

Measuring quality of life

Paap, Muirne C.S. , PhD | University of Twente, Enschede, the Netherlands. | 31 oktober 2013 | 7.12.13.085CO (3.4.11.004)

The main goal of the International Society for Quality of Life research (ISOQOL) conferences is: “...to provide attendees with a conference focused on the most important topics and trends in health-related quality of life research through thought-provoking, relevant presentation”.

This year’s topic was “Energizing the Science of Quality of Life Research: Where have we been and where can we go?” This is the second time I have attended an ISOQOL conference. In addition to the interesting scientific program, it offers many opportunities to form collaborations and increase ones network. This is done through special meetings for new investigators (mentor-mentee evenings), as well as special interest groups in a wide range of topics. The atmosphere at the ISOQOL conferences is welcoming; it is encouraged to go up and talk to presenters and other attendees. This year as well as last year, this has led me to form collaborations with researchers that have similar interests. In this report I will first discuss some important topics presented at the conference, after which I will summarize the presentation I gave at the conference. Finally, the relevance and implications of the conference presentations for our study will be discussed. The range of topics discussed at the conference was very wide. Several topics stood out, however, both because they were relevant to my own research and because these topics came back in many different symposia and presentations. Among them were studies linked in some way to Patient Reported Outcomes Measurement Information System (PROMIS), and studies using modern test theory, such as Item Response Theory (IRT).

PROMIS

The PROMIS project was developed in the USA, funded by the National Institutes of Health. The aim was to develop and validate “...common, accessible item banks to measure key symptoms and health concepts applicable to a range of chronic conditions, enabling efficient and interpretable clinical trial and clinical practice applications of patient-reported outcomes (PROs)”¹. This project resulted in a large number of item banks, covering physical, mental, and social health. Sixteen of these item banks have recently been translated to Dutch by the Dutch PROMIS group at the EMGO institute. The idea behind PROMIS, is that it is a domain-oriented framework, and not a disease-oriented framework². It consists, in other words, mostly of item banks that can be used with any patient group. Several researchers have suggested it may be helpful to add disease-impact banks to the PROMIS framework, since these kind of constructs cannot be captured by generic instruments. Indeed, an asthma-impact module is currently available for children³. Other disease-specific banks may be added in the future. Recent developments involving PROMIS that were presented at the conference include: (1) the introduction of the PROMIS instrument maturity model, which guides both selection and implementation of PROMIS tools in practice⁴; (2) the development of a method ensuring that the PROMIS tools selected are in accordance with patient priorities and preferences⁵; (3) translation of PROMIS tools into other languages than Spanish and Dutch⁶; (4) validation studies of the PROMIS banks in specific patient groups⁷⁻⁹.

IRT

Although Classical Test Theory (CTT)¹⁰, including factor analysis, is still used by many researchers to investigate the psychometric properties of measurement instruments such as questionnaires, the popularity of IRT¹¹ is increasing. IRT is commonly referred to as modern

test theory and focuses more on the properties of individual items and their relationship to the underlying latent trait, whereas CTT focuses more on sum scores and the properties of the test as a whole. The psychometrics special interest group aims to use a case-study (the PROMIS depression item bank) to compare the results of CTT and IRT (including Rasch modeling). Also from the oral presentations and posters, it became apparent that developers of new instruments (especially Computerized Adaptive Tests; CATs) often use IRT or a combination of CTT and IRT to validate their measures. A striking four out of five presentations in the Respiratory Diseases oral session (including our own) mentioned or had made use of some form of IRT¹²⁻¹⁵. Towards a computerized adaptive test: identifying relevant domains of QoL for patients with COPD. We propose a new approach to measuring quality of life (QoL) in patients with Chronic Obstructive Pulmonary Disease (COPD): creating a multidimensional Computerized Adaptive Test based on generic PROMIS item banks and a new, disease-specific, module for COPD. In addition to providing a very broad picture of QoL, it would ensure comparability with other patient groups through use of the existing PROMIS banks, yet provide additional sensitivity for measuring change within this specific patient group (disease-specific bank). We would be able to take into account the correlation among the different domains to increase efficiency and measurement precision. As a first step in this project, existing PROMIS domains that are relevant to patients with COPD need to be identified. Twenty patients with COPD were recruited by pulmonary physicians in two clinics in the Netherlands. In an interview with a trained interviewer, the patients were invited to select the five domains that they deemed most relevant in relation to their COPD, and rank order these five domains according to the level of associated distress. During the interview, the patients were asked to indicate in which way the selected domains impact their lives. Background information, including disease severity, was also gathered. We are currently using a similar setup to elicit responses from health professionals. They were asked which domains they feel are most relevant to patients with COPD. So far, ten health professionals have been interviewed. Results from the patient interviews indicated that the most frequently chosen domains include fatigue, emotional support, instrumental support, physical functioning, and ability to participate in social roles and activities. Four patients indicated none of the domains were relevant to their situation. Preliminary results from the interviews with health professionals showed that there is a large overlap in the domains chosen by the patients, but also one marked difference. The most popular domains among the health professionals were: fatigue, emotional support, physical functioning, satisfaction with participation in social roles and activities, and depression. Most choices for domains were motivated by underlining their own experiences with COPD patients, but depression was an exception. The choice for this domain was mostly based on references from existing literature. Once the interviews with the health professionals are completed, we will the most relevant domains to include in our CAT. One of the next important steps will be identifying candidate items to include in our disease-specific item bank, possibly adapt them, and write new items to fill potential gaps.

Implications and future directions. As mentioned before, recent developments involving PROMIS include a careful selection procedure that ensures the selected domains are relevant to patients, and validation in specific patient groups. These two topics show some degree of overlap with our own goals, but the presenters of studies that fall in either of these two categories did stress that our approach is different from theirs; The added value of our approach lies mostly in that we chose to ask the patients to choose PROMIS domains directly, whereas in other studies domains that were offered by patients are mapped to PROMIS item banks by experts afterwards. I received a lot of positive feedback from other researchers on this point. Although the popularity of IRT seems to be on the increase, it should be noted that QoL researchers have yet to discover the benefits of multidimensional IRT. The first IRT

models were primarily used for unidimensional constructs, but there have been a lot of developments since. These days, IRT models come in many shapes and forms. On the one hand, it is a pity to see that this has yet to be discovered by many researchers in the QoL field, on the other hand it underlines the novelty and added value of our own approach. When asking other researchers why they chose to create unidimensional instruments, such as the group of researchers from RAND who are developing an Asthma Impact item bank, an often-heard response was that it was easier that way; they argued that multidimensional models were highly complex, and the resulting instruments would be difficult to implement in practice. We do concur that the multidimensional modeling approach results in more complex models, but this should not necessarily mean that the resulting instruments will be more difficult to use or interpret for clinicians. From a validity-perspective, we would argue that it is a waste and a pity to throw items out that have gone through careful pre-testing (cognitive interviews), but just do not comply with the unidimensionality assumption. This may lead to an unnecessary narrowing of the construct of interest, which may negatively impact construct validity. We will continue to have contact with some of the researchers mentioned, to see if we can support each other's research efforts.

Please note that most of the references are references to the published abstracts pertaining to presentations at the ISOQOL 2013 conference; these were published in Quality of Life Research Volume 22, Supplement 1.

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