

Brief Report

Information satisfaction in breast and prostate cancer patients: implications for quality of life

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Abstract

Objectives: This study aimed to assess information needs and levels of information satisfaction in breast and prostate cancer patients. It further examined relationships between information satisfaction and multi-dimensional quality of life (QoL).

Methods: An adapted Information Satisfaction Questionnaire (ISQ, 2004) and the Functional Assessment of Cancer Therapy QoL questionnaire (FACT-G, 1993) were randomly distributed to cancer patients during oncology clinic visits (breast cancer, $n = 102$; prostate cancer, $n = 112$). Hierarchical regression analyses examined information satisfaction as a predictor of global QoL and its four dimensions (i.e. physical, social, emotional, and functional well-being).

Results: High levels of information needs and desire for decision involvement were identified, with patients expressing a considerable degree of information satisfaction. After controlling for demographic and illness factors, information satisfaction explained 21% of the variance in global QoL, 12% in physical well-being, 13% in social well-being, 8% in emotional well-being, and 10% in functional well-being (all $p < 0.001$).

Conclusions: This study highlights the importance of information satisfaction for perceived QoL in individuals with cancer. It is clearly important to identify specific information requirements during the diagnosis and treatment process in order to provide information that is congruent with patients' needs.

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Introduction

It is estimated that more than one in three people will develop cancer at some time in their lives. In 2004, 233 600 new cases of cancer were registered in England [1]. Breast and prostate cancer are among the most commonly experienced, with breast cancer accounting for 32% of cases among women and prostate cancer for 25% of cases among men.

A high proportion of patients experience difficulties adjusting to a cancer diagnosis [2–4]. There is strong evidence that information provision can facilitate adjustment to cancer by increasing perceptions of control, reducing feelings of threat and anxiety, and improving perceived quality of life (QoL) [5–7]. When in a clinical setting, however, patients may be too overwhelmed to recognise their own information needs; patients' information requirements can thus go unrecognised by professionals [8,9] and lead to subsequent dissatisfaction with information provision. An audit carried out across two cancer units in the UK

(1998), which found a 69% level of information dissatisfaction among 210 randomly selected cancer patients, has highlighted the extent of this problem [10].

Unmet needs for information about their disease and its progression have been linked to negative psychological outcomes such as anxiety and depression in cancer patients [11]. Randomised and prospective studies have demonstrated that patients offered more information were significantly more satisfied and better psychologically adjusted to their illness [12,13]. Furthermore, relationships have been found between initial satisfaction with information pre-radiotherapy and levels of post-treatment anxiety, depression, and self-care [14,15]. More specific details about patients' information needs were provided in a longitudinal study of 131 newly diagnosed melanoma patients [16]. Findings revealed that providing as much information about the diagnosis as desired, giving written information, presenting information clearly, and discussing any questions on the same day as diagnosis resulted in lower levels of anxiety.

Despite the growing evidence that adequate information provision is vital throughout the cancer experience, studies examining information satisfaction as a potential predictor of QoL are limited [17–19]. Such research typically focuses on how to enhance information satisfaction rather than on its outcomes [20]. The present study aims to examine the implications of information satisfaction for QoL in cancer patients. It further aims to explore the role played by information satisfaction in predicting a broader range of QoL dimensions than has previously been examined (i.e. physical, social, emotional, and functional well-being).

Method

Ethical approval

Ethical approval was granted by Cranfield University (UK) and Bedford Hospital provided Trust approval. As this study was classified as an audit and full patient anonymity was preserved, full ethical scrutiny by the Local Research Ethics Committee was not required.

Participants

Questionnaires were distributed randomly to breast ($n = 102$) and prostate ($n = 112$) cancer patients within the Primrose Oncology Unit of Bedford Hospital. Oncologists offered questionnaires to all patients attending clinics over a number of weeks, who met the inclusion criteria of currently undergoing treatment. Questionnaire uptake was 93% ($n = 214$). For the majority of participants (83%), this was the first cancer diagnosis. Ninety-four percent of participants were 41 years or more, 67% were married, and 96% identified themselves as Caucasian. Treatment pathways varied, with the four most common being hormone therapy (22%), radiotherapy (14%), surgery (13%), and chemotherapy (11%).

All patients attending the Unit receive the following written information in a file designed by service users and health professionals. This is divided into the following sections: information and support, working with professionals, relationships, moods/emotions, treatment side-effects, practicalities, death and bereavement, further information [21]. These files are updated throughout the cancer pathway and according to individual information needs. Patients also have access to an information room within the Unit, which provides leaflets, videos, and internet access.

Questionnaires

Information preferences and satisfaction

This was measured by an adapted version of the 9-item Information Satisfaction Questionnaire

(ISQ) [22], which has been widely used in the field to assess overall information satisfaction and need for involvement [23]. The original measure requires patients to categorise themselves into one of three groups; those who would like (a) all available information and to be involved in all decisions; (b) only positive information; and (c) limited information and the doctor to make decisions on their behalf. As research findings suggest that information and involvement preferences are two independent dimensions [24], the present study utilised five items to assess these separately.

Information involvement

- I would like all available information about my illness.
- I would only like limited information about my illness.
- I would only like positive information about my illness.

Decision involvement:

- I would like to be involved in all decisions about my illness.
- I would prefer the doctor to make the decisions regarding my illness.

Patients were then asked to rate their level of satisfaction with the information they have received about their illness and their treatment.

A 5-point Likert scale, ranging from 'strongly agree' to 'strongly disagree,' was utilised to measure strength of agreement to all six of the aforementioned items. An 'unsure' option was also provided for each item. Two separate scores were obtained: (a) information preferences and (b) information satisfaction.

Quality of life

The 27-item Functional Assessment of Cancer Therapy (FACT-G) [29] was used to assess QoL during the past week. The FACT-G can be used to measure global QoL and/or four different dimensions thereof (i.e. physical well-being (PWB, e.g. I have lack of energy); social well-being (SWB, e.g. I feel close to my friends); emotional well-being (EWB, e.g. I am satisfied with how I am coping with my illness); functional well-being (FWB, e.g. I am able to work). The overall score and four subscale scores were used in order to identify relationships between information satisfaction and global QoL and its components. Responses were assessed on a 5-point Likert scale ranging from 'not at all' to 'very much,' with higher scores representing higher levels of QoL (scale Cronbach = 0.89; subscale Cronbach's = 0.65–0.87).

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Data analysis

Frequencies were calculated for the information preference items, followed by a series of hierarchical multiple regression analyses to assess the proportion of variance accounted for by information satisfaction in global QoL and its components.

Results

Information preferences

As can be seen in Figure 1, information needs are similar across cancer types.

A considerable majority of participants (94%) would like all available information about their illness, supported by 73% indicating that they would not be satisfied if they were presented with positive information only. Indeed, participants were almost unanimous in their desire to be involved in all decisions about their illness (97%). When asked more indirectly if they would prefer the doctor to make the decisions, however, responses were more varied. While the majority of participants disagreed (55%) with this statement, almost one in three (29%) agreed while a further 16% were unsure. Overall, 75% of participants were satisfied and 16% dissatisfied with the information they had received about their illness; the remaining 9% were unsure.

Predicting QoL

Demographic and illness factors (i.e. age, educational status, cancer type, co-morbidities, and treatment pathway) were entered in Step 1 of each regression equation in order to control for potentially confounding effects and to assess their contribution to perceived QoL. Information satisfaction was entered in Step 2 of each equation.

Details of F values, Beta weights, and significance levels are presented in Table 1.

Global QoL

Age and educational status were significant predictors of overall QoL in a positive direction, i.e. younger patients and those who had more qualifications tended to have higher QoL ($p < 0.001$). The significant illness predictors were cancer type and co-morbidities ($p < 0.01$). Breast cancer participants tended to have a lower overall QoL than prostate cancer participants, and those patients with co-morbidities tended to have a lower overall QoL than those patients with cancer alone. Together they accounted for 15% of variance. Information satisfaction, entered in Step 2, accounted for a further 21% of the variance ($p < 0.001$), with higher information satisfaction predicting higher overall QoL.

PWB

The only demographic and illness predictors of PWB were age ($p < 0.001$) and co-morbidities ($p < 0.01$), accounting for 9% of variance. Younger patients reported higher PWB, as did those with no co-morbidities. Information satisfaction, entered in Step 2, accounted for a further 12% of the variance ($p < 0.001$), with higher information satisfaction predicting higher PWB.

SWB

No demographic or illness factors predicted SWB, but information satisfaction was found to explain 13% of the variance ($p < 0.001$). This was again in a positive direction: higher information satisfaction predicted higher SWB.

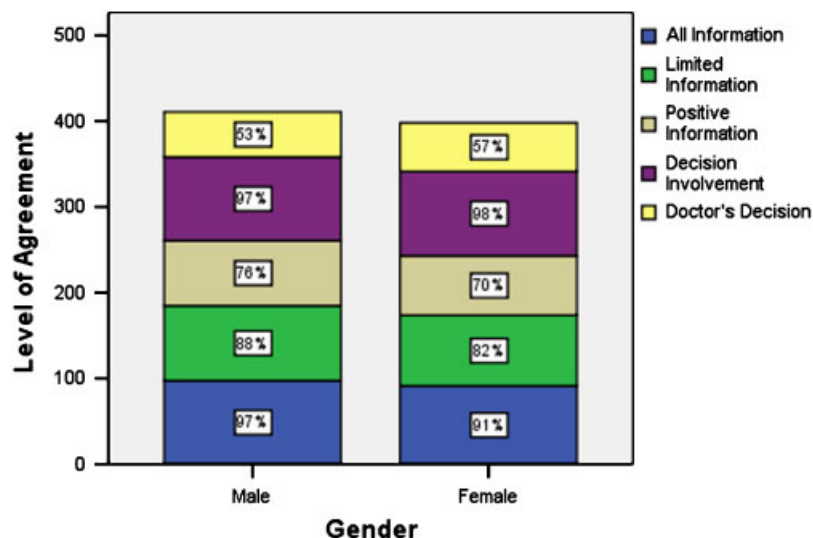


Figure 1. Information preferences of breast and prostate cancer patients.

Table 1. QoL predictors

Variable	F Value	R ²	Beta
<i>Global QoL</i>			
Age	8.089	0.15	0.23**
Education			0.23**
Cancer			0.19*
Co-morbidities			0.19*
Treatment			-0.02
Information satisfaction	10.316	0.21	0.27**
<i>PWB</i>			
Age	4.94	0.09	0.25**
Education			0.13
Cancer			0.05
Co-morbidities			0.19*
Treatment			-0.09
Information satisfaction	5.71	0.12	0.19*
<i>SWB</i>			
Age	1.12	0.00	-0.00
Education			0.05
Cancer			0.09
Co-morbidities			0.12
Treatment			0.04
Information satisfaction	6.01	0.13	0.36**
<i>EWB</i>			
Age	3.00	0.05	0.19*
Education			0.12
Cancer			0.09
Co-morbidities			0.07
Treatment			-0.09
Information satisfaction	3.81	0.08	0.18*
<i>FWB</i>			
Age	3.38	0.05	0.12
Education			0.20*
Cancer			0.07
Co-morbidities			0.19*
Treatment			0.02
Information satisfaction	4.73	0.10	0.22**

* $p < 0.01$; ** $p < 0.001$ **EWB**

Age was the only demographic variable that predicted EWB ($p < 0.01$), accounting for 5% of the variance. Younger participants tended to report higher EWB. Information satisfaction accounted for a further 8% of the incremental variance ($p < 0.001$), with higher information satisfaction predicting higher EWB.

FWB

Educational status was the sole demographic predictor of FWB and co-morbidities the only illness predictor ($p < 0.01$), together explaining 5% of the variance. Information satisfaction explained a further 10% of the variance ($p < 0.001$). Higher educational status, no co-morbidities, and higher information satisfaction predicted higher FWB.

Discussion

This study has demonstrated the importance of adequate information provision within oncology settings. The findings presented here provide strong evidence that patients have specific information needs and that information satisfaction is an important predictor of overall QoL, and its components in terms of physical, emotional, social, and functional well-being.

These findings support previous research indicating the important role that information plays in adjustment to illness and QoL [5–7]. It was, therefore, reassuring to find that information satisfaction (i.e. 75%) was approximately 44% higher in this cohort of patients than that found in a similar audit carried out in 1998 [10]. The present study extends previous knowledge about the implications of information satisfaction experienced by cancer patients in that it was found to be a significant predictor of global QoL and all of its components.

Information satisfaction made the weakest contribution to EWB. Nonetheless, in accordance with previous research [12–15], it emerged as a significant predictor. Information satisfaction made the strongest contributions to PWB and SWB. Of particular interest was the finding that information satisfaction, as opposed to demographic or illness factors, was the only significant predictor of SWB. Since social factors, most notably social support [25–27], have been found to play a significant role in QoL in cancer patients, any potential information strategies to enhance SWB in this group could prove beneficial. In view of the paucity of research in this area, more research is clearly needed.

In order to gain a better understanding of the information needs of people with cancer, further research could focus on different treatment pathways. It is likely that the information needs of those undergoing different treatments vary [28]. Although information about treatment pathways was obtained from participants in this study, they varied considerably and larger samples would facilitate more valid comparisons between groups. Furthermore, longitudinal research could provide insight into the changing information needs of cancer patients throughout treatment.

This study has limitations in that it is cross-sectional and relies wholly on self-report data. Nonetheless, findings provide strong evidence that the information needs of individuals with cancer strongly influence their QoL in several important domains. Although a fairly high level of information satisfaction was found, it is evident that even moderate and low levels of information dissatisfaction and its implications on patient QoL should be examined.

This study involved one oncology unit within the UK with all patients coming from a single, purpose built unit with high provision of information facilities. How do the findings compare across other oncology units? Could levels of patient satisfaction and QoL be improved by oncology units utilising the same measurement instruments to establish benchmarks? It is suggested that a national audit of information satisfaction in oncology units in the UK could supply valuable insight into national improvement strategies in information provision.

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