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Cross sectional survey of patients' satisfaction with information about cancer

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Most patients with cancer want as much information as possible appropriate to their personal needs and circumstances.^{1,2} We surveyed the views of cancer patients entering a randomised trial of computer based information.³ We examined their need for information and their satisfaction with information received and how these varied with their demographic, social, and psychological characteristics.

Patients, methods, and results

Eligible patients were those planned to receive radical radiotherapy, who knew their diagnosis, were without visual or mental handicap, and were without severe pain or symptoms causing distress. Of 715 patients asked to take part, 190 refused, 25 stating they did not want more information. Of the 525 participants, 309 had breast cancer, 129 had prostate cancer, 22 had cervical cancer, and 65 had laryngeal cancer.

Data were collected at the recruitment interview, from a questionnaire the patients completed at home shortly after, and from their case notes. Data included the information patients would like,² a hospital anxiety and depression scale,⁴ the newspaper patients read, and deprivation category (derived from postcode).⁵ Using ² tests and multiple logistic regression analysis, we compared the patients' sources and perceived quantity of information received and their satisfaction with this information, as binary variables, with their age, sex, cancer site, newspaper read (tabloid v broadsheet), deprivation category, and anxiety and

depression scores (table). Information need² ("as much as possible" v other) was considered both as a response variable and as a predictor of sources and satisfaction.

Four out of five patients wanted as much information as possible. In univariate analysis, newspaper read, deprivation category, having a connection with the health service, age, and time since diagnosis were predictors of information need. In multiple logistic regression analysis, however, only newspaper read and age remained predictors.

One in five patients were not satisfied with the information given. Univariate analysis showed that dissatisfied patients were much more likely to be depressed and were marginally more likely to be anxious or to want as much information as possible. In multiple logistic regression age, sex, and depression were predictors of dissatisfaction. Fifteen per cent of patients said there had been many differences in what they had been told by health professionals. Multiple logistic regression showed that these patients were more likely to be anxious.

Patients with breast cancer and readers of broadsheets had received more information and from more people than patients with other cancers but were not significantly more likely to be satisfied. The location of the clinician who gave the diagnosis had no effect on how much information patients had received. Younger depressed patients who wanted as much information as possible were less likely to be satisfied even though they had received more information than others. A third of patients said there were other things that they

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Percentage (number) of cancer patients agreeing with various statements about the information they had received before starting radiotherapy

	Given information from few people (v many)	Not given much information	Many differences in information given (v few or none)	Would like to have been given other information	Non-committal or dissatisfied with information given (v satisfied)
Age:					
<60	73 (193)	49 (112)	18 (45)	36 (93)	21 (56)†
> 60	82 (207)*	59 (119)	13 (31)	32 (77)	17 (43)
Sex:					
Female	71 (240)	46 (131)	17 (55)	33 (109)	17 (58)
Male	89 (160)*	69 (100)*	12 (21)	35 (61)	23 (41)†
Cancer site:					
Breast	70 (213)	44 (116)	16 (48)	33 (99)	17 (52)
Other	89 (187)*†	69 (115)*†	14 (28)	35 (71)	23 (47)
Time since diagnosis (months):					
< 3	79 (205)	57 (118)	13 (32)	29 (73)	19 (48)
4-12	73 (162)	48 (94)	14 (29)	38 (82)	19 (41)
>12	97 (28)*	64 (16)	10 (3)	43 (12)	30 (9)
Where diagnosed:					
Teaching hospital	81 (137)	51 (75)	13 (21)	35 (57)	18 (30)
Other hospital	77 (215)	56 (133)	16 (43)	35 (95)	21 (56)
Elsewhere	70 (45)	47 (22)	20 (12)	25 (15)	18 (12)
Deprivation category (Carstairs category):					
Affluent (1+2)	79 (84)	42 (38)	21 (22)	37 (39)	19 (20)
Middle (3+4)	76 (159)	52 (94)	14 (28)	33 (67)	17 (35)
Deprived (5-7)	79 (153)	62 (95)*†	14 (26)	34 (64)	23 (44)
Newspaper read:					
Broadsheet	73 (143)	44 (71)	16 (31)	34 (66)	16 (32)
Tabloid	81 (211)†	62 (137)*†	14 (35)	33 (85)	21 (54)
Connection with NHS:					
Yes	73 (149)	46 (77)	16 (31)	35 (68)	18 (36)
No	80 (221)	59 (137)*	15 (39)	33 (90)	21 (56)
Hospital anxiety and depression scale:					
Anxiety:					
No	81 (261)	53 (141)	12 (38)	28 (83)	16 (49)
Borderline	73 (75)	52 (44)	14 (14)	35 (34)	23 (23)
Yes	71 (62)	58 (44)	29 (24)*†	54 (46)*†	27 (23)
Depression:					
No	77 (346)	51 (190)	13 (58)	31 (134)	17 (74)
Borderline	80 (37)	64 (27)	37 (15)*	44 (20)	37 (16)
Yes	88 (15)	86 (12)*	19 (3)	71 (12)*	50 (8)*†
Attitude to information:					
As much as possible	76 (324)	51 (180)	16 (66)	36 (148)*†	21 (88)
Only good news or no details	84 (67)	67 (43)*	12 (9)	20 (15)	12 (9)
All patients	78 (400/516)	54 (231/430)	15 (76/494)	34 (170/503)	19 (99/509)‡

*Significant predictors (P<0.01) in analysis. †Significant predictors (P<0.05) in multiple logistic regression analysis.

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would like to have been told. Patients most commonly required further information on the effects of treatment and prognosis and recovery.

Comment

One in five of 525 patients starting radiotherapy were not satisfied with the information they had received. Breast cancer patients were better provided with information than patients with other cancers but were not necessarily more satisfied with it as a result. More should be done to help patients with other cancers obtain suitable information.

Three of the outcome measures were associated with anxiety or depression. The nature of the relation of anxiety, depression, and information among cancer patients would be worthy of further study.

As in other work,² we found that most cancer patients wanted as much information as possible. However, our percentage slightly overestimates this, as refusal to take part in the study might indicate lack of desire for further information. Although those patients living in affluent areas wanted more information, type of newspaper read was a better indicator of information need. Few studies have used this intuitively obvious indicator, and we suggest its use, among older patients, in both clinical practice and research.

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Contributors: RJ had the original idea for the study, designed the study, was the main grant holder, supervised the research assistants, analysed the data, and wrote the paper. JP carried out the pilot study, contributed to the design, was a research assistant with day to day responsibility for data collection and running the study, undertook preliminary analysis, and contributed to final analysis and editing of paper. SMCg contributed to the design of the study, was a research assistant with day to day responsibility for data collection and running the study, undertook some preliminary analysis, and edited the paper. WHG advised on design of the study and analysis of the data and edited the paper. JMA advised on the design of the study and choice of psychological measures, edited the paper, and was a grant holder. AB discussed the original idea, set up opportunities for the pilot study and main study, contributed to the design of the study, edited the paper, and was a grant holder. AJC discussed the original idea, contributed to the design of the study, discussed the analysis of data, edited the paper, and was a grant holder. JMcE discussed the original idea, set up opportunities for the pilot study and main study, edited the paper, and was a grant holder. RJ and AB are guarantors for the study.

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Endpiece Bill Gates's strength

The fox knows many things; the hedgehog knows one big thing; the 800 pound gorilla doesn't give a shit what anybody knows. [Bill] Gates's great strength was in combining all these attributes.

John Lanchester, London Review of Books
September 1999, p 5.