Experiences of Patient-Centered Care Among Japanese and Australian Cancer Outpatients: Results of a Cross-Sectional Study

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Abstract

There have been few international comparisons of patient-centered cancer care delivery. This study aimed to compare the experiences of patient-centered care (PCC) of Japanese and Australian radiation oncology patients. Participants were adults with cancer attending a radiotherapy appointment at a Japanese or Australian clinic. Participants completed a survey asking about 10 indicators of PCC. Overall, 259 Japanese and 285 Australian patients participated. Compared with Japanese participants, Australian participants were significantly more likely to report receiving information about: what the treatment is, and the short-term and long-term side effects of treatment. A higher proportion of Australian participants reported being asked whether they wanted a friend or family member present at the consultation. There were no differences in the frequency with which Japanese and Australian participants were asked by their clinicians about whether they were experiencing physical side effects or emotional distress. International differences highlight the (1) need to exercise caution when generalizing from one country to another; and (2) the importance of context in understanding PCC delivery and the subsequent design of quality improvement interventions.

Keywords

cancer, oncology, patient-centered care, radiation, quality of care, international comparison, evaluation

Introduction

Patient-Centered Care Is an Important Component of Cancer Care

The Institute of Medicine identified patient-centered care (PCC) as one of 6 key dimensions of quality in health care (1). Patient-centered care is respectful and responsive to patient needs and preferences for care related to physical comfort, emotional support, continuity and coordination of care, involvement of significant others in the person's care, and provision of education and information to support informed decision-making (2). These areas of care have long been acknowledged as pertinent to cancer care given that it is complex and often involves multiple health professionals and services, may be associated with difficult treatment decisions, and may result in a significant impact on the person's physical and emotional health (3–6). Systematic reviews suggest that PCC is positively associated

patient-reported outcomes including patient well-being and quality of life. Evidence is mixed, however, regarding a relationship between PCC and intermediate patient

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outcomes (eg, pain levels, symptoms, blood sugar) and distal patient outcomes (eg, hospital readmissions, complications) (3,7).

Radiotherapy clinics are an important setting to explore delivery of PCC: Radiotherapy is the most common outpatient cancer treatment modality; clinics are attended by approximately half of all new cancer patients; and frequent contact with radiotherapy clinics is required over many weeks. This manner of service delivery provides many opportunities for radiotherapy clinics to identify and respond to patient's preferences, needs and values, underscoring the importance of ensuring the delivery of high-quality care.

Does PCC Vary Across Countries?

The World Health Organization (WHO) responsiveness surveys were conducted in 35 countries as a key informant survey (8) and in 69 countries as a household survey/interview (9–13). These are among the few studies that have directly compared experiences of PCC between countries. The studies found that the high performing aspects of care delivery were: respect for privacy during treatment or examination, patient consent sought before testing or treatment, and confidentiality of patient medical records. The worst performing aspects of care were: encouragement to ask questions, being consulted on treatment preferences, and having consultations conducted in a way that protects confidentiality of patient information (8). There was significant variation in responsiveness scores across countries, with a positive relationship between responsiveness and a country's wealth. However, the studies did not specifically focus on cancer care, so the extent to which results apply to cancer care is not known.

The Landscape of Cancer Care in Australian and Japan

Australia, Japan, and other economically developed nations regularly compare health care system performance with a view to identifying both challenges and solutions (14). Both the Australian and Japanese health care systems are high performing (15) and offer universal health care. Citizens in both countries can also buy private insurance coverage to access private facilities or cover out-of-pocket expenses. Cancer care treatment and follow-up in both countries are primarily hospital-centered. However, compared to Japan (16,17), Australia has some unique challenges, including larger travel distances to access radiotherapy centers and split in funding and responsibilities between federal and state governments that results in differences in care between states. There is still uncertainty regarding which quality-improvement strategies, policies and systems, can help deliver the best quality care.

How Should PCC be Assessed?

The delivery of PCC is commonly assessed via patient self-report. This is because PCC is rarely captured in the medical records (18). Further, it may be argued that the patient's view is essential since PCC, by definition, must address needs, values, and preferences of the individual patient. Zucca et al (19) have proposed that PCC be assessed by asking about the extent to which one was asked about one's preferences and needs for particular types of care. International literature suggests significant convergence across 41 countries on the key aspects of PCC, suggesting a universal characterization of PCC (13).

The WHO responsiveness studies have further identified that there may be significant differences in the interpretation of scales across countries, as culture may influence the interpretation of descriptors such as "mild," "moderate," or "strongly" (20). One way to increase comparability of the assessment of PCC across countries is to ask about concrete and specific aspects of care, rather than overall satisfaction with care (21,22). This may reduce the impact of culture on interpretation of questions and provide greater insights as to where differences in care may lie.

Aims

To explore differences between Australian and Japanese radiation oncology outpatients' perceptions regarding: (1) the frequency of screening for physical and emotional symptoms; (2) the extent to which PCC was delivered where preferences for amount of information for cancer care concerns was sought; and (3) delivery of other aspects of PCC, including the involvement of family and friends, appointment scheduling, and treatment-related preferences.

Methods

Study Design

Descriptive cross-sectional survey of a consecutive sample of cancer patients from radiation oncology clinics in Japan and Australia.

Sample

Data were collected between May 2014 and January 2016 from 1 cancer clinic in Australia and between August 2012 and February 2014 from 2 clinics in Japan.

Cancer patients. For the Australian sample, eligible patients had a diagnosis of cancer, were aged 18 or older, attending an appointment at the participating radiotherapy clinic, and English speaking. For the Japanese sample, eligible patients had a diagnosis of cancer, were aged 20 or older, attending an appointment at 1 of the participating radiotherapy clinics, and Japanese speaking. Those who were unable to give

independent informed consent and those who were attending the radiotherapy clinic for the first time were excluded.

Procedure

A research assistant attended the clinic to invite eligible patients to participate. Those who consented were asked to complete a pen and paper survey while waiting for their clinic appointment. Completing surveys in the waiting rooms of radiotherapy clinics has been demonstrated to be feasible and acceptable to cancer patients (23). Only patient self-report data were obtained as clinics were limited by the time and resources that they could contribute to the study. Patients recruited in Japan received reimbursement for their time (approximately $10 AUD). Reimbursement was not provided to Australian participants due to insufficient funding resources.

Survey Translations

The initial survey was developed in English and administered in this language to participants recruited in Australia. The survey administered to participants in Japan was in Japanese, following a forward and backward translation process. The backward translations were reviewed by study investigators native in the English language to ensure the content of the questions was correctly portrayed. Content that was believed to misrepresent the intended meaning of the question was retranslated and underwent subsequent rounds of backward–forward translation until the meaning was correct and consistent between surveys.

Measures

Demographic characteristics. Age at survey completion, sex, marital status, years of education completed, employment status, and health insurance for hospital care were assessed using standard questions.

Cancer-related characteristics. Items assessed cancer type, time since cancer diagnosis, week of radiotherapy treatment, cancer treatments ever received, and number of appointments with clinician.

Delivery of PCC. Given that no tool was available that measured whether health providers ask about key issues across each of the 6 domains of PCC, a measure was derived by the research team. The development of these items in a sample of Australian cancer patients has been described elsewhere (19,24). Ten items assessed whether health providers regularly initiated discussions with their patient across each of the 6 dimensions of PCC endorsed by the Institute of Medicine (1). Patients were asked to indicate whether their doctor or health worker at the radiotherapy clinic specifically asked about: physical comfort (3 items exploring pain, fatigue, side effects); emotional support (1 item exploring anxiety, depression, distress);

receipt of adequate provision of information and education to enable shared decision-making (3 items exploring information about the treatment itself, short- and long-term side effects of the treatment); their preference for receiving the treatment or not; participation of family and friends in consultations; and suitable appointment scheduling.

Patients responding to the physical comfort and emotional support domains were asked to indicate whether they were asked: (1) at every appointment; (2) at most appointments; (3) at about half of their appointments; (4) at less than half of their appointments; (5) never asked, they told the health care worker about the symptoms; and (6) never. Patients responding to the remaining 6 items were asked to indicate to what extent they agreed that they were asked by choosing either: (1) strongly agree, (2) agree, (3) disagree, (4) strongly disagree, and (5) never asked, but initiated the conversation about this issue.

Statistical Analysis

Demographic and cancer-related categorical variables were summarized as frequencies and percentages with P values from chi-square/Fisher's exact tests. Continuous variables were summarized as means (standard deviation) and medians (interquartile range and range), with P values from t tests and Kruskal-Wallis tests, respectively. These are presented in separate tables.

In order to reduce the number of comparisons, we dichotomized responses by collapsing response categories. Specifically, response categories were collapsed for questions about:

1. screening for physical and emotional symptoms (Table 1): screening occurred for those who responded "all" and "most";
2. delivery of PCC (Table 2): patient-centered approach was provided for those who responded "agree" and "strongly agree."

Percentages of patients with affirmative responses were calculated by country with 95% CI. The differences in percentages between countries were obtained with 95% CI and chi-square P values for the difference.

Adjusted differences in percentages between countries were calculated from logistic regression models with identity link. All models attempted to adjust for the variables of sex, marital status, employment, education, week of treatment, and cancer type. However where models did not converge or poor fit was indicated by the Hosmer and Lemeshow statistic, one or both of the disease characteristics were removed (after establishing their negligible effect on country differences) and model fit reassessed. Akaike information criteria (AIC) was used to confirm the best model was selected. False discovery rate (FDR) correction was used to account for multiple testing (35 tests) (25). All P values presented are unadjusted, and those below the FDR adjusted threshold of 0.011 demonstrate

Table 1. Sociodemographic and Cancer-Related Characteristics (Continuous Data).

Characteristic	Statistic	Australia (n = 285)	Japan (n = 263)	Total (N = 548)	P
Age at survey completion	n	282	261	543	
	Median (min, max)	68 (34, 94)	66 (27, 84)	67 (27, 94)	.0051
	Median (Q1, Q3)	68 (62, 74)	66 (56, 73)	67 (59, 73)	
	Mean (SD)	67 (10)	64 (12)	66 (11)	<.0001
Years of school education completed	n	266	257	523	
	Mean (SD)	11 (2)	13 (3)	12 (3)	<.0001
	Median (min, max)	10 (3, 21)	12 (7, 23)	12 (3, 23)	
	Median (Q1, Q3)	10 (9, 12)	12 (12, 16)	12 (10, 14)	
How long ago were you diagnosed with cancer? (months)	n	273	254	527	
	Mean (SD)	11 (18)	15 (28)	13 (23)	.0331
	Median (min, max)	6 (1, 144)	7 (1, 240)	6 (1, 240)	.5033
	Median (Q1, Q3)	6 (4, 9)	7 (3, 12)	6 (3, 10)	
Past 3 months how many appointments has the patient had with the doctor they are seeing today?	n	200	192	392	
	Median (min, max)	3 (0, 32)	4 (0, 45)	4 (0, 45)	.0032
	Median (Q1, Q3)	3 (2, 5)	4 (2, 10)	4 (2, 6)	
	Mean (SD)	4 (4)	7 (8)	6 (6)	<.0001

Abbreviations: max, maximum; min, minimum; SD, standard deviation.

Table 2. Sociodemographic and Cancer-Related Variables (Categorical Data).

Variable	Category	Australia (n = 285)	Japan (n = 263)	Total (N = 548)	P
Sex	Male	176 (62%)	128 (49%)	304 (56%)	.0028
	Female	109 (38%)	133 (51%)	242 (44%)	
	Missing	0	2	2	
Marital status	Married/de facto	201 (71%)	213 (82%)	414 (76%)	.0038
	Divorced/separated/widowed/single	82 (29%)	48 (18%)	130 (24%)	
	Missing	2	2	4	
Current employment	Employed—full-time/part-time/paid or unpaid sick leave	45 (16%)	86 (33%)	131 (24%)	<.0001
	Not employed/other	238 (84%)	173 (67%)	411 (76%)	
	Missing	2	4	6	
Health insurance for hospital care	Yes	142 (50%)	206 (94%)	348 (69%)	<.0001
	No	140 (50%)	13 (5.9%)	153 (31%)	
	Missing	3	44	47	
Cancer type	Breast	61 (22%)	103 (40%)	164 (31%)	<.0001
	Colorectal/bowel	18 (6.6%)	6 (2.3%)	24 (4.5%)	
	Prostate	88 (32%)	70 (27%)	158 (30%)	
	Lung	14 (5.1%)	36 (14%)	50 (9.4%)	
	Other/don't know	92 (34%)	44 (17%)	136 (26%)	
	Missing	12	4	16	
Week of radiotherapy treatment	Last week of RT	97 (34%)	21 (8.0%)	118 (22%)	<.0001
	First week of RT	28 (9.8%)	113 (43%)	141 (26%)	
	Second week of RT	35 (12%)	59 (22%)	94 (17%)	
	Other	125 (44%)	70 (27%)	195 (36%)	
	Missing	0	0	0	
Surgery, ever	Yes	149 (80%)	152 (62%)	301 (70%)	<.0001
	Missing	99	16	115	
Chemotherapy, ever	Yes	99 (64%)	114 (47%)	213 (54%)	.0010
	Missing	131	22	153	
Radiotherapy, ever	Yes	274 (100.0%)	257 (99.2%)	531 (99.6%)	.2357[a]
	Missing	11	4	15	

Abbreviation: RT, radiotherapy.
[a] Exact P value.

significance. Statistical analyses were programmed using SAS software version 9.4 (SAS Institute). The data that support the findings of this study are available from the corresponding author upon request.

Results

Across the 2 Japanese clinics, 393 patients were invited to participate; 282 consented (72%) and 263 (67%) returned a completed survey. In the Australian clinic, 512 patients were

invited to participate; 354 (69%) consented and 285 (56%) returned a completed survey. The Japanese and Australian samples differed with respect to a number of sociodemographic variables (see Tables 1 and 2).

Compared to Japanese patients, a higher percentage of Australian patients reported being asked about pain (63.6% vs 71.4%) and tiredness/fatigue (60.5% vs 70.9%) at all or most appointments (Table 3). These differences were not statistically significant once adjustment was made for sociodemographic variables and cancer type (for pain only).

As shown in Table 4, when compared with Japanese participants, Australian participants were more likely to report delivery of PCC with respect to information about: what treatment is (88.8% vs 53.7%, $P < .0001$); short-term side effects (88.5% vs 53.4%, $P < .0001$); and long-term side effects (81% vs 52.2%, $P < .0001$). A higher proportion of Australian participants (66.8%) than Japanese participants (35.6%) also agreed/strongly agreed that they had been asked whether they wanted a friend or family member present at their consultation ($P < .0001$).

Discussion

This is one of the few studies that has compared experiences of PCC among Japanese and Australian cancer patients. Our results showed no difference in the proportion of Australian and Japanese patients who reported being asked at all or most appointments about physical and psychological symptoms. This suggests that these elements of care were experienced in a similar way by both the Japanese and Australian participants in our study. It may be that these clinical behaviors transcend the geographical and cultural borders. Consistent with previous studies (25–27), more patients reported being asked about physical than psychological symptoms at all or most appointments.

Significant differences in perceptions regarding information provision were identified between Japanese and Australian respondents. A higher proportion of Australian respondents reported being asked whether they had received sufficient information about what treatment is and how it is given, and long-term and short-term side effects of treatment. The Psychosocial Guidelines for the Care of Adults with Cancer (28,29) were the first set of psychosocial oncology guidelines developed in Australia. They included specific recommendations to ask patients whether they received sufficient information about their care. This recommendation was designed to acknowledge that people differ with respect to preferences for the amount and timing of information, and therefore a tailored approach to information provision is needed. Although now rescinded, these guidelines contributed to an increase in communication skills training programs for oncology professionals (30). In contrast, there are no formal guidelines for communicating with patients during cancer consultations in Japan. However, a recent Japanese trial (31) demonstrated that communication skills training for oncologists using the SHARE protocol resulted

Table 3. Number and Percentage of People Asked About Physical and Emotional Symptoms At All or Most Appointments.

Side effect	Australia		Japan		Crude		Adjusted[a]		Total
	n	% (95% CI)	n	% (95% CI)	Difference % (95% CI)	P	Difference % (95% CI)	P	
Pain	197	71.4% (65.7 to 76.6)	157	63.6% (57.2 to 69.6)	7.8% (−0.2 to 15.9)	.0570	8.7% (−2.4 to 19.7)	.1229	67.7% (63.7 to 71.7)
Tiredness/fatigue	195	70.9% (65.2 to 76.2)	147	60.5% (54.0 to 66.7)	10.4% (2.2 to 18.6)	.0128	4.1% (−6.5 to 14.7)	.4529	66.0% (61.9 to 70.1)
Physical side effects	192	69.8% (64.0 to 75.2)	158	64.8% (58.4 to 70.7)	5.1% (−3.0 to 13.2)	.2197	−0.1% (−10.8 to 10.6)	.9832	67.4% (63.4 to 71.5)
Anxiety, distress or depression	129	47.4% (41.4 to 53.5)	102	42.1% (35.9 to 48.6)	5.3% (−3.3 to 13.9)	.2304	6.3% (−5.1 to 17.6)	.2775	44.9% (40.6 to 49.3)

[a]All adjusted differences account for sex, marital status, employment, education, and week of radiotherapy. Pain and anxiety also account for cancer type.

Table 4. Number and Percentage of Participants Who Perceived a Patient-Centered Approach to Information Provision and Care.

	Australia		Japan		Crude		Adjusted[a]		Total
Asked whether sufficient information was given about:	n	% (95% CI)	n	% (95% CI)	Difference % (95% CI)	P	Difference % (95% CI)	P	
What treatment is and how it is given	247	88.8% (84.5 to 92.3)	132	53.7% (47.2 to 60.0)	35.2% (27.9 to 42.5)	<.0001	35.6% (27.2 to 43.9)	<.0001	72.3% (68.5 to 76.2)
Short-term side effects of treatment	247	88.5% (84.2 to 92.0)	133	53.4% (47.0 to 59.7)	35.1% (27.9 to 42.4)	<.0001	36.4% (28.7 to 44.2)	<.0001	72.0% (68.1 to 75.8)
Long-term side effects of treatment	226	81.0% (75.9 to 85.4)	129	52.2% (45.8 to 58.6)	28.8% (21.0 to 36.5)	<.0001	32.1% (23.2 to 41.0)	<.0001	67.5% (63.5 to 71.5)
Asked whether:									
Appointments were scheduled at suitable days and times?	199	73.2% (67.5 to 78.3)	186	73.8% (67.9 to 79.1)	−0.6% (−8.2 to 6.9)	0.8668	0.8% (−9.6 to 11.2)	0.8779	73.5% (69.7 to 77.3)
I wanted a friend or family member present at consultation	183	66.8% (60.9 to 72.3)	89	35.6% (29.7 to 41.9)	31.2% (23.0 to 39.4)	<.0001	31.6% (20.8 to 42.4)	<.0001	51.9% (47.6 to 56.2)
Whether I wanted to receive treatment	221	79.8% (74.6 to 84.4)	180	72.0% (66.0 to 77.5)	7.8% (0.5 to 15.1)	0.0369	9.7% (−0.4 to 19.8)	0.0605	76.1% (72.4 to 79.7)

[a] All adjusted differences account for sex, marital status, employment, and education. Long-term side effects also accounts for cancer type. The last 3 rows also account for week of radiotherapy and cancer type.

in improvements in both doctors' communication skills and patient-reported outcomes. Despite positive results, the extent to which the SHARE protocol and training are implemented in practice is not known. Therefore, our findings may reflect differences in communication skills training and practices between the 2 countries.

Compared to Japanese respondents, a higher proportion of Australian participants reported being asked whether they wanted a friend or family member present at the consultation. It is possible that this may reflect differences in communication skills training and practices between countries. Alternatively, it may also reflect differences in cultural norms and values regarding the role of the family in cancer care consultations. For example, the collectivist Japanese culture may place greater emphasis on the role of family in shaping the agenda within a clinical consultation than is commonly the case in countries with an individualist culture such as Australia (32). Ruhnke's (33) comparative study of patients and physicians in the United States and Japan showed that Japanese patients and physicians placed greater emphasis on the family and physician roles in medical decision-making than did their US counterparts. It is possible our finding reflects that health professionals were more likely to assume Japanese patients wanted a family member with them and that one would attend if possible. Therefore, it may have been considered unnecessary to ask Japanese patients about this.

Limitations

This study recruited participants from 1 radiation oncology clinic in Australia and 2 in Japan. Furthermore, response rates were modest (66% for the Japanese sample and 56% for the Australian sample). It is unlikely that our findings are generalizable to all Japanese and Australian radiation oncology patients. Therefore, our study was exploratory and findings need to be confirmed with a larger and more representative sample from both countries.

Although the Japanese and Australian samples differed with respect to disease and sociodemographic differences, these differences were adjusted for when comparing the 2 samples. We were not able to adjust for cancer stage. Given documented inaccuracies in patients' understanding of cancer stage (34), we did not ask patients to report on this.

Unfortunately, we were unable to collect information about the characteristics of oncologists involved in participants' care. Therefore, the extent to which oncologists' characteristics may have influenced the results is unknown. In addition to sociodemographic characteristics, training, and experience of oncologists, it is also possible that differences in clinic setup in terms of the time allowed for appointments, number of patients seen per day, and the roles of other team members providing patient education contributed to the differences observed for Japanese and Australian participants. The degree to which patients are able to choose their cancer doctor may also play a role in the way care is provided. For

example, Australian patients accessing private cancer care may choose their doctor while those accessing care under the public health care system do not have a choice in doctor. In Japan, patients typically have a choice in which hospital they receive care and which doctor they consult. These factors were not explored in our study, however, could be explored in future research.

While backward and forward translation ensured that patients from both countries were asked about their experiences of care, in the same way, our survey did not allow us to determine whether similar value was placed on these indicators in both countries. This may be a focus of future research. This study is limited by the cross-sectional design, which provides only a snapshot of a patient experience during radiotherapy treatment, which may change over time.

Finally, this manuscript is focused on 1 process of PCC delivery, namely, *question asking* by health care providers about patient issues, preferences, and needs across 10 indicators. However, *asking* is only the first step in ensuring the provision of high-quality PCC. Asking must be followed by an offer of assistance, where applicable. Any assistance provided must be effective in relieving patient suffering and be consistent with patient preferences (24). The type of assistance, and person within the multidisciplinary team who is best placed to provide assistance, may depend on the type of concern that the patient is experiencing and its severity. For example, for emotional support, best practice care requires all health professionals to be able to demonstrate good communication skills, respond with empathy, and provide basic information about services that may be available. The tiered model for psychosocial intervention suggests that specialist care from mental health professionals may be required for people who have more complex or severe needs (35). Other examples of interventions targeted at PCC delivery include routine cancer patient screening for physical and emotional symptoms, communication skills training for clinicians and/or patients, and use of patient question prompt sheets (36). To identify the role of potential health systems and policies on patient care delivery, future research comparing PCC delivery across countries could explore a continuum of processes and outcomes of PCC delivery from the perspective of the patient.

Conclusions

Although recognizing the methodological limitations of the research design, this study provides some preliminary data concerning the cross-cultural generalizability of PCC data. We assessed concrete and specific processes of care, not satisfaction levels. The purpose of this approach was to reduce the impact of culture on interpretation of questions and more accurately identify where differences in care may lie. Our data indicate that Japanese and Australian cancer patients report similar experiences of PCC across most indicators. Compared to Japanese patients, a higher proportion of Australian patients reported being asked whether they were provided with sufficient information and whether they wanted a friend or family member with them at their oncology consultation. These findings may reflect a greater emphasis on communication skills training in the Australian context. These data suggest there may indeed be similarities in aspects of PCC provided for Australian and Japanese radiotherapy patients. However, the differences identified also highlight the (1) need to exercise caution when generalizing results of research from one country to another and (2) the importance of context in understanding care delivery and the design of any subsequent quality improvement interventions.

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