CURRENT ONCOLOGY
A Canadian Cancer Research Journal

CanPROS Scientific Conference 2019 Oral Abstracts

Presented by CanPROS Congress, A Catalyst for Whole-Person Care; Hilton Garden Inn, Calgary, Alberta; 13–15 November 2019

The PROs Value Impact to the Patient and Caregiver

Best Oral Abstract:

Development of health-state classification system for a new breast cancer–specific preference-based measure: the BREAST-Q utility module

Manraj Kaur,* Andrea Pusic,† Louise Bordeleau,‡ Toni Zhong,§ Stefan Cano,‖ Anne Klassen#

Background Generic preference-based measures (PBMs), though commonly used, may not be optimal for use in the economic evaluations assessing the impact of breast cancer interventions. Concerns that are unique to women with breast cancer (for example, body image, appearance, treatment-specific adverse effects) are not adequately captured by the existing generic measures. No breast cancer–specific PBM exists. The objective of this study was to construct a health state classification system specific to breast cancer which is amenable to valuation.
Methods We conducted semi-structured interviews in a heterogeneous sample of women with breast cancer [stages 0–4, any stage of treatment(s)]. Interviews were audio recorded, transcribed verbatim, and coded using the constant comparison approach to develop the conceptual framework. Patients were also asked to describe their most and least important concerns during the interview and to rate items in the related BREAST-Q module (that is, mastectomy, breast-conserving therapy, or reconstruction) on a modified 5-point Likert scale (ranging from Not important to Very important). A face-to-face meeting with an expert panel of health care professionals, health economists, and HRQOL researchers was used to obtain feedback on the health state classification system, response levels, and wording of the items.
Results Interviews ($n = 59$) with patients aged 59.9 years were completed. The resultant conceptual framework included site-specific (that is, abdomen, arm, breast) and overall (that is, body image, appearance, cancer, psychological, sexual, and social) domains. Triangulation of the qualitative and quantitative evidence led to the selection of key constructs for inclusion in the new PBM. The field test version of the BREAST-Q utility health state classification system consisted of 13 attributes with 4 response levels each.
Conclusions The health state classification system for the preference-based module of the BREAST-Q (BREAST-Q-U) was derived using patient and expert feedback. The next phase will involve establishing psychometric properties of the BREAST-Q-U, followed by a valuation study to generate utility weights.

Affiliations: *School of Rehabilitation Sciences, Faculty of Health Sciences, McMaster University, Hamilton, ON; †Brigham and Women's Hospital, Harvard Medical School, Boston, MA, U.S.A.; ‡Department of Oncology, Faculty of Health Sciences, McMaster University, Hamilton, ON; §Division of Plastic and Reconstructive Surgery, University of Toronto, Toronto, ON; ‖Modus Outcomes, Letchworth Garden City, U.K.; #Department of Pediatrics, Faculty of Health Sciences, McMaster University, Hamilton, ON.

The impact of routine ESAS use on overall survival: results of a population-based retrospective matched cohort analysis

Lisa Barbera,*†‡ Rinku Sutradhar,† Hsien Seow,§ Nicole Mittmann,‡ Doris Howell,‖ Craig Earle,† Qing Li,† Deva Thiruchelvam†

Background The study objective was to examine the impact of routine Edmonton Symptom Assessment System (ESAS) use on overall survival in adult cancer patients. We hypothesized that patients exposed to the ESAS would have better overall survival rates than those who didn't have ESAS.
Methods The effect of ESAS screening on survival was evaluated in a retrospective matched cohort study. The cohort included all Ontario patients aged 18 or older who were diagnosed with cancer between 2007 and 2015. Patients completing at least 1 ESAS assessment during the study were considered exposed. The index date was the day of the first ESAS assessment. Follow-up time for each patient was segmented into one of three phases: initial, continuing, or palliative care. Exposed and unexposed patients were matched 1:1 using hard matching (birth year ± 2 years, cancer diagnosis date ± 1 year, cancer type, and sex) and propensity score matching (14 measures, including cancer stage, treatments received, and comorbidity). Matched patients were followed until death or the end of study at 31 December 2015. Kaplan–Meier curves and multivariable Cox regression were used to evaluate the impact of ESAS on survival.
Results There were 128,893 pairs well matched on all baseline characteristics (standardized difference < 0.1). The probability of survival within the first 5 years was higher for those who were exposed to ESAS than for those who were not (73.8% vs. 72.0%, $p < 0.0001$). In the multivariable Cox regression model, ESAS assessment was significantly associated with decreased mortality risk (hazard ratio: 0.49; 95% confidence interval: 0.48 to 0.49), and the protective effect was seen across all phases.
Conclusions ESAS exposure is associated with improved survival in cancer patients, in all phases of care. To the extent possible, extensive matching methods have mitigated biases inherent to observational data. This provides real-world evidence of the impact of routine symptom assessment in cancer care.

Affiliations: *University of Calgary, Department of Oncology, Calgary, AB; †ICES, Toronto, ON; ‡Sunnybrook Research Institute, Toronto, ON; §McMaster University, Department of Oncology, Hamilton, ON; ‖University Health Network, Princess Margaret Cancer Centre, Toronto, ON.

Symptom severity among cancer outpatients in the last 6 months of life: analysis of 92,757 patient-reported symptom assessment scores

Lev D. Bubis,*[a] Laura E. Davis,†[a] Hera Canaj,† Vaibhav Gupta,* Yunni Jeong,* Lisa Barbera,‡ Qing Li,§ Lesley Moody,‖ Paul J Karanicolas,*#** Rinku Sutradhar,§#†† Natalie G. Coburn,*#**[a] Alyson L. Mahar‡‡[a]

Background Understanding the magnitude and risk factors for symptom burden in cancer patients at the end of life is critical to guiding effective patient- and system-level interventions. We aimed to estimate the prevalence of severe patient-reported symptoms among cancer outpatients during the 6 months before death and to identify patient groups at a higher risk for reporting severe symptoms.
Methods This was a retrospective cohort study of cancer decedents at regional cancer centres from 2010 to 2016. Patient-reported Edmonton Symptom Assessment System (ESAS) scores from the last 6 months-of-life were linked to administrative databases. The proportions of patients reporting severe symptom scores (>7) for anxiety, depression, drowsiness, lack of appetite, nausea, pain, shortness of breath, tiredness, and overall well-being during the 6 months before death were described. Multivariable modified Poisson regression analyses were used to identify risk factors for reporting severe symptom scores.

DOI: https://doi.org/10.3747/co.27.6043

Results Of 39,084 cancer decedents, 22,650 had 1 or more symptom records in the last 6 months of life, resulting in 92,757 ESAS assessments. Severe scores were highest for tiredness (56%), lack of appetite (46%), and impaired well-being (45%). The proportion of patients reporting severe scores was stable before progressively increasing at 3 months before death. Elderly individuals, women, patients with high comorbidity, immigrants, and those living in urban areas or with high material deprivation were at increased risk of reporting severe scores.
Conclusions Despite an integrated symptom screening program, rates of severe patient-reported symptom scores before death were high for cancer outpatients. Patient subgroups at increased risk of severe symptom burden might benefit from targeted interventions. Ongoing review of routinely collected symptom data could be used to assess supportive care needs and to guide targeted interventions at the health-system level.

[a] LDB and LED contributed equally to this work. NGC and ALM share senior authorship.

Affiliations: *Division of General Surgery, Department of Surgery, University of Toronto, Toronto, ON; †Sunnybrook Research Institute, Sunnybrook Health Sciences Centre, Toronto, ON; ‡Division of Radiation Oncology, University of Calgary, Calgary, AB; §ICES, Toronto, ON; ||Ontario Health (Cancer Care Ontario), Toronto, ON; #Institute of Health Policy, Management and Evaluation, University of Toronto, Toronto, ON; **Division of General Surgery, Sunnybrook Health Sciences Centre, Toronto, ON; ††Department of Biostatistics, Dalla Lana School of Public Health, University of Toronto, Toronto, ON; ‡‡Department of Community Health Sciences, University of Manitoba, Winnipeg, MB.

How are family-reported outcomes used to benefit patients and families, health care providers, and the health care system? A scoping review

Jennifer C. Pink,*† Shama Bath,‡ John W. Robinson*†

Objectives Cancer can be thought of as a "we disease" that families face together. Patients and family members can report decreased well-being, quality of life, and relationship functioning, and serve as vital sources of support for one another throughout adjustment to cancer, its treatment, and survivorship. Although much research has documented the impact of cancer on families, its translation to the implementation of family-reported outcomes has lagged far behind the implementation of patient-reported outcomes. The purpose of this scoping review is to map the current use of family-reported outcomes in oncology and to make recommendations for future research in this emergent area.
Methods A systematic search of MEDLINE (Ovid), EBM Reviews (includes the Cochrane Database of Systematic Reviews), PSYCINFO, PubMed, CINAHL, MEDLINE (EBSCO), Web of Science, EMBASE, Social Work Abstracts, SOCINDEX with full text, Sociological Abstracts, and the grey literature identified 577 articles after duplicates were removed. Two reviewers will apply inclusion and exclusion criteria to evaluate them for possible inclusion in the review.
Results We will produce a narrative review to summarize key issues and themes within the existing literature on family-reported outcomes in oncology. We will also provide a summary of family-reported outcomes in select other medical specialties (for example, dermatology) that can inform cancer care.
Conclusions This scoping review will provide an overview of the emergent literature on family-reported outcomes in oncology. It will provide recommendations for future research to support further development of family-reported outcome measures and implementation of family-reported outcomes in research and practice to promote optimal cancer care.

Affiliations: *Department of Psychosocial and Rehabilitation Oncology, Tom Baker Cancer Centre, Calgary, AB; †Department of Oncology, Cumming School of Medicine, University of Calgary, Calgary, AB; ‡University of Calgary, Calgary, AB.

Gaps in the management of depression symptoms screening after a cancer diagnosis: a population-based analysis of prospective patient-reported outcomes

Julie Hallet, Laura E. Davis, Elie Isenberg-Grzeda, Alyson L. Mahar, Haoyu Zhao, Victoria Zuk, Lesley Moody, Natalie G. Coburn

Background One of the most common psychological morbidities of cancer is depression. Routine screening for depression symptoms (DS) is recommended, but its ability to lead to psychosocial interventions in clinical practice is limited. We examined the use of and factors associated with psychosocial interventions for patient-reported DS after a cancer diagnosis.
Methods We conducted a population-based cohort study of patients with diagnoses during 2010–2017 who reported more than 1 patient-reported Edmonton Symptom Assessment System (ESAS) score. DS was defined as ESAS greater than 2 of 10 for the depression item within 6 months of diagnosis. Outcomes were psychosocial interventions around the time of DS: palliative care assessment, psychiatric or psychologic assessment, social work referral, and antidepressant therapy (in patients >65 years old with universal drug coverage). We examined reduction in DS (>1 point) after intervention. Modified Poisson regression examined factors associated with interventions.
Results Of 142,270 patients, 65,424 (46.0%) reported DS at a median of 66 days (25% to 75% interquartile range: 34–105 days) post-diagnosis. Of those with DS, 17.1% received palliative assessment, 1.7% psychiatric or psychologic assessment, 8.4% social work referral, and 4.3% antidepressant therapy. DS decreased in 67.2% of those receiving palliative assessment; 63.7%, receiving psychiatric or psychologic assessment; 67.3%, receiving social work referral; and 71.4%, receiving antidepressant therapy. On multivariable analysis, patients with older age, rural residence, lowest income quintile, and genitourinary or oropharyngeal cancer were more likely not to receive interventions other than palliative care.
Conclusions The proportion of patients reporting DS after a cancer diagnosis who receive psychosocial intervention is low. We identified patients vulnerable to not receiving interventions who might benefit from additional support. These data represent a call to action to modify practice and optimize the usefulness of systematic symptom screening.

Affiliations: Sunnybrook Health Sciences Centre, Toronto, ON.

Testing the validity of the EPIC-26 for use with patients with early-stage localized prostate cancer under active surveillance

Trafford Crump, Jing Jang, Carly Barton, Eric Hyndman, Jason Sutherland

Objectives Active surveillance is increasingly being used as a treatment option for men diagnosed with early-stage localized prostate cancer. Current recommendations support use of the EPIC-26 as a patient-reported outcome instrument for measuring quality of life in patients under active surveillance. However, the EPIC-26 instrument has not been validated for use in such patients. The objective of this study was to test the psychometric performance of the EPIC-26 in patients diagnosed with localized prostate cancer under active surveillance.
Methods This is a retrospective analysis of data collected prospectively as part of the Alberta Prostate Cancer Research Initiative. Participants completed the EPIC-26 12 months after initial diagnosis. The EPIC-26 consists of 26 items, 25 of which are used to calculate 5 domains: urinary incontinence, urinary irritative/obstructive, bowel habits, sexual function, and hormonal function. Floor and ceiling effects for each domain are measured. A confirmatory factor analysis model is used to examine each of the 5 domains and how their respective items load onto them. A gradient response model is used to estimate each item's difficulty and discrimination parameters.
Results Of 498 patients under active surveillance, 253 had completed the EPIC-26. Large ceiling effects were observed across all domains excepting sexual function. No floor effects were observed. The confirmatory factor analysis confirmed items loading on domains (that is, >0.4) on their respective domains, with a few exceptions under the urinary incontinence and urinary irritative/obstructive domains. Stronger difficulty and discrimination performance were observed in the sexual function domain. Most other items performed poorly based on the gradient response model.
Conclusions Responses to the EPIC-26 demonstrate poor psychometric properties. In general, the instrument suffers from large ceiling effects, poor discriminability, and poor response difficulty. Use of the EPIC-26 with patients under active surveillance for prostate cancer should be reconsidered.

Affiliations: University of Calgary, Calgary, AB.

Patient experience in radiation oncology

Demetra Yannitsos

Introduction Understanding the patient experience is essential to providing high-quality, person-centred care. A real-time cross-sectional patient experience study is in progress at the Tom Baker Cancer Centre (TBCC) radiation oncology (RO) department. The purpose of this study is to identify gaps in patient experience and service delivery that can be targeted for quality improvement (QI). This study is part of PROSE (Person-centred Radiation Oncology Service Enhancement), a QI initiative specific to the TBCC RO department.
Methods Patient experience data are collected using Your Voice Matters. This survey captures information about the patient's last appointment, including arrival to the clinic, interactions with staff and care providers, departure, and overall experience. Recruitment began May 2019 and will continue until a sample of 400 is reached. Patients are approached in the radiation department waiting areas. Patients are recruited to complete the survey in reference to their initial consultation or previous treatment appointment. We aim to obtain a representative sample across cancer groups by appointment type.
Results To date, 134 initial consultation patients have been recruited. Most patients (78%) report a very good or excellent overall experience. Areas for improvement include contacting the clinic, wait times, and missing information about next steps. Patients who contacted the clinic report the methods or options available for contacting the clinic as good (38%) or

fair/poor (24%). After checking in with reception, 52% of patients waited past their scheduled appointment time. Of the patients who reported leaving their appointment missing information, 65% did not know their next appointment time. Other missing information included test results, referrals, long-term side effects, radiation process, and prognosis.

Significance This study will allow the TBCC RO team to effectively direct QI work aimed at improving the patient experience. Pilot projects will be developed by frontline providers and researchers. Evaluation of projects will determine their impact and integration into routine care.

Affiliation: University of Calgary, Calgary, AB.

The Value Impact in PROs Research

Development and psychometric evaluation of the Cancer Distress Scales for Adolescents and Young Adults

Elena Tsangaris,* Norma D'Agostino,† Charlene Rae,‡ Vicky Breakey,‡ Anne F. Klassen‡

Purpose The use of valid and reliable screening tools to measure distress can help to identify adolescents and young adults (AYAs) with cancer who need additional support. Our study describes a 2-phase approach to adapt the Australian AYA oncology and survivorship distress screening tools for use in Canada.
Methods Phase 1 involved using cognitive interviews with AYAs with cancer and feedback from experts to refine the Australian AYA oncology and survivorship screening tools. In phase 2, a field test was performed, and Rasch measurement theory analysis was used for item reduction and to examine reliability and validity.
Results Cognitive interviews with 45 AYAs with cancer and feedback from 25 experts resulted in a field-test version of the Cancer Distress Scales for Adolescents and Young Adults (CDS-AYA) consisting of 91 items that measure 9 constructs. The field-test sample included 515 participants. Rasch measurement theory analysis identified 5 scales (impact of cancer, physical, emotional, cancer worry, and cognitive) with ordered thresholds, good item fit (–3.70 to 2.82), and acceptable reliability (0.78 to 0.88). Reliability for the remaining 4 scales (employment, education, practical, and social) was low; those scales were retained as checklists, with the exception of the social scale, which was dropped.
Conclusions The final item-reduced CDS-AYA consists of 48 items in 5 scales, with 2 standalone items in the physical and emotional scales, and 23 items in 3 checklists. The CDS-AYA can be used in research and in clinical practice to measure distress in AYAs with cancer.

Affiliations: *Department of Pediatrics, McMaster University, Hamilton, ON; †Department of Supportive Care, Princess Margaret Cancer Centre, Toronto, ON; ‡Department of Pediatrics, McMaster University, Hamilton, ON.

Best Oral Abstract:
Patient-reported symptoms after mastectomy alone or lumpectomy plus radiation for early-stage breast cancer: a cohort study

Laura E. Davis,* Courtney Fulton,† Lev D. Bubis,† Jonathan Sussman,‡§ Lesley Moody,‡ Lisa Barbera,‖ Qing Li,# Alyson L. Mahar,** Natalie G. Coburn,†‡#††‡‡[a] Claire M.B. Holloway‡ ‡‡[a]

Background Studies examining symptom differences between surgeries for patients with breast cancer rarely incorporate the effects of adjuvant treatment choice. We sought to understand differences in patient-reported symptoms between lumpectomy plus radiation and mastectomy in the year after surgery.
Methods This cohort study used linked administrative datasets. The exposure was defined as lumpectomy plus radiation or mastectomy. The outcomes of moderate-to-severe (score ≥ 4) patient-reported symptoms were obtained using the Edmonton Symptom Assessment System (ESAS). Line plots were created to determine symptom trajectories in the 12 months after surgery, and multivariable analyses were used to assess the relationships between surgery and each of the 9 symptoms. Clinical significance was determined as a difference of 10%.
Results Of 13,865 stage I–II patients diagnosed with breast cancer during 2007–2015, 11,497 underwent lumpectomy plus radiation and 2368 underwent mastectomy. Symptom trajectories were similar for all 9 symptoms until approximately 5 months postoperatively, when the trajectories diverged, and mastectomy symptoms started becoming more severe. On multivariable analysis, patients undergoing mastectomy, compared with those undergoing lumpectomy plus radiation, were at an increased risk of reporting moderate-to-severe depression [relative risk (RR): 1.19; 95% confidence interval (CI): 1.09 to 1.30], lack of appetite (RR: 1.11; 95% CI: 1.03 to 1.20), and shortness of breath (RR: 1.16; 95% CI: 1.04 to 1.15).
Conclusions Even with the addition of adjuvant radiation, patients who are treated with lumpectomy fare better in 3 of 9 patient-reported symptoms. Further examination of those differences will assist in better shared decision-making regarding surgical treatments.

[a] NGC and CMBH share senior authorship of this work.

Affiliations: *Evaluative Clinical Sciences, Sunnybrook Research Institute, Toronto, ON; †Division of General Surgery, Department of Surgery, University of Toronto, Toronto, ON; ‡Ontario Health (Cancer Care Ontario), Toronto, ON; §Department of Oncology, McMaster University, Hamilton, ON; ‖Division of Radiation Oncology, University of Calgary, Calgary, AB; #ICES, Toronto, ON; **Department of Community Health Sciences, University of Manitoba, Winnipeg, MB; ††Institute for Health Policy, Management and Evaluation, University of Toronto, Toronto, ON; ‡‡Division of General Surgery, Sunnybrook Health Sciences Centre, Toronto, ON.

Baseline prevalence of Edmonton Symptom Assessment System scores in the general population of Ontario, Canada

Victoria Delibasic,* Laura E. Davis,* Natalie G. Coburn*†

Background In 2007, Ontario Health (Cancer Care Ontario) implemented real-time collection of patient-reported symptoms using the Edmonton Symptom Assessment System (ESAS) across all regional cancer centres in Ontario. ESAS data are collected for cancer patients, and references for moderate and severe symptom scores are validated; however, there is no baseline measure of comparison to determine if ESAS scores in the cancer population are significantly different from those in the general population.
Methods We performed an online cross-sectional survey of the Ontario Health (Cancer Care Ontario) ESAS questionnaire to the general Ontario population in March 2019. The survey was linked to administrative databases for all cancer patients diagnosed between January 2007 and December 2014 who reported an ESAS assessment in months 1 and 2 after diagnosis. Moderate-to-severe (>4) ESAS scores in the general population and in the cancer population at months 1 and 6 after diagnosis were compared using numbers, proportions, and chi-square tests for differences. Symptoms were also stratified by age.
Results 3000 Participants from the general population and 9390 cancer patients were included. Moderate-to-severe symptom scores were higher in the general population than in the cancer population for tiredness (58.87% vs. 44% at month 1 and 39% at month 6), depression (36.17% vs. 23% at month 1 and 18% at month 6), and pain (34.6% vs. 26% at month 1 and 19% at month 6). After stratifying symptoms by age, symptom burden in the general population decreased with age, resulting in scores comparable to those in the cancer population.
Conclusions When compared with the cancer population, the general population in Ontario reports higher symptoms despite the time of ESAS evaluation after a cancer diagnosis. The perception of symptom burden might change with disease and varies between individuals, suggesting that alternative measurements of severity for symptoms should be considered, such as measuring increase of ESAS scores within individual patients.

Affiliations: *Evaluative Clinical Sciences, Sunnybrook Research Institute, Toronto, ON; †Division of General Surgery, Department of Surgery, University of Toronto, Toronto, ON.

Symptom burden of non-resected pancreatic adenocarcinoma: an analysis of 10,753 patient-reported outcome assessments

Michail N. Mavros,*† Laura E. Davis,‡ Julie Hallet,*†‡§ Stephanie Tung,* Alyson L. Mahar,‖ Lev D. Bubis,* Ahmed Hammad,# Haoyu Zhao,§ Craig C. Earle,‡§** Lisa Barbera,‡§†† Natalie G. Coburn*†‡§‡‡

Background Pancreatic adenocarcinoma (PAC) is a debilitating disease. Using a population-based screening system, we analyzed symptom burden and trajectories after a diagnosis of PAC and identified factors associated with high symptom burden for patients not undergoing resection.
Methods Retrospective cohort study of linked administrative health care databases examining patients with PAC not undergoing resection and reporting at least 1 Edmonton Symptom Assessment System (ESAS) score in the 6 months after diagnosis. Primary outcome was severe patient-reported symptoms (ESAS ≥ 7). Prevalence of severe symptoms was described in 2-week intervals from diagnosis for each symptom. Multivariable modified Poisson regression models were used to identify factors associated with reporting severe symptoms.
Results A total of 10,753 symptom assessments from 2168 patients were analyzed. The median age was 67 years, and 47% were female; median survival was 7 months (25% to 75% interquartile range: 4–12 months). Most common severe symptoms were tiredness (54.7%), anorexia (53.6%),

overall impaired well-being (45.3%), and drowsiness (37.1%). Severity of symptoms decreased 1 month after diagnosis and plateaued 4 months after diagnosis. Female sex, comorbidities, and older age were associated with reporting severe symptoms; recent radiation treatment and residence in a rural community were associated with reporting less severe symptoms.
Conclusions The prevalence of severe symptoms in patients with non-resected PAC was high, but potentially modifiable. We identified vulnerable groups of patients that might benefit from focused interventions. This information is important for patient counselling and design of supportive care strategies.

Affiliations: *Division of General Surgery, University of Toronto, Toronto, ON; †Division of General Surgery, Odette Cancer Centre, Sunnybrook Health Sciences Centre, Toronto, ON; ‡Sunnybrook Research Institute, Sunnybrook Health Sciences Centre, Toronto, ON; §ICES, Toronto, ON; ‖Department of Community Health Sciences, University of Manitoba, Winnipeg, MB; #Department of General Surgery, Mansoura University, Mansoura, Egypt; **Division of Medical Oncology, Department of Medicine, University of Toronto, Toronto, ON; ††Division of Radiation Oncology, University of Calgary, Calgary, AB; ‡‡Institute of Health Policy, Management and Evaluation, University of Toronto, Toronto, ON.

Symptom burden among patients with head-and-neck cancer in the first year after diagnosis: association with primary treatment modality

Catherine O. Allen-Ayodabo,*† Antoine Eskander,*†‡§ Laura E. Davis,* Haoyu Zhao,† Alyson L. Mahar,‖ Irene Karam,# Simron Singh,*†**††‡‡ Vaibhav Gupta,†‡§§ Lev D. Bubis,§§ Lesley Moody,†††‡ Lisa Barbera,†**‖‖ Natalie G. Coburn†‡†††‡‡

Purpose Head-and-neck cancer (HNC) and its treatment significantly affects quality of life, with a very high symptom burden. In 2007, Ontario Health (Cancer Care Ontario) initiated routine collection of Edmonton Symptom Assessment System (ESAS) scores in cancer outpatient clinics. The main objectives of our study were to examine symptom trajectories in HNC patients by treatment and to identify factors associated with high ESAS scores.
Methods We used linked health administrative databases to conduct a retrospective cohort study of patients diagnosed with HNC in Ontario, Canada, from 2007 to 2015. The primary outcome was a monthly patient self-reported moderate-to-severe (≥4) symptom score in the year after diagnosis. Multivariable modified Poisson regression analyses with robust variance were used to investigate factors associated with moderate-to-severe scores.
Results Of 13,827 patients with HNC identified, 4793 had a 1 or more ESAS assessments within 12 months of cancer diagnosis. Overall, 60% ($n = 2708$) and 65% ($n = 2903$) of patients respectively reported moderate-to-severe pain and poor appetite. The proportion of patients reporting a score of 4 or greater increased significantly during treatment and was most pronounced for those who received chemoradiation. On multivariable analysis, patients who were female [relative risk (RR): 1.15; 95% confidence interval (CI): 1.08 to 1.23], received chemoradiation, had a higher comorbidity burden (RR: 1.31; 95% CI: 1.23 to 1.39), and had a diagnosis of oropharyngeal (RR: 1.10; 95% CI: 1.02 to 1.19) or oral cavity cancer (RR: 1.31; 95% CI: 1.19 to 1.45) were at increased risk of reporting severe pain scores (all $p < 0.01$).
Conclusions Most patients with HNC report high pain scores, with a symptom burden that is highest during the treatment phase—especially for patients who receive radiation or chemoradiation. This large study highlights the need for proactive symptom management during the cancer journey for patients with HNC.

Affiliations: *Sunnybrook Research Institute, Sunnybrook Health Sciences Centre, Toronto, ON; †ICES, Toronto, ON; ‡Surgical Oncology, Odette Cancer Centre, Sunnybrook Health Sciences Centre, Toronto, ON; §Department of Otolaryngology–Head and Neck Surgery, Sunnybrook Health Sciences Centre, Toronto, ON; ‖Department of Community Health Sciences, University of Manitoba, Winnipeg, ON; #Department of Radiation Oncology, University of Toronto, Toronto, ON; **Medical Oncology, Odette Cancer Centre, Sunnybrook Health Sciences Centre, Toronto, ON; ††Institute of Health Policy, Management and Evaluation, University of Toronto, Toronto, ON; ‡‡Ontario Health (Cancer Care Ontario), Toronto, ON; §§Division of General Surgery, Department of Surgery, University of Toronto, Toronto, ON; ‖‖Division of Radiation Oncology, Department of Oncology, Tom Baker Cancer Centre, University of Calgary, Calgary, AB.

Prospective Outcomes and Support Initiative for gynecologic and head-and-neck radiotherapy patients in British Columbia: patient completion and clinician use

Regina Tam, Clem Ho

Background In British Columbia, patient-reported outcomes (PROs) are collected in radiation oncology through the Prospective Outcomes and Support Initiative (POSI). PROs have been shown to increase clinician and patient awareness of symptoms and to allow for more effective care. This project focuses on POSI questionnaires completed by radiotherapy patients with gynecologic and head-and-neck cancers, and aims to identify

- the proportion of POSI questionnaires completed by eligible patients,
- the frequency of PRO use and how PROs are used by various disciplines, and
- the barriers or facilitators to PRO use.

Methods The proportion of completed POSI questionnaires was assessed by retrospectively comparing completed questionnaires recorded in the POSI database with the number of eligible radiotherapy patients registered in BC Cancer's Information System. A 6-month period (January to June 2018) was reviewed.

To assess the use of PROs by clinicians, an online survey was created, and clinicians were invited to participate over an 8-week period. The survey consisted of open- and close-ended questions exploring clinician experiences with PRO; the frequency, purpose and benefits, and barriers and facilitators of PRO use; and suggestions for improvement.
Results The analysis of results is under way and will be available by the end of July 2019. The results of, and potential correlations between, clinician use of PROs and patient participation in POSI will inform gaps and improvement opportunities with POSI delivery and PRO use at British Columbia's 6 regional cancer centres. Consequently, the analysis will aid in developing strategies to optimize workflows and increase PRO completion and use.
Conclusions This project evaluates the POSI PROs program in British Columbia and provides recommendations to improve PROs collection and use. The results are not only important for PROs program expansion in British Columbia, but the lessons learned can be applied to other cancer centres.

Affiliation: BC Cancer–Surrey Centre, Surrey, BC.

The Value Impact in PROs to Administration and Health Policy

Using machine learning to predict the patient-reported outcomes of patients with prostate cancer

Fatemeh Sharifi, Trafford Crump, Emad Mohammed, Behrouz Far

Introduction Adding patient-reported outcomes (PROs) data to clinical information might help to personalize health care delivery. To achieve that goal, we must first understand how the combined data should be analyzed. Machine learning approaches might offer a solution. In this study, we evaluated machine learning models to predict posttreatment PROs for men diagnosed with localized prostate cancer.
Methods This study is based on a secondary analysis of data collected from participants enrolled in the Alberta Prostate Cancer Research Initiative from 2014 to 2019. The dataset comprised 5093 patients with 1592 dependent and independent variables. Variables were collected at the time of prostate cancer diagnosis and at the 12-month follow-up. The outcomes of interest were the predicted values of the EPIC-26's 5 domains (that is, urinary incontinence, urinary irritative/obstructive, bowel habits, sexual function, and hormonal function) at the 12-month follow-up.

We reduced the number of variables to identify those that were influential in predicting the EPIC-26 domain values. To that end, we trained and tested a deep neural network to extract important variables in groups with the same patients whom we already formed with a clustering algorithm. The performance of extracted variables was evaluated by a prediction model using the variables from time of diagnosis to predict EPIC-26 domain values at the 12-month follow-up.
Results The models identified the variables collected at the time of diagnosis with the highest possible prediction power for each of the 5 EPIC-26 domains. The models predicted the 12-month follow-up EPIC-26 domain values with R^2s of 0.52 (urinary incontinence), 0.75 (urinary irritative/obstructive), 0.71 (bowel habits), 0.74 (sexual function), and 0.62 (hormonal function).
Conclusions The results from this study demonstrate that machine learning methods can be used to predict posttreatment PROs in localized prostate cancer. The resulting models could be used to help inform patients about their risks for negative side effects.

Affiliations: University of Calgary, Calgary, AB.

A pan-Canadian approach to the collection and use of patient reported outcomes in radiation oncology: an initiative of the Canadian Partnership for Quality Radiotherapy

Lisa Barbera,* Erica Brown,† Jennifer O'Donnell,‡ Louise Bird,† Amanda Caissie,§ Carol-Anne Davis,‖ Mike Milosevic,# Robert Olson,** Michael Brundage‡

Background The Canadian Partnership for Quality Radiotherapy (CPQR) supports integration of patient-reported outcomes (PROs) into radiotherapy

clinical practice and launched a pan-Canadian initiative in 2017 promoting local uptake and pan-Canadian learning and knowledge mobilization.

To determine the current landscape of PROs across Canada, an environmental scan was conducted (July to November 2018) with members of radiation oncology programs by semi-structured interviews. Findings included an inventory of PRO measures and implementation barriers and facilitators. Centres expressed a desire to receive guidance on the use of PROs in radiotherapy, prompting development of the document *Patient Reported Outcome Guidance for Canadian Radiation Treatment Programs* and partnership with the multidisciplinary PROs Advisory Committee (PROSAC) at Ontario Health (Cancer Care Ontario) to recommend measures (PROMs) to use.

Methods Candidate guidance statements were drafted based on interview findings and the Delphi method was used to gather feedback from the CPQR PRO Working Group and interviewees to validate the statements. Statements will be incorporated into the document.

PROSAC has established a process to select and evaluate PROMs for their symptom coverage, usability, and psychometrics. This process has been applied to head-and-neck measures and will be used to select other measures over time.

Results Broadly, the guidance statements capture the importance of PROs in clinical practice, PRO selection, target populations, PRO completion, PRO interpretation, timing, follow-up, confidentiality and the evaluation of PROs locally.

CPQR/PROSAC endorsed the MDASI-HN as a measure for head-and-neck cancer. That PROM is currently being used in 4 provinces (BC, ON, NS, NB).

Significance A pan-Canadian approach to PRO collection and use is supported by programs across Canada, facilitating a PRO program that can improve patient care. CPQR endorsed the development of a PRO guidance document that will inform implementation in radiotherapy programs, and will continue to endorse specific measures by tumour types commonly treated with radiotherapy.

Affiliations: *Tom Baker Cancer Centre, Calgary, AB; †Canadian Partnership for Quality Radiotherapy, Calgary, AB; ‡Queen's University, Kingston, ON; §Saint John Regional Hospital, Saint John, NB; ||Nova Scotia Cancer Centre, Halifax, NS; #Princess Margaret Cancer Centre, Toronto, ON; **BC Cancer, Prince George, BC.

Severe symptoms persist for up to 1 year after diagnosis of stage I–III lung cancer: an analysis of province-wide patient-reported outcomes

Dhruvin H. Hirpara,* Vaibhav Gupta,† Haoyu Zhao,† Laura E. Davis,‡ Alyson L. Mahar,§ Rinku Sutradhar,*† Biniam Kidane,|| Gail E. Darling,* Natalie G. Coburn*†

Background Lung cancer (LC) is associated with significant disease- and treatment-related morbidity. We used the Edmonton Symptom Assessment System (ESAS) to examine symptom severity in the 12 months after initial diagnosis of stage I–III LC and to identify predictors of high symptom burden.

Methods This retrospective cohort study included adults diagnosed with stage I–III LC between 2007 and 2016 who had symptom screening within 12 months after diagnosis. ESAS scores were linked to administrative datasets in Ontario, Canada. The proportion of patients experiencing severe symptoms (ESAS ≥ 7) in the year after diagnosis were plotted over time. A modified Poisson regression model was used to identify factors associated with severe symptoms.

Results The study included 69,440 unique symptoms assessments from 11,075 patients with LC. Tiredness was the most prevalent severe symptom (47% reported at least 1 severe score), followed by shortness of breath (40%), for all disease stages. The third most prevalent severe symptom was impaired well-being in patients with stage I (26%) and stage II (34%) disease, and lack of appetite in patients with stage III disease (44%). Severe anxiety and depression were reported by 30% and 20% of patients respectively. The most common predictors of severe symptom scores included younger age, female sex, high comorbidity burden, stage III disease, and urban residence. Symptom trajectories varied in the year after the LC diagnosis. The odds of experiencing severe anxiety and depression decreased over time. Physical symptoms, including tiredness, dyspnea, nausea, drowsiness, and pain did not appear to improve with time, even in patients with stage I disease.

Conclusions LC affects important aspects of physical and mental well-being in the first year after diagnosis. Severe physical symptoms persist during that time, when curative-intent therapy is provided. Those at risk of experiencing a high symptom burden might benefit from targeted supportive care interventions alongside conventional treatment, aimed at improving health-related quality of life.

Affiliations: *University of Toronto, Toronto, ON; †ICES, Toronto, ON; ‡Sunnybrook Research Institute, Toronto, ON; §University of Manitoba, Winnipeg, MB; ||Health Sciences Centre, Winnipeg, MB.

Remote monitoring of treatment toxicities using the Advanced Symptom Monitoring and Management System–Canada: a feasibility study

Doris Howell,* Saeed Moradian,† Eitan Amir,* Vishel Kukretti,* Roma Maguire,‡ Geoff Liu,* Joseph Cafazzo,* Plinio Morita,§ Jackie Bender,* Lisa Le,* Amna Husain,|| Martine M. Puts,† Monica Krzyzanowska*

Background Cancer patients experience distressing treatment toxicities resulting in high rates of emergency department (ED) use. Remote monitoring of patient-reported outcomes (PROs) can improve quality of life and survival, and reduces ED visits when clinicians are prompted to intervene in "real time" through alerting systems. However, there are no trials using a similar mobile phone system in the Canadian cancer context. In this paper, we provide an overview of the Advanced Symptom Monitoring and Management System–Canada (ASyMS-Can) mobile system and its feasibility.

Methods We conducted a prospective open-label randomized controlled feasibility trial of the ASyMS-Can in patients with breast cancer and lymphoma during systemic chemo/immunotherapy compared with usual-care control subjects. In addition to feasibility metrics as the primary aim, data analysis included group comparisons using *t*-tests and mixed models over time on secondary outcomes of symptom distress, quality of life, and ED visits. Qualitative interviews were also conducted to assess acceptability of the technology.

Results We recruited 82 patients during 14 months at the Princess Margaret Cancer Centre. Adherence to daily PRO reporting was 65%, and the mean number of alerts per patient was 14 during a treatment cycle. Results are pending for the secondary outcomes. Patients valued the continued "connection to their cancer team" and felt "secure and safe" that their symptoms were being monitored and that "tailored advice" was received from nurses when symptom thresholds were exceeded.

Conclusions Remote monitoring of PROs during active treatment can enable "real time" precision symptom care and shifts care from reactive to proactive care.

Affiliations: *Princess Margaret Cancer Centre, Toronto, ON; †University of Toronto, Toronto, ON; ‡University of Strathclyde, Glasgow, U.K.; §University of Waterloo, Waterloo, ON; ||Mount Sinai Hospital, Toronto, ON.

Symptoms in the last 6 months of life for patients with esophageal cancer: an analysis of patient-reported outcomes

Vaibhav Gupta, Catherine O. Allen-Ayodabo, Laura E. Davis, Haoyu Zhao, Biniam Kidane, Alyson L. Mahar, Jolie Ringash, Gail E. Darling, Natalie G. Coburn

Background Esophageal cancer symptoms are debilitating, particularly in the palliative phase of care. This study used the Edmonton Symptom Assessment System (ESAS) to describe symptom trajectories and predictors of severe symptoms for patients with esophageal cancer at the end of life.

Methods This retrospective cohort study used linked administrative data from Ontario. Patients with esophageal cancer diagnosed between 2009 and 2016 and treated at a regional cancer centre, who had at least 1 ESAS assessment and who died during the study period, were included. The outcome was defined as moderate-to-severe (≥4) and severe (≥7) ESAS scores in the last 6 months of life. Modified Poisson regression analyses were used to identify predictors of 4 or greater and 7 or greater symptom scores.

Results 2668 Patients reported a median of 3 ESAS assessments (25% to 75% interquartile range: 1–6 assessments). Lack of appetite ($n = 2116$, 79%), poor well-being ($n = 2153$, 81%), and tiredness ($n = 2251$, 84%) were the most prevalent moderate-to-severe symptoms, reported by 80%–85% of patients. More than half the patients reported severe scores for tiredness ($n = 1497$, 56%) and lack of appetite ($n = 1514$, 57%). Plotting symptom trajectories from 6 months before death showed an increasing severe symptom burden for all symptoms in the last 10 weeks of life, with tiredness, lack of appetite, poor well-being, and drowsiness worsening the most. Proximity to death was most strongly associated with reporting severe symptoms [relative risk (RR): 1.68–3.09; $p < 0.001$]. Treatment modality was the only baseline characteristic that predicted high ESAS scores for most symptoms, with chemotherapy only, radiotherapy only, and chemoradiotherapy showing associations with increased risk of severe symptoms compared with no treatment ($p < 0.05$).

Conclusions Patients with esophageal cancer experience significant symptom burden toward the end of life. Tiredness and lack of appetite are the most prevalent severe symptoms. Palliative treatments are associated with reports of severe symptoms. Future work should explore how palliative care interventions affect symptom scores toward the end of life.

Affiliation: Sunnybrook Health Sciences Centre, Toronto, ON.

Exploring routine patient-reported outcomes in oncology: using a symptom complexity score to identify a personalized dose of care

Linda Watson

Introduction Research on symptom complexity in cancer patients is limited, and there is no standardized classification to measure it. This study

proposes a new symptom complexity algorithm, derived from validated and standardized PRO measures, to classify symptom complexity at an individual level. The paper further explores the association between sociodemographic and clinical characteristics and symptom complexity level.

Methods 520 Patients with cancer were randomly selected from those who visited the Tom Baker Cancer Centre from October 2018 to November 2018. A symptom complexity algorithm was developed to classify those patients based on the severity of the symptom scores and the problems or concerns reported. The sociodemographic and disease-related information was stratified by the assigned complexity level and reported through measures of frequencies, percentages, central value, and dispersion. Ordinal logistic regression was applied to identify the predictability of those variables on the symptom complexity level.

Results Of the 520 patients with cancer, 177 were excluded because of incomplete data. Of the 343 patients included, 62 were classified as high complexity (18.1%), 68 as medium complexity (19.8%), and 213 as low complexity (62.1%). Multiple ordinal logistic regression analysis revealed that the predictors of symptom complexity level included employment status, cancer type, and cancer stage. Age, sex, and marital status were found not to be associated with symptom complexity level in patients.

Conclusions This study makes a unique contribution to the literature by proposing a new classification algorithm to classify complexity levels in cancer patients, enabling the clinician to tailor care and resources to the patient's needs. Sociodemographic and disease-specific factors significantly contributed to the assigned symptom complexity level, and clinicians consider those factors when assessing and assigning medical resources for patients with a newly diagnosed cancer.

Affiliation: Alberta Health Services, Edmonton, AB.

The PROs Value Impact to Clinical Implementation

The value of PROs in a multidisciplinary oncology sexual health care clinic in Calgary, Alberta: the Oncology and Sexuality, Intimacy and Survivorship clinic

Carly S. Sears,* Lauren M. Walker,*† Reanne Booker,* Roanne D. Millman,*† Sarah Glaze,*† Corinne Doll,*† Tien Phan,*† Kerrie Brennan,* John W. Robinson*†

Background Cancer-related sexual health concerns are highly prevalent across all cancer types. Those concerns significantly affect quality of life for patients and their partners. To appropriately address the complex and under-assessed sexual health needs of Alberta patients with cancer, a specialized multidisciplinary oncology sexual health clinic was developed and piloted within a tertiary cancer care facility. The purpose of the present study was to use PROs to determine baseline and post-intervention measures of sexual distress, mood, and relationship functioning, and physical symptom scores for patients evaluated in this multidisciplinary care model.

Methods Questionnaires were administered during each initial and follow-up clinic appointment to assess sexual distress (FSDS-R), mood (HADS), relationship functioning (RDAS), vaginal symptoms, and erectile functioning (IIEF). Information about demographics and use of symptom-management strategies was also collected. Follow-up telephone interviews were conducted approximately 3 months after the initial clinic visits by the patients.

Results Over the 2-year pilot, 224 patients were referred to the program, resulting in 79 new and 58 follow-up appointments. The most frequently reported concerns on the part of patients included vulvovaginal symptoms, painful intercourse, lack of desire, and erectile dysfunction. According to baseline responses on the FSDS-R and IIEF respectively, 89.6% of patients reported levels of sexual distress above the clinical cut-off at the time of their initial clinic visit ($n = 77$, M = 29.48, SD = 13.17), and 72.2% of men reported moderately severe to severe erectile dysfunction ($n = 18$, M = 12.22, SD = 8.77). A significant reduction in sexual distress was observed by the 3-month follow-up, $t_{(61)} = 7.16$ ($p < 0.001$).

Conclusions PROs were an efficient and effective way to assess patients with cancer-related sexual health concerns and to monitor their progress over time by comparing baseline with post-intervention measures. Additionally, PROs were valuable in building a compelling argument for the continued support of this multidisciplinary specialized clinic.

Affiliations: *Tom Baker Cancer Centre, Calgary, AB; †University of Calgary, Calgary, AB.

Best Oral Abstract:
Pilot implementation of a cervix cancer–specific patient-reported outcome measure in gynecologic oncology clinics

Soha Atallah,*† Lisa Barbera,*‡ Matthew Folwell,*§ Doris Howell,†‖ Zhihui Amy Liu,#** Jennifer Croke*†

Purpose Incorporation of patient-reported outcome measures (PROMs) positively affects clinical outcomes. Data pertaining to the implementation of disease-specific PROMs is limited. Our objective was to evaluate implementation of a validated cervix cancer–specific PROM, the European Organisation for Research and Treatment of Cancer Quality-of-Life questionnaire–cervical cancer module (EORTC QLQ-CX24), into gynecologic oncology clinics.

Methods This was a prospective, multi-institutional pilot study involving 3 cancer centres. Eligible patients with cervix cancer were recruited from gynecologic oncology follow-up clinics. Patients completed the EORTC QLQ-CX24 before their clinical assessment and then reviewed it with their oncologist. A 19-item feedback questionnaire was used to evaluate the patient experience after the clinical encounter. A 12-item feedback questionnaire was used to evaluate the oncologist experience at the end of the study period. Descriptive statistics were used to summarize the results.

Results Between January 2017 and August 2018, 112 patients were approached, and 84 (75%) consented to participate. Of the 84 patients, 80 (95.2%) completed the EORTC QLQ-CX24, and 76 (90.4%) completed the feedback questionnaire. Median age was 54 years (range: 29–82 years). Item completion rates for the EORTC QLQ-CX24 were high overall (>90%), except for items pertaining to sexual activity (34%–35%). Regarding the feedback questionnaire, most patients (86%) agreed that "The questionnaire helped me remember issues when I met with my doctor," and 80% recommended continued use of the questionnaire. All eligible oncologists ($n = 9$) participated and completed the feedback questionnaire. All oncologists (100%) agreed that the EORTC QLQ-CX24 helped to identify areas of need; however, most (78%) believed that its use increased clinic visit length. Most patients and oncologists preferred paper format to electronic (83% and 56% respectively).

Conclusions Implementation of a cervix cancer–specific PROM into gynecologic oncology clinics was demonstrated to be feasible and was positively endorsed by patients and oncologists alike.

Affiliations: *Department of Radiation Oncology, University of Toronto, Toronto, ON; †University Health Network, Princess Margaret Cancer Centre, Toronto, ON; ‡Sunnybrook Hospital, Odette Cancer Centre, Toronto, ON; §Royal Victoria Regional Health Centre, Barrie, ON; ‖Department of Psychosocial Oncology, University of Toronto, Toronto, ON; #Dalla Lana School of Public Health, University of Toronto, Toronto, ON; **Department of Biostatistics, Princess Margaret Cancer Centre, University Health Network, Toronto, ON.

Response and intervention to elevated ESAS scores: a chart audit of gynecologic oncology clinics

Soha Atallah,*† Jackie Bender,‡§ Tony Fyles,*† Kathy Han,*† Mike Milosevic,*† Sarah E. Ferguson,‖ Stephanie l'Heureux,# Zhihui Amy Liu,§** Jennifer Croke*†

Objective To evaluate health care professional (HCP) documentation of elevated Edmonton Symptom Assessment System revised version (ESAS-r) symptom scores and subsequent intervention in gynecologic oncology clinics.

Methods This was a retrospective chart review of gynecologic oncology patients within a single institution. The ESAS-r is a validated patient-reported outcome (PRO) tool that is completed by patients before a clinical encounter. Gynecologic oncology patients with any ESAS-r symptom score of 4 or greater (>mild) were eligible. A stratified sampling method was used: 100 patients were randomly selected (20 per year from 2012 to 2016). Patient, tumour, and treatment characteristics were collected. HCP documentation of ESAS-r symptoms of 4 or greater and subsequent interventions were assessed by 2 independent oncologists. Descriptive statistics were used to report symptom prevalence, HCP documented response, and intervention. The Fisher exact test was used to evaluate documentation and intervention rates according to symptom severity and total ESAS-r score.

Results Between January 2012 and December 2016, 5849 patients completed the ESAS-r. Symptom scores were rated as 4 or greater by 3216 patients (55%). In our sample of 100, ovarian (42%) and endometrial (34%) malignancies were the most common. Median age was 55 years (range: 47–63 years). Median ESAS-r score was 24 (range: 17–39). The most prevalent symptoms were tiredness (70%) and anxiety (61%). At least 1 symptom rated as 4 or greater was documented in 50 patients (50%), most commonly for pain (71%) and least commonly for nausea (4%). Interventions were offered to only 32 patients (32%), most commonly for pain (56%). Higher median total ESAS-r scores were associated with a higher rate of documentation ($p = 0.002$) and a higher rate of intervention ($p < 0.001$).

Conclusions A significant proportion of gynecologic oncology patients report elevated symptom scores that should prompt an intervention. However, HCPs document symptoms in only half the patients and offer interventions to only one third. Assessment of disease-specific PROs is ongoing.

Affiliations: *Department of Radiation Oncology, University of Toronto, Toronto, ON; †Radiation Medicine Program, University Health Network, and Department of Biostatistics, University Health Network, Toronto, ON; ‡ELLICSR Health, Wellness and Cancer Survivorship Centre, University Health Network, Toronto, ON; §Dalla Lana School of Public Health, University of Toronto, Toronto, ON; ‖Division of Gynecologic Oncology, Princess Margaret Cancer Centre, and Department of Obstetrics and Gynecology, University of Toronto, Toronto, ON; #Division of Medical Oncology and Hematology, Princess Margaret Cancer Centre, Toronto, ON; **Department of Biostatistics, Princess Margaret Cancer Centre, University Health Network, Toronto, ON.

Integrating digital patient-reported outcomes (PROs) into standard ambulatory care processes provincially: exploring the outcomes

Linda Watson

Background Many cancer patients struggle with physical, emotional, and practical concerns. Measuring those symptoms and overall quality of life through patient-reported outcomes (PROs) is an important facilitator of high-quality care. Although evidence that collecting PROs and using them as a part of standard practice improves outcomes and extends survival (Basch *et al.*, 2017), wide-scale integration of PROs as a standard component of ambulatory processes has been slow because of technologic and operational barriers (Wagle, 2016).
Methods In 2017, CancerControl Alberta developed a provincial PRO roadmap to guide the systematic clinical integration of the collection and use of digital PROs across its 17 ambulatory cancer care facilities. With a strong emphasis on change management, more than 20,000 cancer patients are now, every quarter, affected in some way by this new clinical process.
Impact on Practice Because simply having electronic PRO reporting does not translate into improved outcomes for patients or new clinical efficiencies, the primary focus of this work has been to ensure that PRO outputs are reviewed as a meaningful part of clinical processes. This has resulted in improvements in patient experience, clinical outcomes, and clinical efficiencies.
Discussion In this presentation, the PRO tools developed will be shared, and the discussion will revolve around the impact the use of these digital products has had on patient–provider communication, interdisciplinary care, earlier responsiveness to patient symptoms and concerns, and the evolution of new models of care delivery.

Affiliation: Alberta Health Services, Edmonton, AB.

Suicide risk screening and completed suicides in patients at a comprehensive cancer centre

Bryan Gascon,* Yvonne Leung,†‡ Osvaldo Espin-Garcia,§ Gary Rodin,*‡ Dominic Chu,* Madeline Li*‡

Background Suicide rates are 2–3 times higher in cancer patients than in the general population, but whether suicide risk screening prevents suicide is unknown. We report here on the association between completion of a suicide risk screening tool and suicide outcomes in a large heterogeneous cohort of cancer patients.
Methods Sociodemographic and suicide data were extracted from hospital and provincial cancer registries for patients attending Princess Margaret Cancer Centre between 2005 and 2013. Completion of the Distress Assessment and Response Tool (DART), which includes a suicidal intention (SI) item, age, sex, income estimates, marital status, and cancer type and stage were incorporated into propensity score analyses to estimate the hazard ratio for suicide. Chart audits were conducted to characterize clinician response to suicidality.
Results In 78,650 cancer patients, DART non-completion ($n = 64,133$) compared with DART completion was associated with a higher risk of suicide (inverse-probability treatment-weighting hazard ratio: 14.18; stratification by propensity-score hazard ratio: 7.60; $n = 14,517$). Among individuals who had suicided, only 4 of 89 completed the DART; none reported SI. Among DART completers, 0.5% reported SI, but clinician suicide assessment occurred in only 17.4% of those with SI; none committed suicide. DART completers had more psychiatry visits (11.1% vs. 4.6%), psychology visits (1.3% vs. 0.4%), and social work referrals (25.6% vs. 16.5%), all $p < 0.001$.
Conclusions Compared with non-completion, completion of distress screening that includes a SI screen is associated with less suicide and receipt of more psychosocial care. Non-completion, rather than report of SI, might identify a group at higher risk of suicide who might require more urgent clinical attention.

Affiliations: *Department of Supportive Care, Princess Margaret Cancer Centre, University Health Network, Toronto, ON; †de Souza Institute, University Health Network, Toronto, ON; ‡Department of Psychiatry, University of Toronto, Toronto, ON; §Department of Biostatistics, Princess Margaret Cancer Centre, University Health Network, Toronto, ON.

Integrating patient-reported outcomes in neuroendocrine tumour care: an assessment of cognitive and psychological screening tools during follow-up

Julie Hallet, Elie Isenberg-Grzeda, Jordana Kazdan, Kaitlyn A. Beyfuss, Sten D. Myrehaug, Simron Singh, David Chan, Calvin H.L. Law

An association between neuroendocrine tumours (NETS) and neuropsychological symptoms has been suggested, but objective data are limited. We aimed to use validated PROs to assess the burden of neuropsychological symptoms in NETS.

We conducted a prospective cohort study of adult patients with World Health Organization grades 1 and 2 bronchopulmonary and gastroenteropancreatic (GEP) NETs followed at a high-volume specialized multidisciplinary clinic. The Beck Depression Inventory (BDI-II), Functional Assessment of Cancer Treatment–Cognitive domain (FACT-Cog), and the EORTC GEPNET 21 were administered to patients. Patients were also asked about their preference for psychosocial support.

Of 80 patients, 27.5% had bronchopulmonary and 65.2% had GEP primary NETs. Metastases were present in 65% of patients, and 30% of the tumours were hormonally active (elevated 24-hour urinary 5-HIAA). No patients had an established cognitive or psychiatric diagnosis. Median time from NET diagnosis to PROs measure was 82 months [25% to 75% interquartile range–length (IQRL): 64.5–125]. Using the BDI-II, 16.3% of patients presented mood disturbances, 17.5% at or above the level of clinical borderline depression, and 8.8% at moderate-to-severe depression. FACT-Cog assessment revealed moderate perceived cognitive impairment [median: 61; 25% to 75% interquartile range (IQR): 50–68; possible range: 0–72] and considerable reduction in perceived cognitive ability (median: 5; IQR: 2–10; possible score: 0–28). On the EORTC GEPNET 21, social functioning was the most affected domain (median: 16.7; IQRL: 8.3–33.3). Gastrointestinal-, endocrine-, and treatment-related symptoms were mildly affected. Patient preference for psychosocial support (very likely or likely to use) was, for social work, 23.8%; for psychology services, 32.6%; for psychiatry services, 36.2%; and for patient support group, 36.3%.

Using validated PROs, 1 of 5 patients presented signs of clinical depression and showed impairment of perceived cognitive ability during the maintenance phase of care. Although symptoms appeared controlled, social functioning was affected. These results provide insight into the need to routinely screen patients with NET during follow-up to offer support and to improve patient-centred longitudinal care.

Affiliations: Sunnybrook Health Sciences Centre, Toronto, ON.