD)	42.3 (37.0)	7.2 (25.7)	18.3 (23.8)	21.6 (31.7)	0.000
	N (%)	N (%)	N (%)	N (%)	
Sex					
Male	--	26 (77)	21 (51)	47 (45)	0.032 [b]
Female	30 (100)	8 (24)	20 (49)	58 (55)	
Living					
With partner	23 (77)	27 (79)	30 (73)	80 (76)	0.82
Without partner	7 (23)	7 (21)	11 (27)	25 (24)	
Education					
High[c]	8 (27)	7 (21)	16 (39)	31 (30)	0.23
Low[d]	22 (73)	26 (79)	25 (61)	73 (70)	
Net (family) income per month					
Less than EUR 1360	11 (42)	11 (39)	18 (50)	40 (44)	0.67
More than EUR 1360	15 (58)	17 (61)	18 (50)	50 (56)	
Health insurance					
Public health insurance	17 (57)	17 (52)	23 (58)	57 (55)	0.86
Private insurance	13 (43)	16 (49)	17 (43)	46 (45)	
Religious beliefs					
No	12 (40)	14 (41)	16 (39)	42 (40)	0.98
Yes	18 (60)	20 (59)	25 (61)	63 (60)	
Diseasespecific characteristics					
Had received anti-tumor therapy					
Surgery	25 (83)	5 (15)	24 (59)	54 (51)	0.000
Chemotherapy	26 (87)	31 (91)	34 (83)	91 (87)	0.58
Radiotherapy	18 (60)	4 (12)	4 (10)	26 (25)	0.000
None	0 (0)	2 (6)	1 (2)	3 (3)	0.36
Planned anti-tumor therapy					
Surgery	1 (3)	2 (6)	4 (10)	7 (7)	0.55
Chemotherapy	21 (70)	20 (59)	20 (49)	61 (58)	0.20
Radiotherapy	4 (13)	12 (35)	2 (5)	18 (17)	0.002
None	6 (20)	4 (12)	16 (37)	25 (24)	0.04

[a] 22 patients with colorectal cancer, 12 with ovarian cancer and 7 with prostate cancer

[b] Only patients with lung cancer or other type of cancer are included in the Chi-square test.

[c] Higher secondary general education, intermediate or higher vocational education, university

[d] Lower vocational, lower secondary general education or primary school

Table 2-2. Psychological distress, care and care needs after diagnosis of advanced cancer

	N	M (SD)
PANAS – positive affect (range 10-50)	103	27.7 (7.8)
PANAS – negative affect (range 10-50)	105	17.6 (5.9)
		N (%)
Positive affect	103	
Very high / high		11 (11)
Above average / average / below average		29 (28)
Low / very low		63 (61)
Negative affect	105	
Very high /high		16 (15)
Above average / average / below average		56 (54)
Low /very low		33 (31)
		M (SD)
EORTC – emotional functioning (range 0-100)	104	80.8 (21.2)
HADS-anxiety (range 0-21)	105	4.8 (3.7)
HADS-depression (range 0-21)	105	5.2 (4.4)
Euroqol – mental health (range 1-3)	105	1.39 (0.53)
		N (%)
Emotional problems (PNPC)	104	
Fear of metastases		27 (26)
Unpredictability of the future		19 (18)
Fear of physical suffering		16 (15)
Loss of control over own body		11 (11)
Other emotional problems		31 (30)
Often suffering from one or more emotional problems		53 (51)
Problems with relationships	105	
Often suffering from one or more problems with relationships		19 (18)
Care use	104	
Informal care		67 (64)
Formal care		20 (19)
Total		71 (68)
Care needs	104	
Emotional problems		7 (7)
Problems with relationships		3 (3)
Total		9 (9)
Need for more information	101	43 (43)

young; in breast cancer the duration of disease was relatively long. Of all patients, 45% were male, and 76% were living with a partner. Educational level was high in 30%, while 56% had a net family income of more than EUR 1360 per month. All patients had health insurance, 45% privately. More than half held religious beliefs. Most had received chemotherapy, half had undergone surgery, while about a quarter had received radiotherapy. Three patients had received no anti-tumor treatment at all.

Psychological distress and psychosocial care

Table 2-2 gives an overview of the psychological distress scores and care needs of patients with different types of cancer. The mean PANAS positive affect score for the whole group was 28 and the mean negative affect score was 18. The scores on positive and negative affect were classified according to the norm scores of the PANAS (Peeters *et al.* 1996). Sixty-one percent scored low or very low on positive affect, while only 16% scored high or very high on negative affect. Of all patients, 18% had problems with their personal relationships. Only 8% of all patients had a HADS anxiety score above 10, which is often considered to be the cut-off score for anxiety; and 13% had a HADS depression score of more than 10, indicating that they were probably depressed. The mean score for mental health on the Euroqol-5D for the whole group was 1.4. The emotional problems patients mentioned most frequently concerned fear of metastases (26%), the unpredictability of the future (18%), fear of physical suffering (15%), and the loss of control over their own body (11%). Six percent of all patients reported being afraid of death often, and 40% that they were sometimes afraid of death.

The HADS depression-score was negatively related to positive affect and positively related to negative affect, while the HADS anxiety-score was less strongly related to positive affect and rather strongly positively related to negative affect (see table 2-3). Emotional functioning on the EORTC QLQ-C30 showed a weak positive relation to positive affect and a strongly negative correlation with negative affect. Mental health score on the Euroqol-5D was negatively but weakly related to positive affect and showed strong positive association with negative affect. These relationships show that the EORTC QLQ-C30 and the Euroqol-5D predominantly measured negative affect. The HADS Anxiety and Depression scales were highly related to each other ($r=0.65$, $p<0.001$). The PANAS Positive Affect and Negative Affect scales were constructed to be independent factors (Watson *et al.* 1988). In the current study the scales were slightly negatively related to each other ($r=-0.23$, $p=0.02$).

While 64% of all patients reported receiving emotional support from their family, only 19% received professional psychosocial care; and while 9% expressed a need for additional psychosocial support, 43% reported a need for more information, especially concerning food, the causes of cancer, euthanasia, alternative medicine and complementary forms of care.

Table 2-3. Associations between various measures of psychological distress

	Positive affect (N=103)	Negative affect (N=105)
	r	r
HADS-anxiety	-0.38**	0.72**
HADS-depression	-0.62**	0.48**
EORTC – emotional functioning	0.27*	-0.69**
Euroqol – mental health	-0.28*	0.63**

* p<0.01; ** p<0.001

Factors related to positive and negative affect

To determine which factors were related to positive and negative affect, we examined univariate and bivariate relationships between positive and negative affect on the one hand, and patient characteristics and care factors on the other (table 2-4). Less positive feelings were experienced by patients who were older, male, and had a low net income, and by patients for whom surgery was planned. Positive affect was also negatively related to higher levels of fatigue and to lower physical, cognitive and role functioning. Furthermore, less positive feelings were reported by patients who had lower scores for problem-focused coping strategies, that is, patients who did not search actively for solutions for their problems.

More negative feelings were experienced by younger patients, by those who had a low net income, and by patients for whom surgery was planned. Negative affect was also related to relatively high levels of pain or fatigue, and lower levels of physical, cognitive and role functioning. Furthermore, more negative feelings were reported by patients who applied emotion-focused coping strategies, that is, reducing stress by expressing emotions and by searching social support.

We selected 11 and 10 variables, respectively, that contributed bivariately ($p<0.05$) to positive and negative affect to be entered in a regression analysis as potential predictors. Although net income was related to affect, we did not enter it into the multivariate analyses, because of missing values for 15 patients. In the Netherlands, the type of health insurance is directly related to net income (Chi-square: $p=0.011$). By entering the form of health insurance into the multivariate analysis for negative affect, the contribution of net income could partly be substituted.

First, we entered age and sex into the regression model, which showed that positive affect was lower in older patients and in men. In the second step, the level of PA was found to be lower for patients for whom surgery was planned. In the third step, symptoms and functioning were not related to PA. In the fourth step, problem-focused coping was positively related to PA, while entering coping decreased the contribution of age. Finally, entering spirituality showed that meaningfulness contributed to PA, while the

Table 2-4. Factors related to positive and negative affect

	Positive affect (N=103)		Negative affect (N=105)	
	r	p-value	r	p-value
Age (years)	-0.32	0.001	-0.22	0.03
Length of disease (months)	0.06	0.58	0.08	0.40
	M (SD)	p-value	M (SD)	p-value
Type of cancer				
Breast cancer	30.0 (7.4)	0.12	19.2 (5.4)	0.08
Lung cancer	27.5 (8.2)		17.9 (6.7)	
Other type of cancer	26.1 (7.5)		16.1 (5.4)	
Sex				
Male	25.7 (8.3)	0.02	16.6 (5.8)	0.12
Female	29.4 (7.0)		18.4 (6.0)	
Living				
With partner	28.0 (7.7)	0.42	18.1 (6.2)	0.12
Without partner	26.5 (8.3)		16.0 (4.6)	
Education				
High[a]	27.8 (7.8)	0.90	16.2 (5.2)	0.12
Low[b]	27.6 (7.9)		18.2 (6.2)	
Net (family) income per month				
Less than EUR 1360	25.3 (7.2)	0.03	19.8 (6.9)	0.003
More than EUR 1360	29.0 (8.4)		16.1 (4.9)	
Health insurance				
Public health insurance	27.5 (7.6)	0.64	19.2 (6.6)	0.002
Private insurance	28.2 (8.2)		15.8 (4.3)	
Religious beliefs				
No	28.8 (8.6)	0.25	17.8 (6.7)	0.77
Yes	27.0 (7.2)		17.4 (5.4)	
Planned anti-tumor therapy				
Surgery	22.0 (6.0)	0.04	23.3 (7.6)	0.008
No surgery	28.1 (7.8)		17.2 (5.6)	
Chemotherapy	27.5 (6.6)	0.80	18.3 (6.5)	0.15
No chemotherapy	28.0 (9.3)		16.6 (4.9)	
Radiotherapy	30.2 (8.9)	0.14	15.9 (5.9)	0.18
No radiotherapy	27.2 (7.5)		17.9 (5.9)	
No anti-tumor therapy is planned	28.3 (8.6)	0.66	16.4 (4.8)	0.24
Anti-tumor therapy is planned	27.5 (7.6)		18.0 (6.2)	

Table 2-4. Factors related to positive and negative affect (continued)

	Positive affect (N=103)		Negative affect (N=105)	
	r	p-value	r	p-value
Pain (Eortc)	-0.13	0.18	0.20	0.04
Fatigue (Eortc)	-0.23	0.02	0.22	0.02
Physical functioning (Eortc)	0.26	0.01	-0.28	0.005
Role functioning (Eortc)	0.21	0.04	-0.25	0.01
Cognitive functioning (Eortc)	0.28	0.01	-0.27	0.006
Social functioning (Eortc)	0.08	0.42	-0.16	0.10
Social support	0.22	0.03	0.05	0.63
Coping strategies				
Problem-focused coping	0.30	0.003	0.02	0.86
Emotion-focused coping	0.14	0.17	0.30	0.002
Distraction / stress reduction	0.14	0.18	-0.13	0.18
Spirituality				
Sense of meaning and peace	0.43	0.000	-0.39	0.000
Role of faith in illness	0.29	0.003	0.05	0.65

[a] higher secondary general education, intermediate or higher vocational education, university

[b] lower vocational, lower secondary general education or primary school

contribution of problem-focused coping decreased. Table 2-5 shows the parameters of the regression model after this final step.

We used the same procedure for NA. Age was not related to NA, while having public health insurance was associated with higher levels of NA. Patients who had to undergo surgery had higher levels of NA, while symptoms and functioning were not related to NA. Entering symptoms and functioning in the model decreased the contribution of 'planned surgery' to NA. In the fourth step, emotion-focused coping was not related to NA. Finally, the fifth step showed that NA was higher in patients who had problems with meaningfulness (table 2-5).

In conclusion, these regression analyses showed that PA scores were lower in patients who were older, male, patients who did not apply problem-focused coping styles, patients for whom surgery was planned, and patients who had a low sense of meaning and peace. NA scores were higher in patients with public health insurance, in patients for whom surgery was planned, and in patients who had a low sense of meaning and peace.

Table 2-5. Multiple regression analyses: factors related to positive and negative affect

	Standardized ß	t	p-value	Adjusted R^2
Factors related to positive affect				
Model 5				0.35
Constant		1.27	0.21	
Demographic factors				
Age	-0.20	-1.94	0.06	
Sex [a]	0.21	2.29	0.03	
Treatment				
Surgery is planned	-0.22	-2.40	0.02	
Symptoms and functioning				
Fatigue	-0.12	-0.85	0.40	
Physical functioning	-0.00	-0.04	0.97	
Role functioning	0.04	0.30	0.77	
Cognitive functioning	0.15	1.53	0.13	
Coping and social support				
Problem-focused coping	0.15	1.61	0.11	
Social support	0.08	0.82	0.41	
Spirituality				
A sense of meaning and peace	0.23	2.33	0.02	
Role of faith in illness	0.11	1.15	0.25	
Factors related to negative affect				
Model 5				0.26
Constant		4.46	0.000	
Demographic factors				
Age	-0.14	-1.43	0.16	
Type of health insurance [b]	-0.20	-2.16	0.03	
Treatment				
Surgery is planned	0.18	1.75	0.08	
Symptoms and functioning				
Pain	0.07	0.57	0.57	
Fatigue	-0.07	-0.43	0.67	
Physical functioning	-0.14	-1.04	0.30	
Role functioning	-0.03	-0.21	0.83	
Cognitive functioning	-0.06	-0.61	0.55	
Coping				
Emotion-focused coping	0.14	1.35	0.18	
Spirituality				
A sense of meaning and peace	-0.28	-2.71	0.01	

[a] male= 0, female= 1.

[b] public health insurance= 0, private insurance= 1.

Discussion and conclusion

In this study the PANAS positive affect scores of patients with advanced cancer were lower than those of the general population, whereas the negative affect scores were fairly similar to scores in the general population (Peeters *et al.* 1996). Mood disorders such as anxiety and depression in patients with advanced cancer may be predominantly related to the absence of positive feelings and not, as in psychiatric depression and anxiety (Boon and Peeters 1999), to a high level of negative feelings. This would be in agreement with the findings of Ritterband et al, who found that depression in cancer patients was due predominantly to a decreased level of positive feelings (Ritterband and Spielberger 2001). We found an association between positive affect and anxiety. In the study of Boon *et al.* (1999) positive affect was lower in patients with a primary diagnosis of depression as compared to patients with a primary diagnosis of anxiety. This is consistent with our finding that positive affect is more strongly related to depression than to anxiety. Furthermore, the found relationship between positive affect and anxiety may be due to the highly interrelatedness of depression and anxiety in our patient group ($r=0.65$, $p<0.001$). In this group of patients with advanced cancer, we found a rather low prevalence of depression and anxiety as measured by the HADS and rather high scores on the EORTC scale of emotional functioning. Reference values for EORTC emotional functioning of this group of patients range from 65 to 75, depending on the type of cancer. This is somewhat lower than the score of 81 found in this study (Fayers *et al.* 1998). A review study showed that the HADS gave a median prevalence of 'definite depression' of 29% in patients with advanced cancer (Hotopf *et al.* 2002). In the current study, however, this prevalence was only 13%. We therefore suggest that instruments that measure depression or anxiety levels mainly by focusing on negative feelings may miss mood disorders in advanced cancer patients.

Thus, to understand the level and nature of psychological distress that is experienced by patients with advanced cancer, it is important to differentiate between the absence of positive affect and the presence of negative affect. The difference found here, may be considered from the viewpoint that positive and negative emotions are related to different, neurophysiologically distinct motivational systems. Carver *et al.* (1999) and Gray (1981; 1987) argue that positive emotions are predominantly related to Behavioral Approach Systems in humans (our pursuing goals, interests, drive in life and fun seeking) and that negative emotions, in particular anxiety, are related to a different, older Behavioral Inhibition System: a protective system that keeps us 'out of danger' by refraining from behavior that endangers our chances of survival. Lack of positive emotions, in particular depressed mood, would be related to failure to engage in meaningful activity (self-expression), whereas negative emotions, in particular anxiety and stress, are related to perceived failure at self-protection. In view of the adverse medical situation of the advanced cancer patient, dwindling cognitive and social functioning, and the cessation of meaningful activity are likely to be present on a daily basis (perceived approach systems failure). Perception of immediate threat and inescapable danger may, on the other hand, be mainly experienced in relation to disease related events (e.g. to invasive actions such as surgery), and play a less constant role in daily life.

Another explanation of the levels of positive and negative affect may be that, as a consequence of the condition, affect as such is flattened. A generally low physical activation level may dampen both ones ability to become enthusiastic (positive affect) about something *and* ones ability to get 'worked up' about things (negative emotionality). This may explain why the differences with the general population are mainly to be found in the positive area: patients are simply too tired to maintain high levels of stress. The flattened affect could also be caused by a post-traumatic reaction to the diagnosis of advanced cancer. Although only a minority of cancer survivors is formally diagnosed with cancer-related Post Traumatic Stress Disorder (PTSD), sub-threshold reports of PTSD symptoms are more common (Cordova *et al.* 2000). The loss of interest and emotional numbing may also have contributed to low levels of positive and negative affect.

In the univariate and bivariate analyses low positive and high negative affect were related to more fatigue, and to low levels of physical and role functioning and meaningfulness, which is in accordance with other studies (Kallich *et al.* 2002; Clark and Watson 1988; Watson *et al.* 1988). The relatively low positive affect scores and high negative affect scores in patients with a low sense of meaning and peace may be explained by the construction of the FACIT-Sp. The items of this questionnaire may not only measure meaningfulness, but may contain elements of positive affect (pleasant vs. unpleasant) and negative affect (aroused vs. quiet) (Larsen and Diener 1992). The association between physical functioning and affect could be explained by the fact that distress might be caused by boredom, resulting from the absence of activities or sensory inputs (Passik, 2003). However, in the multivariate analyses, only meaningfulness was related to positive and negative affect. This may be caused by the significant correlations between meaningfulness on the one hand, and fatigue (r=0.28; p=0.005), physical functioning (r=0.20; p=0.04) and role functioning (r=0.28; p=0.007) on the other hand: fatigue and physical restrictions may lead to the inability to be engaged in activities, which may cause boredom and loss of meaningfulness, resulting in distress. This is in accordance with a qualitative study by Krishnamany (2000) in which fatigue was found to be an expression of a lack of meaningfulness in life.

In patients who have heard a diagnosis of advanced cancer, we found problem-focused coping to be more favorable than emotion-focused coping, consistent with other studies (Brennan, 2001; Schnoll *et al.* 1998). This is in accordance with the finding of Van 't Spijker (2001) that an active coping style is related to lower psychological distress, especially in the diagnostic phase. However, later on in the course of the disease, active coping appeared to be less favorable. During the diagnostic phase, patients have to cope with the uncertainty of the future. An active stance towards the situation may help them to solve problems and give the patients a feeling of control. When cancer develops into an advanced stage and death is nearing, patients have to adapt to a changed life perspective. In this latter stage, active coping to solve problems is nearly futile. This finding is consistent with Brandtstädter's distinction between assimilation and accommodation (Brandtstadter and Renner 1990; Schmitz *et al.* 1996). Assimilative coping involves, similar to active coping, active attempts to alter unsatisfactory life circumstances and situations in order to get the previous life situation back, while accommodative coping is directed towards revision of self-evaluative and personal goal standards in order to adapt to the current life. Assimilative and accommodative modes of coping are not mutually exclusive but may operate simultaneously in concrete situations, and individual differences exist in the degree to which a person engages in assimilative and accommodative modes of adaptability. When goals are no longer perceived to be attainable, accommodative coping seemed to function as a protective resource, like has been demonstrated in patients with chronic pain (Schmitz *et al.* 1996).

The distinct patterns for positive and negative emotionality are also relevant to caregivers. Most of the patients in our study received informal support from relatives and friends, and a minority received professional support. A small percentage of all patients reported a need for additional support. The high percentage of patients who had low scores on the PANAS positive affect scale, however, suggests that this patient group experiences a considerable amount of psychological suffering, although this suffering does not fulfil classical criteria for depression or anxiety. Whether or not this suffering may be relieved by offering patients additional forms of informal or formal care cannot be concluded from our study. Our data suggest, however, to offer especially psychosocial support to patients who have to undergo surgery, because of high levels of negative affect in those patients. Furthermore, it seems important to find out what activities were important for a patient, and help them to hold on their meaningful activities as much as possible. For example, when it is important for a woman to walk the dog, devices like a wheelchair may facilitate this activity. Furthermore, when some activities become impossible, patients and their caregivers may look for other activities that can be meaningful.

It has to be taken into account that in this study, we tested a large number of associations, because our study concerned a largely unexplored field. Bonferroni's correction results, in the current analysis, in a more stringent criterion for significance of 0.002. However, application of the Bonferroni correction increases the chance of making a type 2 error, that is, no effect or difference is found, while in fact there is an effect (Uitenbroek, 1997). The regression analyses were performed on a rather small sample size and included many variables. Multiple testing may result in overestimation of significance of the associations reported (e.g. in table 2-4), and we must be cautious with regard to interpretation of the current results as 'proof'. Although many of the associations found here are in line with findings in studies in other fields, further research, targeting these variables more explicitly, may shed further light on the robustness of the current findings.

While these data have given more insight into the psychological status of patients shortly after their cancer has developed to an advanced stage, this study has some limitations. First, this group of patients was a selected group, mainly because patients whose health status was very poor and those who died shortly after the diagnosis of advanced cancer could not be interviewed. Second, most patients who declined to participate did not want to talk about their disease because it would have been too burdensome. Our findings may therefore underestimate the level of psychological distress among patient with advanced cancer. Third, the number of patients was limited by the fact that, at this stage of cancer, it is difficult to include patients and ask them to be interviewed and fill out a questionnaire. The number of patients who did nonetheless respond should therefore be considered as a great gift.

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3

Quality of life, functioning and symptoms of cancer patients during the last year prior to death: a prospective study

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Submitted

Abstract

Purpose: When cancer has advanced to a stage in which cure becomes very unlikely, quality of life becomes an important goal of treatment. We studied the quality of life of cancer patients during their last year of life.
Methods: We studied the quality of life of cancer patients during the last year prior to death, by assessing their functioning and symptoms. Every three months, 128 patients with incurable lung, breast, ovarian, colorectal, or prostate cancer filled out a questionnaire about their functioning and symptoms. Further, patient characteristics that may determine functioning and symptoms were assessed. Ninety-nine patients had filled out one or more questionnaires in the last year prior to death.
Results: During the last year of life, most functioning and symptoms scales deteriorated gradually. This deterioration was most outspoken in the last months of life. Our data give no indication of differences between various types of cancer, except that dyspnoea was typical for lung cancer. Patient characteristics did not seem to determine the functioning and symptoms in the last months prior to death. Functioning and symptoms scores in these last months were strongly related to functioning and symptoms scores at the previous measurement.
Conclusions: We conclude that the last year of life of patients with different types of cancer can be characterized by a gradual deterioration in functioning and symptoms with a steeper decline in the last months. Patient characteristics could not predict functioning and symptoms in the last months of life.

Introduction

Cancer is one of the most common causes of death in the western world (WHO Mortality Database). Despite modern treatment advances, approximately 50% of all cancer patients die from their disease (Jordhoy *et al.* 2001a). Traditionally, cancer research is predominantly aimed at finding opportunities to cure patients and to prevent mortality from cancer. Therefore, the disease course after curative treatment has failed is relatively underexposed. People dying of cancer often go through a, sometimes protracted, last phase of life. Although medical treatment cannot realise cure in this stage of the disease, it can play an important role in symptom relief and in the improvement of the patients' quality of life.

Knowledge about quality of life, functioning and symptoms of cancer patients who are in the last phase of life comes predominantly from studies with a cross-sectional design (Osse *et al.* 2005; Stromgren *et al.* 2002). Patients with advanced cancer have been shown to experience a broad variety of symptoms, such as fatigue, pain, loss of hair, shortness of breath, sleeping problems and poor physical functioning (Osse *et al.* 2005; Stromgren *et al.* 2002). The longitudinal course of symptoms and quality of life has also been investigated, especially in studies in which quality of life is examined as an outcome of a specific treatment (Homs *et al.* 2004; Jordhoy *et al.* 2001a). These treatment evaluations often concern selective groups of patients. Therefore, the results cannot be generalised to the whole population of patients dying from cancer. Furthermore, most patients in these studies are not followed until death.

Few longitudinal studies have focussed on quality of life prior to death taking into account the actual moment of passing away. In these studies, most functioning and symptoms scores were deteriorating when death was nearing (Jordhoy *et al.* 2001b). In patients with prostate cancer, health related quality of life was found to decline during the whole final year of life (Litwin *et al.* 2001; Melmed *et al.* 2002). In another study, patients with advanced cancer experienced a gradual deterioration of a general quality of life scale, with a steeper decline in the last months (Hwang *et al.* 2003). Further, the decline in quality of life was related to several patient characteristics (Jordhoy *et al.* 2001b; Melmed *et al.* 2002).

We studied quality of life, functioning and symptoms during the last year prior to death in patients with different types of cancer. Furthermore, we examined whether quality of life shortly before death could be predicted by characteristics of the patient and the disease.

Materials and methods

Patients

From 2001 until 2003, out-patients with lung cancer, breast cancer, colorectal cancer, ovarian cancer, or prostate cancer were asked to participate in the study by forty-five oncologists, pulmonologists, urologists and radiotherapists in the south and south-western part of the Netherlands. Patients were included within two months of being informed that their cancer was in principle incurable. We defined objective criteria for each type of cancer in order to include an unselected group in whom survival is less than two years in the majority of cases (see Box 3-1) (Tumorregistry Munich). The Medical Ethical Committee of Erasmus MC, University Medical Center Rotterdam, approved the research protocol. Patients were included only after they had given their written informed consent. In this study, we used only the measurements filled out in the last year of life of patients who passed away during follow-up.

Of 200 identified patients, eight had died before an interview could take place. Of the 192 eligible patients, 128 agreed to participate (response rate: 66%). Reasons mentioned not to participate were: participation was expected to be too burdensome (n=29) or patients had a poor physical condition or co-morbidity (n=18). In 17 cases the reason was unknown. Participants were on average younger (mean age was 63.6 versus 67.3 years; p= 0.02) than non-participants. There were no differences between participants and non-participants regarding sex, primary diagnosis, metastases, co-morbidity, and the application of chemotherapy, radiotherapy or surgery.

Out of the 128 participating patients, 103 died during the study period. Ninety-nine

Box 3-1. Inclusion criteria

Type of cancer:	Disease stage diagnosed within 2 months before inclusion:
Breast cancer	Metastatic disease at primary presentation (in any organ system) or metastatic disease in at least 2 organ systems after primary treatment
Colorectal cancer	Locally advanced unresectable disease or metastatic disease (without options of curatively aimed surgery) or locally recurrent disease
Ovarian cancer	Recurrent disease
Lung cancer	Metastatic disease or locally advanced disease without curatively aimed treatment options
Prostate cancer	Hormone independent disease and increasing PSA level (PSA > 20 ng/ml)

patients filled out one or more questionnaires in the last year of their lives, but 4 patients had declined to participate any longer prior to their last year of life and thus missed all four measurements in the last year of life.

Data collection

At inclusion, patients were interviewed personally at home. During follow-up, patients filled out a written questionnaire every 3 months about quality of life and received cancer therapy. The interview and questionnaires addressed patients' quality of life by means of the EORTC QLQ-C30 (Aaronson *et al.* 1993; Kaasa *et al.* 1995), which consists of 6 functioning scales and 9 symptom scales. The functioning scales were global quality of life, and physical, role, emotional, cognitive and social functioning. A higher score on these scales means better functioning. The symptom scales were fatigue, nausea/vomiting, pain, dyspnoea, sleeping problems, loss of appetite, constipation, diarrhoea, and financial problems. A higher score on the symptom scales indicates more severe symptoms. The interview also addressed factors that might be related to quality of life, such as the disease duration, and the cancer therapy the patient had received. At inclusion, the patients also filled out a written questionnaire that addressed demographic factors (age, sex, marital status, education, and religion).

When patients passed away during the study, bereaved relatives and health care professionals informed the researchers about the actual date of death and place of death.

Statistical analyses

The number of measurements during the last year of life per patient varied, due to variance in survival time after inclusion in the study and dropout during follow-up. The longitudinal data on quality of life and symptoms were analysed with a linear regression model that included linear and quadratic terms for time to death as a determinant, and a random intercept for the patients to account for statistical dependencies among longitudinal measurements. This model allowed the inclusion of data of all patients, irrespective of their number of measurements and the time interval between their measurements. All models were fitted using 'proc mixed' in SAS version 8.2. We used reference data for EORTC QLQ-C30 scores from the general German population (Schwarz and Hinz 2001)

Scales on which our patient group scored worse than the general German population were used for further analysis to identify possible determinants. When comparing the course of the quality of life, functioning and symptoms between patients with different types of cancer, we could not use the random intercept model, because of small numbers of patients. Therefore, we clustered all measurements in 4 periods: measurements that were carried out 12-9 months prior to death are referred to as T_I measurements; measurements that were carried out 9-6, 6-3 and 3-0 months prior to death are referred to

Table 3-1. Clinical and demographic characteristics of patients who participated in the study during the last year of their lives

	Patients (N=99)
Age at death	
Mean (SD)	65.5 (10.6)
Number of months from diagnosis of cancer to death	
Median (interquartile range)	16 (8-31)
Number of months from inclusion in the study to death	
Median (interquartile range)	7.5 (3.9–12.7)
	N (%)
Type of cancer:	
Lung cancer	46 (47)
Breast cancer	19 (19)
Colorectal cancer	17 (17)
Ovarian cancer	10 (10)
Prostate cancer	7 (7)
Place of death:	
Home	49 (50)
Hospital	35 (35)
End-of-life care unit	6 (6)
Hospice	4 (4)
Other	5 (5)
Sex:	
Male	52 (53)
Female	47 (47)
Marital status:	
Married or living with spouse or partner	73 (74)
Living without spouse or partner	26 (26)
Education:[a]	
Low	67 (68)
High	31 (32)
Having religious beliefs:	
Yes	61 (62)
No	38 (38)

[a] Low education: lower vocational, lower secondary general education or primary school; High education: Intermediate vocational, higher secondary general education, higher vocational education or university.

as T_{II}, T_{III}, and T_{IV} measurements, respectively. We used analysis of covariance and linear regression analysis to examine whether type of cancer, time to death, patient characteristics, and disease factors were related to quality of life, functioning and symptoms at the last measurement prior to death. The level for significance was set at $P = 0.01$ to provide some protection from multiple comparisons. These analyses were done using the Statistical Package for the Social Sciences (SPSS) version 11.0.

Results

Patients

At the time of death, patients were on average 66 years of age and their median disease duration was 16 months (table 3-1). The median survival time after inclusion in the study was 7.5 months: 16 patients died within 3 months after inclusion; 22 patients died 3 to 6 months after inclusion; 20 patients died 6 to 9 months after inclusion and 41 patients died more than nine months after inclusion (table 3-2). Some patients were not able or willing to fill out all possible questionnaires and therefore missed one (n=22), two (n=3) or three (n=5) measurements prior to death. Some patients were too ill, especially patients who missed the last measurement prior to death. We found no differences in quality of life on T_{III} (6-3 months prior to death) between patients who filled out a questionnaire on T_{IV} (3-0 months prior to death) and those who did not. However, patients who participated at the last measurement prior to death (T_{IV}) had received their T_{IV} questionnaire longer before death than others (52 versus 34 days, p=0.01).

Quality of life in the last year prior to death

For eleven out of fifteen scales of the EORTC QLQ C-30 quality of life was fitted as a model with both a linear and quadratic effect of time to death (figure 3-1). Global quality of life, and physical, role, emotional, cognitive and social functioning were all gradually deteriorating during the last year of life, with an steeper decline in the last months prior to death. The same holds for the symptom scales fatigue, nausea and vomiting, sleeping problems, loss of appetite, and constipation. Time to death was only linearly related to pain and dyspnoea, meaning that pain and dyspnoea were getting worse over time, but the decline did not become steeper when death was nearing. The scores on the scales diarrhoea and financial problems were stable over time. Patients in our study had, during the whole last year of life, more restrictions in global quality of life, physical, role and social functioning, and higher levels of fatigue, pain, dyspnoea and loss of appetite than the general population.

Patients with a survival of nine months or less after inclusion could not participate in all of the four measurements during the last year prior to death. To explore whether

Table 3-2. Follow-up of patients with incurable cancer in the last year of life (N=99)

	Number of patients	Number of participants during assessment period [a] T_I	T_{II}	T_{III}	T_{IV}
Survival after inclusion in the study					
Less than 3 months	16				16
3 to 6 months	22			22	22
6 to 9 months	20		20	20	20
More than 9 months	41	41	41	41	41
Total number of patients	99	41	61	83	99
Missing measurements					
No missing measurement	68				
1 missing measurement prior to death	22				-22
2 missing measurements prior to death	4		-1	-3	-4
3 missing measurements prior to death	5		-5	-5	-5
Total number of patients per assessment period		41	55	75	68

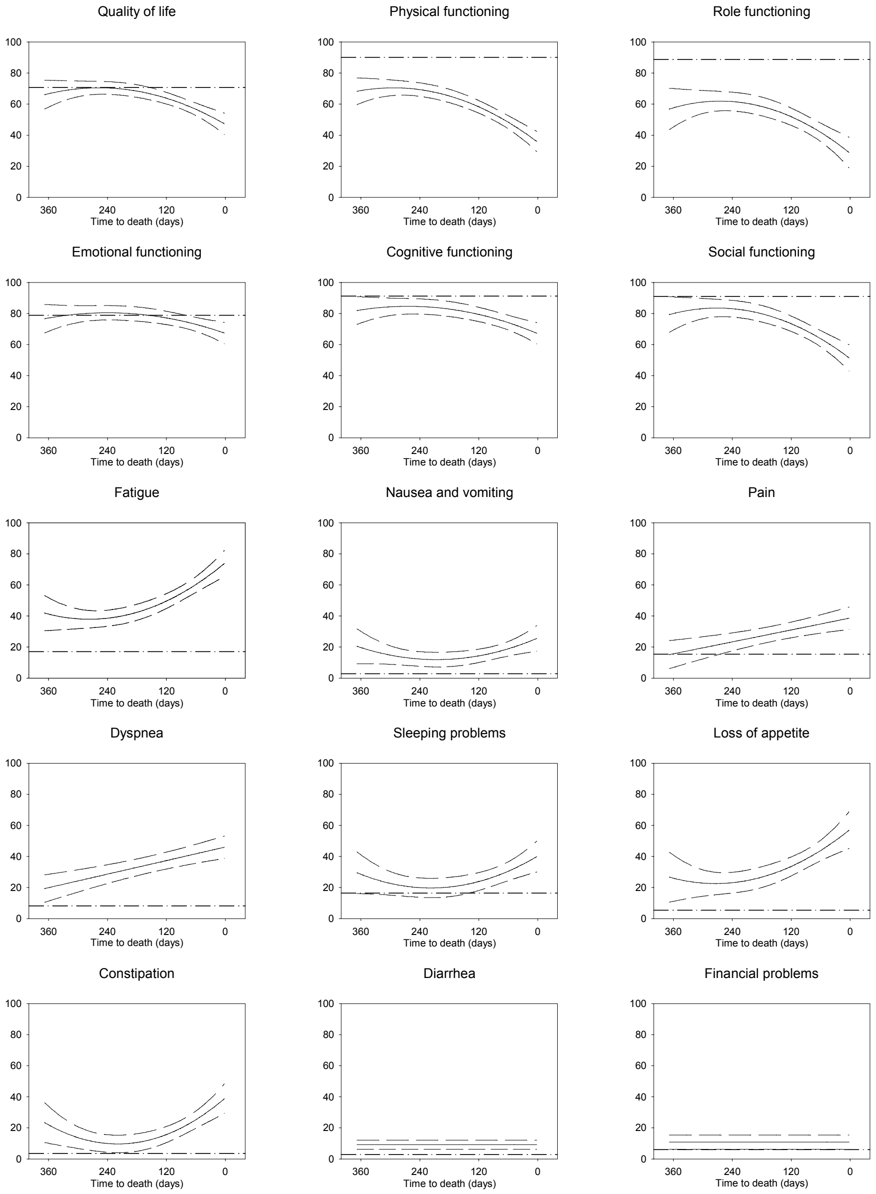
[a] Measurements that were carried out 12-9 months prior to death are referred to as T_I measurements; measurements that were carried out 9-6, 6-3 and 3-0 months prior to death are referred to as T_{II}, T_{III}, and T_{IV} measurements, respectively.

the duration of survival after inclusion in the study was related to the scores on the quality of life scales, we compared scores at T_{IV} of patients with different survival times. Patients who survived 3 to 6 months had better T_{IV} scores on global quality of life than patients who survived less than 3 months (mean was 68 versus 41, $p=0.015$). The outcomes on other scales were not significantly different for patients who survived less than 3 months, 3 to 6 months, 6 to 9 months, and more than 9 months.

Quality of life and type of cancer

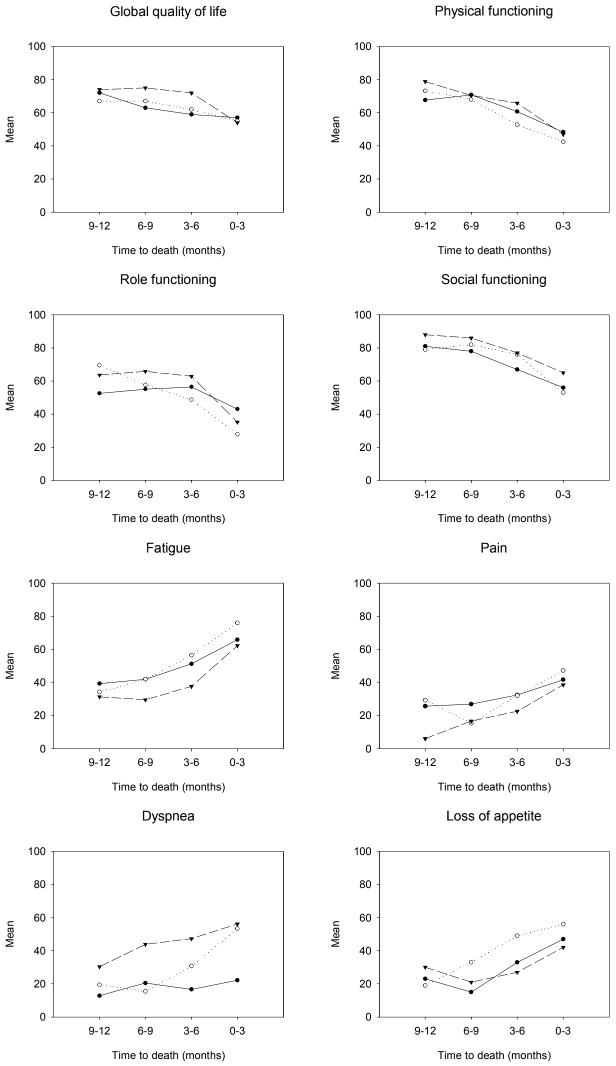
For ovary and prostate cancer the number of participating patients was less than five on one or more measurements. Therefore, only the scores of patients with breast, colorectal, and lung cancer were used to assess the effect of type of cancer on quality of life and symptoms (figure 3-2). No indication was found that the course of global quality of life, physical, role and social functioning, fatigue, pain, dyspnoea, and loss of appetite was different for different types of cancer, except that dyspnoea was typical for lung cancer. Because of a steeper decline in the last months of life, we examined whether patients with these three types of cancer differed in their quality of life at the last measurement prior to death (T_{IV}). Analysis of variance showed that patients with lung cancer had higher scores

Figure 3-1. The mean scores on the scales of the EORTC QLQ-C30 with 95% confidence intervals.



NOTE. All available questionnaires at the assessment points in the last year before death are included. Different groups of patients participated in the assessment points: 9-12 months, n=41; 6-9 months, n=55; 3-6 months, n=75; 0-3 months, n=68. Scales of function (first 6 scales): high score indicates good function. Symptoms (last 9 scales): high score indicates many symptoms. Reference line represents the general population.

Figure 3-2. The mean scores on eight scales of the EORTC QLQ-C30 during the last year of life for three types of cancer.



Global quality of life

Physical functioning

Role functioning

Social functioning

Fatigue

Pain

Dyspnea

Loss of appetite

NOTE. Different numbers of patients participated in the assessment points of 9-12 months, 6-9 months, 3-6 months, and 0-3 months before death:

—●— Breast cancer, n=13, 13, 18, and 12 resp.

····○····· Colorectal cancer, n=12, 13, 13, and 6 resp.

– –▼– – Lung cancer, n=11, 19, 35, and 31 resp.

Scales of function (first 4 scales): high score indicates good function. Symptoms (last 4 scales): high score indicates many symptoms.

on dyspnoea than patients with breast cancer at T_{IV} (mean was 56 versus 22, p=0.013). The scores on the other quality of life scales were not related to type of cancer at T_{IV}.

Determinants of quality of life

The analyses of the influence of patient characteristics, disease factors and quality of life at prior measurements on quality of life and symptoms at the last measurement prior to death (T_{IV}) were corrected for time to death, and in case of dyspnoea, for both time to death and lung cancer. For every possible predictor the relationships to the quality of life scores at T_{IV} were tested by means of separate analyses of covariance or linear regression analyses. No effects were found for sex and age of the patient, living with a partner, the educational level of the patient and having religious beliefs (see table 3-3). Survival since the primary diagnosis of cancer or after inclusion in the study was not related to quality of life on T_{IV} either, which means that disease duration was not related to the level of quality of life shortly before dying. Quality of life scores were not related to received cancer therapy in the three months preceding the measurement (data not shown). However, quality of life scores on T_{III} were strong determinants of the corresponding scores at T_{IV}. For example, dyspnoea in the period 6-3 months before death was a strong predictor of dyspnoea in the period 3-0 months before death. The corresponding scales on T_I and T_{II} were not related to quality of life on T_{IV}.

Discussion

This study first of all shows that research in patients in the last phase of life is feasible: the response rate was sufficient and the attrition rate during follow-up was limited. The numbers of patients who died during follow-up and the survival rates after inclusion were consistent with expectations. Especially lung cancer patients died relatively shortly after inclusion in the study. Most functioning and symptom scores of cancer patients deteriorated gradually during the last year prior to death, with a steeper decline in the last months of life. The course of quality of life seemed rather similar for different types of cancer. We did not find any relationship with patient characteristics, such as sex, age, living arrangement, educational level and having religious beliefs. However, functioning and symptoms scores three months prior to the last measurement were strong determinants of the corresponding scores at the last measurement.

The finding that quality of life decreases during the last year prior to death is consistent with other studies (Hwang *et al.* 2003; Jordhoy *et al.* 2001b; Litwin *et al.* 2001). However, most studies found only a gradual decline during the last phase of life, whereas our study showed a steeper decline during the last months prior to death (Jordhoy *et al.* 2001b; Litwin *et al.* 2001). On average, patients had their worst functioning and symptoms scores shortly before dying. Hwang *et al.* (2003) also showed that patients with advanced cancer experience a gradual decline in quality of life during the last half year of life, with

Table 3-3. Possible predictors of quality of life shortly before death: separate analyses adjusting for time to death and if applicable for type of cancer.

	Functioning scales [a]				Symptoms scales [b]			
	QoL	PF	RF	SF	FA	PA	DY	AP
	ß [c]	ß [c]	ß [c]	ß [c]	ß [c]	ß [c]	ß [d]	ß [c]
Patient characteristics								
Being male	-0.11	0.00	-0.07	0.14	0.01	0.12	0.08	-0.01
Age ≥ 65 years	0.19	-0.06	0.05	0.09	-0.02	-0.04	0.22	-0.04
Living with partner	0.04	-0.01	-0.17	-0.05	-0.09	-0.01	0.09	-0.06
High education level	-0.13	-0.01	0.04	-0.03	0.03	-0.07	0.00	-0.02
Having religious beliefs	-0.12	-0.06	-0.03	-0.09	-0.08	-0.12	-0.03	0.07
Disease duration								
Time since diagnosis	0.15	-0.07	0.10	-0.01	-0.08	0.00	-0.20	0.11
Time since inclusion	0.18	0.01	-0.07	-0.18	-0.06	-0.06	0.02	0.05
Prior quality of life score [e]								
3 months before (n=54)	0.42[f]	0.52[f]	0.40[f]	0.54[f]	0.45[f]	0.40[f]	0.65[f]	0.25
6 months before (n=34)	-0.11	0.29	0.09	-0.14	0.08	0.02	0.33	0.29
9 months before (n=21)	0.37	0.38	0.21	0.37	0.13	0.48[g]	0.22	-0.44[g]

[a] Functioning (QoL=global quality of life, PF=physical, RF=role, SF=social): higher scores mean better functioning;

[b] Symptom scales (FA=fatigue, PA=pain, DY=dyspnoea, AP=loss of appetite): higher scores mean more symptoms;

[c] Standardized ß-coefficient, analyses of covariance and linear regression analyses after adjustment for time to death;

[d] Standardized ß-coefficient, analyses of covariance and linear regression analyses after adjustment for time to death and lung cancer;

[e] Relationship to corresponding quality of life score on prior measurement;

[f] $P \leq 0.01$;

[g] $P \leq 0.05$.

an acceleration in the last 2 to 3 months. However, no specific symptoms were investigated in this study. Our data show a steeper decline in the last months of life for various symptoms, namely fatigue, nausea and vomiting, sleeping problems, loss of appetite, and constipation. Furthermore, our data show no steeper decline for pain and dyspnoea in the last months of life, which might be indicative of good symptom management in the last months of life.

Klinkenberg (2003) has studied patterns of general functional decline. Four patterns of functional decline could be distinguished: terminal decline, gradual decline, prolonged limited, and no decline. Terminal decline was characterised by strong deterioration in the last three months of life. In the study of Klinkenberg (2003), cancer patients most often followed a pattern of terminal decline or gradual decline. In our study, we found similar patterns of decline for several specific symptoms: dyspnoea and pain followed a pattern of gradual decline. However, global quality of life, functioning, and most other symptoms followed patterns with characteristics of both gradual and terminal decline, that is, during the whole last year of life there was a gradual and accelerating deterioration, resulting in a steeper decline during the last months of life.

Whereas we found a deterioration of quality of life in patients with incurable cancer, cancer patients in earlier stages of the disease did often report relatively high and stable levels of overall quality of life (Breetvelt and Van Dam 1991; de Haes and van Knippenberg 1985; Hagedoorn *et al.* 2002). The fact that poor health states are often not accompanied by low ratings for quality of life has broadly been discussed (Essink-Bot *et al.* 2003; Schwartz and Sprangers 2002), and has been attributed to the fact that patients adapt to their new situation (Schwartz and Sprangers 2002). Cognitive mechanisms may also influence patients' self-reports about quality of life. They may reappraise their situation to avoid cognitive dissonance, that is, patients may justify the effort of a treatment by valuing the post-treatment situation as higher than the pre-treatment situation (Jansen *et al.* 2001). We found that the global quality of life remained relatively long stable over time, but deteriorated in the last months of life. This may indicate that in the ultimate last months of life adaptive mechanisms are not sufficient anymore to maintain high scores on global quality of life.

Our data gave no indication that the quality of life in the last phase of life is different for different types of cancer. This may implicate that the last phase of life of cancer patients is characterised by a uniform set of problems and restrictions in functioning, with a limited influence of the specific type of cancer. However, the limited number of patients in our study for the different cancer types restricts drawing firm conclusions on differences in quality of life according to type of cancer.

Quality of life as measured in the last months prior to death could not be predicted by patient characteristics. Comparison with other studies is difficult, because these studies did not adjust for time to death. However, our findings were mainly consistent with the findings of Jordhoy *et al.* (2001b), who found no differences in quality of life according to several patient characteristics, except that in patients with advanced cancer, most functioning and symptom scores showed minor differences between genders, and higher age was associated with less sleeping disturbance, less pain and better emotional functioning.

Our study has some limitations. The group of patients was probably selected, because patients with a very poor health status and patients who died shortly after the diagnosis of incurable cancer could not be interviewed. Furthermore, most patients who declined to participate did not want to talk about their disease because they considered it too burdensome. Moreover, patients who did not participate in the last three months of life might have had a lower quality of life, because they, on average, received their questionnaire more closely before death. These factors may have led to an overestimation of the level of quality of life. The second limitation is the relatively small number of patients. The numbers of patients with ovary cancer or prostate cancer were too small to perform subgroup analyses for quality of life.

We conclude that during the last year before death, the quality of life of cancer patients decreases gradually. This deterioration is most outspoken in the last months of life. The course of symptoms and restrictions in functioning during the last year of life seems rather uniform for patients with different types of cancer. For most patients, the main problems in the last three months of life already existed in an earlier stage. The absence of other predictors of functioning and symptoms in the last months of life underlines the importance of monitoring all patients with incurable cancer.

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4

Patient evaluation of end-of-life care

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Submitted

Abstract

The Dutch health care system is characterized by a strong emphasis on primary care. To get insight in the strengths and gaps in end-of-life care in the Netherlands, data are needed about use and patient evaluation of end-of-life care. We assessed the experiences of patients with end-of-life care during the last months of life. We followed 128 patients with incurable lung, breast, ovarian, colorectal, or prostate cancer. At inclusion they were interviewed personally at home. During follow-up, every half-year, we asked them to fill out a questionnaire on the end-of-life care they had received. Hundred of them died during the research period. Eighty-seven of the deceased patients were able to fill out a questionnaire in the last half-year of their lives. They reported that, on average, 4.2 disciplines were involved in their care. Most patients indicated to be satisfied with the care offered by their caregivers. Problems in end-of-life care concerned communication, difficulties in fine-tuning, accessibility of end-of-life care and responding quickly to acute problems. We conclude that comprehensive and interdisciplinary end-of-life care may address patients' needs, but that it simultaneously is a challenge to optimal communication among disciplines and between caregivers and the patient.

Introduction

Most people in Western countries live long and generally healthy lives (Donaldson and Field 1998). As a consequence of longer life most people today die in old age, of chronic and progressive disease (Donaldson and Field 1998). Therefore, care for patients who are in the last phase of life is an important part of health care. In the Netherlands, the development of end-of-life care has been stimulated by a grant of more than 18 million Euro (about 23 million USD) over a period of five years (1999-2003) from the Ministry of Health Care (Gordijn and Janssens 2000).

The Dutch health care system is characterized by a strong emphasis on primary care (Smeenk *et al.* 2000). Many people die at home in the Netherlands; 67% of all non-sudden deaths occurred outside the hospital, mainly at home (Statistics Netherlands). In 2003, 45% of the deaths due to cancer occurred at home; this percentage is lower in most other Western countries (Bruera *et al.* 2003; Higginson *et al.* 1998; Statistics Netherlands). Thus, end-of-life care in the Netherlands is often provided by primary health care professionals.

Various indicators of quality of care at the end of life have been developed, both from the patients' and relatives' perspective (Donaldson and Field 1998; Sulmasy *et al.* 2002; Teno *et al.* 2004). Outcomes on several domains have been identified as indicators of the quality of end-of-life care, such as survival time, quality of life, family burden, and bereavement (Morrison *et al.* 2000; Patrick *et al.* 2001; Teno *et al.* 2001). Many of these indicators have not been proven to be sensitive to change (Morrison *et al.* 2000). One of the domains that have been shown to be amenable to quality improvement, and therefore can be used as an indicator for the quality of end-of-life care, is patient satisfaction (Morrison *et al.* 2000).

Patients' ratings of satisfaction with care at the end of life are related to several factors. In several studies from the US, patients have been found to give higher ratings to physicians than to nurses. Furthermore, patients who were very close to death were found to be less satisfied with physician care (Sulmasy and McIlvane 2002). A study among family members of decedents showed that many people who died in institutions had unmet needs concerning symptom treatment, physician communication, emotional support, and being treated with respect, whereas decedents who had received hospice services at home were more likely to have had positive experiences (Teno *et al.* 2004).

Until now, data about use of and satisfaction with end-of-life care in the Netherlands are scarce. We studied the content and evaluation of end-of-life care from the patients' perspective. We assessed which health care professionals were involved in the care for patients with incurable cancer and several aspects of medical care, and we asked patients how they evaluated the care received.

Methods

Patients

This study concerns a subsample of a cohort of 128 patients with incurable breast cancer, colorectal cancer, ovary cancer, lung cancer or prostate cancer, who were followed for a study on end-of-life care needs and practices during the last stage of their lives. Reasons mentioned not to participate were: participation was expected to be too burdensome or patients had a poor physical condition or co-morbidity. Participants of the cohort were on average somewhat younger than non-participants (Voogt *et al.* 2005a; Voogt *et al.* 2005b). Of these patients, 100 died within the time frame during which we were able to collect data.

The Medical Ethical Committee of Erasmus MC, University Medical Center Rotterdam, approved the research protocol. Patients were included only after they had given their written informed consent. Participating patients were interviewed at inclusion, and during follow-up, they filled out written questionnaires every three months about topics such as quality of life, psychological well-being, medical care, and care needs. Every six months, these questionnaires addressed the evaluation of care. In this current study only data were used from measurements in the six months prior to death of patients who passed away during the research period. The time to death on the moment of this measurement could range from 1 to 182 days. It is important to note that the variance in time to death is probably related to the occurrence and severity of symptoms and problems.

The questionnaire and the interview

After inclusion, patients filled out a written questionnaire, which included demographic factors (age, sex, living arrangement, and educational level), and questions based upon the "Problems and Needs in Palliative Care Questionnaire" (PNPC) (Osse *et al.* 2002; Osse *et al.* 2004). The PNPC listed eight problems concerning practical and organizational aspects of end-of-life care. Patients had to indicate if these problems had occurred never, sometimes or often during the three months prior to the assessment.

At inclusion, patients were also interviewed personally at home. The interviewers were prepared for interviewing patients with incurable cancer during a two-day course in interview techniques. The interview consisted of Dutch, self-constructed questions about contacts with health care professionals and patient satisfaction with these contacts. Patients were asked whether or not they had had contact with the following health care professionals: general practitioner, clinical specialists, hospital nurse, oncology nurse, district nurse, home-helper, paramedical workers, religious or spiritual caregivers, and complementary or alternative caregivers. Satisfaction was measured by means of a 10-point evaluation scale, ranging from 'very poor' to 'excellent'. Higher evaluation ratings denote better quality of care. In assessing satisfaction with hospital care, this 10-point evaluation scale has shown good psychometric properties (Hendriks *et al.* 2004). Further, we asked whether patients had been admitted to a hospital or other care institutions. The interview also addressed factors that might be related to contacts and satisfaction with health care professionals, such as type of cancer, disease duration, that is the time since the primary diagnosis of cancer, and the cancer therapy the patient had received.

During follow-up, every six months patients filled out written questionnaires in which contacts with health care professionals, received cancer therapy, satisfaction with care, and problems in end-of-life care were assessed. Questions were similar to the questions asked in the written questionnaire and the interview at inclusion. In addition, we asked patients whether they felt a need for additional care and we added three open-ended questions about the quality of end-of-life care.

When patients passed away during the study, bereaved relatives or health care professionals informed the researchers about the actual date and place of death. To assess patients' evaluation of medical care in the last phase of life we used data from the last measurement prior to the death of patients who passed away during the research period.

Statistical analysis

Contact with health care professionals, cancer therapy, and satisfaction about these contacts, as well as problems in end-of-life care are presented in frequency tables. Further, we conducted only bivariate comparisons, with a few exceptions that are noted. We used Chi- square test, and student's t-test to assess the statistical significance of relationships of these characteristics of end-of-life care with patients' and disease characteristics. To analyze the data we used the Statistical Package for the Social Sciences (SPSS) version 11.0.

Results

Patients

Of 100 patients, eighty-seven filled out a questionnaire about the evaluation of care in the last half-year of their lives. Four patients were too ill, six patients decided not to participate any longer during the follow-up period of the study, and three patients were probably not able to fill out the questionnaire, because they received it within two weeks before their death. No differences were found between the patients who filled out a questionnaire in the last half-year of their lives and the patients who did not, regarding age, sex, disease duration, educational level, living arrangement, type of cancer, and cancer therapy prior to inclusion.

Table 4-1. Characteristics of patients

	Patients (N=87)
Age (years)	
Mean (SD)	65.2 (10.6)
Disease duration (months) [a]	
Mean (SD)	25.5 (33.3)
Time to death (months)	
Mean (SD)	2.6 (1.7)
	N (%)
Sex:	
Male	46 (53)
Female	41 (47)
Living arrangement:	
With partner	64 (74)
Without partner	23 (26)
Education:[b]	
High	27 (31)
Low	59 (69)
Type of cancer:	
Lung	44 (51)
Breast	16 (18)
Colorectal	11 (13)
Ovarian	9 (10)
Prostate	7 (8)

[a] Data are missing for two persons

[b] High: Intermediate vocational or higher secondary general education, higher vocational education, university; Low: Lower vocational, lower secondary general education or primary school

Characteristics of patients are described in table 4-1. At the last assessment prior to death, patients were on average 65.2 years of age and their mean disease duration was 25.5 months. Of all patients, 53% were male, and 74% were living with a partner. Forty-nine patients (56%) died at home, 29 patients (33%) died in a hospital, and few patients died in a palliative care unit (n=3), a hospice (n=3) and a nursing home (n=2) or elsewhere (n=1), according to bereaved relatives or health care professionals. In five patients euthanasia was performed. On average, the patients died 2.6 months (range: 2 to 176 days) after filling out this questionnaire about the evaluation of end-of-life care.

Table 4-2. Contacts with health care professionals and admission to a health care institution

	During three months prior to assessment [a] (N= 85)
	N (%)
Patient had contact with:	
General practitioner	69 (81)
One or more clinical specialists	81 (95)
Oncology nurse [b]	37 (52)
Hospital nurse	38 (45)
District nurse	14 (17)
Home helper (dealing mainly with the patient's self-care capacity)	25 (29)
Paramedical workers	15 (18)
Religious or spiritual caregivers	13 (15)
Complementary or alternative caregivers	5 (6)
	Mean (SD)
Total number of disciplines involved in care for one patient	4.2 (1.8)
	N (%)
Patient had received cancer therapy [c]	
Surgery	3 (4)
Chemotherapy	50 (60)
Radiotherapy	21 (26)
Hormonal therapy	7 (8)
None	17 (21)
Admission to hospital	34 (40)
Admission to other care institutions	0 (0)

[a] Assessment during six months prior to death (range: 2 to 176 days before death); data are missing for two patients;

[b] Data are missing for 16 patients because this question was not included in the first version of the patient questionnaire;

[c] Number of missing values for cancer therapy is varying from 0 to 4.

Contacts with health care professionals

Eighty-one percent of the patients indicated to have had contact with their general practitioner in the three months prior to assessment. Almost all patients had met with one or more clinical specialists (table 4-2). More than half of the patients had seen an oncology nurse. The patients who reported to have had contact with a district nurse (17%) were more often living without a partner than others. Eighteen percent of the patients had met with paramedical professionals, that is, a physical therapist (11%), a psychologist (5%) or a social worker (5%). The district nurse was involved in the care for 17% of the patients, and 15% of the patients had had personal contact with a religious or spiritual caregiver. A minority of patients (6%) had received complementary or alternative care. On average, 4.2 disciplines were involved in end-of-life care, and, on average, 1.7 of these disciplines concerned medical specialties. The majority of patients (79%) had received cancer therapy, and thirty-four patients (40%) had been admitted to a hospital in the three months prior to the assessment.

Satisfaction with care and problems in end-of-life care

The care as provided by the health care professionals was, on average, judged to be sufficient or good (see table 4-3). The largest variation was seen for the care provided by general practitioners and for the care provided by religious or spiritual caregivers. Patients with a higher educational level were less satisfied with the care offered by the general practitioner than patients with a lower educational level (mean satisfaction score: 6.5 vs. 7.7; p= 0.02).

Table 4-3. Patients' satisfaction with health care professionals

	Satisfaction score [a]	
	N [b]	Mean (SD)
General practitioner	75	7.3 (2.0)
Clinical specialist	74	7.8 (1.1)
Oncology nurse [c]	40	7.4 (1.6)
Hospital nurse	37	7.4 (1.2)
District nurse	14	7.3 (0.9)
Home helper	24	7.7 (1.4)
Paramedical worker	13	7.6 (1.2)
Religious or spiritual caregiver	11	7.4 (2.0)

[a] Satisfaction score could range from 1 to 10: 1 means very poor and 10 means excellent;

[b] Only patients who had had contact with a specific health care professional gave a satisfaction score;

[c] Data are missing for 16 patients because this question was not included in the first version of the patient questionnaire.

Patients mentioned various problems in end-of-life care. The problem most often mentioned by patients, concerned difficulties in responding quickly to acute problems (table 4-4). Seventeen percent of the patients reported that the fine-tuning of different professionals had been a problem, and also 17% felt uncertain about the possibility of acute hospital admission if necessary. Other problems reported just as often were difficulties with access to help and with getting a second opinion from another physician. On average, patients mentioned one out of eight listed problems in end-of-life care. Of all mentioned problems, 26% were scored as having been present often; the remaining problems had occurred sometimes. The number of problems in end-of-life care patients mentioned was higher when death was nearing (Pearson's correlation between number of problems in end-of-life care and time to death and was -0.26, p= 0.02).

The open-ended questions about care needs and the quality of end-of-life care were only included in the follow-up questionnaires, and not in the first measurement. Because some patients died shortly after the first measurement, only 65 filled out one or more follow-up questionnaires. Of these patients, six (10%) indicated to need additional care

Table 4-4. Problems in end-of-life care

	During three months prior to assessment [a] (N= 87)
	N (%)
Problems in end-of-life care:[b]	
Difficulties in responding quickly to acute problems	17 (21)
Difficulties in fine-tuning the care of different professionals	14 (17)
Being uncertain about possibility of admission to hospital if needed (acutely)	14 (17)
Difficult accessibility to help from agencies / professional organizations	14 (17)
Difficulties in getting a second opinion from another physician	14 (17)
Difficulties in fine-tuning hospital care to the home situation	8 (10)
Lack of information in writing (inability to re-read information)	8 (10)
The impossibility of choosing another care provider	8 (9)
	Mean (SD)
Total number of problems in end-of-life care	1.1 (1.6)

[a] Data received from patients: assessment during last six months of life; number of missing values is varying from 2 to 6;

[b] Questions from the "Problems and Needs in Palliative Care Questionnaire".

for their problems, such as help for activities of daily life (ADL), pain management, and information supply. Twenty patients (31%) mentioned problems in end-of-life care, such as lack of communication, insensitive physicians, side effects and complications of their treatment, delay in diagnostic testing, the delivery of care, or response to complaints.

Discussion

This study among patients with incurable cancer shows that the general practitioner was involved in end-of-life care in virtually all patients. Clinical specialists were also often involved and more than half of the patients had recently seen an oncology nurse. Few patients had seen other health care professionals. A considerable number of patients were admitted to the hospital in the last phase of life. Many patients had received one or more types of cancer therapy shortly before dying. Although most patients were satisfied with the care offered by their health care professionals, many of them identified problems in end-of-life care. These problems concerned difficulties in responding quickly to acute problems, in fine-tuning the care of different professionals and in fine-tuning hospital care to the home situation. Furthermore, patients reported that several aspects of communication could be improved, such as information giving, emotional support, and being treated with respect.

Several factors, which are to a certain extent inherent to research in palliative care, may have led to some selection bias in this study, which is reported in more detail elsewhere (Voogt *et al.* 2005a; Voogt *et al.* 2005b). This group of patients was a selected group, mainly because patients with a relatively poor health status and patients who died shortly after the diagnosis of incurable cancer could not be interviewed. Further, most patients who declined to participate did not want to talk about their disease, because they considered it too burdensome. Finally, the patients who participated in the study were younger than the non-participants. In conclusion, our study is more likely to underestimate than to overestimate the problems in end-of-life care. However, our data regarding place of death and percentage of euthanasia are consistent with national data on deaths due to cancer (Onwuteaka-Philipsen *et al.* 2003; Statistics Netherlands).

In our study, end-of-life care was mainly provided by general practitioners, clinical specialists and hospital nurses. Strong involvement of primary health care professionals is typical for the Netherlands, where many cancer patients die at home (Statistics Netherlands). The involvement of clinical specialists may have been the result of a need for advanced palliative treatments that can only be provided in the hospital. However, involvement of clinical specialists until very late in the disease process might also be related to adhering to the goal of life-extension instead of focusing on the comfort of the patient. Teno *et al.* (2002) found that more than one-third of the seriously ill patients with a preference for comfort care reported that the medical care that they received was focusing on extending life and was therefore inconsistent with their goals. However, Van Leeuwen *et al.* (2004). showed that, at two oncology departments, before making a decision about treatment for inpatients with end-stage cancer, physicians gathered extensive information about what gain is to be expected from an intervention, and the patient's wish was often an important consideration.

Whereas most patients had had contact with medical and nursing professions, only minorities of patient had seen other professions. This finding suggests that patients are primarily in need of medical and nursing care. This is consistent with the finding that most patients with incurable cancer received psychosocial support from their relatives, whereas only a minority of all patients received psychosocial care from formal caregivers and a small minority reported a need for psychosocial care (Voogt *et al.* 2005b).

Patient characteristics were not related to whether or not patients had had contact with specific health care professionals, except that during the last half year of life, the district nurse was more often involved in the care for patients who lived without a partner. Partners of patients with incurable cancer may often provide nursing care. The absence of other relationships may indicate that end-of-life care in the Netherlands is equally accessible to men and women, older and younger people, higher and lower educated, and so on.

Patients with incurable cancer are, on average, satisfied with the care offered by their health care professionals. Other studies have shown that the large majority of medical inpatients were satisfied with the care offered by their health care professionals (Hendriks *et al.* 2004; Sulmasy and McIlvane 2002). Hagedoorn *et al.* (2003) found overall satisfaction ratings of 80.5 on a 0-100 scale among Dutch cancer patients. The satisfaction ratings in our study vary from 7.3 to 7.8, suggesting that cancer patients in the last phase of their lives are somewhat less satisfied with health care as compared to cancer patients in general. Further, the variation in ratings in our study shows that not all patients are satisfied. We should be careful in interpreting satisfaction scores, because patients may fear that expressions of dissatisfaction with care and caregivers might make caregivers angry or neglectful (Donaldson and Field 1998). Another problem in interpreting satisfaction scores is that patient evaluation of the quality of care might be influenced by a number of factors, including gratitude, faith, loyalty, luck and equity. The overall effect of these factors is to prompt positive evaluation, even when the quality of care is poor (Staniszewska and Henderson 2005).

In response to problems with satisfaction measures, it has been suggested to ask people what would have improved their situation rather than ask about areas of dissatisfaction (Donaldson and Field 1998; Morita *et al.*). In response to open-ended questions on possible areas for improvement, one third of the patients mentioned one or more problems in end-of-life care, additional to the problems already mentioned in response to the Problems and Needs in Palliative Care Questionnaire. The topics mentioned by patients concerned, among others, physician communication, emotional support, side effects and complications of their treatment, delay in diagnostic testing, the availability of care, and being treated with respect.

The number of problems in end-of-life care reported by patients was higher when death was nearing. This is consistent with the finding of Sulmasy and McIlvane (2002) that patients who were more likely to be close to death, were more likely to be dissatisfied with physician care. Difficulties in accessibility to help, as well as getting a second opinion from another physician, and patient's uncertainty about the possibility of admissions to an hospital if needed acutely can all be interpreted as signs of difficult access to end-of-life care. You might expect that the need for end-of-life care is higher when death is nearing, which may lead to more perceived problems in end-of-life care.

Further, our data show that in many cases physicians, nurses and paramedical workers from different care settings are involved in the care for one patient. Whereas for patients admitted to a hospital, nursing home or hospice, multidisciplinary meetings may help in fine-tuning care, in the home situation the different health care professionals do not naturally have joint meetings to discuss patients. The specific challenge of home-based end-of-life care might be the fine-tuning of care from health care professionals out of different care settings, such as outpatient clinic, general practice, and home care (Smeenk *et al.* 1998). It is promising that in the Netherlands, recently, several initiatives were taken to enable the fine-tuning in end-of-life care, such as interdisciplinary consultations, case discussions, and co-operation within regional networks of health care providers.

We conclude that most cancer patients receive multidisciplinary end-of-life care, although this care was not always easy accessible. Patients reported that several aspects of communication could be improved. Fine-tuning of interdisciplinary care and easy access to end-of-life care should be important goals in efforts to improve care at the end of life, especially for patients staying at home.

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5

Attitudes of patients with incurable cancer toward medical treatment in the last phase of life

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Abstract

Purpose: When cancer has advanced to a stage in which cure becomes unlikely, patients may have to consider the aim of further treatment. We studied the relationship of patients' attitudes toward treatment with advance care planning and the development of these attitudes after diagnosis of incurable cancer.

Patients and Methods: Patients with incurable cancer were interviewed and asked to fill out a written questionnaire about their attitudes concerning life-prolonging treatment and end-of-life decision-making. These questions were repeated after 6 and 12 months.

Results: One hundred twenty-two patients (mean age, 64 years; standard deviation, 10.5 years; 53% women) participated in the study. Patients' attitudes toward treatment could be categorized into the following three different profiles: striving for quality of life, striving for length of life, and no clear preference. Patients who were older, more tired or had less positive feelings, and patients who had taken more often initiatives to engage in advance care planning were more inclined to strive for quality of life than others. Patients with a history of cancer of less than 6 months were more inclined to prefer life prolongation than patients with a longer history of cancer. During follow-up, no changes in attitudes toward treatment were found, except for patients with a short history of cancer in whom the inclination to strive for length decreased.

Conclusions: Patients who appreciate advance care planning were more inclined to strive for quality of life than other patients. Shortly after the diagnosis of cancer, patients typically seem to prefer life-prolonging treatment, whereas quality of life becomes more important when death is nearing.

Introduction

When cancer has advanced to a stage in which cure becomes very unlikely, decisions have to be made about the aims of further medical treatment. Such treatment can be primarily aimed at prolonging life or at the alleviation of suffering or improvement of quality of life. Patients' preferences concerning the aims of medical treatment and the balance between benefits and side effects of different treatment options are important in medical decision-making when the end of life is nearing (Sepulveda *et al.* 2002).

In a study among patients with metastatic cancer, patients' actual treatment choice was most strongly predicted by patients' treatment preference, and this preference was explained by patients' attitudes toward treatment (Koedoot *et al.* 2003). It is known that cancer patients vary in their attitudes and preferences concerning the aims of medical treatment. Stiggelbout *et al.* (1996) found that younger cancer patients were more often striving for length of life, whereas older patients were more likely to strive for quality of life. Cancer patients who thought that they would survive for at least 6 months were more likely to favor life-prolonging therapy over comfort care than cancer patients who thought they had at least a 10% chance not to survive the next 6 months (Weeks *et al.* 1998). Furthermore, treatment preferences of seriously ill patients who had a limited life expectancy were found to depend on the burden of the treatment, the expected outcome of treatment, and the likelihood of that outcome (Fried *et al.* 2002).

In a European study, physicians reported that end-of-life decisions, such as non-treatment decisions and the alleviation of symptoms with a possible life-shortening effect, most often concerned incompetent patients (Van der Heide *et al.* 2003). However, a vignettes study among oncologists showed that they tend to follow their patients' wishes; oncologists more often preferred palliative chemotherapy for patients who wished to be treated than for patients without such an outspoken wish (Koedoot *et al.* 2002). Therefore, discussion of patients' preferences at an early stage of their disease or completion of an advance directive might enable patients to be involved in medical decision-making concerning the end of their life. However, several studies have shown that advance care planning is mostly ineffective, because advance directives are often vague and the factual situation is often different from the hypothetical situations described in advance directives (Emanuel 2000; Gillick 2004; Meier and Morrison 2002; Thompson *et al.* 2003). Furthermore, only a minority of adults have filled out an advance directive (Gillick 2004). Completion of an advance directive may be stressful for patients because it confronts people with their own possible future deterioration or suffering.

We studied the distribution of patients' attitudes toward medical treatment, how these were related to patient characteristics and the development of these attitudes over time, in a group of patients with incurable cancer. Furthermore, we examined the relationship between patients' attitudes toward treatment and engagement in advance initiatives to participate in medical decision-making concerning their own end of life.

Patients and Methods

Patients

Out-patients with breast cancer, colorectal cancer, ovarian cancer, lung cancer or prostate cancer were asked to participate in the study by forty-five oncologists, pulmonologists, urologists and radiotherapists in the south and southwestern part of the Netherlands. Patients were included within two months of being informed that their cancer was in principle incurable. We defined objective criteria for each type of cancer in order to include an unselected group in whom survival is less than two years in the majority of cases (Table 5-1) (Tumor Registry Munich). Patients were included only after they had given their written informed consent.

Table 5-1. Inclusion criteria

Type of cancer:	Disease stage diagnosed within 2 months before inclusion:
Breast cancer	Metastatic disease at primary presentation (in any organ system) or metastatic disease in at least 2 organ systems after primary treatment
Colorectal cancer	Locally advanced unresectable disease or metastatic disease (without options of curatively aimed surgery) or locally recurrent disease
Ovarian cancer	Recurrent disease
Lung cancer	Metastatic disease or locally advanced disease without curatively aimed treatment options
Prostate cancer	Hormone-independent disease and increasing PSA level (PSA > 20 ng/ml)

Abbreviation: PSA, prostate-specific antigen.

The questionnaire and the interview

The patients filled out a written questionnaire that addressed demographic factors (age, sex, marital status, education, religion, and having children), and psychological status. Positive and negative feelings in the 2 weeks that had preceded the interview were measured with the Positive and Negative Affect Schedule (Peeters *et al.* 1996; Watson *et al.* 1988). The Positive and Negative Affect Schedule contains two subscales, each consisting of ten items; a high positive affect score reflects a state of high energy, full concentration, and pleasurable engagement, and a high negative affect score indicates a high level of distress.

Patients were also interviewed personally at home. The interviewers were prepared for interviewing patients with advanced cancer during a 2-day course in interview techniques. Validated instruments were used in the interview whenever possible. The interview addressed patients' attitudes toward treatment and initiatives to anticipate medical decision-making at the end of life.

The Quality Quantity Questionnaire was used to assess patient's attitudes concerning treatment aimed at quality or length of life (Stiggelbout *et al.* 1996). This questionnaire has been shown to be feasible for use in various groups of cancer patients. Patients had to indicate how strongly they agreed or disagreed with eight items on a five-point Likert scale. A principal components analysis was carried out to analyze the relationships between the items of the Quality Quantity Questionnaire and to identify underlying subscales, in order to confirm the findings of Stiggelbout *et al.* (1996). We used the orthogonal varimax rotation method, which facilitates interpretation by maximizing high correlations between factors and variables and minimizing low ones (Tabachnick and Fidell 1996). The factor solution is based on the eigenvalues (> 1.0). The items could be grouped into two factors (both consisting of four items); one factor contained items indicating an inclination to strive for length regardless of an impaired quality of life (L-scale), whereas the other factor consisted of items indicating an inclination to strive for quality of life at the expense of survival (Q-scale) (Stiggelbout *et al.* 1996). A higher score on the scales means that someone is inclined to strive more strongly for length or quality of life. In our population, only one item loaded on both factors, but more strongly on the Q-scale.

Patients' initiatives to anticipate medical decision-making at the end of their life were addressed by self-constructed questions. We asked patients whether they had refused any potentially life-prolonging treatment, had discussed their wishes concerning medical treatment with their general practitioner, other health care professionals, or their relatives, or felt a need for such a discussion. We also asked the patients whether they had filled out an advance directive. Both these questions and the Quality Quantity Questionnaire were repeated after 6 and 12 months of follow-up.

The interview also addressed factors that might be related to attitudes toward treatment, such as the time since the first diagnosis of cancer, the antitumor treatment the patient had received, and planned antitumor treatment. The European Organisation for Research and Treatment of Cancer Quality of Life Questionnaire C30 (Aaronson *et al.* 1993; Kaasa *et al.* 1995). was used to measure global quality of life, pain and fatigue. The internal consistency of these scales of the European Organisation for Research and Treatment of Cancer ranged from moderate to good (Cronbach's alpha. 0.77 to 0.90).

Statistical analysis

We used Spearman rank correlation test, Student's *t* test, analyses of variances and linear regression analysis to test the statistical significance of relationships between patients' attitudes and type of cancer, patient and care factors. Furthermore, we used the one sample Student's *t* test to test whether the change in patients' attitudes during follow-up was different from 0. To analyze the data we used the Statistical Package for the Social Sciences version 11.0 (SPSS, Inc, Chicago, IL). We used Sigmaplot (Systat Software, Point Richmond, CA) to plot the axes of the Quality Quantity Questionnaire. The Medical Ethical Committee of Erasmus MC, University Medical Center Rotterdam, approved the research protocol.

Results

Patients

Of 200 identified patients, eight had died before an interview could take place. Of the 192 eligible patients, 128 agreed to participate (response rate, 66%). Reasons mentioned not to participate were participation was expected to be too burdensome (n = 29) or patients had a poor physical condition or co-morbidity (n = 18). In 17 cases the reason was unknown. Participants were on average younger (mean age, 63.6 *v* 67.3 years, respectively; P = .02) than non-participants. There were no differences between participants and non-participants regarding sex, primary diagnosis, metastases, co-morbidity, and the application of chemotherapy, radiotherapy or surgery. Sometimes patients agreed to participate and filled out the written questionnaire, but were unable or unwilling to be interviewed on all topics of the interview schedule. Therefore, for six patients, data on attitudes toward treatment were missing.

Attitudes toward medical treatment

The mean scores on the attitude scales are given in table 5-2. In general, patients tended to agree with the items. The mean score on the Q-scale was 15.5 (standard deviation, 3.9) and the mean score on the L-scale was 13.3 (standard deviation, 3.3). Cronbach's alpha was 0.69 for the Q-scale and 0.67 for the L-scale. The scores on the L- and the Q-scale were rather strongly correlated (r = -0.56, P = .000). Of all patients, 38% had simultaneously higher than median scores on the L-scale and lower than median scores on the Q-scale; in contrast, 33% had lower than median scores on the L-scale and higher than median scores on the Q-scale (Fig 5-1). Of the remaining patients, 14% had higher than median scores on both scales and 15% had lower than median scores on both scales.

The associations between personal and disease-specific characteristics of the patients and their attitudes toward treatment are described in table 5-3. Younger patients were

Table 5-2. Scores of patients with incurable cancer on the Quality Quantity Questionnaire

Items of the Quality Quantity Questionnaire[a]	Score			Loadings[b]	
	Mean	SD	Median	Factor 1[c]	Factor 2[d]
To live a bit longer, I would clutch at any straw.	3.4	1.5	4	0.79	-0.20
If I reached a point during treatment at which I felt like giving up, I would probably manage to find the strength to continue.	3.9	1.1	4	0.74	0.05
I would always accept hard-to-tolerate treatment, even if the chance of its prolonging my life was as little as one percent.	2.2	1.5	1	0.59	-0.37
If a treatment could prolong my life, I would always accept it, whatever the side effects might be.	3.8	1.3	4	0.53	-0.31
If a life-prolonging treatment would prevent me from leading a normal life, then I would rather not have it.	4.1	1.2	5	0.04	0.76
A moment might come at which I would say "I have done my best, this is the limit".	3.9	1.4	4	-0.28	0.69
If I had to endure 6 months of intensive treatment to live for an extra half year, then I would not be willing to get that treatment.	3.8	1.4	4	-0.21	0.61
I can imagine some side effects being so bad that I would refuse the treatment, even if that meant a shorter life.	3.8	1.3	4	-0.51	0.61

[a] Scores could range from 1 to 5, with 1 indicating strong disagreement and 5 indicating strong agreement.

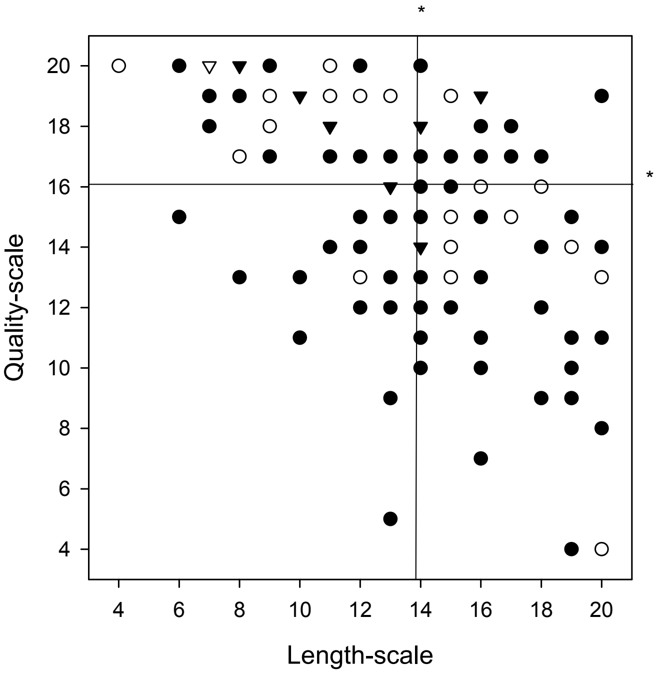
[b] The sizes of the loadings reflect the strength of relationship between each observed variable and each factor.

[c] Factor 1: striving for length of life regardless of impaired quality of life.

[d] Factor 2: striving for quality of life at the expense of survival.

more inclined to prefer life-prolongation. In contrast, patients who were older or more tired, and patients who had less positive feelings were more inclined to strive for quality of life. Patients living without a partner and patients who did not receive chemotherapy also had relatively high scores on the Q-scale. When we adjusted for the effect of age in a linear regression analyses, the associations between the inclination to strive for quality of life and fatigue and positive feelings remained significant, whereas having received chemotherapy was no longer related to the Q-scale. No differences in attitudes toward

Figure 5-1. Scores on the Quality Quantity Questionnaire of patients with incurable cancer. (●), one patient; (○), two patients; (▼), three patients; (▽), five patients. (*) The median length score is 14, and the median quality score is 16.



treatment were found for sex, having children, education, having religious beliefs, and type of cancer. Furthermore, we found no different scores on the Q- and L-scale for patients who had received radiotherapy (36% of all patients) as compared to patients who did not receive radiotherapy, and for those who had received hormonal therapy (21% of all patients) as compared to patients who did not receive hormonal therapy (data not shown).

Attitudes toward treatment and advance care planning

At the time of inclusion, 20% of all patients had discussed their wishes concerning medical treatment at the end of life with a health care professional, most often their general practitioner or clinical specialist, whereas 25% felt a need to do so (table 5-4).

Table 5-3. Characteristics of the patients with incurable cancer related to attitudes toward treatment

	Total	Length-scale (n=122)		Quality-scale (n=120)	
		r [a]	P-value	r [a]	P-value
Individual characteristics					
Age, years		-0.30	0.001	0.22	0.02
Mean	63.5				
SD	10.5				
	N (%)	Mean (SD)		Mean (SD)	
Sex					
Male	57 (47)	13.2 (3.6)	0.66	15.4 (3.4)	0.85
Female	65 (53)	13.5 (4.3)		15.6 (4.2)	
Living					
With partner	94 (77)	13.6 (3.7)	0.20	15.1 (4.1)	0.013
Without partner	28 (23)	12.5 (4.5)		16.8 (2.6)	
Having children					
Yes	105 (86)	14.5 (3.4)	0.18	15.8 (4.5)	0.79
No	17 (14)	13.2 (4.0)		15.5 (3.8)	
Education (n=121) [b]					
Low	87 (72)	13.5 (3.9)	0.33	15.4 (3.8)	0.60
High	34 (28)	12.8 (4.1)		15.6 (4.2)	
Religious beliefs					
Yes	75 (62)	13.1 (4.3)	0.60	15.7 (3.8)	0.68
No	47 (38)	13.5 (3.8)		15.4 (3.9)	
Disease specific characteristics					
Type of cancer			0.14		0.08
Lung	49 (40)	13.7 (3.4)		15.8 (3.2)	
Breast	31 (25)	13.9 (4.0)		14.9 (5.1)	
Colorectal	23 (19)	13.5 (4.0)		14.6 (3.3)	
Ovary	12 (10)	11.0 (4.7)		18.2 (2.0)	
Prostate	7 (6)	11.6 (5.1)		14.6 (4.7)	
Treatment before inclusion					
Surgery	58 (47)	12.9 (4.2)	0.25	15.8 (4.2)	0.49
No surgery	64 (53)	13.7 (3.7)		15.3 (3.5)	
Chemotherapy	94 (77)	13.7 (3.8)	0.051	15.1 (3.9)	0.025
No chemotherapy	28 (23)	12.1 (4.1)		16.9 (3.4)	

Table 5-3. Characteristics of the patients with incurable cancer related to attitudes toward treatment (continued)

	Total	Length-scale (n=122)		Quality-scale (n=120)	
		r [a]	P-value	r [a]	P-value
Quality of life					
EORTC QLQ C30					
Global quality of life		0.03	0.76	-0.16	0.08
Mean	65.7				
SD	19.4				
Pain (n=121)		-0.01	0.94	0.05	0.56
Mean	21.3				
SD	29.8				
Fatigue (n=121)		-0.12	0.21	0.26	0.004
Mean	40.2				
SD	29.5				
PANAS					
Positive affect (n=120)		0.17	0.07	-0.31	0.001
Mean	27.6				
SD	8.0				
Negative affect		0.03	0.78	0.07	0.42
Mean	17.5				
SD	5.8				

Abbreviations: EORTC QLQ C30, European Organisation for Research and Treatment of Cancer Quality of Life Questionnaire C30; PANAS, Positive and Negative Affect Schedule.

[a] Spearman rank correlation coefficient

[b] Low education: lower vocational, lower secondary general education or primary school; High education: Intermediate vocational, higher secondary general education, higher vocational education or university

Furthermore, 39% had discussed such wishes with relatives and 19% felt a need to do so. Wishes discussed concerned pain management, place of death, euthanasia, and conditions for forgoing treatment. Patients who had discussed their wishes were more inclined to strive for quality of life and less to strive for length of life. Only 10 patients had filled out an advance directive (not in table); these patients were less inclined to strive for length of life than those who did not complete an advance directive (mean score on L-scale, 10.4 *v* 13.6, respectively; P = .01). Six patients who had refused a potentially life-prolonging treatment were also less inclined to strive for life-prolongation (mean score on L-scale, 9.7 *v* 13.5; P = .02).

Table 5-4. Relationships between attitudes toward treatment and initiatives to participate in medical decision-making at the end of life in cancer patients, shortly after diagnosis of incurable cancer

	Total	Length-scale (n=122)		Quality-scale (n=120)	
	N (%)	Mean (SD)	P	Mean (SD)	P
Wishes concerning medical treatment					
Discussed these wishes with a health care professional					
Yes	24 (20)	11.3 (4.2)	0.005	17.5 (2.8)	0.003
No	98 (80)	13.8 (3.7)		15.0 (3.9)	
Discussed these wishes with family members or relatives					
Yes	48 (39)	11.8 (3.9)	0.000	17.3 (2.9)	0.000
No	74 (61)	14.4 (3.6)		14.3 (4.0)	
Need to discuss these wishes with a health care professional					
Yes	30 (25)	13.2 (3.8)	0.74	16.5 (3.0)	0.09
No	90 (75)	13.4 (4.0)		15.1 (4.1)	
Need to discuss these wishes with family members or relatives					
Yes	21 (19)	13.9 (3.7)	0.54	15.0 (4.4)	0.59
No	99 (81)	13.3 (4.0)		15.5 (3.8)	

Development of attitudes toward treatment over time

The patients' L- and Q-scores at inclusion were also related to several characteristics of the disease course (table 5-5). Patients with a short history of cancer tended to be more inclined to prefer life-prolongation than patients with a longer history of cancer (P = .06). In contrast, patients who died within 6 months after inclusion had at inclusion higher Q-scores than patients who survived for more than 6 months (P = .01). Of 67 patients who participated 6 months or more in our study, 43% had discussed their wishes concerning end-of-life treatment with a health care professional during the first 6 months of follow-up, but this was not related to the scores on the L- and Q-scale at baseline. Of the patients who participated 6 months or more in our study, 12% had refused a life-prolonging therapy during the first 6 months of follow-up; these patients were more inclined to strive for quality of life than others (mean Q-score, 18.3 *v* 15.2; P = .00). After 6 months of follow-up only 5 patients (7%) had completed an advance directive, and of these patients, only one patient filled out the advance directive during the follow-up

Table 5-5. Development of attitudes toward treatment among patients with incurable cancer

	Total number of patients	Length-scale (n=122) Mean (SD)	P	Quality-scale (n=120) Mean (SD)	P
Baseline scores					
Disease duration until inclusion					
≤ 6 months	72	13.9 (3.6)	0.06	15.2 (3.6) [a]	0.32
> 6 months	50	12.5 (4.3)		15.9 (4.2)	
Survival after inclusion					
≤ 6 months	32	13.6 (4.0)	0.61	16.8 (2.7)	0.01
> 6 months	87	13.2 (4.0)		15.0 (4.2) [a]	
Change in scores compared with baseline					
After 6 months follow-up	67	-0.5 (4.0)	0.33	-0.5 (4.6) [b]	0.38
After 12 months follow-up	32	-0.3 (3.1)	0.61	0.1 (3.5)	0.88

[a] Two missing values;

[b] One missing value.

period. Patients who had completed an advance directive after 6 months of follow-up were at baseline more inclined to strive for quality (mean Q-score, 19.6 *v* 15.2; P = .00) and less inclined to strive for life-prolongation (mean L-score, 9.2 *v* 13.5; P = .02) than patients who had not completed an advance directive.

Furthermore, we did not find changes in attitudes toward treatment 6 or 12 months after inclusion, except for patients with a history of cancer of less than 6 months at inclusion, in whom L-scores decreased (mean score, 14.2 at baseline *v* 12.9 at 6 months; n = 36; P = .02), whereas the Q-scores remained stable over time (mean Q-score, 14.8 *v* 14.5; n = 35; P = .75).

Discussion

Patients with advanced cancer vary in their attitudes concerning the use of life-prolonging treatment. The scores on the scales of the Quality Quantity Questionnaire were consistent with the scores found by Stiggelbout *et al.* (1996) in a group of patients with cancer at various stages of the disease. Furthermore, at baseline, about one third of the patients had relatively high L-scores and low Q-scores, which may be interpreted as indicating a relatively clear preference for the use of life-prolonging treatment even if that would impair their quality of life. Navari *et al.* (2000) also showed that many patients with advanced cancer preferred to be treated although the chance of prolonging life was very small. This preference for potential life-prolonging therapy may be caused by the patient's wish not to give up hope (Finucane 2002) or by a poor understanding of the prognosis (Weeks *et al.* 1998). Another third of our patients had low L-scores and high Q-scores, which may represent an inclination to refrain from life-prolonging intervention because quality of life is considered more important than length of life. The remaining one third of our patients did not have a clear preference for quality or length of life. These patients seemed unable (low scores on both scales) or unwilling (high scores on both scales) to express a preference concerning the aim of medical treatment. Apparently, quality of life and prolonged survival have to be distinguished as separate axes and cannot be interpreted as the ends of one single, continuous scale. This is supported by the two factors that were identified by the principal-component analysis.

An inclination to strive for quality of life and to attach less importance to prolongation of life is related to older age, experiencing fatigue and having a low level of positive feelings. The variability in attitudes toward treatment found in our patients is consistent with studies in elderly patients, other groups of cancer patients, and severely ill patients (Ditto *et al.* 2003; Fried *et al.*; Stiggelbout *et al.* 1996; Weeks *et al.*). The association between having received chemotherapy and striving for quality of life is probably due to the fact that chemotherapy was predominantly given to relatively young patients who more often than others had breast, ovarian or colorectal cancer.

Only a small minority of the patients in our study had completed an advance directive or had refused a potentially life-prolonging treatment. Patients' involvement in actual medical end-of-life decision-making was mostly limited to discussing their wishes with a health care professional or with relatives. Patients who had discussed their wishes or who had taken initiatives to participate in end-of-life decision-making were more inclined to strive for quality of life at the possible expense of length of life than others. Apparently, patients' concerns about the perspective of receiving medical treatment that is predominantly aimed at life-prolongation in the last phase of their lives, more often result in advance care planning than concerns that such treatment will be forgone. Whether a preference for medical care aimed at quality of life is indeed less often granted than a preference for prolonging life cannot be concluded from our study. Teno *et al.* (2002) found, however, that more than one third of the patients who preferred comfort care reported that the medical care they received was focusing on extending life and therefore inconsistent with their goals.

We found that patients with a short history of cancer tended to be more inclined to prefer life-prolongation than patients with a longer history of cancer. In a longitudinal study Danis *et al.* (1994). found that persons were more likely to desire more treatment after they had experienced a health-threatening situation, such as having been hospitalized, having had an accident or had become more immobile. Accordingly, patients in our study may have been more inclined to strive for length of life shortly after they were informed about the diagnosis of cancer than before. In our study, we did not find changes in attitudes toward treatment during 12 months follow-up, except for patients with a history of cancer of less than 6 months in whom the inclination to strive for length of life decreased. It is suggested that quality of life gains importance when death is nearing. Weeks *et al.* (1998) found, e.g., that cancer patients with a more accurate understanding of their poor prognosis were more inclined to favor comfort care over life-extending therapies. Furthermore, in our study, patients who died within 6 months after inclusion were at inclusion more inclined to strive for quality of life than patients who survived for more than 6 months. Thus, changes in attitudes may predominantly occur shortly after the primary diagnosis of cancer and shortly before death, respectively. The fact that in most studies, treatment preferences were found to be rather stable over time (Ditto *et al.* 2003; Patrick *et al.* 1997) may be explained by their follow-up windows, which are often in between these extremely significant points in time. Further, the limited number of patients for whom 12 months follow-up data were available restricts drawing firm conclusions on the stability of attitudes in our study.

Our study has some limitations. Our group of patients was probably somewhat selected, because patients with a very poor health status and patients who died shortly after the diagnosis of advanced cancer could not be interviewed. Furthermore, most patients who declined to participate did not want to talk about their disease because they considered it too burdensome. Another limitation is the relatively small number of patients. Due to a poor prognosis only a small group of patients could be involved in the analyses over time, which makes further longitudinal research to confirm our findings necessary.

We conclude that attitudes toward medical treatment vary in cancer patients in whom the cancer is, in principle, incurable. One third of the patients can be classified as striving for length of life, whereas another third is striving for quality of life; the remaining third of the patients seemed unable or unwilling to express a preference concerning the primary aim of treatment. Older patients, patients who are more tired or have less positive feelings, and patients who appreciate advance care planning are more inclined to strive for quality of life. Discussing wishes concerning medical treatment with doctors predominantly seems to result from patients' attitude to give priority to the quality over the length of life. This suggests that, according to many patients, the standard medical treatment offered in the last phase of life is focused on length of life, whereas a preference for quality of life requires discussion with doctors. Further research is necessary to explore patients' expectations and understanding of the aim of medical treatment at the end of life. A proactive attitude of oncologists and other doctors towards discussing patients' perspectives on anticipatory decision-making may contribute to patient-centered end-of-life care for all types of patients.

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6

Information needs of patients with incurable cancer

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Abstract

Goals: The aims of this study were to describe to what extent cancer patients with incurable cancer report to have been informed about disease-related topics, and how they evaluate the quality of the information giving.

Patients and methods: Hundred-and-twenty-eight patients participated in our study within two months after having had a diagnosis of incurable cancer. They filled out a questionnaire and were interviewed personally. We assessed the level of information, information needs and demographic factors, and we registered the type and duration of the cancer, cancer therapy, other types of received care and contacts with health care professionals. Furthermore, we assessed patients' appreciation of the information giving by their health care professionals.

Main results: The majority of the patients said to have been informed about treatment options, side effects of their treatment, physical symptoms, where to get help, helpful devices, and diet, while less than half of the patients were informed about psychosocial care, euthanasia, and complementary care. Of all patients, 39% felt a need for additional information about topics such as physical symptoms, diet, euthanasia, and alternative or complementary care, while 19% would have appreciated extra written information. Most patients (78%-88%) were satisfied with the information giving by the clinical specialist, oncology nurses, and non-specialised nurses, but only 63% evaluated the information giving by general practitioners as good.

Conclusion: We conclude that most patients feel sufficiently informed about important disease-specific issues and are satisfied with the information giving by health care professionals. Nevertheless, a considerable number of patients appreciate additional information.

Introduction

Most patients with cancer want to be fully informed about their disease and treatment. A study of information needs among 2331 cancer patients in the UK by Jenkins *et al.* (2001) showed that 87% of patients receiving either curative or palliative treatment wanted to be informed about good as well as bad news by their doctors. The 13% who would leave it up to their doctor to disclose information or not were usually above 70 years of age. Possible predictors of information need are patient characteristics such as age, sex and education, and disease-related factors such as type of cancer, disease stage, and time since diagnosis (Jenkins *et al.* 2001; Kutner *et al.* 1999; Mills and Davidson 2002).

Although it is known that most patients want to be informed about their diagnosis and treatment, little is known about what other disease-related topics patients want to be informed about, and it is unknown to what extent information needs change during the course of the disease. The actual need for information may be a consequence of having received little information, but other factors, such as the degree to which information is recalled, are also important. The degree to which information is adequately recalled is related to patients' education level, age and psychological distress (Kessels 2003). Information given directly after hearing a diagnosis of cancer is likely to be forgotten due to anxiety (Kessels 2003).

Data about how cancer patients evaluate the information giving are scarce. A study among cancer patients showed that about 25% of the patients rated the quality of the information giving by the general practitioner as fair or poor, while less than 10% gave a fair or poor rating to the information giving by the specialist nurses (Mills and Davidson 2002).

We studied whether patients with advanced cancer feel to be sufficiently informed about topics related to the disease, and how they evaluate the quality of the information giving.

Patients and methods

Patients

Over a period of 2 years, patients were included by 45 oncologists, pulmonologists, urologists and radiotherapists from 15 hospitals in the south and south-western part of the Netherlands. These clinical specialists selected patients who had one of the five most frequently occurring lethal cancer types, which had recently progressed into a probably incurable stage. In order to include an unselected group in whom survival is less than two years in the majority of cases (Tumorregistry Munich), we defined the following objective inclusion criteria: Breast cancer with either metastases at primary presentation (in any organ system) or metastases in at least two organ systems after primary treatment; Colorectal cancer with either locally advanced unresectable disease or with metastases (without options of curative surgery) or local recurrence of the tumour; Ovarian cancer that recurred after initial treatment; Lung cancer with either metastases or locally advanced disease without curative treatment options; Prostate cancer with hormone independent disease and increasing PSA level (PSA > 20 ng/ml). Patients were informed about the study orally and in writing. Patients were included only after they had given their written informed consent.

The researchers contacted the participants by telephone to affirm their participation, sent them a written questionnaire, and arranged a personal interview. Medical details were registered for each approached patient, anonymously for patients who did not participate in the study. All interviewers were trained in a two-day course by the researchers and by a psychologist to prepare them for interviewing seriously ill patients. The medical ethical committee of each participating hospital approved of the study.

Questionnaire and interview

The written questionnaire, which patients filled out before the interview, included demographic factors (age, sex, living arrangement, education, and religion), the level of information and information need. The information level and the information need were assessed by questions based upon the "Problems and Needs in Palliative Care Questionnaire" (PNPC) (Osse *et al.* 2002). The PNPC lists twelve disease-related topics where patients may be informed about: helpful devices, organisations that provide help and devices, cause of cancer, treatment options and side effects, physical symptoms that may be expected, alternative medicine, euthanasia, food and diet, sexuality, psychosocial care, complementary care, and care settings. Patients were invited to add other topics they had received information about. Patients had to indicate if they were informed sufficiently, to some extent or not about these topics. When patients indicated to have a wish for additional information, they were asked about which topics.

Patients were also interviewed personally at home. In the interview, we registered the type and duration of the cancer, cancer therapy, other types of received care and contacts with health care professionals. Furthermore, we assessed patients' appreciation of the information giving by the general practitioner, the clinical specialist, oncology nurses, and non-specialised nurses.

The interview and questionnaire also addressed psychological factors that might be related to information need. We used the Hospital and Anxiety Scale (HADS) (Spinhoven *et al.* 1997; Zigmond and Snaith 1983) to measure anxiety and depression. Disease-specific coping was operationalised by the adapted Utrecht Coping List (Sanderman and Ormel 1992; Schreurs *et al.* 1993), in which we reformulated the introduction section to focus patients on their current style of coping with (advanced) cancer and disease-related problems (Oldehinkel *et al.* 1992).

Statistical analysis

The number of topics patients were informed about, patients' information need, and patients' appreciation of the information giving by health care professionals are presented in frequency tables. We used Student's t-test, analysis of variance, Pearson's Chi-square, and Yates' correction or the Fisher's exact test if applicable, to test the statistical significance of relationships between the number of topics patients were informed about, the information need and patients' appreciation of the information giving, patient's characteristics, cancer therapy and other types of care, and psychological distress. To analyse the data we used the Statistical Package for the Social Sciences (SPSS) version 11.0.

Results

Patients

From 2001 until 2003, 45 clinical specialists participated for four months or more in the study and identified 200 patients. Nineteen clinical specialists identified 152 of these patients (that is, on average 8 patients per specialist), whereas the other 26 specialists identified 48 patients (on average 2 patients per specialist). Of 200 identified patients, eight had died before an interview could be arranged. Of the 192 eligible patients, 128 agreed to participate (response rate: 67%). Reasons mentioned not to participate were: participation was expected to be too burdensome (n=29) or a poor physical condition or co-morbidity (n=18). In 17 cases the reason was unknown. Participants were younger than non-participants (mean age was 63.6 versus 67.3 years; p= 0.02). There were no differences between participants and non-participants regarding sex, primary diagnosis, metastases, co-morbidity, and the application of chemotherapy, radiotherapy or surgery. Sometimes patients agreed to participate and filled out the written questionnaire, but were unable or unwilling to complete the interview schedule. As a result, for two patients data on contact with health care professionals and appreciation of information giving were missing.

Participants (62 men and 66 women) suffered from cancer of the breast (n=31), lung (n=53), colon and/or rectum (n=23), ovary (n=12), or prostate (n=9). Prior to the interview, 75% of the patients had received chemotherapy. The patients' characteristics are summarised in table 6-1.

Topics patients were informed about

The majority of the patients reported to have been informed about treatment options and side effects (96%), physical symptoms (80%), helpful devices (67%), organisations where to get help and devices (68%), and diet (56%). Less than half of the patients were

Table 6-1. Characteristics of the patients

	Patients (N=128)
Age (years)	
Mean (SD)	63.6 (10.5)
Length of disease (months)	
Mean (SD)	19.8 (30.2)
	N (%)
Sex:	
Male	62 (48)
Female	66 (52)
Living:	
With partner	98 (77)
Without partner	30 (23)
Education:[a]	
Low	92 (72)
High	35 (28)
Religious beliefs:	
No	49 (38)
Yes	79 (62)
Cancer type:	
Breast	31 (24)
Lung	53 (41)
Colon / rectum	23 (18)
Ovary	12 (9)
Prostate	9 (7)
Received cancer therapy:	
Surgery	59 (47)
Chemotherapy	94 (75)
Radiotherapy	46 (36)
Hormonal therapy	27 (21)
None	3 (2)

[a] Low education: Lower vocational, lower secondary general education or primary school; High education: Intermediate vocational, higher secondary general education, higher vocational education or university.

informed about the cause of their cancer (35%), psychosocial care (29%), the impact of cancer on sexuality (28%), care settings (22%), euthanasia (17%), alternative medicine (14%), and complementary care (7%) (see table 6-2).

The number of topics about which the patients were informed varied from 0 to 12 (mean= 5.2, SD= 2.2). On average, patients living without a partner were informed about

5.9 topics on average, compared to 4.9 for patients living with a partner (t-test, p= 0.04). The number of topics patients were informed about did not vary by sex, age, disease duration, education level, having or not having religious beliefs, cancer type, and having or not having received cancer therapy.

Appreciation of information giving

Most patients had consulted several professional caregivers from whom they could have received information, during the three months preceding the interview: all patients had had contact with a clinical specialist, 86% with a general practitioner, 73% with an oncology nurse, and 79% with a non-specialised nurse.

The information giving by clinical specialists was considered to be of good quality by 80% (see table 6-3). The information giving by general practitioners was considered to be of good quality by 63%, of moderate quality by 17%, and of bad quality by 13% of all patients who had seen a general practitioner. 88% of the patients who had seen an oncology nurse considered the information giving by the oncology nurse of good quality. Furthermore, the information giving by non-specialised nurses was considered to be of good quality by 78% of all patients who had seen a non-specialised nurse.

Table 6-2. Reported information level in patients with incurable cancer, reported in response to specific questions (ranked) (N=128)

Informed about? [a]	No N (%)	To some extent N (%)	Sufficiently N (%)
Treatment options and side effects	5 (4)	34 (27)	89 (70)
Expected physical symptoms	25 (20)	39 (31)	64 (50)
Organisations that provide help	40 (32)	31 (25)	54 (43)
Helpful devices	41 (33)	25 (20)	59 (47)
Food and diet	56 (44)	27 (21)	44 (35)
Cause of cancer	83 (65)	25 (20)	20 (16)
Psychosocial care	90 (71)	20 (16)	17 (13)
Sexuality and cancer	88 (72)	15 (12)	20 (16)
Care settings	98 (78)	21 (17)	7 (6)
Euthanasia	106 (83)	10 (8)	12 (9)
Alternative medicine	110 (86)	8 (6)	10 (8)
Complementary care	119 (93)	4 (3)	5 (4)

[a] On six topics data about being informed are missing for one to five patients.

Table 6-3. Cancer patients' appreciation of information giving by professionals with whom patients had had contact in the preceding 3 months (N=125)

	Contact in the last 3 months	Patients' appreciation of information giving			
		Good	Moderate	Bad	Not applicable
	N (%)	N (%)	N (%)	N (%)	N (%)
Professional caregivers					
Clinical specialist [a]	125 (100)	99 (80)	16 (13)	6 (5)	2 (2)
General practitioner	107 (86)	67 (63)	18 (17)	14 (13)	8 (8)
Oncology nurse [b]	66 (73)	58 (88)	7 (11)	0 (0)	1 (2)
Non-specialised nurses	98 (79)	76 (78)	12 (12)	4 (4)	6 (6)

[a] Data about appreciation of information giving are missing for two patients.

[b] Data about contact and information giving are missing for 38 patients, because these questions were not included in the first version of the patient questionnaire.

Thirty-nine percent of the patients felt a need for additional information about one or more topics, such as euthanasia (21%), alternative medicine (19%), physical symptoms (17%), food and diet (16%), complementary care (15%), the cause of cancer (13%), treatment options and side effects (13%), care settings (13%), psychosocial care (6%) or other topics (19%). Nineteen percent of the patients would have appreciated extra written information.

Patient and care characteristics related to information need

The information need was not related to age, sex, having or not having religious beliefs, and having or not having received cancer therapy, but patients living without a partner reported more often a need for additional information than patients living with a partner (59% vs. 33%; Chi-square test, p= 0.02). Further, patients with a high education felt more often a need for additional information than patients who were lowly educated (57% vs. 32%; Chi-square test, p=0.02), and patients with a disease duration of more than six months expressed more often a need for additional information than others (54% vs. 28%; Chi-square test, p=0.006). Information need was also related to type of cancer (Chi-square test; p= 0.02): patients with ovary cancer relatively often felt a need for additional information, whereas patients with lung cancer relatively rarely had a need for additional information. Anxious patients tended to more often feel a need for information than patients without anxiety (see table 6-4), while the level of depression and coping styles were not related to the need for additional information (data on coping styles not shown).

Table 6-4. Associations between information need and psychological characteristics, information giving, and other types of care

	Need for information (N=48)	No need for information (N=76)	
	N (%)	N (%)	P-value
Psychological characteristics			
Anxiety (HADS)			
No	32 (34)	63 (66)	0.06
Yes	16 (55)	13 (45)	
Depression (HADS)			
No	31 (36)	55 (64)	0.47
Yes	17 (45)	21 (55)	
Information giving			
Number of topics informed about (range: 0-12)			
Few topics (< 6)	30 (42)	41 (58)	0.45
Many topics (≥ 6)	18 (34)	35 (66)	
Quality of information giving by HCP [a]			
General practitioner			
Good	21 (31)	46 (69)	0.30
Moderate /bad	15 (44)	19 (56)	
Clinical specialist			
Good	29 (30)	67 (70)	0.001
Moderate /bad	15 (71)	6 (29)	
Oncology nurse			
Good	19 (34)	37 (66)	0.01
Moderate /bad	6 (86)	1 (14)	
Non-specialised nurses			
Good	25 (33)	50 (67)	0.15
Moderate /bad	9 (56)	7 (44)	
Other types of care			
Use of complementary care or alternative medicine	24 (50)	24 (50)	0.04
Yes	22 (30)	51 (70)	
No			
Need for complementary care or alternative medicine	9 (64)	5 (36)	0.07
Yes	38 (35)	70 (65)	
No			

[a] HCP: health care professional

Information need was not related to the number of topics patients were informed about. However, patients who rated the quality of the information giving by the clinical specialist or the oncology nurse as good expressed relatively rarely a need for additional information. There was no relationship between information need and the rating of the quality of information giving by the general practitioner or non-specialised nurses.

Furthermore, information need was not related to whether or not patients had received cancer therapy (data not shown). However, patients who had received complementary care or alternative medicine felt relatively often a need for additional information, and patients who felt a need for extra complementary care or alternative medicine tended to more often express a need for additional information as well (see table 6-4).

Discussion

In our study, most patients with a recent diagnosis of incurable cancer said to have been informed about important medical topics, such as treatment options and side effects, and physical symptoms. The need for additional information seldom involved these topics. Most patients were positive about information giving by their professional caregivers. These results suggest that most patients felt to be sufficiently informed about medical topics.

Few patients were informed about topics such as euthanasia, complementary care or alternative medicine. Irrespective of how well informed patients reported to be, a substantial percentage of patients felt a need for additional information, often about topics such as food, diet, and alternative or complementary care. Because these topics are not strictly medical, professional caregivers might give them less attention than medical topics. Further, patients might have included existential issues ('why me'), when they said they wanted information about the cause of cancer.

Patients in the studied group expressed a need for additional information more often if they lived without a partner. In general, patients living with a partner jointly visit their clinical specialist or other health care professionals. Both patient and partner can ask questions, and afterwards they can discuss the information with each other. Therefore, patients living with a partner may get more information, and their partner may help them to remember what is said during the consultation. Further, patients who live without a partner might need more information because they may consider more than others the possibility of becoming dependent of professional contacts only in the future. The finding that highly educated patients more often expressed a wish for additional information may be due to the fact that highly educated people are more used to solving problems by seeking information. Accordingly, these patients may seek and use information in order to cope with their diagnosis of incurable cancer. The finding that patients with longer disease duration more often feel a need for additional information may be explained by the fact that these patients have had the opportunity to adapt to their new situation. As a result, they may be more capable to digest new information than patients for whom the cancer is found to be incurable at or shortly after its primary presentation.

Anxious patients tended to more often express a need for additional information than patients without anxiety. It has been suggested that a lack of information can cause distress for patients (Jefford and Tattersall 2002). However, a review showed that in the majority of intervention studies, information giving to cancer patients had no effect on psychological indices (McPherson *et al.* 2001). The feeling of being informed insufficiently may also be the effect of anxiety, because information given when someone feels very anxious is likely to be forgotten (Kessels 2003). Information need of anxious patients may, on the other hand, also be an expression of their feeling that they need help. Although psychological distress can probably not be addressed by information giving alone, Ptacek and Ptacek (2001*)* showed that the way of information giving matters. Satisfaction with the bad news transaction was higher if the environment was comfortable, if plenty of time was taken with the patient, and if the physician attempted to empathize with the patient's experiences. The observed variation in patients' appreciation of information giving by professionals in our study may be also due to differences in the way of information giving.

Patients who were involved in complementary care or alternative medicine felt relatively often a need for additional information. Sollner *et al.* (2000) have identified three predictors of use of and interest in complementary care or alternative medicine: younger age, progressive cancer and active coping behaviour. Seeking information and interest in complementary care or alternative medicine may both be expressions of active coping behaviour. Physicians should be aware of a patient's wish to actively fight their disease. It has been suggested that physicians should actively discuss with cancer patients what they can do to improve their situation instead of only relying on medical treatment (Sollner *et al.* 2003). Tasaki *et al.* (2002) have suggested that information materials about complementary care or alternative medicine in the waiting room may set the tone for openness to discuss complementary care or alternative medicine. Burstein *et al.* (1999) found an association between use of alternative medicine and psychological distress. This finding suggests that patients' information need and use of complementary and alternative medicine may both be an expression of a coping strategy or a need for help.

These findings suggest that information needs are not always optimally addressed by increasing the amount of information given. Information needs may be the result of anxiety or of patients' desire to actively fight their disease. Therefore, health care professionals should be aware of and pay attention to problems or needs underlying the information need.

Our study has some limitations. Our group of patients was probably somewhat selected, because patients with a very poor health status and patients who died shortly after the diagnosis of incurable cancer could not be interviewed. Furthermore, most patients who declined to participate did not want to talk about their disease because they considered it too burdensome. Besides, we cannot preclude a selection bias towards patients who were less ill or who had a better or longer relationship with the physician.

These factors may have led to an overestimation of the information level and an underestimation of the information needs. Finally, our data were restricted to patients' experiences. We have no data from the health care professionals and we do not know what was actually said during the consultations.

We conclude that most patients with incurable cancer feel well informed about medical aspects of their disease. However, a considerable number of patients feel a need for additional information about diets, euthanasia, complementary care, alternative medicine and the cause of cancer. It is important that health care professionals are aware of their patients' information need. This does not imply that they should provide as much information as possible. Doctors and nurses should be aware of problems or needs underlying the information need and the information offered should be tailored to individual patients.

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7

Dying at home or in an institution: perspectives of Dutch physicians and bereaved relatives

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Submitted

Abstract

Most people prefer to die at their own home. We investigated whether physicians or bereaved relatives in retrospect differently appreciate the dying of patients in an institution or at home. Of 128 patients with incurable cancer who were followed in the last phase of their lives, 103 passed away during follow-up. After death, physicians filled out a written questionnaire for 102 of these patients and 63 bereaved relatives were personally interviewed. Of 103 patients, 49 died in an institution (mostly a hospital) and 54 died at home (or in 2 cases in a home-like situation). Patients who had been living with a partner relatively often died at home. Bereaved relatives knew of the patient's wish to die at home in 25 out of 63 cases; 20 of these patients actually died at home. Thirty-one patients had no known preference concerning their place of dying. Most symptoms were equally prevalent in patients dying in an institution and patients dying at home. Bereaved relatives were in general quite satisfied about the provision of medical and nursing care in both settings. We conclude that most patients' preferences concerning the place of dying can be met. In about half of all cases, patients do not seem to have a clear preference concerning their place of dying, which is apparently not a major concern for many people. We found no indication that dying in an institution or at home involves major differences in the process and quality of dying.

Introduction

The two most important events in life, that is, birth and death, relatively often occur at home in the Netherlands. Over the period 1995-2000, around one third of all Dutch births were home deliveries (Anthony *et al.* 2005). Further, in 2001, about 40% of all deaths have been found to occur at home, 40% in hospital, and about 20% in nursing homes (Van der Heide *et al.* 2003). Medical care in the Netherlands is strongly founded on home-based general practice. General practitioners or family physicians provide all basic medical care to outpatients and serve as a gate door to specialized care for patients with more complex health problems.

In 2003, around 45% of deaths due to cancer occurred at home in the Netherlands (Statistics Netherlands). In the United Kingdom, the percentage of cancer deaths at home is lower and falling, from 27% in 1994 to 22% in 2003 (Gomes and Higginson 2006). In a study of the place of death of cancer patients in the Houston area, United States, 35% died at home (Bruera *et al.* 2003). End-of-life care is thus especially in the Netherlands rather often provided in the home situation, by general practitioners, homecare nurses and informal caregivers. Research has shown that dying at home is usually preferred to dying in an institution, in the Netherlands as well as in other countries (Higginson and Sen-Gupta 2000). Such a preference seems to be predominantly shaped by whether or not people have sufficient informal carer resources (Thomas *et al.* 2004). In contrast, people who are concerned about the medical management of their symptoms may appreciate the easy access to professional caregivers in an institutional setting. Concerns about burdening relatives has also been found to contribute to a wish to die in an institution (Thomas *et al.* 2004). The finding that people's wish to die at home becomes less predominant when death is nearing may be related to such concerns, since heavily burdening relatives with care duties is one of the most commonly recognized threats to a peaceful dying process (Higginson and Sen-Gupta 2000). A gradual shift in preference may also be due to the growing awareness of seriously ill people that dying sometimes involves problems and symptoms that are best treated by professional caregivers in an institutional setting. Finally, differential experiences of services also influence people's preferences (Thomas *et al.* 2004).

Enabling people to make genuine choices about their end-of-life care and to die at the place they prefer, is often seen as a major challenge to current end-of-life care (Davies and Higginson 2004; Ahlner-Elmqvist *et al.* 2004; Grande *et al.* 1998). Home-care patients have been reported to have more control over the effects of their illness, medical care and treatment received, than patients receiving institutional care (Peters and Sellick 2006). However, it is unclear if the relatively high home death rate in the Netherlands is really beneficial to the quality of death and dying. Little is known about the experiences of dying patients and their caregivers in different health care settings. We investigated to what extent dying in an institution or at home involves differences in care and its appreciation by physicians and bereaved relatives.

Methods

Patients

This study concerns a sub-sample of a cohort of 128 patients with advanced breast cancer, colorectal cancer, ovary cancer, lung cancer or prostate cancer, who were followed for a study on end-of-life care needs and practices during the last stage of their lives (Voogt *et al.* 2005). Of these patients, 103 died within the time frame during which we were able to approach attending clinical specialists, general practitioners and bereaved relatives for an after-death data collection. In 102 cases, physicians were willing to fill out a written questionnaire on the medical treatment and dying process of these patients: questionnaires were filled out by clinical specialists in 30 cases, by general practitioners in 17 cases, and by both in 55 cases. Relatives who had been closely involved with the patient could be contacted in 91 cases; 63 gave their written consent to be personally interviewed at their own home. The reason for not participating was most often that relatives expected participation to be too burdensome. The patients for whom bereaved relatives participated in an interview had on average a longer disease duration (33 vs. 21 months; p=0.03) and were more often women (59% vs. 28%; p=0.004) than other patients.

The Medical Ethical Committee of the Erasmus MC, University Medical Center Rotterdam approved the research protocol.

Questionnaire for attending physicians

As soon as we were informed of the death of a patient, physicians received a self-developed written questionnaire addressing the end-of-life medical treatment and decision-making. The median time between the patient's death and filling out the questionnaire was 12.5 weeks (range, 1 week to 59 weeks). The questions on end-of-life decision-making were based upon questionnaires that have proven to yield valid information in previous studies (Van der Heide *et al.* 2003; Van der Maas *et al.* 1996). In cases where both a clinical specialist and a general practitioner filled out a questionnaire, the information about the patients' anti-tumour treatment history, medical decision-making and any 'negative' aspects of the dying process was considered to be additive.

Interview with bereaved relatives

Interviewers were trained to carry out interviews with vulnerable people during a two-day course. The interviews were on average held 4.9 months after the patient's death (range, 0.8-9.5 months). The interview schedule included the following topics: personal characteristics of the bereaved relatives, such as age, sex, and relationship with the patient; symptoms of the patient, that is, loss of appetite, pain, fatigue, dyspnoea, nausea, mouth or mucous problems, incontinence, bedsores, confusion, anxiety and depression; and whether or not the patient was treated for these symptoms. The patient symptom list was based upon the EORTC QLQ C30 (Aaronson *et al.* 1993; Kaasa *et al.* 1995) and the Problems and Needs in Palliative Care questionnaire (Osse *et al.* 2002; Osse *et al.* 2004) and completed with psychological symptoms. Further, contacts with health care professionals, admission to hospital or other care institutions, the actual and preferred place of death, and problems in end-of-life care during the last 3 days of life were assessed using scales from the Voices Of Informal Carers – Evaluation of Services (VOICES) questionnaire (Addington-Hall and McCarthy 1995). Finally, we asked the bereaved relatives about the burden of care giving. We adapted several questions from the Caregiver Reaction Assessment to make them applicable for an after-death interview with bereaved relatives (Nijboer *et al.* 1999).

Statistical analyses

We compared the characteristics of patients who died in an institution with the characteristics of patients who died at home. Student t-tests and Chi-square tests were used to assess the statistical significance of differences between both groups. All analyses were done using the Statistical Package for the Social Sciences (SPSS) version 11.0.

Results

The characteristics of all 103 deceased patients and of 63 patients for whom an after-death interview with a bereaved relative was available are presented in table 7-1. The mean age at death of all patients was 65 years; 48 patients (47%) were female. The most common types of cancer were lung cancer (48 patients) and breast cancer (19 patients). Of all 103 patients, 49 died within an institution: 35 patients died at a hospital department, 6 patients died after having been admitted to a department within a hospital, nursing home or home for the elderly that was specialized in care for dying patients, 4 patients died within a general department of a nursing home or home for the elderly, and 4 patients died in a hospice. The remaining 54 patients died at home or in a home-like situation: 52 patients died in their own homes, 1 patient died in the home of a son and 1 patient died during a holiday on a boat. The only significant difference between patients dying in an institution and patients dying at home concerned the percentage who had lived with a partner, which was 63% for patients who died in an institution and 83% for patients who died at home. All other characteristics of patients and relatives that are listed in table 1 were similar in both groups. The characteristics of the group of patients for whom a relative could be interviewed were also similar to the characteristics of the total group. The interviewed relative was the patient's spouse in 39 out of the 63 cases; in 19 cases it was a son or daughter, and in 5 cases another relative. The majority of relatives were female and their mean age was 55 years.

Table 7-1. Characteristics of patients and bereaved relatives

	All deceased patients (N=103)	Deceased patients for whom a relative was interviewed (N=63)
Patients		
Age at death, in years		
Mean (SD)	65 (11)	64 (11)
	n/N (%)	n/N (%)
Sex		
Female	48/103 (47)	37/63 (59)
Living arrangement		
With partner	76/103 (74)	47/63 (75)
Education		
Low[a]	71/102 (70)	41/63 (65)
Religion		
Religious	62/103 (60)	40/63 (63)
Urbanisation		
Living in urban area[b]	72/103 (70)	46/63 (73)
Primary tumour site		
Lung	48/103 (47)	31/63 (49)
Breast	19/103 (18)	14/63 (22)
Other	36/103 (35)	18/63 (29)
History of anti-tumour treatment:		
Surgery	45/102 (44)	26/62 (42)
Chemotherapy / hormone therapy	84/101 (83)	51/61 (84)
Radiotherapy	54/101 (54)	36/61 (59)
Place of death		
Institution	49/103 (48)	29/63 (46)
Hospital	35/49	24/29
End-of-life care unit	6/49	2/29
Hospice	4/49	3/29
Nursing home / home for the elderly	4/49	-
At home or in a home-like situation	54/103 (52)	34/63 (54)
At patient's own home	52/54	32/34
Elsewhere	2/54	2/34

Table 7-1. Characteristics of patients and bereaved relatives (continued)

	All deceased patients (N=103)	Deceased patients for whom a relative was interviewed (N=63)
Bereaved relatives		
Age at the time of dying of the patient, in years		
Mean (SD)		55 (15)
		n/N (%)
Sex		
Female		40/63 (63)
Relative was patient's:		
Spouse		39/63 (62)
Son or daughter		19/63 (30)
Other relationship		5/63 (8)

[a] Low education: lower vocational, lower secondary general education or primary school.

[b] Living in an urban area: patients who were treated as an outpatient in a hospital inside the Rotterdam area.

Some aspects of medical care are shown in table 7-2. In both groups, physicians reported that about two thirds of the patients had died peacefully. Patients who died in an institution had less often (37%) been ready to die than patients who died at home (71%). Agitation was a common problem during the dying process. Most patients in both settings had been unconscious prior to death. Physicians had discussed a number of end-of-life decisions each with about one third of their patients: this holds for decisions to forgo potentially life-prolonging treatment, intensive treatment of pain, and active euthanasia. Sedation was the only treatment option that was discussed slightly more often with patients who died in an institution. Life had actually been shortened due to the forgoing of potentially life-prolonging treatment or to the use of potentially life-shortening drugs in about one third of all cases in both settings. Such medical decisions were usually made with clear consent of the patient and life was generally shortened by less than one week.

Bereaved relatives reported in 25 out of 63 cases that the patient had preferred to die at home (table 7-3). Two patients had preferred to die in the hospital, 3 in a hospice, 2 elsewhere, and for 31 patients the relative indicated that the patient had no clear preference. Most patients who had a preference died at the place they preferred, except for 5 patients who preferred home but died in the hospital. Patients who died in an institution had stayed there for on average 7 days. The number of transfers during 3

Table 7-2. Dying in an institution or at home: the physician's perspective

	Place of death		
	In institution (N=49)	At home (N=54)	P-value Chi^2-test
	n/N(%)	n/N(%)	
Physician's evaluation of dying process:[a]			
Patient died peacefully	28/41 (68)	29/42 (69)	0.94
Patient was able to say goodbye to relatives	26/40 (65)	33/44 (75)	0.32
Patient was ready to die	15/41 (37)	31/44 (71)	0.002
Patient died suddenly and unexpectedly	13/42 (31)	14/44 (32)	0.93
Patient's dying was preceded by period of agitation	25/40 (63)	29/41 (71)	0.43
Patient's dying was preceded by period of unconsciousness	30/39 (77)	26/42 (62)	0.14
Physician discussed with patient medical decisions that could shorten life:			
Forgoing treatment	13/49 (27)	15/50 (30)	0.70
Intensified pain treatment	16/49 (33)	16/50 (32)	0.95
Sedation	15/49 (31)	8/50 (16)	0.09
Euthanasia	18/49 (37)	19/50 (38)	0.90
Life was possibly shortened due to:			
Forgoing treatment	15/47 (32)	14/52 (27)	0.59
With clear consent of the patient	11/12	12/13	
Life was shortened by more than 1 week	4/11	0/9	
Use of potentially life-shortening drugs	16/46 (35)	13/45 (29)	0.55
With clear consent of the patient	12/14	9/10	
With the explicit goal of shortening life	1/16	4/13	
Life was shortened by more than 1 week	1/13	2/10	

NOTE. Information as provided by clinical specialist (n=85) and/or general practitioner (n=72). In case of conflicting answers concerning history of treatment, the information as provided by the clinical specialist prevailed. In all other cases, both sources were considered valid.

[a] Statement was considered true if neither the clinical specialist nor the general practitioner considered it untrue.

Table 7-3. Preferred and actual place of death

	Actual place of death				Total
	In institution		At home		
	Hospital	Hospice / end-of-life care unit	At patient's own home	Elsewhere	
	N=24	N=5	N=32	N=2	N=63
	n	n	n	n	n
Preferred place of death [a]					
Hospital	2				2
Hospice		3			3
At home	5		20		25
Other place	1	1			2
No (clear) preference	16	1	12	2	31

[a] Information as provided by bereaved relative.

months prior to death was larger for patients who died in an institution (mean 1.9) than for patients who died at home (mean 1.2), and the number of medical specialties that were involved with the patient was also larger in institutions (mean 2.2) than at home (mean 1.8). Care involved on average six disciplines (medical and non-medical), both in institutions and at home.

During the last 3 days of life, a large proportion of patients in both settings suffered, according to the reports of bereaved relatives, from fatigue, loss of appetite, pain, dyspnoea, and mouth or mucus problems (table 7-4). Patients dying in an institution were somewhat more often incontinent and more often suffered from anxiety. Patients dying at home slightly more often had bedsores. There were no statistically significant differences between the settings in the degree to which symptoms were addressed with some form of medical treatment, except for loss of appetite, for which 6 of 22 patients who died in an institution received treatment, but only 2 of 30 patients who died at home ($p=0.04$). The bereaved relatives' evaluation of end-of-life care was in general positive in both settings. Some relatives of patients who died in an institution felt they had not sufficiently been involved in the decision-making, whereas all relatives in the other group were satisfied about their level of involvement.

Further, of the bereaved relatives who had cared for a patient who died in an institution, 76% reported that it had significantly affected their own social life; this percentage was 94% for relatives who had cared for a patient who died at home (table 7-5). A substantial number of relatives had only received some or no support from other family members (41%) and the number of relatives who reported that their own health had been affected by caring for the patient was also quite large (35%). Caring for a dying relative rarely yielded financial problems. Nearly all relatives thought it very important that they had been involved with caring for the patient.

Table 7-4. Dying in an institution or at home: perspective of bereaved relative

	Place of death		
	In institution (N=29)	At home (N=34)	
	Mean (SD)	Mean (SD)	P-value t-test
Number of days patient stayed at place of death	7 (6)	59 (35)	0.000
Number of transfers	1.9 (1.7)	1.2 (1.3)	0.047
Number of disciplines involved with patient	6.1 (2.3)	5.8 (1.9)	0.64
Number of clinical specialties involved with patient	2.2 (1.2)	1.8 (0.8)	0.011
	n (%)	n (%)	P value Chi^2-test
Patient			
was fatigued	22 (79)	29 (88)	0.33
had loss of appetite	22 (76)	30 (88)	0.20
had pain	20 (69)	29 (85)	0.12
had dyspnoea	18 (62)	17 (52)	0.40
had mouth or mucous problems	18 (62)	16 (49)	0.28
was incontinent	20 (69)	13 (38)	0.015
had nausea	9 (32)	10 (30)	0.88
had bedsores	5 (17)	13 (38)	0.07
was confused	14 (48)	10 (29)	0.12
suffered from anxiety	12 (41)	5 (15)	0.021
was depressed	3 (10)	2 (6)	0.54
Evaluation of care during the last 3 days of life			
Assistance with personal care was sufficient	27 (93)	32 (94)	0.87
Nursing care was sufficient [a]	26 (90)	33 (97)	0.23
Relative was involved in decision-making	25 (89)	33 (97)	0.22
Relative was sufficiently involved in decision-making	24 (89)	33 (100)	0.049
Patient might have disagreed with medical decision(s)	4 (15)	1 (3)	0.10
Relative disagreed with medical decision(s)	7 (24)	7 (21)	0.78
It had been clear that patient was dying	18 (67)	26 (79)	0.29

[a] Including patients who did not need professional nursing care.

Table 7-5. Dying in an institution or at home: experiences of bereaved relatives

	Place of death In institution (N=29)	 At home (N=34)	
	n (%)	n (%)	P value Chi^2-test
How often did you see patient in the last months of life?			
Every day	24 (83)	29 (85)	0.78
Less than daily	5 (17)	5 (15)	
Did caring for patient affect your own social life?			
Yes	32 (76)	32 (94)	0.068
No	7 (24)	2 (6)	
Did caring for patient result in financial problems?			
Yes	4 (14)	1 (3)	0.17
No	25 (86)	33 (97)	
Did you receive support from your family in caring for patient?			
Much support	16 (55)	23 (68)	1.0
Some or no support	13 (45)	11 (32)	
Did caring for patient affect your own health?			
Yes	12 (41)	12 (35)	0.62
No	17 (59)	22 (65)	
Did caring for patient cost you a lot of energy?			
Often or all the time	15 (52)	15 (44)	0.96
Rarely or sometimes	14 (48)	19 (56)	
How important was being involved with care for patient for you?			
Very important	26 (90)	32 (94)	0.65
Important	3 (10)	2 (6)	

Discussion

Medical care for patients who are in the last stage of life has received much attention during the past decade in the Netherlands. The organization of health care services for terminally ill patients has greatly expanded during a 5-year period from 1998 through 2003, during which the government financially supported 6 university-based centres for the further development of end-of-life care. After this period, the government took the position that, whereas death and dying are common events, the provision of end-of-life care should be part of the professional skills of all physicians, including general practitioners providing end-of-life care to patients who are staying at home. For complex problems, general practitioners and other physicians can now in many places seek support from expert teams (Gordijn and Janssens 2000; Smeenk *et al.* 2000; Francke and Kerkstra 2000).

Of the 103 patients in this study, who were at inclusion all treated as outpatients by a clinical specialist, about half died in their own home. Death in an institution mostly concerned a hospital, which was probably not for all patients foreseen as the place of dying. Patient characteristics did not clearly determine the place of dying in our study. Whether or not patients lived with a partner was the only variable that was significantly associated with the place of dying. Having access to informal care support is invariably found to be a strong determinant of being able to die at home (Gomes and Higginson 2006). Other factors that have been found to affect rates of dying at home are the health status and emotional capacity of the main carer, the availability and use of home-based end-of-life care services, the need for specialist symptom control, tumour type, distance to inpatient services, gender and age of the patient, the patient's socio-economic status, and strength and visibility of patient or carer preferences concerning the place and circumstances of dying (Gomes and Higginson 2006; Degenholtz *et al.* 2004; Fukui *et al.* 2004; Chvetzoff *et al.* 2005; Burge *et al.* 2003). Obviously, the number of cases in our study was limited and we did not assess all possibly relevant factors, which precludes firm conclusions on determinants of the place of dying. However, whereas access to the available public end-of-life care services, both institutional and home-based, is virtually unlimited in the Netherlands and financially covered by either private or public insurance, care needs of patients are probably a predominant factor.

The availability of in- and outpatient end-of-life care services is probably another important determinant of place of death. The number of patients who died in a specialized end-of-life care service in our study was limited. National statistics on the place of dying do not include hospices or end-of-life care units as a separate category. However, the percentage of cancer deaths inside such services as found in our study is probably comparable to the percentage in the total Dutch population. Recently, the number of beds in specialized end-of-life care services in the Netherlands has been rapidly increasing (Mistiaen *et al.* 2005). It is therefore likely that the proportion of cancer deaths in end-of-life care services will further increase in the coming years. However, the extent to which dying in a end-of-life care service will substitute dying in a hospital or dying at home is hard to predict. Probably, institutional end-of-life care services address very diverse needs of dying patients and their caregivers. Further, financial and other incentives that are aimed at setting the course for the supply of end-of-life care services may affect developments concerning the place of dying and end-of-life care as well (Mistiaen *et al.* 2005).

It is remarkable that a substantial number of patients in our study did not have a clear preference concerning their place of dying. Obviously, we only have information about the preferences that patients had discussed with their interviewed relative. Patients may also have had wishes that relatives were not aware of. Nevertheless, the data in our study suggest that the place of dying is not a great concern for a substantial number of terminally ill cancer patients in the Netherlands.

In general, we found few differences in the evaluation by physicians and bereaved relatives of the dying phase of patients who died in an institution and patients who died at home. Patients who died in an institution were, according to their physicians, less often ready to die, which may be due to the fact that hospitalization is typically forgone in patients who are expected to die at short notice. A sudden and more rapid deterioration than expected may also have been among the reasons to admit patients to hospital shortly before dying in some cases. We did not find substantial differences between both settings in most end-of-life decision-making characteristics. Relatives in both settings quite often (21-24%) stated that they had not agreed with the decision-making. Relatives of patients who died in an institution somewhat less often than other relatives felt that they had been sufficiently involved in the decision-making. Dissatisfaction of relatives with end-of-life decision-making in an institutional setting has been described elsewhere too (Teno *et al.* 2004; Levy 2001; Baker *et al.* 2000) and has been attributed to many factors, such as a lack of time of professional caregivers, lack of skills in communication, failure to recognize end-of-life decision-making as a subject that could be discussed, ethical barriers, and the lack of emotional support for relatives (Teno *et al.* 2004; Levy 2001; Baker *et al.* 2000; Tulsky 2005a; Tulsky 2005b). It is unclear if our finding that relatives of patients who died outside an institutional setting more often feel satisfied about their involvement in the decision-making process, is due to better communication in the home situation. However, the general practitioner, who often has a longstanding relationship with patients and their family, typically plays a key role in end-of-life care at home and may be better able to adequately communicate with family than institutional caregivers (Borgsteede *et al.* 2006). Medical decision-making may also be less complex or controversial for patients who die at home.

The possibly rather complex decision-making in institutions is not associated with a higher prevalence of most symptoms. Fatigue, pain, and dyspnoea were among the most common symptoms in both settings, as has been found elsewhere too (Solano *et al.* 2006). Incontinence was more common among patients dying in an institution, and this also holds for anxiety, which was reported as a problem for almost half of all patients dying in an institution. In contrast, bedsores were more common at home.

Virtually all relatives in both settings were satisfied about the personal and nursing care that had been provided to their dying relative. This may to some extent be indicative of the relative quality of end-of-life care in institutions and at home, but using satisfaction as an absolute indicator of the quality of palliative care services is quite problematic (Aspinal *et al.* 2003). Further, most relatives were closely involved and appreciated their personal involvement very much, both for patients who died in an institution and patients who died at home. Nevertheless, caring for a dying relative often affected their own social life, especially when dying occurred at home, and took a lot of energy.

Our study has several limitations. Firstly, the patients' perspectives on their own dying process is lacking. Bereaved family members' assessments are known to sometimes disagree with those of the patients, especially for subjective aspects such as psychological symptoms and pain (McPherson and Addington-Hall 2004). This is also true for physicians' assessment of their patients' condition. Secondly, our group of patients is probably not representative for all patients dying from one of the five major types of cancer, because patients with a very poor health status and patients who died shortly after the diagnosis of incurable cancer were not included in the cohort study upon which the data collection for this study was based. Moreover, data from bereaved relatives could only be obtained for 61% of all patients, which may have resulted in an overestimation of the degree of satisfaction of relatives. The fact that patients of whom no bereaved relative participated in the study had a shorter disease duration at inclusion than other patients, suggests that a rapidly progressive disease process makes it more difficult for bereaved relatives to talk about the last phase of life of the patient.

In summary, we did not find major differences in the process and quality of dying between institutional settings and the home setting. Most patients with clear preferences concerning their place of dying were able to die at their preferred place. In about half of all cases, relatives were not aware of any preference of the patient concerning the place of dying, which is apparently not a major concern for many people. We conclude that the current situation in the Netherlands, in which the place of dying is mainly determined by the availability of informal caregivers at home and the care needs of the patient, involves no major threats to the process and quality of dying.

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8

General discussion

8.1 Introduction

In this thesis the results are described of a study on the quality of life of patients with incurable cancer and several aspects of end-of-life care. Patients with breast, lung, colorectal, ovary and prostate cancer who received care in an outpatient clinic in the south or south-western part of the Netherlands were included. Due to the longitudinal design we were able to study the course of quality of life and the health care trajectories in patients, who, in the end, died in various care settings.

In this chapter, we will discuss the main findings of this study. First, some methodological considerations will be addressed in paragraph 8.2. In paragraph 8.3 several aspects of the psychological well being of patients will be reviewed. Further, this paragraph discusses the quality of life during the last year and the last days of life. In paragraph 8.4, the use and evaluation of end-of-life care, and patients' attitudes toward the aim of medical treatment will be discussed. Further, care needs of cancer patients in the last phase of life and their place of death will be addressed. In the last paragraph, 8.5, we will consider the implications of our study for end-of-life care in the Netherlands.

8.2 Strengths and limitations

A lot of research in palliative care concerns the experiences and opinions of bereaved relatives and health care professionals. Until now, research in incurably ill patients is relatively scarce (Hwang *et al.* 2003; McCarthy *et al.* 2000; Teno *et al.* 2002). Further, studies are often restricted to one special patient group, such as patients who are admitted to a palliative care unit, a hospice or a hospital (Astradsson *et al.* 2001; Ng and von Gunten 1998). This selection of respondents and patient groups is mainly related to ethical concerns and doubts whether patients with an incurable disease are willing and able to participate in longitudinal research in their last phase of life (Hopkinson *et al.* 2005; Sherman *et al.* 2005). In our study, patients were interviewed personally shortly after diagnosis of incurable cancer, and after the initial interview they filled out questionnaires every three months. Most patients were willing to continue their participation until the very last months of their life. Therefore, we feel that an important result of our study is that is has shown that it is possible to follow patients in their last phase of life, if they are approached carefully.

Several factors, which are to a certain extent inherent to research in palliative care, may limit the generalizability of this study. Our group of patients was a selected group, because patients with a very poor health status and patients who died shortly after the diagnosis of incurable cancer could not be interviewed. Furthermore, most patients who declined to participate did so because they did not want to talk about their disease as they considered this too burdensome. Besides, we cannot preclude a selection bias towards patients who were less ill or who had a better or longer relationship with the clinical specialist. Finally, the patients who participated in the study were younger than the non-participants. These factors may have led to an overestimation of the level of quality of life in the last phase of life and an underestimation of problems in end-of-life care.

There was also some selection in type of cancer and care setting. The number of patients was not equally distributed over the different types of cancer. We followed 128 patients, but only 12 had ovary cancer and 9 had prostate cancer. Further, few patients died in care settings other than at home or in a hospital. Although these settings are known to be the most common places of death for cancer patients, our study thus cannot be generalized to cancer patients dying in e.g. nursing homes or hospices.

Another limitation is the relatively small number of patients. Although the response was relatively high (67%), especially given the burden in terms of time and energy resulting from participation in the study, the number of patients asked to participate in the study was far more lower than expected based on numbers of incidence. Clinical specialists were not always alert in recognising patients that were eligible for the study and they had not always enough time to inform patients about the study during their full consulting hours. Further, clinical specialists might have been reluctant in asking patients after a 'bad news' message to participate in a study that was not focussed upon cure of their disease or improvement of their health status. Such reluctance was probably especially present in case of patients who were severely ill or who had a relatively short or poor relationship with the physician.

Patients' problems and end-of-life care in the last days of life were studied from the perspectives of bereaved relatives and attending clinical specialists and general practitioners. For all deceased patients but one, a questionnaire was filled out by either a clinical specialist, a general practitioner, or both. For 62% of the deceased patients, a bereaved relative was willing to participate in an after-death interview. Our group of bereaved relatives is probably also a somewhat selected group. Most of the relatives who declined to participate, expected participation to be too burdensome. Further, the patients of whom bereaved relatives participated in an interview had an on average relatively long disease. Patients who died shortly after with the diagnosis of cancer, may have experienced more often unexpected deterioration in symptoms and functioning and more acute problems than others. This selection may have led to a somewhat positively distorted representation of experiences with end-of-life care.

Our study is innovative, because it includes the perspective of the patient in a longitudinal design, and because it addresses a rather wide range of topics that might be important in the last phase of life. We did not only study the quality of life of patients with incurable cancer, but also their attitudes toward the aim of medical treatment, the use of care and their care needs. Further, within our study we were able to relate the patients' perspective to the perspectives of bereaved relatives and health care professionals.

8.3 Quality of life in the last phase of life

The first part of the thesis is focused on the quality of life of cancer patients in their last phase of life. We studied the psychological problems of patients, their quality of life in the last year prior to death as reported by patients themselves, and patients' symptoms in the last three days of life as reported by their bereaved relatives.

8.3.1 Psychological problems

Shortly after a diagnosis of incurable cancer, the emotional problems patients mentioned most frequently were anxiety about metastases (26%), the uncertainty about the future (18%) and anxiety about physical suffering (15%). Six percent of all patients reported being often afraid of death, and 40% that they were sometimes afraid of death. Similar results were found by Osse *et al.* (2005) in patients with metastasised cancer. The most prevalent emotional problems were coping with the unpredictability of the future, anxiety about metastases, and frustrations because patients could do less than before. Further, 62% of the patients reported being often or sometimes afraid of death (Osse *et al.* 2005).

In our study a small proportion of patients were depressed or anxious. This is consistent with an review of Coyne and Palmer (2005), which suggest that around 10% of cancer patients are depressed. Recent studies showed that the prevalence of depression is not as high as 50%, which has been recurrently claimed in the literature. Coyne and Palmer concluded that it is often wrongly assumed that people will become depressed after a diagnosis of cancer. Most patients seem to be able to adapt to their new situation, learn to live with uncertainty, and rearrange their goals.

Although only few patients in our study were depressed, mood disorders were very common. Patients in our study had on average lower positive affect scores than physically and mentally healthy people. Especially patients with a low sense of meaning and peace had low positive affect scores. Further, low levels of positive affect were related to high levels of fatigue. Low positive affect in the last phase of life may represent a different issue than low positive affect in physically healthy people. Low positive affect in the last phase of life may be related to problems in physical functioning and disease-related symptoms, due to which people are no longer able to carry out their 'normal daily activities', the activities that give people feelings of joy and happiness (Clark and Watson 1988). Furthermore, fatigue and low levels of positive affect might both be caused by boredom, resulting from the absence of activities or sensory inputs (Passik 2003). This is consistent with a qualitative study by Krishnamany (2000) in which fatigue was found to be an expression of a lack of meaning in life. Further research on positive affect, well-being and fatigue is necessary to explore these associations in more detail.

The pattern of affect scores in our patients is different from the scores of depressed patients. It has been shown that depression can be best characterized as the loss of positive affect and an increase of negative affect (Boon and Peeters 1999). However, whereas most patients in our study reported low levels of positive affect, the negative affect scores were fairly similar to the scores of physically and mentally healthy people. Therefore, the affect scores confirm our finding that only a small minority all patients in our study were depressed, based on a cut-off score of 10 for the Depression scale of the Hospital Anxiety and Depression Scale. However, we have to be careful in interpreting these data, because the HADS is a screening instrument, and a psychiatric interview may yield other results for depression.

8.3.2 Quality of life during the last year of life

During the last year of life, many problems and symptoms were common, such as restrictions in physical and role functioning, as well as fatigue, dyspnoea, and loss of appetite. There was a broad variety in the symptoms patients suffered from, and in the last year of life, most patients expressed a multitude of problems. Many problems were already present prior to the last year; various physical, psychological, social and existential problems were already present shortly after the diagnosis of incurable cancer (Van der Heide *et al.* 2004).

On most functioning and symptoms scales the scores deteriorated during the last year of life. Especially in the last months prior to death, patients suffered from more severe problems. We found no indication of differences in quality of life and symptoms between various types of cancer, except that dyspnoea was typical for lung cancer. The process of a gradual deterioration in the last phase of life has been described before, but our study shows for the first time that this deterioration concerns so many different symptoms. (Hwang *et al.* 2003; Klinkenberg 2003). Recently, Solana *et al.* (2006) compared the symptom prevalence in five progressive chronic diseases. They identified 64 original studies reporting the prevalence of 11 common symptoms among end-stage patients with cancer, acquired immunodeficiency syndrome (AIDS), heart disease, chronic obstructive pulmonary disease, or renal disease. They found that the prevalence of 11 common symptoms was often widely but homogeneously spread across the five diseases. Three symptoms, namely pain, dyspnoea, and fatigue, were found among more than 50% of patients, for all five diseases. These findings suggest that there is a common pathway toward death for various malignant and non-malignant diseases.

Most symptom and functioning scales deteriorated gradually during the whole last year of life, but severe symptoms and poor functioning were often not accompanied by low ratings for quality of life, which has also been found and discussed by others (Essink-Bot *et al.* 2003; Schwartz and Sprangers 2002). The fact that patients with poor health report relatively high levels of quality of life has broadly been discussed, and has been attributed to the fact that patients adapt to their new situation (Schwartz and Sprangers 2002). Cognitive mechanisms may also influence patients' self-reports about quality of life (Sprangers and Schwartz 1999). They may reappraise their situation to avoid cognitive dissonance, that is, patients may justify the effort of a treatment by valuing the post-treatment situation as higher than the pre-treatment situation (Jansen *et al.* 2001). Further, as found by Tsevat *et al.* (1999) in severely ill HIV patients, patients may not evaluate their health states but also other aspects of their lives. Factors unrelated to health that contributed to health values included spirituality and concern and love for one's children (Tsevat *et al.* 1999). In our study, global quality of life deteriorated especially in the last months prior to death. These findings may indicate that in the ultimate last months of life adaptive mechanisms are not sufficient anymore to maintain high scores on quality of life.

In the last three days of life, quality of life deteriorated even further. Bereaved relatives reported that, in the last three days of life, many patients suffered from fatigue, pain and loss of appetite, and more than half of the patients suffered from dyspnoea, mouth or mucous problems, and incontinence.

8.3.3 Conclusion

In conclusion, shortly after the diagnosis of incurable cancer patients worry about a range of issues. Although most patients do not have a clinical depression or an anxiety disorder, feelings of uncertainty, sadness, anxiety for death, and low positive affect are reported frequently. Further, several symptoms are very common in patients with incurable cancer, but besides there is a broad variety in the symptoms patients suffer from. Symptoms and functioning deteriorate during the last year of life, especially in the last months of life.

8.4 End-of-life care and medical decision making

In the second part of the thesis, we focussed on several aspects of end-of-life care and medical decision making. We studied what kind of health care was offered to cancer patients in the last phase of life and how patients appreciated this care. Further, patients' attitudes toward medical treatment were examined, as well as their care needs.

8.4.1 Patient evaluation of end-of-life care

Patients received multidisciplinary care, mostly in the outpatient clinic or at home. The general practitioner played an important role, especially in the period shortly before the diagnosis of incurable cancer, and in the last months of life. Strong involvement of primary health care professionals is typical for the Netherlands, where many cancer patients die at home (Statistics Netherlands). However, bereaved relatives reported that all patients also had had contact with one or more clinical specialists during their last three months of life. Maintaining such contact was possibly related to a need for advanced palliative treatments that can only be provided in the hospital. However, failing to recognise that patients were incurably ill and in their last months of life might also play a role. Especially when the aim of cancer therapy was not discussed explicitly between the physician and the patient, it is likely that some patients who received cancer therapy were still hoping for cure and did not recognise the reality that they were incurably ill.

Whereas most patients had had contact with medical and nursing professions, only few patients had seen other professionals, such as social workers, and physical therapists. Patients were satisfied with the care offered by their health care professionals, but somewhat less satisfied than cancer patients in general (Hagedoorn *et al.* 2003). Problems in end-of-life care concerned communication, difficulties in fine-tuning, accessibility of end-of-life care and responding quickly to acute problems. Patients reported more problems in end-of-life care when death was nearing.

8.4.2 Attitudes of cancer patients toward medical treatment

Our study also generated insight in the attitudes of cancer patients toward medical treatment, and how these attitudes were related to advance initiatives to participate in medical decision-making concerning their own end of life. Patients who were older, more tired or who had less positive feelings, and patients who had taken initiatives to engage in advance care planning were more inclined to strive for quality of life than others. Shortly after the diagnosis of cancer, patients typically seem to prefer life-prolonging treatment, while quality of life becomes more important when death is nearing. The differences in attitudes between patients and over time underline the importance of individually tailored information about the aims of medical treatment, and good physician-patient communication.

Shortly after the diagnosis of incurable cancer, 20% of all patients had discussed their wishes concerning medical treatment at the end of life with a health care professional, and 39% had discussed such wishes with relatives. During follow-up, discussions about this topic became more common. Forty-three percent of the patients who participated 6 months or more in our study, had discussed their wishes with a health care professional during follow-up. Shortly after diagnosis, only small proportions of patients said to have completed an advance directive (8%) or refused a potentially life-prolonging treatment (5%). Further, few patients reported during follow-up that they had taken one of these actions. Our study shows that discussing wishes concerning end of life treatment is rather common, but only few patients make decisions concerning end of life treatment or articulate their wishes in an advance directive.

In the after-death questionnaire, physicians indicated that in 29% of the patients, life was possibly shortened due to forgoing treatment. Further, in 32% of the patients, use of potentially life-shortening drugs may have led to shortening of life. In general, the patient was involved in these decisions, and gave clear consent. This finding is in agreement with those of Van der Heide *et al.*, who showed that physicians tend to discuss their end-of-life decision making with the large majority of competent patients. Patients who are incompetent, due to unconsciousness, dementia, or other causes, are usually represented by relatives (Van der Heide *et al.* 2003).

In recent decades physicians' attitudes and practices have shifted towards promoting greater patient autonomy, control and participation in the medical decision-making process (Peretti-Watel *et al.*). Patients were encouraged to complete living wills, especially in the United States (Fagerlin and Schneider 2004). However, our data show that not all patients want to discuss their wishes concerning medical treatment at the end of life with health care professionals, and only few patients play an active role by filling out an advance directive or refusing a potentially life-prolonging treatment. Fagerlin and Schneider (2004) analysed the developments around the living wills in the US. They state that living wills have passed from controversy to widely promoted policy. However, their review of many studies shows that many patients prefer to leave end of life decisions to their family and physician. They conclude their analysis with the recommendation to abandon the policy of promoting living wills (Fagerlin and Schneider 2004). Advance care planning is in several studies shown to be mostly ineffective, because advance directives are often vague, and because the factual situation is often different from the hypothetical situations described in advance directives (Emanuel 2000; Gillick 2004; Meier and Morrison 2002; Thompson *et al.* 2003). It is a challenge in end-of-life care to fine-tune the decision making on patients' needs. Good physician-patient communication is essential to find out what patient's preferences concerning end-of-life care are, and advance directives cannot replace this.

8.4.3 Care needs

Finally, we studied the care needs of cancer patients in their last phase of life. Shortly after the diagnosis of incurable cancer, care needs existed in several domains, but in most domains only few patients reported a need for additional care (Van der Heide *et al.* 2004). A need for additional information was reported most frequently. Of all patients in our study, 39% felt a need for additional information about topics such as physical symptoms, diet, euthanasia, and alternative or complementary care, while 19% would have appreciated extra written information. Patients living alone more often reported additional care needs in various domains, such as psychosocial care, help for activities of daily life, and management of physical symptoms (Van der Heide *et al.* 2004). They miss the support and practical help that are often provided by partners. Further, partners are often helpful in getting help from agencies and health care professionals, especially in case of acute problems.

Shortly after the diagnosis of incurable cancer, 9 percent of all patients in our study reported a need for psychosocial care. Relatives play an important role in providing emotional support. Most patients received psychosocial support from their relatives, whereas only a minority of all patients received psychosocial care from professional caregivers. Although only few patients expressed a need for psychosocial care, 51% of the patients often suffered from one or more emotional problems, such as anxiety about metastases and uncertainty about the future. Special attention from health care professionals is indicated to be aware of emotional and social problems in patients. Several studies have shown that physicians are often not able to recognize psychological distress in cancer patients (Lloyd-Williams 2000; Sollner *et al.* 2001). Therefore, Van Halteren *et al.* (2004) advocated a brief screening instrument for psychosocial problems that can be filled out by patients in the waiting room. In cases of high scores on psychological distress, the clinical specialist should offer patients some form of psychosocial care.

In the last months of life, 10% of all patients indicated to need additional care for their problems, such as help for activities of daily life (ADL), pain management, and information supply. These patients had received multidisciplinary care in the three months before the measurement; on average 3.3 disciplines were involved in their care. However, these patients indicated that the care provided to them was not sufficient, and they needed additional care for their problems. In the last phase of life, symptoms and problems may arise or deteriorate unexpectedly. The actual situation of the patient determines the care needs. Therefore, adequate monitoring by health care professionals, and accessibility to health care in case of acute problems is important.

8.4.4 Place of death

Fifty-two percent of the patients died at home, and the other patients died in an institution, mostly at a hospital department. For a substantial number of patients (49%) in our study bereaved relatives reported that patients did not have a clear preference concerning their place of dying. Although patients may also have had wishes that relatives were not aware of, the data in our study suggest that the place of dying is not a great concern for a substantial number of terminally ill cancer patients. Most patients who had a preference died at the place they preferred, except for 5 patients who preferred home but died in the hospital.

On many domains, dying in an institution was rather similar to dying at home. We found no differences in the prevalence of problems in patients dying at home and patients dying in an institution, except that patients dying in an institution suffered more often from anxiety than patients dying at home. This latter finding might be related to patients' feelings of uncertainty, and poor communication in the hospital, and other institutions (Baker *et al.* 2000; Teno *et al.* 2002). Further, physicians characterized the dying process similar for patients dying at home or in an institution. In both groups, physicians reported that about two thirds of the patients had died peacefully. Further, we found no differences in the extent to which end-of-life decisions were discussed or taken in both groups of patients. Bereaved relatives evaluated the end-of-life care delivered at home or in the institution as equally good. The finding that most patients who had a preference died at the place they preferred and the fact that dying in an institution was rather similar to dying at home suggest that there is no great urgency for special efforts to support dying at home in the Netherlands.

8.4.5 Conclusion

Most patients received multidisciplinary end-of-life care. Problems in end-of-life care concerned communication, difficulties in fine-tuning, accessibility of end-of-life care and responding quickly to acute problems. Patients varied in their attitudes toward the aims of medical treatment. Patients who were older, more tired or who had less positive feelings, and patients who had more often taken initiatives to engage in advance care planning were more inclined to strive for quality of life than others. Shortly after the diagnosis of cancer, patients typically seem to prefer life-prolonging treatment, while quality of life becomes more important when death is nearing. Cancer patients reported few care needs in the last phase of their lives, although a need for additional information was expressed by almost half of the patients. Fifty-two percent of the patients died at home, and the other patients died in an institution, mostly at a hospital department. Most patients who had a preference died at the place they preferred and the prevalence of symptoms and the characteristics of the dying process were rather similar for dying in an institution and dying at home.

8.5 Practice implications

Health care for cancer patients in the last phase of life needs to be individually tailored. There is a broad variety in symptoms, psychological problems, attitudes towards medical treatment, and care needs. It is important that health care professionals take into account these individual differences in symptom management, psychosocial care, medical decision-making, and information supply. Careful listening to patients and good communication skills are essential to find out what is needed for a specific patient.

A proactive attitude of oncologists and other doctors towards discussing patients' perspectives on anticipatory decision-making may contribute to patient-centred end-of-life care for all types of patients. Discussing wishes concerning medical treatment with doctors predominantly seems to result from patients' attitude to give priority to the quality over the length of life. This suggests that, according to many patients, the standard medical treatment offered in the last phase of life is focused on length of life, whereas a preference for quality of life requires discussion with doctors.

Health care professionals should be aware of possible psychological distress or spiritual conflicts of their patients, and should offer them the opportunity of professional psychosocial care. Although cancer leads primarily to physical symptoms, the life-threatening aspect of the disease involves all domains in human life, the body, the mind and the spirit. Patients worry about a range of issues. They struggle with the unpredictability of the future, have fears about the course of their disease and physical suffering, and they experience loss of control over their own body.

Initiatives to support relatives of incurably ill patients should be encouraged. Our study showed that many patients did not want professional psychological care, which may indicate that they were able to deal with their situation of illness and nearing death. Close relatives play an important role in offering emotional support. However, many bereaved relatives reported that caring for the patient affected their own health and took a lot of energy.

Good communication among health care professionals within and between care settings and home care is very important. It is a challenge for end-of-life care to fine tune the health care offered by many health care professionals. Transfers from home to the hospital or hospice and vice versa are common. Further, symptoms and functioning may deteriorate unexpectedly. When no formal meeting to discuss the patient can be arranged, health care professionals should look for other ways to come to shared decisions concerning the end-of-life care. Networks of health care professionals may play an important role in facilitating the collaboration.

Death is as common as birth. However, many people seem to be afraid of death. We do not talk about it, and when we talk about it we feel uncomfortable. Our findings show that patients who are living in their last months of life still appreciate sharing their experiences. Although they know that the end of their life is nearing, they live their life, have their social relationships, are proud of their children and grandchildren, and enjoy life. Talking with people in their last phase of life learns us virtually nothing about death, but many things about life.

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Summary

In this thesis, two main subjects are addressed: quality of life of cancer patients in their last phase of life (part 1 of the thesis) and end-of-life care and medical decision making (part 2 of the thesis). The first part of the thesis includes studies on the psychological status and feelings of cancer patients after they have been informed of their diagnosis of incurable cancer, and on the quality of life of these patients during their last year of life. The second part explores the content and evaluation of end-of-life care, and patients' care needs. This part also addresses the attitudes of cancer patients toward medical end-of-life decision making and differences in dying at home or in an institution. The following research questions were investigated (**Chapter 1**):

1. What are the levels of positive and negative feelings in patients with incurable cancer and which psychological problems do these patients report?
2. What is the quality of life of cancer patients during their last year of life?
3. What kind of health care is provided to patients with cancer in the last phase of life in different settings, and how do patients appreciate this care?
4. What are the attitudes of cancer patients toward medical treatment, and how are these attitudes related to advance initiatives to participate in medical decision-making concerning their own end of life?
5. What are the care needs of cancer patients in their last phase of life?
6. Which patients are dying in an institution and which patients are dying at home, and is the place of death related to patients' symptoms, characteristics of the dying process, and satisfaction with care?

We followed a cohort of 128 patients with incurable breast cancer, colorectal cancer, ovary cancer, lung cancer or prostate cancer, during the last stage of their lives. Patients were included within two months of being informed that their cancer was probably incurable. The patients filled out a written questionnaire and were also interviewed personally at home. During follow-up, patients filled out a written questionnaire every 3 months. Shortly after inclusion of a patient, a relative of the patient was asked to participate in the study and to fill out a short questionnaire about socio-demographic characteristics and quality of life. When patients died during the research period, we asked these relatives to participate in a personal interview at home 3 months after the death of the patient. As soon as we were informed of the death of a patient, the attending clinical specialist and the patient's general practitioner received a written questionnaire addressing the end-of-life medical treatment and decision-making.

Quality of life in the last phase of life

Chapter 2 reports on the levels of positive and negative affect in patients with advanced cancer and how these are related to anxiety and depression, and to other patient and care factors. Shortly after the diagnosis of incurable cancer, the patients' levels of positive feelings were lower than those in the general population, but the negative affect scores were fairly similar. We found a rather low prevalence of depression (13%) and anxiety (8%). The depression-score was negatively related to positive affect and positively related to negative affect, whereas the anxiety-score was less strongly related to positive affect and rather strongly positively related to negative affect. Both positive and negative affect were rather strongly related to patient's sense of meaning and peace. Further, low levels of positive affect were related to high levels of fatigue. The high percentage of patients who had low levels of positive feelings, however, suggests that this patient group experiences a considerable amount of psychological suffering, although this suffering does not fulfill classical criteria for depression or anxiety. Low positive affect in the last phase of life may be related to problems in physical functioning and disease-related symptoms, due to which people are no longer able to carry out their 'normal daily activities', the activities that give people feelings of joy and happiness. Furthermore, fatigue and low levels of positive affect might both be caused by boredom, resulting from the absence of activities or sensory inputs. It seems important to find out what activities were important for a patient, and to help patients to continue meaningful activities as much as possible.

The emotional problems patients mentioned most frequently concerned anxiety about metastases (26%), the unpredictability of the future (18%) and anxiety about physical suffering (15%). Six percent of all patients reported that they were often afraid of death, and 40% that they were sometimes afraid of death. Although 51% of the patients often suffered from one or more emotional problems, only 9 percent of all patients in our study reported a need for psychosocial care. Relatives play an important role in providing emotional support. Most patients received psychosocial support from their relatives, whereas only a minority of all patients received psychosocial care from professional caregivers.

Chapter 3 describes the quality of life of cancer patients during their last year prior to death. During the last year of life, many problems and symptoms were common, such as restrictions in physical and role functioning, as well as fatigue, dyspnoea, and loss of appetite. Most patients expressed a multitude of problems. Most functioning and symptoms scales deteriorated gradually. This deterioration was most outspoken in the last months of life. Our data give no indication of differences between various types of cancer, except that dyspnoea was typical for lung cancer. Patient characteristics such as age, sex, living arrangement and educational level did not seem to determine the functioning and symptoms in the last months prior to death.

End-of-life care and medical decision making

In chapter 4, 5, 6 and 7, several aspects of the end-of-life care and medical decision making are addressed. **Chapter 4** reports on the health care offered to cancer patients in the last phase of life and how patients appreciated this care. Patients received care from different disciplines, mostly in the outpatient clinic or at home. They reported that, on average, 4.2 disciplines were involved in their care. The general practitioner played an important role, especially in the period shortly before the diagnosis of incurable cancer, and in the last months of life. Strong involvement of primary health care professionals is typical for the Netherlands, where many cancer patients die at home. Whereas most patients had had contact with medical and nursing professions during the last half year of their lives, only few patients had seen other professionals, such as social workers, and physical therapists. Most patients indicated to be satisfied with the care offered by their caregivers. In the last months of life, 10% of all patients indicated to need additional care for their problems, such as help for activities of daily life (ADL), pain management, and information supply. Problems in end-of-life care concerned communication, difficulties in fine-tuning, accessibility of end-of-life care and responding quickly to acute problems. Patients reported more problems in end-of-life care when death was nearing. Comprehensive and interdisciplinary end-of-life care may address patients' needs, but is also a challenge to optimal communication among caregivers and between caregivers and the patient and his or her relatives.

When cancer has advanced to a stage in which cure becomes unlikely, patients may have to consider the aim of further treatment. **Chapter 5** gives insight in the attitudes of cancer patients toward medical treatment, and how these attitudes were related to advance initiatives to participate in medical decision-making concerning their own end of life. Patients' attitudes toward medical treatment could be categorized into three different profiles: striving for quality of life even at the expense of survival, striving for length of life regardless of an impaired quality of life, and no clear preference. Patients who were old, tired or had a low level of positive feelings, and patients who had taken initiatives to engage in advance care planning were more inclined to strive for quality of life than others. Patients with a history of cancer of less than six months were more inclined to prefer life-prolongation than patients with a longer history of cancer. During follow-up, no changes in attitudes toward treatment were found, except for patients with a short history of cancer in whom the inclination to strive for length decreased. Shortly after the diagnosis of cancer, patients typically seem to prefer life-prolonging treatment, while quality of life becomes more important when death is nearing. The differences in attitudes between patients and over time underline the importance of individually tailored information about the aims of medical treatment, and good physician-patient communication.

Further, we found that discussing wishes concerning end of life treatment was rather common, but only few patients made decisions concerning end of life treatment or articulated their wishes in an advance directive. We discussed these findings in relationship to the policy around the living wills in the US. Advance care planning is in several studies shown to be mostly ineffective, because advance directives are often vague, and because the factual situation is often different from the hypothetical situations described in advance directives. Further, many patients prefer to leave end of life decisions to their family and physician.

In **chapter 6**, the need for additional information for the patients is addressed. Shortly after the diagnosis of incurable cancer, the majority of the patients said to have been informed about treatment options, side effects of their treatment, physical symptoms, where to get help, helpful devices, and diet, whereas less than half of the patients were informed about psychosocial care, euthanasia, and complementary care. Most patients (78%-88%) were satisfied with the information giving by the clinical specialist, oncology nurses, and non-specialised nurses, but only 63% evaluated the information giving by general practitioners as good. Of all patients, 39% felt a need for additional information about topics such as physical symptoms, diet, euthanasia, and alternative or complementary care, while 19% would have appreciated extra written information. Patients living without a partner wanted more often additional information. A need for information could also stem from anxiety. Further, patients who were involved in complementary care or alternative medicine felt relatively often a need for additional information. Information needs are not always optimally addressed by increasing the amount of information given. Information needs may be the result of anxiety or of patients' desire to actively fight their disease.

Chapter 7 describes whether physicians or bereaved relatives in retrospect differently appreciate dying in an institution or at home. Fifty-two percent of the patients died at home, and the other patients died in an institution, mostly at a hospital department. Patients who had been living with a partner relatively often died at home. Bereaved relatives knew of the patient's wish to die at home in 40% of the patients; 80% of these patients actually died at home. In 49% of all cases, bereaved relatives reported that patients did not have a clear preference concerning their place of dying. On many domains, dying in an institution was rather similar to dying at home. Most problems were equally often prevalent in patients dying at home and patients dying in an institution, except that patients dying in an institution suffered more often from anxiety than patients dying at home. Bereaved relatives were in general quite satisfied about the provision of medical and nursing care in both settings, and they evaluated the end-of-life care delivered at home or in the institution as equally good. Further, end-of-life decisions were equally often discussed or taken in both groups of patients. Physicians characterized the dying process similar for patients dying at home or in an institution. In both groups, physicians reported that about two thirds of the patients had died peacefully.

Discussion

Chapter 8 contains a general discussion of the findings presented in this thesis, and addresses implications for practice. Firstly, our findings indicate that health care for cancer patients in the last phase of life needs to be individually tailored, because there is a broad variety in symptoms, psychological problems, attitudes toward medical treatment, and care needs. Careful listening to patients and good communication skills are essential to find out what is needed for a specific patient.

Secondly, it is suggested that a proactive attitude of oncologists and other doctors toward anticipatory decision-making may contribute to patient-centered end-of-life care for all types of patients. Nowadays, discussing wishes concerning medical treatment with doctors predominantly seems to result from patients' attitude to give priority to the quality over the length of life.

Thirdly, encouragement of initiatives to support relatives of incurably ill patients seems useful too. Close relatives play an important role in offering emotional support. However, many bereaved relatives reported that caring for the patient affected their own health and took a lot of energy.

Fourthly, good communication among health care professionals within and between care settings and home care is recommended. It is a challenge for end-of-life care to fine tune the health care offered by many health care professionals.

Finally, the finding that patients in their last phase of life were willing to participate in a longitudinal study shows that they appreciated to share their experiences and should encourage further patient-oriented research in end-of-life care.

Samenvatting

In dit proefschrift worden twee onderwerpen behandeld: de kwaliteit van leven van mensen met kanker in hun laatste levensfase (deel 1) en de zorgverlening en medische besluitvorming in deze periode (deel 2). In het eerste deel wordt stilgestaan bij de gevoelens en psychische klachten die mensen ervaren nadat zij gehoord hebben dat de kanker die zij hebben niet meer te genezen is. In dit eerste deel wordt ook de kwaliteit van leven in het laatste levensjaar van deze mensen beschreven. In het tweede deel van dit proefschrift komt de zorgverlening in de laatste levensfase aan de orde, evenals de zorgbehoefte van patiënten met ongeneeslijke kanker. Verder wordt ingegaan op de opvattingen over het doel van de medische behandeling. Tot slot wordt uiteengezet welke verschillen er bestaan tussen overlijden in de thuissituatie en in een zorginstelling. Het onderzoek was gericht op de volgende vraagstellingen (**hoofdstuk 1**):

1. Welke psychische klachten hebben mensen met ongeneeslijke kanker en in welke mate hebben zij positieve en negatieve gevoelens?
2. Hoe is het beloop van de kwaliteit van het leven gedurende het laatste levensjaar?
3. Welke zorg krijgen mensen met kanker in de laatste levensfase, en wat vinden zij van deze zorg?
4. Welke opvattingen hebben mensen met ongeneeslijke kanker over het doel van de medische behandeling? Hebben deze opvattingen te maken met de wens om invloed uit te oefenen op keuzes in de medische zorg rond het levenseinde?
5. Aan welke zorg hebben mensen met ongeneeslijke kanker behoefte?
6. Welke patiënten sterven thuis en welke in een zorginstelling? Verschillen deze twee groepen patiënten in hun klachten en in de manier waarop de stervensfase verloopt? Hoe tevreden zijn nabestaanden van deze beide groepen patiënten met de zorg?

Aan ons onderzoek deden 128 mensen met ongeneeslijke kanker mee. De behandelend specialist vroeg hen, tijdens een bezoek aan de polikliniek, of zij bereid waren mee te doen met het onderzoek. Het ging in alle gevallen om patiënten die kort geleden, namelijk minder dan twee maanden terug, gehoord hadden dat hun kanker naar alle waarschijnlijkheid niet meer te genezen was. De patiënten vulden een vragenlijst in en werden geïnterviewd, bijna altijd bij hen thuis. Daarna vulden deze mensen elke drie maanden een schriftelijke vragenlijst in over hun klachten en problemen, over de zorg die zij ontvingen en over hun wensen en zorgbehoeften. Kort nadat de patiënt instroomde in het onderzoek vroegen we, na goedkeuring door de patiënt zelf, ook een naaste die nauw bij de patiënt betrokken was om aan het onderzoek mee te doen. De naasten vulden een korte vragenlijst in. Als de patiënt overleed tijdens de onderzoeksperiode vroegen we de naaste om mee te werken aan een interview over de allerlaatste levensfase van de patiënt. Ook vroegen we aan de behandelend specialist uit het ziekenhuis en aan de huisarts om een vragenlijst in te vullen. De vragenlijst ging over de medische zorg en de klachten en problemen van patiënten in de allerlaatste levensfase.

Kwaliteit van leven in de laatste levensfase

Hoofdstuk 2 gaat over de positieve en negatieve gevoelens van de patiënten uit onze onderzoeksgroep en beschrijft welke psychische klachten zij hadden. Kort nadat patiënten gehoord hadden dat hun kanker ongeneeslijk was geworden, hadden zij minder vaak positieve gevoelens, zoals opgewektheid, helderheid en vastberadenheid dan mensen uit de algemene bevolking. Zij hadden echter evenveel negatieve gevoelens, zoals somberheid, nervositeit en gejaagdheid, als mensen uit de algemene bevolking. Dertien procent van onze patiënten was depressief en 8% had last van angst, volgens de criteria van de vragenlijst. Mensen die het gevoel hadden dat hun leven zinvol was, hadden meer positieve gevoelens en minder negatieve gevoelens dan anderen. Ernstig vermoeide mensen hadden weinig positieve gevoelens. De lage scores voor positieve gevoelens wijzen erop dat mensen met ongeneeslijke kanker psychisch te lijden hebben, ook al heeft dus slechts een klein deel van hen een 'echte' depressie of angststoornis. Tevens kan er een relatie zijn met het feit dat veel mensen beperkt waren in het uitvoeren van de gewone dagelijkse bezigheden. Vaak beleven mensen juist aan de activiteiten die ze belangrijk vinden plezier en een gevoel van voldoening. We denken daarom dat het belangrijk is dat zorgverleners proberen na te gaan welke activiteiten voor mensen belangrijk zijn en hen aan te moedigen deze activiteiten zo lang mogelijk vol te houden.

De emotionele problemen van patiënten met ongeneeslijke kanker hadden vooral te maken met angst voor uitzaaiingen (26%), de onvoorspelbaarheid van de toekomst (18%) en angst voor lichamelijk lijden (15%). Kort na de diagnose van ongeneeslijke kanker was 6% van de mensen vaak en 40% soms bang voor de dood. Hoewel de helft van de mensen één of meer emotionele problemen had, gaf slechts 9% aan behoefte te hebben aan psychosociale zorg. Naasten blijken een heel belangrijke rol te spelen in het geven van emotionele steun. Veel mensen kregen emotionele steun van hun naasten en slechts een kleine groep kreeg psychosociale begeleiding van een professionele zorgverlener, zoals een psycholoog of maatschappelijke werker.

Hoofdstuk 3 beschrijft de kwaliteit van het leven gedurende het jaar voor het overlijden. De vragenlijst over de kwaliteit van leven bestond uit vragen over lichamelijke en psychische klachten en beperkingen in het functioneren. Wij vonden in onze onderzoeksgroep veel klachten en problemen, zoals lichamelijke functiebeperkingen, vermoeidheid, benauwdheid en gebrek aan eetlust. Veel mensen konden hun rol, bijvoorbeeld die als vader, moeder of werknemer, minder goed uitoefenen. De meeste klachten namen geleidelijk toe en het functioneren verslechterde geleidelijk tijdens het laatste levensjaar. Bij veel mensen ging de kwaliteit van leven in de allerlaatste maanden van hun leven sneller achteruit. Onze gegevens wijzen er niet op dat het type kanker van invloed is op de symptomen en het functioneren in het laatste levensjaar, behalve dat benauwdheid vooral bij longkankerpatiënten voorkwam. Factoren zoals leeftijd, geslacht, burgerlijke staat en opleidingsniveau lijken de symptomen en het functioneren in de laatste levensmaanden niet te kunnen voorspellen.

Zorg in de laatste levensfase en medische besluitvorming

In de hoofdstukken 4, 5, 6 en 7 komen verschillende aspecten van de zorg en de medische besluitvorming in de laatste levensfase aan de orde. In **hoofdstuk 4** wordt beschreven dat de meeste patiënten in de laatste levensfase multidisciplinaire zorg ontvingen. Gemiddeld waren ruim 4 disciplines betrokken bij de zorg in de laatste levensfase. De huisarts speelde een belangrijke rol, met name in de periode kort na de diagnose van ongeneeslijke kanker en in de laatste maanden van het leven. In Nederland spelen zorgverleners vanuit de eerste lijn een belangrijke rol in de zorg aan het einde van het leven en overlijden patiënten vaker thuis dan in veel andere landen. De meeste patiënten hadden contact met artsen en verpleegkundigen in het laatste half jaar van hun leven en er waren slechts enkele patiënten die contact hadden gehad met andere zorgverleners, zoals een maatschappelijk werker of fysiotherapeut. De meeste patiënten gaven aan tevreden te zijn over hun zorgverleners. In de laatste levensmaanden had 10% van de patiënten behoefte aan extra zorg, zoals hulp bij dagelijkse activiteiten, pijnbestrijding, en informatie. Problemen in de zorg in de laatste levensfase hadden betrekking op de communicatie met zorgverleners, de afstemming van de zorg, de toegankelijkheid van de zorg en de snelheid waarmee op acute situaties werd ingespeeld. Kort voor het overlijden waren er meer problemen in de zorg. Hoofdstuk 4 sluit af met de conclusie dat een breed zorgaanbod vanuit verschillende disciplines aan kan sluiten op de behoeften van de patiënt, maar dat daarbij aandacht nodig is voor de communicatie tussen disciplines onderling en van de zorgverleners met de patiënt en zijn of haar naasten.

Wanneer kanker in een ongeneeslijk stadium is gekomen, kunnen patiënten voor behandelkeuzes komen te staan. In **hoofdstuk 5** worden de opvattingen van mensen over het doel van medische behandeling beschreven. Patiënten konden worden ingedeeld in drie groepen: mensen die streven naar een optimale kwaliteit van leven, ook wanneer dit ten koste van de duur van het leven zou gaan; mensen die streven naar verlenging van hun leven, ook al zou dit betekenen dat zij kwaliteit in moeten leveren; en mensen die geen duidelijke voorkeur hebben voor lengte of kwaliteit van leven. Mensen die ouder waren, vermoeide mensen, en mensen met weinig positieve gevoelens waren meer dan anderen geneigd om hun kwaliteit van leven voorop te stellen. Ook bleek dat mensen die actief bezig waren met het vastleggen van hun wensen rond hun eigen levenseinde meer dan anderen belang hechtten aan hun kwaliteit van leven. Mensen bij wie kortgeleden kanker was vastgesteld, namelijk minder dan zes maanden, waren meer gericht op medische behandelingen die het leven konden verlengen, dan patiënten die al langer kanker hadden. Uit de follow-up vragenlijsten bleek dat de opvattingen hierover bij mensen die langer kanker hadden niet meer veranderden. Patiënten die relatief kort kanker hadden raakten in de loop van de tijd minder sterk gericht op behandelingen die hun leven konden verlengen. Kort na de diagnose lijken patiënten dus vooral te kiezen voor behandelingen die hun leven kunnen verlengen, terwijl de kwaliteit van hun leven belangrijker wordt naarmate het sterven dichterbij komt.

Betrekkelijk veel patiënten in ons onderzoek bespraken hun wensen ten aanzien van de medische behandeling met zorgverleners of naasten, maar slechts een klein aantal mensen nam zelf beslissingen over de zorg rond het levenseinde en slechts enkelen maakten gebruik van een schriftelijke wilsverklaring.

Hoofdstuk 6 gaat over het informeren van patiënten met ongeneeslijke kanker en hun behoefte aan (aanvullende) informatie. De meerderheid van de patiënten was, kort na de diagnose van ongeneeslijke kanker, geïnformeerd over behandelopties, bijwerkingen, lichamelijke klachten, voorzieningen waar men hulp kon verkrijgen, hulpmiddelen en over voeding en dieet. Minder dan de helft van de mensen bleek geïnformeerd te zijn over psychosociale zorg, aanvullende zorgvormen en euthanasie. De meeste patiënten (78%-88%) waren tevreden met de informatieverstrekking door de specialist, oncologieverpleegkundigen en andere verpleegkundigen in het ziekenhuis, terwijl 63% tevreden was met de informatie die de huisarts had gegeven. Negenendertig procent van alle patiënten gaf aan behoefte te hebben aan extra informatie over onderwerpen zoals lichamelijke klachten, voeding en dieet, euthanasie en over aanvullende en alternatieve zorgvormen. Daarnaast had 19% van de mensen liever meer schriftelijke informatie ontvangen. Alleenstaande patiënten hadden vaker behoefte aan extra informatie dan patiënten met een partner. Ook bleek dat mensen die gebruik maakten van aanvullende zorg of alternatieve geneeswijzen relatief vaak behoefte hadden aan extra informatie. Het kan zijn dat informatiebehoefte voortkomt uit angst of onzekerheid of uit de wens om zelf actief de strijd aan te gaan met de ziekte. Het aanbieden van extra informatie aan mensen die dat wensen zal niet altijd een oplossing kunnen bieden voor een onderliggende oorzaak.

Hoofdstuk 7 beschrijft hoe artsen en nabestaanden het overlijden van de patiënt in een zorginstelling of thuis beoordelen. Tweeënvijftig procent van de patiënten overleed thuis, de andere patiënten overleden in een zorginstelling, meestal in het ziekenhuis. Patiënten met een partner overleden vaker thuis dan alleenstaanden. Voor 40% van de patiënten gold dat hun nabestaanden op de hoogte waren van de wens van de patiënt om thuis te sterven; 80% van deze patiënten stierf ook werkelijk thuis. Ongeveer de helft van alle nabestaanden gaf aan dat zij niet wisten of de patiënt een bepaalde voorkeur had ten aanzien van de plaats van overlijden. Overlijden in een zorginstelling was veelal vergelijkbaar aan overlijden in de thuissituatie. Patiënten die thuis stierven hadden last van dezelfde problemen als patiënten die in een zorginstelling stierven. Patiënten die in een zorginstelling overleden hadden wel vaker last van angst dan patiënten die thuis overleden. Nabestaanden waren in het algemeen vrij tevreden over het aanbod van medische en verpleegkundige zorg en tevreden over de zorg zelf in de setting die zij hadden meegemaakt. Beslissingen rond het levenseinde werden even vaak besproken en kwamen even vaak voor in beide groepen van patiënten. Uit de vragenlijsten ingevuld door de artsen bleek dat het stervensproces van patiënten die thuis of in een zorginstelling overleden op vergelijkbare wijze verliep. Uit deze vragenlijsten bleek ook dat voor beide groepen patiënten gold dat tweederde van de patiënten rustig en vreedzaam overleed.

Aanbevelingen

In **hoofdstuk 8** worden de bevindingen uit dit proefschrift besproken en worden enkele aanbevelingen voor de praktijk gedaan. Ten eerste volgt uit onze bevindingen dat de zorg voor patiënten met kanker in de laatste levensfase afgestemd moet zijn op de individuele behoeften van patiënten, omdat er een grote verscheidenheid is in symptomen, psychische problemen, opvattingen over de medische behandeling, en zorgbehoeften. Aandachtig luisteren naar patiënten en goede communicatieve vaardigheden zijn van groot belang om na te gaan wat nodig is voor een bepaalde patiënt.

Ten tweede is het belangrijk dat oncologen en andere artsen zich proactief opstellen in het bespreken van toekomstige besluitvorming met hun patiënten. Het tijdig bespreken van de wensen van de patiënt kan bijdragen aan optimale zorg rond het levenseinde voor alle patiënten. Het lijkt erop dat vooral mensen die de kwaliteit van hun leven belangrijker vinden dan de duur ervan een gesprek met hun artsen aangaan over hun behandelingswensen.

Ten derde lijkt het op grond van onze resultaten van belang om naasten van ongeneeslijk zieke patiënten te ondersteunen. Naasten die nauw betrokken zijn bij de patiënt spelen vaak een belangrijke rol in het verlenen van emotionele steun. Veel nabestaanden gaven aan dat het zorgen voor de patiënt invloed had op hun eigen gezondheid en hen veel energie kostte.

Ten vierde is aandacht nodig voor optimale communicatie, zowel tussen zorgverleners onderling binnen een bepaalde zorginstelling als ook tussen zorgverleners vanuit verschillende zorginstellingen en zorgverleners in de thuissituatie. In de zorg rond het levenseinde is het van groot belang dat de zorg van de vele zorgverleners goed op elkaar wordt afgestemd.

Tot slot is in ons onderzoek duidelijk geworden dat patiënten in hun laatste levensfase bereid zijn zich te laten interviewen en vragenlijsten in te vullen. De meeste patiënten stelden het op prijs hun ervaringen te delen wat een stimulans is voor meer patiëntgericht onderzoek naar de zorg rond het levenseinde.

Dankwoord

Nabeschouwing

In dit proefschrift heb ik verslag gedaan van ons onderzoek naar verschillende aspecten van de laatste levensfase van mensen met kanker. Uit de gesprekken met de mensen met ongeneeslijke kanker kwam naar voren dat in werkelijkheid het leven niet opgedeeld is in specifieke aspecten en categorieën, zoals dat bij onderzoek gebeurt. Het leek alsof de mensen vaak meer bezig waren met het leven zelf, dan met alles wat met de ziekte te maken had. Veel mensen leefden vooral hun leven in het hier en nu, alhoewel velen zich wel bewust leken te zijn van het feit dat hun leven zou eindigen. Daarom heb ik voor mijn proefschrift de titel 'Leven tot het einde' gekozen.

Omdat ik het heel bijzonder vond om bij deze groep mensen onderzoek te mogen doen, wil ik graag aan het einde van dit proefschrift iets vertellen over wat ik gezien heb van deze mensen en hoe ik zelf deze jaren van onderzoek heb ervaren.

Interviewervaringen

Een groot deel van de praktische uitvoering van dit onderzoek heb ik samen met Anna van Leeuwen mogen doen. Bij het samenstellen van het interview en de vragenlijsten, vroeg ik me vaak af of je bepaalde vragen wel aan mensen kon voorleggen wanneer zij ernstig ziek zijn. We vroegen hen bijvoorbeeld "Heeft u wel eens met een zorgverlener gesproken over uw wensen ten aanzien van de medische behandeling indien uw gezondheid achteruit zou gaan?" en "Heeft u wel eens het gevoel dat het allemaal niet meer hoeft, dat u liever niet meer wakker zou willen worden?". Maar toen we aan de slag gingen met de interviews bleek dat de mensen openlijk spraken over hun ervaringen. Veel mensen gaven aan dat ze het fijn vonden om met iemand die op afstand stond hun gedachten en ook hun zorgen te kunnen delen.

Na afloop van een interview voelde ik me vaak aangedaan en wat somber, vooral als het om jonge mensen ging. Om te voorkomen dat het voor de interviewers te zwaar zou worden, deden de interviewers in principe slechts één of twee interviews per week. We hadden vooraf een goede training gehad en met elkaar gesproken over hoe mensen het zouden kunnen ervaren om ongeneeslijk ziek te worden. De interviewtrainer vroeg ons onze toekomst op papier te zetten. Hoe ziet je leven eruit over een half jaar, één, twee, vijf en tien jaar. Vervolgens kwam hij langs met een schaar en deed alsof hij 'de man met de zeis' was. Bij iedereen werd op willekeurige hoogte het papier met de toekomstbeschrijving afgeknipt. Zo bleven we als interviewers achter met slechts zes maanden levensduur, een jaar of twee jaar. Het maakte grote indruk op ons.

Tijdens de duur van het onderzoek hielden we als interviewers contact met elkaar. Telefonisch om even te horen hoe het interview gegaan was, en ook per e-mail. Daarnaast hielden we enkele malen intervisie, waarbij we onze ervaringen uitwisselden en ook inhoudelijke punten uit het interview bespraken. Eén ding is zeker: zonder de inzet van een team van betrokken en goede interviewers had dit onderzoek nooit uitgevoerd kunnen worden.

Telefonisch contact

De mensen met ongeneeslijke kanker kregen elke drie maanden een vragenlijst toegestuurd. Als de vragenlijst na één à twee weken nog niet was binnengekomen, belden we de betrokkene op. Het kon natuurlijk zijn dat hij of zij er nog niet aan toegekomen was. Maar het kon ook zijn dat de man of vrouw inmiddels was overleden. Vooral als Anna en ik wisten dat het vrij slecht met iemand ging, liep je soms met lood in je schoenen naar het 'belkamertje'. Het was een klein kamertje met een telefoon, waar je rustig kon bellen. Vaak kwam je er dan toch weer blij verrast uit. De mevrouw om wie het ging was gewoon de kamer aan het behangen of haar partner gaf aan dat ze boodschappen aan het doen was. Gelukkig. Een mevrouw, die al herhaaldelijk gebeld was omdat ze de vragenlijst niet op tijd terugstuurde, zei 'Ik leg de vragenlijst altijd eerst in een laatje en dan wacht ik tot jullie bellen'. Mensen hadden dus lang niet altijd zin om de vragenlijst in te vullen, maar de meeste mensen deden het toch steeds heel trouw. Tijdens die telefoongesprekken spraken mensen vaak vol lof over de interviewer die was geweest. Alhoewel ik slechts een deel van de interviews zelf heb gedaan, heb ik bij veel mensen toch een bepaald gevoel omdat ik ze telefonisch heb gesproken.

Heel bijzonder vond ik het volgende. In de vragenlijst zat een bladzijde met tien positieve gevoelens en tien negatieve gevoelens. Mensen moesten aangeven in welke mate ze in de afgelopen weken die gevoelens hadden gehad, dus gevoelens als opgewekt, actief, gejaagd, en nerveus. Een mevrouw had slechts 13 van de 20 vragen ingevuld. Alle opengelaten vragen betroffen negatieve gevoelens. Ik dacht 'Nou, dat is duidelijk. Die mevrouw wil die vragen gewoon niet beantwoorden', maar we besloten dat ik die mevrouw toch zou bellen. Mevrouw was duidelijk niet enthousiast, maar deed toch haar best om alsnog de vragen te beantwoorden. Meer dan een jaar later had ik haar opnieuw aan de telefoon. Ze vertelde dat ze ervan had geleerd om ook de negatieve dingen meer te benoemen. Als ze de vragenlijst had ingevuld, dan liet ze hem aan haar man lezen, en dan spraken ze er samen over. Het onderzoek had haar geholpen om ook over moeilijke dingen te spreken, zo gaf ze aan.

Een enkele keer vroeg de patiënt onze hulp bij het invullen van de vragenlijst. Zo belde er een meneer met longkanker op. Het ging over een vraag waarbij hij op een thermometer aan moest geven hoe hij zijn eigen gezondheidstoestand beoordeelde. Hij zei 'Wat moet ik nou invullen? De dokter zegt dat het ongeneeslijk is en dan is het dus 2, maar ik voel me goed, dus dan zou ik een 8 willen invullen.' We kwamen er zelf ook niet goed uit. Tja, het gaat toch echt om uw eigen oordeel, zoiets hebben we ervan gemaakt. Als ik me het goed herinner heeft hij uiteindelijk een 8 ingevuld, omdat dat aangaf hoe hij zijn eigen gezondheid waardeerde.

Betrokkenheid van patiënten

De betrokkenheid van de patiënten bij het onderzoek bleek vooral sterk als het ging om de periode rond het overlijden. Zo belde een partner van een patiënt ons op om aan te geven dat onze vragenlijst die dag was aangekomen, maar dat zijn vrouw op sterven lag. Wat moet je dan zeggen? Natuurlijk was die vragenlijst totaal niet meer van belang. Het werd iets van 'veel sterkte en nog een hartelijke groet voor haar'. Een andere man belde de dag nadat zijn vrouw gestorven was en sprak in op ons antwoordapparaat. Omdat zijn vrouw zo lang aan ons onderzoek had meegedaan, wilde hij dat wij het wisten. Sommige patiënten hadden er tijdens hun leven voor gezorgd dat wij in hun adressenbestand waren opgenomen, zodat we een rouwkaart kregen na hun overlijden.

De mensen gebruikten de laatste bladzijde van de vragenlijst regelmatig om nog iets persoonlijks aan ons door te geven. Een man bood aan dat hij wel wilde praten met mensen die contact met lotgenoten zochten. Bij het ziekenhuis had hij ook al aangegeven dat hij mensen wilde helpen die het moeilijk hadden met hun ziekte. Een vrouw voegde een gedicht toe waaruit bleek hoe zij zelf met de afronding van haar leven bezig was. Heel bijzonder was de tekst in een tiende follow-up vragenlijst. Die mevrouw deed al twee en een half jaar mee aan het onderzoek en vulde elke drie maanden een vragenlijst in. Op de laatste bladzijde schreef ze onder meer "Bedankt voor de aandacht en steun." Het deed haar goed dat wij geïnteresseerd bleven in hoe het met haar ging.

Uitval

Er waren ook mensen die minder positief over het onderzoek dachten. Sommige mensen vonden het onderzoek nutteloos, vreemd of te belastend. Een echtpaar was erg boos na afloop van het interview. De meneer had kanker, maar met name zijn echtgenote was het totaal niet met de onderzoeksvragen eens. Tijdens het interview met deze meneer werd het gesprek verschillende malen onderbroken en kwam er bezoek langs. Na het interview belde die mevrouw boos op. Ze gaf aan dat haar man helemaal geen klachten had van de ziekte en dat het nutteloos was om hem al die vragen te stellen. We zouden beter naar mensen met klachten kunnen gaan. Onze toelichting mocht niet baten. Met name de echtgenote gaf ons te verstaan dat zij samen niet meer meededen aan het onderzoek. Later, na het overlijden van deze patiënt, gaf de huisarts aan dat de echtgenote van deze patiënt tot het einde toe bleef ontkennen dat haar man ging sterven.

De stervensfase

Een groot deel van de mensen die meededen aan ons onderzoek is overleden tijdens de onderzoeksperiode. Vanuit de interviews met de nabestaanden hoorden we hoe de allerlaatste weken voor het overlijden waren verlopen. Niet altijd was voor mensen bij de start van hun deelname aan het onderzoek goed duidelijk hoe groot de kans was om aan hun ziekte te overlijden. Maar wanneer de klachten toenamen, werd voor veel mensen duidelijk dat zij gingen sterven. Veel nabestaanden gaven aan dat zij een belangrijke rol bij de verzorging hadden gespeeld. Vaak was het wel heel zwaar geweest, maar waren ze achteraf toch blij dat ze zo betrokken waren geweest. De nabestaanden speelden ook een belangrijke rol bij het regelen van hulp. Zo wist een echtgenoot van een mevrouw met kanker een traplift voor haar te regelen. Een ander was wel overdag steeds aanwezig bij zijn vrouw, maar had voor de nacht een nachtzuster laten komen. Uit de gesprekken met de nabestaanden begrepen we dat de huisarts vaak heel belangrijk was geweest, met name wanneer een patiënt thuis overleed.

Een deel van de mensen overleed onverwacht. Dat hoeft niet te betekenen dat zij niet beseften dat ze aan de kanker zouden gaan overlijden. Ze hadden het in elk geval nog niet op dat moment verwacht. Een man overleed plotseling aan een longbloeding. Ook hartfalen was nogal eens de reden van plotseling overlijden.

Niet alle nabestaanden konden of wilden meedoen aan een interview. Voor sommigen was het veel te zwaar en anderen wilden alle herinneringen niet opnieuw ophalen. Sommige nabestaanden die wel meededen aan een interview gaven aan dat zij het vooral voor de overledene deden. Ze wilden een bijdrage leveren aan het onderzoek dat voor hun naaste met kanker belangrijk was geweest, om zo het verhaal compleet te kunnen maken.

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In totaal zijn er zo'n 200 interviews afgenomen onder patiënten en nabestaanden. De interviewers die deze interviews afnamen komt veel dank toe voor de voortreffelijke wijze waarop zij contact legden en de mensen door het interviews heen begeleiden. Astrid, Jantina, Natasja Raijmakers, Natasja van de Bovenkamp, Elise, Lucienne, Claudia, Amber, Jelke, Susan en Laetitia, ik wil jullie heel hartelijk bedanken voor jullie belangrijke bijdrage aan het onderzoek. Jullie hebben op een betrokken en persoonlijke wijze contact met de patiënten en nabestaanden gelegd en dat heeft zeker ertoe bijgedragen dat veel patiënten lange tijd aan het onderzoek wilden blijven deelnemen. Velen van jullie hebben je met hart en ziel aan het onderzoek toegewijd. Veel dank daarvoor! Marc, je verzorgde de interviewtraining op onnavolgbare wijze. Dank je wel voor alles wat je ons meegaf voor we op pad gingen. Naast de interviews werden er honderden vragenlijsten verzonden en ingevuld door patiënten en artsen. Susan, Sander en Anne Marie, dank jullie wel voor jullie nauwgezette hulp bij het verzenden van vragenlijsten en het invoeren van alle gegevens in de computer.

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Curriculum Vitae

Elsbeth de Vogel-Voogt werd geboren op 5 mei 1971 te Gouda. In 1989 behaalde ze haar VWO-diploma aan de Gereformeerde Scholengemeenschap Rotterdam. Na een tussenjaar op de Evangelische Hogeschool in Amersfoort, studeerde zij van 1990 tot 1992 Econometrie aan de Erasmus Universiteit Rotterdam en behaalde het propedeuse diploma. Vanaf 1993 studeerde zij Psychologie aan de Rijksuniversiteit Leiden. In 1998 behaalde zij haar doctoraal in de afstudeerrichting Klinische en Gezondheidspsychologie.

Van 1998 tot 2000 was ze in dienst bij de afdeling Huisartsgeneeskunde van het Academisch Medisch Centrum te Amsterdam en werkte ze aan een onderzoek naar de evaluatie van de Huisartsenkliniek in IJmuiden. In die tijd was ze tevens werkzaam als onderzoeksassistent bij het Helen Dowling Instituut te Utrecht. Vanaf juni 2000 werkte zij bij het Instituut Maatschappelijke Gezondheidszorg van het Erasmus MC, waar zij onderzoek deed naar de zorgbehoeften en het zorgbeloop van mensen met kanker in de laatste levensfase. Vanaf mei 2005 is zij als postdoc onderzoeker werkzaam bij de afdeling Medische Besliskunde van het Leids Universitair Medisch Centrum.

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