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Patient and caregiver experiences of advanced cancer care: a qualitative study

Sadia Ahmed, Farwa Naqvi, Aynharan Sinnarajah, Gwen McGhan, Maria Santana

Background Palliative care is an approach that improves quality of life for patients and families facing challenges associated with life-threatening illness. In Alberta, most people who received palliative care received it late. Late palliative care negatively affects patient and caregiver experiences and decreases quality of life. This study aims to understand patient and caregiver experiences of advanced colorectal cancer care to inform an early palliative care pathway for advanced cancer care.

Methods A qualitative study that is embedded within a larger program of research on the implementation of the Palliative Care Early and Systematic (PACES) pathway. Semi-structured telephone interviews with patients and their caregivers living with advanced colorectal cancer were conducted to explore their experiences with cancer care services received before pathway implementation. Interviews were transcribed, and the data were thematically analyzed, supported by the qualitative analysis software NVivo.

Results Interviews with 15 patients and 7 caregivers from Edmonton and Calgary were conducted over the telephone. Most participants found the Putting Patients First tool to be useful at their appointments; however, some mentioned a preference for viewing their scores over time. A total of 6 main themes were identified:

- Meaning of palliative care
- Communication (3 main subthemes: communication of diagnosis, communication between patient and oncologist, communication between providers)
- Relationship with health care providers (including oncologist, family doctor, and nurses)
- Access to care (cost of care, proximity to care, after hours care)
- Patient readiness for advance care planning
- Patient and family engagement in care, with mixed experiences in how patients were involved in their care

Conclusions Most participants misperceived palliative care to mean “end-of-life care,” suggesting a need for improvement in the delivery of palliative care information. Understanding the care experiences of patients and caregivers will inform the development of a care pathway for early palliative care.

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A multi-agent model for improving the collection and use of patient-reported outcomes

Mohammad Mehdi Afsar, Trafford Crump, Behrouz Far

Objective Health care providers wanting to collect patient-reported outcomes (PROs) face two main implementation challenges. The first is collecting PROs in a systematic manner, particularly when data collection extends beyond the clinical encounter. The second is incorporating PROs into the clinical encounter in such a way that it personalizes care and supports decisions. The objective of this study is to design and develop a system that addresses both of those challenges.

Methods We used a multi-agent system as the technology for collecting, analyzing, and reporting. The architecture of our system has 3 layers: data, analytics and decision making, and user interface. Each layer comprises several agents. The advantages of using this layered multi-agent system are threefold:

- It is extendible—features can be added or removed as necessary.
- It can be made intelligent—improved analysis of PRO data can be learned.
- It is flexible—users can input data and interact with the agent using a variety of methods.

Results A proof of concept, called ALAN, has been developed for use with patients diagnosed with prostate cancer. ALAN is a Web-based system, allowing it to be used on any Internet-connected device with a Web browser. ALAN collects data using several PRO instruments, including the Expanded Prostate Index Composite-26. To develop the analytics and decision-making layer, we leveraged data collected as part of the Alberta Prostate Cancer Research Initiative. Based on those data, we developed algorithms to predict posttreatment quality of life. The results from the prediction models are graphically displayed to the patients using type, touch, or a voice-activated interactive agent.

Conclusions ALAN represents an engineered solution to a growing clinical challenge: how to collect PROs and use them in a meaningful way during the encounter. Further study is needed to validate its application.

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Routine follow-up care after curative treatment: a survey of the needs, preferences, attitudes, and fears for health care services after curative treatment for head-and-neck cancers

Kelly Brennan, Stephen Hall, John Yoo, Patti Groome, Susan Rohland, Julie Theurer, Paul Peng, Deborah Feldman-Stewart

Background There is little evidence about the effectiveness of routine follow-up after curative cancer treatment for patients or health care systems on surveillance or survivorship. The objective was to describe the follow-up needs and preferences of patients with head-and-neck cancer and to identify which patient characteristics predict needs.

Methods A prospective cohort study incorporating a cross-sectional survey of patients from the Kingston and London regional cancer centres. Between July 2012 and July 2014, 175 consecutive patients who were 1 year post treatment without recurrence agreed to complete an 89-question survey regarding their attitudes, needs, preferences, and fears at follow-up. We also collected cancer stage, Eastern Cooperative Oncology Group performance, treatment, quality of life, demography, and anxiety or depression (HADS). To identify which patient characteristics were associated with follow-up needs and preferences, bivariate analyses and ordinal logistic regression models were used.

Results After 1 year post treatment, we found a diverse range of needs and preferences for follow-up care. Follow-up needs varied for undergoing tests, receiving information on healthy living, and having discussions on pain and fear. Preferences for the frequency of appointments and providers of care were mixed. Patient characteristics such as psychosocial and well-being measures (functional status, anxiety, fear of recurrence, quality of life), attitudes toward follow-up (assurance, communication, perceived disadvantages), demographics (sex, marital status), and clinical characteristics (T category) predicted needs and preferences for follow-up care ($p < 0.05$).

Conclusions A diversity of needs and preferences suggests that a one-size-fits-all approach might be inappropriate for follow-up care for this group of patients and that follow-up care could be improved by tailoring care to better address individual patient requirements. In the absence of evidence about the effectiveness of routine follow-up, patient characteristics can help to determine needs and preferences for follow-up care, to identify

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patients for individualized regimens, and to improve the survivorship experience for all patients.

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Association between preoperative patient-reported symptoms and postoperative outcomes in rectal cancer patients: a retrospective cohort study

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Background Patients with rectal cancer undergoing preoperative radiotherapy experience significant symptom burden. However, it is unknown whether symptoms during radiotherapy might portend adverse postoperative outcomes and health care use.

Methods A retrospective cohort study of patients with rectal cancer undergoing neoadjuvant radiotherapy and proctectomy in Ontario from 2007 to 2014 was performed. The primary outcome was a complicated postoperative course—a dichotomous variable created as a composite of postoperative mortality, major morbidity, or hospital readmission. Patient-reported Edmonton Symptom Assessment System (ESAS) scores, collected routinely at outpatient provincial cancer centre visits, were linked to administrative health care databases. Receiver operating characteristic analysis was used to compare ESAS scoring approaches and to stratify patients into low and high symptom score groups. Multivariable regression models were constructed to evaluate associations between preoperative symptom scores and postoperative outcomes.

Results During the study period, 1455 patients with rectal cancer underwent sequential radiotherapy and proctectomy, and recorded symptom assessments. Patients with high preoperative symptom scores were significantly more likely to experience a complicated postoperative course [odds ratio (OR): 1.55; 95% confidence interval (CI): 1.23 to 1.95]. High preoperative ESAS scores were also associated with the secondary outcomes of emergency department visits (OR: 1.34; 95% CI: 1.08 to 1.66) and prolonged length of stay (incidence rate ratio: 1.23; 95% CI: 1.04 to 1.45).

Conclusions Patients with rectal cancer reporting elevated symptom scores during neoadjuvant radiotherapy have increased odds of experiencing a complicated postoperative course. Preoperative patient-reported outcomes screening might be a useful tool to identify at-risk patients and to efficiently direct perioperative supportive care.

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Patient-reported symptoms in patients with metastatic gastric cancer in the last 6 months of life

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Background Patients with metastatic gastric cancer have poor survival outcomes and can experience a high symptom burden. We evaluated symptom trajectory and risk factors for increased symptom severity in metastatic gastric cancer patients during the last 6 months of life.

Methods We conducted a retrospective cohort study among patients more than 18 years diagnosed with metastatic gastric cancer from January 2007 to December 2014 in the province of Ontario, Canada. We included patients who died during the study period and who reported at least 1 Edmonton Symptom Assessment System (ESAS) score during the last 6 months of life. We described the proportion of patients who reported moderate-to-severe symptom scores (>4) by month. Multivariable logistic regression models were created to identify risk factors for moderate-to-severe symptom scores.

Results We identified 788 eligible patients with 3286 unique symptom scores completed during their last 6 months of life. The highest prevalence of moderate-to-severe scores were observed for tiredness and lack of appetite; nausea and depression had the lowest prevalence of elevated scores. The prevalence of moderate-to-severe scores was consistently high for all symptoms, particularly approaching end of life. Timing of ESAS scores, receipt of cancer-directed therapy, urban residence, and female sex were associated with increased odds of reporting moderate-to-severe symptom scores.

Conclusions Patients with metastatic gastric cancer experience significant symptom burden at the end of life. Routine screening with patient-reported outcomes tools might assist in shared decision-making and effective palliative care by ensuring that the health status and supportive care needs of patients are identified promptly at the time of clinical encounters.

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Caring for patients with cancer in the community—the Community Paramedics program

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Background The cancer patient population has one of the highest growing rates in Canada and is both complex and diverse. This makes providing integrated care across acute and community settings challenging. In 2014, the Tom Baker Cancer Centre partnered with the Community Paramedics (CP) program to provide symptom assessment and management to cancer patients in their own home, with the goal of avoiding unnecessary emergency department (ED) visits and hospitalizations and improving the experience with care in this population.

Objective Part of an ongoing evaluation study, this qualitative inquiry had the objective to summarize CP views on the experiences and outcomes of cancer patients with the CP program.

Methods We conducted in-depth semi-structured interviews with CPs involved in the care of patients with cancer between 2014 and 2017. The interviews were conducted in person or by telephone using several pre-established topics to guide the discussion. Data collected by transcribing the interview recordings were coded and analyzed in the NVivo software application using a grounded theory approach.

Results The thematic analysis summarized the reflections of the CPs concerning the success of the program in increasing the quality of life, reducing transitions to acute care, and providing integrated community-based care to cancer patients. CPs noted that relatively simple interventions provided in the patient's home can alleviate symptoms related to cancer therapies and avoid unnecessary trips to the ED. The CPs felt that avoiding ED visits is particularly important for immunocompromised patients who can become sicker in that environment, and for their families, who fear long waits to get care for their loved ones.

Conclusions This qualitative analysis provided great insights related to the experiences of CPs in caring for cancer patients and possible improvements that can strengthen the program and ensure the full integration of community-based health services for this patient population.

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The effect of prostate cancer surgery on mental health: a single-site observational study

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Objective Treatment for prostate cancer is associated with risks for several negative side effects, including urinary and sexual dysfunction. The impacts of those side effects on mental health has been understudied. The objective of this study is to measure the association of overactive bladder (OAB) symptoms, urinary incontinence (UI), and erectile dysfunction (ED) with depression and anxiety symptoms in patients.

Methods This study is based on observational data from Calgary's Prostate Cancer Centre (PCC). The PCC runs a clinic for men diagnosed with localized prostate cancer. The clinic sees approximately 78% of all men in Calgary who choose to undergo surgery for their localized disease. Patients are seen before their surgery and 3 months after surgery. Patients complete patient-reported outcomes at both time points, including the OAB-v8 (for OAB), the ICIQ (for UI), the IIEF (for ED), and the HADS (for depression and anxiety).

Results Of the 1050 patients seen by the PCC, paired pre- and post-surgery patient-reported outcomes data were available for 483 and 677 of them. Symptom severity for OAB (mean score: 9.2 vs. 11.1; $p < 0.01$), UI (mean score: 1.7 vs. 7.9; $p < 0.01$), and ED (mean score for IIEF overall satisfaction: 7.7 vs. 5.0; $p < 0.01$) were significantly worse after surgery than before surgery. Anxiety-related symptoms were significantly worse after surgery (mean score: 4.2 vs. 3.3; $p < 0.01$). Depression-related symptoms were unchanged after surgery (mean score: 3.6 vs. 3.8; $p = 0.2$). Analyses are ongoing.

Conclusions Changes in patient-reported OAB, UI, and ED symptoms after prostate cancer surgery were as expected. Change in anxiety moves in a similar direction and might be found to be related in future analyses. The insignificant change in depression was unexpected, requiring further investigation. Those results suggest that the development of suitable interventions is needed for men with prostate cancer experiencing anxiety.

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Patient-reported symptoms after diagnosis in patients with esophagus cancer treated with palliative intent

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Background Most patients diagnosed with esophageal cancer present with incurable disease. For those patients, treatment is focused on improving symptoms and quality of life. However, little work has been done to quantify symptom burden for incurable patients. We described symptoms using the Edmonton Symptom Assessment System (ESAS) for patients with incurable esophageal cancer receiving treatment.

Methods This was a retrospective cohort study, linking administrative datasets to prospectively collected ESAS data. In the Ontario Cancer Registry, we identified adult patients with esophageal cancer diagnosed between 1 January 2009 and 1 September 2016. Patients receiving curative treatment (surgery or chemoradiation, or both, with curative intent) were excluded. For each symptom in each month after diagnosis, we defined moderate-to-severe and severe ESAS assessments as scores of 4 or greater and 7 or greater respectively. Frequencies of moderate-to-severe and severe symptoms were described by month from diagnosis for 6 months for all patients and by treatment type (chemotherapy alone, radiotherapy alone, palliative chemoradiotherapy, and best supportive care).

Results During the study period, 2103 patients with esophageal cancer were diagnosed and reported at least 1 ESAS assessment in the 6 months after diagnosis. Moderate-to-severe tiredness (81.4%), impaired well-being (78.2%), and lack of appetite (76.8%) were the most commonly reported symptoms. Moderate-to-severe symptoms remained stable throughout the 6 months after diagnosis; severe symptoms appeared to decrease slightly in months 3–6. Greater symptoms appeared to be experienced by patients receiving radiation only or best supportive care than by patients receiving chemoradiotherapy or chemotherapy alone. Severe symptoms followed a similar pattern.

Conclusions Patients diagnosed with incurable esophageal cancer experience considerable symptom burden in the first 6 months after diagnosis, and symptoms remain stable throughout that period. This study represents a first step in describing symptom burden for patients with esophageal cancer. Patients with this disease require targeted symptom care throughout the course of their illness.

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To evaluate and compare the expectations and attitude toward precision medicine among patients and physicians in oncology

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Background Despite the potential benefits of genomic testing in cancer diagnosis and treatment, this technology is relatively new to most cancer patients. Prior research has reported insufficient understanding of genomic testing, and an apprehensiveness toward the potentially overwhelming test results. However, there have been very few studies of patient knowledge and expectations of genomic testing, and it remains unclear how the perspectives of patients and physicians differ with respect to the use of this new technology. Such discrepancies in patient and physician knowledge and expectations can often result in suboptimal cancer management and follow-up care. We propose a survey study that aims to examine the potential differences in patient and physician views toward genomic testing in cancer.

Objective To evaluate and compare the expectations and attitude toward precision medicine among patients and physicians in oncology research.

Methods This study will be conducted in the oncology clinics at the Tom Baker Cancer Centre. The participating oncologists will be asked to complete the physician survey and to approach patients whom they are diagnosing and treating and who meet the inclusion criteria. Interested patients will be asked complete the survey questionnaire in paper format. Two separate but complementary self-administered questionnaire surveys have been developed and will be distributed for a period of 1–2 years. Survey responses from patients will be matched with those of their oncologists to form patient–oncologist pairs.

Statistical Analysis Multivariable logistic regression analyses will be conducted to calculate the odds ratios for discordant genomic testing expectations, dependent on patient factors and physician characteristics. All tests will be 2-sided, where a *p* value less than 0.05 will be considered statistically significant.

Conclusions Identifying the areas of agreement and disagreement between patients and providers can assist in the development of strategies

to improve education and counselling about genomic testing, which can in turn enhance its use and optimize patient-specific cancer management.

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Using PROMIS measures to evaluate psychological and cognitive outcomes in association with gut microbiota in young adult cancer survivors: methods and progress report

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Background The gut microbiome is an important modulator for immune, metabolic, psychological, and cognitive function. Chemotherapy adversely affects the gut microbiome, inducing acute dysbiosis, and alters physiologic, psychological, and cognitive function. Cancer in young adults has risen 38% in recent decades. Understanding changes in gut microbiota, and psychological and cognitive function after chemotherapy is crucial to improving psychosocial health for survivors, but remains unexamined.

Methods This longitudinal study investigates chemotherapy-induced long-term gut dysbiosis, and associations of gut microbiota with immune, metabolic, cognitive, and psychological outcomes using data collected at less than 1 month (T1), 3 months (T2), and 6 months (T3) after chemotherapy. Participants will be 18- to 39-year-old survivors of blood or solid tumour cancers (*n* = 50), with a healthy sibling, roommate, partner, or friend as a control (*n* = 50). Gut microbiota composition will be measured from fecal samples. Psychological and cognitive patient-reported outcomes measures will include depression, anxiety, pain, fatigue, and social and cognitive function using PROMIS measures, and posttraumatic stress disorder using the Impact of Life Events Scale.

Results In this ongoing study, analyses using regression and linear mixed effects models will be used to examine associations within time points (T1–T3), between groups, and covariates. Study methodology and preliminary findings about recruitment and psychosocial patient-reported outcomes measures will be discussed.

Conclusions It is critical to examine how chemotherapy alters gut microbiota in the long term, and the implications for psychological and cognitive functioning. With this knowledge, supplementation by co-administering probiotics could potentially be used to prevent or reverse psychophysiological deficits, ultimately leading to improved health and quality of life for young cancer survivors.

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Patient-reported symptoms in the perioperative period of breast cancer treatment

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Background Patient-reported outcomes are an important component in assessing quality care and treatment success. Since 2007, Ontario Health (Cancer Care Ontario) has been using the Edmonton Symptom Assessment System (ESAS) to collect symptom scores from cancer patients. The impact of breast surgery on patient-reported symptoms has not been previously reported at the population level.

Methods This retrospective cohort study used prospectively collected symptom scores linked to administrative data for women with stages I–III breast cancer from 2007 to 2016. Differences in median ESAS scores in the 60 days before and 60 days after mastectomy or breast-conservation surgery were compared using paired *t*-tests, with scores of 1 or greater being considered clinically meaningful for individual patients.

Results 2234 Patients had at least 1 score before and 1 score after surgery, for a total of 8000 assessments in the perioperative timeframe. Anxiety, well-being, depression, and dyspnea improved slightly after surgery; anxiety had the largest change, at –0.88. Tiredness, drowsiness, and pain were slightly worse after surgery; pain had the largest increase, at 0.61. Of all the symptoms, anxiety was the most severe, and most improved, with average scores of 3.53 ± 2.89 before surgery and 2.65 ± 2.47 after. Of the patients, 47% showed an improvement of 1 point or more in anxiety after surgery. In 32%, scores were unchanged, and in 21%, scores had worsened.

Conclusions Patient-reported symptom scores for anxiety decrease for most patients after surgery, perhaps indicating that surgery and the development of a treatment plan mitigate anxiety for patients with breast cancer. All other symptoms showed minimal change in the perioperative period.

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Patient-reported symptoms for patients with esophageal cancer undergoing curative-intent treatment

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Background Patients with esophageal cancer (EC) experience considerable symptom burden from treatment. This study used population-level patient-reported Edmonton Symptom Assessment System (ESAS) scores collected as part of standard clinical care to describe symptom trajectories and characteristics associated with severe symptoms for patients undergoing curative-intent treatment for EC.

Methods Patients with EC treated with curative intent at regional cancer centres and affiliates between 2009 and 2016 and assessed for symptoms in the 12 months after diagnosis were included. The ESAS measures 9 common patient-reported cancer symptoms. The outcome was reporting of severe symptom scores (≥ 7 out of 10). Multivariable analyses were used to identify characteristics associated with severe symptom scores.

Results In the year after diagnosis, 1751 patients reported a median of 7 (25% to 75% interquartile range: 4–12) ESAS assessments, for a total of 14,953 unique ESAS assessments included in the analysis. The most frequently reported severe symptoms were lack of appetite ($n = 918$, 52%), tiredness ($n = 787$, 45%), and poor well-being ($n = 713$, 40.7%). The highest symptom burden is observed within the first 5 months after diagnosis, with moderate improvement in symptom burden in the second half of the first year. Characteristics associated with severe scores for all symptoms included female sex, high comorbidity, lower socioeconomic status, urban residence, and symptom assessment temporally close to diagnosis.

Conclusions This study demonstrates a high symptom burden for patients with EC undergoing curative-intent therapy. Targeted treatment of common severe symptoms, and increased support for patients at risk for severe symptoms, might enhance patient quality of life.

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Changes over time in patient needs and preferences about routine follow-up after curative cancer treatment

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Background There is little evidence about the effectiveness of routine follow-up after curative cancer treatment for patients or health care systems on surveillance or survivorship. Our objective was to follow patient attitudes, needs, and preferences toward routine follow-up from year 1 to year 3 after treatment.

Methods A longitudinal cross-sectional survey of patients with head-and-neck cancer from the Kingston and London regional cancer centres. 175 Consecutive patients (July 2012 to July 2014) who were 1 year post treatment without recurrence agreed to complete an 89-question survey about their attitudes, needs, preferences, and fears at follow-up. We also collected cancer stage, Eastern Cooperative Oncology Group performance, treatment, quality of life, demography, employment, and anxiety or depression (HADS). 110 Patients completed surveys at years 2 and 3. Results were compared over time and by sex, age, marital status, site, stage, treatment, and treatment centre.

Results Mean age was 62 years; 18% of the patients were female. Of the patients, 46% had oropharyngeal cancer, 69% had early-stage disease, and 41% underwent surgery. After year 1, once the effects of the initial treatment had settled, very little changed across all the domains over the next 2 years. Patients with more advanced disease, oral cancer, or surgery experienced declining quality of life. Psychosocial characteristics and well-being measures such as anxiety, depression, and fear of recurrence did not worsen or improve over time. The most commonly and consistently identified need was information about prognosis (95.4%). Comfort in talking with the attending oncologist improved; however, the patient's interpretation or beliefs about prognosis did not. Despite 3 years of reassurance and a declining risk of recurrence, 53% of patients thought that their cancer might return; 64% felt that they might be cured.

Conclusions Patients and their needs, preferences, attitudes, and fears did not change over time compared with year 1 after treatment completion. Survivorship appointments should address prognosis and fears.

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Patterns of symptom burden in neuroendocrine tumours: a population-based analysis of patient-reported outcomes

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Background How best to support patients with neuroendocrine tumours (NETs) remains unclear. Improving symptom management and quality of life requires an understanding of the symptoms experienced by patients. Validated assessments of symptom trajectories over the course of the disease is lacking. This study examined patterns and risk factors of symptom burden over time in NETs, using a patient-reported outcomes tool.

Methods A population-based retrospective observational cohort study of all patients with NETs diagnosed from 2004 to 2015 who survived at least 1 year was conducted. Prospectively collected patient-reported Edmonton Symptom Assessment System scores were linked to provincial administrative health care datasets. Moderate-to-severe symptom scores were presented graphically for both the first year and the first 5 years after diagnosis. Multivariable Poisson regression was used to identify factors associated with moderate-to-severe symptoms scores during the first year after diagnosis.

Results For the 2721 included patients, 7719 symptom assessments were recorded during the first 5 years after diagnosis. Moderate-to-severe scores were most often reported for tiredness (40%–51%), well-being (37%–49%), and anxiety (30%–40%). The proportion of moderate-to-severe symptoms was stable over time, with a 10% reduction in anxiety within 6 months of diagnosis, followed by stability; and less than 5% change in other symptoms. Similar patterns were observed for the first year after diagnosis. Primary tumour site, metastatic disease, younger age, higher comorbidity burden, lower socioeconomic status, and receipt of therapy within 30 days of assessment were independently associated with higher risk of elevated symptom burden.

Conclusions Patients with NETs have a high prevalence of moderate-to-severe patient-reported symptoms, which does not change during the 5 years after diagnosis. Patients remain at risk of a prolonged high symptom burden after diagnosis, highlighting potential unmet needs to be addressed. Combined with identified patient and disease factors associated with moderate-to-severe symptom scores, this information is important to support the design of symptom management strategies to improve patient-centred care for NETs.

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Best Poster Award:

Management of high patient-reported pain scores in noncurative pancreatic adenocarcinoma: a population-based analysis

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Background Pain is a common debilitating symptom in pancreas adenocarcinoma (PA). Data with respect to multidisciplinary pain management for patients reporting a high pain score (HPS) is lacking. We examined the use of, and factors associated with, pain-directed interventions for HPS in noncurative PA.

Methods We linked administrative databases and identified patients with non-resected PA diagnosed during 2010–2016 who reported more than 1 Edmonton Symptom Assessment System (ESAS) score. HPS was defined as ESAS greater than 4 out of 10. Outcomes were pain-directed interventions: opiates (assessed in patients >65 years old with universal drug coverage), nerve block, and radiation therapy around the time of HPS. We also examined reductions in pain score (>1 point) after pain-directed intervention. Modified Poisson regression examined factors associated with the use of opiates and other pain-directed interventions.

Results Of 2623 patients, 1621 had HPS at a median of 38 days (25% to 75% interquartile range: 21–69 days) after diagnosis. Of those with HPS, 75.6% received opiates ($n = 688$ of 910); 13.5%, radiation ($n = 219$ of 1621); and 1.2%, nerve block ($n = 19$ of 1621). The pain score decreased in 62.2% after opiates, in 73.8% after radiation, and in 100% after nerve block. On multivariable analysis, no patient factor (age, sex, comorbidity burden, rurality, income quintile, diagnosis year) was associated with receipt of non-opiate pain-directed intervention for HPS. In patients more than 65 years of age, more advanced age was associated with a lower odds of opiate use.

Conclusions Opiates are the most common pain-directed intervention for noncurative PA. Despite effectiveness in reducing HPS, radiation therapy and nerve block are seldom used. The lack of association of non-opiate pain-directed interventions with patient factors points toward decision-making dependent on established practice patterns. Those data should encourage more consideration of non-opiate interventions, and ensure patients have access to all appropriate pain-directed interventions.

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Symptom burden at the end of life for neuroendocrine tumours: a population-based analysis of patient-reported outcomes

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Background How to best support patients with neuroendocrine tumours (NETs) remains unclear. Although the peri-diagnostic period has been investigated, there are no data regarding symptoms at end of life. This study examined symptom trajectories and factors associated with high symptom burden in patients with NETs at the end of life.

Methods We conducted a population-based retrospective cohort study of patients who were diagnosed with NETs from 2004 to 2015, and who died between 2007 and 2016. Prospectively collected patient-reported Edmonton Symptom Assessment System scores were linked to provincial administrative datasets. Moderate-to-severe symptom scores in the 6 months before death were presented by 2-week intervals. Multivariable Poisson regression identified factors associated with moderate-to-severe symptom scores.

Results For 677 included decedents, 2-weekly symptom assessments before death ($n = 2219$) were analyzed. Overall, moderate-to-severe scores were most common for tiredness (86%), well-being (81%), lack of appetite (75%), and drowsiness (68%). The proportions changed over time, progressively increasing closer to death: to 83.9% from 56.8% for tiredness, to 73.1% from 50.5% for well-being, to 80.6% from 40.9% for lack of appetite, and to 68.8% from 41.5% for drowsiness. The increase was steeper in the 8 weeks before death for lack of appetite, drowsiness, and shortness of breath. On multivariate analyses, the risk of moderate-to-severe symptoms was significantly higher in the last 2 months before death and with shorter survival from diagnosis (<6 months). High burdens of anxiety, nausea, and pain were independently associated with female sex. There was no association of symptom burden with age or primary tumour site.

Conclusions Patients with NETs experience a high symptom burden at the end of life. The proportion of moderate-to-severe symptoms increases steeply as death nears, highlighting an opportunity for improved management. Combined with identified factors associated with moderate-to-severe symptoms, this information is important to improve patient-centred and personalized supportive care for individuals with NETs at the end of life.

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Symptom trajectories and predictors of severe symptoms in pancreatic adenocarcinoma at the end of life: a population-based analysis of 2538 patients

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Background We evaluated symptom trajectories and predictors of reporting severe symptoms in the last 6 months of life for decedents with non-resected pancreatic adenocarcinoma (PAC).

Methods A retrospective cohort study of decedents with non-resected PAC receiving care at regional cancer centres between January 2007 and December 2015. Symptoms were measured using the Edmonton Symptom Assessment System (ESAS). We described the proportion of patients reporting severe symptoms (score 7) by 2-week intervals during the 6 months before death. Multivariable modified Poisson regression models identified predictors of reporting severe symptom scores in the last 6 months of life.

Results In the last 6 months of life, 2538 decedents with non-resected PAC treated at regional cancer centres had 1 symptom ESAS record, for a total of 10,893 unique symptom assessments. Tiredness was the most commonly reported severe symptom (59% reporting 1 severe score), followed by lack of appetite (57%), impaired-well-being (49%), and drowsiness (42%). All symptoms increased closer to death. Older age, female sex, higher comorbidity status, survival less than 6 months, and urban residence were associated with a significantly higher risk of reporting severe symptoms.

Conclusions Patients with non-resected PAC experience a significant symptom burden nearing death. Patient subsets might benefit from personalized supportive care interventions.

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Examining the content validity of BREAST-Q a decade later to determine relevance and comprehensiveness

Manraj Kaur,* Andrea Pusic,† Stefan Cano,‡ Louise Bordeleau,§ Toni Zhong,|| Elena Tsangaris,† Anne Klassen‡

Background Currently, the BREAST-Q is the “gold standard” patient-reported outcome measure (PROM): Used in breast cancer research, it has more than 35 translations, 2019 licensed users, and more than 250 publications in PubMed using it. The BREAST-Q was developed through qualitative research with 48 patients and was field-tested in more than 2000 patients. The purpose of this study was to examine the content validity of the BREAST-Q modules (lumpectomy and reconstruction) in an updated cohort of women with breast cancer and to determine the need for new breast cancer surgery-related PROMs.

Methods Semi-structured one-on-one interviews were conducted with a heterogeneous sample of women diagnosed with breast cancer (stages 0–IV, surgical and nonsurgical treatments). Interviews were audio-recorded and transcribed verbatim. The data were coded using a line-by-line approach. Using constant comparison, a conceptual framework was developed and compared with the original BREAST-Q framework.

Results Of 59 participants, 22 had breast cancer surgery only, and 37 had mastectomy with reconstruction. The conceptual framework consisted of 3594 codes that covered these constructs: abdomen, arms, breast, cancer, and psychological, sexual, and social functioning. Themes such as satisfaction with breasts and physical, psychosocial, and sexual effects overlapped in the original and new conceptual frameworks. Needs were identified for additional BREAST-Q modules for lymphedema (upper extremity), breast sensation, and other types of autologous reconstruction (profunda artery, superior and inferior gluteal artery perforator flaps).

Conclusions Establishing content validity is a critical step in the selection and administration of a PROM. Our study demonstrates that the BREAST-Q content, which was developed using extensive patient input a decade ago, is still highly relevant. To ensure that the BREAST-Q is as comprehensive as possible, new scales covering concepts such as arm lymphedema and the return of breast sensation have been developed.

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Best Poster Award: Design of a PRO collection Web application

Mahmood Khalghollah, Behrouz Far, Trafford Crump

Objective Web applications—accessed through either a computer or a smartphone—are one way that health care providers can collect data such as patient-reported outcomes (PROs) from patients. The use of these applications can lead to better communication between providers and patients and can help to personalize treatment. The objective of this study was to report on the development of our own PRO Web application.

Methods Our Web application, named the Artificial Intelligence and Learning-based Agency Network (ALAN), is based on a C# Model-View-Controller architecture for the back-end server, together with a SQL server as the database management tool. Its front end is developed using the primitive cshtml and JavaScript.

Results ALAN is a highly flexible application on both the back and front ends. On the back-end, using a simple client-server, it can integrate with other data sources (for example, clinical registries). ALAN can also make use of Web services that are made available over the Internet, greatly expanding the usability of the system. ALAN can also gather data from smartphones and wearable devices to link with PRO data for future analysis.

On the front end, ALAN enjoys a customizable environment for health care providers to create their own PROs or use pre-developed ones. The surveys could be sent to a defined group of patients based on a designated trigger or at timed intervals. The completed surveys are collected and stored in a database for further analysis.

Conclusions ALAN is an example of a Web application that can be used by health care providers to collect PRO data from their patients. Attention to developing flexible back and front ends means that ALAN can be tailored to meet the unique needs of health care providers and their patients. ALAN will be implemented in a clinical setting to test the satisfaction of health care providers and patients with its use.

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The impact of routine symptom screening on cancer-related survival: "real world" evidence from a propensity-score analysis of a retrospective hospital-based cohort study

Bryan Gascon,* Yvonne Leung,^{†‡} Osvaldo Espin-Garcia,[§] Gary Rodin,^{**} Madeline Li^{**}

Objective Symptom management is an integral component of cancer care, but evidence demonstrating the clinical benefits of symptom screening is limited. The Distress Assessment and Response Tool (DART) at the Princess Margaret Cancer Centre (PMCC) integrates electronic symptom screening with triaged interprofessional clinical assessment. DART has been administered routinely in all clinics at PMCC since 2010. The impacts of DART on cancer-related survival were evaluated.

Methods The study population consisted of cancer patients who attended PMCC between 2010 and 2013. Sociodemographic, medical, and cause-of-death data (up to 2014 to allow for at least 1 year of follow-up) were extracted from hospital and provincial cancer registries. Propensity for DART completion, accounting for age, sex, marital status, income, and cancer type and stage, were incorporated into inverse probability treatment weighting (IPTW) analyses to estimate the effect of DART completion on overall cancer-related survival. Cancer-related survival was also assessed in subgroups defined by cancer type.

Results During the study period, 29% of patients ($n = 10,215$) completed the DART at least once. During the same period, there were 11,908 cancer-related deaths among all patients attending PMCC. After propensity-score analysis, DART non-completion, compared with DART completion, was associated with higher cancer-related mortality [hazard ratio (HR): 2.18; 95% confidence interval (CI): 2.1 to 2.2]. That association was consistent across all cancer types, with the strongest effect in head-and-neck cancer (HR: 4.28; 95% CI: 4.01 to 4.57) and the smallest effect in prostate cancer (IPTW HR: 1.47; 95% CI: 1.32 to 1.62).

Conclusions DART completion was associated with better overall survival in a large heterogeneous cohort of cancer patients. Further exploration is required to determine the contribution of clinician response rates to the potential mechanisms underlying this association.

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Breast reconstruction decision aids improve decisional conflict and satisfaction: a randomized controlled trial comparing two online decision aids

Cynthia Mardinger

Background Women diagnosed with breast cancer must face challenging decisions concerning lumpectomy, mastectomy, contralateral prophylactic mastectomy, and breast reconstruction. Decision aids can be useful adjuncts to clinical consultations for women considering breast reconstruction. The purpose of this study was to compare the Breast Reconstruction Decision Aid (BRECONDA) with the Alberta Health Services (AHS) decision aid for their effects on decisional conflict, decisional satisfaction, and decisional regret.

Methods This randomized controlled trial included 60 women facing the decision about whether to undergo breast reconstruction. The AHS and BRECONDA decision aids were compared using randomized 2-arm equal allocation. Data were collected at baseline, in 2 consultations, and at the 6-week and 6-month follow-ups. Using a paired *t*-test, change scores for decisional conflict were compared for consult 1 and consult 2 compared with consult 1 and the 6-month follow-up. Secondary outcomes included decisional regret and decisional satisfaction.

Results Both groups were equal in demographic, clinical, and behavioural characteristics at baseline. Groups were imbalanced in the chosen type of reconstruction: 17.9% of the BRECONDA group chose abdominal free flap ($p = 0.02$), and 13.8% of the AHS group chose latissimus dorsi flap ($p = 0.05$). Women spent more time consulting BRECONDA (56.7 ± 53.8 minutes vs. 28.4 ± 27.2 minutes, $p < 0.05$). Decisional conflict improved in the AHS group ($p < 0.05$). Decisional satisfaction improved in the BRECONDA group ($p < 0.05$). There were no differences in decisional regret ($p > 0.05$).

Conclusions Women spent significantly more time consulting BRECONDA, which is a more expansive decision aid than the AHS tool. Although there were no differences in the effect of the decision aids on decisional regret, women in the AHS group demonstrated less decisional conflict. However, women who accessed BRECONDA were more satisfied with their decision. Although women find decision aids useful, the expansiveness of a decision aid does not necessarily seem to contribute to reduced decisional conflict or regret.

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Bridging the gap between the medical system and informal caregivers: barriers and recommendations for the development of family-reported outcomes in cancer care

Danielle Petricone-Westwood,* Jacqueline Galica,[†] Sarah Hales,^{**} Sophie Lebel*

Introduction Our health care system relies on informal caregivers to provide critical support to individuals living with cancer, resulting in burden and compromises to their own quality of life. Caregivers are largely overlooked by the health care system because they are not "the patient," thus presenting several barriers to conducting research and collecting family-reported outcomes. Using our ongoing study of caregivers for patients with ovarian cancer as an example, we will discuss barriers to caregiver research within the health care system and by traditional research protocols.

Methods From October 2017 to June 2019, partners of patients with ovarian cancer were recruited nationally for a cross-sectional survey study. Advertisements were circulated through Ovarian Cancer Canada media outlets, several cancer community support centres, and two ovarian cancer support groups. Two gynecology oncology clinics recently began active recruitment.

Results Throughout our recruitment and data collection, various systemic, practical, and ethics barriers arose. For example, some health care centres have very limited resources for caregivers, posing a systemic barrier. Other centres require caregivers to be approached through patients, presenting a practical barrier. Furthermore, patients might feel burdened by ongoing research, but ethically, they must consent to their medical or other data being used in caregiver research. Recruitment rates in this study were quite low ($n = 27$ over 18 months) until active recruitment strategies were implemented in oncology clinics ($n = 29$ over 2 months), demonstrating that caregivers will report their experiences when asked.

Conclusions Those obstacles illuminate the limitations in caregiver research and the resulting bias that might exist when studying caregivers, suggesting that the current literature likely underrepresents their needs. Development of family-reported outcome programs within the health care system will facilitate better care and improve the understanding of this population. Collaborative efforts, formal institutional recognition of the critical role of caregivers, and caregiver research protocol dissemination are some ways that barriers might be overcome.

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The physician's Achilles heel: surviving an adverse event

Igor Stukalin

Background Of hospitalized patients in Canada, 7.5% experience adverse events (AEs). Physicians whose patients experience AEs often become second victims of the incident. Patient-related outcomes are significantly influenced by the physician's emotional health, particularly during physician recovery from an AE. This study is the first to evaluate how physicians in Canada cope with AEs.

Methods Survey participants included oncologists, surgeons, and trainees at the Foothills Medical Centre, Calgary, Alberta. The surveys were administered through the REDCap software. The Brief COPE inventory, the IES-R Scale, and the Causal Attributions and Institutional Punitive Response scales were used to evaluate coping strategies, posttraumatic stress prevalence, and institutional culture concerning AEs.

Results 51 Responses were used for analysis: 30/51 (58.8%) from surgeons and 21/50 (41.2%) from medical specialists. Of respondents, 54.9% scored greater than 24 on the IES-R scale, which has been correlated with clinically concerning posttraumatic stress. Individuals with a score greater than 24 were more likely to use self-blame ($p = 0.00026$) and venting ($p = 0.042$). Physicians who perceive that there is poor institutional support reported significant posttraumatic stress ($p = 0.023$). On multivariable logistic regression modelling, self-blame was associated with an IES-R score greater than 24 ($p = 0.0031$). There were no significant differences in IES-R scores greater than 24 between surgeons and non-surgeons ($p = 0.15$).

Discussion The implications of AEs on physicians, patients, and the health care system are enormous. More than 50% of our respondents showed emotional pathology related to a patient AE. Higher levels of self-blame, venting, and feeling inadequate institutional support were factors predicting increased posttraumatic stress after patient AEs.

Conclusions Our results identify a desperate need to establish effective institutional supports to recognize and deal with the enormous burden resulting from patient AEs.

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Prevalence of vulvovaginal symptoms and psychometric evaluation of the Day-to-Day Impact of Vaginal Aging questionnaire in women diagnosed with cancer

Kirsti Toivonen, Pablo Santos-Iglesias, Roanne D. Millman, Carly Sears, Lauren M. Walker

Background Vulvovaginal symptoms (vvs) are common after cancer treatment. Symptoms including dyspareunia, vaginal dryness, soreness, itching, and tightness are known to negatively affect not just women's sexual well-being, but also their daily activities, mood, self-concept, and overall quality of life. Despite high anecdotal report, information about the daily impact of vvs after cancer treatment is scarce because of a lack of validated measurement tools. This study aimed at validating the Day-to-Day Impact of Vaginal Aging (DIVA) questionnaire in a sample of cancer patients.

Methods 202 Women (age: M = 51.61) diagnosed with cancer participated. All women reported experiencing at least 1 vvs. Data were collected as part of a group-based vaginal and sexual health educational workshop for women with cancer. Participants completed a questionnaire package including demographics, the DIVA, and measures of vvs, sexual function, and sexual distress.

Results A confirmatory factor analysis affirmed the 4-domain structure of the DIVA: activities of daily living, sexual functioning, emotional well-being, and self-concept and body image. All subscales showed excellent internal consistency reliability; however, item analyses indicated that some items, especially those in the activities of daily living subscale, showed high item difficulty. Correlations with sexual function and distress provided evidence that the DIVA assesses the effects of vvs.

Conclusions This study is the first to validate a patient-reported outcome measure assessing the effects of vvs on women with cancer. Results provide evidence of the DIVA's utility in assessing the effects of vvs on 4 relevant domains of women's lives, not only sexuality. Although certain scale items require further exploration in future studies, the DIVA provides an opportunity to increase cancer-specific knowledge about outcomes relating to vvs. Inclusion of this measure when assessing effects will help to inform clinicians about unmet needs relating to vvs in these patients.

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Patient-reported satisfaction after radiation of implant-based breast reconstruction

Eva Thiboutot, Peter Craighead, Carmen Webb, Claire Temple-Oberle

Background Little is known about patient-reported outcomes (PROs) in the setting of implant-based reconstruction (IBR) with post-mastectomy radiation therapy (PMRT).

Methods In a prospectively compiled database, we identified patients who underwent immediate IBR. The Breast Reconstruction Satisfaction Questionnaire was scored and compared between patients with and without PMRT.

Results Of 64 women who met the study criteria, 48 did not receive PMRT, and 16 did. The indication for PMRT was unanticipated in 9 women. The PMRT group was similar to the control group with regard to baseline characteristics (that is, age, marital status, body mass index, tobacco use, and comorbidities). However, treatment and oncologic characteristics (for example, diagnosis, tumour characteristics, systemic therapy use) differed. Of all complications, only capsular contracture rates differed (1.2% vs. 13%, $p = 0.01$). Of the 9 subscales, 7 showed no difference in satisfaction between the groups. Radiated women scored lower in the arm concerns and breast appearance subscales. Scores were similar whether the indication for PMRT had been anticipated or not.

Conclusions Women with immediate IBR scored similarly to their non-radiated counterparts in 7 of 9 domains of satisfaction. Arm concerns and breast appearance scores are lower with PMRT, likely secondary to more extensive nodal procedures in patients with higher-stage disease and to the side-effect profile of radiotherapy. Our findings are in line with the few available studies using other PRO tools to evaluate the effects of PMRT on patient satisfaction and studies objectively measuring the effects of PMRT on arm morbidity and cosmetic outcomes.

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Development and psychometric evaluation of the BREAST-Q sensation module for patients undergoing post-mastectomy reconstruction

Elena Tsangaris, Anne Klassen, Manraj Kaur, Trisia Breitkopf, Andrea Pusic

Purpose Surgical techniques for breast reconstruction have progressed from implanting alloplastic materials to transplanting free tissue using complex microsurgical techniques. Although surgical techniques continue to evolve, recurrent and debilitating complications such as loss of breast sensation persist. The BREAST-Q is the "gold standard" patient-reported outcome measure (PROM) for breast cancer surgery. The purpose of the

present study was to develop new scales for the BREAST-Q that measure breast sensation.

Methods We used an interpretive-description qualitative approach. Semi-structured interviews were performed with a heterogeneous sample of women with breast cancer recruited from 2 Canadian and 1 U.S. cancer centre. Interviews were audio-recorded, transcribed, and coded using the constant comparison approach. Transcripts were analyzed to identify key themes and subthemes, and an item pool for use in scale development. 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 Qualitative interviews involved 59 women with breast cancer. Patients provided codes that covered a range of concerns related to breast sensation. Data collected were used to develop 3 new BREAST-Q scales including: abnormal breast sensation, return of breast sensation, and effect of breast sensation on quality of life. The 1204 women included in the field-test sample provided 1833 assessments. Rasch measurement theory analysis identified 3 scales with ordered thresholds and acceptable reliability (0.86 to 0.95).

Conclusions The final item-reduced BREAST-Q Sensation module consists of 48 items in 5 scales with 2 standalone items in the physical and emotional scales and 23 items in 3 checklists. The new scales can be used to facilitate research, the advancement of new surgical techniques, and improved patient care and outcomes.

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Population-level symptom assessment after pancreaticoduodenectomy for adenocarcinoma: 6058 patient-reported outcomes

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Background Postoperative morbidity associated with pancreaticoduodenectomy for pancreatic adenocarcinoma (PA) remains as high as 70%. However, few studies have examined quality of life in this patient population.

Methods This population-based study analyzed a cohort of patients undergoing pancreaticoduodenectomy for PA diagnosed between 2009 and 2015. The study linked population-level administrative health care data to routinely prospectively-collected Edmonton Symptom Assessment System (ESAS) scores from 2009 to 2015, with data analysis undertaken in 2018.

Results We analyzed 6058 individual symptom assessments provided by 615 patients with resected PA and ESAS data. Tiredness (72%), impaired well-being (68%), and lack of appetite (65%) were most commonly reported as moderate-to-severe. The proportion of patients with moderate-to-severe symptoms was highest immediately after surgery and decreased over time, stabilizing at around 3 months. Female sex, higher comorbidity, and lower income were associated with higher risk of reporting moderate-to-severe symptoms. Receipt of adjuvant chemotherapy was not associated with risk of moderate-to-severe symptoms.

Conclusions There is a high prevalence of symptoms after pancreaticoduodenectomy for PA, with encouraging improvement during the first 3 months after surgery. In the largest cohort reporting on symptom burden for this population, we identified factors associated with symptom severity. Those findings will aid in managing the perioperative expectations of patients and in designing strategies to improve targeted symptom management.

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Comparison of patient-reported outcomes in laparoscopic and open right hemicolectomy: a retrospective cohort study

Nivethan Vela,* Lev D. Bubis,† Laura E. Davis,‡ Alyson L. Mahar,§ Erin Kennedy,^{†||}†† Natalie G. Coburn^{†||}*^{††††}

Background Open and laparoscopic resection for colon cancer have equivalent perioperative morbidity and mortality. However, few data

concerning patient-reported outcomes (PROs) in the early post-discharge period are available.

Methods In this retrospective cohort study, we examined PROs in the early post-discharge period for open and laparoscopic right hemicolectomy for colon cancer in patients undergoing laparoscopic or open right hemicolectomy for colon cancer from January 2010 to December 2014. The patients were identified using the Ontario Cancer Registry and physician billing data. The primary outcome measured was the presence of moderate-to-severe symptom scores (>4 out of 10) on the Edmonton Symptom Assessment System (ESAS) within 6 weeks of hospital discharge after right hemicolectomy.

Results The study included 1022 patients who recorded at least 1 ESAS assessment within 6 weeks of surgery. Patients undergoing laparoscopic resection were more likely to have an urban residence and to have undergone planned resection; they also had proportionally more stage I disease than did patients undergoing open resection. On multivariable analyses, adjusting for patient demographics, cancer stage, and planned versus unplanned admission status, there were no differences in the adjusted odds of moderate-to-severe symptom scores between the laparoscopic and open approaches.

Conclusions Receipt of open or laparoscopic surgical technique was not associated with increased risk of elevated symptom burden in the early post-discharge period.

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Validation of a novel patient-reported outcomes–driven symptom complexity algorithm: performance and known group

Linda Watson

Introduction The symptom complexity algorithm derived from the validated Edmonton Symptom Assessment System–revised (ESAS-r) PROM and the Canadian Problem Checklist to classify symptom level in cancer patients has not been extensively validated.

Methods This is a retrospective chart review study using data from the Alberta Cancer Registry and the Alberta Cancer Electronic Medical Records (ARIA). The sample comprised cancer patients who visited a palliative radiation oncology clinic at 1 cancer facility in Alberta, Canada, from February 2016 to November 2017 ($n = 1466$). To be included in the sample, the patient had to have completed the electronic ESAS-r twice in ARIA.

Results Known group validity is assessed by comparing health status for the high- and low-complexity groups using the EQ-5D-5L misery index score as indicator. Compared with the low-complexity group, the high-complexity group reported significantly higher mean scores: 14.8 [95% confidence interval (CI): 14.4 to 15.1] compared with 9.91 (95% CI: 9.64 to 10.2) respectively, $p < 0.001$. The effect size ($d = 1.2$) indicates that the magnitude of difference in health status between the two groups is large, and the algorithm effectively classified the subgroups with distinct health status. Using a clinician assessment of Karnofsky performance status at 50% or less as the standard criterion for high complexity, the PRO algorithm shows satisfactory sensitivity, specificity, positive predictive value, negative predictive value, and accuracy. An area under the receiver operating curve (AUC) of 0.824 is found for the complexity algorithm, which is generally regarded as good and superior to the alternative algorithm generated by 2-step cluster analysis (AUC: 0.721).

Conclusions The known group and performance validity of the PRO-driven complexity algorithm is confirmed in this study. As anticipated, the algorithm showed a higher screening capacity than the algorithm generated from 2-step cluster analysis, which reinforces the idea of contextualization when classifying patient symptoms, rather than purely relying on the statistical outcomes.

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Are long-term patient-reported outcomes in patients with prostate cancer treated with external-beam radiation therapy and a brachytherapy boost better than those in patients treated with brachy-monotherapy?

Paul Willinsky, Evan Stewart, Ian Sun

Background Brachytherapy (BT), radiation treatment by an internal source, is considered to be a highly effective treatment for prostate cancer. Recent results from the Androgen Suppression Combined with Elective Nodal and Dose Escalated Radiation Therapy trial indicate that BT is an effective treatment option for patients with intermediate- and high-risk disease when used as a boost combined with external-beam radiation therapy (EBRT) and hormone therapy. BT can also be used as an effective monotherapy in select patients with intermediate- and high-risk disease.

Several studies measuring patient reported outcomes (PROs) comparing radical prostatectomy, BT monotherapy, and EBRT have been done, as have comparisons of EBRT alone with EBRT plus BT boost. However, there is a lack of literature comparing PROs for BT as monotherapy with pelvic EBRT plus BT boost. We will compare long-term PROs (2+ years posttreatment) of patients who receive BT monotherapy and who receive EBRT with a BT boost. **Methods** Our study will be a retrospective quantitative analysis of PROs data collected through the BC Cancer Prospective Outcomes and Support Initiative (POSI) program. We will use statistical analysis to compare the PROs of the two treatment arms at 2, 3, and 5+ years posttreatment. Patients will be stratified by age, hormone therapy treatment, and baseline symptoms.

Results We hope to show a statistical difference between PROs for patients with prostate cancer treated with BT and those treated with EBRT and a BT boost. Our intention is for this information to help guide clinical recommendations to achieve optimal patient satisfaction with treatment results.

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One-year urinary and sexual outcome trajectories in prostate cancer patients treated by radical prostatectomy: a prospective study

Lin Yang, JungAe Lee, Adam S. Kibel, Claire Pearnar, Graham A. Colditz, Ratna Pakpahan, Kellie R. Imm, Sonya Izadi, Robert L. Grubb III, Kathleen Y. Wolin, Siobhan Sutcliffe

Purpose We examined 1-year trajectories of urinary and sexual outcomes, and correlates of those trajectories, in prostate cancer patients treated by radical prostatectomy.

Methods Study participants were recruited from 2011 to 2014 at two U.S. institutions. Using the modified Expanded Prostate Cancer Index Composite [EPIC (scale: 0–100)], self-reported urinary and sexual outcomes were measured at baseline before surgery and at 5 weeks, 6 months, and 12 months after surgery. Using previously reported minimum clinically meaningful differences, changes in EPIC scores from baseline were categorized into “improved,” “maintained,” or “impaired.”

Results Of 395 eligible participants, 329–354 had complete data on each EPIC subscale at baseline, 5 weeks, and 12 months. Although all mean EPIC scores declined markedly 5 weeks after surgery and then recovered to near (incontinence-related measures) or below (sexual outcomes) baseline levels by 12 months after surgery, a proportion of the men (3.3%–51%) experienced improvement above baseline on each subscale. Having benign prostatic hyperplasia (BPH) at baseline (prostate size ≥ 50 g, an American Urological Association score ≥ 15 , or BPH medication use) was associated with postsurgical improvements: voiding dysfunction-related bother at 5 weeks [odds ratio (OR): 3.5; 95% confidence interval (CI): 2.1 to 5.8] and 12 months (OR: 2.9; 95% CI: 1.5 to 5.1), sexual function at 12 months (OR: 3.7; 95% CI: 1.1 to 13.2), and sexual bother at 5 weeks (OR: 3.9; 95% CI: 1.7 to 9.2) and 12 months (OR: 4.4; 95% CI: 2.1 to 9.2).

Conclusions We observed improvements in urinary and sexual outcomes for nontrivial proportions of men who underwent radical prostatectomy, which might reflect an additional consideration when selecting the best management strategy for early-stage prostate cancer.

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