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ORIGINAL ARTICLE

Do haematological cancer patients get the information they need about their cancer and its treatment? Results of a cross-sectional survey

Rochelle Watson[1,2,3] · **Jamie Bryant**[1,2,3] · **Robert Sanson-Fisher**[1,2,3] · **Heidi Turon**[1,2,3] · **Lisa Hyde**[1,2,3] · **Anne Herrmann**[1,2,3]

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Abstract

Purpose To explore the experiences of haematological cancer outpatients in obtaining information about their cancer and its treatment.

Methods A cross-sectional survey of adult haematological cancer outpatients was conducted. Participants completed two pen-and-paper questionnaires: the first examined demographics and disease characteristics; the second, completed four weeks later, asked about the cancer information received. Participants indicated whether they received the information they needed about medical procedures and self-management, experiences regarding doctor-patient communication, and self-efficacy in seeking information and support. Where possible, items were derived from Australian psychosocial cancer care guidelines.

Results Two hundred and ninety-three (84%) patients consented to participate, with 170 (58%) completing both questionnaires. Most participants reported receiving information in accordance with guidelines. Areas identified as requiring improvement included difficulty recalling information (28%); information overload (26%); insufficient opportunity to ask questions (23%); and insufficient information about managing anxiety related to medical procedures (20%).

Conclusion While many haematological cancer patients report receiving adequate information, there is room for improvement. Implementation of evidence-based strategies, such as decision aids or audiotapes of the consultation, may help to improve information experiences.

Practice implications A patient-centred approach to information provision is essential for ensuring information addresses the needs and preferences of the patient.

Keywords Cancer · Information provision · Patient experiences · Communication

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✉ Jamie Bryant
Jamie.Bryant@newcastle.edu.au

Rochelle Watson
Rochelle.Watson@newcastle.edu.au

Robert Sanson-Fisher
Rob.Sanson-Fisher@newcastle.edu.au

Heidi Turon
Heidi.Turon@newcastle.edu.au

Lisa Hyde
Lisa.Hyde@newcastle.edu.au

Anne Herrmann
Anne.Herrmann@newcastle.edu.au

[1] Health Behaviour Research Collaborative, School of Medicine and Public Health, Faculty of Health and Medicine, University of Newcastle, W4, HMRI Building, Callaghan, NSW 2308, Australia

[2] Priority Research Centre for Health Behaviour, University of Newcastle, Callaghan, Australia

[3] Hunter Medical Research Institute, New Lambton Heights, Australia

Introduction

Impact of a diagnosis of haematological cancer

Haematological malignancies account for approximately 9% of all annual cancer diagnoses globally [1]. In 2017, the estimated incidence of leukaemia and lymphoma in Australia was estimated to be 3875 and 6232 new cases, respectively, ranking in the top 10 most commonly diagnosed cancers [2]. A diagnosis of haematological cancer is often associated with poor survival outcomes. Common treatment options, such as bone marrow transplantation, peripheral blood cell transplantation and high dose chemotherapy, are lengthy and invasive and often lead to debilitating side effects, including fatigue, nausea, infection and bleeding [3, 4]. As a result, patients often have poor psychosocial outcomes. Approximately 20% of haematological cancer patients attending treatment centres experience clinically significant levels of anxiety and/or depression [5]. Prior to first treatment, the prevalence of anxiety increases to approximately 45% and to 25% for depression [6]. This leads to poorer quality of life, a higher number of unmet needs and greater likelihood of adverse treatment outcomes [7, 8].

Benefits of effective information provision

Patient-centred care, which is respectful of and responsive to patients' needs, values and preferences, is a central component of quality health care [9]. To enable patients to become active and engaged partners in their health care, it has been argued that patients must receive clear and explicit information regarding the options available to them [10]. Appropriate information may influence patients' treatment choice and facilitate collaborative decision-making based on the patient's informed preferences [11, 12].

Enabling informed and active decision-making

Many haematological cancer patients have to make numerous decisions along the cancer trajectory, such as choosing between alternative treatments [13, 14]. There is considerable evidence to suggest that patients who are involved in decision-making regarding their health care to the degree they want have better outcomes than those that do not, including reduced decisional conflict and increased satisfaction with care [15, 16]. Patients who are actively involved in decision-making have also been shown to have higher physical and social functioning, significantly less fatigue and improved quality of life [17–19]. However, there are numerous barriers to patient involvement in decision-making that operate at the patient (e.g. poor health, lower level of education), physician (e.g. interpersonal skills, presumptions about the patient) and system levels (e.g. lack of continuity of care, time restraints) [20].

Preparing patients for potentially threatening procedures

Poor preparation for medically threatening procedures can hinder treatment decision-making and increase patients' levels of anxiety and concerns prior to treatment [21]. It is important that patients are adequately prepared and understand the implications of their treatment decisions. For optimal care, it is recommended that a multi-disciplinary network of health care professionals provide consistent and timely information about the sensory, procedural, psychosocial and behavioural aspects of treatment [21–24]. This includes what patients will see or feel, the sequence of events, the patient's role in facilitating the procedure and how patients can best manage anxiety before, during and after treatment. The provision of such information has been found to reduce patients' levels of pain and psychological distress prior to cancer treatment [21, 25], as well as improving patients' satisfaction with care [24].

Equipping patients with self-management strategies

The delivery of preparatory information is also integral in establishing patients' skills in the self-management of ongoing side effects of treatment [24]. Self-management information, which describes what the patient can do to help themselves get well, is recognised as the fourth largest unmet need for all cancer patients [26] and one of the basic information needs of haematological cancer patients [27]. The provision of this information promotes a patient-centred approach to health care [28]. It allows patients to actively manage their own care and facilitates the acquisition of skills fundamental to the maintenance of health, including problem solving, resource utilisation, action planning and goal setting [29]. The provision of self-management information has been found to increase cancer patients' perceived level of control and to improve fatigue, depression, anxiety and quality of life [28, 29].

Various factors influence the effectiveness of information provision

Patients vary in their preferences for the type and amount of information they wish to receive, as well as the way information should be presented to them [18, 30]. Patient age, the amount of information provided, high levels of anxiety and a negative prognosis have also been shown to be associated with difficulties remembering information provided during medical consultations [31, 32]. Strategies to improve recall and understanding include categorisation and prioritisation of information, using common and concrete terms and presenting information in multiple formats, such as written, face-to-face or video information [33]. Clinical practice guidelines recommend that patients be continually informed about their disease, symptom management and service availability, and that this information be adapted to the wishes of the individual [34]. Tailoring information to the unique circumstances and preferences of individual patients can improve anxiety levels, recall of information, self-perceived preparedness for treatment and satisfaction with care [34, 35]. This is likely to be particularly important for haematological cancer patients given the diversity of diagnoses within this group, which often require complex and rapidly changing treatment regimes [36].

Aims

There is very little information from previous studies about the extent to which haematological cancer patients receive information in line with these guidelines. The aim of this study was therefore to explore the views of haematological cancer outpatients regarding their experiences of receiving and obtaining information about their cancer and its treatment.

Methods

Design and setting

A cross-sectional questionnaire of haematological cancer outpatients was conducted in three metropolitan hospitals, each treating at least 300 patients for haematological cancer per year. Participating hospitals were located in three different Australian states.

Participants

Eligible patients were adults (aged 18 years or older) who had a diagnosis of any type of haematological cancer and were attending an outpatient clinic appointment at a participating hospital in relation to their cancer. Patients were excluded if they were unable to read or write English sufficiently to complete the questionnaire, were attending their first appointment at the clinic or were unable to provide informed consent or meet the requirements of participation, as judged by clinic staff.

Recruitment

Appropriate ethics approval was obtained from the University of Newcastle Human Research Ethics Committee and the relevant governing bodies at the participating hospitals. Trained research assistants were responsible for participant recruitment and data collection at each hospital. A haematologist or nurse employed at the participating hospital assisted the research assistant to identify potentially eligible patients from the daily clinic appointment schedule. Patients identified as eligible were provided with a written information sheet and a verbal explanation of the study by the research assistant. Patients who were willing to participate were asked to complete a consent form and return it to the research assistant. To enable the examination of consent bias, the research assistant recorded the gender and age of non-consenters on a study log sheet with their permission.

Data collection

Consenting participants were asked to complete two pen-and-paper questionnaires; one at the time of recruitment and one approximately four weeks later in order to reduce patient burden and survey fatigue. The initial questionnaire was provided to participants in the clinic waiting room and included questions about participants' demographics, their cancer diagnosis and treatments received. The second questionnaire was sent to participants via mail along with a pre-addressed reply paid envelope to return their completed questionnaire to the research team. This follow-up questionnaire contained items exploring chemotherapy side effects (reported elsewhere) and experiences of receiving and obtaining information about their cancer and its treatment. A reminder letter and another copy of the questionnaire was sent via mail to participants who did not return their completed questionnaire after two weeks, with a second reminder sent following a further two weeks of non-response. All data was de-identified by the use of a unique ID number for each participant. This allowed the research team to track return rates and to link responses between the two questionnaires.

Measures

Participants were asked to indicate whether they received the information they needed in relation to preparation for potentially threatening medical procedures or treatments and self-management when leaving hospital. Items were also included to explore participants' experiences regarding doctor-patient communication, and self-efficacy regarding information and support seeking. Participants provided responses to all questions on a five-point Likert scale (1 = *strongly disagree* to 5 = *strongly agree*). A 'not applicable' response option was also available. A copy of these items is included in Appendix 1.

Development of the measure involved searching the available literature to identify existing measures related to information seeking, provision and doctor-patient communication. From this search, a list of potential domains was constructed to broadly capture the experiences of patients in receiving and obtaining information about cancer and its treatment. Guidelines for information provision to cancer patients were then mapped against these domains to identify relevant aspects of care and were used to develop individual survey items. Where no or few guidelines were available in relation to a domain, items were adapted from existing measures and created based on issues reported by clinicians and patients in previous pilot work by the authors (unpublished).

Interpersonal communication

Nine items were included to explore patients' experiences regarding the conversations they had with their doctor and family members about disease and treatment information. Items were derived from clinical practice guidelines for the psychosocial care of cancer patients [34] and experiences reported by haematological cancer patients in pilot work conducted by the authors (unpublished).

Preparation for potentially threatening procedures

Eleven items were included to examine the type of information provided to patients prior to having medical procedures or treatments. These items were directly related to the clinical practice guidelines regarding preparation for potentially threatening procedures [34] and included questions addressing sensory and procedural aspects of treatment, anxiety management and after-care.

Post-discharge self-management

Six items were included to explore information provided following discharge from hospital to support self-management of symptoms and side effects of treatment. Items were derived from the clinical practice guidelines for the psychosocial care of cancer patients [34] and recommendations from a multidisciplinary panel of experts in haematological cancer care regarding the information required by patients in the post-discharge phase.

Information-seeking self-efficacy

Four items were included to examine patients' confidence in their ability to seek support and information from family, friends and their health care team.

Demographic, disease and treatment characteristics

The following demographic, disease and treatment characteristics were reported by participants: date of birth, gender, marital status, highest level of education, employment status, country of birth, haematological cancer type, stage of disease at diagnosis, time since diagnosis and treatments received.

Statistical analysis

Statistical analyses were conducted using SAS v9.4 [37]. Age and gender of participants and non-consenters were compared to examine consent bias using F-adjusted Rao-Scott chi-square tests. Participant characteristics (age, gender, education, country of birth, cancer type) of those that completed both questionnaires were also compared with those who completed the first questionnaire only using F-adjusted Rao-Scott chi-square tests. Frequencies and percentages were calculated for each item with responses regrouped as Agree (*Strongly Agree* and *Agree*), Neutral, Disagree (*Strongly Disagree* and *Disagree*) and not applicable. Multivariate analysis to explore potential associations between patient characteristics and information experiences was not possible due to a high number of participants having 'not applicable' responses ($n = 58$). These participants could not be included in such analyses, therefore resulting in very limited power due to the small sample available.

Results

Sample

Of the 349 patients identified as eligible to participate, 293 (84%) consented to take part in the study. Two hundred and thirty-six (81%) consenters completed and returned the first questionnaire. There was no indication of consent bias, with no significant differences in age ($p = 0.14$) or gender ($p = 0.31$) between completers and non-consenters. One hundred and seventy participants (72%) also completed the second questionnaire and are included in the following analyses. There were no significant differences in age ($p = 0.24$) or gender ($p = 0.56$) between those who completed the first questionnaire only and those who completed both questionnaires. Table 1 provides a summary of the socio-demographic, disease and treatment characteristics for the included sample.

Patient experiences of obtaining information related to their disease and treatment

Overall, self-reported information experiences were largely positive. Data from items assessing participant experiences

Table 1 Participant socio-demographic and disease profile ($n = 170$)

Characteristic		*N* (%)[a]
Gender	Male	99 (58%)
	Female	71 (42%)
Age (years)	18–34	8 (5%)
	35–54	42 (25%)
	55–74	94 (57%)
	75+	22 (13%)
Marital status	Married or partner	112 (67%)
	Single, divorced, separated or widowed	55 (33%)
Education completed	High school or below	75 (45%)
	Vocational training or University	91 (55%)
Place of birth	Australia	113 (68%)
	Other	54 (32%)
Cancer type	Non-Hodgkin lymphoma	51 (30%)
	Chronic leukaemia	34 (20%)
	Myeloma	27 (16%)
	Acute leukaemia	22 (13%)
	Hodgkin lymphoma	12 (7%)
	Other	22 (13%)
Time since diagnosis (months)	0–6	14 (8%)
	7–12	25 (15%)
	13–24	23 (14%)
	24+	107 (63%)
Stage of cancer	Early	54 (33%)
	Advanced	37 (22%)
	In remission	29 (18%)
	Do not know	45 (27%)
Treatment received[b]	Chemotherapy	141 (85%)
	Radiation therapy	36 (21%)
	Stem cell transplant	37 (22%)
	Surgery	31 (19%)
	Other	12 (7%)
	No treatment	66 (39%)

[a] Not all columns sum to 170 due to missing data; [b] not mutually exclusive categories

regarding information about diagnosis and treatment are presented in Table 2.

Interpersonal communication

When asked about their discussions with their doctor and family regarding their cancer, a substantial minority of participants indicated problems recalling information provided by their doctor (28%), experiencing information overload (26%) and insufficient opportunity to seek further information and clarification regarding their diagnosis and treatment (23%). Further, 15–18% of participants reported differing opinions amongst their family members regarding the information received and decisions about care.

Preparation for potentially threatening procedures

Most participants reported that guideline-recommended information was provided regarding the procedural and most sensory aspects of medical procedures. However, provision of information about strategies for managing stress and anxiety associated with these procedures was identified as being suboptimal for 20–22% of patients.

Post-discharge self-management

While information provision regarding post-discharge self-management was perceived to be adequate, a small proportion of participants reported receiving insufficient information about

Table 2 Patient experiences of obtaining information related to their disease and treatment

Item	Agree *N* (%)[a]	Disagree	Neutral
When being told information about my disease and treatment:			
The way the doctor discussed the information was confusing	24 (14%)[b]	120 (71%)	23 (14%)
I felt my doctor told me everything s/he could	130 (77%)	18 (11%)	19 (11%)
I forgot important details of what the doctor told me	*47 (28%)*[b]	73 (44%)	44 (26%)
I felt too overwhelmed by the amount of information to make sense of it	*43 (26%)*[b]	84 (51%)	36 (22%)
There wasn't enough time to discuss all my questions with the doctor	*38 (23%)*[b]	106 (63%)	20 (12%)
There have been differing opinions among my family about:			
What the doctor has told us	*29 (18%)*[b]	94 (57%)	26 (16%)
The meaning of the information we have received	*28 (17%)*[b]	91 (55%)	31 (19%)
Decisions made regarding treatment	*24 (15%)*[b]	98 (59%)	29 (18%)
What is best for me	*29 (18%)*[b]	92 (56%)	31 (19%)
When having medical procedures or treatments, I got the information I needed about:			
Purpose of the procedure	148 (88%)	6 (4%)	8 (5%)
Benefits and risks of the procedure	142 (84%)	10 (6%)	10 (6%)
What the procedure involved	144 (85%)	6 (4%)	11 (7%)
Where the procedure would take place	150 (89%)	1 (1%)	9 (5%)
Who would perform the procedure	114 (69%)	10 (6%)	30 (18%)
How long it would take to recover from the procedure	106 (63%)	19 (11%)	29 (17%)
What care I would need after the procedure	116 (69%)	12 (7%)	23 (14%)
How to manage anxiety and stress before the procedure	59 (35%)	*37 (22%)*	56 (34%)
What I might feel during the procedure	124 (74%)	10 (6%)	20 (12%)
What I should do if I experienced pain or discomfort during the procedure	120 (71%)	6 (4%)	23 (14%)
How to manage anxiety or stress during the procedure	72 (43%)	*33 (20%)*	44 (26%)
When leaving hospital, I got the information I needed about:			
Who to call if I experienced worrying symptoms	135 (81%)	6 (4%)	14 (8%)
Which symptoms I should report to my health care team immediately	132 (79%)	7 (4%)	19 (11%)
How to manage symptoms and side effects	110 (65%)	11 (7%)	37 (22%)
Situations or activities I should avoid to reduce risk of infection or developing complications	125 (75%)	10 (6%)	18 (11%)
Foods I should avoid to reduce risk of infection or developing complications	98 (58%)	*26 (15%)*	24 (14%)
How to prepare food safely to reduce risk of infection or developing complications	90 (54%)	*28 (17%)*	29 (17%)
I feel confident in my ability to:			
Ask my family/friends for emotional support when I need it	113 (68%)	20 (12%)	27 (16%)
Ask my family/friends for practical support when I need it	128 (77%)	14 (8%)	20 (12%)
Ask my health care team questions about my disease and treatment options	143 (86%)	7 (4%)	12 (7%)
Be involved in making decisions about my care	137 (82%)	9 (5%)	17 (10%)

[a] Not all rows sum to 170 due to missing data or 'not applicable' responses; [b] agreement indicates a negative patient experience as item was reverse-worded; Note: Areas where more than 15% of participants perceived care was not received in accordance with guidelines or indicated there was scope for improvement in information provision are presented in italic text

foods to avoid (15%) and how to prepare food safely to reduce risk of infection or developing complications (17%).

Information-seeking self-efficacy

Most participants (68–86%) reported feeling confident in their ability to seek support and information from their family, friends, and health care team.

Discussion and conclusion

Discussion

The results of this study indicate that haematological cancer outpatients have positive overall experiences in relation to obtaining required information about their cancer and its treatment. Despite 15–18% of participants reporting disagreement amongst family in terms of cancer information provision and decision-making, more than half of participants had a positive experience in terms of family involvement in these processes. This finding is consistent with the literature. A systematic review of patient-physician-companion communication found that cancer patients appreciated the emotional and information support roles fulfilled by their companions during cancer consultations [38]. This included taking notes, asking questions, recalling essential information post-consultation, and assistance with decision-making [38].

There is room for improvement in the provision of some aspects of guideline-recommended psychosocial care for haematological cancer patients. A substantial minority of participants forgot information they were given during the consultation with their doctor, did not feel they had enough time to ask questions and felt too overwhelmed by the amount of information presented to them to make sense of it. Previous research has reported that patients forgot or remembered incorrectly approximately 40–80% of medical information provided during a consultation [39]. In addition, higher levels of anxiety also have a negative impact on information recall [39, 40], which is of particular importance for haematological cancer patients where the prevalence of anxiety may be as high as 45% [6]. Patient-centred information provision recommends that clinicians ask patients what information they would like to know and in how much detail [41]. This allows for information provision to be tailored according to patients' preferences and may minimise information overload [41]. Decision aids, question prompt lists and patient coaching might also be useful strategies to improve recall and decision-making. Such interventions have been shown to decrease patient anxiety and help patients become engaged in decision-making regarding their care [42, 43]. Additional strategies to aid recall of information post-consultation, minimise information overload and provide additional opportunities to seek clarification regarding the information might include having two consultations to discuss diagnosis and treatment information, or information to take home [33], such as audiotapes of the consultation.

Approximately one fifth of participants indicated that they did not receive the information they needed about managing stress and anxiety associated with a potentially threatening procedure or treatment. This finding may be due to a prioritisation of medical aspects of the procedure in preparatory information provision, highlighted by the comparatively better perception of information received in these areas. Alternatively, it may be that patients place a higher level of importance on procedural, behavioural and sensory aspects of care, leading to lower rates of patient recall of psychosocial information. A multi-disciplinary model of cancer care may be effective at addressing this issue, where various clinical staff are involved in the coordinated delivery of both medical and psychosocial preparatory information. This may result in greater opportunities for discussion, clarification and reinforcement of information [44]. Previous research has also found that providing information aids, such as educational videos and audiotapes, may assist in reducing anxiety and increasing satisfaction with preparatory information [21, 44, 45]. The internet provides one highly accessible and cost-effective modality in which to provide such multimedia information. However, further research is needed to explore the potential use of interactive technology in delivering preparatory information to cancer patients [45].

Several limitations should be considered when interpreting the study findings. Firstly, there was potential for recall bias in survey responses. Over 60% of participants were diagnosed more than 24 months ago and, therefore, may be in the follow-up phase of care rather than undergoing diagnosis and active treatment to which many of the survey items relate. Future research could examine responses of cancer patients who are closer to the time of diagnosis. Sensitivity of the items regarding preparation for potentially threatening procedures may be limited due to the framing of the item stem. Participants were asked to respond taking into account all of the procedures and tests they had received rather than referring to a specific or most recent procedure. There were also a substantial number of neutral responses which were difficult to interpret. Future research may employ an alternative response scale which elicits more discrete responses in terms of whether specific information was received and what patients' preferences for receiving information are. Information provision in Australian haematological cancer treatment centres is likely impacted by a number of factors including clinician preferences and communication skills, patient preferences and learning styles and the availability of information resources. Such factors were not explored in the current study, however may have influenced the experience of patients, particularly if there was a mismatch between information delivery and patient preferences. Future research may benefit from a more in-depth exploration of the interaction between information provision, patient preferences and learning styles, and the patient experience.

Conclusion

While many haematological cancer patients report receiving adequate information, there is room for improvement in relation to some aspects of information provision. Findings highlight the need for implementation of effective strategies to minimise information overload, aid recall of information post-consultation and manage anxiety and stress related to medical procedures.

Practice implications

The majority of haematological cancer patients get the information they need about their cancer and its treatment.

Communication and provision of information by health professionals could be improved for some haematological cancer patients. The implementation of evidence-based strategies, such as decision aids [42, 43], audiotapes of the consultation and multimedia preparatory information [45] may be useful in addressing issues of poor information recall and information overload reported by participants in this study. While there are a number of tools that may be harnessed to improve patients' understanding of their diagnosis and treatment, the use of such strategies should be patient-centred to ensure the type and amount of information provided by health care professionals addresses the needs and preferences of the patient [41].

Author contributions All authors contributed to preparation and review of the manuscript. In addition, HT was the project manager responsible for overseeing data collection. RW, JB, and RSF were responsible for development of the measure.

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Compliance with ethical standards

Appropriate ethics approval was obtained from the University of Newcastle Human Research Ethics Committee and the relevant governing bodies at the participating hospitals.

Competing interests All authors declare that they have no competing interests.

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