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**Manuscript Title: A cross-sectional study of radiation oncology outpatients' concern about, preferences for, and perceived barriers to discussing anxiety and depression**

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## **A cross-sectional study of radiation oncology outpatients' concern about, preferences for, and perceived barriers to discussing anxiety and depression**

### **Abstract**

**Objective** Although elevated psychological distress is commonly reported among cancer patients, our understanding of patients' preferences for, and perceived barriers to, accessing psychological support from key cancer care providers is limited. The aim of this study was to assess cancer patients' level of concern about, and willingness to discuss, their anxiety and depression.

**Methods** Radiation oncology outpatients completed a touchscreen computer survey with questions assessing their concern about and willingness to discuss anxiety and depression.

**Results** Among consenting respondents ( $n = 145$ ), 51% (95% CI: 43%-59%) were concerned about their levels of anxiety, and 34% (95% CI: 26%-42%) about their levels of depression. If experiencing anxiety or depression, 92% (95% CI: 87%-96%) would want to discuss this with their general practitioner (GP), and 60% (95% CI: 52%-68%) with their cancer doctor. Almost half of the 58 respondents who would not want to discuss anxiety or depression with their cancer doctor indicated that this was because there were more important things to talk about during their appointment.

**Conclusions** The majority of cancer patients undergoing radiotherapy would be willing to discuss anxiety and depression with their cancer doctor and GP. These findings provide additional support for service delivery models in which GPs and oncologists play key roles in initiating and coordinating discussions about cancer patients' psychosocial concerns.

**Keywords** anxiety, depression, cancer, oncology, psychological support, radiotherapy

# **A cross-sectional study of radiation oncology outpatients' concern about, preferences for, and perceived barriers to discussing anxiety and depression**

## **Background**

There is a need for effective methods of identification, referral and follow-up of cancer patients with elevated psychological distress [1, 2]. Research in Canada, Australia and the USA has identified that between 42-75% of cancer outpatients with elevated anxiety and depression have not accessed psychological support [3-5]. The authors recently reported that among radiation oncology outpatients who perceived that they were experiencing anxiety (50%) and depression (31%), only about one third would like to be offered professional support [6]. Patients may not want professional psychological support [7] if they view distress to be a normal part of coping with cancer [6] or if they feel they already have adequate support in place [4]. Within a paradigm of patient-centred cancer care, patients' concerns, preferences and expectations should guide the provision of psychosocial support [1, 8, 9].

Dilworth and colleagues suggested that perceived barriers to accessing psychological support may be overcome through improved communication about and promotion of psychosocial care in oncology settings [10]. There is a need to assess patients' preferences for discussing psychosocial issues with key cancer care providers. Oncologists and primary care physicians (referred to as General Practitioners [GPs] in Australia) typically play key roles in the provision and coordination of cancer care, including emotional support [11-15]. The objective of the current study was to extend on past findings by assessing: (1) cancer patients' level of concern about their anxiety and/or depression; and (2) the proportion of patients who, if experiencing anxiety and depression, would discuss this with their oncologist (and if not, the reasons why) or their GP.

## **Methods**

Ethics approvals: The research was conducted in accordance with the Helsinki Declaration of 1975, as revised in 2000. All procedures, including the informed consent process, adhered to the ethical standards of the University of Newcastle and the NSW Population & Health Services Research Ethics Committees.

Study design and setting: A cross sectional touchscreen computer survey was conducted in two radiation oncology treatment centres in metropolitan Australia between February and July 2010. This survey was embedded within a larger patient survey that assessed perceptions of patient-centred cancer care [6, 16, 17].

Participants: Eligible participants were cancer patients who were attending at least their second radiotherapy (RT) appointment; aged 18 years or older; able to complete the touchscreen computer survey in English; and judged by clinic staff to be physically and mentally able to give informed consent. Patients who had previously completed the survey were excluded.

Procedure: Research assistants (RAs) were informed by clinic staff about patient eligibility. RAs approached eligible patients in the treatment waiting room to provide information about participation and seek consent. The RA recorded the sex of all patients approached about the study to assess consent bias. Participants were allocated a unique identification code to login to commence or continue the survey before or after their RT appointment.

Measures: The survey was programmed into a touchscreen computer using Digivey survey software (CREOSO, Arizona, USA).

*Sociodemographic, disease and psychological characteristics.* The following information was assessed via patient self-report: Date of birth; sex; postcode of usual place of residence; country of birth; who the patient lives with; most recent primary cancer diagnosis; year and month of diagnosis; number of radiation therapy appointments attended; and perceived treatment aim. Patient self-report has previously been found to have high accuracy for information related to a cancer diagnosis [18]. Patients also completed the Hospital Anxiety and Depression Scale (HADS), a 14-item self-report measure of anxiety and depression. For the purposes of this study, patients meeting or exceeding anxiety or depression subscale threshold scores of 8 were considered to be possible cases of anxiety or depression, respectively [19]. HADS data from the larger study is published elsewhere [16].

*Level of concern about anxiety and depression.* Respondents were asked two questions about their level of concern about their own anxiety and depression. The first was: “In the last week, have you experienced levels of anxiety that were worrying to you?” The onscreen instruction was “Please select the option that most closely describes how you have been feeling in the past week” and response options were on a 4-point Likert scale (not at all; a little; somewhat; very much so). A similarly worded question was asked for depression. Items were piloted with 16 RT patients. Based on patient feedback, the questions on anxiety and depression were presented on different screens (rather than the same screen), with “anxiety” and “depression” written in capital letters to emphasise the question topic.

*Preferences for discussing anxiety and depression.* Questions related to preferences for support from key cancer care coordinators [11-15] were piloted with 16 RT patients. Three pilot questions were: “If your survey results suggested that you might be anxious or depressed; would you be willing for your cancer doctor to be given a copy of the results?”; “If your cancer doctor suggested it; would you be willing to see a GP in your local area to discuss how the GP might be able to help with any anxiety or depression that you may be experiencing?” and “If the GP recommended it; would you be willing to accept a referral to a specially trained psychologist in your local area to help with any anxiety or depression that you may be experiencing?” Based on participant feedback and review of pilot data, the research team were interested why almost one third of pilot patients indicated that they would not share a copy of their survey results with their cancer doctor if their results suggested that they were anxious or depressed. The revised questions asked study participants: “If you were experiencing anxiety or depression, would you want your cancer doctor to talk to you about what could be done to help you feel better? Please note that your results from the survey today will not be given to your doctor” with response options “Yes”; “No”; or “Not sure”. Those who responded “No” or “Not sure” were also asked “Why wouldn't you want your cancer doctor to talk to you about any anxiety or depression you were experiencing?” Respondents could select as many of the following options as were applicable: “Don't think cancer doctor would help”; “would prefer to talk to somebody else”; “not comfortable talking to my cancer doctor about emotional problems”; “more important things to talk about at my cancer doctor's appointment” and/or “other reasons”. Response options were derived from past research into patient-reported barriers to psychosocial referral uptake [20, 21]. All respondents were asked “If you were anxious or depressed; would you be willing to discuss the matter with your local GP?” with response options “yes and I have a regular GP”; “yes

but I do not have a regular GP”; “no”; and “not sure”. Respondents selecting either of the “yes” options in the previous question were also asked “If you were anxious or depressed; would you accept a referral from your GP to see a psychologist?” with response options “yes”; “no”; and “not sure”.

Statistical methods and sample size: The recruitment target was 150 patients. Based on 50% of patients being concerned about anxiety and 35% for depression, this would allow us to obtain prevalence estimates with 95% CIs within  $\pm 10\%$  of the point estimate. The proportion of patients endorsing each response was reported with 95% confidence intervals. All analyses were conducted using Stata version 11.2 (StataCorp, Texas, USA).

## Results

Consent rates: A pool of approximately 390 patients attended for care during the study period. Of 238 patients screened for eligibility (approached on the basis of research assistant and touch screen computer availability), 27 were excluded because of inadequate English ( $n = 16$ ); not being a current RT patient ( $n = 4$ ), clinic staff concerns about burden/capacity to give informed consent ( $n = 3$ ); not being diagnosed with cancer ( $n = 3$ ); or another unspecified reason ( $n = 1$ ). Of the 211 eligible patients, 184 (87%) consented and 145 of these completed the survey (79%) and were included in the analyses. 39 datasets were not included in the analyses due to respondent withdrawal from the study ( $n = 9$ ); insufficient time to complete the survey ( $n = 23$ ); and data deletion resulting from computer error ( $n = 7$ ). There was no significant difference between proportion of males and female consenters who completed the survey ( $p = 0.08$ ). Characteristics of the sample are presented in Table 1.

Concern about anxiety and depression amongst cancer patients undergoing RT: Table 2 shows the percentage of respondents expressing different levels of concern about their current levels of anxiety and depression. Of the 145 respondents, 51% (95% CI: 43%-59%) had some level of concern (i.e. indicated they were “a little”; “somewhat” or “very much” concerned) about their anxiety levels, and 34% (95% CI: 26%-42%) about their depression levels. Post-hoc power calculations indicated that this sample size still enabled prevalence estimates with 95% CIs within  $\pm 10\%$  of the point estimate.

Willingness to discuss anxiety and depression with health professionals: Sixty percent of respondents ( $n = 87$ ; 95% CI: 52%-68%) indicated that if they were anxious or depressed, they would want to discuss this with their cancer doctor. Twenty-one percent ( $n = 31$ ; 95% CI: 15%-29%) would not want their cancer doctor to talk to them about anxiety and depression and 19% ( $n = 27$ ; 95% CI: 13%-26%) were not sure. Among the 58 participants in the latter two categories (“no” and “not sure”), reasons for not wanting their cancer doctor to talk to them about any anxiety or depression included: Having more important things to talk about at their appointment ( $n = 28$ ; 48%, 95% CI: 35%-62%); preferring to talk to someone else ( $n = 10$ ; 17%, 95% CI: 8.6%-29%); didn’t think that their cancer doctor would help ( $n = 7$ ; 12%, 95% CI: 5%-23%); not comfortable talking to their doctor about emotional problems ( $n = 4$ ; 7%, 95% CI: 1.9%-17%). Twenty-one per cent ( $n = 12$ ; 95% CI: 11%-33%) selected “other” reasons for not wanting to discuss anxiety or depression with their cancer doctor.

Ninety-two percent ( $n = 134$ ; 95% CI: 87%-96%) of respondents indicated that if they were anxious or depressed, they would be willing to discuss the matter with their local GP, and 97% ( $n = 130$ ) of these reported having a regular GP. Of the 134 who indicated that they would discuss anxiety/depression with their GP, 66% ( $n = 89$ ; 95% CI: 58%-74%) indicated that if they were anxious or depressed, they would accept a referral from their GP to see a

psychologist. Twenty-one per cent ( $n = 28$ ; 95% CI: 14%-29%) indicated that they would not accept a referral, and 13% ( $n = 17$ ; 95% CI: 7.6%-20%) were unsure.

Among patients ( $n = 13$ ) who were worried 'very much so' about their anxiety or depression levels, 62% ( $n = 8$ ; 95% CI: 32%-86%) indicated that if they were experiencing anxiety or depression they would discuss this with their cancer doctor, 85% ( $n = 11$ ; 95% CI: 55%-98%) with their GP, and 82% ( $n = 9$ ; 95% CI: 48%-98%) would accept a referral from their GP to a psychologist.

## **Discussion**

Concern about current levels of anxiety and depression: Over half of the respondents (51%; 95% CI: 43%-59%) reported experiencing levels of anxiety, and over one third (34%; 95% CI: 26%-42%) levels of depression, that were worrying them. This is comparable to a similar sample of radiation oncology outpatients where 50% and 31% perceived they were experiencing mild to severe levels of anxiety and depression (respectively) [6]. The proportion concerned about their anxiety and depression in this study also closely corresponds with the upper levels of psychological distress reported in a review which suggested that 21%-54% of patients experience feelings of anxiety and 12%-33% experience symptoms of depression during RT treatment [22].

Willingness to discuss anxiety and depression and accept help: While it is argued that patients who are experiencing complex psychological issues should be referred to mental health professionals [23], GPs and cancer specialists are often the first port of call in accessing more specialised services. In particular, GPs commonly provide treatments for anxiety and depression. Between 43%-73% of cancer patients in the UK and Australia consider GPs and senior surgical, haematology and oncology staff to be important sources of emotional support [13-15], suggesting a need for oncologist- and GP- delivered emotional support be responsive to these varying patients' preferences [13, 23].

Sixty percent of respondents in the current study indicated that, if anxious or depressed, they would want their cancer doctor to discuss this with them. These results are in accordance with past studies. For example, Taylor *et al* [15] reported that 59% of UK cancer patients would be willing to initiate a discussion with their clinician about emotional concerns relating to their disease, and another 30% would discuss emotional concerns if their physician initiated the conversation. Recent research indicated that 82% of radiation oncology outpatients would probably accept (or were currently using) treatment or counselling from their cancer doctor [6]. In the Australian context, this may include general discussions about, and supportive care for, psychosocial concerns, including potential referral to mental health specialists [24].

The most common reason amongst the 40% of respondents who preferred not to discuss emotional concerns with their cancer doctor was having "more important things to talk about" during their appointment (48%). This may reflect a perception that medical symptoms and side-effects are a more important focus than psychological concerns given consultation time limitations [20]. Despite including a range of response options describing reasons for not wanting to discuss anxiety or depression with their cancer doctor, this list appeared to be insufficient, since the second most common reason (21%) was "other". Respondents were not asked to specify what the "other" reasons were, but past studies suggest other reasons for cancer outpatient refusal of psychosocial services may include: a preference for self-management; a view that symptoms were improving on their own; issues related to the timing

of the service offer; and negative perceptions about having any need for psychosocial support [10, 20].

Ninety-two percent of respondents reported they would be willing to discuss anxiety and depression with their local GP, and 66% of these indicated that they would accept a referral from their GP to a psychologist. Recent findings from a separate radiation oncology outpatient sample found that, if experiencing anxiety or depression, 61% would accept (and 10% were currently using) treatment or counselling from their GP [6]. Both of these figures are higher than reported in a 1996 multicentre study of cancer outpatients in the UK, which found that 43% would consult their GP for emotional support [14]. The higher rate of willingness to discuss emotional concerns with GPs among the Australian participants in this study may be due to increasing acceptance over time of the value of and need for support for mental illness [25, 26]. Despite the high levels of perceived acceptability of psychosocial care from GPs found in this study and past research [27], GPs may perceive that they do not have a key role in the provision of psychosocial care [11]. It has been argued that primary care physicians may be well placed to play a coordinating role in the care of patients with cancer, including provision of psychosocial care [12].

Clinical implications: Our results suggest that the majority of cancer patients undergoing RT would be willing to discuss anxiety and depression with their cancer doctor and GP. These findings support models in which either the GP, cancer doctor, or both, play a key role in initiating discussions about and addressing psychosocial concerns [11]. Coordinated psychosocial care pathways between GPs and oncologist are required for cancer patients to ensure that these concerns are adequately addressed [28]. Cancer clinicians perceive that barriers to discussing emotional issues with their patients include: lack of training, skills and poorly defined clinical roles in the assessment and intervention for emotional distress [29, 30], the fast pace of clinical practice [30], and a belief that patients are not willing to discuss emotional concerns [30]. Further, miscommunication between patients and cancer clinicians may result in limited patient awareness of, and referral to, available services [31, 32]. In order to increase the provision of patient-centred psychosocial care, there is firstly a need to ensure that both GPs and oncologists receive adequate training in both the detection and management of psychological distress. Secondly, clear guidelines for how to best approach delineating the role of primary care providers with tertiary care providers in distress detection and management amongst cancer patients are required [12].

A patients' hypothetical willingness to discuss anxiety and depression (if experiencing it) does not necessarily reflect whether psychological assistance is needed, offered to, and accepted by, cancer patients [33, 34]. GPs with established patient relationships are uniquely placed to provide emotional support [35, 36], in accordance with the preference of the majority of patients in this study. However, low rates of GP utilisation during active cancer treatment [37] and slow transition back to GP care [38] suggests opportunities for patients to discuss emotional issues with a GP during active treatment may be limited. There is a need to strengthen 'shared care' models where cancer specialists endorse ongoing GP roles during active treatment. Additionally, carefully coordinated communication between these professionals is needed to ensure that psychosocial issues are addressed during cancer treatment. Promising shared care models include the Uniting Primary Care and Oncology (UPCON) Network in Manitoba, Canada and Cancer Service Networks (CanNET) projects underway across Australia [39, 40].

Limitations: As this study was limited to cancer patients undergoing RT in metropolitan areas, results may not be generalizable to all cancer patients. It is possible that sampling bias may have been introduced to this study. We were unable to assess differences between groups who were and were not screened for inclusion. Although the intended sample size was not met for the main study, post-hoc analyses indicate the study was adequately powered.

This study focused on patients' preferences for discussions with oncologists (and associated barriers), GPs and referrals to psychologists. Preferences for, and barriers to, discussing anxiety and depression with other staff involved in routine patient care in RT settings (including nurses and radiotherapists) and accepting referrals to other psychosocial supports were not assessed. Future research could do more to delineate preferences for and barriers to accessing support from a range of healthcare providers (based within and externally to cancer treatment centres), and could include a wider range of disease and demographic variables and explore predictors of service uptake and acceptability [6, 40].

Conclusions: A high proportion of cancer patients reported some level of concern about the anxiety and depression they were experiencing. In line with past research findings [3], results indicate that cancer patients are willing to discuss anxiety and depression with oncologists and GPs, and many would accept a referral to a psychologist. Further efforts are required to define effective integrated service delivery models in which GPs and oncologists both play key roles in initiating discussions about cancer patients' psychosocial concerns.

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**Table 1** Characteristics of the radiation oncology outpatient sample ( $n = 145$ )

| <b>Characteristic</b>                            | <b><i>n</i> (%)</b>    |
|--|------------------------|
| <b><i>Males</i></b>                              | 68 (47%)               |
| <b><i>Age group</i></b>                          |                        |
| 18-49  | 27 (19%)               |
| 50-59  | 38 (26%)               |
| 60-69  | 46 (32%)               |
| 70+  | 34 (23%)               |
| <b><i>Australian born</i></b>                    | 107 (74%)              |
| <b><i>Perceived palliative treatment aim</i></b> | 11 (7.7%)              |
| <b><i>Cancer type</i></b>                        |                        |
| Breast   | 53 (37%)               |
| Prostate   | 28 (19%)               |
| Head and neck                                    | 13 (9.0%)              |
| Brain  | 7 (4.8%)               |
| Colorectal                                       | 7 (4.8%)               |
| Melanoma   | 5 (3.4%)               |
| Other  | 28 (19%)               |
| Don't know                                       | 4 (2.8%)               |
| <b><i>Usual place of residence</i></b>           |                        |
| Major cities                                     | 114 (79%)              |
| Inner regional                                   | 14 (9.7%)              |
| Outer regional, remote or very remote areas      | 16 (11%)               |
| <b><i>Living with:</i></b>                       |                        |
| With husband/wife/partner                        | 71 (49%)               |
| Children   | 35 (24%)               |
| Other family                                     | 8 (5.5%)               |
| Friend/s, unrelated flatmate/co-tenant           | 4 (2.8%)               |
| Alone  | 27 (19%)               |
| <b><i>Psychological distress<sup>a</sup></i></b> |                        |
| HADS possible anxiety                            | 42 (29%)               |
| HADS possible depression                         | 18 (12%)               |
| HADS possible anxiety or depression              | 46 (32%)               |
|  | <b>Median (Q1, Q3)</b> |
| <b><i>Number of radiotherapy treatments</i></b>  | 10 (4, 20)             |
| <b><i>Weeks since diagnosis</i></b>              | 31.1 (19.8, 47.1)      |

**Notes**

Due to missing values and rounding, numbers for some variables may not add to total sample size.

<sup>a</sup> Assessed using the Hospital Anxiety and Depression Scale (HADS) subscale threshold scores of  $\geq 8$

Q: Quartile

**Table 2** Level of concern about anxiety and depression among cancer patients during radiotherapy (*n* = 145)

| Level of concern    | Anxiety<br><i>n</i> , % (95% CI) | Depression<br><i>n</i> , % (95% CI) |
|---------------------|----------------------------------|-------------------------------------|
| <i>Not at all</i>   | 71, 49% (41%-57%)                | 96, 66% (58%-74%)                   |
| <i>A little</i>     | 50, 34% (27%-43%)                | 33, 23% (16%-30%)                   |
| <i>Somewhat</i>     | 12, 8.3% (4.3%-14%)              | 11, 7.6% (3.8%-13%)                 |
| <i>Very much so</i> | 12, 8.3% (4.3%-14%)              | 5, 3.4% (1.1%-7.9%)                 |