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## **Oncology patient preferences for depression care: A discrete choice experiment**

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### **Authorship**

Dr Heidi Turon, Dr Jamie Bryant, Miss Laura Wall, Professor Scott Brown and Laureate Professor Rob Sanson-Fisher were responsible for inception of the project idea and developed the study vignettes. Dr Heidi Turon was responsible for data collection. Miss Laura Wall and Professor Scott Brown conducted the data analysis. Dr Breanne Hobden was responsible for initial interpretation of the findings and drafting the manuscript. All authors contributed to iterations of the manuscript and to further interpretation of the findings. All authors have reviewed and approved the final version of the manuscript for submission.

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## Conflict of Interest

All authors declare they have no actual or potential competing interests to declare. There are no financial, personal or other relationships that have inappropriately influenced, or could be perceived as inappropriately influencing, the study that is detailed within the manuscript.

## Abstract

**Objectives:** Using a vignette-style DCE in a sample of oncology patients, this study explored: (1) The relative influence of the patient's level of concern about their depression on preferences for care; (2) The relative influence of depression severity according to a mental health checklist on preferred treatment seeking options; and (3) Whether patient age and gender were associated with depression care preference.

**Methods:** A Discrete Choice Experiment (DCE) survey of cancer patients was conducted. Hypothetical vignettes to elicit care preferences were created using two attributes; the cancer patient's level of concern about depression (a little or a great deal) and results of a mental health checklist (not depressed or very depressed). Three response options for care preferences were presented, including a: self-directed approach; shared care approach; and clinician-directed referral approach. Participants chose their most and least preferred options.

**Results:** A total of 281 cancer patients completed the survey. There was a significant association between level of concern and the most preferred option. Those with a great deal of concern about depression preferred to receive referral from their clinician more than those with a little concern about depression. Males were significantly more likely to select a self-directed approach as their most preferred option.

**Conclusions:** An oncology patient's level of concern about depression may influence the type of care they want to receive from their cancer doctor for depression. This finding has implications for depression screening in clinical practice.

**Keywords:** Cancer; Discrete Choice; Depression; Neoplasms; Oncology; Screening

## **Introduction**

### **Depression among people with cancer**

It has been estimated that 15% of patients with cancer will experience a major depressive disorder and almost 20% experience minor depression (Mitchell et al., 2011). Depression during cancer treatment can impact adherence to treatment regimens (Arrieta et al., 2013; Mausbach et al., 2015) and have a debilitating impact on a person's quality and length of life (Brown et al., 2010; Kim et al., 2014; Pinquart and Duberstein, 2010). Recent meta-analytic data found that, among patients with cancer, those who had minor or major depression had a 39% increase in all-cause mortality compared to those without depression (Satin et al., 2009). There is strong evidence for effective depression treatment for cancer patients, including antidepressant medication and psychosocial treatments (Rodin, 2014; Rodin et al., 2007). In addition, psychosocial care provision is considered a critical aspect of cancer care (Cancer Australia, 2013, 2014). It is therefore important that depression is identified and monitored among cancer patients. Despite this, studies have consistently shown that clinicians' unassisted detection of depression is sub-optimal, ranging from 6%-52% (Fallowfield et al., 2001; Gouveia et al., 2015; Newell et al., 1998; Singer et al., 2011).

### **Various tools are recommended to detect depression as part of cancer care**

Several screening tools have been developed and tested in oncology settings to assist clinical staff in assessing and monitoring depression among patients (Vodermaier et al., 2009). Commonly used tools include the Hospital Anxiety Depression Scale (HADS) (Bjelland et al., 2002), the Center for Epidemiological Studies–Depression Scale (CES-D) (Hann et al., 1999) and the Brief Symptom Inventory (BSI) (Derogatis and Melisaratos, 1983). While these tools are not suitable for diagnostic purposes, they can be used to screen for probable or possible depression, which can aid clinicians in identifying which patients may be in need of additional follow-up and/or support. Furthermore, while screening for depression as part of routine care is recommended (Mitchell et al., 2012), it is currently unclear whether this improves patients' rate of treatment seeking for depression, or decreases depressive symptoms (Carlson et al., 2010; Meijer et al., 2011).

### **Patient preferences for depression care among people with cancer**

Previous research suggests the desire to seek help for depression is low among cancer patients (Mackenzie et al., 2014; Mackenzie et al., 2018; Merckaert et al., 2010). Merckaert et al. asked a sample of cancer patients with different cancer types if they had difficulty with any psychological concerns and, if they responded that they had, asked if they would like professional support (Merckaert et al., 2010). While 69% of women and 49% of men reported moderate or high levels of anxiety and depression, only 1 in 4 women and 1 in 10 men indicated they would like psychological support. Preferences for help seeking were impacted by gender and age, however, the level of psychological distress experienced had no influence. In another study conducted with 304 cancer patients receiving radiotherapy, 54% perceived they were experiencing depression or anxiety, however, only 22% indicated they would like to receive help for this (Mackenzie et al., 2014). Only the patient's perception about whether they were experiencing mild to severe depression was associated with preferences for greater help-seeking; their score on the HADS had no effect. Similarly, a study examining 172 cancer patients found that HADS depression scores only accounted for 12% of the variance in

help-seeking preferences (Baker-Glenn et al., 2011). While screening tools are intended to be a proxy indicator for a possible diagnosis of depression, these tools do not include items to measure preferences for help. It is likely that other factors, such as patient perceived severity or level of concern about their distress, may contribute to a patient's preferences for support.

### **What influences patients' preferences for depression care?**

Understanding the factors that influence cancer patients' preferences for depression help-seeking may be useful in identifying these individuals within routine clinical practice. For instance, previous research has suggested that patients may perceive feelings of depression as a normal part of the cancer process and believe that they do not need help, that seeking help for their mental health is not a priority, or that seeking help will not benefit them (Mackenzie et al., 2015; Merckaert et al., 2010). This suggests that, although patients may be aware that they are experiencing depression, they may not be concerned about their symptoms and thus not seek help for them. Alternatively, previously experiencing a depressive illness or having a family history of depression is a strong predictor for experiencing depression following a cancer diagnosis (Dauchy et al, 2013; Hill et al, 2011). Therefore, previous psychiatric history may also influence preferences for assistance. Further information on what contributes to help-seeking preferences could inform new strategies for engaging with patients who may be resistant to more formal care provision. To date, screening tools have been the dominant way to determine when a patient may require support for depression, while the effect of patients' level of concern about their depression on care preferences has had little exploration in the cancer field.

### **Using discrete choice experiments to examine preferences for depression care**

Discrete choice experiments (DCEs) are a robust method of assessing strengths of individual preferences (Louviere, 2001; Ryan, 2004). DCEs involve presenting participants with different hypothetical scenarios consisting of varying attribute levels (i.e. different characteristics) to elicit participants' preferences (Lancsar and Louviere, 2008; Louviere, 2001). When used to assess preferences, DCEs can reduce measurement bias and also the burden on participants, compared with methods such as rating scales or interviews. Participants find the yes/no procedure in DCEs easy to understand and interpret, and the requirement to make a choice helps avoid problems associated with the subjective interpretation of labels placed on rating scales (Jones et al., 2015). No previous studies have used a DCE design to explore the preferences of help seeking for depression among oncology patients.

### **Aims**

Using a vignette-style DCE in a sample of oncology patients, this study explored:

- (1) The relative influence of the patient's level of concern about their depression on preferences for care;
- (2) The relative influence of depression severity according to a mental health checklist on preferred treatment seeking options; and
- (3) Whether patient age and gender were associated with depression care preference.

## **Methods**

**Design:** A cross sectional survey study.

**Participants:** Oncology patients were drawn from an existing database developed by the research team. The database consisted of patients who had previously participated in a large study involving 19 cancer treatment centers across Australia (Carey et al., 2018). Participants who indicated willingness to be contacted to participate in future research were included in the database. To be eligible to participate in this study, participants had to: have received a confirmed diagnosis of cancer in the past; be aged 18 years or older; and be able to complete an English survey. There were no restrictions based on cancer type or stage, or the presence of depression symptoms.

**Procedure:** Participants were identified through the research database. Participants were sent a letter from the research team that provided information about the study, indicating that a formal invitation to participate would be circulated in three weeks. This provided an opportunity for potential participants to opt out of the study if they did not wish to participate in further research. A study package, including an information sheet, the survey, and a reply paid envelope, was mailed approximately three weeks later. A reminder letter with a second copy of the survey was sent out if the participant did not return the survey within three weeks. A second reminder was issued after a further three weeks via a telephone call, if a telephone number was listed. Implied consent was obtained via return of the survey to the research team.

**Development of the DCE:** DCEs for 4 different topics were developed. Participants were allocated two topics to answer according to a counterbalanced Latin square design. This paper will report on the data from one of the topics (preferences for depression care). The depression care DCE content (attributes and levels), format and presentation style was reviewed by an advisory panel, including: health behavioral scientists; psychologists; and cancer care providers. Consensus on the content and format of items was reached within the review, with attribute levels hypothesized to be associated with mild to moderate preference strength. Items and format were then tested with a convenience sample of 20 medical oncology outpatients.

One attribute described the (hypothetical) level of concern caused by the patient's depression and had two levels: either 'a little concern' or 'a great deal of concern'. The second attribute described the (hypothetical) results of a 'health checklist' completed by a healthcare provider and also had two levels: either 'not depressed' or 'very depressed'. By fully crossing the levels of each attribute, four vignettes were created. Participants were allocated to receive one of these vignettes, using block randomization.

**Outcome measures:** The discrete choice involved choosing between three care options, as shown in the example in **Figure 1**. These consisted of a self-directed approach (Option A: Your doctor does not talk to you about depression, and instead leaves it up to you to decide whether to seek help for your depression); a shared care approach (Option B: Your doctor talks with you about the different options for getting help for depression and gets your support to try a treatment you're comfortable with); and a clinician-directed referral approach (Option C: Your doctor talks with you about getting help for depression and provides you with a referral to a health professional such as a psychologist or counsellor). The options were the same across all vignettes, and participants were prompted to choose their *most* and *least* preferred options.

*Demographics.* The following participant characteristics were provided via self-report: age; gender; education; home post code; and employment status. Disease and treatment variables were also self-reported, including: cancer type; perceived stage of disease at diagnosis; time since diagnosis; treatments received; and stage on the cancer treatment trajectory.

<<Insert Figure 1 here>>

**Ethical approval:** This research was approved by the University of Newcastle Human Research Ethics Committee (H- 2015-0285) and the Australian Institute of Health and Welfare (EO2015/4/203).

**Statistical analysis:** Analyses included summary statistics of demographic variables and frequency and contingency tables for the choices, assessed for significance with a chi square test of independence and a 2-sample test for equality of proportions (R prop.test) (R Core Team, 2017). All tests were conducted in R version 3.4.1 using packages eeptools (for recoding of demographic data) and fifer (for post-hoc chi-square tests). All p-values reported from exploratory post hoc tests have been corrected for familywise error. The p-value for hypothesized comparisons remains unchanged.

## Results

### Sample

A total of 947 potential participants were identified and invited to participate. Of these, 28 were deceased (3%), and 206 opted out or were unable to be reached (22%). Of the remaining 713 invited participants, 358 received the depression DCE and 281 completed the survey (78%). On average, participants were aged 65.3 years (SD=11.9), 56% were female and 40% reported they had been diagnosed with hematological cancers. The full participant characteristics can be found in **Table 1**.

<<Insert Table 1 here>>

There was a significant difference in the preferred option across all vignette attribute levels ( $\chi^2 = 66.978$ , 2 df,  $p < 0.001$ ). Regardless of an individual's level of concern about depression or the level of depression according to a standardized checklist, the shared care approach and clinician-directed referral approach were both more than 4 times as likely to be preferred compared to that of the self-directed approach.

### Attribute influence on preferred treatment seeking option for depression

There was a significant association between the level of concern about depression (great deal vs little) and the most preferred option ( $\chi^2 = 6.7513$ , 2 df,  $p = 0.0342$ ). There was no significant association between level of concern and the least preferred option ( $\chi^2 = 1.1838$ , 2 df,  $p = 0.5533$ ). Post hoc comparisons of the most preferred option by level of concern revealed a significant association when comparing options A and C ( $p=0.0378$ ). Option A, a self-directed approach was preferred more by those with a little concern compared to those with a great level of concern (14.2% vs 5.9% respectively); however, the reverse was true for Option C, the clinician-directed approach. Those who had a great deal of concern preferred a

clinician-directed referral approach more than people with a little concern (51.9 % vs 40.4% respectively).

There was no significant association between level of depression (not depressed vs very depressed) with the most preferred option ( $\chi^2 = 3.2848$ , 2 df,  $p = 0.1935$ ) or the least preferred option ( $\chi^2 = 0.30759$ , 2 df,  $p = 0.8574$ ).

### **Patient demographics associated with care preference**

There was no effect of age group ( $\leq 65$  vs  $> 65$ ) on the most preferred option across all attribute levels ( $\chi^2 = 0.17735$ , 2 df,  $p = 0.9151$ ). There was a significant effect of gender on the most preferred option across attribute levels ( $\chi^2 = 6.5256$ , 2 df,  $p = 0.03828$ ). Post-hoc tests revealed that males were significantly more likely than females to select a self-directed approach as their most preferred option (16% vs 6.3%, adj  $p=0.032$ , raw  $p=0.01$  one-tailed). A significant effect of gender was also found for the least preferred option ( $\chi^2 = 14.134$ , 2 df,  $p < 0.001$ ). Planned comparisons revealed that males were more likely to least prefer a clinician referral approach (18.1% of males vs 3.7% of females,  $p < 0.001$ ) and females were more likely to least prefer a self-directed approach (95.5% of females vs 79.8% of males,  $p < 0.001$ ).

## **Discussion**

This is the first study to explore potential influences on oncology patients' preferences for depression care using a DCE design. When presented with hypothetical scenarios designed to elicit depression care preferences, patients were more likely to prefer a shared care approach (Option B) or a clinician-directed referral approach (Option C) compared with a self-directed approach (Option A) to care, regardless of patient perception of concern about depression or the results from a standardized checklist. While this finding differs when compared to previous research that indicates low rates of desire for psychological support among oncology patients in non-hypothetical situations (Mackenzie et al., 2014; Mackenzie et al., 2018; Merckaert et al., 2010), it is consistent with previous research examining hypothetical preferences for help (Mackenzie et al., 2015). Mackenzie et al. found, among 145 radiation therapy outpatients, 60% of patients indicated that if they were experiencing depression or anxiety they would want to discuss this with their cancer doctor (Mackenzie et al., 2015). It is therefore possible that hypothetical scenarios about depression result in higher reported rates of preferences for help than actual preferences. This may be due to a variety of reasons, including those that actually experience depression having a perception that: feeling depressed is a normal part of the cancer process; seeking help for mental health is not a priority; they will be stigmatized for having a depressive illness; or seeking help will not have any benefits (Baker-Glenn et al, 2011; Mackenzie et al., 2015; Merckaert et al., 2010).

### **The impact of attributes on preferences for care**

When examining the preferences for care for the attribute 'level of concern', it was found that those with hypothetically high levels of concern regarding their depression were more likely to prefer the clinician-directed approach over the self-directed approach. However, the level of depression as indicated by a standardized checklist had no impact on patient's responses for the most or least preferred approach to care. Previous research has also shown little

association between standardized depression instruments on preferences for help. For instance, while Mackenzie et al. found anxiety scores according to the HADS influenced help seeking preferences, no association was found for HADS depression scores (Mackenzie et al., 2015). Another study, examining 172 cancer patients, performed path analysis and found that collectively the HADS score and distress thermometer score explained only 42% of the variance in help-seeking preferences (Baker-Glenn et al., 2011). The HADS depression score, specifically, only contributed 12% of this variance and was not statistically significantly associated with preferences. Merckaert et al. also found the general level of psychological distress according to HADS did not impact preferences for help seeking (Merckaert et al., 2010). While it is possible that participants conceptualized a broader concept of distress when reading the hypothetical vignettes, the vignettes were specifically focussed on the construct of depression by providing a lay definition of depression and using the term depression throughout (see Fig 1.)

To the authors' knowledge, no research has examined whether a patient's level of concern for their depression influences their treatment seeking preferences in non-hypothetical scenarios. While one study did examine patients' level of concern about their depression, there was no analysis of whether this influenced help seeking preferences (Mackenzie et al., 2014). Our findings suggest that a person's level of concern about depression influences their preferences for care more than the results of a standardized screening instrument that provides an assessment of the severity of possible depression. It is important to note that there is likely to be a relationship between these two attributes in a real world scenario, i.e. if someone indicates high levels of depression on a standardized instrument, they may also be experiencing concern about these issues. However, considering the link between psychological distress and help seeking has been difficult to establish (Baker-Glenn et al., 2011; Mackenzie et al., 2015; Merckaert et al., 2010), the findings from this study indicate that a patient's level of concern about their depression should be considered in conjunction with screening instruments. Approaches for dealing with discrepancies between the patient's level of concern and the results from a screening instrument may also need to be considered. For example, if the patient shows little concern but their screening results indicate they are at risk for possible depression, the health professionals involved in their care may need to consider educating the patient on the impact depression may have on their quality of life and ensure they are well informed of management strategies.

### **The impact of demographic characteristics on preferences for care**

There was a significant effect found for gender indicating that males preferred a self-directed approach to depression care more often than females, regardless of level of concern and results of a mental health checklist. This finding aligns with previous non-hypothetical literature indicating gender differences in mental health help-seeking and treatment engagement between males and females (Corney, 1990; Galdas et al., 2005). It has been stipulated that the differences in help seeking between genders is not due to males experiencing better mental health, but rather different perceptions in social and gender norms in asking for help (Möller-Leimkühler, 2002). It may, therefore, be more common for men to indicate they have little concern about depression while experiencing exacerbated symptoms. Addressing this gap between individual perception of health and health according to a standardized instrument may be of particular importance for better engaging males in mental health treatment. Ensuring males are able to recognize symptoms and understand how mental

health problems, such as depression, can impact their health and well-being is therefore important (Lizardi and Stanley, 2010).

### **Limitations**

The findings of this study should be considered in light of several limitations. Firstly, the scenarios provided in the DCEs were hypothetical and therefore the findings may not translate to real world situations for oncology patients. Furthermore, the novelty of the DCE is that it is able to target very specific attributes and examine whether they influence participant choices, however, targeting specific attributes doesn't allow for understanding other attributes that may have contributed to participant choices, such as cancer type or prognosis. This study did not have the statistical power to examine all patient characteristics to determine which may have influenced participant choices. Examining other attributes that may impact cancer patients' choices should be considered by future researchers. It should also be noted that there was a selection bias in the sample. The majority of participants had been originally diagnosed with early-stage cancer, treated with an intention of cure and were at least 2 years post-diagnosis. Therefore, the sample is not generalizable to all cancer patients and it is important for future researchers to explore whether this finding translates to oncology patients at other stages of their illness. Actual level of depression was also not measured in this study, so evaluating whether the results differed between those with depression and those without was not possible.

### **Research and clinical implications**

As outlined above, the findings from this study indicate a need for further research examining patients' level of concern about their depression and how this impacts their preferences for how they receive support. Future research could consider using a similar design to that used in the current study, but examine actual levels of depression and concern as predictor variables. Exploring the non-hypothetical relationship of level of concern among oncology patients can help determine if this attribute contributes to the gap between experiencing depression and help-seeking. If level of concern does mediate this relationship, intervention strategies will be needed to test effective ways of educating patients on their mental health experiences to ensure those in clinical settings are able to get the care they require.

### **Conclusion**

The findings from this DCE study indicate that level of concern may be an important mediating influence on whether oncology patients want clinician-directed help for their depression. This may have implications for depression screening in clinical practice and determining whether patients are interested in seeking help. Given that males were more likely to prefer a self-directed approach to depression care than females, ensuring males are aware of the importance of seeking help for depression is another avenue that requires further exploration to reduce the impact of depression on oncology patients.

## **Acknowledgements**

None

## **Conflict of Interest**

All authors declare they have no actual or potential competing interests to declare. There are no financial, personal or other relationships that have inappropriately influenced, or could be perceived as inappropriately influencing, the study that is detailed within the manuscript.

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**Table 1. Participant demographics (n=281)**

	<b>N (%)</b>
<b>Sex</b>	
Male	125 (44%)
Female	156 (56%)
<b>Highest level of education completed</b>	
Primary school (Year 6)	11 (4%)
High school (Year 10 or Year 12)	94 (34%)
Trade or vocational training (e.g. TAFE or college)	100 (36%)
University degree	68 (24%)
Other	5 (2%)
<b>Current employment</b>	
Retired or mature age pension	131 (47%)
Full-time work	49 (18%)
Part-time or casual work	48 (17%)
Disability pension	25 (9%)
Home duties	16 (6%)
Unemployed	6 (2%)
Other	3 (1%)
<b>Type of cancer</b>	
Hematological or blood cancer (e.g. leukemia, lymphoma, myeloma)	110 (40%)
Breast	90 (32%)
Colorectal	23 (8%)
Two or more cancers	11 (4%)
Prostate	10 (4%)
Lung	7 (3%)
Melanoma	3 (1%)
Other	23 (8%)
<b>Stage of cancer when first diagnosed</b>	
Early	197 (71%)
Advanced or incurable	61 (22%)
Don't know	21 (8%)
<b>How long ago were you diagnosed with cancer?</b>	
0-12 months	2 (1%)
More than 1 year but less than 2 years ago	7 (3%)
Between 2 and 5 years ago	144 (52%)
More than 5 years	124 (45%)
<b>Where are you in your cancer journey?</b>	
I haven't had any treatment, 'watch and wait' only	15 (5%)
I am receiving treatment to try and cure my cancer	26 (9%)
I have completed treatment to cure my cancer and am now in follow-up	186 (67%)
Told my cancer cannot be cured and am receiving anticancer treatment	39 (14%)
Told my cancer cannot be cured and am <u>not</u> receiving anticancer treatment	10 (4%)