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Special Paper

The Impact of Cancer on Key Relatives: a Comparison of Relative and Patient Concerns

J. Harrison, P. Haddad and P. Maguire

This study examines the impact of diagnosis on key relatives of 108 newly diagnosed cancer patients. Cancers of the breast, colon, female reproductive tract and testicle were included. Relatives completed a self-report checklist of concerns and the General Health Questionnaire (GHQ) (28 items). Patients were administered a corresponding concerns checklist as part of a semi-structured interview. More relatives than patients expressed each of the nine common concerns; the discrepancy was greatest for concern about the patient's emotional reaction, reported by 95% of relatives and only 18% of patients. The total relatives' concern score (median 16.0) was significantly greater than the patients' score (median 4.0) ($P < 0.0001$). Cancer type, age of patient and nature of relationship to patient had little impact on the frequency of relatives' concerns. 52 (48%) relatives scored above the usual cut-off on the GHQ, suggesting significant psychological morbidity. Relatives of newly diagnosed cancer patients report high levels of concerns and psychological distress, and deserve greater attention than they currently receive.

Key words: relatives, concerns, psychological morbidity
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INTRODUCTION

THE PSYCHOSOCIAL problems encountered by cancer patients have been well documented, but little is known about the impact of cancer on key relatives. Although most relatives appear to adapt well [1, 2], a significant minority may not. Wellisch and associates [3] described a subgroup of husbands of women with breast cancer who became distressed, and reported a downward spiralling of the quality of their relationships. Maguire [4] found that the husbands of mastectomy patients experienced more anxiety, depression and sexual difficulties 1 year after surgery than husbands of women with benign breast disease. Other studies [5, 6] have confirmed an increase in psychological symptoms in family members following a cancer diagnosis.

Certain relatives may be at greater risk. Baider and Kaplan de Nour [7] suggested that male partners of cancer patients have more problems than female partners. Casileth and associates [2] found that relatives of those receiving palliative care fared worse than relatives of those receiving active treatment, while Baider and Kaplan de Nour [7] reported no difference in partners' adjustment according to site of disease. Adjustment to cancer is less of a problem for older patients [8, 9] but whether the same is true for their relatives is unknown.

A relationship between the psychological well-being of relatives and that of the patients themselves has also been reported [2, 8, 10]. For patients, the nature and number of concerns reported have been linked to the later development of anxiety and depression [11]. If a similar relationship exists for relatives, their concerns could become a focus for counselling.

A study was, therefore, conducted to identify the concerns expressed by key relatives of newly diagnosed cancer patients, to compare concerns of relatives and patients, to establish the prevalence of psychological morbidity experienced by such relatives, and to explore the relationship between relatives' concerns and psychological morbidity.

PATIENTS AND METHODS

Patients

The patients included in the study were a consecutive series of newly diagnosed patients recruited to a large prospective investigation of affective disorder in cancer patients. Patients were recruited from five Manchester hospitals. Entry requirements included age between 18 and 75 years, estimated survival of 2 years or more, patient awareness of a cancer diagnosis and being able to follow the interview. Patients were assessed at home 3 months after the cancer diagnosis by trained interviewers. Whenever possible, patients were interviewed privately. At the end of each interview, patients were asked to give consent for a key relative to be approached. Patients who were married or cohabiting were asked to nominate their partner. Patients who were single were asked to nominate the person who had been most involved in providing support during their illness. When

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Correspondence to P. Maguire.

All authors are at the Cancer Research Campaign Psychological Medicine Group, Stanley House, Christie Hospital, Manchester M20 9BX, U.K.

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the patient agreed to a relative being involved, an explanatory letter and two self-report questionnaires were left with a stamp addressed envelope. The letter specified that the relative should complete both questionnaires alone and without discussion with the patient.

Measures

Patients. A checklist was used to elicit patients' concerns during the previous month. This was derived from work by Devlen [12] who used open-ended questions to elicit patients' cancer-related concerns. The resulting checklist has been shown to be reliable and clinically useful in other studies [13]. A self-report measure of psychological morbidity was not used for the patients as it would have interfered with the methodology of the larger study for which details are published elsewhere [14].

Relatives. Relatives' concerns were established using an 11 item self-report checklist, similar to that administered verbally during the patient's semistructured interview. Nine items were common to both the patient and relatives' concerns checklist. The relatives' list contained two additional items thought to be of importance: concern about the effect of the illness on other family members and concern about the relative themselves feeling upset or distressed. Space was left for relatives to describe concerns not covered by the checklist.

Both patients and relatives were asked to rate the degree of worry caused by each potential concern on a scale of 0–3 (0 = none, 1 = small concern, 2 = medium concern, 3 = major concern). In order to compare relative and patient concerns, slight, moderate and major concerns were combined into a single category. For other comparisons, a total concern score was calculated by summing the degree of concern on the individual items.

The 28 item General Health Questionnaire (GHQ) [15] was used to assess psychological morbidity among relatives. This is a widely used screening instrument for depression and anxiety from which the probable prevalence of psychological morbidity can be calculated using estimated cut-offs [16].

RESULTS

Only one of 141 patients refused permission for a relative to be contacted. 140 questionnaires were left, of which 110 (79%) were returned. There were no differences by patient age or type of disease between relatives who did not return the questionnaire and those who participated. Two questionnaires were partially completed, and so the results from 108 completed questionnaires are reported. Types of cancer comprised breast (58, 54%), bowel (20, 18.5%), gynaecological (10, 9%) and testicular cancers (20, 18.5%). 93 (86%) of the 108 relatives were the patient's partner. Of the remaining 15, 7 were sons and daughters and the other 8 included different family members. These 15 relatives were grouped together for the purposes of analysis.

Nature and frequency of concerns

The relatives reported generally high levels of concern (Table 1). Concerns about "the illness", "patient's reaction to the illness" and their "physical state", "patient's treatment", "self feeling upset or distressed", "effect of illness on others" and "the future" were reported by 80% of relatives or more. The only concern mentioned more than once on the "other section" was lack of information from the hospital (4 relatives).

Individual concerns were equally common among male and female partners. Relatives of older patients (40–75 years) were more concerned than relatives of younger patients (18–39 years) about their "relationship with the patient" (chi squared = 7.9, $P > 0.05$) and "effect of the illness on others" (chi squared = 8.6, $P < 0.05$), but age had no significant effect on the other concerns. There were no significant differences in frequency of relatives' individual concerns by cancer type for 10 of the 11 concerns. Similarly, the relatives' total concern scores, calculated by summing the degree of concern for all 11 concerns, showed no association with cancer type, age of patient or nature of relationship to patient (Table 2).

Combining all degrees of concern, more relatives than patients reported each of the nine concerns applicable to both (Table 3). The discrepancy was greatest for concern about the patient's emotional reaction, reported by 95% of relatives but only 18% of the patients themselves. Relatives' total concern scores for these nine concerns (median 16.0) were signficantly greater than patients' scores for the same items (median 4.0) (Wilcoxon signed rank test, $P < 0.0001$), with a weak positive correlation between the scores ($r = 0.29, P < 0.01$).

Psychological morbidity

52 (48%) relatives scored 5 or more on the GHQ-28, suggesting significant morbidity. The highest scores were obtained on the anxiety and insomnia (B) and somatic symptoms subscales (A) (Table 4). GHQ scores in relatives were not affected by cancer type or age of patient, but more female (63%) than male relatives (39%) scored above the cut-off (Table 5).

The relatives' GHQ scores correlated positively with their total concern scores (Spearman, $r = 0.23, P < 0.03$) and with patients' concern scores ($r = 0.24, P < 0.01$).

DISCUSSION

Our results suggest a high level of concern among the relatives of cancer patients in the first few weeks after diagnosis. In keeping with other reports [17], the most common concerns among relatives were the illness itself and the patient's emotional reaction to the illness. More practical concerns such as the patient's inability to carry out their normal activities, finances and the degree of support received from others were of less concern at this early stage in the illness.

A striking finding was that relatives reported concerns significantly more frequently than patients. Although patients were administered the concerns checklist verbally while relatives completed it in questionnaire format, it seems unlikely that this methodological difference alone accounted for the difference. One explanation could be that relatives regard themselves as helpless observers who can do little to influence their loved one's illness and treatment. In contrast, patients can resolve concerns by setting themselves goals, for example, completing their treatment. Patients are also likely to receive more direct contact and support from health professionals at this stage than their relatives. An alternative explanation is that the comparatively low level of concern reported by the patients themselves is at least partly due to the operation of denial as a defence mechanism. Longitudinal data are needed to establish the success of such a defence, but the data suggest that relatives adopt different coping strategies from patients in the weeks after diagnosis.

The different levels of concern expressed by relatives and patients emphasise the importance of basing advice and help on information separately offered. It is a mistake to assume that a relative is not concerned about treatment or the future because these issues are not concerns for the patient. This finding supports the practice of health professionals seeing patients and

Table 1. *Frequency and degree of relative concerns*

Concern	Slight concern (1)	Moderate concern (2)	Major concern (3)	Total no. (%) with concern
Patient's illness	7 (6%)	13 (12%)	88 (81%)	108 (100%)
Patient's reaction to the illness	10 (9%)	35 (32%)	58 (54%)	103 (95%)
Patient's physical state	21 (19%)	27 (25%)	51 (47%)	99 (92%)
Patient's treatment	15 (14%)	31 (29%)	44 (41%)	90 (83%)
Self feeling upset/distressed	33 (31%)	28 (26%)	29 (27%)	90 (83%)
Effect of illness on others	24 (22%)	27 (25%)	37 (34%)	88 (81%)
The future	32 (30%)	30 (28%)	25 (23%)	87 (81%)
Patient's inability to do things	26 (24%)	36 (33%)	19 (18%)	81 (75%)
Own relationship with patient	20 (19%)	13 (12%)	23 (21%)	56 (52%)
Amount of support received from others	14 (13%)	18 (17%)	20 (19%)	52 (48%)
Finances	14 (13%)	18 (17%)	6 (6%)	38 (35%)

Table 2. *Total relative concern scores by disease group, patient age group and relationship to patient*

Categories	Mean concern score (range 0–33)	95% CI
Disease group*		
Breast ($n = 58$)	19.1	17.3–20.9
Bowel ($n = 20$)	18.0	14.8–21.2
Gynae ($n = 10$)	17.1	11.6–22.6
Testis ($n = 20$)	18.0	14.2–21.8
Age group (years)*		
18–39 ($n = 24$)	17.2	14.6–19.8
40–59 ($n = 38$)	19.7	17.4–22.0
60–75 ($n = 46$)	18.2	15.9–20.4
Relationship to patient*		
Female partner ($n = 32$)	17.4	14.9–19.8
Male partner ($n = 61$)	17.7	15.9–19.6
Other relative ($n = 15$)	21.9	18.6–25.3

*Using one-way analysis of variance, none of the group means were significantly different. CI, confidence interval.

Table 3. *Comparison of relative and patient concerns*

Concern	No. (%) of relatives with concern*	No. (%) of patients with concern	Chi-squared value
Patient's illness	108 (100%)	61 (56%)	45.02†
Patient's reaction to the illness	103 (95%)	19 (18%)	82.01†
Patient's physical state	99 (92%)	30 (28%)	65.13†
Patient's treatment	90 (83%)	31 (29%)	51.75†
The future	87 (81%)	33 (31%)	41.39†
Patient's inability to do things	81 (75%)	31 (19%)	41.40†
Relationship with patient/relative	56 (52%)	8 (7%)	36.00†
Amount of support received from others	52 (48%)	5 (5%)	45.02†
Finance	38 (35%)	9 (8%)	42.67†

Using McNemar's test for paired proportions.
*Slight/moderate/major concerns combined; †$P < 0.00001$.

relatives separately, at least for part of the time, so that each feels free to talk frankly about their concerns. We recommend that health professionals should ask relatives about their current concerns and offer help as appropriate. Providing relatives with the opportunity to confide their concerns in this way may be particularly important as the availability of a confidante has been linked with psychiatric morbidity in non-cancer settings [18]. The greatest discrepancy between relatives' and patients' concerns related to the patients' emotional state, reported as a much greater concern by relatives. This difference may reflect the

Table 4. *Relatives' GHQ scores*

Number (and percentage) of relatives in each score category

Subscales	Subscores 0	1	2	3 Plus
A: Somatic symptoms	48 (44)	12 (11)	11 (10)	37 (34)
B: Anxiety + insomnia	38 (35)	12 (11)	15 (14)	43 (40)
C: Social dysfunction	55 (51)	26 (24)	10 (9)	17 (16)
D: Severe depression	98 (91)	7 (6)	2 (2)	1 (1)

Total GHQ-28 score		
0	25 (33)	
1–4	31 (29)	
5–9	33 (31)	52 (48%)
>10	19 (18)	

Table 5. *Relatives' GHQ scores by disease group, patient age group and relationship to patient*

Categories		Number and percentage of relatives scoring 5 or more on GHQ
Disease group		
Breast (n = 58)		25 (43%)
Bowel (n = 20)		14 (70%)
Gynae (n = 10)		3 (30%)
Testis (n = 20)		10 (50%)
Chi-squared = 5.7	Df = 3	P = NS
Age group		
18–39 (n = 24)		14 (58%)
40–59 (n = 38)		14 (37%)
60–75 (n = 46)		24 (52%)
Chi-squared = 3.2	Df = 2	P = NS
Relationship to patient		
Female partner (n = 32)		20 (63%)
Male partner (n = 61)		24 (39%)
Other relative (n = 15)		8 (53%)
Chi-squared = 4.7	Df = 2	P = 0.09*

*If male and female partners only are compared, Chi-squared = 4.5, P = 0.03.

difficulties relatives experience in raising emotional issues with patients, and suggests a further focus for counselling.

The prevalence of probable psychiatric morbidity of 48% in our sample of relatives is significantly higher than that reported in the general population using the same instrument [19, 20], and comparable to that seen in patients with multiple sclerosis [21] and cancer patients with stable disease [22]. The extent of this morbidity is worrying, because these relatives have a central role in providing practical and emotional support for the patient. The finding that female relatives were more likely to be GHQ cases than males is in keeping with the general psychiatric literature on the epidemiology of affective disorders [23].

The relatives' greater scores on the anxiety/insomnia and somatic subscales of the GHQ, and lower scores on social dysfunctioning and severe depression, contrasts with non-cancer samples [24, 25], where social dysfunction scores were greater. This suggests that, despite their predicament, most relatives were able to cope with activities of daily living.

Despite wide variation in the nature of the cancers included in the study, the uniformity of relatives' concerns and psychological morbidity across disease groups was impressive. Hence, one cannot assume that relatives of patients with a good prognosis worry less than those patients with a poor prognosis. It is possible that the absence of variation reflects lack of adequate information from medical staff but, based on our clinical experience in the hospitals involved, we feel this is unlikely. A more likely explanation is that relatives have a fixed concept of "cancer" as a major threat irrespective of the type, grade or stage of tumour.

Our results suggest that relatives merit more support than they currently receive, but providing this raises practical problems. Should relatives be screened for psychiatric disorders? Whose responsibility is it to manage their emotional distress? We suggest that hospital health care professionals should be more aware of the problems faced by relatives. They can help by offering information about the patient's illness and treatment to the relative, assuming the patient has given permission, and providing simple support. If a relative develops more severe distress, the staff should advise the relative that such reactions are well recognised in stressful situations, that effective treatment is available and that the first step is usually to consult their own general practitioner. Hospital staff should also be aware of any locally available support services for the relatives of cancer patients, and offer such information where appropriate.

In this cross-sectional study, female relatives and those with higher concern scores showed higher levels of psychological morbidity. In keeping with other reported results [2, 8], a relationship was also seen between relatives' concerns and the concerns reported by the patients themselves. Before appropriate interventions can be developed, longitudinal studies are needed to determine the outcome of such morbidity, and to identify those relatives at greatest risk of persistent distress.

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