

Getting to the heart of the quality of life



Health is an important factor in an individual's quality of life, but it's not the only consideration. **Professor Mirjam Sprangers** tells us about her work bringing together different areas of research to improve the conceptualisation of quality of life, and the sensitivity by which it is measured

A high proportion of patients with multiple morbidities report a stable quality of life (QoL), despite their health problems. One factor behind this stability is that many of the questionnaires currently used in research may track stable characteristics of an individual, rather than monitor their current state, says Professor Mirjam Sprangers. "The most common type of research in the past 30 years has used retrospective measures. For example, questionnaires asked patients things like; 'have you had a headache in the past week? Did your disease interfere with your social activities? Please provide a rating, from not at all to very much,'" she explains. Based at the University of Amsterdam, Professor Sprangers is the Principal Investigator of a multi-disciplinary project aiming to improve the conceptualisation and measurement of QoL. "We work together with researchers from different disciplines, among which are religious studies and ethics," she outlines.

QoL, while the other would also improve QoL, but not as dramatically," continues Professor Sprangers. "I wanted to pursue research over a time period where people would experience change in their QoL – that was necessary to test my measures and my analytical procedures."

This research is built on group level retrospective data as well as on data about individual patients' QoL, gathered at random intervals during the day. Alongside questions on an individual's mood, such as how they feel at that specific moment, researchers are also gathering data on other issues. "We ask about their physical symptoms, so whether they're experiencing pain and fatigue for example. We also ask for contextual information, such as where are they? Whom are they with?" says Professor Sprangers. An individual's QoL is not necessarily directly related to their health, as there are many cases where people have objectively poor

are developed for example, or when the reference value for a disease is determined, it is important to balance the cost of treatment with the cost per QoL adjusted years gained. "Those are the macro decisions that might be affected by not taking into account the fact that people differ in their dispositions and their ability to adapt to changed circumstances," explains Professor Sprangers. The project will gain important insights in this respect, with two of Professor Sprangers' PhD students working on research papers. "One student has developed a theoretical model and questionnaire to examine how disease can be integrated into one's life and how that might affect QoL," she outlines. "Another student is doing more analytical work, looking at QoL from another perspective which involves - among other areas of research - network analysis."

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Quality of life

The core principle here is that only the individuals themselves can judge their own QoL. A self-report of QoL is still prone to bias however, or to other influences that may affect the measurement, an issue central to the project's research. "We want to improve the measurement of QoL by improving the measurement itself, and the analysis of change over time," says Professor Sprangers.

The project is targeting adults with a cardiac disease and multiple co-morbidities. "I chose a population of cardiac patients who were going to undergo different interventions. One intervention would dramatically improve

health and excellent QoL, and vice-versa, a point of great interest to Professor Sprangers. "What people experience in their own QoL is only partially correlated with objective parameters of health," she says. "In general you would expect that people whose health has improved would also experience a comparable improvement in their QoL, but that relation is generally weak."

Individualised treatment

This research could hold important implications for medical decision-making and healthcare economics. When guidelines on preferred treatment for specific conditions

IMPROVING THE CONCEPTUALISATION

Improving the conceptualisation and measurement of quality of life of patients with multiple chronic morbidities, exemplified by patients with cardiac disease undergoing cardiac intervention

The overall objective is to improve the conceptualisation and enhance the sensitivity and comprehensiveness of its measurement by taking the trait-state distinction and response-shift into account.

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