How do the information needs of cancer patients differ at different stages of the cancer journey? A cross-sectional survey

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DECLARATIONS

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AM, SW and TP conceived the study. AM carried out data collection as part of a student project, supervised by the other authors.

Summary

Objectives Providing information to cancer patients can have significant benefits to their psychological wellbeing. The aim of this study was to investigate whether and how information needs may differ for patients at different stages of the cancer journey.

Design Cross-sectional, self-completed survey using convenience sampling.

Setting Oncology outpatients in Wolverhampton, West Midlands.

Participants Cancer patients aged 18 years and over.

Main outcome measures The survey used Likert scales to determine whether patients wished to know more about 35 items of information categorized under seven domains: cancer (diagnosis); prognosis; treatment; rehabilitation; psychological/spiritual; social/family; and body image/sexuality. Each domain was scored, with higher scores indicating a greater wish for information.

Results There were 187 participants (50% response rate). Patients tended to want more information, particularly related to prognosis. Post-treatment patients continued to have information needs comparable to patients undergoing treatment or at the pre-treatment stage, except with reference to treatment-related information ($p = <0.01$), although as time from diagnosis increased, information needs reduced. Educational attainment, age, treatment status, gender and ethnicity were all significant predictors of scores in various domains.

Conclusion This study indicates that the time since diagnosis may interact with various demographic and disease-related factors in contributing to the information needs of cancer patients. The majority of cancer patients wish to know more about a wide range of factors, and such information seeking

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Reviewer

Stewart Justman

preferences are present regardless of an individual's stage following diagnosis.

Introduction

The benefits of information provision for cancer patients include a positive impact on feelings and attitudes,[1] improved coping ability,[1,2] a reduction in anxiety and mood disturbances,[3,4] and allowing the patient to prepare for the future.[1]

The nature of a patient's information needs may be associated with their stage in the cancer journey as well as sociodemographic factors.[5–8] Much of the existing literature focuses on subgroups of cancer patients (e.g. breast and prostate) at specific intervals during the care pathway, usually when undergoing treatment.[9] This often excludes certain patients, such as those with rarer cancers and/or those who have completed their treatment. There has also been some indication that information needs may differ at different stages of a patient's cancer journey.[9] Time since diagnosis,[1,10,11] gender,[5,8,12] the type of malignancy,[8,10,12] education and ethnicity may all influence information needs.[5,13] Although some studies have attempted to evaluate how information needs change during the cancer journey, their value is limited as time since diagnosis tends to be crudely dichotomized in analyses.[1,10]

The aim of this study was to determine if and how the information needs of a sample of UK-based cancer patients differ according to an individual's stage in the cancer journey. Such information could assist healthcare professionals in providing information relevant to patients' needs, and may also indicate unmet needs that could guide the specification of new services such as the growing number of cancer information centres. The study had three objectives: (1) to determine whether any differences exist in patient preferences for information between patients who have completed their treatment and those who have not; (2) to determine if there is any correlation between information needs and time since diagnosis; and (3) to evaluate factors which may predict variation in the information needs of cancer patients, such as age, gender, ethnicity, type of cancer, and time from diagnosis.

Methods

Participant recruitment

A cross-sectional questionnaire survey was conducted, on a convenience sample of cancer patients. During March and April 2008, patients attending oncology outpatient clinics at New Cross Hospital, Wolverhampton were invited to participate. Patients were approached in the waiting room, informed about the study, and provided with a questionnaire and patient information sheet. Patients were given the option of completing the questionnaire and returning it during their clinic visit or completing and returning the questionnaire in their own time (a Freepost envelope was provided). Patients under the age of 18 years, those who were unable or unwilling to provide consent, illiterate in English, or who were attending the clinic for the first time and, therefore, potentially unaware of their diagnosis were excluded.

Questionnaire development

A literature review was undertaken to identify factors likely to be associated with information needs in order to inform questionnaire design. While some validated questionnaires exist that are relevant to the focus of this study, they typically include only a small number of questions or are designed to evaluate patient satisfaction with information received as opposed to the need for further information.[10,14] The questionnaire aimed to capture information on patient demographics, (age, gender, ethnicity and educational attainment), the patient's diagnosis (cancer type, time since diagnosis and treatment status) and information needs. The questionnaire was piloted on lay people of a variety of ages and of both genders to ensure comprehensibility and ease of completion prior to the study commencing.

The information needs section of the questionnaire consisted of 35 items and seven domains related to the cancer itself: prognosis; treatment; rehabilitation; psychological and spiritual support;

social support; and body image and sexuality. Five-point Likert scales were used with endpoints ranging from 'strongly agree' to 'strongly disagree' in order to assess whether patients wished to know more about any of the 35 items of information at the time they were completing the questionnaire.

Analysis

Any domain of the information needs part of the questionnaire that was incomplete was excluded from the analysis. Responses were scored from +2 ('strongly agree') to −2 ('strongly disagree'). Where a respondent indicated that an item of information was not applicable, this was scored as 0 points, equivalent to the response 'neither agree nor disagree'. For each domain of the questionnaire, a mean score was calculated. As the data were not normally distributed, Spearman's Rho tests were conducted to identify associations between scores and the time since diagnosis, and Mann-Whitney U tests were calculated to determine if there was any difference in scores between patients who had completed treatment and those who had not. Patients were defined as having completed treatment if they were currently receiving no treatment and were unaware of any arrangements for future treatment related to their cancer diagnosis. Multiple linear regression analyses were conducted in order to identify factors predictive of the scores in each domain. Age, gender, educational attainment, ethnicity, time since diagnosis, the type of cancer and whether patients had completed treatment were used as variables in these analyses. Educational attainment was dichotomized, with those patients having no educational attainment or General Certificates of Secondary Education (GCSEs) as their highest attainment being grouped together as a separate category from all other participants. Cancer type was categorized into breast, prostate, gynaecological (ovarian, uterine and cervical) and 'other'. Where a patient recorded more than one site of cancer, the primary malignancy or the cancer that had occurred first was used in the analysis. If the primary site was not known by the patient, they were classified as having multiple cancers. All analyses were performed using SPSS version 15.0.

Results

Participant characteristics

In total, 407 patients were approached to participate. Of these, 33 were ineligible (five were unable to consent, 10 were illiterate in English, and 18 patients were attending their first appointment and were, therefore, potentially unaware of their diagnosis). Of the 374 eligible participants, 187 (50%) returned a completed questionnaire.

All patient demographics were self-reported (Table 1). The mean age of the participants was 58.8 years (range 24–91). The majority of participants were women ($n = 119$; 63.6%) and of White British ethnicity ($n = 166$; 88.8%). A notable proportion ($n = 66$; 35.3%) of study participants had no educational qualifications. Breast cancer was the most commonly reported cancer site ($n = 58$; 31.0%), followed by prostate cancer ($n = 20$; 10.7%). Thirty participants (16.0%) reported multiple cancer sites. Participants were split fairly equally between those at the post-treatment stage ($n = 78$; 41.7%), and those either undergoing treatment or at the pre-treatment stage ($n = 106$; 56.7%).

Information item and domain scores

The mean score for each of the seven domains and for each individual information item in the questionnaire are shown in Table 2. The mean score for all responses was 0.86 (SD = 0.70), indicating that participants tended to express a preference for additional information. Patients were most likely to express a desire to know more about prognosis related information with a domain score of 1.29 (SD = 0.89), the psychological and spiritual domain score was the lowest with a mean score of 0.54 (SD = 0.80). The difference in scores between these two domains was statistically significant (Mann Whitney U test = 10835.50; P = <0.01). Other than the items in the prognosis domain, other individual items which scored highly included the cause of the cancer (1.04, SD = 1.02), how successful treatment is (1.16, SD = 0.91), and the risk of disease to family members (1.11, SD = 0.92). Low scoring items included spiritual support (0.23, SD = 0.90), and how the diagnosis and treatment may affect the patient's sex life (0.42, SD = 0.90 and 0.45, SD = 0.91, respectively).

Table 1
Demographic characteristics of study participants

Characteristic	*n (%)**
Mean age	58.8 (range 24–91)
Gender	
Men	65 (34.8)
Women	119 (63.6)
Ethnicity	
White British	166 (88.8)
Non-White British	21 (11.2)
Educational attainment	
None	66 (35.3)
GCSE/CSE/O levels	53 (28.3)
A levels	8 (4.3)
Degree	20 (10.7)
Other	39 (20.9)
Type of cancer	
Breast	58 (31)
Prostate	20 (10.7)
Multiple	30 (16)
Bowel	15 (8)
Ovarian	13 (7)
Other	12 (6.4)
Testicular	8 (4.3)
Lung	7 (3.7)
Uterine	5 (2.7)
Renal	5 (2.7)
Brain	4 (2.1)
Peritoneal	3 (1.6)
Cervical	3 (1.6)
Treatment status	
Treatment/Pre-treatment	106 (56.7)
Post-treatment	78 (41.7)

*Percentages may not total 100 due to missing responses

The results of Mann Whitney U tests and Spearman's Rho correlation tests are shown in Table 3. The mean treatment domain score for patients who had completed treatment was lower than that for those who were undergoing treatment or at the pre-treatment stage (0.75, SD = 0.82 vs. 1.03, SD = 0.81, respectively; $p = 0.01$). There were no other significant differences between the two groups. The Spearman's Rho correlations were negative for each of the information domains and when all individual items were aggregated. Statistically significant correlations were found in the prognosis domain ($r(165) = -0.17$; $p = 0.03$), treatment domain ($r(153) = -0.19$; $p = 0.03$), body image/sexuality domain ($r(159) = -0.21$; $p = 0.01$) and the mean score for all items ($r(142) = -0.21$; $p = 0.01$).

Predictors of information item/domain scores

A lower level of educational attainment was a significant predictor of higher scores across all items collectively, and in the cancer, rehabilitation, and body image and sexuality domains (Table 4). Age was a significant predictor of scores in both the cancer and the treatment domains, with a greater age predictive of higher scores. Female patients were more likely to score higher in the psychological/spiritual domain. Female patients had a mean score of 0.70 in this domain, compared to a mean score of 0.22 for male patients (U= 2008.5, P =<0.01). Treatment status was a significant predictor of mean scores in the treatment domain, with those who were pre-treatment or currently undergoing treatment more likely to require information related to treatment than those who had completed their treatment. All of the regression models generated were poor in accounting for the variability in the scores of each domain with no model explaining more than 7% (treatment domain) of the variability in scores.

Discussion

Emerging evidence indicates that the information needs of cancer patients change according to their stage in their cancer journey. It was hypothesized that information needs related to treatment and cancer diagnosis would be highest among those patients who had recently been diagnosed, while preferences for information regarding prognosis and rehabilitation would increase for patients at the post-treatment stage of their cancer journey. However, we have demonstrated that the information needs of cancer patients may be more strongly associated with demographic factors than time since diagnosis, and that these interactions are complex.

The scores for each item on the questionnaire tended to be positive, indicating that collectively patients felt that they were under-informed regardless of the information domain concerned. The results indicate that patients had a strongest

Table 2
Mean scores for each item and domain. The mean score was based on averaging scored responses (strongly agree = 2, agree = 1, neither agree nor disagree = 0, disagree = −1, strongly disagree = −2, not applicable = 0). If any item in a domain was missing data, the entire domain was excluded when calculating a domain score

I *<u>currently</u>* *wish to know more about…*	*Strongly agree (%)*	*Agree (%)*	*Neither agree nor disagree (%)*	*Disagree (%)*	*Strongly disagree (%)*	*N/A (%)*	*Missing (%)*	*Mean score (SD)*
Cancer domain	406 (36.2)	341 (30.4)	157 (14.0)	56 (5.0)	30 (2.7)	76 (6.8)	56 (5.0)	0.97 (0.93)
The type of cancer	70 (37.4)	41 (21.9)	40 (21.4)	13 (7)	5 (2.7)	10 (5.3)	8 (4.3)	0.88 (1.10)
The cause of the cancer	74 (39.6)	57 (30.5)	21 (11.2)	11 (5.9)	4 (2.1)	12 (6.4)	8 (4.3)	1.04 (1.02)
The physical effects of the cancer	74 (39.6)	63 (33.7)	18 (9.6)	7 (3.7)	5 (2.7)	11 (5.9)	9 (4.8)	1.09 (1.00)
The symptoms of the cancer	63 (33.7)	60 (32.1)	29 (15.5)	8 (4.3)	5 (2.7)	12 (6.4)	10 (5.3)	0.95 (1.01)
How to manage the symptoms of the cancer	69 (36.9)	62 (33.2)	17 (9.1)	7 (3.7)	5 (2.7)	16 (8.6)	11 (5.9)	0.95 (1.01)
Where to get more information about my cancer diagnosis	56 (29.9)	58 (31.0)	32 (17.1)	10 (5.3)	6 (3.2)	15 (8.0)	10 (5.3)	0.84 (1.05)
Prognosis domain	288 (51.3)	159 (28.3)	37 (6.6)	18 (3.2)	10 (1.8)	27 (4.8)	22 (3.9)	1.29 (0.89)
The chance that my cancer will come back in the future	97 (51.9)	51 (27.3)	12 (6.4)	6 (3.2)	3 (1.6)	11 (5.9)	7 (3.7)	1.29 (0.93)
How the cancer will affect my health in the future	97 (51.9)	55 (29.4)	14 (7.5)	5 (2.7)	3 (1.6)	6 (3.2)	7 (3.7)	1.32 (0.90)
The chances of my cancer spreading	94 (50.3)	53 (28.3)	11 (5.9)	7 (3.7)	4 (2.1)	10 (5.3)	8 (4.3)	1.26 (0.97)
Rehabilitation domain	281 (37.6)	224 (29.9)	73 (9.8)	8 (1.1)	6 (0.8)	93 (12.4)	63 (8.4)	1.11 (0.75)
Self-care or home care during recovery	56 (29.9)	51 (27.3)	29 (16.0)	3 (1.6)	1 (0.5)	27 (14.4)	20 (10.7)	0.95 (0.89)
My diet during recovery	53 (28.3)	64 (34.2)	19 (10.1)	2 (1.1)	1 (0.5)	32 (17.1)	16 (8.6)	0.97 (0.84)
Long-term side-effects of the cancer or its treatment	89 (47.6)	58 (31.0)	10 (5.3)	2 (1.1)	2 (1.1)	15 (8.0)	11 (5.9)	1.31 (0.84)
Preventing complications following treatment	83 (44.4)	51 (27.3)	15 (8.0)	1 (0.5)	2 (1.1)	19 (10.2)	16 (8.6)	1.24 (0.87)
Social/family domain	144 (25.7)	148 (26.4)	90 (16.0)	16 (2.9)	6 (1.1)	115 (20.5)	42 (7.5)	0.79 (0.74)
How my social life may be affected	38 (20.3)	49 (26.2)	44 (23.5)	7 (3.7)	2 (1.1)	31 (16.6)	16 (8.6)	0.67 (0.91)

(Continued)

Table 2
Continued

I currently wish to know more about…	*Strongly agree (%)*	*Agree (%)*	*Neither agree nor disagree (%)*	*Disagree (%)*	*Strongly disagree (%)*	*N/A (%)*	*Missing (%)*	*Mean score (SD)*
The risk of disease for family members	74 (39.6)	54 (28.9)	18 (9.6)	4 (2.1)	2 (1.1)	23 (12.3)	12 (6.4)	1.11 (0.92)
How my diagnosis may affect my work life	32 (17.1)	45 (24.1)	28 (15.0)	5 (2.7)	2 (1.1)	61 (32.6)	14 (7.5)	0.58 (0.86)
Treatment domain	651 (31.6)	526 (25.6)	173 (8.4)	62 (3.0)	21 (1.0)	440 (21.4)	184 (8.9)	0.91(0.82)
Available treatment options	68 (36.4)	49 (26.2)	12 (6.4)	6 (3.2)	2 (1.1)	34 (18.2)	16 (8.6)	1.02 (0.96)
When treatment will start	43 (23.0)	43 (23.0)	17 (9.1)	4 (2.1)	1 (0.5)	59 (31.6)	20 (10.7)	0.74 (0.89)
Where treatment will take place	39 (20.9)	50 (26.7)	16 (8.6)	6 (3.2)	2 (1.1)	54 (28.9)	20 (10.7)	0.71 (0.91)
How long treatment will last	56 (29.9)	46 (24.6)	14 (7.5)	4 (2.1)	1 (0.5)	48 (25.7)	18 (9.6)	0.90 (0.92)
Tests and procedures involved in the treatment process	61 (32.6)	49 (26.2)	13 (7.0)	5 (2.7)	2 (1.2)	41 (21.9)	16 (8.6)	0.95 (0.95)
Reducing side-effects of treatment	73 (39.0)	48 (25.7)	12 (6.4)	3 (1.6)	2 (1.1)	34 (18.2)	15 (8.0)	1.09 (0.93)
How the treatment works	58 (31.0)	60 (32.1)	15 (8.0)	5 (2.7)	2 (1.1)	32 (17.1)	15 (8.0)	0.97 (0.91)
How successful treatment is	80 (42.8)	48 (25.7)	7 (3.7)	5 (2.7)	1 (0.5)	32 (17.1)	14 (7.5)	1.16 (0.91)
Entry into clinical trials	48 (25.7)	30 (16.0)	38 (20.3)	10 (5.3)	2 (1.1)	42 (22.5)	17 (9.1)	066 (0.99)
The purpose of the treatment	63 (33.7)	51 (27.3)	15 (8.0)	7 (3.7)	2 (1.1)	33 (17.6)	16 (8.6)	0.97 (0.96)
How experienced the staff treating me are	62 (33.2)	52 (27.8)	14 (7.5)	7 (3.7)	4 (2.1)	31 (16.6)	17 (9.1)	0.94 (1.00)
Psychological/spiritual domain	142 (19.0)	160 (21.4)	221 (29.5)	36 (4.8)	15 (2.0)	107 (14.3)	67 (9.0)	0.54 (0.80)
Emotionally coping with cancer	51 (27.3)	48 (25.7)	44 (23.5)	6 (3.2)	3 (1.6)	21 (11.2)	14 (7.5)	0.80 (0.96)
Community counselling or support	32 (17.1)	47 (25.1)	55 (29.4)	8 (4.3)	2 (1.1)	27 (14.4)	16 (8.6)	0.58 (0.89)
Support groups for cancer	38 (20.3)	43 (23.0)	52 (27.8)	11 (5.9)	3 (1.6)	22 (11.8)	18 (9.6)	0.60 (0.97)
Spiritual support	21 (11.2)	22 (11.8)	70 (37.4)	11 (5.9)	7 (3.7)	37 (19.8)	19 (10.2)	0.23 (0.90)
Body image/sexuality domain	154 (20.6)	164 (21.9)	175 (23.4)	40 (5.3)	9 (1.2)	148 (19.8)	58 (7.8)	0.59 (0.81)

(Continued)

Table 2
Continued

I currently wish to know more about…	*Strongly agree (%)*	*Agree (%)*	*Neither agree nor disagree (%)*	*Disagree (%)*	*Strongly disagree (%)*	*N/A (%)*	*Missing (%)*	*Mean score (SD)*
How the diagnosis may affect my physical appearance	46 (24.6)	48 (25.7)	41 (21.9)	7 (3.7)	2 (1.1)	31 (16.6)	12 (6.4)	074 (0.93)
How treatment may affect my physical appearance	49 (26.2)	52 (27.8)	33 (17.6)	7 (3.7)	3 (1.6)	31 (16.6)	12 (6.4)	0.78 (0.96)
How the diagnosis may affect my sex life	29 (15.5)	31 (16.6)	52 (27.8)	13 (7.0)	2 (1.1)	43 (23.0)	17 (9.1)	0.42 (0.90)
How treatment may affect my sex life	30 (16.0)	33 (17.6)	49 (26.2)	13 (7.0)	2 (1.1)	43 (23.0)	17 (9.1)	0.45 (0.91)
All items	*2066 (31.6)*	*1722 (26.3)*	*926 (14.1)*	*236 (3.6)*	*97 (1.5)*	*1006 (15.4)*	*492 (7.5)*	*0.86 (0.70)*

Table 3
Mann Whitney U test and Spearman's Rho correlation results for each information domain

Domain	*Mann Whitney U test (*P *value)*	*Spearman's rho (correlation coefficient and* P *value)*
Cancer	0.64	−0.07 (p = 0.40)
Prognosis	0.40	−0.17 (p = 0.03)*
Treatment	0.01*	−0.19 (p = 0.03)*
Rehabilitation	0.12	−0.15 (p = 0.07)
Psychological/Spiritual	0.82	−0.04 (p = 0.60)
Social/Family	0.32	−0.08 (p = 0.32)
Body image/sexuality	0.44	−0.21 (p = 0.01)*
All items	0.12	−0.21 (p = 0.01)*

*Statistically significant results (p = <0.05)

preference for prognosis related information. These findings are consistent with previous literature.[15]

A statistically significant difference in information preferences in the treatment domain between patients who had completed their treatment and those who were at the pre-treatment or ongoing treatment stage suggests that patients continue to require more information about all other domains of the questionnaire, even after they have completed their treatment. There were significant correlations between time since diagnosis and mean scores for the prognosis, treatment and body image and sexuality domains as well as all the items collectively. All of the correlations were negative, indicating that as the time since diagnosis increases, information needs scores tend to decrease. The finding that rehabilitation scores decreased with time since diagnosis indicates that patients who are in the initial phase of the cancer journey may wish to have information about the course of their care, possibly to prepare for issues such as self-care during recovery. Conversely, as information scores in the cancer domain did not differ significantly between the two patient treatment groups, and have no significant correlation with time since diagnosis, this study suggests that post-treatment patients still wish to know more about the type, cause and symptoms of the cancer. Cancer patients at all stages of the cancer journey wish

Table 4
Summary of multiple linear regression models

Domain	*Factors predictive of a higher score**	*Unstandardized coefficients*	P *value*	*Adjusted* R^2
Cancer	Lower educational status	0.39	0.01	0.05
	Older age	0.01	0.04	
Prognosis	–	–	–	–
Treatment	Treatment status	0.33	0.01	0.07
	Older age	0.01	0.02	
Rehabilitation	Lower educational status	0.24	0.05	0.02
Psychological/ Spiritual	Female sex	0.47	<0.01	0.07
Social/Family	–	–	–	–
Body image/Sexuality	Lower educational status	0.33	0.01	0.05
	Ethnicity	0.43	0.04	
All items	Lower educational status	0.22	–	0.02

*Only factors which reached significance in the model have been reported. Blank cells indicate that there were no factors predictive of the score in the domain

to be well-informed irrespective of the length of time since their diagnosis and their treatment status.

A lower level of educational attainment was identified as a significant predictor of a higher score across all 35 questionnaire items when aggregated, as well as the cancer domain, rehabilitation domain, and the body image and sexuality domain. It may be the case that patients with a higher educational attainment are more likely to employ active information seeking strategies utilizing written materials and the Internet and thus are able to satisfy their information needs.[16] Conversely, patients with a lower educational attainment may be more reliant on personal sources of information and in the limited time that physicians have with their patients they may not be able to satisfy all their information needs. It appears that the interaction between educational status and information needs is multifaceted and that education affects information needs in different ways.

Female patients were significantly more likely to have higher scores in the psychological and spiritual domain. This is consistent with research which has found that women were more likely than men to request information about support services and psychosocial issues.[5,8] It may be beneficial for healthcare professionals treating patients to be aware of this need and provide female patients in particular with information related to maintaining psycho-social wellbeing where required.

Patients who were not White British were more likely to have higher scores in the body image and sexuality domain. While there is no available literature reporting how ethnicity influences information needs regarding body image/sexuality, ethnicity has been previously reported to influence more generic information needs.[5,17] This may be due to various factors, for example in a UK-based sample of cancer patients, Asian patients were more likely to cite their GP as their preferred source of information. This may have been because Asian patients preferred to discuss their diagnosis in their mother tongue and many Asian patients had Asian GPs.[17] Therefore, cancer patients from ethnic minorities may have information needs that are not met in the hospital setting. Additionally, communicating with cancer patients from ethnic minorities may be challenging even with the use of interpreters due to cultural practices, e.g. avoiding the term 'cancer'.[18] Consequently, the interplay between language, culture, information needs and information sources may partially explain the results of our study.

Limitations

A key limitation of this study was the potential for response bias given the 50% response rate and the fact that study participants were recruited via convenience sampling. No data were collected on non-responders and routine data-sets describing the demographics of the patients attending the oncology outpatient clinics are not available. Using a convenience sample limits the extent to which the findings of this study can be generalized to all cancer patients, and it is possible that our sample may not adequately represent the target population.

The questionnaire was not validated; however, based on extensive piloting prior to commencement of the full study, it appeared to be acceptable, comprehensible and easy to complete and the instrument had face validity. The questionnaire was designed to acquire a rich data-set covering a range of factors that have not been simultaneously investigated previously. This cross-sectional survey of a range of patients at various stages of the cancer journey may not be as useful as a longitudinal study designed to follow the *same* individuals over time in order to assess changes in information needs. A longitudinal design would minimize the potential for bias related to the nature and severity of a patient's cancer (e.g. simple vs. complex disease, early vs. advanced disease). However, the present study demonstrates a number of significant findings regarding the information needs of cancer patients which offer healthcare professionals involved in the care of cancer patients a broader insight into their information needs.

Conclusions

Our results support recommendations that information provision should be tailored to individual patients, as cancer patients may require different types of information as they progress through the cancer journey.[19,20] Furthermore, we provide evidence that many patients (irrespective of treatment status) would like further information. Referring and encouraging patients to use the growing number of cancer information centres may be an effective way of ensuring patients have access to information. This study reinforces the finding that most cancer patients wish to know more about a wide range of factors. It also demonstrates that information seeking continues from diagnosis to follow-up.

References

1 Sainio C, Eriksson E. Keeping cancer patients informed: a challenge for nursing. *Eur J Oncol Nurs* 2003;**7**:39–49

2 Johnson JE, Nail LM, Lauver D, King KB, Keys H. Reducing the negative impact of radiation therapy on functional status. *Cancer* 1988;**61**:46–51

3 Rainey LC. Effects of preparatory patient education for radiation oncology patients. *Cancer* 1985;**56**:1056–61

4 Fallowfield LJ, Hall A, Maguire GP, Baum M. Psychological outcomes of different treatment policies in women with early cancer outside a clinical trial. *BMJ* 1990;**301**:575–8

5 Squiers L, Finney Rutten LJ, Trieman K, Bright MA, Hesse B. Cancer patients' information needs across the cancer care continuum: evidence from the Cancer Information Service. *J Health Commun* 2005;**10** (Suppl. 1):15–34

6 Manfredi C, Czaja R, Buis M, Derk D. Patient use of treatment-related information received from the Cancer Information Service. *Cancer* 1993;**71**:1326–37

7 Czaja R, Manfredi C, Price J. The determinants and consequences of information seeking among cancer patients. *J Health Commun* 2003;**8**:529–62

8 Boudioni M, McPherson K, Moynihan C, *et al.* Do men with prostate or colorectal cancer seek different information and support from women with cancer? *Br J Cancer* 2001;**85**:641–8

9 Finney Rutten L, Arora NK, Bakos AD, Aziz N, Rowland J. Review: Information needs and sources of information among cancer patients: a systemic review of research (1980–2003). *Patient Educ Counsel* 2005;**57**:250–61

10 Liekweg A, Eckhardt M, Taylor SCM, Erdfelder E, Jaehde U. Psychometric assessment of a questionnaire measuring patient satisfaction with information on cancer treatment. *Pharm World Sci* 2005;**27**:96–103

11 Thewes B, Meiser B, Taylor A, *et al.* Fertility- and menopause-related information needs of younger women with a diagnosis of early breast cancer. *J Clin Oncol* 2005;**23**:5155–65

12 Manning DL, Quigley P. Understanding the needs of people using a cancer information service in Northern Ireland. *Eur J Cancer Care* 2002;**11**:139–42

13 Im E, Chee W, Guevara E, Lim H, Liu Y, Shin H. Gender and ethnic differences in cancer in cancer patients' need for help: An Internet survey. *Int J Nurs Stud* 2007; doi:10.1016/j.ijnurstu.2007.09.006

14 Llewellyn CD, Horne R, McGurk M, Weinman J. Development and preliminary validation of a new measure to assess satisfaction with information among head and neck cancer patients: The Satisfaction with Cancer Information Profile (SCIP). *Head Neck* 2006;**28**:540–8

15 Jenkins V, Fallowfield L, Saul J. Information needs of patients with cancer: results from a large study in UK cancer centres. *BJC* 2001;**84**:48–51

16 Carlsson M. Cancer patients seeking information from sources outside the health care system. *Support Care Cancer* 2000;**8**:453–7

17 Kumar DM, Symonds RP, Sundar S, Ibrahim K, Savelyich BSP, Miller E. Information needs of Asian and

White British cancer patients and their families in Leicestershire: a cross-sectional survey. *BJC* 2004;**90**:1474–8

18 Dohvan D, Levintova M. Barriers beyond words: cancer, culture, and translation in a community of Russian speakers. *J Gen Intern Med* 2007;**22**:300–5

19 Semple CJ, McGowen B. Need for appropriate written information for patients, with particular reference to head and neck cancer. *J Clin Nursing* 2002;**11**:585–93

20 Weinman J. Providing written information for patients: psychological considerations. *J Roy Soc Med* 1990;**83**:303–5