

Top Priorities For Health Service Improvements among Australian Oncology Patients

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ABSTRACT

Objective: To determine among a sample of Australian cancer patients receiving outpatient oncology care: (1) The most frequently endorsed general health service improvements selected by patients; (2) For the three most endorsed general health service improvements, the proportion of participants endorsing specific health service changes; and (3) sociodemographic, disease and treatment characteristics associated with the most frequently endorsed general health service improvements.

Methods: A cross-sectional survey was conducted across six outpatient oncology treatment units located in New South Wales, Australia. Patients receiving chemotherapy for any cancer diagnosis at any of six oncology services were recruited. Participants completed an online survey which included the Consumer Preferences Survey. Logistic regression analyses were conducted to identify sociodemographic, disease and treatment characteristics associated with frequently endorsed health service improvements.

Results: A total of 879 eligible patients initiated the survey (72% consent rate). Participants selected a median of two health service improvements. The three most wanted improvements were car parking (56%), up-to-date information about treatment or condition progress (19%), and hospital catering (17%). Age was the only characteristic significantly associated with identifying car parking as a needed improvement.

Conclusion: Achieving high quality cancer care requires understanding of the views and experiences of patients about the quality of care they receive. Car parking and access to information were the two most frequently endorsed general health service changes desired by this sample of participants

Practice implication: Future studies could examine whether enacting changes as per patient feedback improves patient perceptions of quality of care, and health outcomes.

Keywords: Patient-Centered Care; Cancer; Quality of Healthcare; Patient identified change

BACKGROUND

Patient-centred cancer care is considered optimal health care

Patient-centred care is defined by the Institute of Medicine as care that is respectful of, and responsive to, individual patient preferences, needs and values [1]. Patient-centred care is considered one of six key elements of high-quality care[1]. In the field of cancer care, provision of patient-centred care has been associated with improved psychological outcomes [2], increased medication adherence [3] and increased patient satisfaction [4, 5]. In order to achieve high-quality patient-centred care, it is imperative that we understand the views and experiences of patients about the quality

of care they receive, and use these perspectives to inform quality improvements to the healthcare system [6].

Accurate, efficient and clinically useful methods are needed to capture patient's perspectives

A commonly used method of examining and understanding patient perceptions of the quality of care received is via patient satisfaction surveys or surveys of unmet needs. Such surveys ask patients to either reflect on the care they have received, or report any needs that could be addressed by healthcare providers and/or the healthcare system. These approaches, however, have many well-documented limitations [7-9]. Firstly, most surveys only assess patient's perceptions on the broad aspects of care, rather than

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exploring the specific improvements they would like made [7, 10]. Obtaining more detailed information from patients about specific strategies that they perceive would improve their care, would reduce ambiguity as to what changes are seen by patients as most necessary, thus providing more concrete information that may help to better guide changes initiated by the healthcare system [9]. Secondly, inadequacies in psychometric rigor and difficulties in scoring many of the frequently used patient satisfaction and unmet needs surveys have been identified [11].

In response to these shortcomings, a new tool titled 'The Consumer Preferences Survey' (CPS) was developed to allow collection of detailed data about patient desired health service improvements [10]. The CPS is computer administered and uses dynamic branching software to allow users to endorse both general and specific actionable changes that would help improve their care and experiences. The CPS was developed using a systematic process that included a literature review, advice and feedback from an expert advisory group, and pilot testing [12]. The measure has good acceptability, face validity and adequate test-retest and internal reliability for most items [13]. Unlike previous surveys, the CPS provides a list of concrete and specific changes that patients perceive could be improved [13] (Tables 1-3).

Consumer Preferences Survey data from large heterogeneous samples of cancer patients will help to inform health care improvements

To date, only two studies have used the CPS to explore cancer

Table 1: Sample characteristics (N= 879*).

Column totals may not add to total sample size due to missing values. Percentages may not add to 100 due to missing values.

		N	%
Age	18-49	157	17.9
	50-69	449	51.1
	70+	269	30.6
Gender	Male	392	44.6
	Female	487	55.4
Highest level of education	High school or lower	581	66.1
	Diploma or Trade Certificate	177	20.1
	Bachelor or Post-grad degree	113	12.9
Marital status	Married or living with partner	574	65.3
	Single (never married, divorced, widowed)	294	33.4
Aboriginal or Torres Strait Islander	Yes	32	3.6
	No	838	95.3
Concession card	Yes	579	65.9
	No	291	33.1
Private health insurance status	Yes	335	38.1
	No	535	60.9
Weekly Family income	<\$300 per week	82	9.3
	\$300-\$499 per week	264	30.0
	\$500-\$799 per week	153	17.4
	\$800-\$1000 per week	87	9.9
	> \$1000 per week	115	13.1
	Prefer not to answer	170	19.3

Table 2: Disease and treatment characteristics (N=879*).

		N	%
Site of primary cancer	Blood	211	24.0
	Breast	193	22.0
	Bowel	165	18.8
	Lung	74	8.4
	Other	64	7.3
	Gynaecological, including ovarian	42	4.8
	Prostate	31	3.5
	Pancreatic (stomach)	31	3.5
	Head and Neck	25	2.8
	Liver	16	1.8
Melanoma	11	1.2	
Purpose of treatment	Curative	413	47.0
	Slow growth or reduce symptoms	418	47.6
	Unsure	35	4.0
Type of treatments received	Radiation therapy		
	Yes	217	73.5
	No	646	24.7
	Chemotherapy		
	Yes	824	93.7
	No	39	4.4
	Hormone therapy		
	Yes	59	6.7
	No	804	91.5
	Biological therapy		
	Yes	19	2.2
	No	844	96
	Bone marrow transplant		
Yes	11	1.3	
No	852	96.9	
Stem cell transplant			
Yes	25	2.8	
No	838	95.3	
Surgery			
Yes	341	38.8	
No	522	59.4	
None of these			
Yes		16	
No		847	
Number of visits to the out-patient clinic in the previous 3 months	Once		19
	2-3 times		192
	4-6 times		307
	7 or more times		343

patients' preferences for quality improvements to their care [14,15]. Improved car parking and up-to-date information were the most highly endorsed areas in need of improvement [14,15]. While these studies provide an indication as to what areas of improvement patients perceive as needed, additional information is still required if health service improvements that reflect patient perceptions and wishes are to be made. For instance, one of these previous studies focused on the perceptions of chronic care patients, receiving care from three hospital departments in New South Wales, Australia, including oncology, neurology and cardiology. While this study included the perceptions of cancer patients, the specific initiatives perceived by cancer patients as needing improvement were

Table 3: Top 10 most endorsed general health service improvement items (N=860)*.

Item	N	% (95% CI)
Improved car parking	481	56% (23 , 89)
Provide up-to-date information on your treatment or condition progress	159	19% (12 , 25)
Provide access to good hospital catering	145	17% (12 , 22)
Help to maintain daily activities and healthy lifestyles	129	15% (9.8, 20)
Provide information on possible financial assistance	127	15% (13 , 17)
Reduce the time spent waiting for your appointment	124	14% (3.3, 26)
Provide information or help with physical symptoms or side effects	118	14% (11 , 17)
Provide information you can access at home about your condition and treatment	118	14% (10 , 17)
Support and information for family and friends	114	13% (10 , 17)
Provide information on how to handle a medical emergency	92	11% (8.4, 13)

*Cell totals may not equal total sample size due to missing values.

not explored [15]. The second study explored cancer patients' perceptions specifically, however, this study included only a sub-sample of patients participating in a larger study, and only focused on the association between the initiatives selected by patients and their quality of life [14]. Larger studies that include a diverse range of cancer patients from a range of treatment centres are needed. Such studies should explore both the broad and specific changes patients would like made to their care, as well as those characteristics associated with such changes. Understanding the characteristics associated with the most frequently endorsed changes will help identify what future support and health service changes are most wanted by cancer patients. Obtaining such information will help to inform what quality improvements should be made to improve the delivery of patient-centred care provided to cancer patients.

Aims

To determine, among a sample of Australian cancer patients receiving chemotherapy at outpatient oncology clinics:

1. The most frequently endorsed general health service improvements selected by patients;
2. For the three most endorsed general health service improvements, the proportion of participants endorsing specific health service changes; and
3. The patient sociodemographic, disease and treatment characteristics associated with the most frequently endorsed general health service improvements by patients.

METHODS

Design

This paper reports data collected as part of a stepped wedge cluster randomised controlled trial that aimed to improve the delivery of patient-centred care to cancer patients receiving chemotherapy (ACTRN12614000702617). It also extends previous analyses presented from a sub-sample of patients taking part in the baseline component of this study [14]. As the intervention was not successfully implemented in any of the sites, assessing the effectiveness of the intervention was not possible. Consequently, this paper focuses on presenting an in-depth exploration of the quality improvements identified by a large sample of cancer patients, receiving treatment from a number of cancer treatment centres.

Setting and Participant Eligibility

Six outpatient oncology treatment units located in New South Wales, Australia, participated. Individuals were eligible if they: (i) were aged 18 years or older; (ii) were receiving chemotherapy for any cancer diagnosis; (iii) had attended the treatment unit on at least one previous occasion and therefore were considered able to reflect on aspects of the treatment centre care where they desired change; (iv) were able to complete an English-language survey either independently or with assistance; and (v) could provide informed consent.

Recruitment

Trained research volunteers approached patients in the waiting room or treatment area of the oncology unit and invited participation in the research. Potential participants were provided with a written information statement and assessed for eligibility. Those who were eligible were invited to commence a survey on a tablet computer. Research volunteers recorded information regarding the gender and age of non-consenting participants to allow for determination of consent bias.

Measurement

Participants completed a survey on a tablet computer. Survey items were presented using the online survey system QuON [16]. The QuON system is a dynamic online survey platform which allows the use of dynamic branching to ensure participants only received relevant questions. Participants self-reported the following: (i) *Socio-demographic information*: gender, age, highest level of education, marital status, Aboriginal or Torres Strait Islander status, possession of a concession card, private health insurance status, and weekly family income; (ii) *Disease and treatment information*: site of primary cancer; purpose of treatment; type of treatments received; number of visits to the out-patient clinic in the previous 3 months; (iii) *Consumer Preferences Survey (CPS)*: The CPS is a web-based survey that assesses patients views as to which areas of their care could be improved. Patients are presented with 25 items that represent general areas of health care that are organised into four categories: (1) changes to appointment scheduling; (2) changes when arriving at an appointment, (3) changes during a clinical appointment, and (4) changes to assist with managing at home. For most of the 25-items patients are asked to indicate which areas they believe could be improved [14]. For those general health

service improvements that patients select, they are then prompted to indicate what specific changes could be implemented to improve their care. The number of specific changes presented for patients to select varied from 3-11 depending on the general health service improvement selected. Patients could select as many specific health care changes as they wanted.

Data analysis

As the intervention was not successfully delivered as planned, data were analysed as an observational study. The top ten most frequently endorsed general health service improvements were calculated and reported. For the top three items, the frequency of patients selecting the specific initiatives suggested to improve these top three areas are also reported. For both of these outcomes, the frequency, percentage and 95% confidence intervals (CIs) are reported for each item. The delete-1 cluster jack-knife variance estimation method was used in the calculation of the 95% CIs to adjust for the clustered nature of the data and the variable cluster sizes. Logistic regression analyses were conducted for the most frequently endorsed general health service improvement item, to identify sociodemographic, disease and treatment characteristics associated with patients identifying this item as an area in need of change. The characteristics assessed in the model were hypothesised to impact on patient's perceptions of their care and included: age, sex, marital status, education status, private health insurance coverage, cancer type and number of visits to the clinic in the last three months. To control for any possible effect the intervention may have had on the study outcome, an intervention received variable was included in the regression model. For this variable, participants who completed a survey before the intervention begun at their hospital was coded as not have received the intervention, while patients who completed a survey after the intervention was attempted at their hospital were coded as receiving the intervention. The delete-1 cluster jack-knife variance estimation method was used to account for clustering by hospital site and for the variable cluster sizes. List wise deletion was used to remove observations with missing data from the model so that only complete cases were analysed. Characteristics identified at a p-value <0.05 on the Wald statistic were considered statistically significant. The logistic regression model was assessed for potential outliers and violations in the assumption of multicollinearity.

Ethics Approval

Ethics approval was provided by the Hunter New England Human Research Ethics Committee (13/08/21/4.07) and the University of Newcastle Human Research Ethics Committee (H-2012-0099). Appropriate governance approvals were obtained from all participating treatment centres. All participants provided informed consent for participation.

RESULTS

Sample

Of 1272 patients approached, 922 eligible patients agreed to participate (72% consent rate). A total of 879 patients initiated the CPS survey. Table 1 describes the sociodemographic characteristics and Table 2 details the disease and treatment characteristics of all eligible participants. Most (81.1%) participants were aged between 50 and 69 years at the time of the study, were female (55.4%), in a partnered relationship (65.3%), and did not have private health insurance (60.9). The most common cancer type was blood (24%)

followed by breast (22%). The most common cancer treatment received was chemotherapy (93.7%).

Column totals may not add to total sample size due to missing values. Percentages may not add to 100 due to missing values.

Top ten most frequently endorsed general health service improvements

Out of the 25 general health service improvement items listed in the CPS, participants selected a median of two items for improvement (range 0 to 19). A total of 171 (20%) patients indicated that they did not believe any of the CPS areas of care required improvement at their outpatient clinic, while 175 (20%) indicated that five or more items required improvement. The top 10 most frequently endorsed general health service improvement items are provided in Table 3. The most frequently endorsed item was improved car parking (56%). However, there was variation between hospitals with regards to the percentage of patients who selected this item as an area in need of improvement (reflected by the wide confidence intervals). Specifically, over 50% of patients from sites 2 (75%), 4 (54%), 5 (68%) and 6 (79%) selected this item as an area for improvement. Whereas, only 37% and 6.6% of patients selected this item from sites 1 and 3, respectively. The second most frequently reported quality improvement item was up-to-date information on the patient's treatment or condition progress (19%), followed by having access to good hospital catering (17%).

Proportion of participants endorsing specific health service changes

For each general health service improvement item that was endorsed, participants were asked to select from a list, which specific quality improvement initiatives they believe could help to improve that domain. Table 4 presents the percentage and frequency of patients who selected each of the specific initiatives related to the top three most frequently endorsed general health service improvement items for parking, information and catering.

Of the 481 patients who selected car parking as an area in need of improvement, 472 (98%) selected at least one specific quality improvement initiatives for this domain. Reserved car parking for clinic patients was the most frequently selected initiative (63%). Of the 159 patients who selected up-to-date information on their treatment or condition progress as an area for quality improvement, 135 (85%) responded to the specific improvement initiatives listed for this domain. Knowing the status of their cancer (70%) was the most frequently endorsed initiative. Of the 145 patients who endorsed access to good hospital catering as an area for quality improvement, 141 (97%) answered the specific improvement initiatives listed for this area. Being able to order food from a cafe and have it delivered to the clinic if the patient is unable to leave was the most frequently selected initiative (62%).

Characteristics associated with the most frequently endorsed general health service improvement

A total of 850 (98%) observations were included in the multivariable logistic regression. Table 5 lists the sociodemographic, disease and treatment characteristics associated with the top general health service improvements selected by patients. Age was the only characteristic found to be significantly associated with patient's selecting 'improved car parking' as an area that could be improved. Compared to those aged 70 years and over, patients aged 18-49

Table 4: Frequency and percentage of patients selecting the specific initiatives for improved car parking, information and catering.

Issue	n	% (95% CI)
Parking		
Reserve spaces for clinic patients only	297	63% (56 , 69)
Reserve parking spaces close to the clinic	185	39% (29 , 50)
Provide affordable options for parking	99	21% (12 , 30)
Provide more disabled only parking spaces	85	18% (7.6, 28)
Provide patient drop-off zones or short stay parking for caregivers	78	17% (5.9, 27)
Provide easy to use parking machines	24	5.1%(1.8,8.4)
Information		
Ensure you know the status of your condition	95	70% (60 , 81)
Ensure you are aware of the next steps in your treatment	61	45% (34 , 57)
Ensure you receive test results as soon as possible	50	37% (26 , 48)
Notify you before your appointment if your treatment has been changed by your doctor	28	21% (8.0, 33)
Catering		
The clinic is able to order from a café and items are delivered for those patients unable to leave	87	62% (56 , 67)
Ensure enough variety is provided for meals offered	77	55% (48 , 62)
Have hot and cold food options available in the hospital	66	47% (30 , 63)
Have biscuits and beverages available within the clinic	26	18% (8.1, 29)
Have gluten free or vegetarian options available in the hospital	17	12% (2.5, 22)
Provide a map and operating hours of cafes in the hospital	16	11% (3.1, 20)

Table 5: Characteristics associated with the most frequently endorsed general health service improvement item.

Characteristic	Characteristic level	Unadjusted OR	Unadjusted lower 95%CI	Unadjusted upper 95%CI	Unadjusted p-value	Adjusted OR	Adjusted lower 95%CI	Adjusted upper 95%CI	Adjusted p-value
Education level	Bachelor or Postgraduate degree	0.88	0.48	1.61	0.27	0.80	0.36	1.76	0.26
	Diploma or trade certificate	0.76	0.36	1.57		0.71	0.37	1.38	
Marital status	Married or living with a partner	1.20	0.89	1.62	0.18	1.21	0.89	1.64	0.17
Treatment goal	Don't know	1.04	0.52	2.07	0.97	1.17	0.60	2.31	0.84
	Slow growth	0.97	0.55	1.72		1.03	0.64	1.65	
Age	18 to 49yrs	1.59	1.25	2.03	0.01	1.61	1.36	1.92	<0.001
	50 to 69yrs	1.47	0.98	2.19		1.58	1.03	2.43	
Cancer type	Blood	1.09	0.29	4.06	0.47	1.32	0.44	3.98	0.47
	Bowel	0.96	0.45	2.06		1.15	0.53	2.49	
	Other	0.84	0.42	1.70		1.02	0.48	2.16	
Clinic visits in the last 3 months	6 or more	1.06	0.73	1.55	0.69	1.13	0.75	1.70	0.47
Sex	Female	1.33	0.64	2.76	0.37	1.38	0.73	2.60	0.25
Private health insurance	No	1.05	0.63	1.76	0.81	1.02	0.50	2.08	0.94

years and 50-69 years had significantly higher odds of reporting this item as in need of improve

DISCUSSION

This study examined the most frequently endorsed general health service improvements selected by a sample of Australian cancer patients receiving outpatient chemotherapy using a newly developed measure, the Consumer Preferences Survey. It also identified the patient sociodemographic, disease and treatment characteristics

associated with the most frequently endorsed general health service improvements.

Overall, one-fifth of participants did not endorse any of the suggested general health service improvements. These findings suggest that only a fifth of participating patients did not perceive that any of the pre-specified changes would improve their care, and were thus potentially satisfied with the care they received. This is in contrast to existing research that has examined cancer patient satisfaction with their treatment experience and the care they receive, which show that patients generally report very high rates of

satisfaction [17-19]. In particular, a survey of more than 300 cancer patients attending six outpatient clinics in NSW found that more than 90% of patients thought that hospital staff showed them and their family respect, made sure they received correct treatment, and spoke to them in a way they could understand [20]. Alternatively, this finding may reflect that the domains assessed by the CPS were not comprehensive, and may not have identified general areas of potential change desired by participants. However, given a fifth of participants identified five or more areas that required improvement, this is unlikely.

Changes to car parking were identified by participants as the most important general health service improvement requiring change, with 56% of patients across all six clinics selecting this domain. This aligns with previous international research that has identified car parking as an important barrier to access to cancer services in the UK [21-23]. It also aligns with national research among patients attending chronic disease outpatient clinics, where 60% of respondents selected improved car parking as a domain in need of improvement using the CPS [15]. Age was the only characteristic found to be significantly associated with patient's selecting car parking as an area that could be improved.

The availability of parking for clinic patients only that is in close proximity to the treatment centre was identified as the most important specific change that could be made to improve car parking. This finding highlights the utility of using this dynamic approach to surveying patients as it provides specific and actionable changes to health services. It is important to note however that car parking was not a pertinent issue for all treatment centres. For two sites, less than 50% of patients identified car parking as an area in need of improvement. For one of these sites, less than 10% endorsed car parking as an area of change. This highlights the difficulties in generalising patient's perspectives on quality improvements across sites and emphasises the importance of assessing patient perspectives at the clinic level, and tailoring care towards the needs of patients attending specific treatment centres that have unique characteristics.

Six out of the top 10 general health service improvement items related to participant's desire for additional information about their cancer and its treatment. This finding is consistent with the unmet needs literature among cancer patients, where information needs have consistently been identified as a key area of unmet need for many patients [5,23]. The specific types of information desired by participants were personal information specifically related to their care and treatment, including knowing the status of their condition, the next steps in treatment, and receiving test results as soon as possible. These findings suggest the need for better communication of clinical information from the treatment team to their patients.

STUDY STRENGTHS AND LIMITATIONS

Strength of the current study is that it provides detailed data from a large sample of cancer patients across New South Wales. However, as there were only a small number of treatment centres and all treatment centres were located in one state of Australia, the generalizability of the findings to broader Australia and other countries is limited.

CONCLUSION

Achieving high quality cancer care requires understanding of the

views and experiences of patients about the quality of care they receive. Car parking and access to information were the two most frequently endorsed general health service changes desired by this sample of participants. Future studies should examine whether enacting changes as per patient feedback improves patient perceptions of quality of care, and patient outcomes.

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