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Short communication

An exploratory study of cancer patients' views on doctor-provided and independent written prognostic information

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Abstract

This is the first study to systematically compare cancer patients' views on prognostic information provided by their doctor and written prognostic information obtained from a major cancer organisation (The Cancer Council New South Wales). Twenty-six adult patients who were recruited from a cancer clinic and an oncologist's private rooms completed a questionnaire and an interview. Participants varied in their views about the relative accuracy of doctor-provided and independent written information and responses to contradictory information. Participants' need for certainty, trust in their doctor and concerns about the effect of undermining that trust, appear to influence whether they would discuss independent information with their doctor, and how they would deal with conflicting information. Although preliminary, this study has identified a number of issues that may need to be taken into account both by people developing written prognostic information and by doctors, who may need to address patient concerns about trust to assist patients to deal with conflicting information.

Keywords: Prognosis; Trust; Patient–clinician relationship

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1. Introduction

Cancer patients want to receive information about their prognosis [1–5], but many report receiving inadequate information [6–8]. Thus patients are turning to sources other than the healthcare professionals responsible for their care for information about their illness [6,9,10]. Two popular alternative sources are the Internet and printed materials such as booklets. The Internet is increasing in its popularity as a source of information about cancer. In the United States cancer is the second most common illness for which information is sought on the Internet [11], with 21–53% of cancer patients using the Internet for this reason [6,12,13]. In a recent Canadian survey, a small proportion of patients (7%) reported that the Internet was their primary source of information about their illness [6].

The rise in the use of the Internet as a source of cancer information is concerning given the variability in the quality and accuracy of information on the Internet [14–19]; the lack of distinction between peer-reviewed scientific data, anecdotal information, personal stories and chat groups [20]; the potential for information to conflict with doctors' advice; the readability of the information [21]; and the effect of information on decision making [22–25]. These problems are compounded by patients' inadequate search strategies and lack of critical review skills [26] and the ability of anyone with access to the Internet and some technical knowledge to set up their own website and supply information to the public.

Of particular concern is the reluctance of most patients to discuss *treatment* information they obtain from other sources with their doctor [27]. Patients who trust their doctor are more likely to discuss *treatment* information they obtained from a cancer organisation with this doctor [27], but it is not known whether patients would discuss with their doctor *prognostic* information they obtain from an independent source, nor what they would do if there were differences in information provided by the two sources. We searched the literature and found no published study on patients' views about doctor-provided and written *prognostic* information obtained from a source other than a doctor.

This study was part of a larger study of cancer patients' views on the provision of independent written prognostic information by a state cancer organisation (The Cancer Council New South Wales) [28]. As this is a relatively unexplored area, a qualitative methodology involving a broad cross-section of cancer patients was used. We report here

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the breadth of cancer patient views on the relative accuracy of doctor-provided and independent written prognostic information; their expected responses should the information from these sources differ and their opinion on factors that have affected their views on information from these two sources.

2. Patients and methods

2.1. Participants

Participants were cancer patients aged 18 years or older, who were capable of completing a questionnaire and face-to-face interview in English.

2.2. Measures

2.2.1. Demographic questionnaire

This self-administered questionnaire elicited information on participants' age, gender, martial status, highest level of education completed, current or last employment occupation, diagnosis, time since diagnosis and treatment received.

2.2.2. Interview

The in-depth, face-to-face interview used semi-structured questions and detailed probes to elicit participants' views on whether they would discuss with their doctor prognostic information they had obtained from a booklet produced by, or the website of, The Cancer Council. To give patients an idea of the information they might get from such a booklet or website, they were shown paper examples of survival statistics that The Cancer Council produces from The New South Wales Central Cancer Registry during the interview (these examples are described elsewhere [28]). They were asked the reasons why they would or would not discuss this information with their doctor; how they would feel, and what they would do if the information in The Cancer Council's booklets or on its website was different to the information their doctor gave them; and whether, and how, this differing information would affect their relationship with their doctor.

2.3. Procedure

Two medical oncologists recruited patients, one through his private rooms in a regional centre and the other through a public cancer clinic in a large city. Thus both regional and urban patients' views were represented. Interested patients received an information package from their doctor and were asked to return the consent form to the first author (HD), who then arranged an interview at a place convenient to them. Participants completed a questionnaire eliciting demographic and disease information, followed by an in-depth, face-to-face interview. The interview provided patients with examples of statistical information about survival from cancer. As this is a relatively unexplored area, a grounded theory approach was employed [29], where new concepts emerging in one interview were explored in subsequent interviews. Such an approach is consistent with the semi-structured nature of the interviews and allowed the authors to fully explore the range of issues mentioned by participants.

HD and PB independently reviewed and then discussed the first five tapes. No changes were made to the interview questions reported here. After 26 interviews, a further review of the tapes showed that information redundancy had been reached in the last three interviews and data collection ceased.

HD analysed the transcripts using the constant comparative method [30], which involves comparing and contrasting participant responses to identify recurring ideas and themes. Once completed, HD and PB met to review the analysis and any differences in opinion were resolved by discussing each difference in turn. There were no instances where the difference in opinion was not resolved.

The Ethics Committees of The Cancer Council New South Wales (CCNSW), The Central Sydney Area Health Service and The University of Sydney and The Internal Research Review Committee of The CCNSW approved this study.

3. Results

3.1. Participants

Thirty of 53 eligible patients agreed to participate with 26 completing an interview. Two patients became too ill and two were unavailable in the study period. For ethical reasons demographic data and reasons for refusing to participate were not elicited from those who declined to participate. There were 15 women and 11 men. Five participants were less than 50 years old, 15 were 50–69 years, and six were 70 years or older. The mean age was 60 years and the median 63 years. Half had more than 10 years schooling. Thirteen were married or in a defacto relationship. Participants had been diagnosed with 11 different types of cancer, the largest single number of participants having breast cancer (seven). No more than three participants had any other single type of cancer. Eleven participants had been diagnosed within the past year and six more than 5 years ago. Twenty participants had undergone chemotherapy, 15 surgery and 9 radiotherapy. Ten patients were from a regional area and 16 were from a metropolitan area. Nineteen participants were recruited from the public cancer clinic and seven from the oncologist's private rooms. There were no significant demographic differences between participants from regional and metropolitan areas or between participants recruited from these two sites, except that patients recruited from the private rooms were more likely to have had surgery and chemotherapy (all these patients had undergone both treatments). Nine patients had ever used the Internet, most on a daily basis. Participants nominated lack of access, knowledge or interest, being too old and laziness as reasons for never having used the Internet.