

Quality of life: Measure or listen

A reflection for disability studies

Dick Willems

Studies using 'think aloud' methods with patients filling out Quality of Life (QoL) questionnaires, show that subjects attach different meanings to items and mean different things with their answers. I argue that QoL-studies in people with disabilities should primarily listen to their stories and be aware of the relative value of answers to questionnaires.

[quality of life studies, disability, think aloud]

People with severe disease or disability often report good to excellent (health-related) quality of life (QoL) in questionnaire studies. This has been called the disability paradox (Albrecht et al. 1999). But is this really a paradox or is it an artefact related to the way of obtaining knowledge about quality of life? I think it is the latter.

The concept of QoL has been developed in oncological research, where new treatments, even though effective, sometimes had unacceptable effects on life quality. This led to a need to take QoL as a separate outcome in trials. In line with its origins, the concept is often used quantitatively, within Evidence Based Practice, as part of outcome measurements in medical trials. Investigators then use generic (non-disease-specific) scales like the SF36 or disease-specific scales such as the Minnesota scale for chronic heart failure. Some more sophisticated quantitative scales such as the SeiQoL allow patients to indicate the domain of life that they consider most important, so they can choose (within narrow limits) what the QoL measurement should be about. Even so, all of this conveys the slightly paradoxical idea that quality of life is quantifiable, that it may be and must be expressed in numbers. Increasingly however, there are doubts as to the extent to which the numbers on QoL measurements reflect the lived quality of life of a person.

A few years ago, anthropologist Tony Hak and I investigated this question (Hak et al. 2004). We did a qualitative study among patients with very severe or even terminal heart failure, an extremely disabling condition in which patients get exhausted when performing even the smallest activities. Walking from the couch to the kitchen may be a daunting task for many of them. Our qualitative interviews aimed at knowing

more about the quality of their lives, and as a part of these interviews, we wanted to know how they would fill in a regular disease-specific quality of life questionnaire (the Minnesota Living with Heart Failure Questionnaire). We were not so much interested in their answers to the questions, but in their spontaneous comments about what they meant when they ticked a box in a certain way: a think-aloud approach.

This showed a large discrepancy between what people tick on a QoL questionnaire and what they say if they are asked to think aloud while ticking the boxes. For instance, when asked whether heart failure prevented them from working in their garden on a scale from 1-5, many interviewees who said they had no garden either ticked 1 (“I don’t have a garden, so how could I work in it”) or 5 (“I could work in a garden if I had one”). Still others ticked 1, saying they had always detested working in gardens. Other possible discrepancies were related to the extent to which respondents remembered the exact questions; the questionnaire consistently asks whether heart failure prevented respondents from living as they wanted during the last month. Many answered these questions as if they were questions about the *presence* of symptoms. For instance: “Did heart failure prevent you from living the way you wanted during the last month by making you short of breath?” Some respondents ticked ‘4’ because they felt out of breath, but without literally answering the question about being able to live the way they wanted; others, on the other hand, did take the question completely literally.

Think-aloud procedures also showed that the questionnaire (which had been rigorously validated!) contained double questions that respondents had no clue how to fill out. For instance, one of the items asked whether the disease prevented respondents from living as they wanted by making walking about or climbing stairs difficult. What should they fill in if they can walk about but not climb stairs? Moreover, respondents were asked to restrict themselves to the consequences of heart failure, which they consistently forgot or found very difficult. For instance, some respondents ticked ‘very much’ on a question about worries, but explained that they were worried because their daughter was getting a divorce.

The following quotes are from a paper by Habraken et al., illustrating how people with severe disability due to COPD look at their quality of life (Habraken et al. 2008).

“It just goes so slowly. We don’t really notice but other people do. They see that he can no longer do things that he could do a year ago. For us it’s just normal” (partner Ian, 65).

“These lungs won’t get any better. That’s something you need to accept. Well, compared to other people ... everyone has got something at my age! I feel lucky to have what I have” (Charlotte, 81).

These quotes show some of the considerations that make people fill in a number: both Ian and Charlotte would probably fill in a 2 or a 3 because they had accepted their restrictions, even though their disease might really prevent them from living as they wanted. Other studies, such as the one performed by Bloem and others (Bloem et al. 2008), have found the same results in cancer and other diseases and handicaps.

Is this important? Yes it is, even though sometimes, when we discussed these results with more quantitatively oriented colleagues, their answer was that this was

interesting but not very relevant for quality of life research, because usually questionnaires are used in large populations, which guarantees that misinterpretations will be averaged out and trends will still stand out. To me, this sounds as a cynical way of looking at one's research: even if we don't know what our results mean, we are still satisfied because the numbers add up.

What these studies show is how important it is to listen to what people tell about their lives with chronic disease or disability. If you really want to know about the quality of the lives people with disabilities lead, listen to them! Don't start measuring them!

Note

Dick Willems studied medicine and philosophy and worked as a general practitioner in a Dutch village for about 15 years. Since 2003, he is a professor of medical ethics at the University of Amsterdam / Academic Medical Center. His research focuses on home care technology and care for the dying. E-mail: d.l.willems@amc.uva.nl.

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