

Patient and carer perceptions of cancer care in South Australia

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Abstract

Quality of care from the patient's perspective is an increasingly important outcome measure for cancer services. Patients' and carers' perceptions of cancer care were assessed through structured telephone interviews, 4–10 months post-discharge, which focused on experiences during the most recent hospital admission. A total of 481 patients with a primary diagnosis of cancer (ICD-10 C codes) were recruited, along with 345 carers nominated by the patients. Perceptions of clinical care were generally positive. Less positive aspects of care included not being asked how they were coping, not being offered counselling, and not receiving written information about procedures. Results also highlighted inadequate discharge processes. Carers were more likely than patients to report negative experiences. Perceptions of care also differed by cancer type.

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What is known about the topic?

There is increasing interest in measuring patients' perceptions of care to assess quality of cancer services.

What does this paper add?

This study measured patients' and carers' perceptions of cancer care in the tertiary setting, with the aim of identifying aspects of care that require advocacy or action.

What are the implications for practitioners?

While patients and carers perceived clinical care to be of high standard, cancer care could be further enhanced with more attention to information provision, psychosocial support and better discharge procedures. Giving greater consideration to meeting carers' needs is also required.

CANCER AFFECTS ONE IN EVERY THREE Australians by the age of 75 years,¹ and cancer care constitutes 5% of health care expenditure in this country.² Survival outcomes in Australia are among the best in the world,³ and continue to improve, however quality of life and quality of care are increasingly being viewed as equally important outcome measures for cancer control.

Recently, calls have been made to reform cancer services in Australia. *Optimising cancer care*, a consultative report prepared by the peak cancer organisations in 2003, recommended adopting an integrated, multidisciplinary approach, with more emphasis on psychosocial care, to replace the traditional model of a single specialist offering care.⁴ These recommendations have been echoed in the Commonwealth Government's *National service improvement framework for cancer* (2006)⁵ and several state cancer plans.^{6–8}

Cancer Australia is currently implementing the national strategies for "Strengthening Cancer Care", including the establishment of cancer services networks (CanNET).⁹ The goal of these

networks is to improve outcomes and reduce disparities for people affected by cancer, through the provision of well integrated, multidisciplinary, patient-centred cancer care at a regional level. Engaging with patients to ensure their needs are being met is at the core of service planning and delivery of CanNET.⁹

Other recent initiatives include the development of *Clinical practice guidelines for the psychosocial care of adults with cancer*,¹⁰ trials of multidisciplinary care (for breast cancer patients)¹¹ and the introduction of cancer care coordinators in some states.¹² These initiatives indicate a growing focus on quality of care as well as clinical outcomes.

There is increasing interest, both globally and nationally, in measuring patients' perceptions of care to assess quality of cancer services. Large multisite surveys of cancer patients' experiences have been undertaken in the United Kingdom, Europe, United States and Canada to inform and monitor health care reforms in those jurisdictions.¹³⁻¹⁵ To date, no comprehensive study of patients' perceptions of cancer care in Australia has been reported, though CanNET is currently examining potential tools to evaluate cancer care from the patient's perspective.

In this article we describe the results of a study measuring the quality of cancer care in South Australia, using a Picker-based survey¹⁶ which asked patients and their carers to recall experiences during hospitalisation, focusing on key areas central to patient-centred care. The aim was to identify aspects of care requiring action or advocacy.

Methods

A cross-sectional survey design was used to collect descriptive data about patients' and carers' perceptions of cancer care. Data were collected via computer assisted telephone interviewing (CATI) undertaken by an independent research company with extensive experience in patient surveys and health-system research.

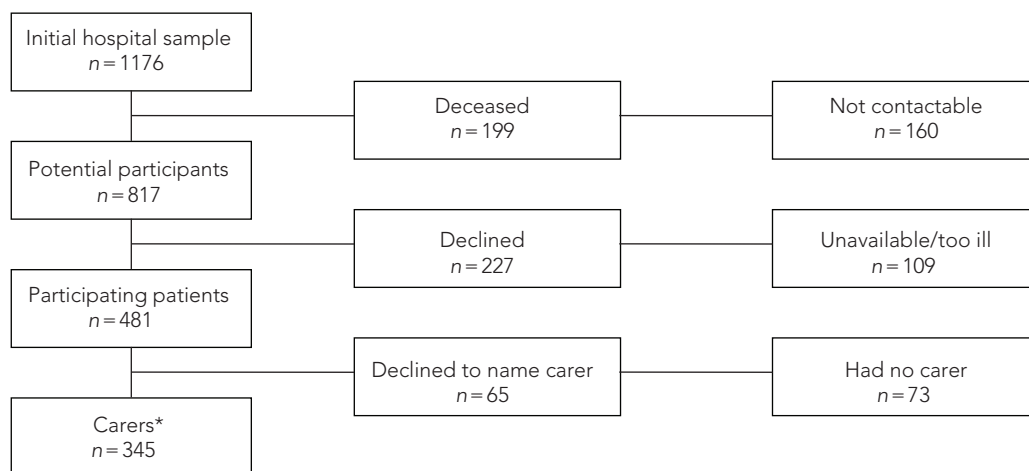
Patients were selected from hospital discharge records of two major public teaching hospitals in South Australia which together treat about half of

all cancer patients in the state. Sampling was retrospective, with interviews occurring about 4–10 months after discharge. The sample comprised all consecutive admissions of adults (18+ years) with a principal diagnosis of malignant cancer (ICD-10 C code) who were admitted for at least one night between December 2004 and April 2005. To avoid oversampling, patients requiring skin grafts and patients with a diagnosis of non-melanocytic skin cancer were excluded. However, patients with melanoma were included.

Invitations were sent to eligible patients via the treating hospitals, which then forwarded contact details of consenting patients to the independent interviewers. Carer participation depended on their nomination as the patient's main carer and their verbal consent at the time of the interview. Members of the largest non-English-speaking communities in South Australia (Greek, Italian and Vietnamese) were able to participate via bilingual interviewers.

Patient and carer questionnaires were developed by the research team, drawing heavily on questions from the National Health Service (NHS) Cancer Plan Baseline Survey¹³ (a Picker-based survey¹⁶) with modifications to suit telephone administration and reflect the South Australian context. Each survey consisted of series of questions relating to domains identified by the Picker Institute as essential for high-quality patient-centred care, through extensive literature review, in-depth interviews and focus groups with patients. These themes included timely access to appropriate services, respect and involvement of patients and family members in decision making, physical comfort, emotional support, communication and information provision, coordination and integration of services, and continuity and transition from hospital to community care.¹⁶ Survey questions asked patients to recall specific experiences during their most recent hospital admission.

Carers were asked a similar set of questions about their own direct experiences during the patient's most recent period of hospital care, covering the themes mentioned above. Questions relating to pain and discomfort and patient services, however, referred to the carers' perceptions

I Recruitment schema for patient and carer samples

* Carer participation rate = 100%.

of the patient's experience. Only carers who were present at discharge were asked questions relating to discharge processes.

Both patient and carer questionnaires were piloted to assess comprehension, relevance, flow and adequacy of response categories, firstly with a small number of volunteers at the Cancer Council South Australia (CCSA) and subsequently with 20 hospital patients and 20 carers. Only minor alterations to wording and ordering of questions were required. Patient surveys took about 30 minutes to complete, while carer surveys took about 20 minutes.

Responses were coded into binary variables (if not already binary) to indicate whether or not patients or carers had negative experiences or suboptimal care. For responses such as "can't say/can't remember" it was assumed that problems had not occurred or perceptions were favourable. Results of univariate analyses are reported as the percentage of patients or carers reporting an aspect of care that was suboptimal. Data from both hospitals were aggregated, as results from both were highly concordant. Multivariate logistic regression analyses were undertaken comparing cancer subtypes within the study sample, for each outcome measure. All models included age group (<50

years, 50–64 years, 65+ years), sex, hospital (A and B) and cancer type (grouped as breast cancer, digestive cancers, prostate cancer, lung cancer, gynaecological, haematological cancers and others). The resulting odds ratios (ORs) represent the likelihood of a particular subgroup reporting a negative aspect of care relative to the reference group (breast cancer patients). Only statistically significant odds ratios ($P < 0.05$ level) are reported.

The Human Research Ethics Committees of the two hospitals and CCSA gave approval for this study.

Results

Participant profile

Interviews were undertaken with 481 patients across both hospitals. As outlined in Box 1, 1176 patients were identified from hospital records, of which 817 were alive and contactable. Among those invited, 227 declined and a further 109 were too ill, unavailable at the time of interview or had language, speech or hearing difficulties which prevented participation. The participation rate among eligible, contactable patients was 59%. Thirteen percent of participating patients

did not wish to nominate a carer, while 15% indicated they had no carer. A total of 345 carers were nominated and all agreed to participate. Box 2 shows the participant profile.

Compared with all cancer patients who were admitted to the two hospitals over the relevant period, participants were slightly younger (mean age, 61.7 years v 64.2 years; $P < 0.001$) and more likely to have a breast cancer diagnosis (17.5% v 11.1%; $P < 0.001$). Participant and hospital admission profiles were similar with respect to length of stay and the proportion of other major cancer types (colorectal, respiratory, skin, prostate, gynaecological and haematological cancers).

Survey results

Overall levels of satisfaction with cancer care were high, with 95% of patients being satisfied with care provided during their most recent admission (69% very and 26% somewhat) and 96% satisfied with care during their most recent outpatient appointment (72% very and 24% somewhat). Very few patients felt they were not treated with respect and dignity (8%) or that their stay was too short (6%), and few reported that doctors had not discussed procedures (6%) or that they did not understand explanations (7%) (Box 3).

However, results indicated a number of areas where patients reported suboptimal care or negative experiences. Areas of concern for patients included experiencing pain or discomfort during their admission (57%; although only 13% felt staff did not do all they could to ease their pain or discomfort), not being offered the opportunity for counselling (38%), not receiving written information about procedures/treatment (38%), not being told of signs to look out for after discharge (31%), and not being given information about self-care (44%) and community support available (49%). A substantial proportion of patients reported experiencing difficulties getting to hospital appointments (30%).

In general, carers were more likely than patients to report negative experiences or problems, with patterns being similar to those of patients. Negative aspects of care most frequently reported by the carers included not being asked

2 Participant profile

Demographic and health profile	Patients* (n=481)	Carers* (n=345)
Female	55.5	65.5
> 65 yrs of age	47.8	31.9
Metropolitan residents	62.0	Not asked
Live with patient		73.9
Secondary education or higher	39.9	46.9
Married or de facto	64.4	88.1
Fair or poor health (current self-reported)	35.3	23.5
Been diagnosed with cancer	100.0	11.9
Diagnosed within previous 12 months	57.0	
Type of cancer		
Breast	17.5	
Colon	12.1	
Skin	9.8	
Lung	7.1	
Prostate	5.0	
Lymphomas	4.7	
Other	43.9	
Last hospital admission for		
Treatment	71.1	
Diagnosis/investigation	9.1	
Side-effects/follow-up/palliation/other	19.8	
Length of stay last admission (mean days)	7.3	
Procedures during admission		
Surgery	62.4	
Radiotherapy	13.9	
Chemotherapy	15.8	
Investigative (scan/biopsy/endoscopy)	52.3	
Main or only carer		82.8
Fairly or very involved in patient's care		92.8

* Values are percentages unless otherwise indicated.

how they were coping (46%), not being offered an opportunity for counselling (62%), not being given any written information about the patient's

3 Proportion of patients and carers reporting negative experiences during hospital admission for cancer care

Negative experiences during cancer care	Patients, %	Carers, %
Respect, involvement		
Not treated with respect/dignity all of the time	8.0	–
Did not always have enough privacy during discussions	15.7	33.0
Staff talked about the patient as if they were not there	16.9	–
Staff did not always involve carer in discussions when present	–	27.5
Patient/carers wanted to be more involved in decision making	12.5	16.8
Patient wanted their family to be more involved in decision making	8.1	–
Reducing anxiety/providing support		
Not trusting in or confident with all staff providing care	29.3	34.4
Never asked how they were coping	20.8	45.5
Not offered opportunity to talk with counsellor/psychologist/social worker	38.3	62.2
Minimising pain and discomfort		
Experienced pain/discomfort during admission*	56.8	69.7
Experienced severe pain/discomfort	22.5	–
Experienced pain/discomfort all or most of the time	18.2	–
Staff did not do all they could to ease pain/discomfort*	13.4	21.5
Communication/ information provision		
Never encouraged to ask questions	11.7	15.1
Doctors did not discuss purpose of tests/procedures	6.0	–
Doctors did not discuss possible side-effects	14.9	–
Doctors did not discuss how procedures had gone	14.1	–
Carer wanted to be better informed about patient's condition	–	19.0
Explanations were difficult to understand	7.0	9.6
Patient/carers wanted more information	13.8	21.8
Not given any written information about procedures	37.5	45.3
Well coordinated, integrated care		
Not given the name of person in charge of patient's care	16.3	29.7
Had to repeat history more than once or twice	24.6	–
Felt doctors were repeating tests unnecessarily	7.4	7.6
Confused about roles of various staff	17.2	23.7
Received conflicting information from different staff	17.9	22.2
Smooth discharge/transition		
No discussion of signs to look out for	31.2	55.0
Not told who to contact if concerned	21.0	33.1
Not given written information about care after discharge	44.1	60.9
Not told about community services that might help	48.5	56.1
Access to appropriate services		
Felt length of stay in hospital was too short	8.1	19.1
Felt outpatient appointments were too infrequent	4.9	5.1
Felt last outpatient appointment was too short	6.0	11.5
Felt that they (the patient) did not get all the services they needed*	26.7	22.2
Difficulty getting to hospital for appointments	30.4	41.5
Experienced financial difficulty while receiving care	21.2	26.0

* Carer's perception of patient's experience rather than their own experience.

4 Adjusted odds ratios relative to breast cancer (with confidence intervals) for negative experiences during care for cancer, by cancer type

	Digestive	Lung/ airways	Melanoma	Prostate	Haem	Gynae
Respect, involvement						
Staff talked about the patient as if not there					2.95 (1.07–8.12)	
Reducing anxiety/providing support						
No offer to talk with counsellor/social worker			2.67 (1.21–5.87)	4.67 (1.61–13.6)		
Good communication						
Doctors did not discuss purpose of procedures		6.81 (1.17–39.7)				
Doctors did not discuss possible side-effects			3.83 (1.32–11.1)			
Doctors did not discuss procedure outcomes					3.35 (1.18–9.53)	
Not given written information about procedures	2.98 (1.38–6.42)	2.80 (1.22–6.46)	3.37 (1.50–7.58)		2.55 (1.08–5.99)	
Well coordinated, integrated care						
Received conflicting information from staff		3.21 (1.11–9.28)			3.20 (1.14–8.97)	
Smooth discharge/transition						
No discussion of signs to look out for	3.59 (1.59–8.12)	3.59 (1.48–8.73)			3.39 (1.38–8.35)	
Not told who to contact if concerned	3.25 (1.29–8.19)	3.10 (1.13–8.19)	3.11 (1.18–8.19)		3.44 (1.25–9.45)	3.27 (1.15–9.27)
No written information on care after discharge	4.50 (2.28–10.9)	4.70 (2.02–10.9)	4.54 (2.00–10.3)		4.75 (2.03–11.1)	
Not told of community services that might help			2.19 (1.01–4.75)		2.51 (1.11–5.68)	
Access to appropriate services						
Felt that they did not get all services needed					2.94 (1.25–6.92)	
Experienced financial difficulty			0.30 (0.10–0.95)		0.17 (0.04–0.81)	0.44 (0.20–0.94)

Haem = haematological. Gynae = gynaecological. Odds ratios (confidence intervals) derived from logistic regression adjusted for age, sex and hospital. Only statistically significant findings ($P < 0.05$) are shown.

procedures (45%), a lack of discussion about signs to look out for after discharge (55%), not being given written information about care after discharge (61%) and not being told about community services that might be helpful (56%). A large proportion of carers (70%) perceived the patients to have experienced pain or discomfort during their admission, with 22% feeling that

staff could have done more to address the patient's comfort. A large proportion of carers also reported difficulty getting to and from hospital appointments (42%), not being confident or trusting of all staff (34%), and a lack of privacy during discussions (33%).

Differences were apparent according to the type of cancer. Box 4 shows odds ratios (adjusted for

age, sex and hospital) of patients with particular cancers having negative perceptions or experiences, relative to breast cancer patients. Patients with melanoma, digestive system, lung/airway and haematological cancers fared worse in relation to information provision and discharge advice compared with breast cancer patients. Patients with melanoma and prostate cancer were less likely to have been offered counselling. Patients with lung/airway cancers and haematological cancers were significantly more likely to report receiving conflicting advice. Patients with haematological cancers were also more likely to have felt they did not receive all the services they needed while in hospital.

Discussion

This study is the first in Australia to report patients' and carers' experiences of cancer care as a measure of quality of cancer services. This survey was modelled on the UK NHS cancer patient survey,¹³ a Picker-based survey which asked patients to recall specific events during an episode of care. Compared with satisfaction surveys, which ask respondents to rate aspects of care, surveys of patient experiences provide a more objective measure of the presence or absence of a problem, relative to best practice.¹⁷ This study is novel in that it successfully adapted the survey to also assess carers' perceptions.

Patients were generally very satisfied with care provided in hospital and were comfortable with the level of access to outpatient services, though some had difficulties getting to and from appointments. Furthermore, perceptions of clinical care were, in the main, positive, with only a small proportion perceiving that they had inappropriate testing, or that there was poor communication from doctors about procedures. Patients' perceptions of the way they were treated by staff and the level of involvement of family members in decision making were also very positive. These results indicate a high level of clinical competence and a respectful attitude among staff, which are valued aspects of a quality cancer service that need to be fostered in current or future reforms.

Results do however highlight other aspects of care that require improvement for both patients and carers. Psychosocial support as yet does not appear to be an integral part of hospital care. While not all cancer patients require or want professional support, guidelines for psychosocial care recommend that all patients be asked how they are coping at every visit, be provided with information about support services, and have access or are referred to support services where appropriate.¹⁰ This also extends to support being offered to family and friends. The routine adoption of these guidelines, including routine assessment of the patient's wellbeing, is advocated in a number of state and national cancer care reform plans.^{5,6,8} While additional resources may be required to address complex needs, for example including more psychologists or social workers within multidisciplinary care teams, simple measures such as assessing patients' emotional wellbeing and referring them as needed to primary care/community services do not require additional resources.

The survey also identified inconsistency in information provision for South Australian cancer patients during hospitalisation, particularly written information, both about procedures and about self-care after discharge. Previous research indicates that most patients want to be well informed about their cancer, treatments and services available.^{18,19} Access to information assists patients to cope with stressful situations by giving them a sense of control and enabling them to actively participate in decision making, and being well informed reduces distress and increases satisfaction with care.^{20,21} Health professionals within treatment centres are the preferred information source, with written information being a popular back-up to verbal information and advice from health care staff.²² Written information is also a valuable source of information for family and friends who provide care outside the hospital setting. The *National service improvement framework for cancer* recommends the provision of both verbal and written information about clinical aspects of cancer, along with written treatment and follow-up plans.⁵ Information provision is a

strong theme within the psychosocial guidelines as well.¹⁰ A systematic approach to providing written information to all patients is therefore a priority in ensuring quality of cancer services.

Results also highlight concerns around the discharge process, with a large proportion being ill-prepared to care for themselves after discharge from hospital with no link to primary or community services. International research indicates that continuity and transition is the most problematic dimension of patient care across five countries where patient experience surveys have been conducted.²³ Several state health departments have also recognised the need for improvements in discharge processes and have developed improvement frameworks to address this issue.^{24,25} Detailed discharge planning is essential for continuity of care for people with ongoing care needs, providing a link between treatments received in hospital and post-discharge care provided in the community. Central to the discharge planning process is information and education for patients, carers and their general practitioners about ongoing health management, signs of complications and worsening condition, when to resume normal activities, post-discharge contacts and community services.²⁴ Effective discharge processes are associated with lower unplanned readmission rates, improved quality of life and increased patient satisfaction.²⁶ Improving discharge processes is likely to impact on both the quality of care and the health and wellbeing of cancer patients and their carers.

Across all the different dimensions measured, carers reported negative experiences or sub-optimal care more frequently than patients. Most notable was the lack of psychosocial support offered to carers and the lack of information (verbal and written) being provided, particularly in relation to caring for the patient after discharge. These issues are compounded by carers' perceived lack of privacy for discussions within the hospital environment. The experience of carers is acknowledged as central to the wellbeing of those affected by cancer. To effectively support the patient, carers need to understand the disease, its treatments and likely outcomes, how to care

for the patient and notice signs of deterioration and know what community services are available.²⁷ While carers play an important role in advocacy and support for the patient, they also have their own needs for information and support. The acute care setting is a key source of information for carers. However, carers face difficulties accessing information because of the uncertainty about their status within the medical setting and because of staff's concerns about privacy.^{28,29} Also they are reluctant to seek support for themselves because they tend to put the patient's needs before their own. A recent survey of carers (ie, anyone caring for sick, elderly or disabled persons) found they had the lowest level of wellbeing of any population group in Australia.³⁰ Welcoming carers into the medical setting is likely to have benefits for both cancer patients and their carers. Strategies to improve carer support and information provision have not been a strong focus of recent cancer reform agendas across the country but warrant further attention.

A substantial proportion of patients and carers reported experiencing difficulties getting to and from hospital appointments, and many also experienced financial difficulties in the course of supporting the patient during this time. While hospitals have some capacity to address these barriers (free or subsidised parking for patients, increased flexibility with regard to appointment times) many are beyond the hospital's control and require broader structural approaches (for instance, increasing access to travel assistance programs and carer benefits). Recommendations from the recent Senate Committee report on the adequacy of the Patient Assistance Travel Scheme are likely to address some barriers faced by rural and remote patients and their carers but are unlikely to address issues for residents in metropolitan areas.³¹

Patients' experiences differed according to cancer type, particularly in relation to communication issues and information provision, during the admission and at discharge. Patients with breast cancer reported more favourable experiences in relation to most aspects of care than patients with

other types of cancer. The existence of well established advocacy agencies with a focus on breast cancer may have led to better models of care for women with breast cancer, ahead of other cancer types. On the other hand, patients with haematological cancers appeared to be least well catered for. This may relate to the complex, often ongoing and aggressive nature of treatment for haematological cancers.³² Generally, better systems appear to be in place to provide written and verbal information for patients with breast cancer, gynaecological cancers and prostate cancer compared with other groups of cancer patients. Reasons for these disparities may include greater availability of resources in relation to certain cancers (eg, breast and prostate cancer), or alternatively, the provision of specialist services (breast care nurses, prostate care nurses, women's health clinics) in these centres. Further research into the needs of specific groups of patients is warranted.

Improved links with non-government organisations such as the Cancer Council may assist hospitals to enhance the quality of cancer care, with minimal resource implications. Cancer Councils can offer written materials covering specific types of cancer, common treatments, possible side effects and self-management advice following treatments for distribution to patients. They can also provide a contact point for concerned patients and carers, answering non-medical concerns, providing ongoing emotional support and arranging referral to other community services where patients have complex needs. Services of non-government organisations are currently under-utilised.

This study had a number of limitations. Telephone survey methodology was chosen over a written survey, primarily to increase response rates, and proved to be acceptable to both patients and carers. Despite this, response rates were lower than desired due to the numbers who were too ill to participate or had died before the study commenced. It is possible that patients who were very ill or died had less favourable experiences than those able to participate. If this were the case, positive perceptions regarding some aspects of care would be overestimated. Also

there was considerable delay between admission and interview dates due to collecting consent (4–10 months). Since recall is likely to decline over time, some outcome measures may be inaccurate (most likely underestimated). However, outcome measures are likely to reflect longer term perceptions, which arguably are as important as immediate reactions.

Another limitation is that the sample only included inpatients, with a high proportion having undergone surgery. As such, the experiences of those whose management was predominantly medical (eg, chemotherapy or radiotherapy provided through outpatient services) may not have been adequately captured in this study. In addition, findings may be slightly biased toward the views of breast cancer patients and younger cancer patients due to their over-representation among the participant group.

Caution is needed in generalising findings from this study, since the sample was drawn from only two hospitals in South Australia. However, these two hospitals are the leading public teaching hospitals, with cancer centres catering for a large proportion of cancer patients being treated in the state, and would be expected to provide leadership for other hospitals. Results were highly concordant across the two hospitals with small but significant differences ($P < 0.05$) identified for only four of the outcome measures, suggesting general rather than hospital-specific issues predominate. Furthermore, many of the issues identified in this study have been highlighted in previous national reports (eg, *Optimising cancer care*⁴ and the *National improvement framework*⁵), indicating that they are likely to be systemic.

Conclusion

With growing interest in the quality of cancer care as well as clinical outcomes, surveys of patient experiences are an important, emerging tool for assessing cancer services. Despite some limitations, this study demonstrates the usefulness of patient and carer perceptions surveys in identifying strengths and weaknesses within cancer care settings. Changes are needed at both the hospital

level and the broader structural level to ensure improvements in psychosocial assessment and support, the provision of written information and discharge procedures.

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Competing interests

The authors declare that they have no competing interests.

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