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Cancer patient preferences for the provision of information regarding emotional concerns in relation to medical procedures: A discrete choice experiment

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Abstract

Objective: To explore the preferences of people with cancer regarding the timing and format of information provision about emotional concerns that may occur when undergoing medical procedures.

Methods: Eligible cancer survivors were mailed a survey containing discrete choice scenarios examining their timing and format preferences for information about potential emotional concerns associated with an upcoming hypothetical medical procedure.

Results: Of 356 eligible patients, 271 (76%) completed the survey. Both face-to-face discussion and written materials were preferred as the mode of information delivery over access to a website. In order of descending preference, participants preferred to receive the information 1 week, 3 days and the day of the procedure. There were no differences in preferences for timing or format between subgroups based on age, gender, education and cancer type.

Conclusion: This study has demonstrated that cancer patients prefer receiving information about emotional concerns that might be experienced as part of a medical procedure in either written or via face-to-face format, and one week before the procedure.

Practice Implications: In order to provide patient-centred care, clinicians and the healthcare system more broadly should consider patient preferences for information delivery about upcoming medical procedures.

Keywords:

information; preparation for medical procedures; discrete choice; oncology; patient preference; emotional response

1. Introduction

While undergoing diagnostic investigations and treatment for cancer, patients are faced with the prospect of various medical procedures that may be associated with pain, discomfort, and anxiety [1-3]. A number of clinical and consensus guidelines [4-6] detail how healthcare providers can assist in preparing patients for treatment. Recommendations include: assessing the patient's preference for information; providing both procedural and sensory information; and psychosocial aspects such as discussing the patient's emotions and coping strategies [4-6].

Despite this, patients with cancer commonly report a lack of information and preparation for medical procedures, with high levels of pre-treatment anxiety suggested as a likely result of patients being poorly informed regarding upcoming treatment [7]. Patients who report feeling poorly informed prior to treatment are more likely to report increased levels of distress and anxiety, occurring prior to, during and following the procedure [8, 9].

Information can be provided verbally by the healthcare provider or health educators, and supplemented with written, video or online information [10]. Several reviews have explored patient preferences for information delivery regarding treatment, and found patients' preferred information format and timing vary at different stages in the disease pathway [11, 12]. Whilst systematic reviews of patients' preparation for cancer treatments including chemotherapy and radiotherapy [13] and surgery [14] have found evidence that providing preparatory information improves some patient outcomes (such as increasing satisfaction and knowledge and reduces anxiety), both reviews concluded that the optimal format and timing of delivery of preparatory information for cancer patients requires further investigation.

A key feature of patient-centred care is the provision of information in line with patient preferences [15]. Discrete choice experiments (DCEs) provide a pragmatic way of exploring patient preferences across a number of key attributes that are theorised to influence their decision. DCEs have been used to explore cancer patients' preferences for a variety of topics [16-19].

Previous research has shown that cancer patients are more commonly provided with procedural information as opposed to information about emotional concerns prior to undergoing treatment [20]. Consequently, this study will explore cancer patients' preferences for the format and timing of information regarding possible emotional concerns that may arise from a hypothetical medical procedure.

2. Methods

2.1 Setting and design

A cross-sectional survey was undertaken in a sample of cancer survivors from across Australia.

2.2 Recruitment and description of sample:

Survivors who had previously participated in a study examining psychosocial wellbeing in cancer patients (see Carey et al. [21] for a description of the study methodology), and who had indicated a willingness to be contacted regarding relevant future studies were eligible to be participate. Eligibility criteria for the previous study included: a confirmed diagnosis of cancer at any stage across the cancer trajectory, aged 18 years or older, and English speaking.

2.3 Recruitment

Eligible participants were mailed a primer letter regarding the study. Approximately 3 weeks later, participants were mailed an information sheet and a survey. Return of a completed survey was taken as implied consent. Participants were mailed a reminder letter and another copy of the survey if they had not returned it after 3 weeks. A reminder phone call was made to non-responders after a further 3 weeks. This research was carried out in accordance with The Code of Ethics of the Declaration of Helsinki and received institutional ethics committee approval from the University of Newcastle. No incentive was offered to participants for completion of the survey.

2.4 Measures

2.4.1 Medical Procedure Information DCE

Participants were invited to complete a series of discrete choice scenarios examining their preferences for receiving information about a hypothetical medical procedure. Participants were informed that it is common for patients to experience emotional concerns when undergoing a medical procedure, and that doctors have a role in proactively addressing these concerns. Participants were presented with three different options of how information could be delivered, and asked to choose which option they MOST preferred, and which they LEAST preferred (see Supplementary Appendix 1). Each option consisted of 2 attributes, each which had one of three alternatives shown (Table 1).

Table 1: Summary of Attributes and Levels for Discrete Choice Experiment

Attribute	Level A	Level B	Level C
Format of information	Your doctor discusses with you the emotions you may feel before, during and after your procedure; as well as discusses with you some strategies on how you may deal with these emotions.	Your doctor discusses with you and provides you with written pamphlets describing the emotions you may feel before, during and after your procedure; as well as provides you with some strategies on how you may deal with these emotions.	Your doctor provides you with access to an online website, which has written and video information about the emotions you may feel before, during and after your procedure; as well as some strategies on how you may deal with these emotions.
Timing of information delivery	You receive the information 1 week before the procedure.	You receive the information 3 days before the procedure.	You receive the information the day of the procedure, just before it is undertaken.

Each DCE was constructed by combining the different alternatives of the 2 attributes in a fully crossed design, resulting in 18 possible combinations. Participants were randomly allocated 3 of these combinations.

2.4.2 Demographic and disease variables

Participants were asked to report their age, gender, education, home post code, and employment status. They were also asked to indicate their cancer type; perceived stage of disease at diagnosis (early vs advanced); time since diagnosis; treatments received; and where they were on the cancer trajectory. Response options for these items are detailed in Table 2.

2.5 Statistical Analysis

Data were analysed in R version 3.4.1 [22]. Initial analyses included summary statistics of demographic variables and frequency and contingency tables for the choices. Inferences regarding the influence of the different information attributes on choice of scenario were examined using cumulative link models to predict choices (for most-preferred scenarios) using attribute levels as predictors [23]. A probit link function was used, corresponding to a Gaussian assumption for a random utility model of preferences. This assumption does not imply that any observed data are normal, but rather that internal psychological preference strengths are normally distributed. This is a standard assumption, for example in signal detection theory, random utility models, and most Thurstonian models [24]. The relative influence of different attributes on choice was quantified by the standard coefficients estimates in these models (z-scores, also known as beta coefficients). A main effects model with no interactions was selected, based on a balance of model fit and flexibility, informed by the Bayesian information criterion [25].

3. Results

356 eligible participants received a survey containing the medical procedure DCE, and 271 returned a survey (consent rate = 76%). Approximately 42% of responders required a reminder letter and/or phone call. Forty percent of participants were male (n=108), and the mean age was 64 years (SD = 12 years, range: 22-95 years). Key sociodemographic and treatment characteristics are shown in Table 2.

Table 2. Demographic and disease characteristics of the study sample (N=271)

Characteristic		Total n (%)
Education completed	High school or below	98 (36%)
	Vocational, University, other	170 (63%)
Employment status	Paid employment	103 (38%)
	Not in labour force, unemployed, other	165 (61%)
Type of cancer	Breast	95 (35%)
	Colorectal	26 (9.6%)
	Haematological/blood (eg Leukaemia, lymphoma)	87 (32%)
	Prostate	16 (5.9%)
	Lung	6 (2.2%)
	Other	34 (13%)
Stage at diagnosis	Early	191 (70%)
	Advanced or incurable	58 (21%)
	Don't know	14 (5.2%)

Time since diagnosis	Within the last 5 years	143 (53%)
	More than 5 years	122 (45%)
Treatments Received [^]	Surgery	165 (61%)
	Chemotherapy	222 (82%)
	Radiation Therapy	146 (54%)
	Hormone Therapy	81 (30%)
	Biological Therapy	39 (14%)
	Bone marrow or stem cell transplant	35 (13%)
	No treatment, "watch and wait" only	5 (1.8%)
	Other	6 (2.2%)
Stage of Cancer Journey	No treatment yet, "watch and wait" only	11 (4.1%)
	Receiving treatment to try and cure cancer	24 (8.9%)
	Completed treatment to cure cancer and in follow-up	180 (66%)
	Told cancer cannot be cured and receiving anticancer treatment	38 (14%)
	Told cancer cannot be cured and not receiving anticancer treatment	12 (4.4%)

Note: Totals may not add up to 100% due to missing values.

[^] participants could select multiple responses

<insert Figure 1 here>

As can be seen in Figure 1, there was a significant effect of information format. Participants had no clear preference for receiving information in person as opposed to written information ($p = .814$), however, both options were strongly preferred to receiving information via a website ($p < .001$). Participants were 40 times less likely to choose an option with information delivered via website, compared to written information.

The results also showed that there was a significant effect of timing. Participants preferred receiving information 1 week before the medical procedure compared to 3 days before ($p < .001$), which in turn was preferred to receiving information on the same day as the procedure ($p < .001$).

We also explored whether variables including age, gender, highest level of education completed and cancer type (haematological versus non-haematological) influenced participant's preferences for format and timing of medical procedure information. The pattern of response did not differ between subgroups (data not shown).

4. Discussion

4.1 Discussion

This study explored the effect of timing and modality on the preferences of cancer patients for receiving information about the emotional concerns potentially associated with a medical procedure. We found that patients did not have a clear preference for receiving information in person from the healthcare provider, or in a written format. However, both modalities of communication were preferred compared to receiving information via a website. This finding is in

contrast to other studies which have identified a patient preference for face-to-face or telephone delivery of information over written information. The difference in our findings may be attributable to the wording of the response option for written information, which also mentioned a discussion with the doctor (see Table 1). The finding that participants least preferred information via a website also somewhat surprising given that the proportion of cancer patients who report searching the internet for health-related information related to their diagnosis and treatment is high [26]. This finding may be influenced by the average age of participants (64 years). Previous research has shown that older adults are less likely to access the internet for health information [27]. Web-based delivery of information has many benefits such as; the ability to update information regularly at low cost, inclusion of information in multiple modalities (written, auditory, visual), and the possibility of providing links to other websites. Given the financial and resource constraints facing many healthcare systems, it is important to explore cost efficient and flexible methods of providing patient centred care. Future research could aim to explore methods for improving acceptability of web-based information amongst older cancer patients, or less resource intensive methods of delivering information in a written or face-to-face format.

With regard to the timing of information, patients showed a clear preference for receiving information earlier, rather than closer to their procedure. Receiving information 1 week before the procedure was preferred to receiving information 3 days before the procedure, which in turn was preferred to receiving information the day of the procedure. The time periods chosen were selected as they have high ecological validity, representing points at which patients may have an interaction with a healthcare provider regarding a procedure (depending on that nature of the procedure). Given the lack of previous studies exploring patient preferences for when information is received prior to a procedure, this result provides a novel contribution to the literature. It is possible that patients would prefer to receive information even earlier than 1 week prior to a procedure, and this could be explored in future studies.

Several limitations with this study should be noted. Firstly, this study included a heterogeneous group of cancer patients in terms of diagnosis. While this is a strength in terms of generalisability, the majority had completed treatment and were in follow-up, and almost half were more than 5 years post diagnosis. Further research will be required to determine if recently diagnosed patients and those actively receiving treatment have similar preferences to this group. We also did not examine whether personal experience impacted patient preferences. For example, some participants may have undergone a variety of cancer treatment procedures which they could recall when imagining the hypothetical medical procedure. Related to this, when participants were asked to imagine preparing for a medical procedure (of which surgery and chemotherapy were given as examples), we acknowledge that participants may have reflected on alternative and potentially non-cancer related procedures, which may have influenced their responses. Finally, due to the way the attributes were worded, we cannot determine whether the implied lack of discussion with their doctor about the information in the “online” format contributed to patients preferring this option the least. Future research will be needed to further explore this possibility.

4.2 Conclusions and implications

The findings of this study suggest that patients prefer to receive information about the emotional aspects of a medical procedure 1 week before the procedure, and from the clinician or via written

materials. Increased preference for internet delivery of information may occur over time as the proportion of older adults using the internet for health related purposes increases. This is the first study that we are aware of that has elicited patient preferences for the timing and format of emotional needs information in relation to medical procedures. In order to deliver patient-centred care, healthcare providers and the healthcare system more broadly, should consider patient preferences for information delivery.

CRedit author statement

Heidi Turon: Investigation, Writing- Original draft preparation, Visualization, Project Administration.

Laura Wall: Methodology, Formal Analysis, Writing- Original draft preparation, Visualization. **Kristy**

Fakes: Visualization, Writing- Original draft preparation. **Scott Brown:** Methodology, Formal

Analysis, Writing – Review and Editing, Supervision. **Rob Sanson-Fisher:** Conceptualization,

Methodology, Writing – Review and Editing, Supervision, Funding Acquisition.

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