

Patient reported experience in a radiation oncology department

Demetra Yannitsos

Department of Oncology, University of Calgary, Calgary, Canada

Petra Grendarova

Department of Oncology, University of Calgary, Calgary, Canada

Abdulla Al-Rashdan

Department of Oncology, University of Calgary, Calgary, Canada; Tom Baker Cancer Centre, Calgary, Canada

Linda Watson

CancerControl Alberta, Calgary, Canada

Wendy Smith

Department of Oncology, University of Calgary, Calgary, Canada

See next page for additional authors

Follow this and additional works at: <https://pxjournal.org/journal>



Part of the [Oncology Commons](#), [Quality Improvement Commons](#), and the [Radiology Commons](#)

Recommended Citation

Yannitsos D, Grendarova P, Al-Rashdan A, Watson L, Smith W, Lochray F, Wu J, Barbera L. Patient reported experience in a radiation oncology department. *Patient Experience Journal*. 2022; 9(1):119-130. doi: 10.35680/2372-0247.1595.

This Research is brought to you for free and open access by Patient Experience Journal. It has been accepted for inclusion in Patient Experience Journal by an authorized editor of Patient Experience Journal.

Patient reported experience in a radiation oncology department

Cover Page Footnote

Acknowledgments The Person-centered Radiation Oncology Service Enhancement (PROSE) program has received funding from the Cadmus Fund of the Calgary Foundation. This article is associated with the Policy & Measurement lens of The Beryl Institute Experience Framework (<https://www.theberylinstitute.org/ExperienceFramework>). You can access other resources related to this lens including additional PXJ articles here: http://bit.ly/PX_PolicyMeasure

Authors

Demetra Yannitsos, Petra Grendarova, Abdulla Al-Rashdan, Linda Watson, Wendy Smith, Fiona Lochray, Jackson Wu, and Lisa Barbera

Patient reported experience in a radiation oncology department

Demetra Yannitsos, *Department of Oncology, University of Calgary, demetra.yannitsos@albertahealthservices.ca*

Petra Grendarova, *Department of Oncology, University of Calgary, petra.grendarova@albertahealthservices.ca*

Abdulla Al-Rashdan, *Department of Oncology, University of Calgary, abdulla.al-rashdan@outlook.com*

Linda Watson, *CancerCare, Linda.Watson@albertahealthservices.ca*

Wendy Smith, *Department of Oncology, University of Calgary, Wendy.Smith@albertahealthservices.ca*

Fiona Lochray, *Department of Oncology, University of Calgary, Fiona.Lochray@albertahealthservices.ca*

Jackson Wu, *Department of Oncology, University of Calgary, Jackson.Wu@albertahealthservices.ca*

Lisa Barbera, *Department of Oncology, University of Calgary, Lisa.Barbera@albertahealthservices.ca*

Abstract

Understanding patient experience is essential to providing high quality, person-centered care. A real-time baseline cross-sectional study was completed to identify gaps in patient experience that can be targeted for quality improvement (QI). This study is part of PROSE (Person-centered Radiation Oncology Service Enhancement), a QI initiative developed to improve patient experience at a tertiary cancer centre Radiation Oncology (RO) Department. Data was collected using the Your Voice Matters (YVM) questionnaire. The YVM captures information on the patient's last visit, and questions are organized based on dimensions of person-centered care. Recruitment occurred between May and August 2019 in the radiation department. Consecutive patients during the study period were approached to complete the YVM either in reference to their initial consultation or previous treatment appointment. Percent positive scores were calculated for quantitative data and a content analysis was completed for open-text data. Of 512 patients approached, a total of 400 patients participated across tumors groups. Overall, patients highly endorsed positive experiences with feeling respected by their healthcare provider. Contacting the clinic, emotional support and wait times were rated as the least positive components of experience across appointment types and tumors groups. The Lung tumour group demonstrated worse experiences across all domains during treatments compared to all other tumour groups. Gaps and differences in patient experience were demonstrated across appointment types and tumour groups. This study provides direction to effectively develop and implement QI work aimed at improving patient experience.

Keywords

Patient experience, person-centered care, quality improvement, radiation oncology

Background

Person-centered care (PCC) is a key component of health care quality.^{1,2} PCC is characterized by considering the patient as a person first and by including the patient's perspective and their active participation in all aspects of their care.³ Patient experience has been defined as "the sum of all interactions within the health care system, shaped by an organization's culture that influences patient perceptions across the continuum of care."^{4,5}

Evaluation of patient experience includes an assessment of specific aspects of an encounter between the patient and health care providers, such as inclusion of the patient and their family in decision making or coordination of their care. Patient experience is one of the most important measures of health care system performance and is associated with improved communication between patients and health care providers, adherence to

recommended treatments, improved patient safety, lower utilization of unnecessary health care services and better clinical outcomes.⁵⁻⁸

Patient reported experience measures (PREMs) are validated questionnaires that capture many aspects of the patient's experience with their health care and the quality of care they received.⁹ PREMs have been primarily used to measure and compare quality of health care systems and performance.⁹ In several studies, PREMs have been used to identify specific deficiencies in patient experience to pursue quality improvement initiatives.^{10,11} PREMs are typically administered retrospectively, and the results might be subject to recall and/or selection bias. They often exclude experiences of patients who are sick and unlikely to complete the questionnaires months after their care delivery. Further, there is little data about point-of-care PREMs and a limited understanding of how these measures should be used to improve the quality of care in a cancer clinic environment. This study aims to address

these gaps by administering a near real-time PREM tool to patients in clinic to identify gaps in patient experience that could lead to quality improvement (QI) work.

Methods

Study Design

This was a comprehensive real-time cross-sectional study using a point-of-care validated PREM tool (Your Voice Matters). Data were collected across tumour groups and at two different appointment types (initial consultations and radiation treatment appointments). This study was a baseline PROSE project.

PROSE program

The PROSE program (Person-centered Radiation Oncology Service Enhancement) is a multiyear programmatic QI initiative established to improve patient experience and quality of care in the radiation oncology department at a tertiary cancer centre. The PROSE team includes health services researchers, a radiation oncology fellow and a clinical program coordinator. A quality council provides additional oversight and opportunity for stakeholder involvement. Its membership includes content experts, leadership from the oncology department and patient advisors. The program aims to identify and target gaps in patient experience within the radiation department and engage the entire radiation therapy (RT) department team to participate in QI projects led by PROSE. The ultimate program goal is a departmental culture shift towards person-centered care.

The PROSE program's ethics proposal was reviewed and approved by the Health Research Ethics Board of Alberta (HREBA) – Cancer Committee (CC) on October 2, 2018 (protocol identifying number: HREBA.CC-18-0588).

Your Voice Matters (YVM) Survey

Patient experience data were collected using Your Voice Matters (YVM). This electronic survey was developed and validated by CancerCare Ontario (CCO) for real-time use in an outpatient oncology setting.¹² The 28-core item YVM was a product of a psychometric validation study.¹² The tool underwent cognitive testing with patient advisors, was administered using various delivery modes (paper, tablets, patient portals, etc.) and was piloted at 6 cancer centres. Reliability and validity of the tool was calculated using Cronbach's alpha and multivariable regression analyses.¹²

The YVM domains and sub-questions reflect the order of the patient journey, including arrival to the clinic, wait times, the appointment, departure and overall experience. This project used the original 28-item version.

The structured YVM questions collect quantitative data. Most questions use a 5-point scale and ask patients to rate

their experiences with response options including excellent, very good, good, fair, poor. The survey also included Yes/No questions. Two open-text questions allowed patients to provide feedback on improving their patient experience.

The YVM was administered for patients to complete electronically on tablet devices. Data were collected and managed using a secure, web-based software platform REDCap hosted at the University of Calgary.^{13,14}

Sampling

Adult cancer patients attending an initial consultation with a radiation oncologist or radiation treatment appointment were eligible to participate. A convenience sample stratified by tumour group was used to obtain a representative sample across cancer sites. The aim was to obtain a total sample of 400 patients, 200 referencing their consultation and 200 referencing their treatment.

Recruitment

Recruitment occurred from May to August 2019 and was completed by the research coordinator. Survey completion was voluntary and anonymous. Patients were recruited from the CT simulation/radiation treatment waiting areas. Patients recruited from CT simulation whose previous appointment was a consultation were asked to complete the YVM in reference to their consultation. Patients whose previous visit was a radiation treatment were asked to complete the YVM in reference to that appointment. Waiting areas and times of day are common to all patients attending the appointments and they are not specific to tumour groups. The research coordinator recruited from various waiting areas per day and at various time points within clinic hours.

Analysis

Percent Positive Scores

We analyzed this project's YVM data using percent positive scores and following the CCO analysis plan for consistency. Percent positive scores (the proportion of positive experience responses) were calculated for quantitative YVM items using the equation: Percent Positive Score (%) = Positive / (Positive + Negative) X 100.

For questions using a scale of excellent to poor, positive responses included 'excellent' and 'very good'. The denominator included all responses, excluding 'not applicable' and 'don't know'. For yes/no questions, the positive response was context-dependent, with the denominator being the sum of yes and no responses. Percent positive scores were overlaid with a heat map to visualize differences in scores across appointment types and tumour groups. Darker colours represent more

positive experiences and lighter colours represent less positive experience.

For each table, YVM items were grouped by dimensions of person-centered care including: Access to Care; Information & Education; Patient Preference; Physical Comfort; Emotional Support; Family & Friends; Coordination of Care, and; Continuity & Transitions^{15,16}[Table 1, 2]. We also included an Overall Experience section in our results.

Logistic Regression

Multivariable logistic regression was conducted for overall experience. The overall experience YVM responses were dichotomized into positive/negative patient experience outcome. Covariates included demographic variables (gender, age, education), appointment type (consultation, radiation treatment) and tumour group. Statistical tests were performed with a significance level of 5%.

Content Analysis

Two open-text questions included: “Is there one thing that would have made your last visit to the Cancer Centre better?” and “Was there something at your visit that you wanted to give feedback on that is not asked in this survey?” Responses were analyzed using a content analysis. All comments were organized based on appointment type and codes were organized into themes. Two separate reviewers (DY and PG) coded each comment independently and differences were resolved by discussion.

Results

A total of 513 patients were approached to participate in the study. Between May and August 2019, 400 patients (78%) agreed to complete the YVM. Two-hundred patients completed the YVM in reference to their consultation and 200 in reference to their last radiation treatment appointment. Demographics and sample sizes by tumour groups are shown in the Appendix, Table 3. Tumour groups included: Brain, Breast, Gastrointestinal (GI), Gynecology (Gyne), Head and Neck (H&N), Lung, Prostate/Testicular and Other.

Percent Positive Scores

Overall Experience

Overall experience percent positive scores for consultations and treatment appointments were 79.9% and 85.0%, respectively. The highest positive experience scores >90% included confidence in the system, reception being polite, being treated with respect, feeling involved in decisions and inclusion of friends & family. The lowest experience scores were reported for options/methods of contacting the clinic (32.7% for consultations and 25.0% for treatments), wait times (38.0%; 22.0%), clinic

responsiveness (50.9%; 45.4%), and discussing worries & concerns (53.6%; 62.4%).

Experience by Dimensions of Person-Centered Care

Participants reported highest experience scores during both radiation consultations and treatments within the dimensions of “Patient Preferences”, “Family & Friends” and “Information, Communication & Education”. The dimensions “Emotional Support” and “Coordination of care” received the lowest scores (Table 1, 2).

Access to Care. Overall, the options available to patients to contact the clinic received the lowest percent positive scores at consultation (32.7%) and treatment (25.0%) appointments (Table 1, 2). Most patients during consultations (84.0%) and treatments (85.0%) had positive experiences with the length of time healthcare providers spent with them, with positive experience scores >80% across all tumour groups, except lung (63.0%).

Information, Communication & Education. Most patients during treatment appointments felt listened to (93.5%), things were explained well (86.5%) and they could ask questions (95.0%), with positive experience scores consistently higher compared to consultations by 8.0%, 4.5% and 2.5%, respectively.

How the clinic responded to patients who had contacted the clinic reflected low experience scores for both consultations (50.9%) and treatments (45.4%). Scores varied across tumour groups and were lowest for the brain tumour group during consultations (64.0%). The largest difference in positive experience scores between appointments was the information patients received about their care plan, in which 12.4% more patients during treatment reported a positive experience compared to consultations.

Patient Preferences and Friends & Family. Patient preferences percent positive scores were positive during both encounters. Positive experience scores were >90% for the reception staff being polite and patients feeling respected.

More patients felt included in decisions about their care during treatment (86.7%) compared to consultations (79.6%). During consultations, Other (68.0%), Lung (68.2%) and H&N (69.2%) groups reported the lowest experience scores. During treatment, Lung reported the lowest experience score (74.1%) for feeling involved in decisions. Most patients during consultations (92.5%) and treatment (95.0%) had a positive experience with involving friends and family in their care.

Physical Comfort. Overall positive experience scores for discussing physical symptoms with healthcare provider(s) were 81.0% and 87.9% for consultation and treatment

appointments, respectively. The largest difference in scores between appointments was patients' comfort in the waiting areas, as 18.5% less patients reported treatment waiting areas as comfortable/clean compared to consultations. The Gyne tumour group reported the lowest experience scores for the waiting area being comfortable/clean for both consultations (55.0%) and treatment (50.0%) appointments.

Emotional Support. Discussing emotional worries and concerns received low patient experience scores during consultations (53.6%) and treatment (62.9%). During consultations, scores ranged from Gyne (27.8%) to Breast (78.3%). The Lung tumour group indicated the lowest treatment score (42.1%).

Coordination of Care and Continuity & Transitions. During consultations, only 38% of patients did not have to wait past their appointment time and 55.3% reported a positive experience with their wait time. Breast patients stood out with the highest positive experience score (73.1%) regarding waiting for the consultation to start.

Compared to consultations, 16% more patients had to wait past their treatment appointment time and 15% less patients had a positive experience with their treatment wait times. Positive experience scores for waiting for treatment appointments ranged from 30.0% in Gyne to 57.1% in Breast patients. Most patients reported positive experiences with the coordination of their radiation oncology care team during consultations (76.9%) and treatment (82.9%) appointments.

More patients during treatments reported positive experiences with receiving clinic contact information (84.9%), knowing next steps in their care plan (96.5%) and receiving clear guidelines/instructions (84.6%), with scores higher than consultations by 9.4%, 22.0% and 11.1%, respectively.

Logistic regression

Multivariable logistic regression results demonstrated patients with breast (OR=3.82, p=0.041), GI (OR=7.93, p=0.012) and prostate cancer (OR=3.86, p=0.030) were more likely to have a positive overall experience compared to lung (reference group). Patients over the age of 60 (OR=2.90, p=0.039) were more likely to report a positive overall experience compared to the age group 18-40. Gender, education and appointment type were not statistically significant. We did not have enough power in our sample to stratify our analysis by appointment type.

Content Analysis

Consultation Appointments

A total of 104 open-text comments were documented for initial consultations (Table 4). The most frequently

reported concerns were in the "Access to Care" dimension (n=38), including concerns with contacting the clinic, burdensome parking and transportation. One patient stated *"Not a good experience trying to contact [the cancer centre]. Completely roundabout and frustrating experience. Only thing that has been an issue..."* The "Information, Communication & Education" dimension received 33 comments and included a lack of clinical information and scheduling issues. The third highest number of comments were in the "Coordination of Care" dimension (n=22), with patients reporting long wait times: *"Had to wait over two and a half hours...very long and not a good feeling to wait so long when newly diagnosed and not so sure what is going on."* Few comments were reported regarding the remaining dimensions.

Treatment Appointments

There were 125 open-text comments regarding treatment encounters (Table 4). The most frequently documented comments pertained to "Access to Care" (n=56), including parking concerns and transportation. The second highest number of comments were in "Coordination of Care" (n=37), mainly issues with wait times and a lack of coordination within the radiation department. As one patient noted: *"Treatment runs late, then late for review or miss other appointments like OT. Better coordination, so no appointments are missed."* The third most common dimension was "Physical Comfort" (n=21), including physical and environmental discomforts, such as uncomfortable seating or lack of wi-fi. Relatively high number of comments related to issues within "Information, Communication & Education" (n=19), however less frequent compared to Consultations. Few comments were documented regarding issues with "Patient Preferences" or "Continuity & Integration."

Discussion

This study reports on the experiences of patients coming for radiation oncology consultations and radiation therapy appointments at a tertiary cancer centre, using a validated point-of-care questionnaire related to a specific encounter. Consistently high patient experience scores across appointment types and tumour groups included the domains of "Patient preferences" and "Family & Friends," specifically with patients feeling respected, including family and friends in their care, and with polite reception staff. Compared to consultations, treatment experiences were more positive for "Information, Communication & Education" and "Continuity & Transitions" dimensions. Scores within "Coordination of Care" in reference to wait times were consistently low, and worse during treatment. "Physical Comfort" dimension, specifically the comfort of the waiting areas, were lower during treatment compared to consultations.

Long wait times, delays in treatment start, lack of coordination and emotional support as limitations to

optimal cancer patient experience have been consistently reported in other studies.^{17–24} A Canadian study by Hashmi et al. used a minute survey to obtain patient experience data from patients undergoing radiation therapy.²⁵ In this study, 83% of participants reported excellent experience in radiation oncology. The most common feedback for improving experience included same day waits and better management of appointment delays. Bridge et al. noted in their qualitative analysis of Ontario AOPSS data that patients had experienced delays at all steps of their encounters, including waiting for tests, for their providers, as well as treatments.²³ Patients reported concerns with long wait times in our study, shown through low “Coordination of Care” scores and a high frequency of open-text comments. Coordination of care within the cancer centre and with other providers has become more complex, with increased need for multi-disciplinary and interdisciplinary care. Finding a balance between interdisciplinary single day appointments and the exhaustion of long appointments is required.

Hashmi et al. found environmental improvements to be the second most common recommendation, including more distractions in waiting areas and functional wifi, similar to our findings.²⁵ Parking and appointment scheduling were less common gaps in their study,²³ compared to our results. Bridge et al. also noted stress regarding accessibility and cost of parking frequently reported on patients’ comments.² Amenities including parking have been considered separate from patient experience and quality of care and are not included in structured PREMs questions but are frequently reported on free-text comments and may impact overall experience scores.^{11,17,23} Other consistently low items across appointment and tumour groups included options of contacting the clinic and discussing emotional worries. Low scores for discussing emotional worries have been consistently reported in the literature,^{26,27} despite presence of clinical guidelines for anxiety and depression in oncology patients. Continued research and QI work is needed to help improve emotional wellbeing for patients.^{28,29}

Sociodemographic factors have been shown to be associated with patient experience in previous studies.^{30,31} Of cancer patients completing the YVM survey in Ontario, males and genitourinary cancer patients were more likely to have a positive patient experience.³⁰ Patients aged 18–39 were more likely to have a negative experience compared to 65+ patients^{30,31} as were patients in the lowest income bracket.³⁰ Patients diagnosed with central nervous system (CNS) or lung cancer were more likely to report a negative experience.^{30,31} Similarly, we found older patients and those diagnosed with prostate cancer were more likely to report positive overall patient experience, as did GI patients in our study.

This study identified important differences in patient experience among tumor groups. The gynecological patients had particularly poorer experiences with wait times and physical comfort. However, over 95% of gynecological patients responded positively to the overall quality of care they received, indicating the physical clinic environment is affecting their overall experience, possibly related to their distinct physical symptoms. QI initiatives to address this discomfort may include adding more comfortable seating options in the waiting area, such as recliner chairs or donut seating.

Breast and prostate patients had the highest percent positive scores for YVM categories. This may reflect the high incidence of these cancers resulting in well-established supports and resources. Additionally, higher proportions of these patients receive curative intent treatments and are overall well. While YVM did not include questions about intent of treatment, Watson et al. showed lower experience scores in ambulatory cancer patients with palliative-intent treatments, compared to patients treated with curative intent.³² Although lung cancer is among the most common cancers, patient experience during treatment is consistently poorer relative to the other tumour groups. Other studies have also reported on less favourable experience scores of patients with lung cancer compared to other tumour groups, such as breast and colorectal cancer.^{33,34} Reasons for poor patient experience have been attributed to diagnostic delays,³⁵ poor symptom management/support^{26,27} and poor communication with healthcare professionals.²⁶ Similarly, our results may highlight the relative lack of resources available to lung cancer patients. Additionally, due to the severity and nature of lung cancer, radiation treatment is more commonly given with palliative intent. Specific supports or strategies, such as early specialized palliative care referral, may be needed to personalize the care appropriate to these patients’ specific clinical needs.

The results of this study helped prioritize and develop future QI work in the department based on tumour-specific results. Oncology practice at our department and across our province is primarily operated within multidisciplinary tumor group teams. Our results have facilitated discussions with the lung tumor group clinicians on enhancing aspects of care to better address patient needs. PROSE has also conducted further follow up studies to investigate why patients with lung cancer in our radiation department report worse treatment experience. A retrospective chart audit found patients with lung cancer have greater diagnostic delays between initial investigations and receiving a diagnosis, as well as more severe symptoms on treatment compared to patients with GI cancer at our institution.³⁶ One of the limitations to the results of this study is an inability to link our patient experience data with other outcome data, such as the diagnostic delays or symptom severity. Anonymous data collection in this

patient experience study was done to promote safe reporting by participants. Future patient experience studies can be designed to either collect more clinical data from patients by including additional questions or add patient identifiers to link participants to other clinical data. Additional data that would be useful to collect include the patients' current treatment details (i.e. are they receiving radiation alone vs. concurrent chemoradiation; intent of treatment), as these factors likely have impacted patient experience.

Other patient experience gaps identified by this study are being addressed by ongoing projects. The Division of Radiation Oncology at our institution has piloted a care pathway, where patients receive their CT simulation appointment date and time prior to leaving their consultation, aiding patients in knowing their next steps. Other deficiencies addressed across our health authority include the Mycare Conversation App – developed to securely record conversations during consultations.

There were several limitations to this study, including the small number of patients in each tumour group. Small sample sizes limited stratification and more in-depth statistical analyses. Another limitation may include response bias, as unwell patients may have been less likely to complete the survey, however we obtained a relatively high response rate (78%) which can help reduce nonresponse bias. Although the YVM was developed for patients to complete the tool in reference to their last clinic visit, it is possible that some patients completed the tool in reference to more general cancer centre experiences. Therefore, results may reflect general experiences in addition to the intended specific single-visit experience. Further, anonymous data collection did come with limitations regarding interpretation of our data and linkage to other important outcomes. A strength of this study was having greatly minimized recall bias by asking patients to complete the YVM in near real-time. Another strength includes using the YVM in a specific department. CCO utilizes the YVM by collecting patient experience data on a province-wide scale. Although the large-scale implementation in Ontario produces important data for institutional comparisons, we have demonstrated the value in implementing the YVM in a small-scale single-institution and department setting. Our results can effectively direct and prioritize QI work within our radiation department context, whereas high-level aggregate data can disguise otherwise important trends and findings.

This study can be of value to other organizations looking to undergo quality improvement work. Our study demonstrates the use of a PREM to highlight strengths and weaknesses of care within a department, and direct where resources would be most effective to improve patient experience. Specific results from a PREM will likely differ across institutions and departments but the

actual process of investigating patient experience and defining quality improvement strategies remains the same. Further, collection of PREMs should encourage responsive actions to improve evident gaps in patient care. Therefore, our study can be used as a framework for other organizations/QI teams. Understanding and improving patient experience can in return improve the quality of care that patients receive at their institution.

Conclusions and Future Directions

This study shows variation in patient experience across different appointment types and tumour groups. Patient experience was consistently positive for meeting patient preferences and including family and friends in patient care plans. Areas for improvement include managing wait times and improving physical comfort. Across both appointments, improving the process for contacting the clinic as well as improving emotional support can be areas for quality improvement work within the radiation department. These observations will help guide future evaluations and interventions.

References

1. Institute of Medicine. *Crossing the Quality Chasm: A New Health System for the 21st Century*. Academies Press (US); 2001.
2. Institute of Medicine. *Delivering High-Quality Cancer Care: Charting a New Course for a System in Crisis*. (Levit L, Balogh E, Nass S, Ganz P, eds.). National Academies Press (US); 2013.
3. Person-Centred Care. Cancer Care Ontario website. Accessed June 10, 2019. <https://www.cancercareontario.ca/en/guidelines/-advice/modality/person-centred-care>
4. Defining Patient Experience. The Beryl Institute website. Accessed October 28, 2020. <https://www.theberylinstitute.org/page/definingpatientexp>
5. What is Patient Experience? Agency for Healthcare Research and Quality website. Updated January 2021. Accessed May 2, 2019. <https://ahrq.gov/cahps/about-cahps/patient-experience/index.html>
6. Health Care Quality Indicators - Responsiveness and Patient Experiences. Organisation for Economic Co-operation and Development website. Updated 2018. Accessed August 4, 2019. <https://oecd.org/els/health-systems/hcqi-responsiveness-and-patient-experiences.htm>
7. Doyle C, Lennox L, Bell D. A systematic review of evidence on the links between patient experience and clinical safety and effectiveness. *BMJ Open*. 2013;3(1). doi:10.1136/bmjopen-2012-001570
8. Mollica MA, Lines LM, Halpern MT, et al. Patient experiences of cancer care: scoping review, future

- directions, and introduction of a new data resource: Surveillance Epidemiology and End Results-Consumer Assessment of Healthcare Providers and Systems (SEER-CAHPS). *Patient Exp J*. 2017;4(1):103-121. doi:10.35680/2372-0247.1167
9. Patient Experience. Canadian Institute for Health Information website. Published 2020. Accessed October 28, 2020. <https://www.cihi.ca/en/patient-experience%0D>
 10. Miller D, Steele Gray C, Kuluski K, Cott C. Patient-Centered Care and Patient-Reported Measures: Let's Look Before We Leap. *Patient*. 2015;8(4):293-299. doi:10.1007/s40271-014-0095-7
 11. Cleary PD. Evolving concepts of patient-centered care and the assessment of patient care experiences: Optimism and opposition. *J Health Polit Policy Law*. 2016;41(4):675-696. doi:10.1215/03616878-3620881
 12. Moody L, Benn S, Ieraci L, Ingale S, Singh S. Validation of a real-time patient-reported experience measurement tool for cancer patients in Ontario. *J Clin Oncol*. 2016;34(7):174-174. doi:10.1200/jco.2016.34.7_suppl.174
 13. Harris PA, Taylor R, Thielke R, Payne J, Gonzalez N, Conde JG. Research electronic data capture (REDCap)-A metadata-driven methodology and workflow process for providing translational research informatics support. *J Biomed Inform*. 2009;42(2):377-381. doi:10.1016/j.jbi.2008.08.010
 14. Harris PA, Taylor R, Minor BL, et al. The REDCap Consortium: Building an International Community of Software Platform Partners. *J Biomed Inf*. Published online 2019:1-24. doi:10.1016/j.jbi.2019.103208.The
 15. Eight dimensions of patient-centered care. NCR Health website. Accessed June 10, 2019. <https://nrhealth.com/?s=Eight+Dimensions+of+Patient+Centered+Care&submit=□>
 16. Moody L, Nicholls B, Shamji H, Bridge E, Dhanju S, Singh S. The Person-Centred Care Guideline: From Principle to Practice. *J Patient Exp*. 2018;5(4):282-288. doi:10.1177/2374373518765792
 17. Wiseman T, Lucas G, Sangha A, et al. Insights into the experiences of patients with cancer in London: Framework analysis of free-text data from the National Cancer Patient Experience Survey 2012/2013 from the two London Integrated Cancer Systems. *BMJ Open*. 2015;5(10):1-10. doi:10.1136/bmjopen-2015-007792
 18. Black G, Sheringham J, Spencer-Hughes V, et al. Patients' experiences of cancer diagnosis as a result of an emergency presentation: A qualitative study. *PLoS One*. 2015;10(8):1-17. doi:10.1371/journal.pone.0135027
 19. Lipczak H, Dorflinger L, Enevoldsen C, Vinter M, Knudsen J. Cancer patients' experiences of error and consequences during diagnosis and treatment. *PXJ 2015;2102-10*. 2015;2:102-110.
 20. Beach MC, Inui T, Frankel R, et al. Relationship-centered care: A constructive reframing. *J Gen Intern Med*. 2006;21(SUPPL. 1). doi:10.1111/j.1525-1497.2006.00302.x
 21. Stewart MA. Effective physician-patient communication and health outcomes: A review. *Cmaj*. 1995;152(9):1423-1433.
 22. Coronado AC, Tran K, Chadder J, et al. The experience of patients with cancer during diagnosis and treatment planning: A descriptive study of Canadian survey results. *Curr Oncol*. 2017;24(5):332-337. doi:10.3747/co.24.3782
 23. Bridge E, Gotlib Conn L, Dhanju S, Singh S, Moody L. The patient experience of ambulatory cancer treatment: A descriptive study. *Curr Oncol*. 2019;26(4):e482-e493. doi:10.3747/co.26.4191
 24. Fitch MI, Coronado AC, Schippke JC, Chadder J, Green E. Exploring the perspectives of patients about their care experience: identifying what patients perceive are important qualities in cancer care. *Support Care Cancer*. 2020 May;28(5):2299-2309. doi: 10.1007/s00520-019-05057-9.
 25. Hashmi F, Gregor N, Liszewski B, et al. It Only Takes a Minute: The Development and Implementation of a Patient Experience Survey in Radiation Therapy. *J Med Imaging Radiat Sci*. 2019;50(1):5-11. doi:doi.org/10.1016/j.jmir.2018.07.006
 26. Fitch MI. The changing face of lung cancer: Survivor perspectives on patient engagement. *Asia-Pacific J Oncol Nurs*. 2019;6(1):17-23. doi:10.4103/apjon.apjon-43-18
 27. Sanders SL, Bantum EO, Owen JE, Thornton AA, Stanton AL. Supportive care needs in patients with lung cancer. *Psychooncology*. 2010;19(5):480-489. doi:10.1002/pon.1577
 28. Howell D, Keshavarz H, Esplen MJ, Hack T, Hamel M, Howes J, Jones J, Li M, Manii D, McLeod D, Meyer C, Sellick S, Riahihazadeh S, Noroozi H AM. A Pan Canadian Practice Guideline: Screening, Assessment and Care of Psychosocial Distress (Depression, Anxiety) in Adults with Cancer: Canadian Partnership Against Cancer (Cancer Journey Advisory Group) and Canadian Association of Psychosocial Oncology. *Toronto Can Partnersh Against Cancer Can Assoc Psychosoc Oncol*. Published online 2015.
 29. Riba MB, Donovan KA, Andersen B, et al. Distress management, version 3.2019. *JNCCN J Natl Compr Cancer Netw*. 2019;17(10):1229-1249. doi:10.6004/jnccn.2019.0048
 30. Mahler M, Nicholls B, Chan C, Nazeri-Rad N, Chan K, Singh S. Demographic, socioeconomic, and clinical factors associated with oncology patient experience in the Ontario cancer system [ASCO abstract 160]. *J Clin Oncol*. 2020;38(29 suppl). doi:10.1200/JCO.2020.38.29_suppl.160

31. Bridge E, Singh S, Murdoch A, Mozuraitus M, Nicholls B, Moody L. Examining patient and visit characteristics associated with the cancer patient experience [ASCO abstract 204]. *J Clin Oncol*. 2019;37(27 suppl). doi:10.1200/JCO.2019.37.27_suppl.204
32. Watson L, Qi S, Photitai E, DeJure A. A Cross-Sectional Analysis of Ambulatory Oncology Experience by Treatment Intent. *Curr Oncol*. 2020;28(1):98-106. doi:10.3390/currenol28010013
33. Ayanian JZ, Zaslavsky AM, Arora NK et al. Patients' experiences with care for lung cancer and colorectal cancer: findings from the cancer care outcomes research and surveillance consortium. *J Clin Oncol*. 2010;28(27):4154–4161. doi.org/10.1200/JCO.2009.27.3268
34. Halpern MT, Urato MP, Lines LM, Cohen JB, Arora NK, Kent EE. Healthcare experience among older cancer survivors: analysis of the SEER-CAHPS dataset. *J Geriatr Oncol*. 2018;9(3):194–203. doi.org/10.1016/j.jgo.2017.11.005
35. Tsianakas V, Robert G, Maben J, Richardson A, Dale C, Wiseman. Implementing patient-centred cancer care: using experience-based co-design to improve patient experience in breast and lung cancer services. *Support Care Cancer*. 2012;20(11):2639–2647. <https://doi.org/10.1007/s00520-012-1470-3>
36. Yannitsos D, Barbera L, Al-Rashdan A, Grendarova P. Diagnostic timelines and self-reported symptoms of patients with lung and gastrointestinal cancers undergoing radiation therapy. Retrospective case control study. *Support Care Cancer*. 2022;30(2):1501-1509. doi: 10.1007/s00520-021-06522-0

Appendix

Table 1. Percent Positive Scores (%) for Consultation Experiences by Tumour Groups

Dimensions of Person-centered Care	YVM Question	Brain (n=25)	Breast (n=26)	GI (n=26)	Gyne (n=20)	H&N (n=26)	Lung (n=25)	Prostate (n=26)	Other (n=26)	Total Consultation (n=200)
Access to Care	Options available to contact clinic	62.5	40.0	50.0	20.0	0.0	33.3	20.0	33.3	32.7
	Convenient hours	71.4	87.5	82.6	90.1	72.7	68.4	87.5	77.3	79.5
	Clinic is easy to find	60.0	73.1	69.2	55.0	76.0	76.0	80.8	57.7	68.8
	Spent enough time	76.0	96.2	92.3	70.0	76.9	84.0	100.0	73.1	84.0
Information, Communication & Education	How the clinic responded	75.0	70.0	100.0	40.0	40.0	33.3	20.0	55.6	50.9
	Listened to you	88.0	92.3	84.6	85.0	88.5	72.0	88.5	84.6	85.5
	Explained things well	64.0	96.2	84.6	75.0	76.9	84.0	92.3	80.8	82.0
	Let you ask questions	96.0	100.0	88.5	95.0	84.6	88.0	100.0	88.5	92.5
Patient Preferences	Information provided	60.0	92.3	84.6	65.0	69.2	64.0	69.2	57.7	70.5
	Reception was polite	88.0	100.0	92.3	100.0	96.2	96.0	96.2	96.2	95.5
	Treat you with respect	100.0	100.0	92.3	100.0	88.5	88.0	100.0	96.2	95.5
Physical Comfort	Involved in decisions	84.0	88.5	88.5	80.0	69.2	68.2	88.5	68.0	79.6
	Wait room comfortable and clean	64.0	100.0	92.3	55.0	76.9	88.0	92.3	69.2	80.5
	Discussed symptoms	84.0	88.5	88.5	72.2	76.9	69.6	84.0	80.8	81.0
Emotional Support	Exam room comfortable and clean	64.0	92.3	88.5	65.0	76.9	84.0	92.3	76.9	80.5
Family & Friends	Discussed worries and concerns	56.5	78.3	60.0	27.8	41.7	54.5	58.3	42.3	53.6
Coordination of Care	Involved friends or family	96.0	100.0	91.7	100.0	82.6	86.4	100.0	83.3	92.5
	Wait time past appointment*	36.0	76.9	42.3	10.0	26.9	52.0	30.8	23.1	38.0
	Wait time to check-in	80.0	88.5	88.5	73.7	80.8	76.0	76.9	72.0	79.8
	Wait time for appointment	48.0	73.1	65.4	31.6	50.0	56.0	53.8	57.7	55.3
Continuity & Transitions	Coordination of team	80.0	92.3	84.6	75.0	73.1	72.0	84.6	65.4	78.5
	Contact information provided	76.0	96.2	80.8	70.0	76.9	68.0	69.2	65.4	75.5
	Next steps provided**	68.0	80.8	80.0	75.0	69.2	84.0	60.0	76.0	74.2
Overall Experiences	Clear guidelines/instructions given	68.0	88.5	80.8	70.0	73.1	68.0	84.6	53.8	73.5
	Arrival experience (reception, waiting area, wait times)	68.0	100.0	76.9	50.0	73.1	72.0	73.1	64.0	72.8
	Quality of care received during appointment	80.0	92.3	84.6	95.0	80.8	76.0	100.0	69.2	84.5
	Overall last visit experience	72.0	96.2	88.5	57.9	80.8	76.0	92.3	69.2	79.9
	Overall confidence in the health system	92.0	100.0	88.5	100.0	80.8	76.0	96.2	80.8	91.5

*YVM item with yes/no response. "No" is the positive response.

**YVM item with yes/no response. "Yes" is the positive response.

Appendix

Table 2. Percent Positive Scores (%) for Treatment Experiences by Tumour Groups

Dimensions of Person-centered Care	YVM Question	Brain (n=25)	Breast (n=28)	GI (n=26)	Gyne (n=20)	H&N (n=26)	Lung (n=27)	Prostate (n=26)	Other (n=22)	Total Treatment (n=200)
Access to Care	Options available to contact clinic	44.4	0.0	25.0	28.6	40.0	0.0	40.0	0.0	25.0
	Convenient hours	83.3	100.0	91.7	78.9	88.0	74.1	100.0	95.5	89.7
	Clinic is easy to find	64.0	64.3	61.5	45.0	76.9	65.4	80.8	54.5	64.8
	Spent enough time	88.0	89.3	96.2	90.0	80.8	63.0	92.3	81.8	85.0
Information, Communication & Education	How the clinic responded	55.6	40.0	50.0	42.9	60.0	25.0	80.0	0.0	45.4
	Listened to you	96.0	96.4	96.2	100.0	100.0	77.8	96.2	86.4	93.5
	Explained things well	84.0	89.3	96.2	90.0	92.3	66.7	88.5	86.4	86.5
	Let you ask questions	100.0	92.9	100.0	100.0	92.3	85.2	96.2	95.5	95.0
Patient Preferences	Information provided	87.5	85.7	92.3	85.0	84.6	66.7	96.2	68.2	82.9
	Reception was polite	92.0	92.9	100.0	100.0	100.0	85.2	100.0	90.5	94.9
	Treat you with respect	96.0	96.4	96.2	100.0	96.2	81.5	92.3	90.9	93.5
	Involved in decisions	84.0	92.9	91.7	95.0	85.4	74.1	92.0	81.0	86.7
Physical Comfort	Wait room comfortable and clean	64.0	64.3	53.8	50.0	69.2	51.9	80.8	59.1	62.0
	Discussed symptoms	84.0	88.5	91.7	95.0	88.5	80.8	91.3	85.0	87.9
	Exam room comfortable and clean	88.0	89.3	92.3	75.0	76.9	70.4	92.0	90.9	84.4
Emotional Support	Discussed worries and concerns	61.9	68.0	66.7	58.9	71.4	42.1	75.0	64.3	62.4
Family & Friends	Involved friends or family	95.7	96.0	95.8	100.0	95.8	85.2	96.0	95.2	94.7
Coordination of care	Wait time past appointment*	20.0	10.7	34.6	25.0	26.9	22.2	19.2	18.2	22.0
	Wait time to check-in	75.0	92.9	88.5	85.0	73.1	73.1	92.3	100.0	84.8
	Wait time for appointment	36.0	57.1	42.3	30.0	42.3	30.8	46.2	36.4	40.7
	Coordination of team	92.0	85.7	92.3	90.0	84.6	63.0	96.0	59.1	82.9
Continuity & Transitions	Contact information provided	92.0	85.7	88.5	80.0	92.3	70.4	96.0	72.7	84.9
	Next steps provided**	100.0	92.9	100.0	100.0	96.2	92.6	96.2	95.2	96.5
	Clear guidelines/instructions given	72.0	85.7	96.2	85.0	84.0	74.1	88.5	77.3	84.6
Overall Experiences	Arrival experience (reception, waiting area, wait times)	72.0	71.4	65.4	55.0	65.4	59.3	80.8	50.0	65.5
	Quality of care received during appointment	96.0	92.9	100.0	100.0	92.3	85.2	92.3	95.5	94.0
	Overall last visit experience	80.0	85.7	96.2	95.0	76.9	70.4	88.5	90.0	85.0
	Overall confidence in the health system	100.0	96.4	96.2	100.0	96.2	92.6	96.2	90.9	96.0

*YVM item with yes/no response. “No” is the positive response.

**YVM item with yes/no response. “Yes” is the positive response.

Appendix

Table 3. Demographic Data of the Study Population

Demographic	Consultation	Treatment	Total
Gender (n, %)			
Male	104 (52.0%)	97 (51.5%)	201 (50.2%)
Female	96 (48.0%)	103 (48.5%)	199 (49.8%)
Total (n)	200	200	400
Age (n, %)			
18 to 40	13 (6.5%)	21 (10.7%)	34 (8.6%)
41 to 60	58 (29.0%)	67 (34.2%)	125 (31.6%)
Over 60	129 (64.5%)	108 (55.1%)	237 (59.8%)
Total (n)	200	196	396
Highest grade of school completed (n, %)			
Some high school/grade 9 or less	19 (10.2%)	20 (10.9%)	39 (9.9%)
High school graduate	44 (23.5%)	42 (23.1%)	86 (23.3%)
College, trade or technical school	64 (34.2%)	54 (29.7%)	118 (31.9%)
University undergraduate degree	44 (23.5%)	49 (26.9%)	93 (25.2%)
Post-university/graduate education	16 (8.6%)	17 (9.3%)	33 (8.9%)
Total (n)	187	182	369
Cancer Type (n, %)			
Brain	25 (12.5%)	25 (12.5%)	50 (12.5%)
Breast	26 (13.0%)	28 (14.0%)	54 (13.5%)
Gastrointestinal (GI)	26 (13.0%)	26 (13.0%)	52 (13.0%)
Gynecology (Gyne)	20 (10.0%)	20 (10.0%)	40 (10.0%)
Head and Neck (H&N)	26 (13.0%)	26 (13.0%)	52 (13.0%)
Lung	25 (12.5%)	27 (13.5%)	52 (13.0%)
Prostate	26 (13.0%)	26 (13.0%)	52 (13.0%)
Other	26 (13.0%)	22 (11.0%)	48 (12.0%)
Total (n)	200	200	400

Appendix

Table 4. Content Analysis of Patient Feedback for Improving Patient Experience

Dimension of Person-centered Care	Themes	Consultation* Frequency (n) of comments	Treatment** Frequency (n) of comments
Access to Care	Parking: Accessibility	8	13
	Parking: Cost	4	16
	Transportation burdensome	10	10
	Clinic location challenging to find	6	8
	Lack/delay in accessing supportive services	3	2
	Inability to contact TBCC	3	3
	Inconvenient scheduling (form of appt. booking, suggested use of email)	4	0
	Total count for Access to Care	38	52
Information, Communication & Education	Lack of scheduling information/confusion with scheduling	13	4
	Lack of clinical information	9	4
	Issues with form of information (for patients with difficulty comprehending/ retaining information, e.g. central nervous system involvement)	4	4
	Negative interaction with healthcare provider (poor communication skills)	2	4
	Delay in healthcare provider calling the patient back	2	1
	Lack of confidence about quality of care	1	1
	Information not right for the person (focus on clinical trials and not on personal clinical information)	1	0
	Clarity about the roles of healthcare professional and who to contact	1	0
	Lack of information/guidance on support groups	0	1
Total count for Information, Communication & Education	33	19	
Patient Preferences	Did not feel included in decisions about care	2	1
	Preference for consistent RT staff	-	3
	Scheduled appointment times not patient's preference	0	2
	Total count for Patient Preferences	2	6
Physical Comfort	Wi-fi not functional	3	6
	Uncomfortable physically (e.g. symptoms/side-effects of pain/discomfort)	0	8
	Uncomfortable physical space (waiting area is uncomfortable)	2	7
	Immobilization mask very claustrophobic	2	0
	Total count for Physical Comfort	7	21
Emotional Support	Uncertainty/overwhelmed	2	1
	Lack of attention/empathy to patient's concerns (e.g. anxiety with immobilization mask)	2	0
	Anxiety caused by changes/delays in treatment plans (lack of explanation)	0	3
	Total count for Emotional Support	4	4
Coordination of Care	Wait times	10	19
	Lack of coordination within the clinic	2	8
	Lack of coordination within TBCC (RT and chemo)	2	5
	Lack of coordination between TBCC and other clinics/places (e.g. ER)	4	2
	Missed check-in	4	1
	Total count for Coordination of Care	22	35
Continuity & Integration of Care	Uncertain <i>where to call</i> with more questions/wish to address further/follow-up	3	1
	Missing information about next steps	1	1
	Total count for Continuity & Integration of Care	4	2
Other: Positive Experience	Positive interaction with healthcare professional	4	4
	General Comment	4	2
	Total count for Positive Experience	8	6

* There were 104 total comments documented for consultations. Comments could be coded into more than one theme.

** There were 125 total comments documented for treatments. Comments could be coded into more than one theme.