

Original Article

Perspectives on Death and an Afterlife in Relation to Quality of Life, Depression, and Hopelessness in Cancer Patients Without Evidence of Disease and Advanced Cancer Patients

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Abstract

Context. It is unknown whether cancer patients with different life expectancies have different attitudes and emotions toward death and an afterlife. Also, it is unclear whether these attitudes and emotions toward death and afterlife influence patients' distress.

Objectives. To assess the relationship of attitudes and emotions towards death and an afterlife with quality of life, depression and hopelessness in cancer patients without evidence of disease and advanced cancer patients facing death.

Methods. Ninety-one cancer patients without evidence of disease and 57 advanced cancer patients completed the Dutch Attitudes Toward Death and Afterlife Scale. Emotions toward death were measured using the Self-Confrontation Method. Quality of life was measured with the Satisfaction with Life Scale and the European Organization for Research and Treatment of Cancer (EORTC) Quality-of-Life Questionnaire. Depression and hopelessness were measured with the Beck Depression Inventory for Primary Care and the Beck Hopelessness Scale.

Results. Average scores on attitudes and emotions toward death and an afterlife were not significantly different between the two groups. However, in the no evidence of disease group, a negative association between negative emotions and social functioning was observed, which was not present in the advanced cancer group. In the advanced cancer group, associations were observed that were not

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present in the no evidence of disease group: positive associations between an explicitly religious attitude and global health status and between reincarnation belief and role and cognitive functioning, and a negative association between other-directed emotions and social functioning.

Conclusion. Patients without evidence of disease and advanced cancer patients do not differ in attitudes or emotions toward death, but the relationship between these attitudes and emotions and aspects of quality of life varies. When there is no evidence of disease, negative emotions play the most important role, whereas in the advanced cancer situation, attitudes toward death and an afterlife, which may provide meaning and value, become more prominent. *J Pain Symptom Manage* 2011;41:1048–1059. © 2011 U.S. Cancer Pain Relief Committee. Published by Elsevier Inc. All rights reserved.

Key Words

Death, afterlife, quality of life, depression, hopelessness, palliative care

Introduction

Cancer is one of the most frequent causes of death in the Western world. Therefore, despite the fact that many people can be cured, the diagnosis of cancer is still associated with imminent death. As a consequence, at least temporarily, the comfortable sense of both invulnerability and immortality is shattered, making the patient thoroughly aware that life is finite and limited.¹ To cope with cancer implies, among other things, to cope with the inescapable finitude of life. For patients with advanced incurable cancer, this process is even more complicated. The clinical course of a patient with advanced cancer has been characterized as a “living-dying experience” in which the individual and his or her family attempts to maintain control and continue everyday life despite the confrontation with the incompatibility of life and death.² Patients with advanced cancer have to perform the hard work of living in the face of death.³ This may be a period of life review and give the opportunity to close old conflicts, to say good-bye, seek forgiveness, and fulfill life goals, but it also can be a period of overwhelming distress.⁴ Patients are confronted with problems such as fear of death, unresolved issues, parting with family, and pain.⁵ Knowledge of end-of-life issues is vital for distress management and to provide comprehensive cancer care.^{6,7}

Direct comparative studies in cancer patients with different life expectancies that explore the perspectives on and feelings toward death and an afterlife in relation to

distress are limited and report conflicting results. For example, McClain-Jacobson et al.⁸ showed that among 276 terminally ill cancer patients, belief in an afterlife was associated with lower levels of end-of-life despair (hopelessness, desire for a hastened death, and suicidal ideation) but not with levels of depression or anxiety. However, when multivariate analysis included a measure of spiritual well-being, the beneficial effect of afterlife beliefs disappeared. No comparison with cancer patients in a less advanced stage of disease was made. Of note, in this study, belief in an afterlife was measured with just one single question (“Do you believe in an afterlife?”), without distinguishing between different afterlife beliefs. It may well be that a more differentiated approach toward afterlife beliefs would have led to different results.

Previously, it has been observed in a group of 35 cancer patients with a life expectancy of less than two years that patients were significantly more afraid of death than healthy control subjects on a nonconscious level, although most patients disclaimed fear of death on a verbal level.⁹ Similarly, in a study of 102 inpatients with hematologic malignancies treated with curative intent, these patients had significantly more preoccupation with death than a control group of 33 patients with benign dysfunction.¹⁰ In this study, preoccupation with death was related to a depressive coping style and symptoms of depression and anxiety. Sherman et al.¹¹ reported higher death anxiety in 38 patients with advanced cancer compared with

36 cancer patient caregivers. Greater death anxiety was associated with lower quality of life. In contrast, in a study of 90 young adult male cancer survivors and a normative comparison group, death anxiety was related to somatic and psychological distress, but the cancer survivors did not have higher death anxiety than the comparison group.¹² Also, in a recent study of 254 patients with Stage I–IV ovarian cancer, 55% reported fear of dying. However, stage of disease and number of prior treatments were not associated with worry about dying.¹³

Thus, the question remains whether cancer patients with different life expectancies have different attitudes and emotions toward death and afterlife. Also, it is unclear whether these attitudes and emotions toward death and afterlife influence patients' distress. Therefore, in the present study, the following three questions were addressed:

1. Do attitudes and emotions about death and afterlife differ between cancer patients without evidence of disease and advanced cancer patients who are facing death?
2. Do these attitudes and emotions about death and afterlife influence patients' distress, operationalized as quality of life, depression, and hopelessness?⁶
3. Do the relationships among attitudes and emotions about death and afterlife, and distress differ between cancer patients without evidence of disease and advanced cancer patients?

We approached patients' attitudes toward death and afterlife in a differentiated way and distinguished among an agnostic attitude, three nonexplicitly religious attitudes, and an explicitly religious attitude^{14,15} Moreover, we did not only examine negative emotions toward death but also positive, self-directed, and other-directed emotions.¹⁶

Methods

Patients

As part of a larger project on quality of life, a self-administered questionnaire was given out to patients without evidence of disease and advanced cancer patients from the departments

of surgery, urology, gynecology, internal medicine, and medical oncology and the palliative care unit of one university and two general hospitals; two hospices; and a regional consultation service for palliative care in the Netherlands. The study was approved by the institutional medical ethics board, and all participating patients gave written informed consent. The inclusion criteria for patients without evidence of disease were patients with a history of treatment for a solid tumor; end of treatment less than one year ago; no signs of acute treatment toxicities; and no evidence of disease at the moment of inclusion. Patients who were on adjuvant hormonal therapy also could be included in this group. The inclusion criteria for the advanced cancer patients were patients with advanced solid tumors; no longer receiving antitumor therapies; and recovered from acute treatment toxicities at the moment of inclusion. Exclusion criteria for both groups were inability to read Dutch or extreme morbidity precluding filling out a questionnaire.

Measurement Instruments

Sociodemographic data were collected from all participants. Disease information was provided by the treating physician. Participants also were asked to indicate whether they believed in God or a higher being on a scale from 1 (absolutely not convinced) to 5 (absolutely convinced).

To measure attitudes toward death and afterlife, we used the Dutch measurement instrument developed by Scherer-Rath et al.^{14,15} for patients who were in the middle of a suicide crisis. Although the situation of patients in a suicide crisis may be quite different from patients confronted with cancer, the common denominator in these two patient populations is that they are both confronted with a radical existential life event. To accommodate potential differences between the two groups, we performed a new factor analysis on the original items of the instrument (factor analysis fixed to five factors, oblimin rotation, communality ≥ 0.2 , factor loading ≥ 0.4). Five different attitudes toward death and afterlife were distinguished: an agnostic attitude, three nonexplicitly religious attitudes, and an explicitly religious attitude (total explained variance 68%). The distinction between agnostic and

religious attitudes reflected the fact that both religious and agnostic people try to come to terms with death. The agnostic attitude referred to death as a natural ending of life or doubt about the possibility of any meaning of death (Cronbach's alpha [α] = 0.73). The distinction between nonexplicitly religious and explicitly religious attitudes reflected that God or transcendency is not always brought up explicitly. In the nonexplicitly religious attitudes, the concepts "soul" and "higher reality" symbolized the transcendental, whereas in the explicitly religious attitudes, reference was made to the "one God." For the explicitly religious attitude, Cronbach's α was 0.96. Nonexplicitly religious attitudes were further differentiated into the belief in the continuation of the soul despite death ("continuation," Cronbach's α = 0.92), belief in reincarnation ("reincarnation," Cronbach's α = 0.83), and belief in the reencounter with and community of all deceased after death ("community," Cronbach's α = 0.95). In the data set of Scherer-Rath, both the religious attitude and agnostic attitude could be further differentiated. However, these further differentiations were not found in our patient population and were, therefore, not used in the present study. Each attitude was scored on a scale from 1 (fully disagree) to 5 (fully agree).

Emotions toward death were measured using the Self-Confrontation Method developed by Hermans.¹⁶ This is an idiographic method that may be used to identify specific domains of value in someone's life and assess which emotions are attached to these domains.^{17,18} In our study, respondents were asked to think of their own death and then rate the relevance of eight emotions that reflect four domains of self-valuation: 1) self-enhancement (strength, pride: self-directed emotions; Cronbach's α = 0.69), 2) attachment to others (carefulness, love: other-directed emotions; Cronbach's α = 0.85), 3) positive affect (security, warmth: positive emotions; Cronbach's α = 0.74), and 4) negative affect (loneliness, powerlessness: negative emotions; Cronbach's α = 0.68). For each domain, a sum score was calculated, 0 indicating that the emotion was not present at all and 10 indicating that the emotion was very much present.

Overall quality of life was measured with the Satisfaction with Life (SWL) scale¹⁹ and the

score for global health status from the European Organization for Research and Treatment of Cancer Quality-of-Life Questionnaire version 2 (EORTC QLQ-C30v2).²⁰ For the SWL, a sum score was constructed,¹⁹ 5–9 indicating extremely dissatisfied, 10–14 dissatisfied, 15–19 slightly below average, 20–24 average, 25–29 high satisfaction, and 30–35 very high satisfaction. The scale for global health status of the EORTC QLQ-C30v2 ranged from 0, very bad, to 100, excellent (cf. reference values for the EORTC QLQ-C30 at http://groups.eortc.be/qol/downloads/reference_values_manual2008.pdf). The subscales physical functioning, role functioning, social functioning, and emotional and cognitive functioning of the EORTC QLQ-C30v2 were used to measure quality of life in functional terms. The scales ranged from 0, very bad, to 100, excellent. The EORTC QLQ-C30 has proven to be a reliable and valid measure of quality of life, also in palliative care cancer patients.²¹

Depression was measured by Beck's Depression Inventory for Primary Care (BDI-PC).²² The assessment of depression in cancer patients can be confounded by physical symptoms caused by the cancer or its treatment. The use of the BDI-PC can circumvent this problem, because it does not include somatic items. The BDI-PC contains seven items, scored on a 0–3 scale. A sum score of ≥ 4 indicates clinically relevant depression. As depression and hopelessness are mutually reinforcing but distinct constructs,²³ hopelessness was measured separately with Beck's Hopelessness Scale (0 indicated no hopelessness, 20 indicated maximum hopelessness).²⁴

Statistical Analysis

Associations between attitudes and emotions toward death (low vs. high) and patient characteristics were analyzed using the chi-squared test and *t*-tests when appropriate. Agreement with an attitude toward death was computed "low" if a patient scored < 3.5 and "high" if scored ≥ 3.5 (on a scale from 1 to 5). Agreement with an emotion toward death was computed "low" if a patient scored < 6 and "high" if scored ≥ 6 (on a scale from 0 to 10). To answer the first research question—Do attitudes and emotions about death and afterlife differ between patients without evidence of disease and advanced cancer patients?—differences in

means between the two groups were assessed using covariance analysis with the significant associations between sociodemographic variables and attitudes and emotions toward death as covariates.

To answer the second research question—Do these attitudes and emotions about death and afterlife influence patients' distress, operationalized as quality of life, depression and hopelessness?—we performed correlation and regression analyses. Associations of attitudes and emotions toward death and afterlife with measures of quality of life, depression, and hopelessness were analyzed by partial correlation analysis including relevant sociodemographic factors. Relevant factors were considered to be those sociodemographic patient characteristics that were significantly associated with both an attitude and feeling toward death and any of the measures of quality of life, depression, or hopelessness. Patient age, sex, and belief in God or a higher being were identified as such factors. Significant associations with a correlation coefficient $r \geq 0.2$ were taken up in a stepwise regression model including the relevant sociodemographic factors. In stepwise regression in SPSS (SPSS Inc., Chicago, IL), each variable was entered in sequence and its value assessed. If adding the variable contributed to the model, then it was retained, but all other variables in the model were then retested to see if they were still contributing to the success of the model. If they no longer contributed significantly, they were removed. This method ensured we would end up with the simplest equation with the best predictive power. In case more than one attitude or emotion toward death and afterlife correlated with the same outcome variable, they were all taken up in that regression model.

Finally, to answer the third research question—Do relations of attitudes and emotions about death and afterlife with distress differ between patients without evidence of disease and advanced cancer patients?—it was assessed whether a significant partial correlation coefficient identified in one patient group was significantly different from that in the other patient group, using Fisher's r -to- Z formula.²⁵

All statistical analyses were performed with SPSS (version 16.0.1). Statistical inferences

were based on two-sided tests, with $P < 0.05$ considered to be statistically significant.

Results

Participants

A questionnaire was administered to 236 eligible patients, 123 cancer patients without evidence of disease, and 113 advanced cancer patients. Twenty-three patients without evidence of disease and 40 advanced cancer patients did not return the questionnaire. In both groups, the most important reason (50% in the no evidence of disease group and 39% in the advanced cancer group) for not participating was not specified ("I just don't feel like filling out the papers anymore"). Eleven patients in the advanced cancer group deteriorated or died before they could return the questionnaire. Nine patients without evidence of disease and 16 advanced cancer patients did not fully complete the scales on attitudes and emotions toward death and were excluded from the analysis. Thus, data from 91 patients without evidence of disease and 57 advanced cancer patients were available for analysis. Participants and nonparticipants did not significantly differ by age or sex.

Breast cancer (17%), and prostate, colorectal, and lung cancer (all 7%) were the most common tumor types. Baseline characteristics of the sample and baseline characteristics of the sample by level of agreement with the attitudes and emotions toward death are presented in [Tables 1 and 2](#).

Research Question 1: Do Attitudes and Emotions About Death and Afterlife Differ Between Patients Without Evidence of Disease and Advanced Cancer Patients?

The average scores on attitudes toward death and afterlife were quite similar for patients without evidence of disease and advanced cancer patients ([Table 3](#)). Both patient groups scored highest on an agnostic attitude toward death and afterlife, directly followed by belief in the continuation of the soul despite death. Also, the scores on the emotions about death were statistically significant between the without evidence of disease group and the advanced cancer group, although on average patients without evidence of disease

Table 1
Patient Characteristics

Patient Group	No Evidence of Disease	Advanced Cancer
Age (mean \pm SD)	53 \pm 14	62 \pm 10
Karnofsky Performance score (mean \pm SD)	95 \pm 6	62 \pm 17
Sex (%)		
Female	48 (53)	28 (49)
Male	43 (47)	29 (51)
Living with a partner		
Yes	75 (84)	38 (68)
No	14 (16)	18 (32)
Education level		
Less than vocational level	38 (42)	27 (47)
Vocational level or higher	52 (58)	30 (53)
Employment		
Yes	41 (46)	17 (30)
No	49 (54)	40 (70)
Believe in God or a higher being		
Yes	69 (76)	43 (77)
No	22 (24)	13 (23)

SD = standard deviation.

scored lower on all emotions toward death compared with advanced cancer patients. Negative emotions and other-directed emotions scored highest in both patient groups.

Research Question 2: Do Attitudes and Emotions About Death and Afterlife Influence Patients' Distress, Operationalized as Quality of Life, Depression, and Hopelessness?

Tables 4 and 5 show partial correlation and regression analyses of attitudes and emotions toward death and afterlife with SWL, measures of quality of life, depression, and hopelessness. In the advanced cancer group, the explicitly religious attitude was positively correlated with global health status, but in the regression analysis, it did not show predictive value. In both the no evidence of disease group and the advanced cancer group, the agnostic attitude was positively associated with hopelessness, which remained significant in the regression analysis. Also, in the advanced cancer group, the agnostic attitude was negatively associated with SWL, although in the regression analysis the variable negative emotions toward death was the only significant predictor for SWL. Of the nonexplicitly religious attitudes, the attitude reincarnation was associated with the outcome variables role function and cognitive function. This

association also had predictive value in the regression analysis.

In the advanced cancer group, other-directed feelings were negatively associated with and had negative predictive value for social function. Although positive emotions were negatively associated with social function, this was not significant in the regression analysis. Self-directed feelings were negatively associated with and had negative predictive value for physical function. In the no evidence of disease group, negative emotions were negatively associated with social and emotional function and positively associated with depression. This remained significant in the regression analysis.

Research Question 3: Do Relations of Attitudes and Emotions About Death and Afterlife With Distress Differ Between Patients Without Evidence of Disease and Advanced Cancer Patients?

Overall, in the no evidence of disease group, four significant partial correlations were observed of attitudes and emotions toward death and afterlife with the outcome variables SWL, measures of quality of life, depression, and hopelessness. In the advanced cancer group, nine significant correlations were observed. Directly comparing these partial coefficients between the two groups, using Fisher's *r*-to-*Z* formula, the association negative emotions-social functioning in the no evidence of disease group was significantly different from the advanced cancer group. The following associations in the advanced cancer group were significantly different from the no evidence of disease group: explicitly religious attitude-global health status; reincarnation-role functioning; reincarnation-cognitive functioning; other-directed emotions-social functioning.

Discussion

To the best of our knowledge, this is the first study examining the relation between attitudes and emotions toward death and afterlife, and patients' distress in a group of patients without evidence of disease and advanced cancer patients. On average, no significant differences were observed in the mean scores on attitudes and emotions toward death for both patient groups. This is in line with earlier findings that self-reported

Table 2
Patient Characteristics by Level of Agreement with Attitudes and Feelings Toward Death and Afterlife

Attitude or Emotion About Death	Patient Group	Score	Age (SD, n)	Karnofsky Performance score (SD, n)	Male Sex (% , n)	Living with a Partner (% , n)	Education: <Vocational Training (% , n)	Employment (% , n)	Belief in God or a Higher Being (% , n)
Explicitly religious	No evidence of disease	Low	51.6 ^a (13.5, 73)	94.9 (6.1, 71)	35 (47.9, 73)	63 ^a (88.7, 71)	29 (40.3, 72)	33 (45.8, 72)	26 ^b (35.6, 73)
		High	58.6 (12.9, 18)	94.4 (7.8, 18)	8 (44.4, 18)	12 (66.7, 18)	9 (50.0, 18)	8 (44.4, 18)	18 (100.0, 18)
	Advanced cancer	Low	59.8 ^a (9.1, 36)	64.7 (17.0, 30)	22 ^a (61.1, 36)	25 (71.4, 35)	18 (50.0, 36)	12 (33.3, 36)	8 ^b (22.2, 36)
		High	66.4 (10.4, 21)	58.9 (17.9, 19)	7 (33.3, 21)	13 (61.9, 21)	9 (42.9, 21)	5 (23.8, 21)	20 (100.0, 20)
Agnostic	No evidence of disease	Low	49.2 ^a (13.8, 39)	94.9 (6.4, 39)	20 (51.3, 39)	31 (83.8, 37)	16 (42.1, 38)	21 (53.8, 39)	21 (53.8, 39)
		High	55.8 (12.8, 52)	94.8 (6.5, 50)	23 (44.2, 52)	44 (84.6, 52)	22 (42.3, 52)	20 (39.2, 51)	23 (44.2, 52)
	Advanced cancer	Low	63.3 (11.5, 27)	57.0 (14.3, 23)	12 (44.4, 27)	14 ^a (53.8, 26)	12 (44.4, 27)	10 (37.0, 27)	16 (59.3, 27)
		High	61.3 (8.6, 30)	67.3 (18.7, 26)	17 (56.7, 30)	24 (80.0, 30)	15 (50.0, 30)	7 (23.3, 30)	12 (41.4, 29)
Reincarnation	No evidence of disease	Low	52.8 (13.9, 83)	95.0 (6.5, 81)	40 (48.2, 83)	70 (86.4, 81)	36 (43.9, 82)	36 (43.9, 82)	38 (45.8, 83)
		High	54.5 (10.0, 8)	92.5 (4.6, 8)	3 (37.5, 8)	5 (62.5, 8)	2 (25.0, 8)	5 (62.5, 8)	6 (75.0, 8)
	Advanced cancer	Low	62.2 (9.8, 52)	62.6 (17.9, 45)	28 (53.8, 52)	35 (68.6, 51)	25 (48.1, 52)	15 (28.8, 52)	24 (47.1, 51)
		High	62.6 (13.2, 5)	60.0 (11.5, 4)	1 (20.0, 5)	3 (60.0, 5)	2 (40.0, 5)	2 (40.0, 5)	4 (80.0, 5)
Community	No evidence of disease	Low	53.7 (12.8, 78)	95.0 (6.2, 76)	39 (50.0, 78)	68 ^b (88.3, 77)	31 (40.3, 77)	33 (42.9, 77)	35 (44.9, 78)
		High	48.4 (17.4, 13)	93.8 (7.7, 13)	4 (30.8, 13)	7 (58.3, 12)	7 (53.8, 13)	8 (61.5, 13)	9 (69.2, 13)
	Advanced cancer	Low	62.7 (9.4, 45)	64.4 (17.8, 41)	27 ^b (60.0, 45)	31 (70.5, 44)	23 (51.1, 45)	11 (24.4, 45)	18 ^b (40.9, 44)
		High	60.7 (12.4, 12)	52.5 (11.6, 8)	2 (16.7, 12)	7 (58.3, 12)	4 (33.3, 12)	6 (50.0, 12)	10 (83.3, 12)
Continuation	No evidence of disease	Low	54.4 (12.7, 64)	95.0 (6.2, 62)	30 (46.9, 64)	58 ^b (90.6, 64)	29 (46.0, 63)	25 (39.7, 63)	25 ^b (39.1, 64)
		High	49.6 (15.2, 27)	94.4 (7.0, 27)	13 (48.1, 27)	17 (68.0, 25)	9 (33.3, 27)	16 (59.3, 27)	19 (70.4, 27)
	Advanced cancer	Low	59.8 ^a (8.2, 33)	65.2 (18.2, 29)	21 ^a (63.6, 33)	24 (75.0, 32)	16 (48.5, 33)	9 (27.3, 33)	8 ^b (25.0, 32)
		High	65.6 (11.5, 24)	58.5 (15.7, 20)	8 (33.3, 24)	14 (58.3, 24)	11 (45.8, 24)	8 (33.3, 24)	20 (83.3, 24)
Other-directed feelings	No evidence of disease	Low	51.3 (14.0, 65)	95.0 (6.4, 64)	34 (52.3, 65)	55 (87.3, 63)	25 (39.1, 64)	30 (46.2, 65)	31 (47.7, 65)
		High	57.1 (11.5, 26)	94.4 (6.5, 25)	9 (34.6, 26)	20 (76.9, 26)	13 (50.0, 26)	11 (44.0, 25)	13 (50.0, 26)
	Advanced cancer	Low	59.1 ^a (8.3, 27)	67.1 (16.8, 24)	17 (63.0, 27)	20 (76.9, 26)	12 (44.4, 27)	11 (40.7, 27)	11 (40.7, 27)
		High	65.1 (10.7, 30)	58.0 (17.1, 25)	12 (40.0, 30)	18 (60.0, 30)	15 (50.0, 30)	6 (20.0, 30)	17 (58.6, 29)
Self-directed feelings	No evidence of disease	Low	53.7 (12.6, 72)	95.2 (6.1, 71)	34 (47.2, 72)	61 (85.9, 71)	26 ^a (36.6, 71)	30 (42.3, 71)	35 (48.6, 72)
		High	50.1 (16.8, 19)	93.3 (17.7, 18)	9 (47.4, 19)	14 (77.8, 18)	12 (63.2, 19)	11 (57.9, 19)	9 (47.4, 19)
	Advanced cancer	Low	63.2 (9.7, 48)	63.1 (17.9, 41)	24 (50.0, 48)	30 (63.8, 47)	22 (45.8, 48)	12 (25.0, 48)	24 (50.0, 48)
		High	57.2 (10.8, 9)	58.8 (14.6, 8)	5 (55.6, 9)	8 (88.9, 9)	5 (55.6, 9)	4 (50.0, 8)	4 (50.0, 8)
Positive feelings	No evidence of disease	Low	52.6 (12.8, 67)	95.0 (6.4, 66)	34 (50.7, 67)	59 ^a (89.4, 66)	28 (42.4, 66)	32 (48.5, 66)	33 (49.3, 67)
		High	54.0 (15.7, 24)	94.3 (6.6, 23)	9 (37.5, 24)	16 (69.6, 23)	10 (41.7, 24)	9 (37.5, 24)	11 (45.8, 24)
	Advanced cancer	Low	61.1 (8.5, 40)	64.7 (17.6, 36)	23 (57.5, 40)	28 (71.8, 39)	19 (47.5, 40)	13 (32.5, 40)	16 ^a (40.0, 40)
		High	64.9 (12.9, 17)	56.2 (15.6, 13)	6 (35.3, 17)	10 (58.8, 17)	8 (47.1, 17)	4 (23.5, 17)	12 (75.0, 16)
Negative feelings	No evidence of disease	Low	52.1 (14.3, 64)	95.0 (6.4, 64)	30 (46.9, 64)	49 ^a (79.0, 62)	28 (43.8, 64)	29 (45.3, 64)	28 (43.8, 64)
		High	55.1 (11.5, 27)	94.4 (6.5, 25)	13 (48.1, 27)	26 (96.3, 27)	10 (38.5, 26)	12 (46.2, 26)	16 (59.3, 27)
	Advanced cancer	Low	63.7 (9.8, 34)	61.3 (19.1, 30)	18 (52.9, 34)	23 (67.6, 34)	17 (50.0, 34)	12 (35.3, 34)	17 (50.0, 34)
		High	60.1 (10.1, 23)	64.2 (14.6, 19)	11 (47.8, 23)	15 (68.2, 22)	10 (43.5, 23)	5 (21.7, 23)	11 (50.0, 22)

SD = standard deviation.

Karnofsky Performance score was measured on a scale of 0–100, in which 0 indicates dead and 100 indicates asymptomatic. Agreement with an attitude toward death and afterlife was computed “low” if a patient scored <3.5 and “high” if scored ≥3.5 (on a scale from 1 to 5). Agreement with an emotion about death was computed “low” if a patient scored <6 and “high” if scored ≥6 (on a scale from 0 to 10).

^aSignificant difference between low and high scores, $P < 0.05$.

^bSignificant difference between low and high scores, $P < 0.01$.

Table 3
Mean Values of the Attitudes and Feelings
Toward Death and Afterlife

	No Evidence of Disease	Advanced Cancer
Explicitly religious		
Mean	2.86	2.80
SE	0.09	0.11
Agnostic		
Mean	3.48	3.42
SE	0.08	0.10
Reincarnation		
Mean	2.47	2.29
SE	0.09	0.11
Community		
Mean	2.63	2.74
SE	0.09	0.12
Continuation		
Mean	3.04	3.23
SE	0.09	0.11
Other-directed feelings		
Mean	4.11	5.27
SE	0.35	0.45
Self-directed feelings		
Mean	2.75	3.52
SE	0.29	0.38
Positive feelings		
Mean	3.50	4.10
SE	0.32	0.41
Negative feelings		
Mean	4.34	4.97
SE	0.33	0.42

SE = standard error.

Mean scores and SEs of attitudes and feelings about death and afterlife are given for the group of patients without evidence of disease and advanced cancer patients. Mean values are corrected for the sociodemographic variables sex, age, living with a partner, education, and belief in God or a higher being that were significantly associated with attitudes or feelings about death and afterlife (cf. Table 1). For scale ranges, see *Methods*. To assess differences in means, covariance analysis was performed using sex, age, living with a partner, education, and belief in God or a higher being as covariates. No significant differences between the two patient groups were observed.

fear of death was not significantly different in a group of terminally ill patients compared with controls or across different disease stages.^{9,13,26} Looking at the four associations of attitudes and emotions toward death and afterlife with aspects of quality of life observed in the palliative group, which were absent in the curative group (i.e., explicitly religious attitude-global health status; reincarnation-role functioning; reincarnation-cognitive functioning; other-directed emotions-social functioning), this may suggest that the relation of attitudes and emotions with quality of life is stronger in the group of advanced cancer patients who were facing death than in the group of patients without evidence of disease. However, vice versa, in the group without evidence

of disease, an association was observed that was not present in the advanced cancer group (namely, negative emotions-social functioning). Therefore, in patients with advanced cancer, the relation between attitudes and feelings toward death and quality of life, depression, and hopelessness was not necessarily stronger compared with patients without evidence of disease, but rather in both groups different relationships were observed.

Let us look in more detail into the observed relationships. In the group without evidence of disease, only (negative) emotions toward death were related to aspects of quality of life and depression. Attitudes toward death and afterlife were not related to any of the outcome variables, except for the association of the agnostic attitude with hopelessness, which we will discuss below. In contrast, in the advanced cancer group, several attitudes toward death and afterlife were related with measures of quality of life and hopelessness. This suggests that when one is faced with imminent death, finding meaning and value becomes a more central focus of attention.²⁷ In fact, in terminally ill patients, concerns about meaning and value may be more prominent than complaints about physical symptoms.²⁸ All emotions toward death showed negative correlations with measures of quality of life and a positive correlation with depression. Apparently, any emotion toward death, even if its content is positive, has a negative connotation in terms of distress. However, this does not imply that the content of the emotion is of no importance at all, because, for example, other-directed feelings were specifically related to social function and self-directed feelings to physical function.

In both the group of patients without evidence of disease and the advanced cancer patients, the agnostic attitude was associated with hopelessness. Previously, it has been argued that not the content of a belief is important but rather the certainty with which a belief is held.²⁶ Patients appear to derive comfort from a firm belief, whatever the content of that belief may be. Based on our results, this conclusion should be nuanced. Patients with a firm belief that life ends with death and there is no meaning to death score higher on hopelessness. The lack of meaning may be crucial in this respect. In dealing with the finitude of life,

Table 4

Partial Correlations Between Attitudes and Emotions Toward Death and Afterlife and Measures of Quality of Life, Depression, and Hopelessness

		Explicitly Religious		Agnostic		Reincarnation		Community		Continuation		Other-Directed feelings		Self-Directed feelings		Positive Emotions		Negative Emotions	
		NED	Adv	NED	Adv	NED	Adv	NED	Adv	NED	Adv	NED	Adv	NED	Adv	NED	Adv	NED	Adv
SWL	<i>r</i>				−0.308 ^a									0.259				−0.351 ^a	
	sig				0.039									0.086				0.018	
Global health status	<i>r</i>		0.388 ^b			−0.207	0.278									−0.228			
	sig		0.009			0.059	0.064									0.132			
Physical function	<i>r</i>											−0.248		−0.323 ^a		−0.226		0.260	
	sig											0.101		0.031		0.135		0.084	
Role function	<i>r</i>						0.448 ^b					−0.225							
	sig						0.002					0.138							
Social function	<i>r</i>											−0.420 ^b		−0.293		−0.296 ^a		−0.255 ^a	
	sig											0.004		0.051		0.049		0.019	
Emotional function	<i>r</i>											−0.258						−0.330 ^b	
	sig											0.087						0.002	
Cognitive function	<i>r</i>						0.297 ^a		0.208										
	sig						0.048		0.171										
Depression	<i>r</i>		−0.249															0.295 ^b	
	sig		0.099															0.006	
Hopelessness	<i>r</i>			0.263 ^a	0.366 ^a														
	sig			0.016	0.013														

NED = no evidence of disease group; Adv = advanced cancer group.

Partial correlation coefficient *r* is given when $r \geq 0.200$. Control variables were age, sex, and belief in God or a higher being.^a $P < 0.05$.^b $P < 0.01$.

Table 5
Stepwise Regression Analysis of Attitudes and Emotions Toward Death and Afterlife and Measures of Quality of Life, Depression, and Hopelessness

Dependent Variable	Group	Model	Independent Variables	Standardized Coefficients Beta	Sig.	R ² change	R ²	Adjusted R ²
SWL	Advanced cancer	1	Negative emotions	-0.298	0.027	0.089 ^a	0.089 ^a	0.072
Physical function	No evidence of disease	1	Belief in God or a higher being	-0.223	0.034	0.050 ^a	0.050 ^a	0.039
		2	Belief in God or a higher being	-0.222	0.031	0.047 ^a	0.097 ^a	0.077
Role function	Advanced cancer	1	Sex	-0.218	0.034	0.101 ^a	0.101	0.084
		2	Self-directed emotions	-0.317	0.018			
Social function	No evidence of disease	1	Sex	-0.278	0.038	0.077 ^a	0.077 ^a	0.060
		2	Sex	-0.385	0.005	0.107 ^a	0.184 ^b	0.153
Emotional function	Advanced cancer	1	Reincarnation	0.344	0.011	0.091 ^a	0.091 ^a	0.074
		2	Negative emotions	-0.223	0.024			
Cognitive function	No evidence of disease	1	Negative emotions	-0.232	0.024	0.050 ^a	0.050 ^a	0.039
		2	Negative emotions	-0.232	0.024	0.050 ^a	0.050 ^a	0.039
Depression	Advanced cancer	1	Age	0.217	0.035	0.047 ^a	0.097 ^a	0.076
		2	Other-directed emotions	-0.302	0.027	0.091 ^a	0.091 ^a	0.074
Hopelessness	No evidence of disease	1	Negative emotions	-0.343	0.001	0.118 ^b	0.118 ^b	0.108
		2	Negative emotions	-0.343	0.001	0.118 ^b	0.118 ^b	0.108
Depression	Advanced cancer	1	Age	0.275	0.040	0.076 ^a	0.076 ^a	0.058
		2	Reincarnation	0.316	0.018	0.100 ^a	0.100 ^a	0.083
Hopelessness	No evidence of disease	1	Negative emotions	0.315	0.003	0.099 ^b	0.099 ^b	0.089
		2	Negative emotions	0.315	0.003	0.099 ^b	0.099 ^b	0.089
Depression	Advanced cancer	1	Agnostic attitude	0.241	0.022	0.058 ^a	0.058 ^a	0.047
		2	Agnostic attitude	0.287	0.037	0.082 ^a	0.082 ^a	0.064

Stepwise regression analysis was performed of attitudes and emotions toward death and afterlife on relevant measures of quality of life, depression, and hopelessness as determined from the correlation analysis (see *Methods*). Patient age, sex, and belief in God or a higher being were entered in each model as independent relevant sociodemographic variables. Per outcome variable, all significant models are shown with the independent variables, which were entered successively.

^a $P < 0.05$.

^b $P < 0.01$.

the ability to ascribe meaning is essential and, indeed, may be more important than the specific content that reflects this meaning.²⁹ However, if the only “meaning” that can be given is “meaningless,” this may not provide the comfort and sense of hope that patients need when they are confronted with death. It should be noted that hope is essential for the well-being of patients, even in the last phase of life.^{30,31} Hope should not be equated with hope of cure because it also may be hope for valued and caring relationships or reconciliation with life and death.^{30–35}

Limitations of the Study

Clearly, from our study, no definite conclusion can be drawn about the causal or influential relationship between the life phase of a patient (no evidence of disease vs. advanced cancer) and the relation of attitudes and

emotions about death and afterlife with distress. A longitudinal follow-up study would be necessary to corroborate our suggestion that the relation between attitudes and emotions about death and afterlife, and patients’ distress changes in the course of illness, when the prospects of a patient change from the curative to the palliative setting, or even vice versa.³⁶ Also, our patient group was relatively small, and we have tested multiple hypotheses, with the possibility of reporting spurious associations. Ideally, because of our relatively small study sample, our results should be validated in a second independent set of data to allow for definite conclusions. Finally, the observed correlations were not very strong, and it is still an open question whether direct counseling of patients, either in the curative or the palliative setting, on attitudes and emotions about death and afterlife will reduce distress, although

a pilot study has suggested that preparation and life completion discussion may improve functioning and quality of life in seriously ill patients.³⁷ Awaiting the results of further studies on this issue, we advocate that if physicians are confronted with patients who are overtly struggling with the finitude of their lives, they should start an appropriate counseling trajectory. Therefore, clinicians should be attentive to beliefs and feelings of patients regarding death and afterlife. As many clinicians feel uncertain about these issues, well-developed training programs for clinicians are urgently needed.^{38–40}

Conclusion

Patients without evidence of disease and advanced cancer patients do not have different attitudes or emotions toward death, but the relation of these attitudes and emotions with quality of life, depression, and hopelessness varies between the two groups. When there is no evidence of disease, negative emotions play the most important role, whereas in the setting of advanced cancer, attitudes toward death and afterlife, which may provide meaning and value, become more prominent. A careful exploration of these attitudes and emotions is essential to provide optimal cancer care.

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References

1. Efficace F, Marrone R. Spiritual issues and quality of life assessment in cancer care. *Death Stud* 2002;26:743–756.
2. Muzzin LJ, Anderson NJ, Figueredo AT, et al. The experience of cancer. *Soc Sci Med* 1994;38:1201–1208.
3. Coyle N. The hard work of living in the face of death. *J Pain Symptom Manage* 2006;32:266–274.
4. Penson RT, Partridge RA, Shah MA, et al. Fear of death. *Oncologist* 2005;10:160–169.
5. Grumann MM, Spiegel D. Living in the face of death: interviews with 12 terminally ill women on home hospice care. *Palliat Support Care* 2003;1:23–32.
6. National Comprehensive Cancer Network. Distress management. NCCN Clin Pract Guidel Oncol 2011;v.1. Available from www.nccn.org. Accessed February 28, 2011.
7. Taylor EJ. Spiritual needs of patients with cancer and family caregivers. *Cancer Nurs* 2003;26:260–266.
8. McClain-Jacobson C, Rosenfeld B, Kosinski A, et al. Belief in an afterlife, spiritual well-being and end-of-life despair in patients with advanced cancer. *Gen Hosp Psychiatry* 2004;26:484–486.
9. Feifel H, Freilich J, Hermann LJ. Death fear in dying heart and cancer patients. *J Psychosom Res* 1973;17:161–166.
10. Vollmer TC, Wittmann M, Schweiger C, Hiddemann W. Preoccupation with death as predictor of psychological distress in patients with haematologic malignancies. *Eur J Cancer Care (Engl)* 2010. [Epub ahead of print].
11. Sherman DW, Norman R, McSherry CB. A comparison of death anxiety and quality of life of patients with advanced cancer or AIDS and their family caregivers. *J Assoc Nurses AIDS Care* 2010;21:99–112.
12. Cella DF, Tross S. Death anxiety in cancer survival: a preliminary cross-validation study. *J Pers Assess* 1987;51:451–461.
13. Shinn EH, Taylor CL, Kilgore K, et al. Associations with worry about dying and hopelessness in ambulatory ovarian cancer patients. *Palliat Support Care* 2009;7:299–306.
14. Scherer-Rath M. *Lebensackgassen*. Living dead ends. Challenges for pastoral advice and assistance of people in life crises. Münster: Lit Verlag 2001.
15. Scherer-Rath M, Van der Ven JA, Felling A. Images of death as perspectives in a life crisis. *J Empir Theolog* 2001;14:5–26.
16. Hermans HJM, Hermans-Jansen E. *Self-narratives: The construction of meaning in psychotherapy*. New York: The Guilford Press, 1995.
17. Oles PK, Hermans HJM. *The dialogical self: Theory and research*. Lublin, Poland: Polish Scientific Publishers, 2005.
18. Hermans HJM. *The person as a motivated storyteller: valuation theory and the self-confrontation*.

- method. In: Neimeyer RA, Neimeyer GJ, eds. *Advances in personal construct psychology*. New York: Praeger, 2002: 3–38.
19. Diener E, Emmons R, Larsen R, et al. The Satisfaction with Life Scale. *J Pers Assess* 1985;49:71–75.
20. Aaronson NK, Ahmedzai S, Bergman B, et al. The European Organization for Research and Treatment of Cancer QLQ-C30: a quality-of-life instrument for use in international clinical trials in oncology. *J Natl Cancer Inst* 1993;85:365–376.
21. Mystakidou K, Tsilika E, Parpa E, et al. The EORTC core quality of life questionnaire (QLQ-C30, version 3.0) in terminally ill cancer patients under palliative care: validity and reliability in a Hellenic sample. *Int J Cancer* 2001;94:135–139.
22. Beck AT, Guth D, Steer RA, et al. Screening for major depression disorders in medical inpatients with the Beck Depression Inventory for Primary Care. *Behav Res Ther* 1997;35:785–791.
23. Rodin G, Lo C, Mikulincer M, et al. Pathways to distress: the multiple determinants of depression, hopelessness, and the desire for hastened death in metastatic cancer patients. *Soc Sci Med* 2009;68:562–569.
24. Beck AT, Weissman A. The measurement of pessimism: the hopelessness scale. *J Consult Clin Psychol* 1974;42:861–865.
25. Cohen J, Cohen P, West SG, et al. *Applied multiple regression/correlation analysis for the behavioral sciences*. Mahwah, NJ: Lawrence Erlbaum Associates, 2003.
26. Smith DK, Nehemkis AM, Charter RA. Fear of death, death attitudes, and religious conviction in the terminally ill. *Int J Psychiatry Med* 1983;13:221–232.
27. Sulmasy DP. Spiritual issues in the care of dying patients: "... it's okay between me and God". *JAMA* 2006;296:1385–1392.
28. Portenoy RK, Thaler HT, Kornblith AB, et al. The Memorial Symptom Assessment Scale: an instrument for the evaluation of symptom prevalence, characteristics and distress. *Eur J Cancer* 1994;30:1326–1336.
29. Marrone R. Dying, mourning, and spirituality: a psychological perspective. *Death Stud* 1999;23:495–519.
30. Herth K. Fostering hope in terminally-ill people. *J Adv Nurs* 1990;15:1250–1259.
31. Buckley J, Herth K. Fostering hope in terminally ill patients. *Nurs Stand* 2004;19:33–41.
32. Benzein E, Norberg A, Saveman BI. The meaning of the lived experience of hope in patients with cancer in palliative home care. *Palliat Med* 2001;15:117–126.
33. Duggleby W, Wright K. Transforming hope: how elderly palliative patients live with hope. *Can J Nurs Res* 2009;41:204–217.
34. Elliott JA, Olver IN. Hope, life, and death: a qualitative analysis of dying cancer patients' talk about hope. *Death Stud* 2009;33:609–638.
35. Daneault S, Dion D, Sicotte C, et al. Hope and noncurative chemotherapies: which affects the other? *J Clin Oncol* 2010;28:2310–2313.
36. Laarhoven HW, Leget CJ, van der Graaf WT. Dying at the right time: a modern dilemma. *Oncologist* 2009;14:642–643.
37. Steinhäuser KE, Alexander SC, Byock IR, et al. Do preparation and life completion discussions improve functioning and quality of life in seriously ill patients? Pilot randomized control trial. *J Palliat Med* 2008;11:1234–1240.
38. Lo B, Ruston D, Kates LW, et al. Discussing religious and spiritual issues at the end of life: a practical guide for physicians. *JAMA* 2002;287:749–754.
39. Williams CM, Wilson CC, Olsen CH. Dying, death, and medical education: student voices. *J Palliat Med* 2005;8:372–381.
40. van Laarhoven HWM, Schilderman J, Prins J. Religious coping and life-prolonging care. [letter]. *JAMA* 2009;302:257.