



Radiation oncology outpatient perceptions of patient-centred care: A cross-sectional survey

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ABSTRACT:

Objectives. The Institute of Medicine has indicated the urgency of evaluating and improving quality of health care, including patient-centred care. We aimed to describe the proportion and characteristics of cancer patients who perceived that better care would have greatly improved their wellbeing in a) specific, and b) multiple domains of patient-centred care.

Design. Cross sectional touchscreen computer survey.

Setting. Four Australian radiation therapy departments located within major urban public hospitals.

Participants. Radiation therapy outpatients were invited to participate in a touchscreen computer survey. Eligible patients were aged at least 18 years old, diagnosed with cancer, and had sufficient English to complete the survey.

Primary outcome measure. Participants were asked whether their wellbeing could have been greatly improved if better care had been provided across eight domains of patient-centred care. Characteristics of those respondents who identified a) specific and b) multiple domains where it was perceived that better care would have greatly improved their well-being, were examined.

Results. Of 508 eligible radiation therapy patients, 344 (68%) completed the survey. Patients most frequently perceived that better care in the following domains could have improved their wellbeing: information and communication about their cancer (22%;

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2
3 95% CI: 18-27%); emotional and spiritual support (22%; 95% CI: 18-27%);
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5 management of physical symptoms (21%; 95% CI: 17-26%); and involvement of friends
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7 and family (21%; 95% CI: 17-26%). Just under one third of respondents (31%; 95% CI:
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9 26-36%) indicated that their wellbeing could have been improved by better care across
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11 two or more domains of care.

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16 **Conclusions.** Patients in younger age groups and migrants to Australia had higher odds
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18 of identifying multiple domains of patient-centredness where better care would have
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20 greatly improved their wellbeing. Further investigation of patients' perceptions
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22 regarding how their perceived quality might be improved is warranted.
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INTRODUCTION.

Why assess patient views of quality of care?

The Institute of Medicine (IOM) has indicated the urgency of assessing and improving the quality of health care [1]. Quality health care is care that is safe, timely, effective, efficient, equitable and patient-centred [2]. A patient-centred approach to care is defined as being respectful of, and responsive to, patients' physical, social and emotional preferences and needs [3]. Provision of patient-centred care may contribute to improvements in patients' physical, mental and social well-being [4 5]. A patient-centred approach to care is now endorsed as a key component of quality health care by many organisations (including the World Health Organisation [6]) and governments (e.g. in Australia, USA, UK, Canada, Germany, France, Netherlands and Switzerland [7]). Examining patients' judgements of how their experiences of care correspond with their preferences and needs is required in order to assess the quality of patient-centred care [8].

What has previous patient-centred care research contributed to knowledge about prioritising quality improvement efforts?

Although previous research has indicated that up to 50% of cancer outpatients are dissatisfied with the level of information provided about physical symptom management, emotional support, involvement of family, and some aspects of access to care,[9-11] these studies have not provided an indication of the relative importance that patients place on quality improvement in these different domain areas. The patient satisfaction approach to assessing quality of care has been criticised for failing to consider differences in patient expectations, leading to emerging research comparing discrepancies between patients' perceived ideal and actual care [12]. However, this

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3 approach still does not capture patient perceptions of the degree to which their
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5 wellbeing would benefit from improved care across different domains [13]. Perceptions
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7 of relative benefit received by improvements in different domains of care may assist in
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9 prioritising quality improvement efforts.
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14 Previous work on patient-centred care has identified that some subgroups of patients
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16 may receive poorer care than others. For instance, older patients may be more likely
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18 than younger patients to express satisfaction with care, possibly relating to differences
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20 in the expectations for care provision [14]. Additionally, cancer patients who have
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22 clinically significant levels of anxiety have been found to give lower ratings of
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24 satisfaction with care [15]. Wellbeing in patients diagnosed with chronic illness may be
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26 linked to aspects of social support such as having a partner,[16] and also potentially to
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28 ethnicity [17]. It is of interest to assess both the relative importance of different domains
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30 of patient-centred care; and to identify the characteristics of patients who perceive the
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32 need for better care.
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39 **Patient-centred care for radiation therapy patients**

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41 Approximately 50% of cancer patients undergo radiation therapy treatment [18]. Given
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43 that this treatment is often characterised by frequent contact with the healthcare system
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45 over the course of treatment, the radiation therapy setting provides an opportunity for
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47 addressing patient needs across the multiple domains of patient-centred care [18]. To
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49 the best of our knowledge, this is the first study to ask cancer patients undergoing
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51 radiation therapy about their perceptions of how better care across patient-centred
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53 domains could improve their wellbeing [19]. Further, no previous studies have
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3 identified whether characteristics within radiation therapy patients are likely to receive
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5 better patient-centred care than others [20].
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10 This study aimed to examine the proportion and characteristics of radiation therapy
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12 patients who indicate that their well-being could have been greatly improved by better
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14 cancer care across each of eight domains of patient-centred care. We also aimed to
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16 assess characteristics associated with a patient perception that better care across
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18 multiple domains of patient-centred care would have improved their well-being.
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21 22 23 **METHODS.**

24 25 **Design**

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27 Cross sectional survey completed using touchscreen computers.
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30 31 32 **Participants**

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34 Radiation oncology outpatients were recruited from four radiation therapy departments
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36 in a major urban centre in Australia between March and December 2010. Each radiation
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38 therapy department was attached to a major public teaching hospital, and had at least
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40 three Linear Accelerators available for treatment. Eligible patients were aged 18 years
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42 or older; diagnosed with cancer; and had sufficient command of English to complete the
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44 touchscreen computer survey. Patients who were attending the clinic for the first time
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46 or who were considered by clinic staff to be too unwell or unable to give informed
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48 consent were excluded.
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51 52 53 54 55 **Procedure**

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3 Patients waiting for a radiation therapy treatment were invited to participate in the
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5 study by a research assistant. Consenting patients were given a unique identification
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7 code to login to the touchscreen computer questionnaire. If patients were called into
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9 their treatment before finishing their survey, they had the option of resuming after their
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11 treatment. Touchscreen computer surveys have been reported as being faster and easier
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13 to use for outpatients than pencil and paper surveys,[21] and have been found to be
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15 acceptable to oncology patients [22].
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21 **Measures**

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23 Digivey survey software (CREOSO - Digivey Survey Center, Phoenix, Arizona) was used
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25 to program the patient survey, which was administered using Dell Latitude XT2
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28 touchscreen laptop computers.
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32 Quality of Care: patient-centred care.

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34 Questions were developed to correspond with domains of patient-centred care
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36 described in the literature,[9 11] ensuring face validity of the items. Survey items were
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38 extensively pilot tested and modified based on feedback from 67 patients. Eight items,
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40 each assessing a different domain of care, were presented on separate screens with the
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42 stem "During my cancer care, my well-being would have been greatly improved by."
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46 Table 1 lists the eight items and a short description of each domain that was presented
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48 at the bottom of the touchscreen. Patients were asked to indicate their level of
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50 agreement with each statement on a 4-point Likert scale (Strongly disagree, Disagree,
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52 Agree, Strongly agree). Internal consistency of the items was assessed using Cronbach's
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54 alpha.
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Table 1. Survey items and descriptions (each assessing a different domain of care)

Item	On screen description
Better management of my physical symptoms	May relate to your pain, sleeplessness, other side-effects and symptoms.
Better information and communication about my cancer and care	May include: clear and consistent information about your diagnosis, test results, treatment, taking medications, food you should be eating, exercise you can do safely etc.
Better emotional and/or spiritual support	May include services or support to help you cope with: the impact of cancer on your life, doubts/worries, feelings of anxiety or sadness, changes to your body images etc.
Better services, information and support for my friends/family	May include helping them to cope with the impact of your cancer, or providing opportunities for them to be involved in your care.
Better staff approachability and respect for me	Describes staff who are easy to contact and up-to-date with your medical history, and who give you opportunities to ask questions and be involved in treatment decisions.

Getting better access to the care I need when required	Describes not having to wait too long to get appointments, and having treatment and medical advice available when needed.
Better services/support to cope with changes to my relationships	May include: knowing what changes to expect, and having some strategies to reduce the impact of cancer on your work, usual social activities, friendships or sexual relationships.
Better services/advice to assist me with practical concerns	May include being able to access financial support, transport to treatment, home help services or other support needed to manage practical issues.

Demographic characteristics.

Patient self-report was used to collect age, gender, whether participants were born in Australia, living with a partner and the postcode of usual place of residence.

Disease characteristics.

A multiple choice question "What is your most recent primary cancer diagnosis?" was used to determine respondents' most recent primary cancer diagnosis. Common cancer types were listed on screen, along with the categories "other - please specify" and "don't know". Approximate time since diagnosis was calculated from patient self-reported year and month of diagnosis and their recruitment date. Patients were asked to indicate the number of radiation therapy treatment and outpatient appointments they had attended; whether they had experienced a second diagnosis and/or recurrence, and whether they

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3 perceived that the aim of their treatment was to cure the cancer; prevent the cancer
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5 from coming back or control symptoms of cancer (cure is not possible).
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9 Psychological characteristics.

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11 The Hospital Anxiety and Depression Scale (HADS) is a 14-item self-report measure of
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13 anxiety and depression [23]. Both the anxiety and depression subscales provide scores
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15 of between 0 and 21 where 0-7= Normal; 8-10= Mild; 11-14 = Moderate; 15-21 = Severe.
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17 The scale has been utilised in research and in clinical practice,[24] with demonstrated
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19 reliability and validity [25]. HADS scores have been found to be comparable when
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21 administered by touchscreen computer and pen-and-paper in a cancer patient
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23 population [26].
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30 **Statistical Methods**

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32 Radiation therapy patients were defined as having endorsed each domain if they
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34 indicated that they “agreed” and “strongly agreed” that better care would have greatly
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36 improved their well-being. The proportion of patients endorsing each domain was
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38 reported with 95% confidence intervals. Respondents were then dichotomised on the
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40 basis of: a) 0-1 domains endorsed or b) multiple (2 or more) domains endorsed.
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42 Univariate logistic analysis was used to investigate the relationship between
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44 demographic characteristics, disease factors and psychological distress and patient
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46 endorsement of a) each of the 8 domains of care and b) multiple (2 or more) domains of
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48 care requiring improvement. The explanatory variables examined included age (18-49,
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50 50-59, 60-69, 70 plus), sex (male, female), cancer diagnosis (Breast, Prostate,
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52 Other/Don’t Know), second diagnosis and/or recurrence (no, yes), Australian born (no,
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54 Other/Don’t Know), second diagnosis and/or recurrence (no, yes), Australian born (no,
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56 Other/Don’t Know), second diagnosis and/or recurrence (no, yes), Australian born (no,
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58 yes), living with a partner (no, yes), anxiety (no, yes), depression (no, yes), usual place of
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3 residence (urban/rural, based on Accessibility/Remoteness Index of Australia (ARIA+)
4 score) and socioeconomic status (Socio-Economic Indexes for Areas (SEIFA) average
5 scores[27]). Variables with a *p* value of 0.2 or less on the univariate likelihood ratio test
6 were included in the multiple logistic regression model. The backwards stepwise
7 method was then used to remove all variables with a *p* value of 0.1 or more on the
8 likelihood ratio test, with recruitment site included in all multiple regression models.
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10 The fit of the final model was assessed using the Hosmer-Lemeshow goodness of fit test.
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12 For individual domains, odds ratios with 95% confidence intervals are reported for
13 multiple regression models. For the assessment of characteristics associated with
14 endorsing multiple domains, odds ratios with 95% confidence intervals are reported for
15 univariate and multiple regression models. Analysis was conducted using STATA version
16 11.2, and a significance level of 0.05 used.
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32 **Sample size and statistical power**

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34 We aimed to recruit a total of 450 patients which, based on 50% of patients perceiving
35 the need for better care in each domain, would allow us to obtain prevalence estimates
36 with 95% CI's within $\pm 5\%$ of the point estimate. This sample size would also be
37 sufficient to detect differences of approximately 15% in characteristics between those
38 who perceive the need for better care in each domain of care with 80% power and 5%
39 significance level.
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50 **RESULTS.**

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52 Of the 639 patients screened for eligibility, 110 were ineligible due to: inadequate
53 English (n=51); not currently receiving RT (n = 32); had already been approached about
54 the study (n = 6); not being diagnosed with cancer (n = 3); clinic staff concern about
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3 patient burden or ability to give informed consent (n = 3); being aged under 18 (n = 2),
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5 or no specified reason (n=13). Of the 529 eligible patients, 85% (n = 451) consented, and
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7 69% (n = 365) completed the survey. Incomplete surveys were primarily because
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9 patients were called into their treatment appointment before survey completion, and no
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11 data was available from these surveys. An additional 21 patients were excluded because
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13 they reported that they were attending their first RT treatment. Once these participants
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15 were ruled ineligible, the overall response rate was 68% of 508 eligible radiation
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17 therapy patients. Table 2 shows the characteristics of the 344 respondents. 51% were
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19 male, the median age was 63.3 (Quartile [Q] 1: 52.2, Q3: 70.5) and the median number of
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21 weeks since diagnosis was 27.6 (Q1: 16.0, Q3: 57.3). The majority of respondents (97%)
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23 were currently receiving radiation therapy treatment, with the remainder reporting that
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25 they were attending the treatment centre for a check-up. The distribution of primary
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27 cancer type within the sample can be seen in Table 2.
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Table 2. Demographic and disease characteristics of respondents (n = 344)

Characteristic	n (%)
Males	176 (51%)
Region of birth	
Australia	231 (67%)
UK/Ireland	30 (8.7%)
Europe	29 (8.4%)
Asia	25 (7.2%)
Other	29 (8.4%)
Perceived palliative treatment aim	46 (14%)
Primary cancer type	
Breast	93 (27%)
Prostate	73 (21%)
Head and neck	33 (9.6%)
Colorectal	20 (5.8%)
Brain	15 (4.4%)
Lung	15 (4.4%)
Other	89 (26%)
Don't know	6 (1.7%)
Second diagnosis/recurrence	96 (28%)
	Median (Q1, Q3)
Completed appointments with doctor	3 (2, 5)
Completed radiation therapy appointments	9 (4, 17)
Weeks since diagnosis	27.6 (16, 37.3)

Note. Observations within each variable may not add to the total due to missing values

Internal consistency of items

When considering the items with responses on a 4-point Likert scale, the internal consistency (Cronbach's α) was 0.92. When the responses were dichotomised (agree versus disagree), Cronbach's α was 0.89.

Proportion of patients endorsing individual domains of patient-centred care

Table 3 shows the number and proportion of radiation oncology patients who agreed that their well-being could have been improved by better care across 8 different domains of patient-centred care. It can be seen that each domain was endorsed by between 12% and 22% of patients.

Table 3. Proportion who reported that their wellbeing would have been improved by better care across 8 domains ($n = 344$)

	Agree
	<i>n</i> (% , 95% CI)
Information and communication about my cancer and care	76 (22%, 18-27%)
Emotional and/or spiritual support	75 (22%, 18-27%)
Management of my physical symptoms	72 (21%, 17-26%)
Services; information and support for my friends/family	72 (21%, 17-26%)
Services/advice to assist me with practical concerns	69 (20%, 16-25%)
Access to the care I need when required	62 (18%, 14-23%)
Services/support to cope with changes to my relationships	56 (16%, 13-21%)

Staff approachability and respect for me42 (12%, 8.9-16%)

Characteristics associated with endorsement of domains

Multiple logistic regression analysis identified that Australian born participants had lower odds of endorsing perceiving “better management of physical symptoms” would have greatly improved their well-being (OR = 0.4; 95% CI: 0.2-0.7; $p = 0.0008$). No other characteristics were significantly associated with endorsing better management of physical symptoms.

Better information and communication about my cancer and care: Australian born patients had lower odds of perceiving that “better information and communication about my cancer and care” would have greatly improved their well-being (OR = 0.5; 95% CI: 0.3-0.9; $p = 0.0153$), as did patients living with a partner (OR = 0.5; 95% CI: 0.3-0.8; $p = 0.0083$). It was also found that patients aged 60-69 years (OR = 0.3; 95% CI: 0.1-0.7) and aged 70 or over (OR = 0.3; 95% CI: 0.2-0.8) had lower odds of endorsing this domain than younger participants ($p = 0.0042$). Patients with a likely presence of depression had three times the odds of endorsing this domain (OR = 3.1; 95% CI: 1.1-9.0; $p = 0.0396$).

Better emotional and/or spiritual support: Patients aged 60-69 years (OR = 0.3; 95% CI: 0.1-0.6) and aged 70 or over (OR = 0.4; 95% CI: 0.2-0.8) had lower odds of endorsing this domain than younger participants ($p = 0.0011$). Australian born patients had lower odds of endorsing this domain (OR = 0.3; 95% CI: 0.2-0.5; $p < 0.0001$), whilst patients

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3 with clinically significant levels of depression had higher odds of endorsing (OR = 3.5;
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5 95% CI: 1.2-10.1; $p = 0.0250$).

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10 Better services, information and support for my friends/family: Lower odds of
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12 endorsing this domain were found in older patients aged 60-69 years (OR = 0.2; 95% CI:
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14 0.1-0.5) and aged 70 or over (OR = 0.2; 95% CI: 0.1-0.4) compared to younger
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16 participants ($p < 0.0001$), and also in Australian born patients (OR = 0.4; 95% CI: 0.2-0.6;
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18 $p = 0.0004$).

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23 Better staff approachability and respect for me: Australian born patients had
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25 significantly lower odds of endorsing this domain (OR = 0.3; 95% CI: 0.1-0.5; $p =$
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27 0.0001). Marginally non-significantly lower odds of endorsing this domain were found in
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29 older patients aged 60-69 years (OR = 0.3; 95% CI: 0.1-0.9) compared to younger
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31 participants ($p = 0.0683$).

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37 Getting better access to the care I need when required: Older patients aged 60-69 years
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39 (OR = 0.2; 95% CI: 0.1-0.5) and aged 70 or over (OR = 0.3; 95% CI: 0.1-0.8) had lower
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41 odds of endorsing this domain compared to younger participants ($p = 0.0003$). Once
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43 again, Australian born patients had lower odds of endorsing this domain (OR = 0.3; 95%
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45 CI: 0.2-0.6; $p = 0.0003$). Marginally non-significantly lower odds were also found in
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47 socioeconomic Group 2 (OR = 0.2; 95% CI: 0.1-0.9) and Group 3 (OR = 0.3; 95% CI: 0.1-
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49 0.9) compared to the lowest SES Group 1 ($p = 0.0837$).

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55 Better services/support to cope with changes to my relationships: Older patients aged
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57 60-69 years (OR = 0.1; 95% CI: 0.1-0.4) and aged 70 or over (OR = 0.2; 95% CI: 0.1-0.4)

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3 had lower odds of endorsing this domain compared to younger participants ($p <$
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5 0.0001). Once again, Australian born patients had lower odds of endorsing this domain
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7 (OR = 0.3; 95% CI: 0.1-0.5; $p = 0.0001$). Patients with clinically significant levels of
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9 depression had higher odds of endorsing this domain (OR = 7.2; 95% CI: 2.3-22.5; $p =$
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11 0.0007).

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16 Better services/advice to assist me with practical concerns: Older patients aged 60-69
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18 years (OR = 0.1; 95% CI: 0.1-0.3) and aged 70 or over (OR = 0.3; 95% CI: 0.1-0.6) had
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20 lower odds of endorsing this domain compared to younger participants ($p < 0.0001$).
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22 Australian born patients also had lower odds of endorsing this domain (OR = 0.5; 95%
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24 CI: 0.3-0.8; $p = 0.0070$).

25 26 27 28 29 30 **Proportion of patients endorsing multiple domains where better care would have** 31 32 **improved their well-being**

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34 Figure 1 shows the percentage of respondents endorsing none, one and multiple
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36 domains where better care would have improved their wellbeing. Overall 31% of
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38 respondents ($n = 107$) endorsed multiple domains where they agreed or strongly agreed
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40 that their wellbeing could have been improved by better care.
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46 FIGURE 1 ABOUT HERE
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51 For 55% of participants, it was perceived that improvement in well-being would not
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53 have resulted from better care in any of the examined domains. Fourteen percent of
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55 participants identified only one domain where better care would have greatly improved
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57 their well-being. Table 4 shows the results of analyses examining factors associated with
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the perception that wellbeing could have been improved by better care in multiple (2 or more) domains. It can be seen that compared with the younger age group (18-49 years), being aged 60 years or over was associated with significantly lower odds of endorsing multiple domains as requiring improvement. Additionally, relative to patients not born in Australia, those who were Australian born had significantly lower odds of endorsing multiple domains in which wellbeing would have been improved by better care.

Outpatients living with a partner had significantly lower odds of identifying multiple domains where better care would have greatly improved their wellbeing. There were significantly higher odds of endorsing multiple domains amongst outpatients with a likely presence of anxiety.

Table 4. Demographic, disease and HADS associations with endorsement of multiple domains as requiring improvement¶

	Multiple domains endorsed <i>n</i> (%)	LR Chi², <i>p</i> Unadjusted OR (95% CI) 	LR Chi², <i>p</i> Adjusted OR (95% CI)
Hospital		5.0, <i>p</i> = 0.1752	2.9, <i>p</i> = 0.4002
Site 1	36 (36%)	1.0	1.0
Site 2	22 (23%)	0.5 (0.3-1.0)	0.6 (0.3-1.2)
Site 3	23 (32%)	0.8 (0.4-1.6)	0.9 (0.4-1.8)
Site 4	26 (34%)	0.9 (0.5-1.7)	1.0 (0.5-2.0)
Age category		35.9, <i>p</i> <0.0001	28.9, <i>p</i>
18-49 years	36 (51%)	1.0	<0.0001*

50-59 years	34 (46%)	0.8 (0.4-1.5)	1.0
60-69 years	20 (18%)	0.2 (0.1-0.4)	0.7 (0.4-1.4)
70 years plus	17 (19%)	0.2 (0.1-0.4)	0.2 (0.1-0.4)
			0.2 (0.1-0.5)
Sex§		2.5, p = 0.1159	
Male	48 (27%)	1.0	
Female	59 (35%)	1.4 (0.9-2.3)	
Cancer type§		3.8, p = 0.1469	
Breast	31 (33%)	1.0	
Prostate	16 (22%)	0.6 (0.3-1.1)	
Other cancer types†	60 (34%)	1.0 (0.6-1.7)	
Second diagnosis or recurrence		1.0, p = 0.3123	
No	81 (33%)	1.0	
Yes	26 (27%)	0.8 (0.5-1.3)	
Born in Australia		8.5, p = 0.0037	5.4, p = 0.0205*
No	47 (42%)	1.0	1.0
Yes	60 (26%)	0.5 (0.3-0.8)	0.5 (0.3-0.9)
Socioeconomic status		0.3, p = 0.5758	
Low	5 (22%)	1.0	
Medium	8 (16%)	0.7 (0.2-2.4)	
High	59 (22%)	1.0 (0.4-2.9)	
Usual place of residence		0.3, p = 0.5758	
Major city	87 (32%)	1.0	
Regional or rural	19 (28%)	0.8 (0.5-1.5)	

Living with partner		5.2, p = 0.0224	3.9, p = 0.0481*
No	50 (38%)	1.0	1.0
Yes	57 (27%)	0.6 (0.4-0.9)	0.6 (0.4-1.0)
Clinically significant anxiety‡		10.4, p = 0.0013	4.3, p = 0.0383*
No	82 (28%)	1.0	1.0
Yes	25 (52%)	2.8 (1.5-5.2)	2.1 (1.0-4.1)
Clinically significant depression‡§		5.7, p = 0.0167	
No	97 (30%)	1	
Yes	10 (59%)	3.3 (1.2-9.0)	

Note. Observations within each variable may not add to the total due to missing values

†Including brain, colorectal, head and neck, lung, non-Hodgkin's lymphoma, and other cancer types

‡Assessed using the Hospital Anxiety and Depression Scale (HADS)

§Eliminated during backwards stepwise multiple logistic regression analysis

|| Reported *p*-values are from the Likelihood ratio test

¶ *p*-values for the Hosmer-Lemeshow goodness of fit test were between 0.2 and 0.9 for specific domain models; and was 0.1 for the multiple domain model

DISCUSSION

In which domains would better care greatly improve wellbeing for the most patients?

For each of the eight domains of care assessed, between 12-22% of respondents agreed or strongly agreed that their wellbeing would have greatly improved with better care.

One fifth or more agreed that improvements to the following domains would have improved their care: better information and communication about my cancer and care (22%); better emotional and/or spiritual support (22%); better management of physical symptoms (21%); better services information and support for friends/family (21%); and better services/advice to assist with practical concerns (20%). Overall, these frequencies were lower than identified in comparable domains in recent international studies of cancer patient experiences of care in Australia, New Zealand, British Columbia, Canada and Europe [9 10 15 28 29]. This discrepancy may be a consequence of the differences in measures. Although past measures have assessed experiences of care or unmet need, they have not assessed the impact that patients perceive better care in these patient-centred domains would have on their wellbeing. Alternatively, the discrepancies between findings may be a result of improved delivery of patient centred care over time.

Characteristics associated with endorsing each domain of patient-centred care

Country of birth

Australian born patients had lower odds of endorsing each of the assessed domains of patient-centred care. It may be that Australian born patients receive better care than migrants. Alternatively, it may be that Australian born patients have lower expectations

1
2
3 of care and of the degree to which their well-being would be improved by better care
4
5 [30]. Linguistic and cultural barriers to patient perceptions of high quality health care
6
7 have been previously identified, highlighting the need for responsiveness to cultural
8
9 background for optimal health care delivery [30]. There is a need to investigate this
10
11 finding amongst more culturally and linguistically diverse cancer communities, given
12
13 that the current research was limited to patients with adequate English to complete the
14
15 survey.
16
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18
19

20 21 Age group

22
23 Older age was associated with lower odds of endorsing a need for improvement in all
24
25 domains of patient-centred care, with the exception of management of physical
26
27 symptoms and staff approachability and respect for the patient. This is consistent with
28
29 previous studies suggesting that older age is associated with higher overall patient
30
31 satisfaction ratings [31]. It may be that older patients perceive pain management and
32
33 interpersonal care as a traditional role of the doctor, leading to similar perceptions
34
35 about the need for improvement in these domains as held by younger age groups.
36
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40 41 HADS classified depression

42
43 Patients with HADS classified depression had higher odds of endorsing the following
44
45 three domains than non-depressed respondents: Information and communication about
46
47 cancer and care; emotional and spiritual support; and support with changes to
48
49 relationships. A diagnosis of chronic disease with comorbid depression has previously
50
51 been associated with perceptions of poor doctor-patient communication [32]. This may
52
53 be because depressive symptoms such as negative affect may make interactions with
54
55 health care providers more strained and less effective than for non-depressed patients
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3 [33 34]. Alternatively it may be that there are patient recall difficulties arising from
4
5 depressive symptoms such as poor concentration, leading to negative patient
6
7 perceptions of information provision and communication [32].
8
9

10 11 Socioeconomic status

12
13 Higher socioeconomic groups were found to have marginally significantly lower odds of
14
15 endorsing issues relating to getting access to care when required. Patients from higher
16
17 SES areas may be more likely to live in wealthier urban areas that are closer to health
18
19 care facilities, and therefore have less difficulties with access [35]. Given Australia's
20
21 dispersed population, access to cancer care service delivery can be challenging for
22
23 patients from lower SES areas, particularly those in rural and regional areas. This is
24
25 particularly the case for accessing radiation therapy treatment, which is only available in
26
27 metropolitan centres and very few major regional centres [36].
28
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34 35 **Multiple domains of patient-centred care: Characteristics of particularly** 36 37 **vulnerable groups**

38
39 Overall, 31% of patients indicated that better care in multiple domains of patient-
40
41 centred care would have greatly improved their well-being. Older patients had lower
42
43 odds of reporting that improvements in their care were needed multiple domains of
44
45 care. This finding has been frequently reported in patient satisfaction research [31]. It
46
47 has been suggested that this may reflect differences in the expectations or preferences of
48
49 care of older people compared to younger people [14]. Consistent with the findings
50
51 across the individual domains of care, patients born in Australia had lower odds of
52
53 endorsing multiple domains where better care would have greatly improved their
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1
2
3 wellbeing. This is consistent with findings of lower patient satisfaction has been
4
5 reported in migrant groups in international settings [30].
6
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8
9
10 A significant trend towards lower odds of reporting improvements in their care were
11
12 needed was seen in those respondents living with a partner. Spranger et al [16] reported
13
14 that quality of life in individuals with chronic disease was higher amongst those with a
15
16 partner. Family members and carers may play an important role in assisting patients to
17
18 navigate the health care system and may advocate on the patient's behalf [37]. Patients'
19
20 self-management skills may also be complemented by having a support person,[38]
21
22 however these findings warrant further exploration in cancer settings [39].
23
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25

26
27
28 As expected, an association was found between clinically significant anxiety levels and
29
30 patients' perceptions that their well-being could be improved by better care across
31
32 multiple patient-centred domains. This is consistent with findings suggesting that
33
34 individuals suffering from elevated levels of anxiety may be more likely to be critical of
35
36 the health care system [40]. Alternatively, anxiety may affect interactions with health
37
38 care providers and the effectiveness of help seeking behaviours, resulting in the receipt
39
40 of poorer care across multiple domains. This finding suggests that there is a need to
41
42 identify these patients in clinical practice and reduce their perceived room for
43
44 improvement in wellbeing by alleviating their anxiety and improving their perceptions
45
46 of care [41].
47
48
49

50 51 52 **Strengths and Limitations**

53
54
55 The current study achieved a high consent rate compared to recent research examining
56
57 cancer outpatient satisfaction with care,[10] and to the best of our knowledge, is also the
58
59

1
2
3 first large study to assess patient-centred care in radiation therapy outpatients [42].
4
5 Heterogeneous cancer sites and stages were included to provide clinics with information
6
7 about which patient groups may be missing out on elements of patient-centred care. The
8
9 quality of care measure was developed following extensive pilot testing and with
10
11 reference to the literature, and the domains have been supported by a recent qualitative
12
13 study with radiation oncology patients [42]. Therefore, it appears to have face validity as
14
15 well as internal reliability. However, further examination of its psychometric properties
16
17 is needed. Demographic information was collected via patient self-report. Accuracy of
18
19 this method has been questioned,[43] however has been shown to produce reliable
20
21 responses for these demographic variables,[44] and is a cost effective and feasible way
22
23 of collecting these data.
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30 **Conclusions**

31
32 Thirty-one percent of respondents identified that better care across multiple domains
33
34 would have greatly improved their well-being. “Information and education”, “emotional
35
36 and spiritual support”, “management of physical symptoms” and “involvement of friends
37
38 and family” were the 4 domains most commonly identified where better care would
39
40 have increased respondent well-being. Older patients and patients born in Australia had
41
42 significantly lower odds of identifying multiple domains of patient-centred care where
43
44 better care would have improved their well-being. This suggests that younger patients
45
46 and migrants to Australia appear to be more likely to identify that better care would be
47
48 of benefit to their wellbeing. Further investigation of how these factors interact with
49
50 wellbeing and the provision of patient-centred care may assist in developing targeted
51
52 interventions to improve outcomes for these groups.
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REFERENCE LIST.

1. Chassin MR, Galvin RW, and the National Roundtable on Health Care Quality. The Urgent Need to Improve Health Care Quality. *JAMA* 1998;**280**(11):1000-05 doi: 10.1001/jama.280.11.1000
2. Institute of Medicine. *Crossing The Quality Chasm: A New Health System for the 21st Century*. Washington DC: National Academy Press, 2001.
3. Lewin S, Skea Z, Entwistle VA, et al. Interventions for providers to promote a patient-centred approach in clinical consultations. *Cochrane Database Syst Rev* 2001(4):Art. No.: CD003267. doi: 10.1002/14651858.CD003267
4. Kinmonth AL, Woodcock A, Griffin S, et al. Randomised controlled trial of patient centred care of diabetes in general practice: impact on current wellbeing and future disease risk. The Diabetes Care From Diagnosis Research Team. *BMJ* 1998;**317**(7167):1202-8 doi: 10.1136/bmj.317.7167.1202
5. Epstein RM, Fiscella K, Lesser CS, et al. Why The Nation Needs A Policy Push On Patient-Centered Health Care. *Health Aff (Millwood)* 2010;**29**(8):1489-95 doi: 10.1377/hlthaff.2009.0888
6. Arah OA, Westert GP, Hurst J, et al. A conceptual framework for the OECD Health Care Quality Indicators Project. *Int J Qual Health Care* 2006;**18**(Suppl 1):5-13 doi: 10.1093/intqhc/mzl024
7. Groene O, Skau JKH, Frølich A. An international review of projects on hospital performance assessment. *Int J Qual Health Care* 2008;**20**(3):162-171 doi: 10.1093/intqhc/mzn008
8. Stewart M. Towards a global definition of patient centred care. *BMJ* 2001;**322**(7284):444-45 doi: 10.1136/bmj.322.7284.444

- 1
2
3 9. Ouwens M, Hermens R, Hulscher M, et al. Development of indicators for patient-
4
5 centred cancer care. *Support Care Cancer* 2010;**18**(1):121-30 doi:
6
7 10.1007/s00520-009-0638-y
8
9
10 10. Cancer Institute NSW. New South Wales Cancer Patient Satisfaction Survey 2008.
11
12 Sydney: Cancer Institute NSW, July 2009.
13
14 11. Jenkinson C, Coulter A, Bruster S, et al. Patients' experiences and satisfaction with
15
16 health care: results of a questionnaire study of specific aspects of care. *Qual Saf*
17
18 *Health Care* 2002;**11**(4):335-39 doi: 10.1136/qhc.11.4.335
19
20
21 12. Goldzweig G, Meirowitz A, Hubert A, et al. Meeting Expectations of Patients With
22
23 Cancer: Relationship Between Patient Satisfaction, Depression, and Coping. *J Clin*
24
25 *Oncol* 2010;**28**(9):1560-65 doi: 10.1200/jco.2009.25.4987
26
27
28 13. Carr AJ, Gibson B, Robinson PG. Is quality of life determined by expectations or
29
30 experience? *BMJ* 2001;**322**(7296):1240-43 doi: 10.1136/bmj.322.7296.1240
31
32
33 14. Wan GJ, Counte MA, Cella DF, et al. An analysis of the impact of demographic, clinical,
34
35 and social factors on health-related quality of life. *Value Health* 1999;**2**(4):308-18
36
37 doi: 10.1046/j.1524-4733.1999.24006.x
38
39 15. Von Essen L, Larsson G, ÖBerg K, et al. 'Satisfaction with care': associations with
40
41 health-related quality of life and psychosocial function among Swedish patients
42
43 with endocrine gastrointestinal tumours. *Eur J Cancer Care* 2002;**11**(2):91-99
44
45 doi: 10.1046/j.1365-2354.2002.00293.x
46
47
48 16. Sprangers MAG, de Regt EB, Andries F, et al. Which chronic conditions are associated
49
50 with better or poorer quality of life? *J Clin Epidemiol* 2000;**53**(9):895-907 doi:
51
52 10.1016/s0895-4356(00)00204-3
53
54
55
56
57
58
59
60

- 1
2
3 17. Gotay CC, Holup JL, Pagano I. Ethnic differences in quality of life among early breast
4
5 and prostate cancer survivors. *Psychooncology* 2002;**11**(2):103-13 doi:
6
7 10.1002/pon.568
8
9
10 18. Delaney G, Jacob S, Featherstone C, et al. The role of radiotherapy in cancer
11
12 treatment. *Cancer* 2005;**104**(6):1129-37 doi: 10.1002/cncr.21324
13
14 19. Siekkinen M, Laiho R, Ruotsalainen E, et al. Quality of care experienced by Finnish
15
16 cancer patients during radiotherapy. *Eur J Cancer Care (Engl)* 2008;**17**(4):387-93
17
18 doi: 10.1111/j.1365-2354.2007.00883.x
19
20
21 20. Sandoval GA, Brown AD, Sullivan T, et al. Factors that influence cancer patients'
22
23 overall perceptions of the quality of care. *Int J Qual Health Care* 2006;**18**(4):266-
24
25 74 doi: 10.1093/intqhc/mzl014
26
27
28 21. Larsson BW. Touch-screen versus paper-and-pen questionnaires: effects on patients'
29
30 evaluations of quality of care. *Int J Health Care Qual Assur Inc Leadersh Health*
31
32 *Serv* 2006;**19**(4-5):328-38 doi: 10.1108/09526860610671382
33
34
35 22. Newell S, Girgis A, Sanson-Fisher R, et al. Are touchscreen computer surveys
36
37 acceptable to medical oncology patients. *J Psychosoc Oncol* 1997;**15**:37-46 doi:
38
39 10.1300/J077v15n02_03
40
41
42 23. Zigmond A, Snaith R. The Hospital Anxiety and Depression Scale. *Acta Psychiatr*
43
44 *Scand* 1983;**67**:361-70
45
46 24. Herrmann C. International experiences with the Hospital Anxiety and Depression
47
48 Scale-A review of validation data and clinical results. *J Psychosom Res*
49
50 1997;**42**(1):17-41 doi: 10.1016/s0022-3999(96)00216-4
51
52
53 25. Moorey S, Greer S, Watson M, et al. The factor structure and factor stability of the
54
55 Hospital Anxiety and Depression Scale in Patients with Cancer. *Br J Psychiatry*
56
57 1991;**158**:225-59.
58
59
60

- 1
2
3 26. Boyes A, Newell S, Girgis A. Rapid assessment of psychosocial well-being: Are
4 computers the way forward in a clinical setting? *Qual Life Res* 2002;**11**(1):27-35
5
6 doi: 10.1023/A:1014407819645
7
8
9
10 27. Australian Bureau of Statistics. SEIFA: Socio-economic indexes for areas. Secondary
11 SEIFA: Socio-economic indexes for areas 2008.
12
13 http://www.abs.gov.au/websitedbs/D3310114.nsf/home/Seifa_entry_page.
14
15
16 28. O'Brien I, Britton E, Sarfati D, et al. The voice of experience: results from Cancer
17 Control New Zealand's first national cancer care survey. *N Z Med J*
18
19 2010;**123**(1325):10-9 doi: 10.1016/j.radonc.2011.08.005
20
21
22
23 29. Watson DE, Mooney D, Peterson S. Patient experiences with ambulatory cancer care
24 in British Columbia, 2005/06: UBC Centre for Health Services and Policy
25
26 Research, March 2007.
27
28
29
30 30. Harmsen JAM, Bernsen RMD, Bruijnzeels MA, et al. Patients' evaluation of quality of
31 care in general practice: What are the cultural and linguistic barriers? *Patient*
32
33 *Educ Couns* 2008;**72**(1):155-62 doi: 10.1016/j.pec.2008.03.018
34
35
36
37 31. Jaipaul CK, Rosenthal GE. Are Older Patients More Satisfied With Hospital Care Than
38
39 Younger Patients? *J Gen Intern Med* 2003;**18**(1):23-30 doi: 10.1046/j.1525-
40
41 1497.2003.20114.x
42
43
44 32. Schenker Y, Stewart A, Na B, et al. Depressive symptoms and perceived doctor-
45
46 patient communication in the Heart and Soul study. *J Gen Intern Med*
47
48 2009;**24**(5):550-6 doi: 10.1007/s11606-009-0937-5
49
50
51 33. Hall JA, Horgan TG, Stein TS, et al. Liking in the physician-patient relationship.
52
53 *Patient Educ Couns* 2002;**48**(1):69-77 doi: 10.1016/s0738-3991(02)00071-x
54
55
56
57
58
59
60

- 1
2
3 34. Hall JA, Roter DL, Milbrun MA, et al. Patients' Health as a Predictor of Physician and
4
5 Patient Behavior in Medical Visits: A Synthesis of Four Studies. *Med Care*
6
7 1996;**34**(12):1205-18.
8
9
10 35. Paul C, Carey M, Anderson A, et al. Cancer patients' concerns regarding access to
11
12 cancer care: perceived impact of waiting times along the diagnosis and treatment
13
14 journey. *Eur J Cancer Care (Engl)* Published Online First: 23 November 2011. doi:
15
16 10.1111/j.1365-2354.2011.01311.x
17
18
19 36. Lehmann F, Hedges A, Hunt B. Barriers to rural patients electing to have
20
21 radiotherapy. Special report: Radiotherapy Summit 2000: Cancer Council
22
23 Australia, November 2002.
24
25
26 37. Sales E. Family burden and quality of life. *Qual Life Res* 2003;**12**(Suppl 1):33-41 doi:
27
28 10.1023/a:1023513218433
29
30 38. Clark PC, Dunbar SB. Family partnership intervention: a guide for a family approach
31
32 to care of patients with heart failure. *AACN Clin Issues* 2003;**14**(4):467-76
33
34
35 39. Rijken M, Jones M, Heijmans M, et al. Supporting self-management. In: Nolte E, McKee
36
37 M, eds. *Caring for people with chronic conditions: a health system perspective*.
38
39 Berkshire: Open University Press, 2008:116-42.
40
41 40. Shilling V, Jenkins V, Fallowfield L. Factors affecting patient and clinician satisfaction
42
43 with the clinical consultation: Can communication skills training for clinicians
44
45 improve satisfaction? *Psychooncology* 2003;**12**(6):599-611 doi: 10.1002/pon.731
46
47
48 41. Lin H-R, Bauer-Wu SM. Psycho-spiritual well-being in patients with advanced cancer:
49
50 an integrative review of the literature. *J Adv Nurs* 2003;**44**(1):69-80 doi:
51
52 10.1046/j.1365-2648.2003.02768.x
53
54
55
56
57
58
59
60

- 1
2
3 42. Nijman JL, Sixma H, Triest Bv, et al. The quality of radiation care: The results of focus
4
5 group interviews and concept mapping to explore the patient's perspective.
6
7 *Radiother Oncol* 2012;**102**(1):154-60 doi: 10.1016/j.radonc.2011.08.005
8
9
10 43. Manjer J, Merlo J, Berglund G. Validity of self-reported information on cancer:
11
12 Determinants of under- and over-reporting. *Eur J Epidemiol* 2004;**19**(3):239-47
13
14 doi: 10.1023/B:EJEP.0000020347.95126.11
15
16 44. Bergmann MM, Calle EE, Mervis CA, et al. Validity of self-reported cancers in a
17
18 propsective cohort study in comparison with data from state cancer registries.
19
20 *Am J Epidemiol* 1998;**147**(6):556-62
21
22
23
24
25
26
27
28
29
30
31
32
33
34
35
36
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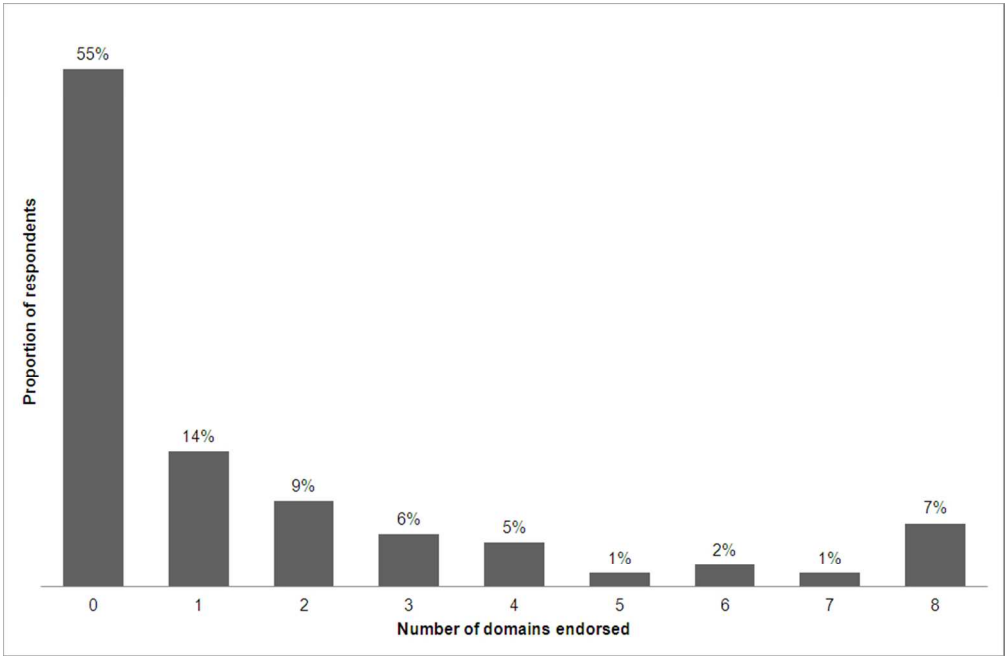


Figure 1. Percentage of respondents endorsing 0-8 domains in which better care would have greatly improved their well-being

Review only

STROBE Statement—Checklist of items that should be included in reports of *cross-sectional studies*

	Item No	Recommendation
Title and abstract	1	(a) Indicate the study's design with a commonly used term in the title or the abstract "Radiation oncology outpatient perceptions of patient-centred care: A cross-sectional survey" (b) Provide in the abstract an informative and balanced summary of what was done and what was found See pages 2-3
Introduction		
Background/rationale	2	Explain the scientific background and rationale for the investigation being reported See pages 4-6
Objectives	3	State specific objectives, including any prespecified hypotheses See page 6
Methods		
Study design	4	Present key elements of study design early in the paper See "Design" section on page 6
Setting	5	Describe the setting, locations, and relevant dates, including periods of recruitment, exposure, follow-up, and data collection See "Participants" and "Procedure" sections on pages 6-7
Participants	6	(a) Give the eligibility criteria, and the sources and methods of selection of participants See "Participants" and "Procedure" sections on page 6-7
Variables	7	Clearly define all outcomes, exposures, predictors, potential confounders, and effect modifiers. Give diagnostic criteria, if applicable See "Measures" section on pages 7-10, including Table 1.
Data sources/ measurement	8*	For each variable of interest, give sources of data and details of methods of assessment (measurement). Describe comparability of assessment methods if there is more than one group See "Measures" section on pages 7-10, including Table 1.
Bias	9	Describe any efforts to address potential sources of bias See "Statistical methods" section on pages 10-11.
Study size	10	Explain how the study size was arrived at See "Sample size and statistical power" section on page 11.
Quantitative variables	11	Explain how quantitative variables were handled in the analyses. If applicable, describe which groupings were chosen and why See "Statistical methods" section on pages 10-11.
Statistical methods	12	(a) Describe all statistical methods, including those used to control for confounding See "Statistical methods" section on pages 10-11. (b) Describe any methods used to examine subgroups and interactions See "Statistical methods" section on pages 10-11. (c) Explain how missing data were addressed See "Statistical methods" section on pages 10-11. (d) If applicable, describe analytical methods taking account of sampling strategy N/A (e) Describe any sensitivity analyses N/A. For assessment of internal consistency of items see "Measures" section page 7.

Results

Participants	13*	(a) Report numbers of individuals at each stage of study—eg numbers potentially eligible, examined for eligibility, confirmed eligible, included in the study, completing follow-up, and analysed See page 11-12
		(b) Give reasons for non-participation at each stage See page 12
		(c) Consider use of a flow diagram Reported in text.
Descriptive data	14*	(a) Give characteristics of study participants (eg demographic, clinical, social) and information on exposures and potential confounders See Table 2.
		(b) Indicate number of participants with missing data for each variable of interest See Table 2 and Table 4.
Outcome data	15*	Report numbers of outcome events or summary measures See pages 14-20.
Main results	16	(a) Give unadjusted estimates and, if applicable, confounder-adjusted estimates and their precision (eg, 95% confidence interval). Make clear which confounders were adjusted for and why they were included See pages 14-20, “Statistical methods” pages 10-11, and Tables 3 & 4.
		(b) Report category boundaries when continuous variables were categorized See “Statistical methods” section on pages 10-11, and Table 4.
		(c) If relevant, consider translating estimates of relative risk into absolute risk for a meaningful time period N/A
Other analyses	17	Report other analyses done—eg analyses of subgroups and interactions, and sensitivity analyses N/A

Discussion

Key results	18	Summarise key results with reference to study objectives See pages 21-25.
Limitations	19	Discuss limitations of the study, taking into account sources of potential bias or imprecision. Discuss both direction and magnitude of any potential bias See pages 24-25.
Interpretation	20	Give a cautious overall interpretation of results considering objectives, limitations, multiplicity of analyses, results from similar studies, and other relevant evidence See pages 21-24.
Generalisability	21	Discuss the generalisability (external validity) of the study results See page 25.

Other information

Funding	22	Give the source of funding and the role of the funders for the present study and, if applicable, for the original study on which the present article is based No specific funding, so a general funding statement is included in the acknowledgements on page 26.
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*Give information separately for exposed and unexposed groups.



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ABSTRACT:

Objectives. We aimed to describe the proportion and characteristics of cancer patients who perceived that better care would have greatly improved their wellbeing in a) specific, and b) multiple domains of patient-centred care.

Design. Cross sectional touchscreen computer survey.

Setting. Four Australian radiation therapy departments located within major urban public hospitals.

Participants. Radiation therapy outpatients were invited to participate in a touchscreen computer survey. Eligible patients were aged at least 18 years old, diagnosed with cancer, and had sufficient English to complete the survey.

Primary outcome measure. Participants were asked whether their wellbeing could have been greatly improved if better care had been provided across eight domains of patient-centred care. Characteristics of those respondents who identified a) specific and b) multiple domains where it was perceived that better care would have greatly improved their well-being, were examined.

Results. Of 508 eligible radiation therapy patients, 344 (68%) completed the survey. Patients most frequently perceived that better care in the following domains could have improved their wellbeing: information and communication about their cancer (22%; 95% CI: 18-27%); emotional and spiritual support (22%; 95% CI: 18-27%); management of physical symptoms (21%; 95% CI: 17-26%); and involvement of friends

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3 and family (21%; 95% CI: 17-26%). Just under one third of respondents (31%; 95% CI:
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5 26-36%) indicated that their wellbeing could have been improved by better care across
6
7 two or more domains of care. Patients in younger age groups and migrants to Australia
8
9 had higher odds of endorsing multiple domains where better care would have improved
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11 their wellbeing.
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16 **Conclusions.** Further investigation of patients' perceptions regarding how their
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18 perceived quality might be improved is warranted, particularly amongst patients in
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20 younger age groups and migrants to Australia.
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INTRODUCTION.

Why assess patient views of quality of care?

The Institute of Medicine (IOM) in the United States of America, an independent organisation for gathering evidence to assist health decision making, has indicated the urgency of assessing and improving the quality of health care [1]. Quality health care is care that is safe, timely, effective, efficient, equitable and patient-centred [2]. A patient-centred approach to care is defined as being respectful of, and responsive to, patients' physical, social and emotional preferences and needs [3]. Provision of patient-centred care may contribute to improvements in patients' physical, mental and social well-being [4 5]. A patient-centred approach to care is now endorsed as a key component of quality health care by many organisations (including the World Health Organisation [6]) and governments (e.g. in Australia, USA, UK, Canada, Germany, France, Netherlands and Switzerland [7]). Although quality of care is often examined through audit and benchmarking of clinical outcomes data [8], examining patients' judgements of how their experiences of care correspond with their preferences and needs is required in order to assess the quality of patient-centred care [9].

What has previous patient-centred care research contributed to knowledge about prioritising quality improvement efforts?

Quality of patient-centred care has been assessed using a variety of patient reported outcomes measures including surveys of patient satisfaction and experiences which are closely linked to the IOM patient-centred care conceptual framework [10 12]. Patient satisfaction surveys' have been criticised because responses may be heavily dependent upon patients' expectations of care, leading to the development of patient experience

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2
3 surveys [12]. The Picker Institute survey assesses outpatients' experiences of care
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5 across the domains of patients' preferences; emotional support; physical comfort;
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7 information and education; coordination of care; access to care; and involvement of
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9 family/friends [11 12 15]. More recently, indicators of the quality of patient-centred
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11 care have been developed from international patient-centred oncology clinical practice
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13 guidelines [10 16]. These indicators have been grouped across the domains of
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15 information; coordination/organisation of care; physical support; emotional and
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17 psychological support; communication and respect; involvement; access; and follow-
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19 up/after-care. To date, these approaches have not attempted to capture patient
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21 perceptions of the degree to which their wellbeing would benefit from improved care
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23 across these different domains [14]. Drawing upon the formal supportive care needs
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25 assessment approach which aims to identify the level of patient need for help [17],
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27 identification of patients' views of the relative benefit that would be conferred by
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29 improvements in different patient-centred domains care may assist with identifying and
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31 prioritising quality improvement efforts [10].
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39 Some subgroups of patients may perceive that they receive poorer care than others. For
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41 instance, older patients may be more likely than younger patients to express satisfaction
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43 with care, possibly relating to differences in the expectations for care provision [18].
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45 Additionally, cancer patients who have clinically significant levels of anxiety have been
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47 found to give lower ratings of satisfaction with care [19]. Wellbeing in patients
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49 diagnosed with chronic illness may be linked to aspects of social support such as having
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51 a partner, [20] and also potentially to ethnicity [21]. Given that there is some evidence
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53 of increased psychological distress and supportive care needs prior to and during
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3 treatment [22 23], it may also be that treatment stage may impact on perceptions of
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5 care.
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7 **Patient-centred care for radiation therapy patients**

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9 It is recommended that approximately 50% of cancer patients undergo radiation
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11 therapy treatment [24]. Given that this treatment is often characterised by frequent
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13 contact with the healthcare system over the course of treatment, the radiation therapy
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15 setting provides an opportunity for addressing patient perceived needs across the
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17 multiple domains of patient-centred care [24]. Although research into specific domains
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19 and specific cancer types has been conducted in radiotherapy settings [22 25 26], to the
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21 best of our knowledge, this is the first study to ask cancer patients undergoing radiation
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23 therapy about their perceptions of how better care across multiple patient-centred
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25 domains could improve their wellbeing [27]. Further, no previous studies have
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27 identified characteristics of radiation therapy patients who are likely to perceive better
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29 patient-centred care [28].
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37 This study aimed to examine the proportion and characteristics of radiation therapy
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39 patients who indicate that their well-being could have been greatly improved by better
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41 cancer care across each of eight domains of patient-centred care. We also aimed to
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43 assess characteristics associated with a patient perception that better care across
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45 multiple domains of patient-centred care would have improved their well-being.
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50 **METHODS.**

51 **Ethics approvals**

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53 Ethics approval was obtained from the University of Newcastle and NSW Population &
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55 Health Services Research Ethics Committees.
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Design

Cross sectional survey completed using touchscreen computers.

Participants

Radiation oncology outpatients were recruited from four radiation therapy departments in a major urban centre in Australia between March and December 2010. Each radiation therapy department was attached to a major public teaching hospital, and had at least three Linear Accelerators available for treatment. Eligible patients were aged 18 years or older; diagnosed with cancer; and had sufficient command of English to complete the touchscreen computer survey. Patients who were receiving both radical and palliative treatment were eligible. Those who were attending the clinic for the first time or who were considered by clinic staff to be too unwell or unable to give informed consent were excluded.

Procedure

Patients waiting for a radiation therapy treatment were invited to participate in the study by a research assistant. Consenting patients were given a unique identification code to login to the touchscreen computer questionnaire. If patients were called into their treatment before finishing their survey, they had the option of resuming after their treatment. Touchscreen computer surveys have been reported as being faster and easier to use for outpatients than pencil and paper surveys,[29] and have been found to be acceptable to oncology patients [30].

Measures

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3 Digivey survey software (CREOSO - Digivey Survey Center, Phoenix, Arizona) was used
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5 to program the patient survey, which was administered using Dell Latitude XT2
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7 touchscreen laptop computers.
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12 Quality of Care: patient-centred care.

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14 Questions and domain descriptions were developed to correspond with domains of
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16 patient-centred care described in the literature,[10 12] ensuring face validity of the
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18 items and clinical relevance to patients currently undergoing treatment. Survey items
19
20 were extensively pilot tested and modified based on feedback from 67 patients. Eight
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22 items, each assessing a different domain of care, were presented on separate screens
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24 with the stem "During my cancer care, my well-being would have been greatly improved
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26 by." Table 1 lists the eight items and a short description of each domain that was
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28 presented at the bottom of the touchscreen. Patients were asked to indicate their level of
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30 agreement with each statement on a 4-point Likert scale (Strongly disagree, Disagree,
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32 Agree, Strongly agree). Internal consistency of the items was assessed using Cronbach's
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Table 1. Survey items and descriptions (each assessing a different domain of care)

Item	On screen description
Better management of my physical symptoms	May relate to your pain, sleeplessness, other side-effects and symptoms.
Better information and communication about my cancer and care	May include: clear and consistent information about your diagnosis, test results, treatment, taking medications, food you should be eating, exercise you can do safely etc.
Better emotional and/or spiritual support	May include services or support to help you cope with: the impact of cancer on your life, doubts/worries, feelings of anxiety or sadness, changes to your body images etc.
Better services, information and support for my friends/family	May include helping them to cope with the impact of your cancer, or providing opportunities for them to be involved in your care.
Better staff approachability and respect for me	Describes staff who are easy to contact and up-to-date with your medical history, and who give you opportunities to ask questions and be involved in treatment decisions.

Getting better access to the care I need when required	Describes not having to wait too long to get appointments, and having treatment and medical advice available when needed.
Better services/support to cope with changes to my relationships	May include: knowing what changes to expect, and having some strategies to reduce the impact of cancer on your work, usual social activities, friendships or sexual relationships.
Better services/advice to assist me with practical concerns	May include being able to access financial support, transport to treatment, home help services or other support needed to manage practical issues.

Demographic characteristics.

Patient self-report was used to collect age, gender, whether participants were born in Australia, living with a partner and the postcode of usual place of residence.

Disease characteristics.

A multiple choice question "What is your most recent primary cancer diagnosis?" was used to determine respondents' most recent primary cancer diagnosis. Common cancer types were listed on screen, along with the categories "other - please specify" and "don't know". Approximate time since diagnosis was calculated from patient self-reported year and month of diagnosis and their recruitment date. Patients were asked to indicate the number of radiation therapy treatment and outpatient appointments they had attended; whether they had experienced a second diagnosis and/or recurrence, and whether they

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3 perceived that the aim of their treatment was to cure the cancer; prevent the cancer
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5 from coming back or control symptoms of cancer (cure is not possible).
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10 Psychological characteristics.

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12 The Hospital Anxiety and Depression Scale (HADS) is a 14-item self-report measure of
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14 anxiety and depression [31]. Both the anxiety and depression subscales provide scores
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16 of between 0 and 21 where 0-7= Normal; 8-10= Mild; 11-14 = Moderate; 15-21 = Severe.
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18 The scale has been utilised in research and in clinical practice,[32] with demonstrated
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20 reliability and validity [33]. HADS scores have been found to be comparable when
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22 administered by touchscreen computer and pen-and-paper in a cancer patient
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24 population [34].
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30 **Statistical Methods**

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32 Radiation therapy patients were defined as having endorsed each domain if they
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34 indicated that they “agreed” or “strongly agreed” that better care would have greatly
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36 improved their well-being. The proportion of patients endorsing each domain was
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38 reported with 95% confidence intervals. Respondents were then dichotomised on the
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40 basis of: a) 0-1 domains endorsed or b) multiple (2 or more) domains endorsed.
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42 Univariate logistic analysis was used to investigate the relationship between
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44 demographic characteristics, disease factors and psychological distress and patient
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46 endorsement of a) each of the 8 domains of care and b) multiple (2 or more) domains of
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48 care requiring improvement. The explanatory variables examined included age (18-49,
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50 50-59, 60-69, 70 plus), sex (male, female), cancer diagnosis (Breast, Prostate,
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52 Other/Don’t Know), second diagnosis and/or recurrence (no, yes), Australian born (no,
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54 yes), living with a partner (no, yes), anxiety (no, yes), depression (no, yes), usual place of
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3 residence (urban/rural, based on Accessibility/Remoteness Index of Australia (ARIA+)
4 score), socioeconomic status (Socio-Economic Indexes for Areas (SEIFA) average
5 scores[35]), and number of radiotherapy treatment appointments attended (continuous
6 measure). Variables with a *p* value of 0.2 or less on the univariate likelihood ratio test
7 were included in the multiple logistic regression model. The backwards stepwise
8 method was then used to remove all variables with a *p* value of 0.1 or more on the
9 likelihood ratio test, with recruitment site included in all multiple regression models.
10 The fit of the final model was assessed using the Hosmer-Lemeshow goodness of fit test.
11 For individual domains, odds ratios with 95% confidence intervals are reported for
12 multiple regression models. For the assessment of characteristics associated with
13 endorsing multiple domains, odds ratios with 95% confidence intervals are reported for
14 univariate and multiple regression models. Analysis was conducted using STATA version
15 11.2, and a significance level of 0.05 used.
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35 **Sample size and statistical power**

36 We aimed to recruit a total of 450 patients which, based on 50% of patients perceiving
37 the need for better care in each domain, would allow us to obtain prevalence estimates
38 with 95% CI's within $\pm 5\%$ of the point estimate. This sample size would also be
39 sufficient to detect differences of approximately 15% in characteristics between those
40 who perceive the need for better care in each individual domain and also multiple
41 domains of care with 80% power and 5% significance level.
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52 **RESULTS.**

53 Of the 639 patients screened for eligibility, 110 were ineligible due to: inadequate
54 English (n=51); not currently receiving RT (n = 32); had already been approached about
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3 the study (n = 6); not being diagnosed with cancer (n = 3); clinic staff concern about
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5 patient burden or ability to give informed consent (n = 3); being aged under 18 (n = 2),
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7 or no specified reason (n=13). Of the 529 eligible patients, 85% (n = 451) consented, and
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9 69% (n = 365) completed the survey. Incomplete surveys were primarily because
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11 patients were called into their treatment appointment before survey completion, and no
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13 data was available from these surveys. An additional 21 patients were excluded because
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15 they reported that they were attending their first RT treatment. Once these participants
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17 were ruled ineligible, the overall response rate was 68% of 508 eligible radiation
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19 therapy patients. Table 2 shows the characteristics of the 344 respondents. 51% were
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21 male, the median age was 63.3 (Quartile [Q] 1: 52.2, Q3: 70.5) and the median number of
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23 weeks since diagnosis was 27.6 (Q1: 16.0, Q3: 57.3). The majority of respondents (97%)
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25 were currently receiving radiation therapy treatment, with the remainder reporting that
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27 they were attending the treatment centre for a check-up. The distribution of primary
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29 cancer type within the sample can be seen in Table 2.
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Table 2. Demographic and disease characteristics of respondents (*n* = 344)

Characteristic	Mean (min, max)
Age (years)	61.4 (18.9-91.4)
	<i>n</i> (%)
Males	176 (51%)
Region of birth	
Australia	231 (67%)
UK/Ireland	30 (8.7%)
Europe	29 (8.4%)
Asia	25 (7.2%)
Other	29 (8.4%)
Perceived palliative treatment aim	46 (14%)
Primary cancer type	
Breast	93 (27%)
Prostate	73 (21%)
Head and neck	33 (9.6%)
Colorectal	20 (5.8%)
Brain	15 (4.4%)
Lung	15 (4.4%)
Other	89 (26%)
Don't know	6 (1.7%)
Second diagnosis/recurrence	96 (28%)
	Median (Q1, Q3)
Completed appointments with cancer doctor	3 (2, 5)

Completed radiation therapy appointments	9 (4, 17)
Weeks since diagnosis	27.6 (16, 37.3)

Note. Observations within each variable may not add to the total due to missing values

Internal consistency of items

When considering the items with responses on a 4-point Likert scale, the internal consistency (Cronbach's α) was 0.92. When the responses were dichotomised (agree versus disagree), Cronbach's α was 0.89.

Proportion of patients endorsing individual domains of patient-centred care

Table 3 shows the number and proportion of radiation oncology patients who agreed that their well-being could have been improved by better care across 8 different domains of patient-centred care. It can be seen that each domain was endorsed by between 12% and 22% of patients.

Table 3. Proportion who reported that their wellbeing would have been improved by better care across 8 domains ($n = 344$)

	Agree
	<i>n</i> (%), 95% CI
Information and communication about my cancer and care	76 (22%, 18-27%)
Emotional and/or spiritual support	75 (22%, 18-27%)
Management of my physical symptoms	72 (21%, 17-26%)
Services; information and support for my friends/family	72 (21%, 17-26%)

Services/advice to assist me with practical concerns	69 (20%, 16-25%)
Access to the care I need when required	62 (18%, 14-23%)
Services/support to cope with changes to my relationships	56 (16%, 13-21%)
Staff approachability and respect for me	42 (12%, 8.9-16%)

Characteristics associated with endorsement of domains

Multiple logistic regression analysis identified that Australian born participants had lower odds of endorsing perceiving “better management of physical symptoms” would have greatly improved their well-being (OR = 0.4; 95% CI: 0.2-0.7; $p = 0.0008$). No other characteristics were significantly associated with endorsing better management of physical symptoms.

Better information and communication about my cancer and care: Australian born patients had lower odds of perceiving that “better information and communication about my cancer and care” would have greatly improved their well-being (OR = 0.5; 95% CI: 0.3-0.9; $p = 0.0153$), as did patients living with a partner (OR = 0.5; 95% CI: 0.3-0.8; $p = 0.0083$). It was also found that patients aged 60-69 years (OR = 0.3; 95% CI: 0.1-0.7) and aged 70 or over (OR = 0.3; 95% CI: 0.2-0.8) had lower odds of endorsing this domain than younger participants ($p = 0.0042$). Patients with a likely presence of depression had three times the odds of endorsing this domain (OR = 3.1; 95% CI: 1.1-9.0; $p = 0.0396$).

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3 Better emotional and/or spiritual support: Patients aged 60-69 years (OR = 0.3; 95% CI:
4 0.1-0.6) and aged 70 or over (OR = 0.4; 95% CI: 0.2-0.8) had lower odds of endorsing
5 this domain than younger participants ($p = 0.0011$). Australian born patients had lower
6 odds of endorsing this domain (OR = 0.3; 95% CI: 0.2-0.5; $p < 0.0001$), whilst patients
7 with clinically significant levels of depression had higher odds of endorsing (OR = 3.5;
8 95% CI: 1.2-10.1; $p = 0.0250$).
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19 Better services, information and support for my friends/family: Lower odds of
20 endorsing this domain were found in older patients aged 60-69 years (OR = 0.2; 95% CI:
21 0.1-0.5) and aged 70 or over (OR = 0.2; 95% CI: 0.1-0.4) compared to younger
22 participants ($p < 0.0001$), and also in Australian born patients (OR = 0.4; 95% CI: 0.2-0.6;
23 $p = 0.0004$).
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32 Better staff approachability and respect for me: Australian born patients had
33 significantly lower odds of endorsing this domain (OR = 0.3; 95% CI: 0.1-0.5; $p =$
34 0.0001). Marginally non-significantly lower odds of endorsing this domain were found in
35 older patients aged 60-69 years (OR = 0.3; 95% CI: 0.1-0.9) compared to younger
36 participants ($p = 0.0683$).
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46 Getting better access to the care I need when required: Older patients aged 60-69 years
47 (OR = 0.2; 95% CI: 0.1-0.5) and aged 70 or over (OR = 0.3; 95% CI: 0.1-0.8) had lower
48 odds of endorsing this domain compared to younger participants ($p = 0.0003$). Once
49 again, Australian born patients had lower odds of endorsing this domain (OR = 0.3; 95%
50 CI: 0.2-0.6; $p = 0.0003$). Marginally non-significantly lower odds were also found in
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3 socioeconomic Group 2 (OR = 0.2; 95% CI: 0.1-0.9) and Group 3 (OR = 0.3; 95% CI: 0.1-
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5 0.9) compared to the lowest SES Group 1 ($p = 0.0837$).
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10 Better services/support to cope with changes to my relationships: Older patients aged
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12 60-69 years (OR = 0.1; 95% CI: 0.1-0.4) and aged 70 or over (OR = 0.2; 95% CI: 0.1-0.4)
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14 had lower odds of endorsing this domain compared to younger participants ($p <$
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16 0.0001). Once again, Australian born patients had lower odds of endorsing this domain
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18 (OR = 0.3; 95% CI: 0.1-0.5; $p = 0.0001$). Patients with clinically significant levels of
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20 depression had higher odds of endorsing this domain (OR = 7.2; 95% CI: 2.3-22.5; $p =$
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22 0.0007).
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27 Better services/advice to assist me with practical concerns: Older patients aged 60-69
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29 years (OR = 0.1; 95% CI: 0.1-0.3) and aged 70 or over (OR = 0.3; 95% CI: 0.1-0.6) had
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31 lower odds of endorsing this domain compared to younger participants ($p < 0.0001$).
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33 Australian born patients also had lower odds of endorsing this domain (OR = 0.5; 95%
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35 CI: 0.3-0.8; $p = 0.0070$).
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39 40 41 **Proportion of patients endorsing multiple domains where better care would have** 42 43 **improved their well-being** 44

45
46 Figure 1 shows the percentage of respondents endorsing none, one and multiple
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48 domains where better care would have improved their wellbeing. Overall 31% of
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50 respondents ($n = 107$) endorsed multiple domains where they agreed or strongly agreed
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52 that their wellbeing could have been improved by better care.
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57 FIGURE 1 ABOUT HERE
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For 55% of participants, it was perceived that improvement in well-being would not have resulted from better care in any of the examined domains. Fourteen percent of participants identified only one domain where better care would have greatly improved their well-being. Table 4 shows the results of analyses examining factors associated with the perception that wellbeing could have been improved by better care in multiple (2 or more) domains. It can be seen that compared with the younger age group (18-49 years), being aged 60 years or over was associated with significantly lower odds of endorsing multiple domains as requiring improvement. Additionally, relative to patients not born in Australia, those who were Australian born had significantly lower odds of endorsing multiple domains in which wellbeing would have been improved by better care. Outpatients living with a partner had significantly lower odds of identifying multiple domains where better care would have greatly improved their wellbeing. There were significantly higher odds of endorsing multiple domains amongst outpatients with a likely presence of anxiety.

Table 4. Demographic, disease and HADS associations with endorsement of multiple domains as requiring improvement¶

	Multiple domains endorsed	LR Chi², p	LR Chi², p
	n (%)	Unadjusted	Adjusted
		OR (95% CI) 	OR (95% CI)
Hospital		5.0, p = 0.1752	2.9, p = 0.4002
Site 1	36 (36%)	1.0	1.0

Site 2	22 (23%)	0.5 (0.3-1.0)	0.6 (0.3-1.2)
Site 3	23 (32%)	0.8 (0.4-1.6)	0.9 (0.4-1.8)
Site 4	26 (34%)	0.9 (0.5-1.7)	1.0 (0.5-2.0)
Age category		35.9, p <0.0001	28.9, p
18-49 years	36 (51%)	1.0	<0.0001*
50-59 years	34 (46%)	0.8 (0.4-1.5)	1.0
60-69 years	20 (18%)	0.2 (0.1-0.4)	0.7 (0.4-1.4)
70 years plus	17 (19%)	0.2 (0.1-0.4)	0.2 (0.1-0.4)
			0.2 (0.1-0.5)
Sex§		2.5, p = 0.1159	
Male	48 (27%)	1.0	
Female	59 (35%)	1.4 (0.9-2.3)	
Cancer type§		3.8, p = 0.1469	
Breast	31 (33%)	1.0	
Prostate	16 (22%)	0.6 (0.3-1.1)	
Other cancer types†	60 (34%)	1.0 (0.6-1.7)	
Second diagnosis or recurrence		1.0, p = 0.3123	
No	81 (33%)	1.0	
Yes	26 (27%)	0.8 (0.5-1.3)	
Born in Australia		8.5, p = 0.0037	5.4, p = 0.0205*
No	47 (42%)	1.0	1.0
Yes	60 (26%)	0.5 (0.3-0.8)	0.5 (0.3-0.9)
Socioeconomic status		0.3, p = 0.5758	
Low	5 (22%)	1.0	

Medium	8 (16%)	0.7 (0.2-2.4)	
High	59 (22%)	1.0 (0.4-2.9)	
Usual place of residence		0.3, p = 0.5758	
Major city	87 (32%)	1.0	
Regional or rural	19 (28%)	0.8 (0.5-1.5)	
Living with partner		5.2, p = 0.0224 3.9, p = 0.0481*	
No	50 (38%)	1.0	1.0
Yes	57 (27%)	0.6 (0.4-0.9)	0.6 (0.4-1.0)
Clinically significant anxiety‡		10.4, p = 0.0013 4.3, p = 0.0383*	
No	82 (28%)	1.0	1.0
Yes	25 (52%)	2.8 (1.5-5.2)	2.1 (1.0-4.1)
Clinically significant depression‡§		5.7, p = 0.0167	
No	97 (30%)	1	
Yes	10 (59%)	3.3 (1.2-9.0)	
Completed radiation therapy appointments		0.02, p = 0.8893	

Note. Observations within each variable may not add to the total due to missing values

†Including brain, colorectal, head and neck, lung, non-Hodgkin's lymphoma, and other cancer types

‡Assessed using the Hospital Anxiety and Depression Scale (HADS)

§Eliminated during backwards stepwise multiple logistic regression analysis

|| Reported *p*-values are from the Likelihood ratio test

¶ *p*-values for the Hosmer-Lemeshow goodness of fit test were between 0.2 and 0.9 for specific domain models; and was 0.1 for the multiple domain model

DISCUSSION

In which domains would better care greatly improve wellbeing for the most patients?

For each of the eight domains of care assessed, between 12-22% of respondents agreed or strongly agreed that their wellbeing would have greatly improved with better care.

One fifth or more agreed that improvements to the following domains would have improved their care: better information and communication about my cancer and care (22%); better emotional and/or spiritual support (22%); better management of physical symptoms (21%); better services information and support for friends/family (21%); and better services/advice to assist with practical concerns (20%). Overall, these frequencies were lower than identified in comparable domains in recent international studies of cancer patient experiences of care in Australia, New Zealand, British Columbia, Canada and Europe [10 11 19 36 37]. This discrepancy may be a consequence of the differences in measures. Although past measures have assessed experiences of care or unmet need, they have not assessed the impact that patients perceive better care in these patient-centred domains would have on their wellbeing. Alternatively, the discrepancies between findings may be a result of improved delivery of patient centred care over time.

Characteristics associated with endorsing each domain of patient-centred care

Country of birth

Australian born patients had lower odds of endorsing each of the assessed domains of patient-centred care. It may be that Australian born patients perceive that they are receiving better care than migrants. Alternatively, it may be that Australian born

1
2
3 patients have lower expectations of care and of the degree to which their well-being
4
5 would be improved by better care [38]. Linguistic and cultural barriers to patient
6
7 perceptions of high quality health care have been previously identified, highlighting the
8
9 need for responsiveness to cultural background for optimal health care delivery [38].
10
11 Although the current research was limited to patients with adequate English to complete
12
13 the survey, there has been increased research attention on some of these challenges
14
15 faced by people with cancer from culturally and linguistically diverse backgrounds in
16
17 Australia [39 40].
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19

20 21 22 23 Age group

24
25 Older age was associated with lower odds of endorsing a need for improvement in all
26
27 domains of patient-centred care, with the exception of management of physical
28
29 symptoms and staff approachability and respect for the patient. This is consistent with
30
31 previous studies suggesting that older age is associated with higher overall patient
32
33 satisfaction ratings [41] and that older patients undergoing radiation treatment have
34
35 lower information needs [25]. It may be that older patients perceive pain management
36
37 and interpersonal care as a traditional role of the doctor, leading to similar perceptions
38
39 about the need for improvement in these domains as held by younger age groups.
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45 46 HADS classified depression

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48 Patients with HADS classified depression had higher odds of endorsing the following
49
50 three domains than non-depressed respondents: Information and communication about
51
52 cancer and care; emotional and spiritual support; and support with changes to
53
54 relationships. A diagnosis of chronic disease with comorbid depression has previously
55
56 been associated with perceptions of poor doctor-patient communication [42]. This may
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3 be because depressive symptoms such as negative affect may make interactions with
4 health care providers more strained and less effective than for non-depressed patients
5 [43 44]. Alternatively it may be that there are patient recall difficulties arising from
6 depressive symptoms such as poor concentration, leading to negative patient
7 perceptions of information provision and communication [42].
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16 Socioeconomic status

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18 Higher socioeconomic groups were found to have marginally significantly lower odds of
19 endorsing issues relating to getting access to care when required. Patients from higher
20 SES areas may be more likely to live in wealthier urban areas that are closer to health
21 care facilities, and therefore have less difficulties with access [45]. Given Australia's
22 dispersed population, access to cancer care service delivery can be challenging for
23 patients from lower SES areas, particularly those in rural and regional areas. This is
24 particularly the case for accessing radiation therapy treatment, which is only available in
25 metropolitan centres and very few major regional centres [46].
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39 **Multiple domains of patient-centred care: Characteristics of particularly** 40 **vulnerable groups**

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42 Overall, 31% of patients indicated that better care in multiple domains of patient-
43 centred care would have greatly improved their well-being. Older patients had lower
44 odds of reporting that improvements in their care were needed multiple domains of
45 care. This finding has been frequently reported in patient satisfaction research [41]. It
46 has been suggested that this may reflect differences in the expectations or preferences of
47 care of older people compared to younger people [18]. Consistent with the findings
48 across the individual domains of care, patients born in Australia had lower odds of
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3 endorsing multiple domains where better care would have greatly improved their
4
5 wellbeing. This is consistent with findings of lower patient satisfaction has been
6
7 reported in migrant groups in international settings [38].
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11 A significant trend towards lower odds of reporting improvements in their care were
12
13 needed was seen in those respondents living with a partner. Spranger et al [20] reported
14
15 that quality of life in individuals with chronic disease was higher amongst those with a
16
17 partner. Family members and carers may play an important role in assisting patients to
18
19 navigate the health care system and may advocate on the patient's behalf [47]. Patients'
20
21 self-management skills may also be complemented by having a support person,[48]
22
23 however these findings warrant further exploration in cancer settings [49].
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30 As expected, an association was found between clinically significant anxiety levels and
31
32 patients' perceptions that their well-being could be improved by better care across
33
34 multiple patient-centred domains. This is consistent with findings suggesting that
35
36 individuals suffering from elevated levels of anxiety may be more likely to be critical of
37
38 the health care system [50]. Alternatively, anxiety may affect interactions with health
39
40 care providers and the effectiveness of help seeking behaviours, resulting in the receipt
41
42 of poorer care across multiple domains. This finding suggests that there is a need to
43
44 identify these patients in clinical practice and reduce their perceived room for
45
46 improvement in wellbeing by alleviating their anxiety and improving their perceptions
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48 of care [51]. There have been some partially successful intervention studies conducted
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50 in radiotherapy settings [52 53] and more generally [3] that have aimed to improve
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52 patient-centredness of care.
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Strengths and Limitations

The current study achieved a high consent rate compared to recent research examining cancer outpatient satisfaction with care,[11] and to the best of our knowledge, is also the first large study to assess patient-centred care in radiation therapy outpatients [54].

Heterogeneous cancer sites and stages were included to provide clinics with information about which patient groups may be missing out on elements of patient-centred care. The quality of care measure was developed following extensive pilot testing and with reference to the literature, and the domains have been supported by a recent qualitative study with radiation oncology patients [54]. Therefore, it appears to have face validity as well as internal reliability. However, further examination of its psychometric properties is needed. Demographic information was collected via patient self-report. Accuracy of this method has been questioned,[55] however has been shown to produce reliable responses for these demographic variables,[56] and is a cost effective and feasible way of collecting these data.

It should also be noted that due to extended pilot testing and low survey completion rates, our final sample size was smaller than planned. However, given that the proportion of patients perceiving the need for better care in each domain was lower than expected, we were still able to obtain prevalence estimates with 95% CI's within $\pm 5\%$ of the point estimate, and detect differences of approximately 15% in characteristics between those who did and did not perceive the need for better care in each domain of care with 80% power and 5% significance level.

Conclusions

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3 Thirty-one percent of respondents identified that better care across multiple domains
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5 would have greatly improved their well-being. “Information and education”, “emotional
6
7 and spiritual support”, “management of physical symptoms” and “involvement of friends
8
9 and family” were the 4 domains most commonly identified where better care would
10
11 have increased respondent well-being. Older patients and patients born in Australia had
12
13 significantly lower odds of identifying multiple domains of patient-centred care where
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15 better care would have improved their well-being. This suggests that younger patients
16
17 and migrants to Australia appear to be more likely to identify that better care would be
18
19 of benefit to their wellbeing. Further investigation of how these factors interact with
20
21 wellbeing and the provision of patient-centred care may assist in developing targeted
22
23 interventions to improve outcomes for these groups.
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REFERENCE LIST.

1. Chassin MR, Galvin RW, and the National Roundtable on Health Care Quality. The Urgent Need to Improve Health Care Quality. *JAMA* 1998;**280**(11):1000-05 doi: 10.1001/jama.280.11.1000
2. Institute of Medicine. *Crossing The Quality Chasm: A New Health System for the 21st Century*. Washington DC: National Academy Press, 2001.
3. Lewin S, Skea Z, Entwistle VA, et al. Interventions for providers to promote a patient-centred approach in clinical consultations. *Cochrane Database Syst Rev* 2001(4):Art. No.: CD003267. doi: 10.1002/14651858.CD003267
4. Kinmonth AL, Woodcock A, Griffin S, et al. Randomised controlled trial of patient centred care of diabetes in general practice: impact on current wellbeing and future disease risk. The Diabetes Care From Diagnosis Research Team. *BMJ* 1998;**317**(7167):1202-8 doi: 10.1136/bmj.317.7167.1202
5. Epstein RM, Fiscella K, Lesser CS, et al. Why the nation needs a policy push on patient-centered health care. *Health Aff (Millwood)* 2010;**29**(8):1489-95 doi: 10.1377/hlthaff.2009.0888
6. Arah OA, Westert GP, Hurst J, et al. A conceptual framework for the OECD Health Care Quality Indicators Project. *Int J Qual Health Care* 2006;**18**(Suppl 1):5-13 doi: 10.1093/intqhc/mzl024
7. Groene O, Skau JKH, Frølich A. An international review of projects on hospital performance assessment. *Int J Qual Health Care* 2008;**20**(3):162-71 doi: 10.1093/intqhc/mzn008
8. Eden J, Simone JV, editors. *Assessing the quality of cancer care: an approach to measurement in Georgia*. Washington, D.C.: National Academy of Sciences, 2005.

- 1
2
3 9. Stewart M. Towards a global definition of patient centred care. *BMJ* 2001;**322**(7284):444-
4
5 45 doi: 10.1136/bmj.322.7284.444
6
7
8 10. Ouwens M, Hermens R, Hulscher M, et al. Development of indicators for patient-centred
9
10 cancer care. *Support Care Cancer* 2010;**18**(1):121-30 doi: 10.1007/s00520-009-0638-
11
12 y
13
14 11. Cancer Institute NSW. New South Wales Cancer Patient Satisfaction Survey 2008.
15
16 Sydney: Cancer Institute NSW, July 2009.
17
18 12. Jenkinson C, Coulter A, Bruster S, et al. Patients' experiences and satisfaction with health
19
20 care: results of a questionnaire study of specific aspects of care. *Qual Saf Health Care*
21
22 2002;**11**(4):335-39 doi: 10.1136/qhc.11.4.335
23
24
25 13. Goldzweig G, Meirowitz A, Hubert A, et al. Meeting expectations of patients with cancer:
26
27 relationship between patient Satisfaction, depression, and coping. *J Clin Oncol*
28
29 2010;**28**(9):1560-65 doi: 10.1200/jco.2009.25.4987
30
31
32 14. Carr AJ, Gibson B, Robinson PG. Is quality of life determined by expectations or
33
34 experience? *BMJ* 2001;**322**(7296):1240-43 doi: 10.1136/bmj.322.7296.1240
35
36
37 15. Gerteis M, Edgman-Levitan S, Daley J. *Through the Patients' Eyes. Understanding and*
38
39 *Promoting Patient-Centred Care* San Francisco, CA: Jossey-Bass, 1993.
40
41 16. Uphoff EPMM, Wennekes L, Punt CJA, et al. Development of generic quality indicators
42
43 for patient-centered cancer care by using a RAND modified delphi method. **Publish**
44
45 **Ahead of Print:**10.1097/NCC.0b013e318210e3a2
46
47
48 17. Bonevski B, Sanson-Fisher R, Girgis A, et al. Evaluation of an instrument to assess the
49
50 needs of patients with cancer. 2000;**88**(1):217-25
51
52 18. Wan GJ, Counte MA, Cella DF, et al. An analysis of the impact of demographic, clinical,
53
54 and social factors on health-related quality of life. *Value Health* 1999;**2**(4):308-18 doi:
55
56 10.1046/j.1524-4733.1999.24006.x
57
58
59
60

- 1
2
3 19. Von Essen L, Larsson G, Öberg K, et al. 'Satisfaction with care': associations with
4 health-related quality of life and psychosocial function among Swedish patients with
5 endocrine gastrointestinal tumours. *Eur J Cancer Care* 2002;**11**(2):91-99 doi:
6 10.1046/j.1365-2354.2002.00293.x
7
8
9
10
11 20. Sprangers MAG, de Regt EB, Andries F, et al. Which chronic conditions are associated
12 with better or poorer quality of life? *J Clin Epidemiol* 2000;**53**(9):895-907 doi:
13 10.1016/s0895-4356(00)00204-3
14
15
16
17 21. Gotay CC, Holup JL, Pagano I. Ethnic differences in quality of life among early breast
18 and prostate cancer survivors. *Psychooncology* 2002;**11**(2):103-13 doi:
19 10.1002/pon.568
20
21
22
23 22. Halkett GK, Kristjanson LJ, Lobb E, et al. Information needs and preferences of women
24 as they proceed through radiotherapy for breast cancer. *Patient Educ Couns*
25 2012;**86**(3):396-404 doi: 10.1016/j.pec.2011.05.010
26
27
28
29
30 23. Harrison J, Young J, Price M, et al. What are the unmet supportive care needs of people
31 with cancer? A systematic review. *Support Care Cancer* 2009;**17**(8):1117-28 doi:
32 10.1007/s00520-009-0615-5
33
34
35
36 24. Delaney G, Jacob S, Featherstone C, et al. The role of radiotherapy in cancer treatment.
37 *Cancer* 2005;**104**(6):1129-37 doi: 10.1002/cncr.21324
38
39
40
41
42 25. Zeguers M, de Haes HCJM, Zandbelt LC, et al. The information needs of new
43 radiotherapy patients: how to measure? do they want to know everything? and if not,
44 why? *Int J Radiat Oncol Biol Phys* 2012;**82**(1):418-24
45
46
47
48
49 26. Douma KL, Koning CE, Zandbelt L, et al. Do patients' information needs decrease over
50 the course of radiotherapy? *Support Care Cancer* 2012;**20**(9):2167-76 doi:
51 10.1007/s00520-011-1328-0
52
53
54
55
56
57
58
59
60

- 1
2
3 27. Siekkinen M, Laiho R, Ruotsalainen E, et al. Quality of care experienced by Finnish
4
5 cancer patients during radiotherapy. *Eur J Cancer Care (Engl)* 2008;**17**(4):387-93 doi:
6
7 10.1111/j.1365-2354.2007.00883.x
8
9
10 28. Sandoval GA, Brown AD, Sullivan T, et al. Factors that influence cancer patients' overall
11
12 perceptions of the quality of care. *Int J Qual Health Care* 2006;**18**(4):266-74 doi:
13
14 10.1093/intqhc/mzl014
15
16 29. Larsson BW. Touch-screen versus paper-and-pen questionnaires: effects on patients'
17
18 evaluations of quality of care. *Int J Health Care Qual Assur Inc Leadersh Health Serv*
19
20 2006;**19**(4-5):328-38 doi: 10.1108/09526860610671382
21
22
23 30. Newell S, Girgis A, Sanson-Fisher R, et al. Are touchscreen computer surveys acceptable
24
25 to medical oncology patients. *J Psychosoc Oncol* Published Online First: doi:
26
27 10.1300/J077v15n02_03
28
29
30 31. Zigmond A, Snaith R. The hospital anxiety and depression scale. *Acta Psychiatr Scand*
31
32 1983;**67**:361-70
33
34 32. Herrmann C. International experiences with the Hospital Anxiety and Depression Scale-A
35
36 review of validation data and clinical results. *J Psychosom Res* 1997;**42**(1):17-41 doi:
37
38 10.1016/s0022-3999(96)00216-4
39
40
41 33. Moorey S, Greer S, Watson M, et al. The factor structure and factor stability of the
42
43 Hospital Anxiety and Depression Scale in Patients with Cancer. *Br J Psychiatry*
44
45 1991;**158**:225-59.
46
47 34. Boyes A, Newell S, Girgis A. Rapid assessment of psychosocial well-being: Are
48
49 computers the way forward in a clinical setting? *Qual Life Res* 2002;**11**(1):27-35 doi:
50
51 10.1023/A:1014407819645
52
53
54
55
56
57
58
59
60

- 1
2
3 35. Australian Bureau of Statistics. SEIFA: Socio-economic indexes for areas. Secondary
4
5 SEIFA: Socio-economic indexes for areas 2008.
6
7 http://www.abs.gov.au/websitedbs/D3310114.nsf/home/Seifa_entry_page.
8
9
10 36. O'Brien I, Britton E, Sarfati D, et al. The voice of experience: results from Cancer Control
11
12 New Zealand's first national cancer care survey. *N Z Med J* 2010;**123**(1325):10-9 doi:
13
14 10.1016/j.radonc.2011.08.005
15
16 37. Watson DE, Mooney D, Peterson S. Patient experiences with ambulatory cancer care in
17
18 British Columbia, 2005/06: UBC Centre for Health Services and Policy Research,
19
20 March 2007.
21
22
23 38. Harmsen JAM, Bernsen RMD, Bruijnzeels MA, et al. Patients' evaluation of quality of
24
25 care in general practice: What are the cultural and linguistic barriers? *Patient Educ*
26
27 *Couns* 2008;**72**(1):155-62 doi: 10.1016/j.pec.2008.03.018
28
29
30 39. Butow P, Sze M, Dugal-Beri P, et al. From inside the bubble: migrants' perceptions of
31
32 communication with the cancer team. *Support Care Cancer* 2011;**19**(2):281-90 doi:
33
34 10.1007/s00520-010-0817-x
35
36 40. Mitchison D, Butow P, Sze M, et al. Prognostic communication preferences of migrant
37
38 patients and their relatives. *Psychooncology* Published Online First: doi:
39
40 10.1002/pon.1923
41
42
43 41. Jaipaul CK, Rosenthal GE. Are Older Patients More Satisfied With Hospital Care Than
44
45 Younger Patients? *J Gen Intern Med* 2003;**18**(1):23-30 doi: 10.1046/j.1525-
46
47 1497.2003.20114.x
48
49
50 42. Schenker Y, Stewart A, Na B, et al. Depressive symptoms and perceived doctor-patient
51
52 communication in the Heart and Soul study. *J Gen Intern Med* 2009;**24**(5):550-6 doi:
53
54 10.1007/s11606-009-0937-5
55
56
57
58
59
60

- 1
2
3 43. Hall JA, Horgan TG, Stein TS, et al. Liking in the physician–patient relationship. *Patient*
4
5 *Educ Couns* 2002;**48**(1):69-77 doi: 10.1016/s0738-3991(02)00071-x
6
7 44. Hall JA, Roter DL, Milbrun MA, et al. Patients' Health as a Predictor of Physician and
8
9 Patient Behavior in Medical Visits: A Synthesis of Four Studies. *Med Care*
10
11 1996;**34**(12):1205-18.
12
13 45. Paul C, Carey M, Anderson A, et al. Cancer patients' concerns regarding access to cancer
14
15 care: perceived impact of waiting times along the diagnosis and treatment journey.
16
17 *Eur J Cancer Care (Engl)* Published Online First: 23 November 2011. doi:
18
19 10.1111/j.1365-2354.2011.01311.x
20
21
22 46. Lehmann F, Hedges A, Hunt B. Barriers to rural patients electing to have radiotherapy.
23
24 Special report: Radiotherapy Summit 2000: Cancer Council Australia, November
25
26 2002.
27
28 47. Sales E. Family burden and quality of life. *Qual Life Res* 2003;**12**(Suppl 1):33-41 doi:
29
30 10.1023/a:1023513218433
31
32
33 48. Clark PC, Dunbar SB. Family partnership intervention: a guide for a family approach to
34
35 care of patients with heart failure. *AACN Clin Issues* 2003;**14**(4):467-76
36
37
38 49. Rijken M, Jones M, Heijmans M, et al. Supporting self-management. In: Nolte E, McKee
39
40 M, eds. *Caring for people with chronic conditions: a health system perspective*.
41
42 Berkshire: Open University Press, 2008:116-42.
43
44
45 50. Shilling V, Jenkins V, Fallowfield L. Factors affecting patient and clinician satisfaction
46
47 with the clinical consultation: Can communication skills training for clinicians
48
49 improve satisfaction? *Psychooncology* 2003;**12**(6):599-611 doi: 10.1002/pon.731
50
51
52 51. Lin H-R, Bauer-Wu SM. Psycho-spiritual well-being in patients with advanced cancer: an
53
54 integrative review of the literature. *J Adv Nurs* 2003;**44**(1):69-80 doi: 10.1046/j.1365-
55
56 2648.2003.02768.x
57
58
59
60

- 1
2
3 52. Halkett G, Merchant S, Jiwa M, et al. Effective communication and information provision
4
5 in radiotherapy—the role of radiation therapists. *J Radiother Pract* 2010;**9**(1):3-16
6
7 53. Halkett GK, Schofield P, O'Connor M, et al. Development and pilot testing of a radiation
8
9 therapist-led educational intervention for breast cancer patients prior to commencing
10
11 radiotherapy. *Asia Pac J Clin Oncol* 2012;**8**(3):e1-8 doi: 10.1111/j.1743-
12
13 7563.2012.01520.x
14
15 54. Nijman JL, Sixma H, Triest Bv, et al. The quality of radiation care: The results of focus
16
17 group interviews and concept mapping to explore the patient's perspective. *Radiother*
18
19 *Oncol* 2012;**102**(1):154-60 doi: 10.1016/j.radonc.2011.08.005
20
21 55. Manjer J, Merlo J, Berglund G. Validity of self-reported information on cancer:
22
23 Determinants of under- and over-reporting. *Eur J Epidemiol* 2004;**19**(3):239-47 doi:
24
25 10.1023/B:EJEP.0000020347.95126.11
26
27 56. Bergmann MM, Calle EE, Mervis CA, et al. Validity of self-reported cancers in a
28
29 prospective cohort study in comparison with data from state cancer registries. *Am J*
30
31 *Epidemiol* 1998;**147**(6):556-62
32
33
34
35
36
37
38
39
40
41
42
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48 Health Care Quality, Access, and Evaluation

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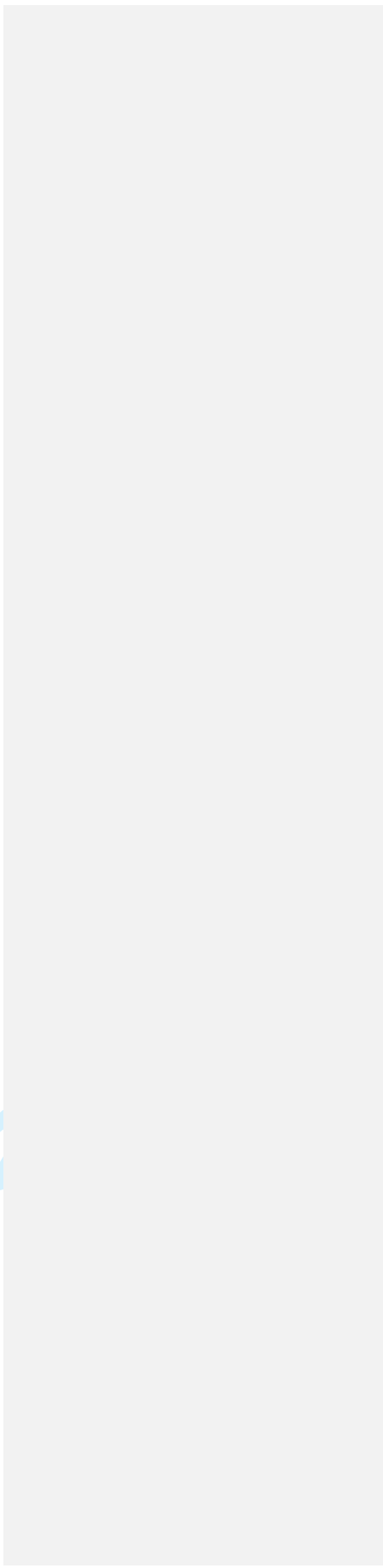
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ABSTRACT:

Objectives. ~~The Institute of Medicine has indicated the urgency of evaluating and improving quality of health care, including patient-centred care.~~ We aimed to describe the proportion and characteristics of cancer patients who perceived that better care would have greatly improved their wellbeing in a) specific, and b) multiple domains of patient-centred care.

Design. Cross sectional touchscreen computer survey.

Setting. Four Australian radiation therapy departments located within major urban public hospitals.

Participants. Radiation therapy outpatients were invited to participate in a touchscreen computer survey. Eligible patients were aged at least 18 years old, diagnosed with cancer, and had sufficient English to complete the survey.

Primary outcome measure. Participants were asked whether their wellbeing could have been greatly improved if better care had been provided across eight domains of patient-centred care. Characteristics of those respondents who identified a) specific and b) multiple domains where it was perceived that better care would have greatly improved their well-being, were examined.

Results. Of 508 eligible radiation therapy patients, 344 (68%) completed the survey. Patients most frequently perceived that better care in the following domains could have improved their wellbeing: information and communication about their cancer (22%;

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7 95% CI: 18-27%); emotional and spiritual support (22%; 95% CI: 18-27%);
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9 management of physical symptoms (21%; 95% CI: 17-26%); and involvement of friends
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11 and family (21%; 95% CI: 17-26%). Just under one third of respondents (31%; 95% CI:
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13 26-36%) indicated that their wellbeing could have been improved by better care across
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15 two or more domains of care. Patients in younger age groups and migrants to Australia
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17 had higher odds of endorsing multiple domains where better care would have improved
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19 their wellbeing.

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22 **Conclusions.** ~~Patients in younger age groups and migrants to Australia had higher odds~~
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24 ~~of identifying multiple domains of patient-centredness where better care would have~~
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26 ~~greatly improved their wellbeing.~~ Further investigation of patients' perceptions
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28 regarding how their perceived quality might be improved is warranted, particularly
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30 amongst patients in younger age groups and migrants to Australia.
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INTRODUCTION.

Why assess patient views of quality of care?

The Institute of Medicine (IOM) [in the United States of America, an independent organisation for gathering evidence to assist health decision making](#), has indicated the urgency of assessing and improving the quality of health care [1]. Quality health care is care that is safe, timely, effective, efficient, equitable and patient-centred [2]. A patient-centred approach to care is defined as being respectful of, and responsive to, patients' physical, social and emotional preferences and needs [3]. Provision of patient-centred care may contribute to improvements in patients' physical, mental and social well-being [4 5]. A patient-centred approach to care is now endorsed as a key component of quality health care by many organisations (including the World Health Organisation [6]) and governments (e.g. in Australia, USA, UK, Canada, Germany, France, Netherlands and Switzerland [7]). [Although quality of care is often examined through audit and benchmarking of clinical outcomes data](#) [8]. Examining patients' judgements of how their experiences of care correspond with their preferences and needs is required in order to assess the quality of patient-centred care [9].

What has previous patient-centred care research contributed to knowledge about prioritising quality improvement efforts?

~~Although previous research has indicated that up to 50% of cancer outpatients are dissatisfied with the level of information provided about physical symptom management, emotional support, involvement of family, and some aspects of access to care,[10-12] these studies have not provided an indication of the relative importance that patients place on quality improvement in these different domain areas. The patient satisfaction approach to assessing quality of care has been criticised for failing to~~

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consider differences in patient expectations, leading to emerging research comparing discrepancies between patients' perceived ideal and actual care [13]. However, this approach still does not capture patient perceptions of the degree to which their wellbeing would benefit from improved care across different domains [14]. Perceptions of relative benefit received by improvements in different domains of care may assist in prioritising quality improvement efforts.

Quality of patient-centred care has been assessed using a variety of patient reported outcomes measures including surveys of patient satisfaction and experiences which are closely linked to the IOM patient-centred care conceptual framework [10 12]. Patient satisfaction surveys' have been criticised because responses may be heavily dependent upon patients' expectations of care, leading to the development of patient experience surveys [12]. The Picker Institute survey assesses outpatients' experiences of care across the domains of patients' preferences; emotional support; physical comfort; information and education; coordination of care; access to care; and involvement of family/friends [11 12 15]. More recently, indicators of the quality of patient-centred care have been developed from international patient-centred oncology clinical practice guidelines [10 16]. These indicators have been grouped across the domains of information; coordination/organisation of care; physical support; emotional and psychological support; communication and respect; involvement; access; and follow-up/after-care. To date, these approaches have not attempted to capture patient perceptions of the degree to which their wellbeing would benefit from improved care across these different domains [14]. Drawing upon the formal supportive care needs assessment approach which aims to identify the level of patient need for help [17].
identification of patients' views of the relative benefit that would be conferred by

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7 improvements in different patient-centred domains care may assist with identifying and
8 prioritising quality improvement efforts [10].

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12 ~~Previous work on patient-centred care has identified that s~~Some subgroups of patients
13 may perceive that they receive poorer care than others. For instance, older patients may
14 be more likely than younger patients to express satisfaction with care, possibly relating
15 to differences in the expectations for care provision [18]. Additionally, cancer patients
16 who have clinically significant levels of anxiety have been found to give lower ratings of
17 satisfaction with care [19]. Wellbeing in patients diagnosed with chronic illness may be
18 linked to aspects of social support such as having a partner, [20] and also potentially to
19 ethnicity [21]. Given that there is some evidence of increased psychological distress and
20 supportive care needs prior to and during treatment [22 23], it may also be that
21 treatment stage may impact on perceptions of care.

22 23 24 25 26 27 28 29 30 31 32 33 **Patient-centred care for radiation therapy patients**

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36 It is recommended that Aapproximately 50% of cancer patients undergo radiation
37 therapy treatment [24]. Given that this treatment is often characterised by frequent
38 contact with the healthcare system over the course of treatment, the radiation therapy
39 setting provides an opportunity for addressing patient perceived needs across the
40 multiple domains of patient-centred care [24]. Although research into specific domains
41 and specific cancer types has been conducted in radiotherapy settings [22 25 26]T, to
42 the best of our knowledge, this is the first study to ask cancer patients undergoing
43 radiation therapy about their perceptions of how better care across multiple patient-
44 centred domains could improve their wellbeing [27]. Further, no previous studies have

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6 identified ~~whether~~ characteristics ~~within of~~ radiation therapy patients who are likely to
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8 perceive better patient-centred care ~~than others~~ [28].
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12 This study aimed to examine the proportion and characteristics of radiation therapy
13 patients who indicate that their well-being could have been greatly improved by better
14 cancer care across each of eight domains of patient-centred care. We also aimed to
15 assess characteristics associated with a patient perception that better care across
16 multiple domains of patient-centred care would have improved their well-being.
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23 24 **METHODS.**

25 26 **Ethics approvals**

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28 Ethics approval was obtained from the University of Newcastle and NSW Population &
29 Health Services Research Ethics Committees.

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30 31 32 33 34 **Design**

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36 Cross sectional survey completed using touchscreen computers.
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40 41 **Participants**

42 Radiation oncology outpatients were recruited from four radiation therapy departments
43 in a major urban centre in Australia between March and December 2010. Each radiation
44 therapy department was attached to a major public teaching hospital, and had at least
45 three Linear Accelerators available for treatment. Eligible patients were aged 18 years
46 or older; diagnosed with cancer; and had sufficient command of English to complete the
47 touchscreen computer survey. Patients who were receiving both radical and palliative
48 treatment were eligible. Those Patients who were attending the clinic for the first time or
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7 who were considered by clinic staff to be too unwell or unable to give informed consent
8 were excluded.
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10 11 12 **Procedure**

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14 Patients waiting for a radiation therapy treatment were invited to participate in the
15 study by a research assistant. Consenting patients were given a unique identification
16 code to login to the touchscreen computer questionnaire. If patients were called into
17 their treatment before finishing their survey, they had the option of resuming after their
18 treatment. Touchscreen computer surveys have been reported as being faster and easier
19 to use for outpatients than pencil and paper surveys,[29] and have been found to be
20 acceptable to oncology patients [30].
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30 31 **Measures**

32 Digivey survey software (CREOSO - Digivey Survey Center, Phoenix, Arizona) was used
33 to program the patient survey, which was administered using Dell Latitude XT2
34 touchscreen laptop computers.
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40 Quality of Care: patient-centred care.

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42 Questions and domain descriptions were developed to correspond with domains of
43 patient-centred care described in the literature,[10 12] ensuring face validity of the
44 items and -clinical relevance to patients currently undergoing treatment. Survey items
45
46 were extensively pilot tested and modified based on feedback from 67 patients. Eight
47 items, each assessing a different domain of care, were presented on separate screens
48 with the stem “During my cancer care, my well-being would have been greatly improved
49 by.” Table 1 lists the eight items and a short description of each domain that was
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presented at the bottom of the touchscreen. Patients were asked to indicate their level of agreement with each statement on a 4-point Likert scale (Strongly disagree, Disagree, Agree, Strongly agree). Internal consistency of the items was assessed using Cronbach's alpha.

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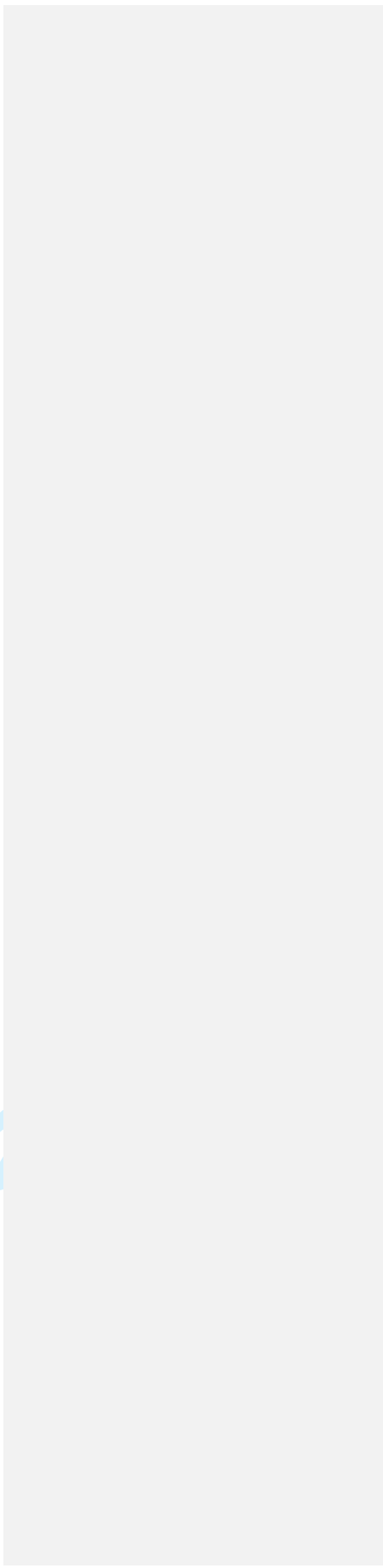


Table 1. Survey items and descriptions (each assessing a different domain of care)

Item	On screen description
Better management of my physical symptoms	May relate to your pain, sleeplessness, other side-effects and symptoms.
Better information and communication about my cancer and care	May include: clear and consistent information about your diagnosis, test results, treatment, taking medications, food you should be eating, exercise you can do safely etc.
Better emotional and/or spiritual support	May include services or support to help you cope with: the impact of cancer on your life, doubts/worries, feelings of anxiety or sadness, changes to your body images etc.
Better services, information and support for my friends/family	May include helping them to cope with the impact of your cancer, or providing opportunities for them to be involved in your care.
Better staff approachability and respect for me	Describes staff who are easy to contact and up-to-date with your medical history, and who give you opportunities to ask questions and be involved in treatment decisions.

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Getting better access to the care I need when required	Describes not having to wait too long to get appointments, and having treatment and medical advice available when needed.
Better services/support to cope with changes to my relationships	May include: knowing what changes to expect, and having some strategies to reduce the impact of cancer on your work, usual social activities, friendships or sexual relationships.
Better services/advice to assist me with practical concerns	May include being able to access financial support, transport to treatment, home help services or other support needed to manage practical issues.

Demographic characteristics.

Patient self-report was used to collect age, gender, whether participants were born in Australia, living with a partner and the postcode of usual place of residence.

Disease characteristics.

A multiple choice question "What is your most recent primary cancer diagnosis?" was used to determine respondents' most recent primary cancer diagnosis. Common cancer types were listed on screen, along with the categories "other - please specify" and "don't know". Approximate time since diagnosis was calculated from patient self-reported year and month of diagnosis and their recruitment date. Patients were asked to indicate the number of radiation therapy treatment and outpatient appointments they had attended; whether they had experienced a second diagnosis and/or recurrence, and whether they

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7 perceived that the aim of their treatment was to cure the cancer; prevent the cancer
8 from coming back or control symptoms of cancer (cure is not possible).
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12 Psychological characteristics.

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14 The Hospital Anxiety and Depression Scale (HADS) is a 14-item self-report measure of
15 anxiety and depression [31]. Both the anxiety and depression subscales provide scores
16 of between 0 and 21 where 0-7= Normal; 8-10= Mild; 11-14 = Moderate; 15-21 = Severe.
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19 The scale has been utilised in research and in clinical practice,[32] with demonstrated
20 reliability and validity [33]. HADS scores have been found to be comparable when
21 administered by touchscreen computer and pen-and-paper in a cancer patient
22 population [34].
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30 **Statistical Methods**

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32 Radiation therapy patients were defined as having endorsed each domain if they
33 indicated that they “agreed” ~~and-or~~ “strongly agreed” that better care would have greatly
34 improved their well-being. The proportion of patients endorsing each domain was
35 reported with 95% confidence intervals. Respondents were then dichotomised on the
36 basis of: a) 0-1 domains endorsed or b) multiple (2 or more) domains endorsed.
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40 Univariate logistic analysis was used to investigate the relationship between
41 demographic characteristics, disease factors and psychological distress and patient
42 endorsement of a) each of the 8 domains of care and b) multiple (2 or more) domains of
43 care requiring improvement. The explanatory variables examined included age (18-49,
44 50-59, 60-69, 70 plus), sex (male, female), cancer diagnosis (Breast, Prostate,
45 Other/Don't Know), second diagnosis and/or recurrence (no, yes), Australian born (no,
46 yes), living with a partner (no, yes), anxiety (no, yes), depression (no, yes), usual place of
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residence (urban/rural, based on Accessibility/Remoteness Index of Australia (ARIA+) score) ~~and~~ socioeconomic status (Socio-Economic Indexes for Areas (SEIFA) average scores[35]), and number of radiotherapy treatment appointments attended (continuous measure). Variables with a *p* value of 0.2 or less on the univariate likelihood ratio test were included in the multiple logistic regression model. The backwards stepwise method was then used to remove all variables with a *p* value of 0.1 or more on the likelihood ratio test, with recruitment site included in all multiple regression models. The fit of the final model was assessed using the Hosmer-Lemeshow goodness of fit test. For individual domains, odds ratios with 95% confidence intervals are reported for multiple regression models. For the assessment of characteristics associated with endorsing multiple domains, odds ratios with 95% confidence intervals are reported for univariate and multiple regression models. Analysis was conducted using STATA version 11.2, and a significance level of 0.05 used.

Sample size and statistical power

We aimed to recruit a total of 450 patients which, based on 50% of patients perceiving the need for better care in each domain, would allow us to obtain prevalence estimates with 95% CI's within $\pm 5\%$ of the point estimate. This sample size would also be sufficient to detect differences of approximately ~~in~~ 15% in characteristics between those who perceive the need for better care in ~~each domain of care~~ each individual domain and also multiple domains of care with 80% power and 5% significance level.

RESULTS.

Of the 639 patients screened for eligibility, 110 were ineligible due to: inadequate English (n=51); not currently receiving RT (n = 32); had already been approached about

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7 the study ($n = 6$); not being diagnosed with cancer ($n = 3$); clinic staff concern about
8 patient burden or ability to give informed consent ($n = 3$); being aged under 18 ($n = 2$),
9 or no specified reason ($n=13$). Of the 529 eligible patients, 85% ($n = 451$) consented, and
10 69% ($n = 365$) completed the survey. Incomplete surveys were primarily because
11 patients were called into their treatment appointment before survey completion, and no
12 data was available from these surveys. An additional 21 patients were excluded because
13 they reported that they were attending their first RT treatment. Once these participants
14 were ruled ineligible, the overall response rate was 68% of 508 eligible radiation
15 therapy patients. Table 2 shows the characteristics of the 344 respondents. 51% were
16 male, the median age was 63.3 (Quartile [Q] 1: 52.2, Q3: 70.5) and the median number of
17 weeks since diagnosis was 27.6 (Q1: 16.0, Q3: 57.3). The majority of respondents (97%)
18 were currently receiving radiation therapy treatment, with the remainder reporting that
19 they were attending the treatment centre for a check-up. The distribution of primary
20 cancer type within the sample can be seen in Table 2.
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Table 2. Demographic and disease characteristics of respondents (n = 344)

Characteristic	Mean (min, max) n (%)
Age (years)	61.4 (18.9-91.4)
	n (%)
Males	176 (51%)
Region of birth	
Australia	231 (67%)
UK/Ireland	30 (8.7%)
Europe	29 (8.4%)
Asia	25 (7.2%)
Other	29 (8.4%)
Perceived palliative treatment aim	46 (14%)
Primary cancer type	
Breast	93 (27%)
Prostate	73 (21%)
Head and neck	33 (9.6%)
Colorectal	20 (5.8%)
Brain	15 (4.4%)
Lung	15 (4.4%)
Other	89 (26%)
Don't know	6 (1.7%)
Second diagnosis/recurrence	96 (28%)
	Median (Q1, Q3)
Completed appointments with <u>cancer</u> doctor	3 (2, 5)

Completed radiation therapy appointments	9 (4, 17)
Weeks since diagnosis	27.6 (16, 37.3)

Note. Observations within each variable may not add to the total due to missing values

Internal consistency of items

When considering the items with responses on a 4-point Likert scale, the internal consistency (Cronbach's α) was 0.92. When the responses were dichotomised (agree versus disagree), Cronbach's α was 0.89.

Proportion of patients endorsing individual domains of patient-centred care

Table 3 shows the number and proportion of radiation oncology patients who agreed that their well-being could have been improved by better care across 8 different domains of patient-centred care. It can be seen that each domain was endorsed by between 12% and 22% of patients.

Table 3. Proportion who reported that their wellbeing would have been improved by better care across 8 domains (n = 344)

	Agree
	n (%), 95% CI)
Information and communication about my cancer and care	76 (22%, 18-27%)
Emotional and/or spiritual support	75 (22%, 18-27%)
Management of my physical symptoms	72 (21%, 17-26%)
Services; information and support for my friends/family	72 (21%, 17-26%)

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Services/advice to assist me with practical concerns	69 (20%, 16-25%)
Access to the care I need when required	62 (18%, 14-23%)
Services/support to cope with changes to my relationships	56 (16%, 13-21%)
Staff approachability and respect for me	42 (12%, 8.9-16%)

Characteristics associated with endorsement of domains

Multiple logistic regression analysis identified that Australian born participants had lower odds of endorsing perceiving “better management of physical symptoms” would have greatly improved their well-being (OR = 0.4; 95% CI: 0.2-0.7; $p = 0.0008$). No other characteristics were significantly associated with endorsing better management of physical symptoms.

Better information and communication about my cancer and care: Australian born patients had lower odds of perceiving that “better information and communication about my cancer and care” would have greatly improved their well-being (OR = 0.5; 95% CI: 0.3-0.9; $p = 0.0153$), as did patients living with a partner (OR = 0.5; 95% CI: 0.3-0.8; $p = 0.0083$). It was also found that patients aged 60-69 years (OR = 0.3; 95% CI: 0.1-0.7) and aged 70 or over (OR = 0.3; 95% CI: 0.2-0.8) had lower odds of endorsing this domain than younger participants ($p = 0.0042$). Patients with a likely presence of depression had three times the odds of endorsing this domain (OR = 3.1; 95% CI: 1.1-9.0; $p = 0.0396$).

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7 Better emotional and/or spiritual support: Patients aged 60-69 years (OR = 0.3; 95% CI:
8 0.1-0.6) and aged 70 or over (OR = 0.4; 95% CI: 0.2-0.8) had lower odds of endorsing
9 this domain than younger participants ($p = 0.0011$). Australian born patients had lower
10 odds of endorsing this domain (OR = 0.3; 95% CI: 0.2-0.5; $p < 0.0001$), whilst patients
11 with clinically significant levels of depression had higher odds of endorsing (OR = 3.5;
12 95% CI: 1.2-10.1; $p = 0.0250$).
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20 Better services, information and support for my friends/family: Lower odds of
21 endorsing this domain were found in older patients aged 60-69 years (OR = 0.2; 95% CI:
22 0.1-0.5) and aged 70 or over (OR = 0.2; 95% CI: 0.1-0.4) compared to younger
23 participants ($p < 0.0001$), and also in Australian born patients (OR = 0.4; 95% CI: 0.2-0.6;
24 $p = 0.0004$).
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32 Better staff approachability and respect for me: Australian born patients had
33 significantly lower odds of endorsing this domain (OR = 0.3; 95% CI: 0.1-0.5; $p =$
34 0.0001). Marginally non-significantly lower odds of endorsing this domain were found in
35 older patients aged 60-69 years (OR = 0.3; 95% CI: 0.1-0.9) compared to younger
36 participants ($p = 0.0683$).
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44 Getting better access to the care I need when required: Older patients aged 60-69 years
45 (OR = 0.2; 95% CI: 0.1-0.5) and aged 70 or over (OR = 0.3; 95% CI: 0.1-0.8) had lower
46 odds of endorsing this domain compared to younger participants ($p = 0.0003$). Once
47 again, Australian born patients had lower odds of endorsing this domain (OR = 0.3; 95%
48 CI: 0.2-0.6; $p = 0.0003$). Marginally non-significantly lower odds were also found in
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socioeconomic Group 2 (OR = 0.2; 95% CI: 0.1-0.9) and Group 3 (OR = 0.3; 95% CI: 0.1-0.9) compared to the lowest SES Group 1 ($p = 0.0837$).

Better services/support to cope with changes to my relationships: Older patients aged 60-69 years (OR = 0.1; 95% CI: 0.1-0.4) and aged 70 or over (OR = 0.2; 95% CI: 0.1-0.4) had lower odds of endorsing this domain compared to younger participants ($p < 0.0001$). Once again, Australian born patients had lower odds of endorsing this domain (OR = 0.3; 95% CI: 0.1-0.5; $p = 0.0001$). Patients with clinically significant levels of depression had higher odds of endorsing this domain (OR = 7.2; 95% CI: 2.3-22.5; $p = 0.0007$).

Better services/advice to assist me with practical concerns: Older patients aged 60-69 years (OR = 0.1; 95% CI: 0.1-0.3) and aged 70 or over (OR = 0.3; 95% CI: 0.1-0.6) had lower odds of endorsing this domain compared to younger participants ($p < 0.0001$). Australian born patients also had lower odds of endorsing this domain (OR = 0.5; 95% CI: 0.3-0.8; $p = 0.0070$).

Proportion of patients endorsing multiple domains where better care would have improved their well-being

Figure 1 shows the percentage of respondents endorsing none, one and multiple domains where better care would have improved their wellbeing. Overall 31% of respondents ($n = 107$) endorsed multiple domains where they agreed or strongly agreed that their wellbeing could have been improved by better care.

FIGURE 1 ABOUT HERE

For 55% of participants, it was perceived that improvement in well-being would not have resulted from better care in any of the examined domains. Fourteen percent of participants identified only one domain where better care would have greatly improved their well-being. Table 4 shows the results of analyses examining factors associated with the perception that wellbeing could have been improved by better care in multiple (2 or more) domains. It can be seen that compared with the younger age group (18-49 years), being aged 60 years or over was associated with significantly lower odds of endorsing multiple domains as requiring improvement. Additionally, relative to patients not born in Australia, those who were Australian born had significantly lower odds of endorsing multiple domains in which wellbeing would have been improved by better care. Outpatients living with a partner had significantly lower odds of identifying multiple domains where better care would have greatly improved their wellbeing. There were significantly higher odds of endorsing multiple domains amongst outpatients with a likely presence of anxiety.

Table 4. Demographic, disease and HADS associations with endorsement of multiple domains as requiring improvement¶

	Multiple domains endorsed <i>n</i> (%)	LR Chi ² , <i>p</i> Unadjusted OR (95% CI)	LR Chi ² , <i>p</i> Adjusted OR (95% CI)
Hospital		5.0, <i>p</i> = 0.1752	2.9, <i>p</i> = 0.4002
Site 1	36 (36%)	1.0	1.0

Site 2	22 (23%)	0.5 (0.3-1.0)	0.6 (0.3-1.2)
Site 3	23 (32%)	0.8 (0.4-1.6)	0.9 (0.4-1.8)
Site 4	26 (34%)	0.9 (0.5-1.7)	1.0 (0.5-2.0)
Age category		35.9, p <0.0001	28.9, p
18-49 years	36 (51%)	1.0	<0.0001*
50-59 years	34 (46%)	0.8 (0.4-1.5)	1.0
60-69 years	20 (18%)	0.2 (0.1-0.4)	0.7 (0.4-1.4)
70 years plus	17 (19%)	0.2 (0.1-0.4)	0.2 (0.1-0.4)
			0.2 (0.1-0.5)
Sex§		2.5, p = 0.1159	
Male	48 (27%)	1.0	
Female	59 (35%)	1.4 (0.9-2.3)	
Cancer type§		3.8, p = 0.1469	
Breast	31 (33%)	1.0	
Prostate	16 (22%)	0.6 (0.3-1.1)	
Other cancer types†	60 (34%)	1.0 (0.6-1.7)	
Second diagnosis or recurrence		1.0, p = 0.3123	
No	81 (33%)	1.0	
Yes	26 (27%)	0.8 (0.5-1.3)	
Born in Australia		8.5, p = 0.0037	5.4, p = 0.0205*
No	47 (42%)	1.0	1.0
Yes	60 (26%)	0.5 (0.3-0.8)	0.5 (0.3-0.9)
Socioeconomic status		0.3, p = 0.5758	
Low	5 (22%)	1.0	

Medium	8 (16%)	0.7 (0.2-2.4)	
High	59 (22%)	1.0 (0.4-2.9)	
Usual place of residence		0.3, p = 0.5758	
Major city	87 (32%)	1.0	
Regional or rural	19 (28%)	0.8 (0.5-1.5)	
Living with partner		5.2, p = 0.0224	3.9, p = 0.0481*
No	50 (38%)	1.0	1.0
Yes	57 (27%)	0.6 (0.4-0.9)	0.6 (0.4-1.0)
Clinically significant anxiety‡		10.4, p = 0.0013	4.3, p = 0.0383*
No	82 (28%)	1.0	1.0
Yes	25 (52%)	2.8 (1.5-5.2)	2.1 (1.0-4.1)
Clinically significant depression‡§		5.7, p = 0.0167	
No	97 (30%)	1	
Yes	10 (59%)	3.3 (1.2-9.0)	
Completed radiation therapy appointments		0.02, p = 0.8893	

Note. Observations within each variable may not add to the total due to missing values

†Including brain, colorectal, head and neck, lung, non-Hodgkin's lymphoma, and other cancer types

‡Assessed using the Hospital Anxiety and Depression Scale (HADS)

§Eliminated during backwards stepwise multiple logistic regression analysis

|| Reported *p*-values are from the Likelihood ratio test

¶ *p*-values for the Hosmer-Lemeshow goodness of fit test were between 0.2 and 0.9 for specific domain models; and was 0.1 for the multiple domain model

DISCUSSION

In which domains would better care greatly improve wellbeing for the most patients?

For each of the eight domains of care assessed, between 12-22% of respondents agreed or strongly agreed that their wellbeing would have greatly improved with better care.

One fifth or more agreed that improvements to the following domains would have improved their care: better information and communication about my cancer and care (22%); better emotional and/or spiritual support (22%); better management of physical symptoms (21%); better services information and support for friends/family (21%); and better services/advice to assist with practical concerns (20%). Overall, these frequencies were lower than identified in comparable domains in recent international studies of cancer patient experiences of care in Australia, New Zealand, British Columbia, Canada and Europe [10 11 19 36 37]. This discrepancy may be a consequence of the differences in measures. Although past measures have assessed experiences of care or unmet need, they have not assessed the impact that patients perceive better care in these patient-centred domains would have on their wellbeing. Alternatively, the discrepancies between findings may be a result of improved delivery of patient centred care over time.

Characteristics associated with endorsing each domain of patient-centred care

Country of birth

Australian born patients had lower odds of endorsing each of the assessed domains of patient-centred care. It may be that Australian born patients perceive that they are receiving better care than migrants. Alternatively, it may be that Australian born

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7 patients have lower expectations of care and of the degree to which their well-being
8 would be improved by better care [38]. Linguistic and cultural barriers to patient
9 perceptions of high quality health care have been previously identified, highlighting the
10 need for responsiveness to cultural background for optimal health care delivery [38].

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14 ~~There is a need to investigate this finding amongst more culturally and linguistically~~
15 ~~diverse cancer communities~~ Although, given that the current research was limited to
16 patients with adequate English to complete the survey, there has been increased
17 research attention on some of these challenges faced by people with cancer from
18 culturally and linguistically diverse backgrounds in Australia [39 40].
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25 26 Age group

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28 Older age was associated with lower odds of endorsing a need for improvement in all
29 domains of patient-centred care, with the exception of management of physical
30 symptoms and staff approachability and respect for the patient. This is consistent with
31 previous studies suggesting that older age is associated with higher overall patient
32 satisfaction ratings [41] and that older patients undergoing radiation treatment have
33 lower information needs [25]. It may be that older patients perceive pain management
34 and interpersonal care as a traditional role of the doctor, leading to similar perceptions
35 about the need for improvement in these domains as held by younger age groups.
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45 HADS classified depression

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47 Patients with HADS classified depression had higher odds of endorsing the following
48 three domains than non-depressed respondents: Information and communication about
49 cancer and care; emotional and spiritual support; and support with changes to
50 relationships. A diagnosis of chronic disease with comorbid depression has previously
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7 been associated with perceptions of poor doctor-patient communication [42]. This may
8 be because depressive symptoms such as negative affect may make interactions with
9 health care providers more strained and less effective than for non-depressed patients
10 [43 44]. Alternatively it may be that there are patient recall difficulties arising from
11 depressive symptoms such as poor concentration, leading to negative patient
12 perceptions of information provision and communication [42].
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20 Socioeconomic status

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22 Higher socioeconomic groups were found to have marginally significantly lower odds of
23 endorsing issues relating to getting access to care when required. Patients from higher
24 SES areas may be more likely to live in wealthier urban areas that are closer to health
25 care facilities, and therefore have less difficulties with access [45]. Given Australia's
26 dispersed population, access to cancer care service delivery can be challenging for
27 patients from lower SES areas, particularly those in rural and regional areas. This is
28 particularly the case for accessing radiation therapy treatment, which is only available in
29 metropolitan centres and very few major regional centres [46].
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40 **Multiple domains of patient-centred care: Characteristics of particularly** 41 **vulnerable groups**

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43 Overall, 31% of patients indicated that better care in multiple domains of patient-
44 centred care would have greatly improved their well-being. Older patients had lower
45 odds of reporting that improvements in their care were needed multiple domains of
46 care. This finding has been frequently reported in patient satisfaction research [41]. It
47 has been suggested that this may reflect differences in the expectations or preferences of
48 care of older people compared to younger people [18]. Consistent with the findings
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7 across the individual domains of care, patients born in Australia had lower odds of
8 endorsing multiple domains where better care would have greatly improved their
9 wellbeing. This is consistent with findings of lower patient satisfaction has been
10 reported in migrant groups in international settings [38].
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16 A significant trend towards lower odds of reporting improvements in their care were
17 needed was seen in those respondents living with a partner. Spranger et al [20] reported
18 that quality of life in individuals with chronic disease was higher amongst those with a
19 partner. Family members and carers may play an important role in assisting patients to
20 navigate the health care system and may advocate on the patient's behalf [47]. Patients'
21 self-management skills may also be complemented by having a support person,[48]
22 however these findings warrant further exploration in cancer settings [49].
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32 As expected, an association was found between clinically significant anxiety levels and
33 patients' perceptions that their well-being could be improved by better care across
34 multiple patient-centred domains. This is consistent with findings suggesting that
35 individuals suffering from elevated levels of anxiety may be more likely to be critical of
36 the health care system [50]. Alternatively, anxiety may affect interactions with health
37 care providers and the effectiveness of help seeking behaviours, resulting in the receipt
38 of poorer care across multiple domains. This finding suggests that there is a need to
39 identify these patients in clinical practice and reduce their perceived room for
40 improvement in wellbeing by alleviating their anxiety and improving their perceptions
41 of care [51]. There have been some partially successful intervention studies conducted
42 in radiotherapy settings [52 53] and more generally [3] that have aimed to improve
43 patient-centredness of care.
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Strengths and Limitations

The current study achieved a high consent rate compared to recent research examining cancer outpatient satisfaction with care,[11] and to the best of our knowledge, is also the first large study to assess patient-centred care in radiation therapy outpatients [54].

Heterogeneous cancer sites and stages were included to provide clinics with information about which patient groups may be missing out on elements of patient-centred care. The quality of care measure was developed following extensive pilot testing and with reference to the literature, and the domains have been supported by a recent qualitative study with radiation oncology patients [54]. Therefore, it appears to have face validity as well as internal reliability. However, further examination of its psychometric properties is needed. Demographic information was collected via patient self-report. Accuracy of this method has been questioned,[55] however has been shown to produce reliable responses for these demographic variables,[56] and is a cost effective and feasible way of collecting these data.

It should also be noted that due to extended pilot testing and low survey completion rates, our final sample size was smaller than planned. However, given that the proportion of patients perceiving the need for better care in each domain was lower than expected, we were still able to obtain prevalence estimates with 95% CI's within ±5% of the point estimate, and detect differences of approximately 15% in characteristics between those who did and did not perceive the need for better care in each domain of care with 80% power and 5% significance level.

Conclusions

Thirty-one percent of respondents identified that better care across multiple domains would have greatly improved their well-being. “Information and education”, “emotional and spiritual support”, “management of physical symptoms” and “involvement of friends and family” were the 4 domains most commonly identified where better care would have increased respondent well-being. Older patients and patients born in Australia had significantly lower odds of identifying multiple domains of patient-centred care where better care would have improved their well-being. This suggests that younger patients and migrants to Australia appear to be more likely to identify that better care would be of benefit to their wellbeing. Further investigation of how these factors interact with wellbeing and the provision of patient-centred care may assist in developing targeted interventions to improve outcomes for these groups.

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54
55
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60

1
2
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4
5
6
7 **REFERENCE LIST.**

- 8
9 1. Chassin MR, Galvin RW, and the National Roundtable on Health Care Quality. The Urgent
10 Need to Improve Health Care Quality. *JAMA* 1998;**280**(11):1000-05 doi:
11 10.1001/jama.280.11.1000
12
13
14 2. Institute of Medicine. *Crossing The Quality Chasm: A New Health System for the 21st*
15 *Century*. Washington DC: National Academy Press, 2001.
16
17
18 3. Lewin S, Skea Z, Entwistle VA, et al. Interventions for providers to promote a patient-
19 centred approach in clinical consultations. *Cochrane Database Syst Rev* 2001(4):Art.
20 No.: CD003267. doi: 10.1002/14651858.CD003267
21
22
23
24 4. Kinmonth AL, Woodcock A, Griffin S, et al. Randomised controlled trial of patient centred
25 care of diabetes in general practice: impact on current wellbeing and future disease
26 risk. The Diabetes Care From Diagnosis Research Team. *BMJ* 1998;**317**(7167):1202-8
27 doi: 10.1136/bmj.317.7167.1202
28
29
30
31 5. Epstein RM, Fiscella K, Lesser CS, et al. Why the nation needs a policy push on patient-
32 centered health care. *Health Aff (Millwood)* 2010;**29**(8):1489-95 doi:
33 10.1377/hlthaff.2009.0888
34
35
36
37 6. Arah OA, Westert GP, Hurst J, et al. A conceptual framework for the OECD Health Care
38 Quality Indicators Project. *Int J Qual Health Care* 2006;**18**(Suppl 1):5-13 doi:
39 10.1093/intqhc/mzl024
40
41
42
43 7. Groene O, Skau JKH, Frølich A. An international review of projects on hospital
44 performance assessment. *Int J Qual Health Care* 2008;**20**(3):162-71 doi:
45 10.1093/intqhc/mzn008
46
47
48
49 8. Eden J, Simone JV, editors. *Assessing the quality of cancer care: an approach to*
50 *measurement in Georgia*. Washington, D.C.: National Academy of Sciences, 2005.
51
52
53
54
55

- 1
2
3
4
5
6
7 9. Stewart M. Towards a global definition of patient centred care. *BMJ* 2001;**322**(7284):444-
8 45 doi: 10.1136/bmj.322.7284.444
9
- 10 10. Ouwens M, Hermens R, Hulscher M, et al. Development of indicators for patient-centred
11 cancer care. *Support Care Cancer* 2010;**18**(1):121-30 doi: 10.1007/s00520-009-0638-
12 y
13
- 14 11. Cancer Institute NSW. New South Wales Cancer Patient Satisfaction Survey 2008.
15 Sydney: Cancer Institute NSW, July 2009.
16
- 17 12. Jenkinson C, Coulter A, Bruster S, et al. Patients' experiences and satisfaction with health
18 care: results of a questionnaire study of specific aspects of care. *Qual Saf Health Care*
19 2002;**11**(4):335-39 doi: 10.1136/qhc.11.4.335
20
- 21 13. Goldzweig G, Meirowitz A, Hubert A, et al. Meeting expectations of patients with cancer:
22 relationship between patient Satisfaction, depression, and coping. *J Clin Oncol*
23 2010;**28**(9):1560-65 doi: 10.1200/jco.2009.25.4987
24
- 25 14. Carr AJ, Gibson B, Robinson PG. Is quality of life determined by expectations or
26 experience? *BMJ* 2001;**322**(7296):1240-43 doi: 10.1136/bmj.322.7296.1240
27
- 28 15. Gerteis M, Edgman-Levitan S, Daley J. *Through the Patients' Eyes. Understanding and*
29 *Promoting Patient-Centred Care* San Francisco, CA: Jossey-Bass, 1993.
30
- 31 16. Uphoff EPMM, Wennekes L, Punt CJA, et al. Development of generic quality indicators
32 for patient-centered cancer care by using a RAND modified delphi method. **Publish**
33 **Ahead of Print**:10.1097/NCC.0b013e318210e3a2
34
- 35 17. Bonevski B, Sanson-Fisher R, Girgis A, et al. Evaluation of an instrument to assess the
36 needs of patients with cancer. 2000;**88**(1):217-25
37
- 38 18. Wan GJ, Counte MA, Cella DF, et al. An analysis of the impact of demographic, clinical,
39 and social factors on health-related quality of life. *Value Health* 1999;**2**(4):308-18 doi:
40 10.1046/j.1524-4733.1999.24006.x
41
42
43
44
45
46
47
48
49
50
51
52
53
54
55
56
57
58
59
60

- 1
2
3
4
5
6
7 19. Von Essen L, Larsson G, ÖBerg K, et al. 'Satisfaction with care': associations with
8 health-related quality of life and psychosocial function among Swedish patients with
9 endocrine gastrointestinal tumours. *Eur J Cancer Care* 2002;**11**(2):91-99 doi:
10 10.1046/j.1365-2354.2002.00293.x
11
12
13
14 20. Sprangers MAG, de Regt EB, Andries F, et al. Which chronic conditions are associated
15 with better or poorer quality of life? *J Clin Epidemiol* 2000;**53**(9):895-907 doi:
16 10.1016/s0895-4356(00)00204-3
17
18
19
20 21. Gotay CC, Holup JL, Pagano I. Ethnic differences in quality of life among early breast
21 and prostate cancer survivors. *Psychooncology* 2002;**11**(2):103-13 doi:
22 10.1002/pon.568
23
24
25
26 22. Halkett GK, Kristjanson LJ, Lobb E, et al. Information needs and preferences of women
27 as they proceed through radiotherapy for breast cancer. *Patient Educ Couns*
28 2012;**86**(3):396-404 doi: 10.1016/j.pec.2011.05.010
29
30
31
32 23. Harrison J, Young J, Price M, et al. What are the unmet supportive care needs of people
33 with cancer? A systematic review. *Support Care Cancer* 2009;**17**(8):1117-28 doi:
34 10.1007/s00520-009-0615-5
35
36
37
38 24. Delaney G, Jacob S, Featherstone C, et al. The role of radiotherapy in cancer treatment.
39 *Cancer* 2005;**104**(6):1129-37 doi: 10.1002/cncr.21324
40
41
42 25. Zeguers M, de Haes HCJM, Zandbelt LC, et al. The information needs of new
43 radiotherapy patients: how to measure? do they want to know everything? and if not,
44 why? *Int J Radiat Oncol Biol Phys* 2012;**82**(1):418-24
45
46
47 26. Douma KL, Koning CE, Zandbelt L, et al. Do patients' information needs decrease over
48 the course of radiotherapy? *Support Care Cancer* 2012;**20**(9):2167-76 doi:
49 10.1007/s00520-011-1328-0
50
51
52
53
54
55
56
57
58
59
60

- 1
2
3
4
5
6
7 27. Siekkinen M, Laiho R, Ruotsalainen E, et al. Quality of care experienced by Finnish
8 cancer patients during radiotherapy. *Eur J Cancer Care (Engl)* 2008;**17**(4):387-93 doi:
9 10.1111/j.1365-2354.2007.00883.x
10
11
12 28. Sandoval GA, Brown AD, Sullivan T, et al. Factors that influence cancer patients' overall
13 perceptions of the quality of care. *Int J Qual Health Care* 2006;**18**(4):266-74 doi:
14 10.1093/intqhc/mzl014
15
16 29. Larsson BW. Touch-screen versus paper-and-pen questionnaires: effects on patients'
17 evaluations of quality of care. *Int J Health Care Qual Assur Inc Leadersh Health Serv*
18 2006;**19**(4-5):328-38 doi: 10.1108/09526860610671382
19
20 30. Newell S, Girgis A, Sanson-Fisher R, et al. Are touchscreen computer surveys acceptable
21 to medical oncology patients. *J Psychosoc Oncol* Published Online First: doi:
22 10.1300/J077v15n02_03
23
24 31. Zigmond A, Snaith R. The hospital anxiety and depression scale. *Acta Psychiatr Scand*
25 1983;**67**:361-70
26
27 32. Herrmann C. International experiences with the Hospital Anxiety and Depression Scale-A
28 review of validation data and clinical results. *J Psychosom Res* 1997;**42**(1):17-41 doi:
29 10.1016/s0022-3999(96)00216-4
30
31 33. Moorey S, Greer S, Watson M, et al. The factor structure and factor stability of the
32 Hospital Anxiety and Depression Scale in Patients with Cancer. *Br J Psychiatry*
33 1991;**158**:225-59.
34
35 34. Boyes A, Newell S, Girgis A. Rapid assessment of psychosocial well-being: Are
36 computers the way forward in a clinical setting? *Qual Life Res* 2002;**11**(1):27-35 doi:
37 10.1023/A:1014407819645
38
39
40
41
42
43
44
45
46
47
48
49
50
51
52
53
54
55
56
57
58
59
60

- 1
2
3
4
5
6
7 35. Australian Bureau of Statistics. SEIFA: Socio-economic indexes for areas. Secondary
8 SEIFA: Socio-economic indexes for areas 2008.
9
10 http://www.abs.gov.au/websitedbs/D3310114.nsf/home/Seifa_entry_page.
11
12 36. O'Brien I, Britton E, Sarfati D, et al. The voice of experience: results from Cancer Control
13 New Zealand's first national cancer care survey. *N Z Med J* 2010;**123**(1325):10-9 doi:
14 10.1016/j.radonc.2011.08.005
15
16 37. Watson DE, Mooney D, Peterson S. Patient experiences with ambulatory cancer care in
17 British Columbia, 2005/06: UBC Centre for Health Services and Policy Research,
18 March 2007.
19
20 38. Harmsen JAM, Bernsen RMD, Bruijnzeels MA, et al. Patients' evaluation of quality of
21 care in general practice: What are the cultural and linguistic barriers? *Patient Educ*
22 *Couns* 2008;**72**(1):155-62 doi: 10.1016/j.pec.2008.03.018
23
24 39. Butow P, Sze M, Dugal-Beri P, et al. From inside the bubble: migrants' perceptions of
25 communication with the cancer team. *Support Care Cancer* 2011;**19**(2):281-90 doi:
26 10.1007/s00520-010-0817-x
27
28 40. Mitchison D, Butow P, Sze M, et al. Prognostic communication preferences of migrant
29 patients and their relatives. *Psychooncology* Published Online First: doi:
30 10.1002/pon.1923
31
32 41. Jaipaul CK, Rosenthal GE. Are Older Patients More Satisfied With Hospital Care Than
33 Younger Patients? *J Gen Intern Med* 2003;**18**(1):23-30 doi: 10.1046/j.1525-
34 1497.2003.20114.x
35
36 42. Schenker Y, Stewart A, Na B, et al. Depressive symptoms and perceived doctor-patient
37 communication in the Heart and Soul study. *J Gen Intern Med* 2009;**24**(5):550-6 doi:
38 10.1007/s11606-009-0937-5
39
40
41
42
43
44
45
46
47
48
49
50
51
52
53
54
55
56
57
58
59
60

- 1
2
3
4
5
6
7 43. Hall JA, Horgan TG, Stein TS, et al. Liking in the physician–patient relationship. *Patient*
8 *Educ Couns* 2002;**48**(1):69-77 doi: 10.1016/s0738-3991(02)00071-x
9
- 10 44. Hall JA, Roter DL, Milbrun MA, et al. Patients' Health as a Predictor of Physician and
11 Patient Behavior in Medical Visits: A Synthesis of Four Studies. *Med Care*
12 1996;**34**(12):1205-18.
13
- 14 45. Paul C, Carey M, Anderson A, et al. Cancer patients' concerns regarding access to cancer
15 care: perceived impact of waiting times along the diagnosis and treatment journey.
16 *Eur J Cancer Care (Engl)* Published Online First: 23 November 2011. doi:
17 10.1111/j.1365-2354.2011.01311.x
18
- 19 46. Lehmann F, Hedges A, Hunt B. Barriers to rural patients electing to have radiotherapy.
20 Special report: Radiotherapy Summit 2000: Cancer Council Australia, November
21 2002.
22
- 23 47. Sales E. Family burden and quality of life. *Qual Life Res* 2003;**12**(Suppl 1):33-41 doi:
24 10.1023/a:1023513218433
25
- 26 48. Clark PC, Dunbar SB. Family partnership intervention: a guide for a family approach to
27 care of patients with heart failure. *AACN Clin Issues* 2003;**14**(4):467-76
28
- 29 49. Rijken M, Jones M, Heijmans M, et al. Supporting self-management. In: Nolte E, McKee
30 M, eds. Caring for people with chronic conditions: a health system perspective.
31 Berkshire: Open University Press, 2008:116-42.
32
- 33 50. Shilling V, Jenkins V, Fallowfield L. Factors affecting patient and clinician satisfaction
34 with the clinical consultation: Can communication skills training for clinicians
35 improve satisfaction? *Psychooncology* 2003;**12**(6):599-611 doi: 10.1002/pon.731
36
- 37 51. Lin H-R, Bauer-Wu SM. Psycho-spiritual well-being in patients with advanced cancer: an
38 integrative review of the literature. *J Adv Nurs* 2003;**44**(1):69-80 doi: 10.1046/j.1365-
39 2648.2003.02768.x
40
41
42
43
44
45
46
47
48
49
50
51
52
53
54
55
56
57
58
59
60

- 1
2
3
4
5
6
7 52. Halkett G, Merchant S, Jiwa M, et al. Effective communication and information provision
8 in radiotherapy—the role of radiation therapists. *J Radiother Pract* 2010;**9**(1):3-16
9
10 53. Halkett GK, Schofield P, O'Connor M, et al. Development and pilot testing of a radiation
11 therapist-led educational intervention for breast cancer patients prior to commencing
12 radiotherapy. *Asia Pac J Clin Oncol* 2012;**8**(3):e1-8 doi: 10.1111/j.1743-
13 7563.2012.01520.x
14
15
16
17 54. Nijman JL, Sixma H, Triest BV, et al. The quality of radiation care: The results of focus
18 group interviews and concept mapping to explore the patient's perspective. *Radiother*
19 *Oncol* 2012;**102**(1):154-60 doi: 10.1016/j.radonc.2011.08.005
20
21
22
23 55. Manjer J, Merlo J, Berglund G. Validity of self-reported information on cancer:
24 Determinants of under- and over-reporting. *Eur J Epidemiol* 2004;**19**(3):239-47 doi:
25 10.1023/B:EJEP.0000020347.95126.11
26
27
28
29 56. Bergmann MM, Calle EE, Mervis CA, et al. Validity of self-reported cancers in a
30 prospective cohort study in comparison with data from state cancer registries. *Am J*
31 *Epidemiol* 1998;**147**(6):556-62
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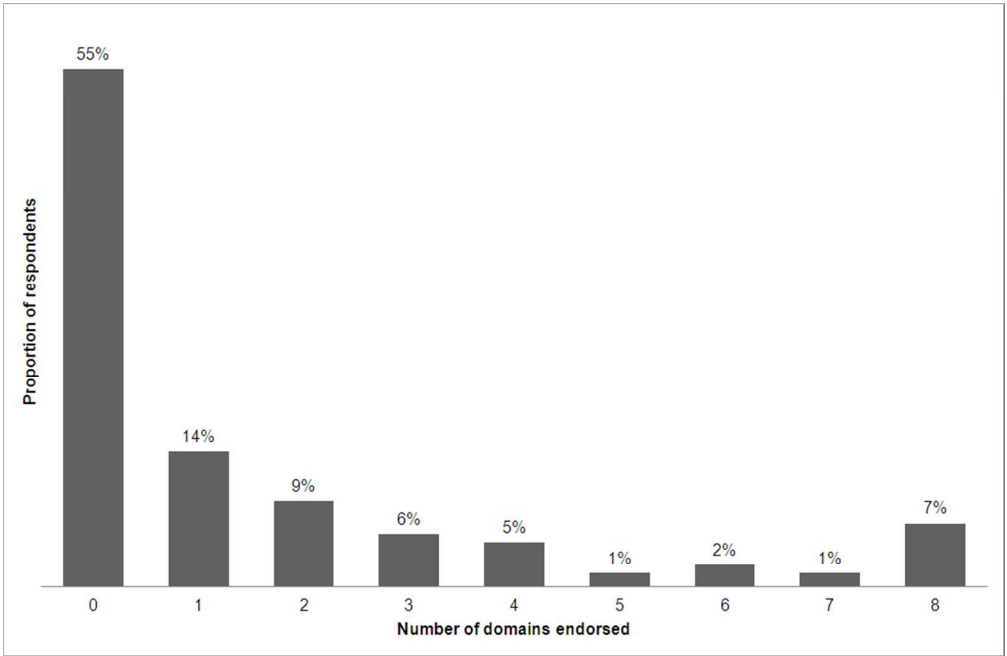


Figure 1. Percentage of respondents endorsing 0-8 domains in which better care would have greatly improved their well-being

Review only

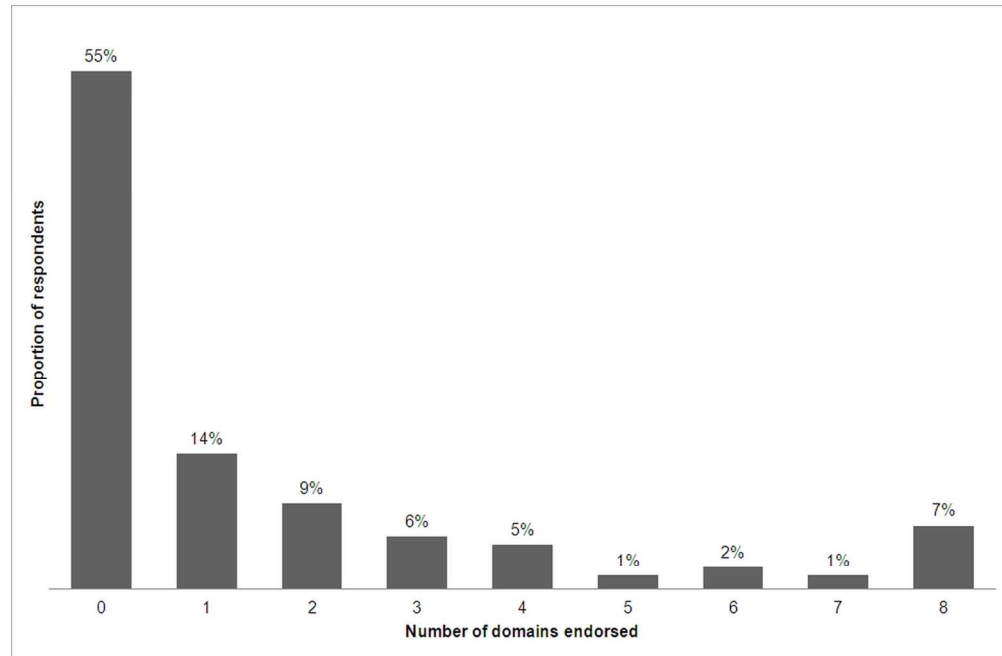
STROBE Statement—Checklist of items that should be included in reports of *cross-sectional studies*

	Item No	Recommendation
Title and abstract	1	(a) Indicate the study's design with a commonly used term in the title or the abstract "Radiation oncology outpatient perceptions of patient-centred care: A cross-sectional survey" (b) Provide in the abstract an informative and balanced summary of what was done and what was found See pages 2-3
Introduction		
Background/rationale	2	Explain the scientific background and rationale for the investigation being reported See pages 4-6
Objectives	3	State specific objectives, including any prespecified hypotheses See page 6
Methods		
Study design	4	Present key elements of study design early in the paper See "Design" section on page 6
Setting	5	Describe the setting, locations, and relevant dates, including periods of recruitment, exposure, follow-up, and data collection See "Participants" and "Procedure" sections on pages 6-7
Participants	6	(a) Give the eligibility criteria, and the sources and methods of selection of participants See "Participants" and "Procedure" sections on page 6-7
Variables	7	Clearly define all outcomes, exposures, predictors, potential confounders, and effect modifiers. Give diagnostic criteria, if applicable See "Measures" section on pages 7-10, including Table 1.
Data sources/ measurement	8*	For each variable of interest, give sources of data and details of methods of assessment (measurement). Describe comparability of assessment methods if there is more than one group See "Measures" section on pages 7-10, including Table 1.
Bias	9	Describe any efforts to address potential sources of bias See "Statistical methods" section on pages 10-11.
Study size	10	Explain how the study size was arrived at See "Sample size and statistical power" section on page 11.
Quantitative variables	11	Explain how quantitative variables were handled in the analyses. If applicable, describe which groupings were chosen and why See "Statistical methods" section on pages 10-11.
Statistical methods	12	(a) Describe all statistical methods, including those used to control for confounding See "Statistical methods" section on pages 10-11. (b) Describe any methods used to examine subgroups and interactions See "Statistical methods" section on pages 10-11. (c) Explain how missing data were addressed See "Statistical methods" section on pages 10-11. (d) If applicable, describe analytical methods taking account of sampling strategy N/A (e) Describe any sensitivity analyses N/A. For assessment of internal consistency of items see "Measures" section page 7.

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Results		
Participants	13*	(a) Report numbers of individuals at each stage of study—eg numbers potentially eligible, examined for eligibility, confirmed eligible, included in the study, completing follow-up, and analysed See page 11-12
		(b) Give reasons for non-participation at each stage See page 12
		(c) Consider use of a flow diagram Reported in text.
Descriptive data	14*	(a) Give characteristics of study participants (eg demographic, clinical, social) and information on exposures and potential confounders See Table 2.
		(b) Indicate number of participants with missing data for each variable of interest See Table 2 and Table 4.
Outcome data	15*	Report numbers of outcome events or summary measures See pages 14-20.
Main results	16	(a) Give unadjusted estimates and, if applicable, confounder-adjusted estimates and their precision (eg, 95% confidence interval). Make clear which confounders were adjusted for and why they were included See pages 14-20, “Statistical methods” pages 10-11, and Tables 3 & 4.
		(b) Report category boundaries when continuous variables were categorized See “Statistical methods” section on pages 10-11, and Table 4.
		(c) If relevant, consider translating estimates of relative risk into absolute risk for a meaningful time period N/A
Other analyses	17	Report other analyses done—eg analyses of subgroups and interactions, and sensitivity analyses N/A
Discussion		
Key results	18	Summarise key results with reference to study objectives See pages 21-25.
Limitations	19	Discuss limitations of the study, taking into account sources of potential bias or imprecision. Discuss both direction and magnitude of any potential bias See pages 24-25.
Interpretation	20	Give a cautious overall interpretation of results considering objectives, limitations, multiplicity of analyses, results from similar studies, and other relevant evidence See pages 21-24.
Generalisability	21	Discuss the generalisability (external validity) of the study results See page 25.
Other information		
Funding	22	Give the source of funding and the role of the funders for the present study and, if applicable, for the original study on which the present article is based No specific funding, so a general funding statement is included in the acknowledgements on page 26.

*Give information separately for exposed and unexposed groups.



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