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Patient-Reported Outcomes in Surgical Oncology: An Overview of Instruments and Scores

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Abstract

Traditional measures of quality and effectiveness in surgical oncology have focused on morbidity, mortality and, when available, recurrence rates. Measuring patient reported outcomes (PROs) has become more widely accepted over the last decade. This article will review commonly used instruments in the surgical treatment of cancer patients to evaluate PROs. In addition, we will discuss the linkage of PROs and health-related quality of life measures with traditional surgical complications and highlight future directions related to the expanding use of PROs in the surgical care of cancer patients.

Introduction

Cancer significantly impacts the health system in the United States, with nearly \$150 billion spent annually on cancer care [1]. Fortunately, the overall incidence of cancer is declining [2], but it is estimated that over 15.5 million Americans are currently living with cancer, and this number is expected to increase to over 20 million by 2026 [3]. Surgery is the mainstay of treatment for many solid organ cancers, particularly when they are diagnosed at an early stage. Traditionally, measures of surgical quality and effectiveness have been captured via morbidity and mortality rates, as well as other outcomes measures such as cancer recurrence rates.

While these outcomes measures are quantifiable and readily identifiable, they do not inherently capture the patient's perspective of their illness and treatment [4]. Patient-centered care has come to be defined as a critical pillar of the overall definition of healthcare quality [5]. Coupled with advances in treatment and evolution of patient-provider relationships, there is an increased emphasis on the evaluation of patient-reported outcomes (PROs) which describe aspects of a patient's health status, as directly reported by patients.

The evaluation of health-related QOL (HRQOL) brought an early focus to PROs that defined a patient's self-reported and self-perceived physical and mental health status, including health conditions, functional status, and social support. Work on PROs has evolved over several decades to more directly encompass elements of function, disability, mobility,

depression, anxiety, pain, and a host of other specific symptoms. Condition-specific measures are now available to capture the patient perspective on treatment effectiveness. However, despite the development and validation of numerous instruments, challenges related to the how best to implement and utilize PROs in surgical oncology practice remain.

Many common surgical procedures such as hip and knee arthroplasty and inguinal herniorrhaphy are performed, in large part, to alleviate pain and improve function. As such, clinical outcomes such as imaging changes are less reflective of outcomes that matter to patients, such as improvement in symptoms. The effectiveness of these operations are optimally measured by PROs. While clinicians have assessed outcomes of interest by asking questions such as “How bad is the pain?” in the pre-operative period and questions such as “Is the pain improved?” in the post-operative period, formalized questions regarding these outcomes are not yet included in all patient assessments. Gaps in knowledge exist around which types of PROs are the most useful for improving health outcomes and quality of care, how PROs are actually used by both patients and providers, and which types of patients may benefit most from monitoring with these PROs [6].

Importantly, PROs seek to elucidate aspects and perceptions of health directly from patients, without interpretation by others. When patients with cancer and their clinicians were asked about symptom severity, results show that the dyads generally agreed on the severity of symptom grades, but when symptom grading was different, patients generally reported greater severity of symptoms than their clinicians did, especially with more subjective categories. Results further demonstrated that self-reporting allowed patients to notify their clinicians of symptoms, improving self-efficacy and allowing for the possibility of such reporting on a triggered or as needed basis, even without a formal clinical encounter [7].

PROs are commonly are grouped into five levels: biological and physiological factors, symptoms, functioning, general health perceptions, and overall QOL [4, 8]. The development, validation, and refinement of PRO assessment tools have spanned decades, but implementation by clinicians continues to be slow. Beginning in the mid-2000s, there has been increasing recognition that many postoperative outcomes, such as symptoms, functional improvement, and quality of life are best measured by asking the patient [9]. Currently PROs are important aspects of comparative effectiveness research and are emerging as outcomes (often primary outcomes) in surgical trials [10]. In addition, the Centers for Medicare and Medicaid Services (CMS) has begun to include patient-reported data in the Hospital Value-Based Purchasing structure, tying these metrics to reimbursement [11].

There is growing enthusiasm related to PROs in surgical oncology, but current issues with logistics and methodology have somewhat limited their widespread implementation [12]. This article will review commonly used instruments to evaluate PROs in surgical oncology patients. In addition, we will discuss the linkage of PROs and HRQOL with traditional surgical complications and highlight future directions related to the expanding use of PROs.

Assessment Questionnaires

Multiple assessment tools across multiple cancers have been utilized to evaluate PROs for surgical oncology. In order to be useful, these tools must be clinically meaningful and formally developed and tested to ensure reliability, validity, and responsiveness (i.e., the ability to measure the impact of surgery) [13]. These instruments typically fall into three categories: general, cancer specific and disease specific. In addition, some post-operative instruments have also been developed (Table).

General Instruments

General questionnaires can be broadly considered as generic and symptom-focused. Commonly used generic instruments include the Medical Outcomes Study 36-Item Short-Form Health Survey (SF-36) and the shorter 20-item version (SF-20) [14, 15]; Spitzer QOL Index [16]; the EuroQol-5D (EQ-5D) [17]; and the 15D instrument of health-related quality of life (15D) [18]. The SF-36 and SF-20 were designed for the general population for use in clinical practice and research, as well as health policy evaluations and general population surveys [19]. These tools focus on aspects of physical function, pain, general health, vitality, social functioning and psychologic aspects of emotion and mental health [20]. The Spitzer QOL Index was designed for cancer patients and assesses activity, daily living, health, social support and outlook [20]. The EQ-5D was also designed for the general population and evaluates mobility, self-care, activity, social relationships, pain, and mood [17]. The 15D is a generic, comprehensive 15-dimensional, standardized measure of HRQOL [18]. The questionnaire is self-administered and consists of 15 dimensions: moving, seeing, hearing, breathing, sleeping, eating, speech, elimination, usual activities, mental function, discomfort and symptoms, depression, distress, vitality, and sexual activity [21].

More recently, the National Institutes of Health (NIH) funded the Patient-Reported Outcomes Measurement Information System (PROMIS) Network, with the overall goal to develop a publicly available set of standardized instruments for measuring self-reported health domains that are affected by many chronic illnesses [22]. The National Cancer Institute (NCI) provided supplementary funding to ensure developed measures were valid for cancer patients and researchers across multiple tumor types and treatment stages. Resulting work has led to the creation of domains that include PROs of pain, fatigue, emotional distress, physical function and social function. Libraries in these domains are then used to generate PRO assessments. By using a variety of short-form modules across health domains, surveys can be customized to a patient population and disease process of interest [23]. A recent review of surgical studies indicated that the PROMIS instruments efficiently, accurately and reliably assessed patient reported HRQOL in multidisciplinary surgical settings, allowing better communication with patients in the perioperative period [24]. These assessments can be given pre- and postoperatively, and used to better inform patients about surgical decision making and their expected functional recovery. Surgical oncology studies using PROMIS Network tools have recently been published in colorectal [25], lung [26], metastatic bone [27], prostate [28], and gynecologic cancers [29].

Symptom-specific tools utilized in surgical oncology include the Gastrointestinal Quality of Life Index (GIQLI)[30] and the Gastrointestinal Symptom Rating Scale (GSRS) [31]. The

GIQLI was initially developed for patients with benign and malignant pathologies including periampullary carcinoma [32] and for patients undergoing laparoscopic cholecystectomy, focusing on domains of physical-being, mental well-being, and gastrointestinal symptoms [20]. The GSRS was developed for patients with inflammatory bowel disease and peptic ulcer disease and focused on a range of gastrointestinal symptoms such as abdominal pain, reflux, and bowel evaluations. It has subsequently been validated in a multi-national study in patients with dyspeptic symptoms [33]. The GIQLI and GSRS measure gastrointestinal symptoms specifically, noting that QOL would need to be measured separately.

Cancer and Disease Specific Instruments

Numerous cancer-specific questionnaires have been developed and used, primarily in the pre- and post-operative settings to evaluate QOL changes. One of the most widely utilized is the European Organization for Research and Treatment of Cancer (EORTC) QLQ-C30 [34]. This questionnaire incorporates five functional scales (physical, role, cognitive, emotional, and social), three symptom scales (fatigue, pain, and nausea/vomiting), and a global health and QOL scale. It has been utilized in surgical patients with gastric, esophageal, lung, ovarian, uterine, head and neck, and colorectal cancers [13, 19, 20, 35–40]. The EORTC QLQ can be supplemented with additional domains for disease specific cancers, including esophagus (OES18 and OES24) [19], lung (LC13) [23], stomach (STO22) [20], head and neck (Head and Neck Module) [41], and breast (B23) [42]. The MD Anderson Symptom Inventory (MDASI) is a validated PRO assessment tool that evaluates multiple cancer-related symptoms and the subsequent interference with daily functioning [43]. This inventory includes 13 symptom items and 6 measurements of symptom interference with daily life. It has demonstrated differences in functional recovery following minimally invasive surgery versus thoracotomy for lung cancer [44]. In addition, it has been used to assess symptom severity before and after pelvic exenteration for a variety of gynecologic malignancies [45], early post-operative symptoms following radical cystectomy for bladder cancer [46], and other major abdominal cancer operations. The MDASI has also been used to compare symptom burden and functional recovery in ovarian cancer patients undergoing primary cytoreductive surgery compared to a neoadjuvant chemotherapy approach within an enhanced recovery after surgery (ERAS) program [47] as well as in patients undergoing hepatectomy under an ERAS program [48].

The Rotterdam symptom checklist (RSCL) has 34 items and can be used to measure psychological and physical distress, activity level, and overall valuation of life as experienced by cancer patients [19, 49]. This tool has been used in surgical patients with ovarian cancer [50], breast cancer [51, 52], esophageal cancer [53–55], mesothelioma [56], colorectal cancer [57], and gastric cancer [58].

The Functional Assessment of Cancer Therapy (FACT)-General is a 33-item general cancer QOL measure for evaluating patients receiving cancer treatment [59]. This tool was developed in patients with breast, lung, and colorectal cancer and produces scores for physical, functional, social, and emotional well-being, as well as satisfaction with treatment. More specific versions of this tool have been created and utilized in surgical patients with

esophageal [60], gastric [20], lung [61], liver [62], pancreatic [63], breast [64], colorectal [65], gynecologic [29], head and neck [66], and bladder/prostate cancers [67].

The Common Terminology Criteria for Adverse Events (CTCAE) maintained by the NCI is the standard approach used for AE reporting in cancer trials. Beginning in 2006, the Food and Drug Administration (FDA) advocated for PROs to be used in the process of developing and evaluating medical technology, including devices and has more recently promoted the standardized measurement and interpretation of PROs in drug development [4]. Currently, AEs are graded by clinicians and researchers in clinical trials. However, evidence suggests that compared to patient-reporting, clinicians may underestimate symptom onset and severity [68]. Further, clinician-only reports may lack reliability and less accurately reflect underlying health status than direct patient reporting [69]. The three general categories of AEs in the CTCAE are laboratory-based events, observational/measurable events, and symptomatic adverse events [70]. To address these concerns and incorporate the patient's perspective, the NCI developed the PRO-CTCAE item library, which is composed of subjective AEs with and without observable components (such as vomiting and nausea, respectively), and observable AEs that contain plain-language descriptor terms. This tool is publically available from the NCI [71] and was designed to complement the original CTCAE and ultimately enable a more informed decision-making process by patients, clinicians and investigators for different treatment strategies [69].

CTCAE consists of 124 items representing 78 symptomatic AEs that are scored on a 0 to 4 scale. For each AE, individual items evaluate frequency, severity, and interference with daily activities. Currently, there is no standardized scoring rule for how to combine attributes into a composite score or how to use this data longitudinally [71]. Clinical trials may select appropriate items from the library for a given study and generate a custom survey for patients. Feasibility of frequent use of this tool has been demonstrated in an in-clinic setting with lung cancer patients undergoing chemoradiation [72], as well as multiple time points at home in a multi-institutional study of rectal cancer patients receiving multi-modality therapy [73]. In an effort to avoid ascertainment bias introduced by PRO-CTCAE item selection during survey creation, patients may provide supplemental symptomatic AE information via a free text box with dropdown options that dynamically populate terms from the PRO-CTCAE library. These terms may be selected or patients may continue with a free text response. A recent pooled analysis demonstrated that 58% of patients enrolled in three large multi-center trials using the PRO-CTCAE tool provided supplemental symptomatic AE entries [74]. Sixty-two percent of these entries were successfully structured into dropdown menu entries, highlighting both the potential benefit of software tools that better assist patients in finding structured terms that correspond to their symptoms.

Post-operative Assessments

The optimal application of PROs to monitor patients and subsequently intervene to prevent complications following cancer surgery is a topic of active investigation [75, 76]. Several surgical post-operative specific questionnaires have been developed in order to evaluate the impact of surgical procedures on QOL in cancer patients. A recent review noted that PROs are commonly used in the care of breast cancer patients to assess the patient's perspective,

attitudes and expectations in the areas of body image, breast reconstruction, and results of surgery [77]. One common surgical instrument is the BREAST-Q, which includes the domains of satisfaction with breasts, overall outcome, and process of care; and psychosocial, physical and sexual well-being [78]. This measure contains three modules depending on the type of procedure (augmentation, reconstruction, or reduction), and can be used both pre- and post-operatively. Normative data for this tool to provide a clinical reference point for the interpretation of data in breast cancer and reconstruction has recently been published [79]. The BREAST-Q and Concerns About Recurrence Scale [80] have also been used to evaluate the decision to have contralateral prophylactic mastectomy and reconstruction in patients with unilateral breast cancer [81]. PRO data can also be used to counsel patients on which type of surgical intervention they may prefer for their breast cancer treatment [82].

Patients with colorectal cancer are also well-studied, as they often have significant post-operative changes in bowel function that can lead to embarrassment and shame with dramatic impact on their QOL. The Colorectal Functional Outcome Questionnaire (COREFO) consists of 27 items concerning the frequency of symptoms over the previous 2-week period in patients following colorectal surgery [83]. The Colostomy Impact Score was developed and validated in rectal cancer patients living with an end colostomy [84]. This tool includes seven items related to the stoma that were found to most strongly impact an individual's QOL, including odor, leakage, stool consistency, pain at the stoma site, skin problems, herniation, and stoma management help. The Low Anterior Resection Syndrome (LARS) Score was developed and validated in patients with rectal cancer to assess bowel function following surgery [85]. Elements of this tool including incontinence of flatus and liquid stool, frequency of bowel movements, clustering of stools and urgency, and patients are grouped into three categories based on their score: No LARS, minor LARS and major LARS. A recent longitudinal follow-up study demonstrated that the prevalence of major LARS did not change over time, and nearly 50% of patients experienced major LARS seven to sixteen years after surgery [86]. The Postoperative Recovery Profile (PRP) is a 19 item, multi-dimensional survey designed to evaluate the progress of postoperative recovery and potential long-term effects [87]. It contains elements in the dimensions of symptoms, function, psychological, social and activity. This instrument identified several factors that seemed to be related to poorer recovery, and patients with these issues may benefit from individualized follow-up routines during the recovery period [88].

The Dysfunction After Upper Gastrointestinal Surgery (DAUGS) questionnaire was developed to assess post-operative function in patients following gastric and esophageal cancer surgery [89]. This tool assesses items in the domains of activity, food intake, reflux, dumping syndrome, nausea and vomiting, difficulty swallowing, and pain. The modified Korenaga Score has also been used to evaluate patient's QOL following gastrectomy for cancer [90, 91]. This tool assesses symptoms related to appetite, consistency and volume of food tolerated, eating frequency, eating time, postprandial fullness, heartburn, diarrhea, constipation, nausea, vomiting, insomnia, weight loss, dysphagia, and dizziness.

Significance of Patient Reported Outcomes

Traditional surgical clinical outcomes have focused on perioperative morbidity and mortality and oncologic outcomes such as recurrence-free survival and disease-specific survival. These outcomes are often reported in administrative and clinical databases and allow for easy capture and quantification. While such outcomes are important and allow for benchmarking and hospital- and disease-specific tracking, these types of outcome measures do not incorporate the patient perspective of their illness and medical care or the potential functional and psychological limitations that result from their disease and its treatment. PROs allow for self-reporting of patients' health status.

It is, however, important to note that PROs are not truly subjective instruments. Many of these tools undergo a rigorous development and validation process in order to demonstrate objectivity, validity and reproducibility. It is also important to distinguish PROs from measures of patient experience, which, while self-reported, focus on the description of elements of satisfaction around a clinical encounter. Patient experience has been defined as "the sum of all interactions, shaped by an organization's culture, that influence patient perceptions across the continuum of care"[4].

PROs can be utilized to focus interventions to expediently identify developing issues with patients post-operatively and intervene in an effort to reduce or prevent subsequent morbidity. While symptoms are carefully managed after surgery in the inpatient setting, once discharged, patients enter into a potential vulnerable time until their next follow-up. As ERAS programs become more widely adopted, there are increasing opportunities to proactively address shorter post-operative lengths of stay. There are many opportunities to proactively address and manage symptoms in patients in an effort to avoid complications, readmission and urgent care evaluations. PROs vary across hospitals and surgeons and may provide an opportunity to improve quality and decrease variation [92]. Evidence is also emerging that patient's poor perception of their health preoperatively may be associated with the development of postoperative morbidity and readmission following cancer resection, suggesting that such patient concerns should be considered when embarking on treatment decisions and used to identify higher-risk patients who may need more targeted pre-and post-operative interventions [36, 93]. In addition, the occurrence of complications can affect how patients view their HRQOL long after surgery, particularly with respect to anxiety [29].

Future Avenues

While there has been enthusiasm for PROs in cancer surgery, challenges remain. The collection of these data can be time-consuming, labor intensive, and expensive. Furthermore, there are limitations to the applicability of the current PROs to specific cancers and surgical procedures. Identified areas for future directed research for PROs in surgery include incorporation of PROs in the decision-making process, integration of PROs into the electronic health records, and measurement of a global construct of quality in surgery including PROs [10]. The Prospective Multicentre Cohort Study of Patient-Reported Outcomes and Complications Following Major Abdominal Neoplastic Surgery (PATRONUS) Study began enrollment in early 2018. This is a non-interventional, prospective, multicenter cohort study that seeks to investigate how perioperative

complications affect cancer-related symptoms and HRQOL in patients undergoing abdominal cancer operations [94]. This study will evaluate the association of clinical outcomes and PROs.

In addition, development and implementation of electronic PROs (ePROs) to actively monitor perioperative patients frequently and potentially in real time is on the horizon [95]. The authors are involved in the prospective, multicenter Symptom Management IMplementation of Patient Reported Outcomes in Oncology (SIMPRO) Research Center, which will develop, implement, and evaluate a multi-component ePRO reporting and management system to improve symptom control for patients recovering from cancer surgery (as well as patients receiving chemotherapy). The study will include an implementation and dissemination science framework to guide future ePRO interventions to improve cancer care delivery. Overall, issues related to the creation of the infrastructure for monitoring and intervening in care with PROs are the topic of much research.

Conclusion

Multiple PRO assessment tools exist for the evaluation and management of patients undergoing cancer surgery. Research was initially focused on demonstrating the validity of these instruments and, more recently, has shifted to the evaluation of their potential uses in measuring the effectiveness of surgical treatments for cancer as well as to the implementation of PROs as part of standard practice. Surgeons are increasingly accepting that PROs offer additional information to help tailor treatment options and improve the quality of healthcare in the perioperative period. Additional research focusing on the rigorous evaluation of disease- and treatment-specific measures continues to accumulate. The next steps in PROs implementation will focus on strengthening the infrastructure to effectively utilize ePRO systems to help manage postoperative symptoms and complications, in order to decrease morbidity and improve QOL.

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Synopsis:

This article will review instruments commonly used to collect patient reported outcomes (PROs) in cancer patients who undergo surgical treatment and discuss the association of PROs and health-related quality of life measures with traditional surgical complications.

Table.

Commonly Used Assessment Tools in Surgical Oncology

Type of Questionnaire	Name (Ref #)	Abbreviation	# of Questions	Focus Areas
General				
	Medical Outcomes Study 36-Item Short-Form Health Survey (14)	SF-36	36	Limitations in physical activities, social activities, and usual role activities; bodily pain; general mental health; vitality; and general health perceptions
	Medical Outcomes Study 20-Item Short-Form Health Survey (15)	SF-20	20	Physical functioning, role functioning, social functioning, mental health, health perceptions, and pain
	Spitzer Quality of Life Index (16)	Spitzer QOL Index	15	Activity, daily living, health, support, outlook
	EuroQol-5D (17)	EQ-5D	15	Mobility, self-care, main activity, social relationships, pain, mood
	15D Instrument of Health-Related Quality of Life (18)	15D	15	Mobility, vision, hearing, breathing, sleeping, eating, speech, elimination, usual activities, mental function, discomfort and symptoms, depression, distress, vitality, sexual activity
Symptom-Specific				
	Gastrointestinal Quality of Life Index (30)	GIQLI	36	Core symptoms, physical items, psychological items, social items, GI specific symptoms
	Gastrointestinal Symptom Rating Scale (31)	GSRS	15	Upper and lower GI symptoms
Cancer-Specific				
	European Organization for Research and Treatment of Cancer QLQ-C30 ^a (34)	EORTC QLQ-C30	30	Function Scales (Physical, Role, Cognitive, Emotional, Social, Global QOL) and Symptoms (Fatigue, Nausea/Vomiting, Pain, Dyspnea, Sleep, Appetite, Bowels, Financial Impact)
	MD Anderson Symptom Inventory (43)	MDASI	19	Core symptoms (13) and Interference items (6)
	Rotterdam Symptom Checklist (49)	RSCL	34	Physical and Psychological Symptoms
	Functional Assessment of Cancer Therapy-General ^b (59)	FACT-G	33	Physical Well-Being (8), Social/Family Well-Being (8), Relationship with Doctor (3), Emotional Well-Being (6), and Functional Well-Being (8)
Post-operative				
	BREAST-Q (78)	BREAST-Q	Variable	Satisfaction with breasts, outcome, surgeon/team and information; Psychosocial, Sexual, Physical Well-being
	Concern About Recurrence (80)	Concern About Recurrence	4	Frequency, intrusiveness and degree of stress; perceived risk of recurrence

Type of Questionnaire	Name (Ref #)	Abbreviation	# of Questions	Focus Areas
	Colorectal Functional Outcome (83)	COREFO	27 (26 scored)	Incontinence (9), Social Impact (9), Frequency (2), Stool-related aspects (3), Need for Medication (3)
	Colostomy Impact Score (84)	CIS	7	Negative impact on QOL from colostomy
	Low Anterior Resection Syndrome Score (85)	LARS Score	5	Frequency of incontinence for flatus or stool, frequency of bowel movements, clustering of stools, urgency
	Dysfunction After Upper Gastrointestinal Surgery (89)	DAUGS	31	Slower activity due to decreased food intake, Reflux, Dumping, Nausea and Vomiting, Deglutition Disturbances, Pain, Difficulty in Stool Formation and Passage
	Korenaga Score (90)	Korenaga Score	16	Food Intolerance, Body-Weight, and Performance Status

^a Additional supplemental domains available for specific cancers: esophagus (OES18/OES24), lung (LC13), stomach (STO22), head and neck (Head and Neck Module), and breast (B23).

^b Disease specific versions exist for specific cancers: esophagus, gastric, lung, hepatocellular, head and neck, and bladder/prostate.