The current trend of administering a patient-generated index in the oncological setting: a systematic review

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Abstract

The patient-generated index (PGI) is a more novel approach to evaluating health-related quality of life (HRQOL) that allows patients to formulate their own responses in an open-ended format in order to measure HRQOL based on each patient's own stated goals and expectations. To date the use of PGI in the setting of patients diagnosed with cancer remains relatively less common compared to other health conditions. This systematic review primarily aims to identify current literature in which PGI has been used as a tool to assess quality of life in cancer patients. A systematic review using the MEDLINE database from January 1990 to July 2013 was performed with the following search terms to identify the implementation of PGI in oncology settings: (PGI OR *patient generated index* OR patient-generated OR patient-reported OR *patient generated* OR *patient reported*) AND (cancer OR oncology OR tumor OR neoplasm OR malignancy). Of the 2167 papers initially identified, 10 papers evaluated quality of life in oncology patients by collecting free-form responses from the patient, 4 of which actually used PGI. An overarching theme observed in these studies highlighted the concerns mentioned by patients that were not targeted or detected by standardized quality of life measures. While implementing the PGI may require slightly more investment of resources in the beginning, the potential implications of allowing patients to characterize their quality of life on their own terms are tremendous.

Introduction

Over the past few decades, the practice of modern health care has borne witness to a paradigmatic evolution in which emphasis is increasingly placed on adopting a more holistic and patient-centered[1] approach to patient care. As a reflection of this, health-related quality of life (HRQOL) surveys that consider the patient's quality of life (QOL) - as opposed to focusing purely on quantitative metrics such as presence versus absence of diseases, or survival times - have become an important component in the delivery of personalized care. Current HRQOL surveys, however, are not without limitations. For instance, many are formatted such that patients rank their agreement with pre-specified statements pertaining solely to symptom and physical functionality. As a result, patients do not have the option to express the unique perspectives, goals, or priorities that they may find to be particularly meaningful. Traditional QOL measures also assume consistent themes among patient experiences, and probe feedback based on generic answer choices that may not account for the diversity inherent in the patient population. Furthermore, existing outcome measures assume that all dimensions measured on a certain patient-reported outcome (PRO) are weighted equally by the patient, which may not be an accurate assumption to make.[2]

The patient-generated index (PGI) is a recent and novel approach to evaluating HRQOL. In brief, the PGI consists of three stages in which patients: i) self-identify the most important areas or activities of their lives affected by their condition; ii) score the degree to which each area is affected; and iii) allocate points among the items listed to represent the amount in which they would like each area improved.[3] Thus, unlike traditional HRQOL surveys, the PGI is unique in that it allows patients to formulate and voice their own responses in an open-ended format, which may improve the clinician's ability to identify individual patients' goals and expectations for their care (Figure 1).

To date, PGI-based surveys have already been validated and administered to patients with low back pain, menorrhagia, suspected peptic ulcers, varicose veins, atopic dermatitis, lower limb amputation, and stress urinary incontinence.[3-7] Collectively, these studies have substantiated the importance and value of PGIs in accounting for individual patients' hopes and expectations of treatment. When Tavernier *et al.*[8] conducted interviews to confirm the ability of the PGI to accurately define quality of life as an individualized construct, 66% of patients felt the PGI captured the areas most relevant to their current HRQOL as well as the *essence* of their current HRQOL.

Interestingly, the use of PGI in the setting of patients diagnosed with cancer remains relatively less common. In oncological practice, the Functional Assessment of Cancer Therapy (FACT)[9] and European Organization for Research and Treatment of Cancer (EORTC)[10] questionnaires are among the more widely used HRQOL surveys for cancer patients, and have been validated for disease-specific modules including breast, lung, head and neck, esophageal, ovarian, gastric, cervical,

multiple myeloma, prostate, colorectal, liver, and brain cancers.[9,11-15] It seems, however, that this patient population may derive great benefit from individualized HRQOL measures such as the PGI. Conventional metrics when discussing treatment success or failure in cancer have largely revolved around goals such as prolongation of survival and/or extension of remission times. However, given their potentially terminal illness, cancer patients may derive value in aspects of their life not pertaining to survival, and these factors may not be immediately recognized and, by extension, inadvertently ignored by the physician. The results of such PGI questionnaires may thus prove enlightening to physicians. Especially in oncologic sub-specialties such as neuro-oncol-

ogy that deal with highly lethal tumors, it is uncertain but nevertheless worth investigating whether shifting the focus from treatment paradigms to patient QOL may improve patient satisfaction and care.

Given the rising evidence of the value of HRQOL measures as a prognostic factor for survival in cancer patients, QOL may play a more important role in long-term survival than originally considered.[16-22] Montazeri conducted a systematic review of the literature from 1982 through 2008 investigating HRQOL as prognostic indicators in cancer patients,[17] and found significant evidence for a positive relationship between HRQOL and the duration of survival, with pre-treatment HRQOL scores being the most reliable.[17] Application of PGI as an

Figure 1. Stages of the patient-generated index to evaluating health-related-quality-of-life.

instrument for evaluating QOL in patients diagnosed with cancer may thus offer insights not readily apparent, and has the potential to increase focus on factoring QOL into treatment decisions. This systematic review, therefore, primarily aims to identify current literature in which PGI has been used as a tool to assess QOL in cancer patients. The potential value of a PGI tailored to cancer patients is enormous, especially because it would allow the patient to participate in the decision-making process which may ultimately alter the course of his or her treatment.

Methods of research

A systematic review of the English literature using the MEDLINE database from January 1990 to July 2013 was performed. The most recent search was conducted in July 2013 with the following search terms: (PGI OR *patient generated index* OR patient-generated OR patient-reported OR *patient generated* OR *patient reported*) AND (cancer OR oncology OR tumor OR neoplasm OR malignancy). Inclusion criteria were the following: i) papers written in English; ii) patient samples including cancer patients; iii) administration of HRQOL or PGI questionnaires; and iv) articles specifically allowing cancer patients to define and rate their own quality of life through free-form responses. While the PGI, in and of itself, is a recognized questionnaire with a specific, validated format, we considered any survey or in which patients were allowed to provide such free-form responses as *PGI* questionnaires, regardless of variations in individual formats, since the main focus was to identify unique benefits inherent to giving patients freedom to express concerns in their own words. Exclusion criteria were as follows: i) questionnaires lacking free-form answer choices; ii) questionnaires with pre-set scoring systems; and iii) questionnaires that involved descriptions of purely disease-specific symptoms. Three independent blinded reviewers identified all articles, and initially screened them using the title and abstract alone. All articles that did not immediately meet exclusion criteria were individually reviewed in full text to confirm eligibility. Given the descriptive nature of this review, no outcomes data were collected.

Results

Article selection and search results

Based on the search terms, a total of 2167 papers were initially iden-

tified. More detailed screening revealed a total of 10 papers that evaluated quality of life in oncology patients by collecting free-form responses from the patient. Table 1 presents a comprehensive summary of the individual studies retrieved from the systematic review.[23-32]

The topics studied, as stratified by oncology classification, included the following: 4 multiple cancer diagnoses, 2 head and neck cancers, 1 hematological malignancy, 1 rectal cancer, 1 bladder cancer, and 1 lung cancer. All ten studies were case series with level 4 evidence based on the guidelines established by the Oxford Center of Evidence-Based Medicine (CEBM), which is defined as case series or analyses without sensitivity analysis. Four of the ten studies[23-26] used the validated PGI while the remaining six studies captured free-form responses from patients in describing their quality of life in unique ways not necessarily through a standardized, validated PGI.

Utilization of patient-generated index in oncology

Camilleri-Brennan *et al.*[23] was the first group to adopt the PGI model for study in oncology. A total of 32 patients with rectal cancer were given the PGI, as well as the more traditional SF-36, quality of life questionnaire-Core 30 (QLQ-C30), and QLQ-CR-38 questionnaires as benchmark. As expected, the variability in patient concerns was dramatic, running the gamut from concern over *sports* to concern over *work* with *social life* as the most commonly cited cause for concern. When compared to the SF-36, QLQ-C30, and QLQ-CR-38, PGI scores were found to correlate positively with traditional QOL variables but negatively with symptom variables. Overall, the PGI was more sensitive to changes in HRQOL than all three standardized scales; only micturition problems in the QLQ-CR38 were deemed more sensitive (P=0.01).

Tavernier *et al.*[27] were able to validate the PGI as a measurement of quality of life against the already-established distress thermometer and QLQ-C30 measures for 86 cancer patients receiving their first course of radiation therapy.

In head and neck cancers, pre-treatment PGI score in 40 patients predicted each individual's QOL 6-8 months after treatment (P<0.001) and correlated with both global QOL and health status (EORTC) and mental component summary scores (SF-12).[24]

Other studies in cancer, while not specifically applying the PGI, utilized and tested for similar principles of generating open-ended responses. In lung cancer, Tishelman *et al.*[28] interviewed 343 patients with inoperable lung cancer by asking: *What do you perceive as most distressing at present?* Patient responses were diverse, and were broadly subdivided into 5 overarching categories (bodily distress, life situation, iatrogenic, distress unrelated to above, and no distress). Although most patients (90%) expressed concerns over bodily symptoms, concern over life situation and iatrogenic distress was reported in 80% and

Table 1. List of the 10 oncology studies investigating patient-generated health-related-quality-of-life (HRQOL) measures with the study type, level of evidence, sample size, cancer diagnoses, and the specific type of patient generated HRQOL measure employed.

Author	Year	Sample size	Cancer diagnoses	Patient-generated HRQOL measure used
Corner *et al.*[31]	2013	3300	Multiple	Free text comments box at end of 4 standard surveys
Cella *et al.*[32]	2011	533	Multiple	Patient generated 10 item most important symptom list
Morganstern *et al.*[30]	2011	50	Bladder	Brief quality of life appraisal profile
Tavernier *et al.*[26]	2011	86	Multiple	PGI
Tishelman *et al.*[28]	2010	343	Lung	Interview to asses most distressing concern
Llewellyn *et al.*[25]	2007	50	Head and neck	PGI
Llewellyn *et al.*[24]	2007	82	Head and neck	PGI
Tasmuth *et al.*[27]	2006	102	Multiple	Phone interview assessing patients concerns
Frick *et al.*[29]	2003	79	Hematologic	SEIQoL-DW
Camilleri-Brennan *et al.*[23]	2002	36	Rectal	PGI

HRQOL, health-related-quality-of-life; PGI, patient-generated index; SEIQoL-DW, schedule for the evaluation of individual QoL - direct weighting.

27% of patients, respectively. Comparatively, this open-ended format was able to capture a minimum of 32%-38% of unique responses not covered by benchmarks.

Frick et al.[29] analyzed the schedule for the evaluation of individual QoL - direct weighting (SEIQoL_DW) in 79 patients undergoing autologous stem cell transplantation for cancers of hematologic ontogeny. Of interest, they found family to be the most important concern (87.5% of patients) while spiritual/religious concerns ranked lowest (13.9%).

In bladder cancer patients, Morganstern et al.[30] evaluated pre-operative concerns and goals for surgical intervention. Seven arenas of patient life - achievement, problem resolution, problem avoidance, prevention, maintenance of status quo, acceptance of disease, disengagement from roles or responsibilities (e.g. family), and reaching important life events/milestones - were evaluated. In contrast to the standard PGI, patients could list 3 answers per question, leading to 21 answers total per patient.

Corner et al.[31] asked 3300 cancer patients, *If you have anything else you would like to tell us about living with and beyond cancer, please do so here*. Responses, as expected, varied dramatically. As an illustrative example, 62 patients discussed social/financial problems such as impact on family/friends/relatives (n=14). Another 122 patients designated emotional/psychological problems such as poor body image (n=14) and genetic concerns for family (n=8). However, unlike the PGI, patients were not required to place weights in order to stratify relative importance of values.

Tasmuth et al.[27] interviewed 102 patients with cancers of different types by phone using a structured questionnaire to determine in more detail their description of pain. They were also able to assess their level of satisfaction with their care and they were asked free comments about the palliative care they had received. For the free comments, 39% of the patients mentioned the palliative care they received to be of poor quality with the primary concerns surrounding pain, quality of care, and psychosocial support. 53% of the patients wished to receive more information about their disease and treatment.

Cella et al.[32] investigated the identity and relative importance of various symptoms or concerns related to chemotherapy in order to develop symptom indices for 11 different cancers. The authors surveyed 533 patients with diagnoses that included bladder, brain, breast, colorectal, head and neck, hepatobiliary/pancreatic, kidney, lung, ovarian, prostate cancers and lymphoma. The patients generated 10 important symptoms/concerns they felt physicians should monitor when assessing the value of chemotherapy for their given disease. They were then asked to rate on a scale from 0 to 10 the relative importance of the reported symptoms/concerns. Based on the ranking of the symptoms, a list was created for each cancer type and used to create a physician survey. Physician experts in each of the listed diseases were surveyed to differentiate the symptoms that were predominately disease based from those that were treatment based. The patient responses were also compared against the standard Functional Assessment of Chronic Illness Therapy (FACIT) measurements, and any previously unmentioned items were added to the physician survey. 11 new symptom indices were created with the symptoms and concerns receiving the highest ranking across all 11 cancers being lack of energy (fatigue), ability to enjoy life, worry that the condition will worsen, nausea, ability to sleep well, contentment with QOL, and pain.

Discussion

Traditional HRQOL surveys place a heavy emphasis on assessing symptoms that patients endure rather than focusing on their perspectives or goals for therapy that may potentially yield deeper insight into their priorities and what they individually consider important in defin-

ing QOL. Furthermore, pre-defined answer choices administered in standard questionnaires may be insufficient to capture the diversity inherent in the patient population. Llewellyn et al.[25] suggest that coping strategies and responses to a cancer diagnosis play a large role in contributing to a patient's perception of QOL which, in turn, influences patient responses to patient-reported outcome measures of QOL. With this in mind, the authors believe there is promise in improving QOL that may narrow the gap between patients' hopes, their expectations, and the reality of their current condition. Undoubtedly, others have found similar value in using PGI to evaluate other health conditions.[3-7] Thus, open-ended patient answers are important because cultural, religious, or personal beliefs about illness may ultimately shape patient outcomes, a phenomenon that may not be accurately captured by many contemporary surveys.[24,25] More often than not, patients will also report satisfaction despite existing concerns if not prompted to elaborate.[27] The advantage of the PGI therefore lies in its ability to both give patient freedom to dictate their responses and to extract unique QOL measures that may transcend beyond the constraints of physical functioning and wellness. The value of free-form responses is worth noting, as studies implementing interviewing or focus groups[33-35] were able to glean insights into patient perspective that would have otherwise escaped detection in traditional HRQOL surveys. These types of responses thus offer an extra dimension of dynamism to our understanding of patient values. Furthermore, PGI-related questionnaires can help providers address patient understanding of their care plan, which can have ramifications on overall patient outcome. Among 102 cancer patients undergoing palliative care, for example, Tasmuth et al.[27] demonstrated that greater than 50% patients declared their knowledge of their condition and treatment plan to be inadequate. An overarching theme frequently observed in these studies highlighted the concerns mentioned by patients that were not targeted or detected by standardized QOL measures. However, the PGI surveys were useful for measuring the inherently dynamic and subjective aspect of QOL that, while not adequately discerned by generic quality of life devices, can sufficiently complement more self-reported, empirical, patient-reported outcome measures of QOL that assess physical function. In essence, patients may lend insight through their responses into physical limitations not captured by QOL measures administered with set questions.

Among these subjective factors inadequately identified by questionnaires, features of patient care that could be improved by better communication with physicians and the health care system were consistently identified. A common pattern demonstrated that patients often felt ill-prepared in regards to what to expect from the impact of cancer diagnosis and the side effects of treatment.[27,28,31] In fact, Tasmuth et al.[27] found that more than half of patients had wished to receive more information regarding their disease and treatment. In patients with lung cancer, more than one quarter of patients close to the end of life reported some facet of contact with health care system as causing them most distress.[28]

Aside from their ability to bring awareness to the shortcomings of individualized patient care, these PGI-themed surveys found that emerging themes among patient responses satisfactorily complemented the more formal patient-reported outcome measures and provided understanding of QOL issues in cancer patients. The studies that validated their novel patient-generated measure found positive correlations with currently implemented QOL assessments, and were even sensitive enough to detect changes in quality of life over time.[23,24,26,29]

However, implementation of PGI surveys also present with several drawbacks, the most salient of which is that there is a lack of a structured approach to categorize free-form answers. In that manner, it may prove more beneficial to patients and clinicians alike to administer PGI surveys as complementary tools, and not as replacements, to standard HRQOL surveys. Furthermore, it is worth to noting that existing PRO

measures of HRQOL carry certain advantages, including overall convenience in scoring results and the ability to compare across populations and establish meaningful cut-off scores. In contrast, the PGI requires more extensive resources for developing and training personnel to score answers in a standardized format and are less amenable for deriving comparisons across populations. As a matter of such, these aforementioned factors may explain why PGI surveys have yet to be adopted on a wider scale. Another potential limitation lies in the lack of a *set* PGI, which could lead to a lack of standardization as well as discrepancies between reports issued by different institutions.

Nevertheless, while implementing the PGI may require slightly more investment of time and resources to implement, the potential benefits and implications of allowing patients to characterize their quality of life on their own terms could be remarkable. The ten studies examined in this systematic review shed light on otherwise unapparent sentiments expressed by patients regarding not only their individual needs relevant to optimizing their care, but also aspects of their encounter with the health care system that could be improved. Future research could potentially aim to compare and contrast potentially novel PGI surveys with currently established questionnaires in each field of medicine in order to identify any benefits or insufficient information that may be ameliorated with new designs to sample patient beliefs.

Conclusions

Of the PGIs currently in practice, only a few are applied in the field of oncology. While the current study reinforces the validity and power of PGIs in assessing HRQOL for cancer, no PGI exists to measure quality of life among brain tumor patients. It is especially this patient population, however, that may benefit from a PGI that would allow physicians to better understand their goals in the setting of a more dire diagnosis. If a PGI administered to brain tumor patients can guide physicians' decision-making in tailoring treatment toward extending survival or maintaining quality of life, then in a sense, physicians will have ultimately succeeded in offering the highest quality care to their patients by addressing their most relevant and deepest needs.

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