

Challenges in Selecting Patient-Reported Outcome Measures for Use in a Patient-Facing Technology

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Abstract. Patient-reported outcome measures (PROMs) have been increasingly integrated into patient-facing technologies to engage and empower patients in cancer self-management at home. However, researchers and developers face several challenges in selecting the best-suited PROMs for patient-facing technologies, due to the complex nature of the disease, the multitude of PROMs with high psychometric quality, and the lack of clear standards for PROM utilization. In this paper, we have discussed these challenges, illustrated by breast cancer instruments.

Keywords. Patient-facing technology, patient-reported outcome measures, breast cancer, quality of life, symptom management

1. Introduction

Patient-reported outcome measures (PROMs) are self-completed questionnaires, used to measure patient-reported outcomes (PROs), [1] and are commonly adopted in clinical and translational studies. [2,3] Our ongoing project is to design and develop a patient-facing technology application to support cancer patients to manage their oral-anticancer agents (OAAs) at home. In this article, we aimed to describe the challenges faced by developers in selecting the best-suited PROMs.

2. Methods

In the present version of our application, the following PROMs are explored: PRO-CTCAE for assessing adverse drug reactions/ toxicities, and PROMIS-10 Global Health for global health status. We conducted a comprehensive literature review to explore a range of PROMs to identify the most appropriate ones. Our investigation primarily focused on breast cancer, along with lung, colorectal, and prostate cancer patients who were recruited for our study.

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3. Results

Several challenges exist in PROM selection for patient-facing technologies. First, “the use, reporting, and analysis” of PROMs “are not standardized in clinical trials and are often poorly implemented in clinical practice.” [3] Secondly, a many-to-many mapping between instruments (or their subscales or their standalone items) and measurement concepts (outcome domains) exists. There are also overlaps between outcome domains. Further, there is no consensus on how to score and analyze PROM results. PRO-CTCAE is the most recommended form for patient-reported assessments of adverse events across all cancer types. EORTC QLQ-BR23 and FACT-B are the only HR-QOL instruments “that have been developed specifically for patients with breast cancer facing different disease stages and treatment.” [4] How these different instruments can be best integrated into a patient-facing technology for a comprehensive evaluation of PROs remains challenging. Since disease subtypes, stages, treatment, and patient-related factors may have typical symptoms associated with them, personalization may be warranted in PROMs/item selection for individual patients. It is common knowledge that instruments with more items increase the patient burden. A very large questionnaire such as the PRO-CTCAE may not be very practical to implement. The psychometric properties of an instrument must be re-tested for use in eHealth technologies (smartphone, tablet, or computer format) [5]. The evidence for the above PROMs was identified in the literature.

4. Conclusions

We identified and presented the challenges and complexities associated with PROM selection for breast cancer patients in the context of a patient-facing technology. More research is needed for patient-facing technologies to set guidelines regarding PROM selection, implementation, and data analysis.

Acknowledgment

This project is supported by grant number R01HS027846 from the Agency for Healthcare Research and Quality.

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