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Patient-reported Symptoms and Quality of Life Integrated into Clinical Cancer Care

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Abstract

Objectives—To provide an overview of research and practice related to patient-reported symptom and quality of life assessment integrated into clinical care.

Data sources—Literature retrieved through the PUBMED and CINAHL databases.

Conclusion—Assessing and incorporating patient preferences, engaging the patient in self-report and extending the interaction to the place and time favored by the patient are necessary to bring meaning to the term, *patient-centered*. There is beginning evidence that these approaches can make a difference, improving care quality.

Implications for nursing practice—Oncology nurses no longer need to be constrained by paper symptom checklists. Patient-reported symptom and quality of life information can be electronically collected and simultaneously made available for home and clinical use through the utilization of Web-based programs.

Keywords

cancer symptoms; quality of life; patient centered care; clinical informatics; patient reported outcomes

Cancer symptoms and quality of life issues (SQLI) are of the highest priority to oncology clinicians and researchers.¹ Screening for patient-reported concerns is a first step in triaging each patient's needs to the most appropriate provider or service. The workday of an oncology nurse is often focused on symptom assessment, treatment and teaching across the broad spectrum of the individual patient's physiological, emotional, sensory and behavioral experiences. Attending to treatment-related side effects promotes safe delivery of cancer therapies. Physician specialists in oncology are keenly aware that adverse events reported by patients reduce the likelihood of administering the full therapeutic dose required to adequately treat a malignancy.² Providing focus to the subjective report by the patient in the clinic in order to efficiently address the most important concerns without extending the time required for face-to-face assessment is the ideal in resource-constrained environments.

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Collecting patient-reported information throughout the trajectory of treatment was once accomplished solely through the verbal *history* component of the clinician's assessment. By the 1990's several large cancer clinics were utilizing paper symptom checklists to facilitate the patient reports.³ With the advent of the electronic resources and then the Internet, patient-reported experiences are now being collected with interactive methods, not only in clinics, but also at times and locations more convenient to the patient. The purpose of this article is to review various approaches to methods and procedures that have been developed and tested as patient-centered technologies for SQL self-report and the integration of these approaches into clinical cancer care.

Why must we carefully assess the SQL experiences of our patients?

Cancer symptoms indicate physiologic changes associated with disease and treatment toxicity, and also reflect linkages to patients' perceived reality, including social, psychological and cultural factors.⁴ Pain and fatigue are the two pre-eminent, significant symptoms that are addressed in virtually every publication about cancer experiences and supportive care of persons with cancer. The prevalence of elevated psychosocial distress among patients with cancer at diagnosis and recurrence is reported to be at least 30%,⁵ with clinical depression occurring in 25% of cases.⁶ Kroenke et al.⁷ reported highly prevalent somatic symptoms in 405 subjects with pain and depression from 16 rural cancer clinics; the most common being fatigue, sleep concerns and memory difficulty. This group of symptoms also was strongly associated with self-reported bother and disability scores. Most research literature about cancer treatment and symptoms assumes that symptoms mediate between types of treatment and diminishing aspects of function. For example, Given and colleagues⁸ studied the relationship between symptoms and physical functioning in elderly patients with cancer, reporting a significant relationship between symptoms and function which was independent of treatment modality or cancer site. With the incidence of individual and groups of cancer symptoms at such a high level across various diagnoses and stages and the apparent impact of such experiences on dimensions of quality of life, the consequences of inadequate symptom management are complex and can be overwhelming to patients and their caregivers. For example: animal models suggest that uncontrolled pain may shorten survival,⁹ severe mucositis¹⁰ or radiation-associated skin changes¹¹ put patients at risk for additional complications¹² and gastrointestinal complications can compromise quality of life in practically all domains.¹³ Adequate SQL assessment and management also have implications for cancer therapy outcomes. For example, in squamous cell carcinomas of the head and neck and cervix, longer overall treatment times due to delays have resulted in poorer cancer-control outcomes.¹⁴ The adverse effect of treatment prolongation in cervical cancer by high-dose-rate brachytherapy suggests that poorly-controlled treatment-related symptoms are a key source of treatment delays.¹⁵ The program of research conducted by the Givens' team with multiple diagnoses in the community setting has informed our understanding of cancer symptoms in ambulatory patients and how home monitoring, nursing support and self-care impacts symptom intensity^{16, 17}, hospital admissions¹⁸ and emergency room care.¹⁹

Other demographic variables and treatment scenarios bring cancer SQLI to the forefront. Because adults over 65 years comprise 61% of all patients with cancer,²⁰ we must note that co-morbid illnesses experienced by older adults, notably congestive heart failure, have deleterious effects on cancer survival.²¹ Unfortunately, there is a paucity of information concerning the factors that modify treatment effect, tolerance and toxicity in elderly patients. Quality of life and symptom profiles are important factors when making treatment decisions in prostate cancer²² and breast cancer care. This may be particularly true when the disease is either incurable (stage 4) or likely to be cured with any of a variety of approaches (stage 1).

There is evidence that clinicians under-report toxicities for patients with breast cancer and that patient-reported outcomes are more accurate.²³

Early screening for psychosocial distress is recommended as a preferred practice by the National Quality Forum²⁴ and the National Comprehensive Cancer Network (NCCN)²⁵ and may enable clinicians to identify patients at higher risk and intervene to prevent development of crisis events.²⁶ Discussing SQLI in the clinic can promote partnership between clinicians and patients, validating the patients' experiences and enhancing communication and satisfaction.²⁷ Yet, recent trends in ambulatory care to reduce clinician time spent with each patient have rendered existing measures less feasible.⁶ Rapid, predictive screening may help reduce unnecessary health care utilization costs and prolonged medical treatments, as well as enhance quality of life.²⁸ The challenge of efficient, systematic and meaningful assessment is important and timely in current clinical cancer settings.

Because of developments in the science of cancer screening, detection, and treatment, plus collaborative involvement of various professionals and consumers, quality of life (QoL) and symptom assessment is now an established, integral component of cancer clinical trials. While major comprehensive cancer centers have developed and reported the routine clinical use of multi-symptom assessment tools,²⁹ the routine clinical use of QoL questionnaires (including symptom scales) has been reported and evaluated only on a limited basis and rarely in the United States (US).^{27, 30–34}

How can we improve patient–clinician communication about SQL?

Various strategies to enhance communication between patients with cancer and clinicians have been studied. Pilot, feasibility studies are plentiful^{34,35} yet randomized trials to establish the efficacy of patient-reported SQL systems enhancing communication or diminishing symptom distress are uncommon. Previous European randomized clinical trials (RCT) in oncology have shown that computerized measurement of patients' symptoms had positive impact on patient-clinician communication. Velikova and colleagues³⁶ compared computerized self-report using the EORTC QLQ C-30, both with or without provision of the printed results to the clinician and to a control group, respectively. A significant, but small difference on mean number of symptoms discussed was found between the intervention group whose clinician received the results and the control group, 3.3 (SD=1.63) and 2.7 (SD=1.63) respectively. The availability of the printed result in the clinic visit did increase the proportion of visits in which certain C-30 symptoms were mentioned, notably insomnia and appetite, but not pain or nausea/vomiting. In a more recent Dutch study, Hilarius et al.³⁷ used a non-randomized, sequential cohort design to test touch-screen C30 assessments in 219 patients and a graphical summary given to 10 oncology clinic nurses. The authors reported that the patients in the post-intervention cohort discussed significantly more symptoms with their nurses. Finally, in a Norwegian trial, Ruland et al.³⁸ reported a significant impact for their interactive tailored patient assessment on chart notes in a study of 145 inpatients with hematologic malignancies or lymphoma. The authors also reported lower symptom distress over time in those patients randomized to use the assessment.

In the one RCT conducted in the United States,³⁹ patients with various cancer diagnoses and stages at two institutions of a comprehensive cancer center (Figure 1) answered the Web-based assessment, Electronic Self Report Assessment-Cancer (ESRA-C). The 660 participants were randomized to an experimental condition in which the patient-reported SQLI were automatically displayed on a graphical summary and provided to the clinical team prior to a treatment visit or the control condition in which no summary was provided. The clinic visit was audio-recorded for each participant and then scored for discussion of

each SQLI. The likelihood of SQLI discussed was significantly higher in the experimental condition, depending on whether SQLI was first reported as problematic ($p=0.032$). The ESRA-C summaries did not extend the clinic visits and clinicians reported the summary as useful. At the cancer center where ESRA-C was developed and tested, the patient-report program is continuing to date as a clinical adjunct to ambulatory visits in the stem cell transplant setting. Nurses view the summary prior to each visit and use the results to initiate focused discussions of SQLI beginning with the patient-ranked, top two problems. (personal communication, R. Ford, 3/7/2011).

Multiple small pilot studies have demonstrated feasibility of computerized SQL assessment in cancer clinics or by remote access, but there have been few evaluations of routine clinical use. Erharter and colleagues in Austria⁴⁰ provided tablet computers to all cognitively intact patients over 3.5 years at a neuro-oncology clinic on which to answer cancer specific QoL and symptom questionnaires. Patient (N=110) and clinician acceptance was reported as “high” but only anecdotal comments were published. DuBenske et al.⁴¹ evaluated a cancer-specific adaption of a web-based data collection application used in 107 Wisconsin patients with advanced cancer and also delivered a real-time clinician report (CR). Study staff interviewed the three physicians and four nurses to examine the use and perceptions of the CR. Using content analysis, the investigators described benefits reported by the clinicians as: enhanced visit communication, including the caregivers’ involvement; and increased early intervention for problematic symptoms. Challenges included functionality and design of the CR; lower use by patients than caregivers leading to questioning the integrity of the reported symptom level; a belief that the screening approach of questionnaire cannot replace verbal interaction between patients and clinicians. Basch et al.^{34, 42} have led an effort to create, validate and test a web-based, patient-reported version of the National Cancer Institute’s Common Toxicity Criteria; preliminary results suggest feasibility of such electronic reporting. Feasibility of in-clinic, pre-visit measurement of patient-reported symptoms also was established by an industry-sponsored initiative at 15 community clinics, however measures reported were limited to whether the clinic staff had implemented key processes involved with the program.⁴³

Why have cancer centers not implemented routine patient-reported SQLI?

Clinician barriers

The manner in which clinicians respond to computer-generated symptom reports or to verbal patient-initiated discussions about symptoms may be barriers. Earlier work at an academic cancer clinic reflects some of this phenomenon. Clinicians in the Cancer Pain Coaching study⁴⁴ were attentive to problems relevant to treatment side effects; however, the results also indicated a pattern of communication during the clinic visit that was typically clinician-oriented, including interruptions and many closed-ended questions. There is also evidence that clinical providers may not always respond to electronic summaries of self-reported symptom and quality of life issues in a way that facilitates communication and subsequent treatment.⁴⁵ The nature of such communication may prevent the patient from sharing significant facts and experiences relevant to cancer pain and thus compromise the quality of symptom management. The mixed results illustrate a possible clinical dilemma; clinicians are intent on helping their patients through the treatment but may attend only to the issues with which the clinician is most familiar. Additionally time constraints, lack of resources for referral, institutional policy or reimbursement issues may preclude comprehensive symptom management and dissuade clinicians from accepting a patient-reported summary. These factors were identified as possible contributors to inadequate symptom care by the National Institutes of Health (NIH) conference panel in 2002.⁴⁶ Assuring expedient clinician access to resources for symptom management and referrals is essential to any attempt to alleviate

symptom distress. Finally, clinicians are not always convinced when planning technologies for patient-reported SQLI that the system will fit well into the established workflow.⁴⁷

Patient Barriers

Preferred method to report SQLI—A barrier for patients as they try to articulate their SQL experiences, and one that is rarely addressed in the professional literature, is that of burdensome, irrelevant or static assessments. Kim et al.⁴⁸ used contingent valuation to ascertain patient preference for symptom reporting approaches; they concluded that patient preference for self-report tools increases when tools are more relevant to patient-specific issues (i.e., customized). Web-based applications have the most potential of any method to deliver not only assessments specific to a particular diagnosis or stage of cancer but also customized to particular characteristics of a patient, such as learning style or language.

Language and cultural issues—Although many immigrants and visitors with minimal English skills are challenged when navigating our treatment settings, Spanish-speaking individuals represent the largest group. In the U.S., Hispanics/Latinos are estimated to be 15.1% of the total population and are the fastest-growing minority group.⁴⁹ Over 12% of the U.S. population speaks Spanish at home.⁵⁰ New cancer cases were estimated to be 98,900 and deaths from cancer 28,800 in this population for 2009.⁵¹ Despite the large population, Hispanics are an underserved population on various health care access and quality measures. Barriers may vary by geographic locations, but often include language, insurance coverage, immigration status, cultural beliefs, and lack of services. Moreover, grouping all Hispanics masks diversity by geographic location, socioeconomic characteristics, level of acculturation, and national origin/heritage which have been linked to cancer^{52,53} and other health outcomes.^{54–58} Given the diversity and needs of this population, health care services and clinical care are needed that are linguistically appropriate and culturally sensitive. Cultural sensitivity has been defined with regard to health care and health information that incorporates the health attitudes, customs and beliefs of its target patient or consumer population.⁵⁹ A model has been developed for increasing cultural sensitivity of health promotion and disease prevention interventions by matching both surface structure (superficial, observable characteristics) and deep structure (social, cultural, psychological, historical, and environmental factors) of the target population.⁶⁰ For addressing SQL, three related areas are especially salient for Hispanic patients: the symptom experiences; patient-provider communication factors; and the information needs and seeking behaviors of patients.

Studies of cancer treatment-related symptoms in Hispanic patients regularly find higher symptom burden, especially depression and pain.^{61, 62} This is variously attributed to patient culture, family beliefs and religion (e.g., a stoic attitude toward pain)^{63, 64} and physician underestimation of the problems.^{65, 66} Religion or spirituality is consistently found important, both as an area of psychosocial need and as a coping resource^{67, 68} as is interest in complementary and alternative medicine to manage treatment side effects.⁶² Poor provider-patient communication adversely impacts the ability of patients to communicate their SQL experience and understand and adhere to SQL management recommendations. A survey of 624 key opinion leaders around the country, conducted by the NCI's National Hispanic/Latino Cancer Network, identified patient-doctor communication as one of five cancer prevention and control issues of greatest significance to the Hispanic-Latino population.⁶⁹ A study of low-income patients treated for breast cancer suggested that symptom disparities can be moderated by intervention targeting patient-provider communication.⁶⁶

Health Care System Barriers

Health care consumers have experiences, opinions, knowledge and objective data about their health that are not systematically incorporated into their care. Human biology and behavior are complex under normal health states. These complexities are intensified in the context of health risks or adverse health conditions. Modern assessment and monitoring of an individual's health status, and delivery of cutting-edge interventions, require orchestration of not only patients and direct care providers, but also an entire community of technology experts, innovators and service providers. However, our current health system is characterized by limited face-to-face patient-clinician contacts that are scheduled at inconvenient times and locations. Our health systems have often failed to provide adequate opportunities for the integration of clinical data with patients' subjective and objective information, which are required to provide care that is "safe, effective, patient-centered, timely, efficient, and equitable" (p. 25).⁷⁰ Time constraints within the context of an exam visit and patients' hesitancy to verbally report certain symptoms,⁷¹ can result in missed or under-communicated SQL of important clinical significance. This has become such an important issue in oncology care that a bill was introduced in the US House of Representatives (HR1927) in 2009 that would mandate reimbursement for nurse visits for all patients on oral chemotherapeutic agents and provide increased funding for symptom management research.

Changes in payment and organization of care have resulted in a changing work environment for many clinicians. Many health care services, including much of the care provided to cancer patients, have shifted from inpatient to ambulatory settings.⁷² A move from traditional fee-for-service payment systems to capitated care has created incentives for health care organizations to provide care using fewer resources.^{73, 74} One common result of these changes has been an increase in the numbers of ambulatory patients evaluated within a given time period. Patient surveys have reported that clinicians spent less time talking with patients and offered less explanation of care in a managed care setting than in settings primarily reimbursed through traditional fee-for-service payment structures.⁷⁵ At the same time, effective clinician-patient communication is increasingly emphasized as an important aspect of quality cancer care, as reflected in standards for clinical care and clinical outcomes promoted by government⁷⁶ and accreditation bodies⁷⁷ and by oncology professionals.^{78, 79} The Patient Protection and Affordable Care Act (HR 3590)⁸⁰ enacted in March 2010, has mandated the creation of an 'Innovation Center' within Medicare by 2011 to test approaches to improve quality and outcomes while reducing costs.

Conclusion

The deployment of assessment techniques must be distributed in all locations as health care delivery in the United States moves beyond the boundaries of the centralized, hospital based system. Assessing and incorporating patient preferences, engaging the patient in self-report and extending the interaction to the place and time favored by the patient are necessary to bring meaning to the term, *patient-centered*. There is beginning evidence that these approaches can make a difference, improving care quality. Technological approaches to distributing patient assessments and interventions in clinical cancer care can offer the patient an opportunity to participate more fully in the clinical process, allowing information gathering and follow-up to occur at a convenient location and time, and without the clock ticking away minutes of an office visit.

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Figure 1.
Patient completing ESRA-C prior to clinic visit on wireless, touch-screen notebook computer