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End of Life Care Among Head and Neck Cancer Patients

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Abstract

Objective—This study is designed to (1) determine the perceived quality of care received by patients with head and neck cancer at the end of their lives, in order to (2) better anticipate and improve upon the experiences of future patients.

Study Design—Cross-sectional survey.

Setting-Single-institution, academic tertiary care medical center.

Subjects and Methods—A validated survey instrument, the Family Assessment of Treatment at the End of life (FATE), was administered to families of patients who died of head and neck cancer (n=58). The primary outcome was the overall FATE score. Independent variables included clinical characteristics, treatments received and the care provided at the time of death.

Results—Overall FATE scores and the domains assessing management of symptoms and care at the time of death did not vary by disease status (logoregional vs. distant metastasis) at the end of life (p=.989). The location of death in the home or in hospice (vs. hospital) significantly improves scores in all three categories (p=.023). Involvement of a palliative care team improved the care at the time of death (p<.001), and palliative treatments (radiation and/or chemotherapy) improved scores in management of symptoms and care at the time of death (p=.011, p=.017).

Conclusion—The FATE survey is a useful measure of the end of life experience of head and neck cancer patients. Palliative treatments of head and neck cancer, death outside of the hospital and palliative care team involvement all improve the end of life experience in this population.

Keywords

Head and neck cancer; quality of life; end of life care

Introduction

Despite significant improvements in the treatment of head and neck cancer, it remains a source of considerable morbidity and mortality, as a substantial proportion of patients will succumb to their disease. Due to unique properties of the disease itself in combination with the organs and tissues affected, functional deficits and symptomatic consequences are particularly difficult to manage. There is a relative dearth of data that describe the end-of-

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life experience associated with head and neck cancer, and that likewise suggest strategies for improving upon its management.

Conducting research about the dying process is inherently difficult. Prospective studies are limited by the need to remain unobtrusive during what is a difficult time for all involved parties. Moreover, death is not always predictable, making recruitment for research fraught with challenges. For these and other reasons, retrospective analyses have been shown to be effective instruments in assessing the end of life experience. Focus groups have proven effective in deriving consensuses with regard to patient and family desires and preferences concerning treatment of terminal head and neck cancer.¹ Moreover, patient and family-oriented strategies to assess efficacy of palliative and end of life care are crucial.^{2,3} In addition, telephone surveys of family members of deceased head and neck cancer patients are feasible and provide valuable data.⁴

A recently validated survey instrument has been designed to assess the quality of treatment at the end of life based upon the responses of family members of deceased cancer patients. This Veterans Affairs (VA) initiative is entitled the PROMISE project (Performance Reporting of Outcome Measures to Improve the Standard of care at End-of-life).^{5,6} This group has devised a Family Assessment of Treatment at the End of life (FATE) survey to be administered to the family members and significant others of deceased veterans. The survey has been validated, with good discriminant validity when compared to a global-assessment as well as via subgroup analysis, and with strong homogeneity.⁷ The FATE survey proves a useful instrument for the assessment of the quality of care provided at the end of patients' lives that is facile, well-tolerated and brief.

The recent emergence of this valid and powerful survey instrument designed to describe the quality of the end of life experience has created an opportunity to better assess related outcomes in head and neck cancer. We have utilized this survey instrument, coupled with a large, prospectively collected database of head and neck cancer patients, in order to describe the quality of care received by patients with head and neck cancer at the end of their lives, with the goal of better anticipating and improving upon the experiences of future patients. We hypothesize that the FATE survey will ably describe the experiences of head and neck cancer patients at the end of life, and will suggest specific predictors of better outcomes among this cohort.

Methods

The SPORE Database

The University of Michigan established the Head and Neck Cancer Specialized Program of Research Excellence (SPORE) in 2002 through funding by the National Cancer Institute. This comprehensive, multidisciplinary research program maintains a prospectively-collected database including clinical characteristics, treatments and outcomes for thousands of patients who have been diagnosed and treated for head and neck cancer at our institution.

Patients and Recruitment

After approval by the University of Michigan Medical School IRB, the SPORE database was accessed for patient recruitment. The families of deceased SPORE patients treated at the University of Michigan for whom contact information was available were recruited by mail. Exclusion criteria included non-English speaking interviewees, interviewees who reported being unfamiliar with care received during the last month of life, interviewees who did not identify themselves as one of the patient's primary social supports during the last month of life, and interviewees who were not physically present with the deceased at least once during the last week of his/her life.

Survey

A one-time telephone interview was conducted in accordance with the original description of the FATE instrument. The survey, as initially described, included 32 items in nine domains. The nine domains (Well-being and dignity; Information and communication; Respect for treatment preferences; Emotional and spiritual support; Management of symptoms; Choice of inpatient facility; Care at the time of death; Access to services; and Access to benefits) each consist of between one and six individual questions, and are independently validated. In order to ask relevant and targeted questions given our study population, we chose to use the overall FATE score as well as the domain scores for Management of Symptoms and Care at the Time of Death as our outcome measures.

The FATE survey was scored and analyzed as described in the publication of its validation.⁸ To briefly summarize, "best possible" scores were totaled and divided by the number of responses. Overall FATE and domain scores are expressed as a percentage of valid responses for which respondents gave the best possible response. These scores were averaged and reported.

Five of the questions from the original survey were omitted because they related directly to care provided by the Department of Veterans Affairs. Accordingly, two questions concerning transportation assistance within the "Access to Services" domain were omitted, and the three questions comprising the postmortem benefits domain were omitted. The only other alteration was a change of wording to one question within the "Management of Symptoms" domain. The initial question concerned whether patients re-experienced the stress and emotions associated with prior combat experience during the last month of life; this was altered to ask more generally about the level of stress experienced by patients during the last month of life. As a result of these changes, our survey included 27 questions within eight domains. Survey responders were also given the opportunity to make unsolicited comments at the conclusion of the survey, which were recorded verbatim.

Independent Variables

Demographic and clinical data were prospectively collected within a database as part of the SPORE study. These variables were independently verified via chart abstraction, with the survey respondent providing clarification in the event of missing or conflicting information. The following variables were included: gender, age at death, disease status at death (including locoregional recurrence, distant metastasis, mortality during initial treatment, and second primary), smoking status ("any" tobacco use, stratified into current, former or never), alcohol use (defined as two or more drinks weekly, stratified into current, former or never), primary site, TNM status and AJCC stage at the time of diagnosis, and all treatments received in the initial, adjuvant and salvage settings.

Additional clinical information was collected through chart abstraction and verified/clarified with the survey respondents. This included documentation of the location of death, whether or not the patient received inpatient care during the last month of life, the presence/absence of an advanced directive, DNR/DNI status, any bleeding or respiratory complaints within the last month of life, and whether palliative care consultation was obtained.

Statistical Analysis

We focused our statistical analysis upon the factors that could be most easily modified in a way to improve the end-of-life experience. The dependent variables analyzed included the overall FATE score as well as the domain scores for Management of Symptoms and Care at the Time of Death. The Kruskal-Wallis test was used to perform bivariate analyses to determine if FATE scores were significantly different based upon the following independent

variables: disease status at death, location of death, palliative care involvement, palliative treatments received, and whether patient experienced bleeding during last month of life.

Results

Recruitment

A total of 371 deceased patients who were treated at UMHS were identified within the SPORE database, for which 286 had updated next-of-kin/family contact information and were initially contacted by mail. A total of 58 individuals consented by phone to participate in the study and completed the survey, for an overall response rate of 20%.

FATE Survey Results

The mean overall FATE score was 62. Mean domain scores ranged from 31 (Management of Symptoms) to 79 (Treatment Preferences). Means, ranges and standard deviations for overall scores and their domains are summarized in Table 1. The mean scores reported in this study were markedly similar to scores reported in the study which validated the survey; these are also reported in Table 1 for comparative reference. Table 2 lists a representative sample of the unsolicited comments offered by the survey respondents.

Patient Characteristics

Table 3 summarizes FATE scores organized by demographic and clinical variables. Approximately three-quarters of the population were male, with a mean age of 64. Seventynine percent were former or current smokers at the time of death, and approximately half used alcohol regularly. Most patients had advanced stage tumors, with T3 or T4 primaries. Most were treated primarily with chemotherapy and/or radiation, and 43% received surgical salvage. Fifty-five percent had locoregional disease at the time of death, and approximately one third died with distant metastases. The majority of patients with disease in the head and neck could not be categorized as having purely "local" or "regional" neoplasms due to either tumors infiltrating both sites, and/or simultaneous masses in both locations; thus, this group was categorized as "locoregional disease." Slightly more than half received palliative treatment, most of which involved chemotherapy with or without radiation therapy.

Approximately one third of patients died in the hospital; the rest died at home or in an inpatient hospice setting. Palliative care consultation was involved in 69 percent of the cases, and 90 percent of decedents had advanced directives; many also had documented DNR orders.

Bivariate Analyses (Table 3)

Overall FATE Scores—There was no difference in overall FATE scores between patients who had locoregional disease and patients who had distant metastasis at time of death (62 vs. 63; p=.989). Patients who died at the hospital had significantly lower FATE scores than patients who died at home or in hospice (55 vs. 67; p=.023). There was not a significant difference in FATE scores dependent upon palliative treatments received (p=.110).

Management of Symptoms—Disease status did not have an effect on the symptom domain (p=.405). Patients dying in the hospital scored lower than their counterparts (p=. 026). We did not find any variation in scores between patients who received palliative care consultation and patients who did not (p=.745). Patients who were treated with palliative chemotherapy and/or XRT had higher scores (p=.011) than those without palliative treatment.

Care at the Time of Death—Disease status at the end of life did not affect the Care at the Time of Death domain score (p=.411). Patients dying at the hospital had lower scores than their counterparts (44 vs. 80; p<.0001). Patients with palliative care involvement scored higher than those without palliative care (77 vs. 41; p<.0001). Patients who were treated with chemotherapy and/or XRT had higher scores than those who did not receive palliative treatments (p=.017).

Discussion

Palliative Care

End-of-life care in head and neck cancer is complicated by the unique aspects of the disease itself. In general, palliative care with respect to head and neck cancer is similar in design and execution to its general application, with focus upon alleviating pain, treating bothersome symptoms and allowing for patients to live with dignity and respect.⁹ Specifically with head and neck cancer, accurate and timely assessment and management of pain, addressing difficulty swallowing and maintenance of an adequate airway is to be stressed.¹⁰ The importance of palliative care teams and the utilization of hospice services cannot be overstated.^{11,12} Given the poor prognosis of many advanced tumors, initial treatments, even those with seemingly curative intent, might be considered by some to be palliative.¹³ Timon estimates that 20% of patients would qualify for palliative care at the time of initial diagnosis, with an average survival of 5 months within this cohort.¹⁴

Our data confirm the importance and impact of palliative care consultation. While not significantly affecting the overall FATE score, their involvement in both inpatient, outpatient and hospice settings was associated with significantly higher domain scores with regard to symptom control and care at the time of death. This confirms prior findings of the FATE survey.¹⁵ It is important to note that palliative care involvement need not immediately precede death; in cases in which symptoms are not being effectively managed, when social factors significantly impact care, or in many other situations, palliative care may be incredibly helpful, even when the end of life is not imminent. The stigma of palliative care involvement as "giving up" should be replaced with a positive movement towards better control of symptoms and facilitating a pro-active role among patients and families. Moreover, opportunities for patients to discuss and implement advanced directives and surrogate decision-makers can significantly increase the likelihood that their wishes are respected.¹⁶

Treatments in the Palliative Setting

We were surprised to find that disease status at the time of death did not influence FATE scores. Due to the consequences of locoregional disease upon function and symptoms, we postulated that these patients would have lower scores than those succumbing of distant metastasis; this was incorrect. These findings are in need of further study, with use of multiple measures of quality of life and end-of-life experiences, and adequate control for potential confounders. That said, obtaining locoregional control in the face of incurable disease must be carefully considered, particularly when treatments themselves are morbid.

Our data corroborate the utility of palliative chemotherapy and radiation therapy. While a survival benefit is important in its own right, our data suggest that these treatments may improve the quality of patients' lives. The optimal regimen of palliative radiation therapy that balances efficacy with limited toxicity remains undetermined; perhaps the FATE survey could be utilized in future such efforts.¹⁷ Other studies investigating the impact of palliative chemotherapy in this population have found that only certain aspects of quality of life improve with such treatments; our data add a new dimension to these preliminary efforts.¹⁸

We believe that these findings deserve more rigorous study in order to be substantiated, and plan to use the FATE survey in prospective trials assessing the utility and effectiveness of various palliative treatments. Even seemingly heroic treatments, particularly for recurrent cancers, may be essentially palliative in nature, as death from uncontrolled disease is devastating for patients and caregivers alike.

A Multidisciplinary Approach

Reports suggest that patients with head and neck cancer may not receive optimal care at the end of their lives. In one study, only 22% of patients had family members present at the time of death, and 35% did not have code status documented.¹⁹ Due to the multidisciplinary nature of care, it is critical to ensure that all involved parties communicate effectively. One survey of primary care providers caring for end-stage head and neck cancer patients revealed that only 33% felt comfortable with their management, and a minority believed that symptom control was adequate.²⁰ In our study, the information and communication domain score was similar to that found in prior FATE surveys.

The importance of collaboration between patients, families and caregivers is vital in facilitating discharge from the hospital, as we found this to be one of the most important predictors of better FATE scores. Further research is required, as demographic and cultural factors significantly influence trends and preferences regarding the location of death.²¹ Moreover, many of the comments provided by survey responders specifically addressed the need for good communication and illustrated significant problems when deficiencies arose.

Strengths and Weaknesses

This study applied a validated and powerful survey instrument to a population of deceased head and neck cancer patients' families for whom clinical data was accrued prospectively. To our knowledge, this is the first attempt of its kind to quantify and describe the end of life experience of head and neck cancer patients in a study with methodological rigor. The use of a prospectively-enrolled sample of patients with prospectively-collected demographic, clinical and outcome data strengthen the weight of the analysis by limiting selection bias.

The relatively poor response rate is a significant weakness of our study and compares unfavorably with that achieved in prior studies utilizing this survey. We attribute this finding to the recruitment process itself; our institution's IRB did not allow us to initiate contact with potential respondents by phone as was done in prior studies. Moreover, participants were not financially compensated, as they were in prior publications of the FATE survey. Despite this limitation, our study population was of sufficient size and diversity to facilitate statistical analyses. We chose to limit the dependent variables to the overall FATE score and two of the domain scores, with a small number of independent variables in an effort to limit the possibility of type 1 and 2 errors.

The retrospective, survey-based nature of the FATE instrument makes controlling for bias problematic. That said, in the survey's original validation, the FATE score was not associated with the respondent's relationship to the patient, frequency of the respondent's contact with the patient in the last month of life, or the elapsed time between death and the interview.⁷ Controlling for social status and cultural influences, among other variables which may influence respondents' answers, is difficult. We recognize that the end-of-life experience is quite varied and that multiple confounders may exist, but in our opinion, the use of a validated instrument, coupled with a satisfactory sample size (albeit less than desired), facilitate a valid analysis.

Another potential weakness of our study is the different environment in which it was utilized; all prior testing and validation occurred within the VA system. In order to

administer the survey to our patient population, five questions were eliminated and one question was slightly altered from the published, validated survey. We contend that this does not diminish the strength of our conclusions due to the design and scoring of the survey itself, in which questions that were either not applicable or unanswered were simply omitted from the data analysis. The applicability and transmissibility of the study is confirmed by the remarkable association between our overall and domain scores when compared to the prior implementation of the survey.

Conclusion

The FATE survey is a useful measure of the end of life experience of head and neck cancer patients. Palliative treatments of head and neck cancer, death outside of the hospital and palliative care team involvement were associated with significantly improved scores measuring the end of life experience in this population. It stands to reason that evidence-based changes in care paradigms modeled upon these findings may benefit future patients. This study, with its utilization of a validated survey instrument, coupled with a large, prospectively collected database of head and neck cancer patients, facilitated a concrete and valid analysis of the end-of-life experience of head and neck cancer patients.

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Table 1

Family Assessment of Treatment at the End of Life (FATE) survey scores^{*} among head and neck cancer patients compared with prior survey results.

		-	-	
	Mean	Range	Standard deviation	Mean (Cassarett et al) ⁷
Overall score	62	22–93	16.16	60
Well-being and dignity	69	25-100	23.53	61
Information and communication	61	0-100	32.05	62
Treatment preference	79	0-100	28.15	72
Emotional and spiritual support	70	0-100	35.64	65
Management of symptoms	31	0-100	27.72	40
Choice of facility	76	0-100	43.15	85
Access to services	78	0-100	35.36	57
Care at time of death	66	0-100	27.60	64

*Possible scores 0–100 in each category.

Table 2

Selected Comments of Survey Responders

Selected Comments of Survey Responders
"I wish we would have known that the chemo was not going to work sooner, so we would not have had to put him through it."
"Nothing can prepare you for a carotid blowout. I wish I had more warning that the cancer was back."
"The hospital staff was not as attentive with regard to pain control as hospice was."
"Communication between the specialists and our primary doctor was awful."
"I was very happy that I was allowed to stay with him up until the end."
"We greatly appreciated the honesty and compassion of the doctors when they gave us bad news."
"Assisting with logistics and other customer services goes a long way for people who are lost and confused for many different reasons."

Table 3

Demographic and clinical variables and mean Family Assessment of Treatment at the End of Life (FATE) survey scores.*

	Number (%)	Overall FATE Score	Management of Symptoms Domain Score	Care at Time of Death Domain Score
Gender				
Male	43 (74)	63	34	67
Female	15 (26)	62	20	62
Age at death (years)				
<60	21 (36)	65	31	75
60–69	15 (26)	62	33	65
70–79	12 (21)	60	29	53
>80	10 (17)	60	28	63
Smoking status				
Never	12 (21)	66	29	71
Current	15 (26)	63	42	67
Former	31 (53)	60	26	63
Alcohol consumption (>2 drinks/week)				
Never	26 (45)	63	29	66
Current	8 (14)	63	47	64
Former	24 (41)	62	27	66
Primary site				
Oral cavity	15 (26)	60	18	60
Pharynx	22 (38)	60	37	63
Glottis	14 (24)	64	30	71
Other	7 (12)	71	36	76
Tumor stage at diagnosis				
1–2	11 (19)	60	20	59
3–4	47 (81)	63	33	67
T grading at diagnosis				
1–2	18 (31)	60	24	60
3–4	37 (69)	62	32	66
Disease status at death				
Locoregional disease	32 (55)	62	34	65
Distant metastasis	20 (34)	63	39	72
No evidence of disease	5 (9)	67 (p=.99)*	25 (p=.41)*	74 (p=.41)*
Initial treatment				
Surgery	21 (36)	62	25	63

	Number (%)	Overall FATE Score	Management of Symptoms Domain Score	Care at Time of Death Domain Score
Dediction	26 (62)	62	22	47
Chemotherapy	33 (57)	62	33	68
Chemotherapy	33 (37)	02	J-	00
Adjuvant treatment				
None	41 (71)	63	32	67
Radiation	17 (29)	61	28	63
Chemotherapy	6 (10)	73	46	67
Salvage treatment				
None	32 (55)	61	28	66
Surgery	25 (43)	64	35	66
Radiation/Chemotherapy	1 (2)	62	0	50
Palliative treatment				
None	26 (45)	59	20	56
Radiation	13 (22)	59	33	74
Chemotherapy	26 (45)	67 (p=.11)**	40 (p=.011)**	76 (p=.017) ^{**}
Location of Death		<u> </u>		
Home	28 (48)	67	37	77
Hospital	18 (31)	55	21	44
Inpatient hospice	32 (55)	67 (p=.023)***	34 (p=.026)***	82 (p<.0001) ^{***}
Palliative care involvement		<u> </u>	 	
No	18 (31)	57	29	41
Yes	40 (69)	65 (p=.16)	31 (p=.75)	77 (p<.0001)
Advanced directive				
No	6 (10)	64	38	40
Yes	52 (90)	62	30	69
Do not resuscitate status				
No	14 (24)	62	30	45
Yes	44 (76)	63	31	72
Bleeding during last month of life				
No	15 (26)	62	30	63
Yes	43 (74)	63 (p=.64)	31 (p=.91)	75 (.15)

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 * Compares scores between locoregional disease and distant metastasis.

** Compares scores between palliative treatment vs. any palliative treatment (XRT and/or Chemo)

*** Compares scores between hospital and home/hospice