

Virtual Mentor

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Journal Discussion

Thoughts on Koch's Postulates

by Peter Ubel, MD

Six months ago at a departmental meeting, I presented a series of research studies I had led, exploring the happiness and quality of life for people with a wide range of illnesses and disabilities. In these studies, our research group had developed several novel ways of testing the validity of subjects' self-reports, an important task because numerous studies have shown that people are not always able to provide accurate assessments of their global well-being [1]. On sunny days, for example, people report significantly higher overall well-being than on cloudy days, with their current mood strongly influencing their global assessment. Our studies confirmed several flaws in people's self-reports. For example, Parkinson's patients report different levels of well-being when they participate in studies of "people with Parkinson's" than when they are approached as "members of the general public"[2]. In another study, we found that dialysis patients overestimate the frequency with which they experience extremely good and bad moods in a typical week [3].

Despite these misreports, I presented detailed evidence that people with chronic illness and disabilities report very high levels of life satisfaction and positive mood and very low levels of negative mood; that they are largely happy, and, in fact, report levels of happiness equivalent to those of healthy control subjects.

Upon completing my presentation, one of the leaders of my health institution burst out: "You've done a brilliant job, Peter, of showing just how deep these people's denial runs!"

Here is a fact: many people with chronic illness and disability report higher levels of happiness and well-being than healthy people believe is possible. This clearly bothers Dr Koch, and his anger is both palpable and understandable. The unfortunate truth is that many members of the general public hold terrible views of what life with any disability must be like. Discrimination, bias, and stigmatization are all too common. In such a climate, research on the quality of life of people with chronic illness and disability will generate strong emotions, and will often be misinterpreted.

It is still crucial to figure out why people with severe illness or disability often report negligible declines in their overall quality of life, even if such research will ruffle some feathers. Quality of life measurement is an imprecise, but necessary, business. Without quantitative measures, like QALYs, SF-36 scores, and the like, it is impossible to measure the impact of clinical interventions or determine the cost-effectiveness of new health care technologies.

As a primary care physician, I care for hundreds of chronically ill patients, many of whom amaze me with their emotional resilience. However, a substantial minority experience mood disorders and chaos in their lives because of their health problems. In fact, regardless of how disability and illness have influenced their lives, most of my patients are very clear that they want my help in *improving* their health and function. I believe this phenomenon deserves serious inquiry.

About 10 years ago, I experienced rapid onset of repetitive strain injury in both of my arms, leaving me unable to hold a pen, type at a computer, or practice piano (a passionate hobby I had been pursuing for 30-odd years). For 6 to 9 months, I was forced to stay away from the piano, hoping the pain in my hands would subside. My pain did eventually subside. But in the interim, I have to tell you, I was not miserable. Rather than practice piano, I read books and listened to music. Rather than type at a computer, I began dictating manuscripts into a tape recorder, a practice I continue to this day. By any measure of quality of life, my life was just as good as ever.

And yet, when my hands healed and I was able to resume piano practicing, I did so with renewed passion.

Would my life be diminished if I had never been able to resume my hobby? Of course not. Did learning the Liszt piano sonata improve my quality of life? Of course it did. And that is a paradox worth studying.

References

1. Riis J, Loewenstein G, Baron J, Jepson C, Fagerlin A, Ubel PA. Ignorance of hedonic adaptation to hemo-dialysis: a study using ecological momentary assessment. *J Exp Psychol Gen*. In press.
2. Smith DM, Schwarz N, Roberts TR, Ubel PA. Why are you calling me? How survey introductions change response patterns. Working paper.
3. Ubel PA, Loewenstein G, Schwarz N, Smith D. Misimagining the unimaginable: the disability paradox and healthcare decision making. *J Health Psychol*. In press.

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