



Patients' perception of information after completion of adjuvant radiotherapy for breast cancer



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A B S T R A C T

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Purpose of the research: The aims of the present study were to examine patients' perceptions of received information and satisfaction with information after completion of adjuvant radiotherapy (RT) for breast cancer. Associations between satisfaction with information and health related quality of life (HRQoL), and clinical variables were also studied.

Methods and sample: A total of 93 consecutive women planned for adjuvant RT were asked to complete two questionnaires (EORTC QLQ-C30 and QLQ-INFO25) in connection with their last treatment.

Key results: A total of 88 patients (95%) responded. The mean values for the information subscale scores, on a 0 to 100 point scale (QLQ-INFO25) regarding "the treatments" and "the disease" were 46 and 53 respectively. A total of 48% of the patients expressed a wish for more information. Patients treated with chemotherapy previous to RT reported statistically significant lower levels of information about "the disease". Age was statistically significant related to satisfaction with received information. Younger women were less satisfied with the information received, and a higher proportion wanted more information (55%), as well among women treated with chemotherapy previous to RT (63%). Patients satisfied with information scored significantly higher on global health status and emotional functioning and reported less fatigue. Positive associations were found between "satisfaction with information" and HRQoL.

Conclusions: Improvements of information to breast cancer patients during their treatments are needed. The results also underline the need for patient-centred information in general and that extra attention should be paid to younger women and patients undergoing combined treatment.

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Introduction

Providing cancer patients with information is a key element of supportive care. Adequate information increases patients' possibilities to participate in decisions regarding their treatments, follow-ups, and to report and cope with side effects. Well-informed patients are more likely to comply with treatment recommendations, which is essential for the outcome. Benefits for adequately informed patients also include higher levels of satisfaction with care, improvements in sense of control, lower levels of anxiety and better quality of life (Cox et al., 2006; Davies et al., 2008; Husson et al., 2011; Luutonen et al., 2011; Mallinger et al., 2005; Mesters

et al., 2001). It has been demonstrated that most patients with cancer want as much information as possible about their disease, its treatments and rehabilitation (Jenkins et al., 2001). However, lack of adequate information is frequently reported and patients' wishes for information are likely to change over time (Harrison et al., 2009; Jenkins et al., 2001).

The completion of radiotherapy (RT) might be seen as the starting point for patients in the transition from the treatment phase to survivorship, although the adjuvant treatment continues for many patients with endocrine and/or monoclonal antibody therapy. Despite the relief of treatment termination, many patients experience difficulties in this new situation and might have unanswered questions and other supportive needs. The treatment period for adjuvant chemotherapy for patients with breast cancer varies between 6 and 8 months and the treatment period for adjuvant RT varies between 3 and 7 weeks. During the RT, the patients have daily contact with health care professionals with daily possibilities of information exchange. A recent study of breast

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cancer patients' information needs during the course of RT showed that many needs persisted during the treatment period (Halkett et al., 2012). In the current study, level of information received by patients was measured with EORTC QLQ-INFO25 (Arraras et al., 2010) on completion of RT.

The aims of the present study were to investigate patients' perceptions of received information, and satisfaction with information after completion of adjuvant RT for breast cancer. Associations between satisfaction and health related quality of life (HRQoL), and clinical variables (age, type of surgery, hormonal treatment) were also studied.

Material and methods

Patients and procedure

Consecutive women with breast cancer, 18 years or older, planned for adjuvant RT, following partial mastectomy (lumpectomy) or modified radical mastectomy were asked to participate in a pilot study (February–March 2009) in which frequency and severity of acute radiation skin reactions were investigated. Patients were provided with oral and written study information by the RT nurses at their first visit at the RT unit. After obtaining informed consent, clinical data (e.g. type of surgery, treatment area) and patient reported measures (e.g. health related quality of life, pain, itching) were collected. The adjuvant radiotherapy was fractionated in 2 Gy five days a week up to 50 Gy, or 2.66 Gy five days a week up to 42.56 Gy (≈ 3 –5 weeks). In addition, all patients under the age of 40 years received an additional boost of 16 Gy, 2 Gy per fraction (≈ 2 weeks). The study sample, treatments characteristics and results are described elsewhere (Sharp et al., 2011). In the present paper we report data on patients' perception of received information and HRQoL. Data were collected by questionnaires developed within the European Organization for Research and Treatment of Cancer (EORTC). Patients completed the questionnaire in the waiting room at the RT unit in connection to the last treatment.

Questionnaires

Patients' perception of received information was measured by the EORTC QLQ-INFO25 and EORTC QLQ-C30 was used to measure HRQoL (Aaronson et al., 1993; Arraras et al., 2010). The EORTC QLQ-INFO25 is a 25-items questionnaire and includes items about the level of information received about the disease (4 items), medical tests (3 items), treatment (6 items) and other services (4 items), and 8 single items (care settings, self care strategies, written information, information on CD, tape/video, satisfaction with received information, wish for more or less information and if the information overall had been helpful). Response format is a four-point scale from 1 (not at all) to 4 (very much). Four items have response format "yes" or "no". The EORTC QLQ-INFO25 is a validated module suitable for clinical practice and research (Arraras et al., 2010). The time frame covered in the EORTC QLQ-INFO25 is "during the current disease or treatment period".

HRQoL was measured by the EORTC QLQ-C30, which consists of 30 items constituting five functional scales (physical, role, emotional, social and cognitive functioning), three symptom scales (fatigue, pain, and nausea/vomiting), six single items (financial impact and symptoms) and global quality of life (Aaronson et al., 1992). Responses are scored in four categories from 1 (not at all) to 4 (very much) with the exception of two items in global health status ranging from 1 (very poor) to 7 (excellent). The time frame covered in the EORTC QLQ-C30 is "the past week".

Statistical methods

Item scores were transformed to a 0–100 scale (Fayers et al., 2002). Higher scores represent higher levels of information received, higher information wishes and higher satisfaction in EORTC QLQ-INFO25 and higher functioning and global quality of life in EORTC QLQ-C30. Lower scores represent lower levels of problems and symptoms on the symptom scales of the EORTC QLQ-C30. The following predefined dimensions were assumed to be associated with information: global health status, emotional functioning, cognitive functioning, fatigue and pain.

In analyses of the effect of satisfaction, the EORTC QLQ-INFO25 item "Were you satisfied with the amount of information received?", the 4-point response format was dichotomized into "satisfied" (very much) and "less satisfied" (quite a bit, a little and not at all). This was made in order to distinguish patients that responded that they were clearly satisfied from those less satisfied, as dissatisfaction was not possible to identify with this item.

The expected mean score for each of the selected QLQ-C30 subscales was calculated using indirect standardization with the age distribution from the study group and age-specific mean reference scale scores from the Swedish population (Michelson et al., 2000).

The effects of clinical and demographic variables on the HRQoL and information scales were evaluated using linear regression. In the univariate analysis the effect of age (<54 ys, 54–63 ys, >63 ys), type of surgery (modified radical mastectomy, partial mastectomy), previous chemotherapy (No, Yes), ongoing hormone therapy (No, Yes) were studied by including each variable separately in the regression model. In the multivariate analysis all variables were included in the model. Results are presented as mean scale differences together with 95% confidence intervals.

Unconditional logistic regression was used in the analysis of the variable "Were you satisfied with the amount of information received?" Responses were dichotomized into "satisfied" or "less satisfied". Both univariate and multivariate analyses were performed using the clinical and demographic variables mentioned above. Results from the logistic regression models are presented as ratios of the odds of being "satisfied" versus "less satisfied" together with 95% confidence intervals. All reported *p*-values from the regression models refer to Wald-tests. The study was approved by the Regional Ethical Review Board, Stockholm (2009/4:7).

Results

Out of the 93 patients who consented to participate in the study and who started the RT, 88 patients (95%) responded to the questionnaire at the final treatment at the RT unit. Patients' characteristics are presented in Table 1. Mean values for the EORTC QLQ-INFO25 information subscale scores are displayed in Fig. 1. In Fig. 2, observed and expected mean scale scores for the selected

Table 1
Patient characteristics.

Characteristic	N (%)
Age, mean [SD, min–max]	58 [11.6, 33–85]
Surgery	
Modified radical mastectomy	23 (26)
Partial mastectomy	65 (74)
Chemotherapy	
Earlier chemotherapy	28 (32)
Hormone therapy	
Ongoing hormone therapy	44 (50)
Total number of patients	88 (100)

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