Presenting patient-reported outcomes (PROs) so that they can actually be understood by patients and their clinicians

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Background/Research Question

Patient-reported outcomes (PROs) are reports directly from patients about a health condition or treatment (e.g., symptoms, functional status, health-related quality-of-life). PRO results from clinical trials and other comparative studies can inform treatment decision-making, thereby enhancing patient-centered care. However, patients and clinicians experience challenges interpreting data due to variations in scoring (e.g., whether higher scores are better or worse) and scaling (e.g., whether 0-100 or normed to population average of 50). We evaluated formats for presenting PRO data from comparative research studies to optimize understanding and use in patient education materials and decision aids.

Methods

We conducted an online survey of cancer survivors, cancer clinicians, and PRO researchers via email lists and snowball sampling. The survey displayed line graphs comparing Treatments X and Y over time on 2 function and 2 symptom domains, with 1/3 of participants randomized to evaluate "*better*" line graphs (higher scores always = better), 1/3 to "*more*" line graphs (higher scores=better for function, worse (more) symptoms), and 1/3 to "*normed*" line graphs (population average = 50). Formats were evaluated based on 3 interpretation accuracy questions and a clarity rating. The online survey was supplemented with 1-on-1 in-person interviews with cancer survivors and clinicians from an academic-community hospital consortium, who verbally responded to prompts as they completed the online survey.

Results

The online sample included 1017 respondents total. Survivors (n=629) had a mean age of 58 years, were 87% female, 94% white, and 23%<college graduate. Clinicians (n=139) included oncologists, nurse practitioners/physician assistants, and had a mean age 44 years, 54% female, 70% white, and in practice for an average of 16 years. PRO researchers (n=249) were mean age 45 years, 67% female, 79% white, with 46% working in the field for >10 years. In descriptive analyses, patients randomized to the *Better* format (56%) were more likely to get all 3 accuracy questions correct compared those randomized to *More* (41%) or *Normed* (40%). Clinicians also were more likely to interpret *Better* formats correctly (70%) vs *More* (65%) or *Normed* (65%). However, researchers interpreted *More* formats correctly most often (75%) versus *Better* (65%) or *Normed* (40%). Over 75% of patients, clinicians, and researchers rated the 3 formats as very or somewhat clear; the *Better* format was most likely (>80% in each group) to be assessed as clear (compared to the *More* or *Normed* format). In multivariate analyses, *Better* formats were interpreted more accurately than *More* formats (OR=1.43, CI 1.07- 1.91; p=0.01) or *Normed* formats (OR=1.88, CI 1.42-2.50; p=0.04). Moreover, *Better* formats were more likely to be rated as somewhat clear or very clear compared to *More* (OR=1.51, CI 1.00-2.29, P=0.05). The qualitative interviews provided insight into aspects survivors and clinicians liked and disliked about each format, as well as aspects that were helpful and confusing.

Conclusions/Implications

For PRO data from clinical trials to inform patient-centered care, results have to be clear and understandable to patients and clinicians. These results demonstrate important differences across PRO data presentation formats and support presenting line graphs with higher scores representing better outcomes.