

The quality of patient-centred care: haematological cancer survivors' perceptions

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Abstract

Objective: Patient-reported outcome measures (PROMs) that assess the quality of patient-centred cancer care have failed to measure all six patient-centredness dimensions endorsed by the Institute of Medicine (IOM). This study is the first to use the Quality of Patient-Centered Cancer Care (QPCCC) measure that covers all six IOM patient-centredness dimensions to examine haematological cancer survivors' perceptions of care and characteristics associated with perceived quality of care.

Methods: Haematological cancer survivors diagnosed in the last 6 years and aged 18–80 years were recruited from two Australian state population-based cancer registries. Survivors were mailed the 48-item QPCCC measure.

Results: Overall, 545 haematological cancer survivors completed the measure. Areas of care most commonly identified as delivered were hospital staff showing respect to survivors (93%) and making sure the correct treatment was received (93%). Aspects of care most frequently nominated as not delivered were hospital staff helping family and friends (34%) or the survivor (32%) to find other people with similar experiences to talk to. Characteristics associated with survivors perceiving higher quality care was delivered included being employed, having private health insurance, being younger, a Non-Hodgkin lymphoma diagnosis and more recent diagnosis. Being depressed or stressed was associated with perceived lower quality of care.

Conclusions: Provision of peer support programs that allow haematological cancer survivors and families and friends to talk to others in similar situations could be improved. Using PROMs to identify areas where cancer survivors perceive improvements are needed is essential to quality improvement efforts.

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Background

Haematological cancers, including leukaemias, lymphomas and myelomas, develop in the blood or bone marrow [1]. Haematological cancers include incurable chronic conditions requiring constant monitoring and fast growing cancers needing immediate treatment [2]. Haematological cancer survivors often have prolonged exposure to health care and may require care from multiple specialists [2]. In Australia, acute myeloid leukaemia patients have a longer average hospital stay than other cancer types [3]. Identifying areas of care that haematological cancer survivors perceive as high quality or needing improvement is essential to quality improvement efforts.

The Institute of Medicine (IOM) recommended improvements to *safety, effectiveness, timeliness, efficiency, equity* and *patient-centredness* to achieve quality care [4]. The IOM also endorsed six patient-centredness dimensions [5], which stipulate care should be respectful to patients' values, preferences, and expressed needs; be coordinated and integrated; provide information, communication, and education; ensure physical comfort; provide emotional support; and involve family and friends [4]. Psychometrically robust patient-reported outcome measures (PROMs) assess patients' perspectives and are essential to monitoring quality of care

[6]. Cancer survivors' perceptions of quality of care have been associated with quality of life [7–9], anxiety and depression [8,9], treatment under-utilisation [10,11] and mistrust of the medical system [12,13].

Few studies have examined haematological cancer survivors' perceptions of quality of care. Haematological cancer survivors (44%) reported not participating in treatment decision-making as preferred [14], while lymphoma survivors wanted more discussion of late treatment effects [15]. Further, almost 60% of haematological cancer patients thought talking with a healthcare professional after treatment about their cancer experiences would have helped [16]. Leukaemia and lymphoma survivors reported that factors contributing to adjustment difficulties after treatment ended included poor continuity of care, lack of support for survivorship issues, difficulty finding appropriate services and inadequate follow-up [17]. The limited evidence examining characteristics associated with haematological cancer survivors' perceptions of quality of care found that currently receiving treatment was associated with participating in treatment decision-making as preferred [14] and a shorter waiting time associated with greater satisfaction with a consultation [15]. Research with other cancer types reported that age [18], education [19], marital status [19], income [18], anxiety [9] and

depression [9,18] were associated with survivors' perceptions of quality of care.

A review of PROMs developed to assess quality of patient-centred cancer care [4] identified one measure that addressed all six IOM patient-centredness dimensions, which was judged to have limited psychometric rigour [20]. No study has used a psychometrically robust PROM that covers all six IOM patient-centredness dimensions to measure haematological cancer survivors' perceptions of care [20].

Our study used the Quality of Patient-Centered Cancer Care (QPCCC) measure which includes items that cover all six IOM patient-centredness dimensions and has demonstrated validity and reliability [21]. The study examined the following among haematological cancer survivors:

- 1) Perceptions of quality of patient-centred cancer care.
- 2) Characteristics associated with survivors' perceived quality of patient-centred cancer care.

Methods

Sample

Between November 2011 and August 2013, survivors were recruited if diagnosed with a haematological cancer within the last six years, aged 18–80 years and proficient in English.

Procedure

Two Australian state population-based cancer registries identified haematological cancer survivors. The sample was stratified by survivors' residential postcodes (major cities/inner regional versus outer regional/remote/very remote) according to the Accessibility and Remoteness Index of Australia. All eligible survivors living in outer regional/remote/very remote locations and a random sample of survivors residing in major city/inner regional locations were approached.

Cancer registries sought passive consent from survivor's clinician. Survivors who received clinician consent or whose clinician did not respond within 4 weeks to the registries' request were contacted via mail. Registries sought survivors' permission to pass their contact details to the researchers. Consenting survivors were mailed an invitation letter, questionnaire, consent form and reply-paid envelope. Non-respondents received one mailed and one telephone reminder at four weekly intervals.

The University of Newcastle Human Research Ethics Committee and committees associated with each registry granted ethical approval.

Measures

Quality of Patient-Centered Cancer Care measure

The 48-item QPCCC measure examines survivors' perceptions of waiting times and overall cancer care at the hospital where most treatment was received [21]. Response options

are *Strongly agree*, *Agree*, *Disagree*, *Strongly disagree* and *Not applicable to me*. The QPCCC measure contains 10 subscales: *timely care* (four items); *respectful communication* (three items); *cancer information* (three items); *treatment decision-making* (eight items); *treatment delivery* (seven items); *patient preferences and values* (three items); *equitable care* (two items); *coordinated and integrated care* (seven items); *emotional support* (four items); *follow-up care* (five items); and two single items. Psychometric evaluation of the QPCCC measure demonstrated strong face validity, content validity, construct validity and internal consistency for our haematological cancer survivor population [21].

Other measures

Consenting survivors had age, sex, postcode, cancer type and diagnosis date extracted from registry records. Survivors indicated marital status, education, employment, private health insurance, cancer treatments and completed the Depression, Anxiety and Stress Scale (DASS-21) [22]. De-identified data related to non-participants' age at diagnosis, sex, postcode and cancer type were extracted from the registries.

Statistical analysis

Analysis was completed using SAS software (SAS Institute Inc, Cary, NC, USA).

Participant and non-participant characteristics

Chi-square tests compared participant and non-participant characteristics.

Survivors' perceptions of quality of care

Depending on QPCCC item wording, quality care corresponded to the response of either 'strongly agree/agree' or 'strongly disagree/disagree' and vice versa for care not received. For example, to indicate quality care for '*The staff at the hospital helped me deal with being worried, upset or sad*', survivors responded 'strongly agree or agree'. Respondents chose 'strongly disagree or disagree' to indicate such care was not delivered. In contrast, for '*I had to wait too long from getting a referral to a cancer doctor to my first visit with him/her*', survivors selected 'strongly disagree or disagree' to represent quality care. Percentages indicated areas of care perceived as high quality (endorsed by $\geq 80\%$) or not delivered (endorsed by $\geq 20\%$).

Quality of Patient-Centered Cancer Care subscale scores

Means and medians were calculated for each QPCCC subscale. Items were scored so 1 related to lowest quality care, 2 to low quality care, 2.5 to 'not applicable to me' as care was not needed or desired, 3 to high quality care and 4 to highest quality care. Not applicable was

coded as 2.5 as this represents a neutral position and is the midpoint between the low and high care scores. Placing these neutral responses midway between low and high scores gives better discrimination for the polarised responses. Subscale scores were calculated by summing all subscale items and dividing by number of non-missing items for participants answering $\geq 70\%$ of subscale items.

Characteristics associated with perceived quality of care

Multiple linear regression models used each QPCCC subscale score as the outcome and demographic, cancer-related and psychological characteristics as independent variables. Estimates with robust standard errors and adjusted Wald *p*-values were calculated.

Results

Of 1726 eligible survivors identified by cancer registries, 700 agreed to be mailed the questionnaire and 545 completed the survey (78% mailed survey; 32% eligible survivors). Compared with non-participants, leukaemia and younger survivors at diagnosis were significantly under-represented among participants, but there were no differences for sex and residence.

Characteristics and treatment factors

Participant mean age was 61.6 years, most were male (59%) and had trade/vocational or university qualifications (59%). Most survivors were married/living with partner (76%), an urban resident (82%), not employed (60%), had private health insurance (69%) and diagnosed with Non-Hodgkin lymphoma (59%). Treatments received were chemotherapy (85%), radiotherapy (32%), bone marrow or stem cell transplant/harvest (25%) and hormone/antibody treatment or targeted therapy (24%).

Areas of high quality care

Table 1 outlines areas of care received by $\geq 80\%$ of haematological cancer survivors. Most survivors strongly agreed/agreed that hospital staff showed respect for them (92.9%), hospital staff made sure they received the correct treatment (92.6%) and hospital staff talked to them in a way they understood (92.0%). Of 14 areas endorsed by $\geq 80\%$ of respondents as high quality, seven were related to the QPCCC's *treatment delivery* subscale, three to *respectful communication*, two to *treatment decision-making* and two to *cancer information*.

Areas of care not delivered

As Table 2 indicates, $\geq 20\%$ of haematological cancer survivors perceived 12 features of care were not delivered. Survivors most commonly strongly disagreed/disagreed

Table 1. Areas of high quality care

Item ^a	Strongly agree/agree		QPCCC subscale
	n	% ^b (95% CIs)	
The staff at the hospital showed respect for me	495	92.9(90.7–95.1)	Respectful communication
During my treatment, staff at the hospital made sure I received the treatment I was meant to have	497	92.6(90.3–94.8)	Treatment delivery
The staff at the hospital talked to me in a way I could understand	494	92.0(89.7–94.3)	Respectful communication
The staff at the hospital showed respect for my family or friends	479	88.9(86.2–91.5)	Respectful communication
During my treatment, staff at the hospital had up-to-date information about my cancer care	475	88.8(86.1–91.5)	Treatment delivery
During my treatment, staff at the hospital made sure I received treatment that was based on scientific knowledge	469	88.5(85.8–91.2)	Treatment delivery
During my treatment, staff at the hospital gave me consistent information about my treatment	470	87.5(84.7–90.3)	Treatment delivery
During my treatment, staff at the hospital attended promptly to my pain or discomfort	468	86.8(84.0–89.7)	Treatment delivery
During my treatment, staff at the hospital co-ordinated my appointments so that I did not have to go to hospital more than necessary	452	86.6(83.7–89.5)	Treatment delivery
The staff at the hospital gave me information about cancer that was easy to understand	461	85.7(82.7–88.6)	Cancer information
During my treatment staff at the hospital made sure I did not receive unnecessary tests or treatments	453	85.3(82.3–88.3)	Treatment delivery
The doctors at the hospital explained to me the short-term side effects of each treatment option	443	83.0(79.8–86.1)	Treatment decision-making
The staff at the hospital gave me information about cancer and treatments to take home (e.g. booklets, websites)	441	82.0(78.7–85.2)	Cancer information
The doctors at the hospital explained to me all of the treatments I could have	434	81.3(78.0–84.6)	Treatment decision-making

QPCCC, Quality of Patient-Centered Cancer Care.

^aThe following are *n*(%) of 'not applicable to me' responses (as not needed or desired) for each item: 28(5.3%); 39(7.3%); 28(5.2%); 52(9.6%); 43(8.0%); 55(10.4%); 44(8.2%); 59(10.9%); 56(10.7%); 42(7.8%); 55(10.4%); 54(10.1%); 48(8.9%); 52(9.7%).

^bDenominators used to calculate percentages may differ because of missing data.

Table 2. Aspects of care most commonly not received

Item ^a	n	Strongly disagree/disagree	QPCCC subscale
		% ^b (95% CIs)	
The staff at the hospital helped my family or friends find others in a similar situation to talk to	180	33.8(29.8–37.9)	Coordinated and integrated care
The staff at the hospital helped me find other cancer patients I could talk to about their cancer experiences	172	32.3(28.4–36.3)	Coordinated and integrated care
The doctors at the hospital explained to me I could get a second medical opinion if I wanted to	157	29.5(25.6–33.4)	Treatment decision-making
The doctors at the hospital explained to me how each treatment option might affect my length of life	129	24.2(20.6–27.8)	Treatment decision-making
The staff at the hospital helped me get parking at the hospital that was affordable	117	22.1(18.6–25.7)	Coordinated and integrated care
I had to wait too long from my first visit with my general practitioner about cancer-related symptoms or screening to getting a referral to a cancer doctor ^c	115	21.9(18.3–25.4)	Timely care
During my treatment, I was able to choose which doctor provided my treatment	115	21.7(18.2–25.3)	Patient preferences and values
The staff at the hospital gave me a list of questions that cancer patients commonly ask	115	21.6(18.1–25.1)	Cancer information
The staff at the hospital helped me get financial assistance	110	21.0(17.5–24.5)	Coordinated and integrated care
During my treatment, I was able to choose which doctor I saw for each appointment	110	20.9(17.4–24.3)	Patient preferences and values
The staff at the hospital helped me deal with changes in my personal relationships	109	20.6(17.2–24.1)	Emotional support
The staff at the hospital helped me deal with day-to-day tasks (e.g. childcare, housework)	105	20.0(16.6–23.5)	Coordinated and integrated care

QPCCC, Quality of Patient-Centered Cancer Care.

^aThe following are n(%) of 'not applicable to me' responses (as not needed or desired) for each item: 274(46.4%); 241(45.3%); 115(21.6%); 85(15.9%); 244(46.1%); 93(17.7%); 113(21.4%); 62(11.7%); 332(63.5%); 112(21.3%); 281(53.1%); 317(60.5%).

^bDenominators used to calculate percentages may differ because of missing data.

^cItem corresponded to strongly agree/agree options reflecting care not received.

that hospital staff helped family or friends find others in a similar situation to talk to (33.8%), hospital staff helped them find other cancer patients to talk to about their cancer experiences (32.3%) and doctors explained to them they could get a second medical opinion if they wanted to (29.5%). Five features not received by $\geq 20\%$ of respondents

Table 3. Quality of Patient-Centered Cancer Care (QPCCC) subscale scores

QPCCC subscale	n ^a	Mean(SD)	Median
Respectful communication	533	3.68(0.58)	4.00
Treatment delivery	536	3.55(0.58)	4.00
Cancer information	530	3.29(0.74)	3.00
Treatment decision-making	535	3.21(0.73)	3.00
Follow-up care information	533	3.13(0.73)	3.00
Timely care	531	3.16(0.90)	3.00
Equitable care	525	3.01(0.72)	3.00
Patient preferences and values	521	2.97(0.85)	3.00
Emotional support	534	2.77(0.63)	2.50
Coordinated and integrated care	534	2.46(0.49)	2.50

SD, standard deviation.

^aCompleted $\geq 70\%$ of subscale items.

related to *coordinated and integrated care*, two to *treatment decision making*, two to *patient preferences and values* and one to *cancer information*, *timely care* and *emotional support*, respectively.

Quality of Patient-Centered Cancer Care subscale scores

As Table 3 reported, *respectful communication* and *treatment delivery* had the highest and second highest mean quality care scores, respectively. This aligns with the highest-ranked items survivors perceived were high quality (Table 1). In contrast, coordinated and integrated care had the lowest mean quality care scores. This is consistent with results in Table 2 where most of this subscale's items (5 of 7) were considered by $\geq 20\%$ of respondents as areas where such care was not delivered.

Characteristics associated with perceived quality of care

Table 4 indicated that being employed was associated with higher quality *timely care* and *equitable care* scores. Private health insurance was associated with higher perceived quality care regarding *patient preferences and values* while being 18–39 years old was associated with higher perceived quality of *respectful communication* and *cancer information*. A Non-Hodgkin lymphoma diagnosis was associated with higher perceived quality regarding *treatment delivery* and *cancer information* compared with a leukaemia diagnosis. Being diagnosed within 24 months was associated with higher perceived quality of *emotional support*.

In contrast, being depressed was associated with survivor perceptions of lower quality care regarding *treatment delivery*, *treatment-decision making*, *follow-up care*, *respectful communication*, *patient preferences and values* and *cancer information*. Being stressed and private health insurance were associated with lower perceived quality of *cancer information*.

Table 4. Characteristics associated with survivors' perceptions of care

	Treatment delivery		Treatment decision-making		Coordinated and integrated care		Emotional support		Timely care	
	Estimated change (95% CI)	p	Estimated change (95% CI)	p	Estimated change (95% CI)	p	Estimated change (95% CI)	p	Estimated change (95% CI)	p
Education	0.04	0.52	0.02	0.80	0.06	0.24	0.09	0.14	-0.10	0.25
High school or less	(-0.07,0.14)		(-0.12,0.15)		(-0.04,0.15)		(-0.03,0.21)		(-0.27,0.07)	
University/ trade/vocational										
Employment	-0.03	0.62	-0.08	0.26	-0.04	0.45	0.01	0.84	0.19	0.03*
Employed	(-0.13,0.08)		(-0.21,0.06)		(-0.13,0.06)		(-0.11,0.13)		(0.02,0.35)	
Unemployed										
Private health insurance	0.03	0.57	-0.09	0.20	-0.03	0.54	-0.06	0.36	0.07	0.44
Yes	(-0.08,0.15)		(-0.24,0.05)		(-0.13,0.07)		(-0.19,0.07)		(-0.11,0.25)	
No										
Sex	-0.06	0.28	-0.01	0.91	0.06	0.18	0.03	0.67	-0.00	0.98
Male	(-0.16,0.05)		(-0.14,0.13)		(-0.03,0.16)		(-0.10,0.15)		(-0.17,0.17)	
Female										
Residence	0.06	0.36	0.14	0.10	0.07	0.22	0.09	0.25	0.05	0.62
Rural	(-0.07,0.19)		(-0.03,0.31)		(-0.04,0.19)		(-0.06,0.24)		(-0.16,0.26)	
Urban										
Age	0.17	0.10	0.07	0.60	-0.03	0.75	-0.06	0.58	0.09	0.57
18-39 years	(-0.03,0.37)		(-0.19,0.33)		(-0.20,0.15)		(-0.29,0.16)		(-0.23,0.41)	
40+ years										
Time since diagnosis	0.06	0.42	0.07	0.47	0.01	0.83	0.21	0.01*	0.01	0.94
1-24 months	(-0.08,0.20)		(-0.11,0.24)		(-0.11,0.13)		(0.05,0.37)		(-0.21,0.23)	
25+ months										
Cancer type	0.19	0.02*	0.22	0.06	-0.15	0.38	-0.03	0.97	-0.02	0.28
Hodgkin lymphoma	(-0.02,0.40)		(-0.05,0.49)		(-0.34,0.03)		(-0.27,0.21)		(-0.35,0.31)	
Non-Hodgkin lymphoma	0.23		0.28		-0.07		-0.00		-0.04	
(0.07,0.39)			(0.08,0.48)		(-0.21,0.07)		(-0.19,0.18)		(-0.29,0.21)	
Myeloma	0.08		0.18		-0.03		0.03		0.20	
(-0.11,0.28)			(-0.07,0.43)		(-0.20,0.14)		(-0.20,0.25)		(-0.12,0.51)	
Leukaemia										
Depression	-0.19	0.01*	-0.37	<0.0001*	-0.09	0.17	-0.07	0.42	-0.01	0.90
Yes	(-0.33,-0.05)		(-0.56,-0.19)		(-0.22,0.04)		(-0.23,0.10)		(-0.24,0.22)	
No										
Anxiety	-0.06	0.40	0.00	1.00	0.08	0.21	0.09	0.30	-0.21	0.08
Yes	(-0.21,0.08)		(-0.19,0.19)		(-0.05,0.21)		(-0.08,0.25)		(-0.44,0.02)	
No										
Stress	-0.08	0.35	0.01	0.92	-0.06	0.39	-0.18	0.07	-0.07	0.62
Yes	(-0.25,0.09)		(-0.20,0.23)		(-0.21,0.08)		(-0.37,0.01)		(-0.33,0.20)	
No										

* $p < 0.05$.

Conclusions

This is the first study to assess haematological cancer survivors' perceptions of care across items based on the six IOM patient-centredness dimensions [4] using a psychometrically robust measure [21]. Haematological cancer survivors perceived *respectful communication* as an area of high quality care. This is consistent with evidence that most cancer patients thought doctors and nurses were empathetic [23], respectful [24,25], friendly to them [23] and family and friends [25] and communicated clearly [23]. Haematological cancer survivors also considered *treatment delivery* to be of high quality. This is similar to research that reported medical care was the second highest

feature cancer patients were satisfied with [25]. Errors in chemotherapy delivery are also infrequent [26].

The most common areas of care not received by haematological cancer survivors were related to hospital staff helping survivors and family and friends find others in similar situations to talk to. Previous studies identified that some haematological cancer survivors expressed a need to talk to individuals in similar situations [16,27]. Systematic reviews of cancer peer support programs reported benefits [28-30], including increased knowledge about cancer and treatment [28,29], reassurance [28] and psychosocial adjustment [30]. The health system should therefore examine strategies that proactively connect haematological cancer survivors and families with individuals with similar experiences.

Follow-up care		Respectful communication		Patient preferences and values		Cancer information		Equitable care	
Estimated change (95% CI)	p	Estimated change (95% CI)	p	Estimated change (95% CI)	p	Estimated change (95% CI)	p	Estimated change (95% CI)	p
0.10 (-0.04,0.24)	0.17	-0.03 (-0.14,0.08)	0.56	0.11 (-0.05,0.27)	0.16	0.08 (-0.05,0.22)	0.22	-0.13 (-0.27,0.0)	0.06
-0.06 (-0.20,0.08)	0.42	-0.04 (-0.15,0.07)	0.46	-0.12 (-0.28,0.04)	0.13	-0.02 (-0.15,0.12)	0.80	0.27 (0.13,0.41)	0.0001*
-0.02 (-0.16,0.13)	0.83	-0.06 (-0.18,0.06)	0.32	0.33 (0.16,0.50)	0.0002*	-0.15 (-0.29,-0.0)	0.04*	0.07 (-0.07,0.22)	0.33
0.11 (-0.03,0.25)	0.12	-0.02 (-0.13,0.09)	0.70	0.08 (-0.08,0.24)	0.33	-0.06 (-0.19,0.08)	0.42	0.00 (-0.14,0.14)	0.99
0.13 (-0.04,0.31)	0.13	0.11 (-0.03,0.25)	0.11	0.04 (-0.16,0.24)	0.67	0.14 (-0.03,0.31)	0.10	-0.16 (-0.33,0.01)	0.07
0.08 (-0.18,0.34)	0.57	0.29 (0.09,0.50)	0.005*	-0.16 (-0.46,0.13)	0.28	0.27 (0.01,0.52)	0.04*	-0.03 (-0.29,0.23)	0.81
0.07 (-0.11,0.25)	0.44	0.13 (-0.02,0.27)	0.08	0.14 (-0.07,0.35)	0.18	0.03 (-0.15,0.20)	0.77	0.04 (-0.14,0.23)	0.64
-0.01 (-0.28,0.26)	0.26	0.00 (-0.21,0.22)	0.50	0.13 (-0.17,0.44)	0.59	0.07 (-0.20,0.33)	0.02*	0.27 (-0.00,0.55)	0.17
0.16 (-0.05,0.36)		0.10 (-0.07,0.26)		0.09 (-0.14,0.33)		0.27 (0.07,0.47)		0.21 (0.01,0.42)	
0.08 (-0.18,0.33)		0.12 (-0.08,0.32)		-0.03 (-0.33,0.26)		0.14 (-0.11,0.38)		0.16 (-0.09,0.41)	
-0.26 (-0.45,-0.07)	0.007*	-0.22 (-0.37,-0.07)	0.003*	-0.41 (-0.62,-0.19)	0.0002*	-0.23 (-0.42,-0.05)	0.01*	-0.08 (-0.27,0.11)	0.41
0.05 (-0.14,0.24)	0.63	-0.06 (-0.21,0.09)	0.44	-0.04 (-0.26,0.17)	0.70	0.07 (-0.12,0.25)	0.48	0.01 (-0.18,0.19)	0.93
-0.12 (-0.34,0.10)	0.28	0.13 (-0.04,0.30)	0.14	0.09 (-0.16,0.33)	0.49	-0.31 (-0.52,-0.10)	0.004*	0.01 (-0.21,0.22)	0.93

Cancer patients have the right to obtain a second medical opinion [31]. Almost 30% of haematological cancer survivors disagreed that doctors explained they could get a second medical opinion if the survivor wished. This item identified whether or not doctors initiated discussions with survivors about the option to obtain a second medical opinion if survivors wished to do so. Doctor-initiated discussion ensures patients are aware of the option of a second opinion [31]. A second opinion changed breast cancer management for around 20% of patients [32]. Furthermore, cancer patients' reasons for seeking a second medical opinion included obtaining treatment information, reassurance about diagnosis or treatment and dissatisfaction with first opinion [33].

Characteristics associated with survivors perceiving higher quality care was delivered included being employed,

having private health insurance, being younger, a Non-Hodgkin lymphoma diagnosis and more recent diagnosis. In contrast, being depressed or stressed was associated with perceived lower quality of care. This is consistent with research with other cancer types that reported lower income [18], and younger age [18] were associated with perceived higher quality care and depression with perceived lower quality care [9,18]. Providing additional support to subgroups of haematological cancer survivors who report lower quality care may lead to improved care.

The QPCCC measure's development focussed on haematological cancer survivors [21] but could potentially measure patient-centred care among other groups of cancer survivors following psychometric evaluations with different cancer types. Future research could compare the perceptions

of haematological cancer survivors to survivors of other cancer types to determine if quality of patient-centred care differs between survivor groups. Further research could also use the QPCCC measure to examine whether cancer survivors' perceptions of quality of care vary between hospitals.

Study strengths included that a large number of haematological cancer survivors with diverse sub-types were recruited via population-based cancer registries that provide a representative sampling frame of all cancer survivors from across the state [34]. Furthermore, the QPCCC measure is psychometrically robust and measures patient-centredness across the six IOM-endorsed dimensions [21]. However, limitations include that 32% of eligible survivors participated and that leukaemia and younger survivors at diagnosis were under-represented among participants. Other studies that used registry recruitment also reported low response rates (26% [35] and 41% [36]).

Using PROMs to assess haematological cancer survivors' perceptions of care are essential to identifying areas of high

quality care and informing quality improvement efforts. Consumer and professional groups may also use such information to proactively advocate for improvements to care.

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Conflict of interest

The authors have no conflict of interest.

References

- Evans J, Ziebland S, Pettitt A. Incurable, invisible and inconclusive: watchful waiting for chronic lymphocytic leukaemia and implications for doctor-patient communication. *Eur J Cancer Care* 2012;**21**:67-77.
- National Institute for Clinical Excellence. Improving Outcomes in Haematological Cancers. National Institute for Clinical Excellence: London, 2003.
- Australian Institute of Health and Welfare. Cancer in Australia 2010: An Overview. Australian Institute of Health and Welfare: Canberra, 2010.
- Institute of Medicine. Crossing the Quality Chasm: A New Health System for the 21st Century. National Academy Press: Washington DC, 2001.
- Gerteis M, Edgman-Levitan S, Daley J. Through the Patient's Eyes. Understanding and Promoting Patient-centered Care. Jossey-Bass: San Francisco, CA, 1993.
- Wensing M, Elwyn G. Methods for incorporating patients' views in health care. *BMJ* 2003;**326**:877-879.
- Wong WS, Fielding R. The association between patient satisfaction and quality of life in Chinese lung and liver cancer patients. *Med Care* 2008;**46**:293-302.
- Von Essen L, Larsson G, Oberg K, Sjoden PO. 'Satisfaction with care': associations with health-related quality of life and psychosocial function among Swedish patients with endocrine gastrointestinal tumours. *Eur J Cancer Care* 2002;**11**:91-99.
- Frojd C, Lampic C, Larsson G, von Essen L. Is satisfaction with doctors' care related to health-related quality of life, anxiety and depression among patients with carcinoid tumours? A longitudinal report. *Scand J Caring Sci* 2009;**23**:107-116.
- Bickell NA, Weidmann J, Fei K, Lin JJ, Leventhal H. Underuse of breast cancer adjuvant treatment: patient knowledge, beliefs, and medical mistrust. *J Clin Oncol* 2009;**27**:5160-5167.
- Mandelblatt JS, Sheppard VB, Hurria A, et al. Breast cancer adjuvant chemotherapy decisions in older women: the role of patient preference and interactions with physicians. *J Clin Oncol* 2010;**28**:3146-3153.
- Shin DW, Park JH, Shim EJ, Hahm MI, Park EC. Predictors and outcomes of feeling of insufficient consultation time in cancer care in Korea: results of a nationwide multicenter survey. *Support Care Cancer* 2012;**20**:1965-1973.
- Kowalski C, Nitzsche A, Scheibler F, Steffen P, Albert U-S, Pfaff H. Breast cancer patients' trust in physicians: the impact of patients' perception of physicians' communication behaviors and hospital organizational climate. *Patient Educ Couns* 2009;**77**:344-348.
- Carey M, Anderson A, Sanson-Fisher R, Lynagh M, Paul C, Tzelepis F. How well are we meeting haematological cancer survivors' preferences for involvement in treatment decision making? *Patient Educ Couns* 2012;**88**:87-92.
- Arden-Close E, Absolom K, Greenfield DM, et al. Gender differences in self-reported late effects, quality of life and satisfaction with clinic in survivors of lymphoma. *Psycho-Oncology* 2011;**20**:1202-1210.
- Lobb EA, Joske D, Butow P, et al. When the safety net of treatment has been removed: patients' unmet needs at the completion of treatment for haematological malignancies. *Patient Educ Couns* 2009;**77**:103-108.
- Parry C, Morningstar E, Kendall J, Coleman EA. Working without a net: leukemia and lymphoma survivors' perspectives on care delivery at end-of-treatment and beyond. *J Psychosoc Oncol* 2011;**29**:175-198.
- Ayanian JZ, Zaslavsky AM, Arora NK, et al. Patients' experiences with care for lung cancer and colorectal cancer: findings from the Cancer Care Outcomes Research and Surveillance Consortium. *J Clin Oncol* 2010;**28**:4154-4161.
- Noh DY, Nam SJ, Ahn SH, et al. Association of clinical experiences with patient-reported outcomes among breast cancer surgery patients: breast cancer quality care study. *Qual Life Res* 2008;**17**:215-225.
- Tzelepis F, Rose SK, Sanson-Fisher RW, Clinton-McHarg T, Carey ML, Paul CL. Are we missing the Institute of Medicine's mark? A systematic review of patient-reported outcome measures assessing quality of patient-centred cancer care. *BMC Cancer* 2014;**14**:41.
- Tzelepis F, Sanson-Fisher RW, Hall AE, Carey ML, Paul CL, Clinton-McHarg T. Development and psychometric evaluation of the Quality of Patient-Centered Cancer Care (QPCCC) measure with hematological cancer survivors. *Cancer* Under editorial review.
- Antony MM, Cox BJ, Enns MW, Swinson RP. Psychometric properties of the 42-item and 21-item versions of the Depression Anxiety Stress Scales in clinical groups and a community sample. *Psychol Assess* 1998;**10**:176-181.
- Kleeberg UR, Feyer P, Günther W, Behrens M. Patient satisfaction in outpatient cancer care: a prospective survey using the PASQOC questionnaire. *Support Care Cancer* 2008;**16**:947-954.
- de Kok M, Sixma HJM, van der Weijden T, et al. A patient-centred instrument for assessment of quality of breast cancer care: results of a pilot questionnaire. *Qual Saf Health Care* 2010;**19**:e40.
- Singer S, Gotze H, Mobius C, et al. Quality of care and emotional support from the inpatient cancer patient's perspective. *Langenbecks Arch Surg* 2009;**394**:723-731.

26. Markert A, Thierry V, Kleber M, Behrens M, Engelhardt M. Chemotherapy safety and severe adverse events in cancer patients: strategies to efficiently avoid chemotherapy errors in in- and outpatient treatment. *Int J Cancer* 2009;**124**:722–728.
27. Hall A, Campbell HS, Sanson-Fisher R, *et al*. Unmet needs of Australian and Canadian haematological cancer survivors: a cross-sectional international comparative study. *Psycho-Oncology* 2013;**22**:2032–2038.
28. Campbell HS, Phaneuf MR, Deane K. Cancer peer support programs—do they work? *Patient Educ Couns* 2004;**55**:3–15.
29. Dunn J, Steginga SK, Rosoman N, Millichap D. A review of peer support in the context of cancer. *J Psychosoc Oncol* 2003;**21**:55–67.
30. Hoey LM, Ieropoli SC, White VM, Jefford M. Systematic review of peer-support programs for people with cancer. *Patient Educ Couns* 2008;**70**:315–337.
31. Cancer Council Australia. Cancer care and your rights: a practical guide for people with cancer and their families and friends. Woolloomooloo: Cancer Council Australia 2013.
32. Clauson J, Hsieh YC, Acharya S, Rademaker AW, Morrow M. Results of the Lynn Sage Second-Opinion Program for local therapy in patients with breast carcinoma. Changes in management and determinants of where care is delivered. *Cancer* 2002;**94**:889–894.
33. Tattersall MHN, Dear RF, Jansen J, *et al*. Second opinions in oncology: the experiences of patients attending the Sydney Cancer Centre. *MJA* 2009;**191**:209–212.
34. Sanson-Fisher R, Carey M, Mackenzie L, Hill D, Campbell S, Turner D. Reducing inequities in cancer care: the role of cancer registries. *Cancer* 2009;**115**:3597–3605.
35. Courtney RJ, Paul CL, Carey ML, *et al*. A population-based cross-sectional study of colorectal cancer screening practices of first-degree relatives of colorectal cancer patients. *BMC Cancer* 2013;**13**:13.
36. Boyes AW, Girgis A, D'Este C, Zucca AC. Prevalence and correlates of cancer survivors' supportive care needs 6 months after diagnosis: a population-based cross-sectional study. *BMC Cancer* 2012;**12**:150.