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Editorial

Patient-reported outcome measures in cancer care: Integration with computerized adaptive testing

Introduction

Within the context of bio-psycho-social medicine, a patient-centered approach has been proposed as a pivotal method to achieve better health outcomes (ie, patient survival and quality of life), greater patient satisfaction, and reduced healthcare costs.[1,2] Subsequently, patient-reported outcome measures (PROMs), which directly measure patients' experiences of their health without interpretation or amendment by others, allow the integration of patients' perspectives into their medical decision-making, thereby attracting increasing attention in clinical practice and research.[3] In addition, the Commission on Cancer standards, as updated in 2020 and dedicated to improving the survival and quality of life of oncological patients, reiterates the need for continuous measurement of patients' health outcomes from their own perspectives to identify the problems and guide the ongoing quality improvement initiatives.[4] While the benefits and significance of employing PROMs to guide patient healthcare are well-established, they have not been used by a large number of oncology institutions worldwide due to unsatisfactory feasibility.[5,6] Feasibility emphasizes on necessary key areas including implementation, practicality, acceptability, and adaptation based on the feasibility study design.[7] It may be measured by clinic benefit (ie, patients' outcomes), cooperation of patients (ie, time, completion rates) and acceptance of clinicians' measurement (ie, resources/expense).[8] However, the existing PROMs pose challenges in fulfilling these aspects.[6]

For one aspect, considerably various PROMs and inflexible test strategies impede tracing the trajectory of cancer experience, potentially reducing the quality of patients' outcomes.[9] The variability of PROMs is associated with extensively different cancer experiences among different cancer patients (ie, various types, tumor stage, cancer trajectory).[10,11] The diversity of cancer experiences complicates measurement development. A systematic review of 523 PROMs among patients with cancers identified 203 distinct tools to measure PROMs across 31 domains and found that even within a single domain, there was a marked difference in the tools used.[12] A previous study also demonstrated that the similar domain had widespread inconsistencies in outcome reporting.[13] The variety of PROMs is unfavorable to identifying the common mechanism of the cancer experience which is critical for the rational development of effective cancer care.[14] Besides, traditional PROMs assessments largely rely on paper-pencil method. It is associated with recall bias, a large amount of missing data, and transcription errors.[14,15] In addition, the inflexible test method has difficulty performing outside the clinical setting like home, impeding the tracking of patient's outcomes during the disease trajectory (ie, at diagnosis, during treatment, short- and long-term survivorship, and at end-of-life).[16] Consequently, the diversity measurement of cancer and inflexible test strategy would constitute an obstacle for comparisons across various groups, the monitoring of how these issues change over different trajectories, and the improvement of ongoing supportive approaches, underscoring the need for establishing common metrics.

For the other aspect, the current PROMs have a heavy test burden, limiting cooperation of patients and acceptance of clinicians' measurement. Due to the nature of their disease and treatment, cancer patients often undergo multiple time-consuming appointments, procedures, and tests. A recent review reported that the most frequent patient-level barrier to completing PROMs was the contradiction between the demands of testing and the time constraints because of the nature of their treatment (multiple time-consuming tests).[5] In addition, cancer patients often experience many symptom burdens, such as pain, fatigue, depression, and anxiety.[17] Heavy test burden may result in respondent fatigue and low response rate especially for the terminal cancer patients, restricting their generalization to a limited population.[18,19] Most PROMs focus on the stage of cancer rehabilitation, few focus on advanced oncological patients, who are often too unwell to respond.[20] A systematic review of 46 studies covering 39 PROMs revealed that no psychometrically sound PROMs exist for advanced oncological patients, because of limited evidence.[20] In addition, the excessive testing burden also increases staffing requirement for data collection. A study revealed that it needed to reconsider human resource and make effort to finish assessments even outside of therapies. And the added burden on health professors resulted in many missed assessments, especially in the chemotherapy stage which had short stays in hospital.[21]

Integration of PROMs with computerized adaptive testing

Computerized adaptive testing (CAT) is the modern psychometric technique and widely employed in educational and psychological assessments.[22] It establishes item bank and sets up the algorithm which help select the most appropriate items from the entire available item bank for each respondent according to its latent trait.[23,24] It may address the challenges associated with PROMs.

Firstly, with CAT, item bank can be constructed and updated, facilitating establishing common metrics and tracing the trajectory of cancer experience. Accordingly, the quality of patient outcome will be enhanced. The process of item bank establishing consists of two steps: constituting a framework and calibrating items.[22] Identifying a framework is the initial phase of establishing an item bank.[22] And detecting similar latent constructs in various measurement frameworks is the potential way to develop a common framework. Conceptually meaningful linking strategies have been proposed to fulfill this function, which

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has attracted increasing attention in recent years. For instance, the conceptually meaningful linking method for the International Classification of Functioning, Disability and Health (ICF) framework defines how to link items covering ICF categories, or content not explicitly named in an ICF category.[25–27] This approach has been employed for comparing the item content of PROMs such as EORTC quality-of-life questionnaire core 30, EORTC breast cancer-specific quality-of-life questionnaire, 36-item short-form health survey, and the Patient-Reported Outcomes Measurement Information System (PROMIS) Cancer Item Bank.[28,29] However, the ICF stresses physical function assessments while neglecting the psychological domain and global health, which warrants further exploration. While linking rules on the ICF framework used in current studies focus on validating or comparing the content of items in different measurements, the creation of common item banks using these linking rules warrants further investigation.[28,29] Another linking method is based on the EORTC guidelines, which are based on the same concept as the scale of the quality-of-life questionnaire core 30. These guidelines collect potential candidate items through a literature search.[30] According to the concept of quality-of-life questionnaire core 30, several cancer-related item banks, such as overall health and functional domains (ie, physical, role, emotional, cognitive, and social functioning) have been established.[31–37] Similarly, symptom domains (pain, appetite) have been reconstructed using items from subscales or questionnaires aiming to assess the same latent trait or a closely related construct.[38] Compared to the linking rules on the ICF framework, concepts of latent traits in EORTC guidelines align more closely with the characteristics of oncological patients.[31] As a result, the EORTC guidelines can be recommended as the appropriate linking method for the development of common item banks tailored specifically for oncological patients.

Then, item bank is calibrated using item response theory (IRT). One of the most obvious advantages of IRT is its ability to equate item parameters. This may enable comparability and interpretability in different item sets and groups.[39,40] By equating item parameters, some items from the original scale that are included in the new item bank help link the CAT to a mass of data from various groups, diagnoses, treatment stages, treatments, and countries. Such integration can enrich item banks with a broader latent continuum for oncological patients.[35,36,41–43] Eventually, item banks can be constructed and updated by collecting different scale items corresponding to respondents' specific trait levels. This helps accumulate a large number of items covering different levels of a latent trait, providing the condition for developing common metrics. Using IRT, PROMIS, and EORTC projects have tried to deliver common metrics for oncological patients by creating a wide range of items measuring the same construct (ie, pain interference, fatigue, and depression) from cross-cultural patients with cancers in all developmental phases.[30,41,42,44–47] In the PROMIS project, item banks concerning domains such as anxiety/fear, depression/sadness, fatigue, pain, and physical function have been calibrated on multiple cancer populations.[48] In the EORTC project, the common item banks (ie, overall health,[31] functional domains,[32,33] role,[34] emotional,[35] cognitive,[36,37] social functioning[34]), and symptom domains[38]) were developed from cross-culture patients with cancers in all development phases.[30] Although a wide range of item banks have been established by these two projects, a score threshold for detecting clinic problems has not been defined. Besides, longitudinal outcome changes have not been addressed, as item banks predominantly rely on cross-sectional samples. Thus, future studies should not only focus on the formation of common item banks but should also prioritize determining score thresholds and analyzing longitudinal outcome changes in order to enhance clinical utility.

Secondly, with CAT, the algorithm is set up, which can tailor the most suitable items to each respondent, minimizing test burden and enhancing patient cooperation.[24] Some studies have shown that by applying CAT to instruments such as the FACE-Q Skin Cancer Module, measurement of emotional function, and the disabilities of the arm, shoulder, and hand assessment, test burdens can be reduced by at least 50% without compromising precision.[24,35] Patients are willing to complete assessment with CAT due to its short completion time and its convenience. Studies demonstrated that CAT was well accepted by cancer patients (as high as over 85% respondent rate) and could be performed in an efficient and timely way (completing each CAT within 2 min), and in a wide range of settings (ie, acute care setting, treatment setting, rehabilitation settings, palliative setting, patients' homes).[21,49–53] However, it is noteworthy that different combinations of various scoring methods, item selection, and stopping rules influence both the test burden and precision.[23,24] The optimal algorithm can minimize the test burden and maximize precision, which is worth exploring further. However, few studies have focused on finding the optimal algorithm in terms of the best scoring method and item selection strategies.[54] While stopping rules have received considerable attention, they often draw from previous rather than current research.[49,55] Thus, scoring method, item selection, and stopping rule should be given much more attention to define the optimal algorithm.

Thirdly, health professors prefer to perform PROMs through CAT because of its less assessment burden and its guidance for personalized cancer care. A study revealed that most patients (90%) completed the assessment at home prior to medical visits. It would direct the routine cancer care without adding more human resource.[56] Another study reported that most staff (at least 80%) in palliative care units wished to use CAT for routine surveillance of cancer symptoms even though taking more effort to support the completion of CAT.[57]

Lastly, development of internet and availability of electronic devices are the prerequisites for the implementation of PROMs with CAT. Owing to the widespread of computers and mobile devices, and their manifold benefits, including precision and promptness in automatic scoring, efficient recording, and instant database entry of responses, a growing number of internet-based CAT platforms integrated with PROMs are receiving unprecedented attention.[39] CAT platforms are rapidly developing in many countries, for instance, the LIVECAT platform in Korea and the Open-Source Concerto Platform in England.[58,59] They provide examination administrators, even those without psychometric expertise, the ability to carry out CAT at their convenience through multiple internet-connected devices, such as desktops, laptops, smartphones, and tablets. This may accelerate the incorporation of CAT into clinical practice.

Barriers and further studies on incorporation of CAT in PROMs

While CAT shows great promise for cancer PROMs, several barriers still exist. One primary barrier for both patients and healthcare professionals may be the perceived uselessness of building clinical pathways activated spontaneously according to CAT scores. Because few studies explore the meaning of CAT scores (ie, threshold), making it impossible to construct clinical pathways to identify patients' concerns.[21] Besides, the patients in chemotherapy treatment stage or at end-of-life turn out to be a challenge for health professors, as patients with inadequate cognitive or low physical abilities are unable to complete questionnaires and need more support. And it also needs a balancing act between proxy assessment and self-assessment.[21,57] In addition, inadequate service support may impede the implementation of CAT. The existing hospital electronic medical records cannot support CAT.[5] Health professors need to use multiple systems which may add to their work burdens and the risk of inefficiencies in care coordination. Ultimately, technology barrier is another barrier. Health professors find it unfriendly to log in as it always requires assistance from third-party software.[60]

Some measures should be explored to integrate the new computerized testing into clinical practice. First, healthcare professionals should be equipped with a comprehensive understanding of test selection, score interpretability, and creative planning, which may guarantee that the tests provide significant evidence for clinical decision-making. Second, integrating the new computerized testing into electronic medical records may promote patient participation, foster care coordination, and enhance the efficiency of activating clinical initiatives. Third, establishing multidisciplinary collaboration between healthcare professionals and the

institution's IT team is important for the smooth integration of a user-friendly and accurate CAT system into clinical practice. Fourth, determining the optimal CAT algorithm is essential, especially when short-form formats of PROMs are being calibrated, particularly where the CAT technology is unavailable to develop an appropriate institutional CAT platform.

Conclusions

Considerably various PROMs, inflexible test strategy, and heavy test burden associated with PROMs for oncological patients limit their clinical utility owing to challenges in measurement feasibility. CAT can address these issues and may serve as a promising technique to establish common metrics and relieve test burden.

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Declaration of competing interest

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Minyu Liang[a], Zengjie Ye[b,*]

[a] *School of Nursing, Guangzhou University of Chinese Medicine, Guangzhou, China*

[b] *School of Nursing, Guangzhou Medical University, Guangzhou, China*

* *Corresponding author.*
E-mail address: zengjieye@qq.com (Z. Ye).