

Cancer patient distress – roles of gender, family and psychological care

E. Carter,^{1,2} S. Collier,¹ R. Plunkett,¹ E. Beirne,¹ B.D. Kelly²

1. Department of Psychological Medicine, St James's Hospital, James's Street, Dublin 8, Ireland.
2. Department of Psychiatry, Trinity College Dublin, Trinity Centre for Health Sciences, Tallaght University Hospital, Tallaght, Dublin 24, Ireland.

Abstract

Introduction

Cancer burden is rising worldwide, with 20 million new diagnoses annually. Psychological needs of cancer patients are increasingly recognised, and psycho-oncology teams are developing. We aimed to assess distress among cancer patients in the oncology day-ward of a large urban hospital in Ireland.

Methods

Cross-sectional observational study of patient-rated distress at cancer diagnosis and treatment. We assessed distress among 142 patients using an existing survey tool.

Results

Women reported more extreme distress during cancer diagnosis and treatment, with 39 (46.4%) reporting 'extreme' distress at diagnosis and 82 (21.2%) during treatment, compared to 8 (17.8%) men at diagnosis and 43 (4.7%) men during treatment. Patients were likely to perceive their families as more distressed than themselves. On multi-variable testing, female gender was independently associated with higher patient distress at diagnosis and treatment. Patients reported work, fatigue, and fear for the future as areas of life most extremely affected by cancer. Only 3 (2.6%) patients reported extreme difficulties with relationships.

Discussion

High rates of extreme distress for cancer patients, particularly women, and their families highlights the need for enhanced, gender-aware, family-oriented psychological supports during cancer diagnosis and treatment. Future research could usefully include family members, assess distress longitudinally, and evaluate the impact of psychological supports.

Introduction

The burden of cancer worldwide is rising, with 20 million new cancer cases diagnosed in 2022 and 9.7 million cancer related deaths.¹ One fifth of the population will develop cancer in their lifetime. It is estimated that there will be over 35 million cancer diagnoses in 2050. Advances in medicine have led to timely diagnosis and improved cancer treatment, resulting in increased survival rates. Despite these advances, the psychological needs of cancer patients and their families have been neglected historically with the primary focus on medical treatment. While this is a medical success story, it is important to acknowledge, recognise and address the psychological needs of cancer patients and their families.

These needs are increasingly recognised in recent years and specialist psycho-oncology teams are developing worldwide. In Ireland, the National Cancer Strategy, aims to develop psycho-oncology services nationally by 2026 to address “the psychological responses of patients to cancer at all stages of the disease”.² As defined in this strategy, ‘the term ‘distress’ is the preferred term to describe the psychological challenges that patients with cancer experience’³.

The distress related to cancer is often considered along a spectrum called the ‘distress continuum’. This ranges from normal adjustment and coping, through to adjustment disorders, subclinical mental health diagnoses and clinical psychiatric disorders⁴. There are many aspects associated with a cancer diagnosis and treatment which can cause significant emotional and psychological distress for patients. The uncertainty around prognosis, treatment and survival can be significantly anxiety provoking for patients. Practical aspects associated with a cancer diagnosis include sick leave due to physical symptoms or attendance at medical appointments, resulting in loss of income and employment and a significant level of emotional distress for cancer patients. Physical symptoms such as pain, loss of appetite, poor energy and sleep disturbance can have an impact on cancer patients’ emotional wellbeing. The identity shift from a ‘healthy person’ to a ‘cancer patient’ can affect self-esteem and self-confidence.

There are various levels of clinically significant psychological distress among cancer patients reported in the literature, ranging from one quarter to half of cancer patients^{5,6}. A large published meta-analysis found high rates of psychiatric disorders among cancer patients, including depression (20.7%), anxiety (10.3%) and adjustment disorder (19.4%)⁷.

The literature reports that cancer patients who experience clinically significant levels of anxiety and depression have poorer cancer survival and increased cancer incidence⁸. A meta-analysis has shown that mortality rates from cancer are 25% higher in cancer patients with depressive symptoms and increased by 39% in cancer patients with a clinically diagnosed

depressive episode⁹. There is some evidence that a reduction in distress levels can lead to improved cancer outcomes for breast cancer patients¹⁰.

It is important that the implementation of the National Cancer Strategy is informed by evidence. Evidence to date indicates a clear need for psycho-oncology services¹¹, but further and ongoing evidence is required to shape services and ensure maximal patient benefit.

Against this background, we aimed to assess distress among cancer patients in the oncology day-ward of a large urban hospital in Ireland. We assessed patient rated distress and examined its relationship with other variables. We also sought to identify the areas of patients' lives most affected by cancer and cancer treatment in order to inform psycho-oncology service delivery. Results of this study may help shape psycho-oncology services in line with patient need as they continue to develop nationally.

Methods

This cross-sectional, observational study was based in St James's Hospital in Dublin, Ireland's largest acute academic teaching hospital. It is the largest designated national cancer centre in the country.

Patients were recruited from the Haematology Oncology Day Ward where they received outpatient cancer treatment, from April to May 2023. Inclusion criteria were that the patient was aged 18 years or over; had a cancer diagnosis, was proficient in the English language and provided consent. All patients meeting these criteria were invited to participate.

We assessed distress among patients using an existing survey tool (Appendix 1).¹¹ The self-report tool asked patients about their type of cancer, time since diagnosis, if they had experienced a recurrence, areas of life affected by cancer and their self-perceived coping with cancer and cancer treatment. Patients were asked to recall the level of distress they and their family experienced at time of diagnosis and about their current level of distress during cancer treatment.

For statistical analysis we used SPSS (version 26). We performed two multi-variable regression analyses with level of distress at diagnosis and treatment as the dependent variables; independent variables were age, gender, single or not single, type of cancer and history of psychiatric or psychological difficulties pre-cancer diagnosis. To test for multicollinearity, a "tolerance value" was calculated for each independent variable¹², with no evidence of multicollinearity in either model.

Results

One hundred and forty-two patients participated in the study. Almost two thirds (64.1%; n=91) were female; 64% (n=89) were married; 10.5% (n=15) were aged under 40 years, 42.9% (n=61) were between 40 and 60, and 46.5% (n=66) were over 60. A majority had no history of psychiatric or psychological difficulties (90.9%; n=120).

Breast cancer was the most common cancer (33.8%) (Table 1). Among women, the most common cancers were breast (51.6%), gynaecological (13.2%) and colorectal (7.7%), while lymphoma/leukaemia (21.6%), colorectal (17.6%) and prostate/renal/bladder cancers (17.6%) were most common among men ($\chi^2 = 64.621$, $p < 0.01$). At the time of the study, approximately half of patients (53.9%; n=76) had received their cancer diagnosis within the previous year; almost one third (30.8%; n=41) were experiencing a recurrence; and chemotherapy was the most common treatment (85.2%; n=121), followed by surgery (40.1%; n=57), steroids (35.9%; n=51), radiotherapy (27.5%; n=39), hormonal therapy (9.2%; n=13), bone marrow transplant (5.6%; n=8), and immunotherapy (1.4%; n=2).

Over two thirds of patients rated their cancer diagnosis as very distressing (33.3%) or extremely distressing (36.4%) (Table 2). Females experienced more distress than males, with 46.4% of women reporting “extreme” distress at their cancer diagnosis, compared to 17.8% of men ($\chi^2 = 13.166$, $p = 0.10$). Distress at diagnosis for patient was not related to cancer type ($\chi^2 = 50.422$, $p = 0.125$), age ($\chi^2 = 17.233$, $p = 0.839$), or history of psychiatric or psychological difficulty ($\chi^2 = 0.818$, $p = 0.936$). Patients were more likely to perceive their families as extremely distressed compared to themselves ($\chi^2 = 70.016$, $p < 0.01$).

Almost half of patients rated treatment as very (30.6%) or extremely distressing (16.1%), but patients were, overall, less likely to report extreme distress at time of treatment compared to time of diagnosis ($\chi^2 = 49.455$, $p < 0.01$). Females experienced more distress than males during cancer treatment, with 21.2% (n=82) of females reporting cancer treatment as “extremely” distressing compared to 4.7% (n=43) of males ($\chi^2 = 11.526$, $p = 0.042$).

Almost half of patients (48.9%; n=64) reported that cancer diagnosis and treatment impacted a great deal on daily life. A majority (84.8%; n=111) reported that cancer diagnosis and treatment had a moderate or great deal of impact on their quality of life. Less than a quarter of patients (22.7%; n=30) felt that they were coping very well with cancer treatment and associated side effects. The areas in life that were most extremely affected by cancer and its treatment were work (27.9%), fatigue (19.0%) and fear for the future (17.3%); the areas least extremely affected were relationships (2.6%), parenting (4.8%) and fertility (6.7%) (Table 3). Other areas affected by cancer and its treatment, included planning for the future (0.7%; n=1), social restrictions (0.7%; n=1) and social life (0.7%; n=1).

Areas of life affected by cancer and its treatment did not differ significantly across genders, apart from levels of anxiety and worry, with more females reporting 'extreme' or 'quite a bit' of worry (49.4%; n=40), than men (19.1%; n=8; $\chi^2=10.792$; $p=0.029$).

On multi-variable testing, female gender was the only variable associated with higher levels of patient distress at cancer diagnosis and treatment (Table 4).

Discussion

In summary, this study found that females experienced more extreme levels of distress than males during both cancer diagnosis and treatment, with almost half of females reporting 'extreme' distress at diagnosis and over one-fifth during treatment. This compares to less than one-fifth of males at diagnosis and under five percent during treatment. Patients were likely to perceive their families as more distressed than themselves. Patients were less likely to report extreme distress at treatment than cancer diagnosis.

On multi-variable testing, female gender was the only variable independently associated with higher levels of patient distress at cancer diagnosis and treatment.

Patients reported work, fatigue and fear for the future as the areas of life most extremely affected by cancer and treatment. Only 2.6% of patients reported extreme difficulties with relationships due to their cancer diagnosis and treatment.

A previous Irish study highlighted significant levels of distress in psycho-oncology patients with 57.9% of patients reporting 'very' high or 'extreme' levels of distress in relation to their cancer diagnosis, but that study did not report differences in gender.¹¹ Another Irish study of patients already referred to the psycho-oncology service reported that females experienced increased levels of distress¹³. An international study of female breast cancer patients has also shown a decrease in distress over time from diagnosis to treatment.¹⁴ International studies report varying levels of distress among cancer patients. In Canada, a large-scale study estimated that 37% of patients experienced significant distress levels.¹⁵

A large multicentre study in Canada reported 19% of cancer patients had clinical levels of anxiety with 22.6% experiencing subclinical symptoms.¹⁶ Other international studies report gender based differences in distress among cancer patients, with females diagnosed with non-metastatic renal cell carcinoma experiencing higher levels of anxiety and distress.¹⁷ A Chinese study of patients with gastroenteropancreatic neuroendocrine tumour estimated the prevalence of psychological distress as 31.5%, with females experiencing more distress.¹⁸ Another Chinese study of gastrointestinal cancer patients found that a greater proportion of females (52.8%) had clinically significant psychological distress compared to males (35.9%).¹⁹

Our study replicates these findings, linking female gender with distress in cancer in Ireland. In addition, we report that over two thirds of patients rate their cancer diagnosis as very or extremely distressing. We also report that work is the area of life most commonly impacted by cancer diagnosis and treatment. Relationships were reported as the least affected area of life, suggesting that the impact of cancer on relationships is more nuanced rather than solely negative.

Strengths of this paper include that to our knowledge, this is the first significant study of gender based distress among Irish cancer patients in the last decade and includes all cancer types. In addition, we identified a potentially vulnerable patient cohort who may benefit from increased psychological support during cancer diagnosis and treatment, allowing streamlining of psycho-oncology services nationally.

Limitations of this paper include possible selection bias given that patients were recruited from the haematology oncology day ward where they were undergoing cancer treatment. This would not include cancer patients undergoing surgical or radiation therapy only, those not on active treatment, and those in palliative care. Future studies could look to include these patients by recruiting via palliative care, radiotherapy centres, oncology and surgical teams. In addition, it was not possible to collect any data about patients who declined to participate owing to data protection regulations.

Our study was cross-sectional in nature, with participants reporting distress at diagnosis retrospectively, which may have been subject to recall bias. Future work may look to follow up distress longitudinally, although assessing distress at time of diagnosis for patients would be difficult owing to the sensitive nature of the subject and would be ethically challenging.

In conclusion, the high rates of extreme distress for cancer patients and their families in our study, particularly among women, highlights the need for enhanced provision of psychological support for patients during both cancer diagnosis and treatment, informed by patterns identified in evidence such as this study. In Ireland, services have been developing nationally under the National Cancer Strategy 2017-2026 and this research emphasises the ongoing need for this service for the Irish population. Future research could usefully include family members, aim to assess distress amongst cancer patients longitudinally and evaluate the impact of psychological supports on distress.

Declarations of Conflicts of Interest:

None declared.

Corresponding author:

Eva Carter,
Department of Psychological Medicine,
St. James's Hospital,
James's Street,
Dublin 8,
Ireland

E-Mail: cartereva.22@gmail.com

Table 1 Cancer type:

Variable	Overall (Female and male)	Female <i>n</i> (%)	Male <i>n</i> (%)
Breast	48 (33.8%)	47 (51.6%)	1 (2.0%)
Colon/ rectal	16 (11.3%)	7 (7.7%)	9 (17.6%)
Lymphoma/ leukaemia	16 (11.3%)	5 (5.5%)	11 (21.6%)
Gastric/ oesophageal	12 (8.5%)	6 (6.6%)	6 (11.8%)
Gynaecological	12 (8.5%)	12 (13.2%)	0 (0%)
Prostate/ renal/ bladder	10 (7.0%)	1 (1.1%)	9 (17.6%)
Lung	9 (6.3%)	2 (2.2%)	7 (13.7 %)
Other	8 (5.6%)	6 (6.6%)	2 (3.9%)
Multiple myeloma	6 (4.2%)	2 (2.2%)	4 (7.8%)
Melanoma	3 (2.1%)	2 (2.2%)	1 (2.0%)
Head/neck	2 (1.4%)	1 (1.1%)	1 (2.0%)

Table 2: Distress of cancer diagnosis and treatment for patient and family

Variable	Extremely <i>n</i> (%)	Very <i>n</i> (%)	Moderately <i>n</i> (%)	A little <i>n</i> (%)	Not at all <i>n</i> (%)
Distress of diagnosis for patient (<i>n</i> =129)	47 (36.4%)	43 (33.3%)	32 (24.8%)	6 (4.7%)	1 (0.8%)
Distress of diagnosis for family (<i>n</i> =129)	64 (49.6%)	44 (34.1%)	16 (12.4%)	4 (3.1%)	1 (0.8%)
Distress of treatment for patient (<i>n</i> =124)	20 (16.1%)	38 (30.6%)	47 (37.9%)	16 (12.9%)	3 (2.4%)
Distress of treatment for family (<i>n</i> =123)	22 (17.9%)	48 (39.0%)	43 (35.0%)	5 (4.1%)	5 (4.1%)

Table 3: Areas patients had difficulties with due to cancer and its treatment

Variable	Extremely <i>n</i> (%)	Quite a bit <i>n</i> (%)	Moderately <i>n</i> (%)	A little bit <i>n</i> (%)	Not at all <i>n</i> (%)
Work (<i>n</i> =111)	31 (27.9%)	29 (26.1%)	11 (9.9%)	8 (7.2%)	32 (28.8%)
Fatigue (<i>n</i> =126)	24 (19.0%)	47 (37.3%)	33 (26.2%)	20 (15.9%)	2 (1.6%)
Fear for the future (<i>n</i> =127)	22 (17.3%)	33 (26.0%)	30 (23.6%)	27 (21.3%)	15 (11.8%)
Sexual intimacy (<i>n</i> =113)	20 (17.7%)	28 (24.8%)	17 (15.0%)	15 (13.3%)	33 (29.2%)
Fear of recurrence (<i>n</i> =122)	19 (15.6%)	32 (26.2%)	26 (21.3%)	31 (25.4%)	14 (11.5%)
Finances (<i>n</i> =119)	15 (12.6%)	21 (17.6%)	25 (21%)	27 (22.7%)	31 (26%)
Physical appearance (<i>n</i> =122)	14 (11.5%)	34 (27.9%)	20 (16.4%)	32 (26.2%)	22 (18.0%)
Anxiety or worry (<i>n</i> =123)	14 (11.4%)	34 (27.6%)	34 (27.6%)	30 (24.4%)	11 (8.9%)
Pain (<i>n</i> =115)	10 (8.7%)	21 (18.3%)	26 (22.6%)	31 (27.0%)	27 (23.5%)
Sleep	7 (5.6%)	37 (29.6%)	28 (22.4%)	29 (23.2%)	24 (19.2%)

(n=125)					
Low mood or sadness (n=126)	6 (4.8%)	20 (15.9%)	41 (32.5%)	41 (32.5%)	18 (14.3%)
Fertility (n=90)	6 (6.7%)	4 (4.4%)	4 (4.4%)	8 (8.9%)	68 (75.6%)
Parenting (n=105)	5 (4.8%)	14 (13.3%)	19 (18.1%)	27 (25.7%)	40 (38.1%)
Relationships (n=115)	3 (2.6%)	15 (13.0%)	23 (20%)	24 (20.9%)	50 (43.5%)

Table 4: Predictors of level of patient distress at cancer diagnosis and treatment: multi-variable linear regression models

Independent variables	Level of patient distress at cancer diagnosis ^a				Level of patient distress at cancer treatment ^b			
	β	Standard error	p value	Tolerance value ^c	β	Standard error	p value	Tolerance value ^c
Age	-0.033	0.069	0.637	0.942	-0.038	0.077	0.626	0.936
Gender	0.624	0.176	0.001	0.916	0.425	0.196	0.032	0.925
Single or not single	0.226	0.156	0.151	0.971	0.279	0.176	0.115	0.967
Type of cancer	0.022	0.027	0.401	0.962	0.017	0.030	0.564	0.973
History of psychiatric or psychological difficulties pre-cancer	0.115	0.276	0.679	0.975	0.468	0.306	0.128	0.974
Constant	2.441	0.480	0.000	-	2.009	0.532	0.000	-

Notes

This multi-variable linear regression model includes all patients who responded to the survey on the Oncology Day ward during the recruitment period for the study.

^a The dependent variable was level of distress at cancer diagnosis, where 0 indicates no distress and 4 indicates extreme distress. R square value for this model was 12.0%, indicating that variables in the model explained 12% of the variance in level of distress.

^b The dependent variable was level of distress at cancer treatment, where 0 indicates no distress and 4 indicates extreme distress. R square value for this model was 8.2%, indicating that variables in the model explained 8.2% of the variance in level of distress at treatment.

^c To test for multicollinearity, a “tolerance value” was calculated for each independent variable; tolerance values below 0.25 indicate possible multicollinearity, and tolerance values below 0.10 indicate significant problems with multicollinearity ¹².

Appendix 1: Participant survey

1. Age (please tick the appropriate box):

- 18 – 21years ☐ 22 - 25years ☐ 26 – 30 years ☐ 31 – 35 years ☐
 36 – 40 years ☐ 41 – 50 years ☐ 51 – 60 years ☐ 61 years + ☐

2. Gender

Male ☐ Female ☐ Other (please describe) _____

3. Marital Status:

Single ☐ Long term partner ☐ Married ☐ Divorced ☐ Widowed ☐

4. Type of cancer:

Lung ☐ Gastric/Oesophageal ☐
 Breast ☐ Melanoma ☐
 Prostate/Renal/Bladder ☐ Head/Neck ☐
 Lymphoma/Leukaemia ☐ Gynaecological ☐
 Colon/Rectal ☐
 Other (Please state) _____

5. How long has it been since your initial cancer diagnosis:

< 1 month ☐ 1 – 3 months ☐ 4-6 months ☐ 7 – 12 months ☐ >1 year ☐

6. Have you had a recurrence of your cancer?

Yes ☐ No ☐

If Yes, how many _____

7. What treatment have you received for your cancer to date?

Surgery ☐

Bone marrow transplant ☐

Chemotherapy ☐

Steroids ☐

Radiotherapy ☐

Other (Please describe below)

Hormonal treatments ☐

8. How distressing or stressful were the following aspects for you, and for your family:

	Extremely	Very	Moderately	A little	Not at all
How distressing or stressful was your cancer diagnosis for you ?					
How distressing or stressful was your cancer diagnosis for your family ?					
How distressing or stressful was your cancer treatment for you ?					
How distressing or stressful was your cancer treatment for your family ?					

9. To what degree do you find that your diagnosis of cancer and its treatment has negatively affected aspects of your daily life?

☐ Not at all ☐ Not very much ☐ Moderately ☐ A great deal

10. To what degree do you find that your diagnosis of cancer and its treatment has negatively affected your quality of life?

☐ Not at all ☐ Not very much ☐ Moderately ☐ A great deal

11. Do you have a history of psychological or psychiatric difficulties prior to your cancer diagnosis and treatment?

☐ No ☐ Yes (please describe) _____

12. How well do you think you are coping with cancer, treatment and side-effects?

Poorly ☐

Less well than I'd like ☐

Reasonably well ☐

It varies ☐

Very well ☐

13. Has cancer and its treatment caused you to experience problems with? (please tick)

	Not at all	A little bit	Moderately	Quite a bit	Extremely
Pain					
Fatigue / energy					
Sleep					
Physical Appearance					
Anxiety or worry					
Sadness / Low mood					
Fear of recurrence					
Fear for the future					
Sexual intimacy					
Work					

Parenting					
Fertility					
Finances					
Relationships					
Other (please state)					

14. Please list the three areas in your life that cancer and its treatments has had the most negative or serious impact.

A) _____

B) _____

C) _____