

Original Article

Emotional Numbness Modifies the Effect of End-of-Life Discussions on End-of-Life Care

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Abstract

Context. Overall, end-of-life (EOL) discussions are unrelated to psychological distress and associated with lower rates of aggressive care near death. Nevertheless, patients who report that they feel emotionally numb about their illness might encounter difficulties cognitively processing an EOL discussion.

Objectives. We hypothesized that emotional numbness would modify the effect of EOL discussions on the receipt of less aggressive EOL care.

Methods. Data were derived from structured interviews with 290 participants in the federally-funded Coping with Cancer Study, a multisite, prospective cohort study of patients with advanced cancer followed-up till their death. Patients' reports of EOL discussions with their physician and emotional numbness were assessed at a median of 4.6 months before their death. Information about aggressive EOL care (i.e., ventilation, resuscitation in the last week of life, death in the intensive care unit) was obtained from postmortem caregiver interviews and medical charts. Main and interactive effects of EOL discussions and emotional numbness on aggressive EOL care, adjusting for potential confounds, were evaluated using multiple logistic regression.

Results. The likelihood of aggressive EOL care associated with having EOL discussions increased by a factor of nine (adjusted odds ratio = 9.02, 95% CI 1.37, 59.6, $P = 0.022$) for every unit increase in a patient's emotional numbness score.

Conclusion. Emotional numbness diminishes a patient's capacity to benefit from EOL discussions. The EOL decision making may be more effective if clinical communications with emotionally numb patients are avoided. *J Pain Symptom Manage* 2013;45:841–847. © 2013 U.S. Cancer Pain Relief Committee. Published by Elsevier Inc. All rights reserved.

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Key Words

Cancer, terminal illness, end-of-life care, communication, numbness, psychological reactions, grief, dissociation

Introduction

Conversations in which patients and physicians discuss the care that patients would want to receive if they were dying are generally associated with patients' heightened prognostic awareness,¹⁻³ increased rates of advance care planning,^{1,3,4} and hospice use,^{1,2} as well as decreased use of expensive aggressive end-of-life (EOL) procedures that impair their quality of life without enhancing survival.¹⁻⁵ EOL discussions also increase the likelihood that patients will receive EOL care that is consistent with their expressed preferences.³ Nevertheless, conversations about death and dying are difficult to initiate,^{6,7} require considerable skill and sensitivity,⁷ may provide more information than what patients actually want,⁸ and are often simply avoided.⁶ Despite the likely benefits of EOL discussions, most terminally ill patients report not having EOL conversations with their health care providers.¹

A common view is that health care professionals should initiate discussions about EOL issues when patients seem ready to have them,⁷ an approach that relies heavily on intangible capacities such as clinical intuition, sensitivity, and common sense. Patients who are or who might become overwhelmed or distraught by thoughts of death and dying may not be ready to have an EOL discussion. The threatening nature of a terminal illness or of an EOL discussion may trigger a dissociative response in some patients that manifests itself as emotional numbness.^{9,10} The fourth edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM-IV)¹¹ (p. 519) defines dissociation as "a disruption in the usually integrated function of consciousness, memory, identity, or perception of the environment." Dissociation and emotional numbness impose psychological barriers to normal human interactions. Gershuny and Thayer¹² assert that "when emotional pain is acute and deemed unbearable by the sufferer, dissociation may be called upon as a means of escape." (p. 647) In dissociative responses to psychological

threats, symptoms of "freezing, analgesia, and emotional numbing" are believed to be elicited automatically.¹³ (p. 65)

Dissociation and the associated symptom of emotional numbness in patients with terminal illnesses may indicate a lack of patient readiness to engage effectively in EOL discussions. Enlisted as a way to avoid processing shocking and upsetting information, emotional numbness may result in cognitive difficulties such as memory and attention problems.^{10,14} Patients with advanced cancer who are emotionally numb may have restricted capacities to process health status and treatment information and not benefit from EOL discussions to the same extent as their less numb counterparts. Consequently, EOL discussions may not reduce the odds that cancer patients who are or who become emotionally numb will receive aggressive care at the EOL when the patient's ability to weigh the pros and cons of life-prolonging treatment is compromised. In fact, EOL discussions with patients who are numb in their wake may exacerbate their fears and result in an instinctive demand that everything possible be done to keep them alive at all costs.

The present study sought to determine whether and to what extent patients' emotional numbness modifies the effect of EOL discussions on receipt of aggressive EOL care. We hypothesized that greater emotional numbness would diminish the influence of EOL discussions on the receipt of less aggressive EOL care.

Methods**Study Sample**

Participants ($N=290$) came from the Coping with Cancer (CwC) Study, a National Cancer Institute- and National Institute of Mental Health-funded multi-institutional investigation of patients with advanced cancer and their informal caregivers. Conducted from September 2002 through August 2008, CwC Study

was designed to examine the relationships between psychosocial factors and EOL outcomes such as utilization of aggressive medical care near death. Patients were recruited from six outpatient sites: Yale Cancer Center (New Haven, CT), Veterans' Affairs Connecticut Healthcare System Comprehensive Cancer Clinics (West Haven, CT), Simmons Comprehensive Cancer Care Center (Dallas, TX), Parkland Hospital Palliative Care Service (Dallas, TX), Dana-Farber/Harvard Cancer Center (Dana-Farber Cancer Institute and Massachusetts General Hospital, Boston, MA), and New Hampshire Oncology-Hematology (Hooksett, NH). Eligibility criteria included: 1) diagnosis of an advanced cancer with metastases, 2) disease progression after first-line chemotherapy, 3) aged at least 20 years, 4) availability of an informal caregiver (e.g., spouse), 5) adequate stamina to complete the 45-minute interview, and 6) ability to speak either English or Spanish. Patient-caregiver dyads in which either party was significantly cognitively impaired (by neurobehavioral cognitive status examination with more than five errors¹⁵) were excluded. Both patients and caregivers provided written informed consent in accordance with protocols approved by the institutional review board of each participating site.

Each week, outpatient clinic lists were reviewed by research and clinical staff to identify eligible participants. Of the 939 eligible patients, 661 (70.4%) participated. The most common reasons for nonparticipation were "not interested" ($n = 106$), "caregiver refuses" ($n = 32$), and "too upset" ($n = 21$). Participants and nonparticipants did not differ significantly in age, gender, race/ethnicity, or years of education.

Because this report focuses on predictors of EOL care, the sample for the present study was restricted to deceased individuals with postmortem data and complete baseline assessments of EOL discussions and emotional numbness. At the time of the analysis, 385 participants had died. Postmortem data were available for 369 (95.8%) of the deceased patients, and complete EOL discussion and emotional numbness assessments were present for 290 (78.6%) of these. Those with incomplete data did not differ significantly from those with complete data with respect to gender, race, education, and marital status. Subjects

with missing data were significantly younger than those with complete data: mean = 57.7 (SD = 12.7) vs. 61.6 (SD = 10.9) years of age ($t = -2.50$, degrees of freedom = 366; $P = 0.013$).

The final cohort for the present study consisted of 290 patients with advanced cancer who provided a baseline interview (for which they received \$25 compensation) and who died at a median of 4.6 months after the baseline assessment.

Measures

Baseline Sociodemographic and Health Status Characteristics. Patients' age, gender, race/ethnicity, years of education, and marital status were reported by the patient. Disease information was obtained from medical charts. Performance status was determined by trained interviewers using the Karnofsky scale.¹⁶ Karnofsky performance status ratings included: 100 = patient has no symptoms, carries out all normal activities; 50 = patient requires medical care and much assistance with self-care; and 0 = patient is dead. Karnofsky scores were significantly associated with the number of days from patients' baseline interviews until death (Spearman rank correlation $r_s = 0.35$, $P < 0.001$).

EOL Discussions. Patients were asked "Have you and your doctor discussed any particular wishes you have about the care you would want to receive if you were dying?" Responses were coded as 1 = yes and 2 = no.

Patient Emotional Numbness. The Prolonged Grief Disorder scale (PG-12)¹⁷ asks patients about their current emotional state in relation to their illness. Patient emotional numbness was assessed at the time of the baseline interview using a single item from the patient version of the PG-12 that asked patients about the extent to which they felt emotionally numb about their illness. Responses were rated: 1 = not at all, 2 = slightly, 3 = somewhat, 4 = quite a bit, and 5 = overwhelmingly. As an indication of its construct validity, the numbness item in the present sample was significantly associated with the PG-12 grief summary score (Spearman rank correlation $r_s = 0.58$, $P < 0.001$), with disbelief ($r_s = 0.33$, $P < 0.001$), bitterness ($r_s = 0.33$, $P < 0.001$),

and yearning ($r_s = 0.16$, $P = 0.005$). The numbness item also was significantly associated with patients' feeling traumatized by their initial cancer diagnosis ($r_s = 0.14$, $P = 0.015$), assessed using the Structured Clinical Interview for Diagnostic and Statistical Manual of Mental Disorders-IV^{18,19} screening question for post-traumatic stress disorder as it pertained to the initial cancer diagnosis. Patients were asked "When you received your diagnosis, were you very afraid or did you feel terrified or helpless?" Responses were coded as 1 = yes/somewhat and 2 = no.

Aggressive Medical Care at the EOL. Patients' receipt of aggressive, life-prolonging care at the EOL, defined here as the use of mechanical ventilation or resuscitation in the last week of life or occurrence of death in the intensive care unit, was documented from primary caregiver interviews and verified with medical chart reviews.

Statistical Methods

Bivariate associations between patient characteristics and primary study outcome variables, that is, EOL discussions, emotional numbness, and receipt of aggressive EOL care, were assessed using logistic (for EOL discussions and aggressive EOL care as outcomes) and ordinal logistic (for emotional numbness as outcome) regression without adjustment for other variables. Multiple logistic regression was used to test the hypothesis that emotional numbness modifies an association between EOL discussions and receipt of aggressive EOL care. Receipt of aggressive medical care at the EOL was regressed on the main and interactive effects of EOL discussions and emotional numbness score (mean = 1.70, SD = 1.08), adjusting for patient characteristics (age and race) at least marginally significantly associated ($P < 0.10$) with aggressive EOL care. Statistical analyses were performed using SAS Version 9.1 (SAS Institute Inc., Cary, NC).

Results

Table 1 presents descriptive statistics of the patient sample ($N = 290$) at the baseline assessment. Patients were, on average, middle aged

Table 1
Patient Characteristics and Outcomes ($N = 290$)

	N (%)
Characteristics	
Age (y), mean (SD)	57.7 (12.7)
Gender, male	152 (52.4)
Race/ethnicity	
White	184 (63.5)
Black	56 (19.3)
Hispanic	45 (15.5)
Other	5 (1.7)
Education (y), mean (SD)	12.4 (4.1)
Marital status, married	154 (54.0)
Cancer type	
Lung	56 (19.7)
Colon	39 (13.7)
Pancreatic	22 (7.7)
Other gastrointestinal	36 (12.6)
Breast	41 (14.4)
Other	91 (31.9)
Karnofsky Performance Status score, mean (SD)	64.3 (14.7)
Outcome	N (%)
EOL discussions	102 (35.2)
Emotional numbness (score)	
Not at all (1)	185 (63.8)
Slightly (2)	41 (14.1)
Somewhat (3)	37 (12.8)
Quite a bit (4)	20 (6.9)
Overwhelmingly (5)	7 (2.4)
Aggressive EOL care	31 (10.7)

EOL = end-of-life.

Missing observations: marital status ($n = 5$), cancer type ($n = 5$), Karnofsky score ($n = 4$).

(mean = 57.7 years, SD = 12.7 years), 52.4% male, and racially/ethnically diverse (63.5% White, 19.3% Black, 15.5% Hispanic, and 1.7% other). Patients' average performance status (mean = 64.3, SD = 14.7) was partway between "patient is able to care for self, but is unable to do normal activities or active work" (Karnofsky score = 70) and "patient is able to care for self, but requires occasional assistance" (Karnofsky score = 60). A substantial minority of patients (35.2%) reported EOL discussions. Small minorities of patients were either "quite a bit" (6.9%) or "overwhelmingly" (2.4%) emotionally numb. A minority of patients (10.7%) received aggressive EOL medical care.

Table 2 presents odds ratios (ORs) between patient characteristics and EOL discussions, patient emotional numbness, and patient receipt of aggressive EOL care. Karnofsky performance status score was significantly inversely related to EOL discussions (OR = 0.71 per 10 unit change in Karnofsky score, $P < 0.001$). Higher

Table 2
Odds Ratios Between Patient Characteristics and EOL Discussions, Emotional Numbness, and Aggressive EOL Care (N = 290)

Patient Characteristics	EOL Discussions		Emotional Numbness		Aggressive EOL Care	
	OR	P-value	OR	P-value	OR	P-value
Age (y)	0.99	0.435	0.99	0.095	0.97	0.065
Gender, male	1.17	0.532	0.85	0.485	1.75	0.157
Race, White	1.02	0.943	1.21	0.441	0.37	0.011
Education (y)	1.01	0.787	0.97	0.273	0.99	0.889
Marital status, married	0.97	0.902	0.91	0.703	1.63	0.218
Karnofsky score/10	0.71	<0.001	0.79	0.004	1.17	0.239

EOL = end-of-life; OR = odds ratio.

Missing observations: marital status ($n = 5$), cancer type ($n = 5$), Karnofsky score ($n = 4$). Karnofsky score/10 represents the Karnofsky Performance Status score divided by 10. The ORs for Karnofsky score/10 represent the change in the odds of the outcome per 10 unit change in Karnofsky score.

performance status was related to lower levels of emotional numbness (OR = 0.79 per 10 unit change in Karnofsky score, $P = 0.004$). White as opposed to non-White patient race/ethnicity was inversely related to aggressive medical care near death (OR = 0.37, $P = 0.011$).

Table 3 shows that there was a significant interaction whereby the adjusted relative odds of receipt of aggressive EOL care associated with having EOL discussions increased by a factor of nine for every unit increase in the patient's emotional numbness score (interaction adjusted OR = 9.02, $P = 0.022$). As illustrated in Fig. 1, patients who were "overwhelmingly" numb, that is, those with an emotional numbness score of 5, were predicted to be approximately nine times more likely to receive aggressive EOL care if they reported an EOL discussion than if they did not.

Table 3
Patients' Emotional Numbness Modifies an Association Between EOL Discussions and Aggressive EOL Care (N = 290)

Predictor	Aggressive EOL Care	
	AOR ^a	P-value
EOL discussions	0.001	0.038
Emotional numbness score	0.62	0.101
EOL discussions × emotional numbness score	9.02	0.022

EOL = end-of-life; AOR = adjusted odds ratio.

^aAOR: odds ratio adjusted for age and race (White vs. non-White).

Discussion

The results of the present study demonstrate rather dramatically that patients' emotional numbness diminishes the effect of EOL discussions on the receipt of less aggressive EOL care. We found that the odds of aggressive EOL care associated with having EOL discussions increased by a factor of nine for every unit increase in a patient's emotional numbness score. Elsewhere we have shown a relationship between aggressiveness of care received in the last week and worse quality of life in that week.¹ For this reason, we consider patients' receipt of less aggressive EOL care to be a beneficial outcome of EOL discussions. From this perspective, our present findings indicate that EOL discussions are most beneficial to patients who are least emotionally numb. Any step that clinicians might take to reduce a patient's level of emotional numbness would be expected to enhance the benefit of having EOL discussions by reducing the likelihood that the patient receives aggressive, noncurative EOL care.

There appear to be many missed opportunities for physicians to engage in beneficial EOL discussions with patients diagnosed with terminal illnesses. In the present study, only 35.2% of patients with advanced cancers reported having EOL discussions with their physicians. Based on the present findings, EOL discussions would likely protect most of the patients (90.7%) with advanced cancer who were either not at all, slightly, or somewhat numb from receiving aggressive, noncurative care near death. Still, EOL discussions will not affect all patients similarly; EOL discussions would be expected to be of questionable benefit to a small subset (9.3%) of patients who were either quite a bit or overwhelmingly emotionally numb. Indeed, EOL discussions for a small minority (2.4%) of patients who were overwhelmingly numb may actually heighten rather than protect patients from the risk of receipt of aggressive, expensive, burdensome EOL care.

We found that EOL discussions were more likely to occur in patients with worse performance status, and that worse performance status was linked to greater emotional numbness. This suggests that physicians wait until patients are in a state of severe physical decline (presumably

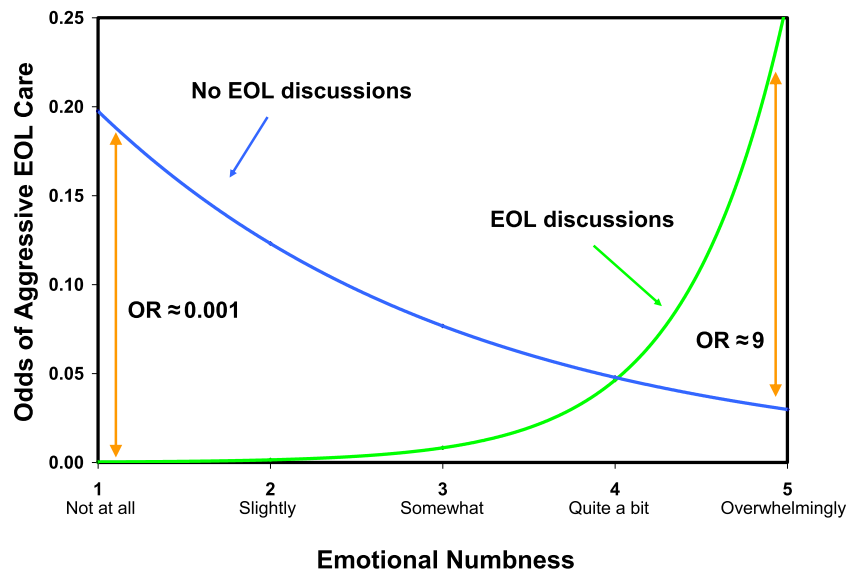


Fig. 1. Patient emotional numbness modifies relationship between EOL discussions and aggressive EOL care ($N = 290$). Predicted odds of aggressive EOL care adjusting for age and race (White vs. non-White). EOL = end-of-life; OR = odds ratio.

close to death) before engaging in EOL discussions. This practice results in EOL discussions occurring with patients who are both physically and psychologically compromised and lacking the capacity to benefit from these conversations (and who potentially might be harmed by EOL discussions if these patients are or become overwhelmingly numb). One reason to have EOL discussions earlier in the course of illness would be to reduce the odds of patients being in physically and psychologically fragile states when they occur.

This study was limited by the cross-sectional nature of the assessments of patients' reports of EOL discussions and present state of emotional numbness. Thus, the causal association and direction between these baseline variables cannot be known with absolute certainty. Nevertheless, the wording and intent of the CwC survey places these two variables in a distinct time sequence, that is, EOL discussions in the past (implicitly since the time of diagnosis) and degree of emotional numbness presently at the time of the baseline assessment. Additionally, EOL discussions were based on potentially biased patient self-report. Longitudinal studies of patients and their oncology providers that include documentation of EOL discussions, perhaps via audio-taped clinic visits, are needed to confirm the results reported

here. Another limitation is that emotional numbness was assessed using a single-item measure. Nevertheless, the single item of numbness was significantly associated with patient grief, other individual grief symptoms, and feelings of fear or helplessness at the time of the initial cancer diagnosis. It is worth noting that only patient emotional numbness, and neither other individual grief symptoms nor the grief summary measure (data not shown), modifies the effect of EOL discussions on care received in the last week of life. Evidently, there is something particular to emotional numbness, and not other aspects of grief, that affects the impact of EOL discussions on EOL care. Future studies are needed to refine measurement and advance understanding of emotional numbness and its effects on medical decision making.

In conclusion, emotionally numb patients are unlikely to benefit from EOL discussions in terms of receipt of less aggressive EOL care. There also appears to be a need for clinicians to identify and selectively not engage in EOL discussions with patients who display higher levels of emotional numbness or who are likely to become excessively numb in response to them. Finally, there is a need to understand the signs and risks of emotional numbness so that it can be prevented or

reduced and thereby enhance the effectiveness of communication at the EOL.

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References

1. Wright AA, Zhang B, Ray A, et al. Associations between end-of-life discussions, patient mental health, medical care near death, and caregiver bereavement adjustment. *JAMA* 2008;300:1665–1673.
2. Prigerson HG. Socialization to dying: social determinants of death acknowledgement and treatment among terminally ill geriatric patients. *J Health Soc Behav* 1992;33:378–395.
3. Mack JW, Weeks JC, Wright AA, Block SD, Prigerson HG. End-of-life discussions, goal attainment, and distress at the end of life: predictors and outcomes of receipt of care consistent with preferences. *J Clin Oncol* 2010;28:1203–1208.
4. Mack JW, Paulk ME, Viswanath K, Prigerson HG. Racial disparities in the outcomes of communication on medical care received near death. *Arch Intern Med* 2010;170:1533–1540.
5. Zhang B, Wright AA, Huskamp HA, et al. Health care costs in the last week of life: associations with end-of-life conversations. *Arch Intern Med* 2009;169:480–488.
6. Quill TE. Perspectives on care at the close of life. Initiating end-of-life discussions with seriously ill patients: addressing the “elephant in the room”. *JAMA* 2000;284:2502–2507.
7. Clayton JM, Butow PN, Tattersall MH. When and how to initiate discussion about prognosis and end-of-life issues with terminally ill patients. *J Pain Symptom Manage* 2005;30:132–144.
8. Fried TR, Bradley EH, O’Leary J. Prognosis communication in serious illness: perceptions of older patients, caregivers, and clinicians. *J Am Geriatr Soc* 2003;51:1398–1403.
9. Nijenhuis ER, Spinhoven P, van Dyck R, van der Hart O, Vanderlinden J. Psychometric characteristics of the somatoform dissociation questionnaire: a replication study. *Psychother Psychosom* 1998;67:17–23.
10. Giesbrecht T, Lynn SJ, Lilienfeld SO, Merckelbach H. Cognitive processes in dissociation: an analysis of core theoretical assumptions. *Psychol Bull* 2008;134:617–647.
11. American Psychiatric Association. Diagnostic and statistical manual of mental disorders, 4th ed. Text Revision. Washington, DC: American Psychiatric Association, 2000.
12. Gershuny BS, Thayer JF. Relations among psychological trauma, dissociative phenomena, and trauma-related distress: a review and integration. *Clin Psychol Rev* 1999;19:631–657.
13. Nijenhuis ER, Spinhoven P, Vanderlinden J, van Dyck R, van der Hart O. Somatoform dissociative symptoms as related to animal defensive reactions to predatory imminence and injury. *J Abnorm Psychol* 1998;107:63–73.
14. Wright DB, Osborne JE. Dissociation, cognitive failures, and working memory. *Am J Psychol* 2005;118:103–113.
15. Pfeiffer E. A short portable mental status questionnaire for the assessment of organic brain deficit in elderly patients. *J Am Geriatr Soc* 1975;23:433–441.
16. Karnofsky DA, Abelmann WH, Craver LF, Burchenal JH. The use of the nitrogen mustards in the palliative treatment of carcinoma—with particular reference to bronchogenic carcinoma. *Cancer* 1948;1:634–656.
17. Jacobsen JC, Zhang B, Block SD, Maciejewski PK, Prigerson HG. Distinguishing symptoms of grief and depression in a cohort of advanced cancer patients. *Death Stud* 2010;34:257–273.
18. First MB, Spitzer RL, Gibbon M, Williams JBW. Structured clinical interview for the DSM-IV axis I disorders—Patient edition (SCID-I/P) version 2.0. New York, NY: New York State Psychiatric Institute, 1995.
19. Williams JB, Gibbon M, First MB, et al. The structured clinical interview for DSM-III-R (SCID). II. Multisite test-retest reliability. *Arch Gen Psychiatry* 1992;49:630–636.