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Original Article

A Survey of Expectations and Understanding of Palliative Radiotherapy from Patients with Advanced Cancer

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Abstract

Aims: : To assess patients' understanding of their illness and expectations of palliative radiotherapy for symptomatic metastases before and after consultation and to explore the relationship between response and demographics/Edmonton Symptom Assessment Scale (ESAS) scores.

Materials and methods: In total, 100 participants completed a survey before and after consultation from March to October 2009. Descriptive statistics and statistical analyses were conducted to compare responses and to determine any relationship between responses and demographics or ESAS variables.

Results: Up to 25% believed their cancer was curable; there was no change in belief that radiotherapy would cure their cancer (17% before and 15% after) or prolong their life (40% before and 45% after). There were significant differences in radiotherapy expectation for symptom relief (P = 0.0094) and for patients who did not know the role of radiotherapy (P = 0.0025). Patient anxiety was reduced after consultation on questions about radiotherapy (P < 0.001), concerns on effectiveness (P < 0.0001) and side-effects of treatment (P < 0.0001); 96, 24 and 46% said after consultation that they were satisfied with information from the team, better understood their diagnosis of cancer and the role of radiotherapy, respectively.

Conclusion: A significant proportion of patients with advanced disease believe their cancer is curable, expect that radiotherapy will cure their cancer and prolong their life despite understanding the intent of radiotherapy is for symptom relief. After consultation, patients say they have a better understanding of their cancer and feel more confident about treatment. More work is needed to improve patients' understanding of their illness and expectations of the role of palliative radiotherapy.

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Key words: Metastatic cancer; palliative radiotherapy; patient understanding

Introduction

Patient satisfaction is an integral component of quality of care, and is derived from the congruence between patients' and their healthcare teams' expectations of consultation and treatment [1–3]. A large proportion of cancer patients do not have a clear understanding of their disease prognosis [3,4] or treatment [2,3]. A survey conducted in 2001 revealed that 35% of patients with symptomatic metastases referred for a palliative radiotherapy consultation did not have a clear understanding of their illness and believed their cancer was curable. Furthermore, 20% expected palliative radiotherapy would cure their advanced cancer, and

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38% believed treatment would prolong their lives, thus, rendering their expectations to be unrealistic [1].

Patient dissatisfaction or misunderstanding may influence patients' preferences for treatment and potentially have a negative effect on quality of life [4,5]. Patient dissatisfaction has been linked with non-compliance with medical advice, poorer coping [6] and pursuing more aggressive and potentially harmful treatment regimens [5].

To determine if patient expectations and understanding of their advanced cancer and radiotherapy treatment have changed over the past decade, a prospective patient-administered questionnaire was repeated both before and after consultation with the Rapid Response Radiotherapy Program (RRRP). The primary objective was to assess patients' understanding of their illness and expectations of palliative radiotherapy to treat symptomatic metastases both before and after consultation with the RRRP. The secondary objective was to explore the

relationship between response and demographics/Edmonton Symptom Assessment Scale (ESAS) scores.

Materials and Methods

After receiving the institution's research ethics board approval, patients referred for palliative radiotherapy at the RRRP were prospectively asked to complete a survey consisting of 11 questions before and after consultation with their radiation oncologist. The survey items included the patient's understanding of their illness, radiotherapy treatment, its aims and satisfaction with the information they were given before and after the radiation consultation. The following demographic information was also collected in the clinic: age, gender, site of primary cancer, sites of metastases, Karnofsky Performance Scale (KPS) score, analgesic consumption during the 24 h before the clinic visit, any concurrent treatment, radiation treatment offered, dose and fractionation prescribed. Furthermore, patients were also asked to rate on an 11-point categorical scale (0 = best, 10 = worst) their symptom distress by using the ESAS. The ESAS includes a total of nine symptoms: current pain, activity, nausea, depression, anxiety, drowsiness, appetite, sense of well-being and shortness of breath.

All new patients to the clinic who were referred for a palliative radiotherapy consultation were included in the study provided they were able to speak English, provide informed consent and complete the questionnaire.

Descriptive results were expressed as mean, standard deviation and median for demographics (age, KPS and oral

morphine equivalence) and ESAS scales in all patients. Primary cancer site and concurrent therapy were described as number of patients. The proportion of patients who answered each survey question was calculated before and after consultation. To compare survey results that included both pre- and post-consultation questions, the McNemar test and the Wilcoxon signed rank test were used for categorical variables and ordinal variables. To search for which factors (i.e. demographics, current therapy and ESAS scales) were significantly related to the survey response change, the Wilcoxon rank-sum test was applied for continuous variables and Fisher's exact test was applied for categorical variables. All results were conducted in the Statistical Analysis Software (SAS version 9.2 for Windows); a *P* value less than 0.05 was considered as statistical significance.

Results

Seventy-seven physicians referred 100 patients to the RRRP for a palliative radiotherapy consultation from March to October 2009. The median age was 66 years (range: 38–93). Fifty-six were men and 44 were women. The median KPS and current pain score for these patients were 70 (30–100) and 3 (0–10), respectively. Most patients had a primary cancer diagnosis of lung (38%), prostate (19%) or breast (17%). Concurrent chemotherapy, hormone therapy or any other concurrent therapy involved 15, seven and 14 patients, respectively. Most patients were treated to the spine, brain and pelvis, with some patients receiving treatment to more than one anatomical site. The most common

Table 1Patient demographics and Edmonton symptom assessment scale

Variable	n	Mean	Median	Standard deviation
Age	100	66.22	66.00	11.33
Gender (male/female)	56/44	_	_	_
Primary cancer				
(Top 4)				
1. Lung	38	_	_	_
2. Prostate	19			
3. Breast	17			
4. Colon	6			
Karnofsky Performance Scale	100	68.50	70.00	16.84
Concurrent therapy				
1. Chemotherapy	15	_	_	_
2. Hormone	7			
3. Other	14			
Pain	100	3.30	3.00	3.16
Tired	99	4.11	4.00	3.24
Nausea	100	0.73	0.00	1.97
Depressed	99	1.59	0.00	2.60
Anxiety	100	2.74	1.00	3.33
Drowsiness	99	2.32	0.00	3.17
Appetite	100	4.05	4.50	3.65
Sense of well being	99	4.52	5.00	3.18
Shortness of breathe	100	2.00	0.00	2.75
Oral morphine equivalent (past 24 h; mg)	70	33.37	10.00	58.19

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