Original Study

Less Satisfaction With Information in Patients With Prostate Cancer Treated With Surgery and Salvage Radiotherapy Compared With Patients Treated With Curative Radiotherapy Alone, Despite Similar Health-Related Quality of Life

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Abstract

Patients' perception of and satisfaction with information at their visits was examined by the following questionnaires: European Organisation for Research and Treatment of Cancer Quality of Life Questionnaire Core 30 (EORTC QLQ-C30) and EORTC QLQ information module (EORTC-INFO25) in 660 Swedish men with localized prostate cancer. Statistically significant differences were observed favoring patients treated with radiation alone compared with those treated with both prostatectomy and radiotherapy (RT). This is important information for patients.

Background: This study examined patient perception of information received, satisfaction with that information, and its relation to health-related quality of life (HRQoL) and clinical and demographic variables before, during, and after radiotherapy (RT) for localized prostate cancer. Patients and Methods: In 2010, 2 questionnaires (European Organisation for Research and Treatment of Cancer Quality of Life Questionnaire Core 30 [EORTC QLQ-C30] and EORTC QLQ information module [QLQ-INFO25]) were sent to 660 consecutive patients with prostate cancer who had undergone or were to undergo RT with curative intent between December 2006 and March 2010. Results: The response rate was 92%. Although most patients (69%) were satisfied with the information they received, statistically significant differences were found for all but 2 EORTC QLQ-INFO25 variables, favoring those who were treated with RT alone compared with those treated with both prostatectomy and salvage RT. Statistically significant associations between all HRQoL variables and satisfaction with information were found; higher levels of satisfaction were associated with better functioning and lower levels of symptoms and problems. Conclusion: Satisfaction with the information received was studied in patients with prostate cancer with localized disease. Despite the fact that the majority of patients reported being satisfied with the information received, there is room for improvement, especially regarding "the disease," "other services," "different places of care," and "things you can do to help yourself." Patients treated with both prostatectomy and salvage RT reported significantly lower levels of satisfaction with information received and of having received significantly less information than did patients treated with RT alone.

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Introduction

Providing adequate information to patients with cancer facilitates their adjustment to their disease by increasing perceptions of control, reducing feelings of threat and anxiety, and improving health-related quality of life (HRQoL). ¹⁻³ Satisfaction with information has been shown to contribute to physical and social well-being, ⁴ and unmet information needs about the disease and its progression have

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been linked to negative psychological outcomes such as anxiety and depression.⁵ The provision of information is a key component of supportive care throughout the cancer trajectory, and the prevalence of unmet needs does not seem to diminish in patients at follow-up.⁶ Most patients would like to get as much information as possible regarding their disease, treatment options, rehabilitation, and follow-up.⁷ Personally meaningful information communicated between patients and clinicians is paramount.⁸ The information needs of patients with prostate cancer have been shown to be similar across 9 countries,⁹ and a substantial fraction (73%) of patients searched for additional information. Helping patients to understand the rationale for treatment options, eg, salvage therapy, is a challenge, which requires knowledge and excellent communication skills. To make it possible for patients to take part in shared decision making, education is needed.¹⁰

European guidelines state that active treatment is mostly recommended for patients with localized disease and a long life expectancy. 11 Today, there are 2 effective treatment modalities for localized prostate cancer: radical prostatectomy (RP) and radiotherapy (RT). It was stated in the US guidelines that: "A patient with clinically localized prostate cancer should be informed about the commonly accepted initial interventions including, at a minimum, active surveillance, RT including External Beam Radiation Therapy interstitial radiotherapy and RP. Men choosing active surveillance represent a patient group with unique vulnerabilities that require new psychoeducational interventions to provide information and support that will maintain and improve quality of life. 12 It is not an easy task for an individual patient to gain information about advantages and disadvantages of different techniques. 13 In Sweden, as in other countries, all patients with suspected prostate cancer are referred to a urologist, who confirms the diagnosis by performing core biopsies. It has been reported that urologists preferably suggest surgery as the treatment of choice. ¹⁴ Too often, the other option, RT, is only briefly mentioned or not mentioned at all during this consultation. Generally, patients referred from a urology clinic to a oncology clinic for curative RT are those who need salvage RT after nonradical surgery, those whose tumors are deemed locally advanced, or those who themselves are actively seeking a second opinion. RT, which usually takes 7 to 8 weeks, can be given either with external technology (external-beam RT) or as combination therapy with low-dose or high-dose brachytherapy. The latter technique was used in patients who were treated with combination RT in the present study.

After the completion of RT, 1 medical visit is usually scheduled for all patients. They are followed thereafter by written communication (questionnaires), blood tests, and phone calls, unless there are any signs of relapse. Thus, the completion of RT also sets the starting point for the patients' shift of being in the treatment phase to survivorship.

For the majority of patients with prostate cancer who have localized nonadvanced disease, there is a choice between RT and RP because these treatments are considered equally effective. However, to make this choice, there is a need for substantial information about these options. The primary aim of the present study was to compare patients after RP + salvage RT with those who underwent curative RT alone with respect to their perception of received information and satisfaction with that information. In addition,

because lower levels of HRQoL could be expected in those who had RP + salvage RT because of PSA relapse, associations were analyzed between HRQoL, demographic, and clinical variables; amount of information received; and satisfaction with information.

Patients and Methods

Patients and Procedures

A total of 660 patients with localized prostate cancer were included in this cross-sectional study. They had undergone or were to undergo curative-intent RT, either as monotherapy or salvage RT after non-RP, between December 2006 and March 2010 at the Department of Oncology, Karolinska University Hospital. Patients were identified in the computerized system for patients' medical files. Patients with metastatic disease or PSA relapse after curative-intent RT during the study period were excluded (n=4), leaving 656 patients to constitute the final sample. In April 2010, questionnaires, together with an information letter about the study, and a prepaid return envelope were sent to the patients from the Unit for Outcome and Quality Assessment at Oncology Department, Karolinska University Hospital. One reminder was sent, together with a new questionnaire and return envelope after 3 weeks to those who did not return questionnaires.

Treatment and Follow-Up of Patients Included in the Study

After referral to the urology clinic for the confirmation of prostate cancer, the treatment option recommended by the urologist in the vast majority of cases was surgery. Patients referred to the oncology clinic for curative RT were generally recommended for neoadjuvant and concomitant endocrine treatment because of intermediate- or high-risk factors for metastatic disease. The procedures and follow-up of patients in the present study after referral to the oncology clinic for RT are presented in Table 1.

Questionnaires

The European Organisation for Research and Treatment of Cancer Quality of Life Questionnaire Core 30 (EORTC QLQ-C30) is a questionnaire for the assessment of HRQoL in patients with cancer. It consists of 30 items, constituting 5 functional scales (physical, role, emotional, social, and cognitive functioning), 3 symptom scales (fatigue, pain, and nausea/vomiting), 6 single items (consisting of financial impacts and symptoms), and global quality of life. Each item is scored in 4 categories from (1) "not at all," (2) "a little," (3) "quite a bit," and (4) "very much," with the exception of 2 items in global health status, which range from (1) "very poor" to (7) "excellent." The time frame asked about is the past week. The validity and reliability of an earlier Swedish version of the EORTC QLQ-C30 has been established. 16,17

The EORTC information module (QLQ-INFO25) consists of 25 items regarding patients' perception of information received during the current disease or treatment period organized into 4 multiitem subscales (disease, medical tests, treatment, and other services) and 8 single-item scales (information about different places of care, things you can do to help yourself get well, written information, information on CD and tape/video, satisfaction with information received, wish for less information, and if the information overall had been helpful). For 21 items, the response

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