Taking Aim: Reflections on Quality-of-Life "Research"—A Sinner's Plea for Salvation

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Over the past decade, there has been an explosive growth in the number of published reports focusing on quality of life. The majority of these papers are dubious with respect to theory, content, results, and implications. From a scientific perspective, they have little redeeming grace.

I will minimize my arrogance by confessing my sins. I have made many contributions to the very literature I have come to abhor. However, I did so as a shameless adolescent scientist who merely followed in the footsteps of two outstanding sociologists—Renee Fox and Roberta Simmons.

As a graduate student, I became transfixed with advanced medical technology. I was initially fascinated with kidney dialysis and, somewhat later, transplantation. I could not fathom why people would subject themselves to 40 hours of dialysis per week in hopes of staying alive.

In search of an answer, I soon came across a book by Renee C. Fox and Judith P. Swazey entitled *The Courage to Fail*. It became clear that Fox and Swazey understood technology in a way a novice like me would take years to appreciate. Ultimately, Fox and Swazey taught me that there was no shame in using a technological crutch to climb the stairway to heaven.

As I grasped the societal implications of medical technology, I remained perplexed as to why a life at end could instill the spirit of immortality. I was eventually introduced to the work of Roberta G. Simmons. A book she co-authored, *The Gift of Life*, enabled me to remove the remaining nails from the metaphorical coffin in which I had placed the bodies of those persons who depended on technology to sustain their lives.

Simmons, like no one before her and few people since, laid bare, for all to experience, the social psychology of organ transplantation. As Simmons painstakingly pointed out, even as organs failed, there was reason to live, and people, as organ donors, were ready to help others do so.

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I have gone on unashamedly to follow in the footsteps of Fox and Simmons, but their shoes have always proven to be more than I can fill. As I have callously asked about the economic value of life, I suppose I have added my own twist on the thoughts and theories of my predecessors. Philosophically, however, this undoubtedly relegates me to the role of a bottom feeder. Indeed, perhaps my intellectual nourishment has a lot in common with a carp—somewhat tasteless, at times disgusting.

Thanks to Renee Fox and Roberta Simmons, I have never lost sight of the importance of examining quality of life in relationship to advanced medical technology. Unfortunately, many people who have become enamored with the concept have little appreciation of its theoretical history, or its methodological complexity.

Robert K. Merton, another great sociological theorist, has explored Newton's aphorism, "If I have seen farther, it is by standing on the shoulders of giants." In his book, *On the Shoulders of Giants*, Merton examined the tension between tradition and originality in science.

By standing on the shoulders of Fox and Simmons, and with the precision of the Manneken Pis, I would like to take aim at what I see as a litany of frivolous quality-of-life studies. Many of these studies have neither a sense of tradition nor an ounce of originality. Here, in no particular order, are some of the major issues as I see them.

Quality of life is a misleading concept. Quality of life is rarely defined in an existential sense. Most often it is equated with health status, disease symptomatology, disability, functional status, employment, stress, anxiety, depression, coping, compliance, and the list goes on. The problem here is simple: Independent predictors are being confused with quality of life outcomes.

Quality of life cannot be directly measured. Let us face reality. At best, we have objective and subjective quality-of-life indicators. We manipulate variables and analyze data we think tell us something about life. Frankly, these variables may ultimately tell us nothing about quality. I often think of Jean Paul Sartre when I try to make sense of much of the rubbish that is stuffed in my mailbox as "quality-of-life research." I happen to like the concepts of meaningfulness and purposefulness.

"Health-related quality of life" is nonsense. This terminology illustrates the problem of conceptually confusing independent predictors ("health-related") and dependent outcome variables. I often wonder: Do people really distinguish between their health-related

quality of life and some other kind of quality of life? What are the other kinds of quality? In summary, health-related quality of life is a bogus concept that should be sent back to Seattle where I believe it originated with Don Patrick.

Quality-of-life scales are like after-market automobile accessories. I have often considered walking into my local NAPA automobile parts store an asking for an "SF-36." Most studies that incorporate this "quality-of-life scale" have no conceptual, let alone a theoretical, basis for doing so. Like a "bra" fitted to a Dodge Ram pickup, the SF-36 is often bolted on to clinical trials as an afterthought—nice look, but such an unpleasant feel!

Quality of life is substantively insignificant and clinically unimportant. I am appalled at how often trivial differences in quality-of-life scale "scores" are declared statistically significant and, therefore, clinically important. Honestly, in most studies, statistical significance is a function of sample size, and qualitative importance cannot be meaningfully interpreted, even if it were to exist. What does it mean to have one's quality of life improve by 2 points on a 50-point scale?

Quality-of-life research has been a boon to the pharmaceutical industry. Here there can be no doubt. When "real" benefits are expected to be negligible to nonexistent, quality of life often becomes a primary "end point." Couple pharmacoeconomics with quality-of-life research and you have a marriage made in heaven for the consulting industry. Unfortunately, if it comes to searching for hair on a frog's back, I assume a product has little to offer, regardless of how the "benefits" are measured and the results are presented.

I am not sure what Renee Fox and Roberta Simmons would have to say about contemporary research that examines the relationship between technology and quality of life. I suspect they would be disappointed beyond belief.

In conclusion, based on what I see, I think it is time we declare a moratorium on "quality-of-life studies." If this is unacceptable, we should convene an annual awards ceremony for those people who persist in pursuing this line of "research." During the ceremony, the authors of the most "outstanding" quality-of-life paper would be required to publicly participate in a mock quality-of-life interview using their own ridiculous questionnaires. In addition, the "winners" would be rewarded with a functional replica of the Manneken Pis. The first 5 runner's up would be given fender skirt lapel pins. I am prepared to offer my services as master of ceremonies, but barf bags will be mandatory for all attendees. If we are lucky, perhaps we can embarrass people into submission. Clearly, quality of life has become a worthless concept, and research related to it is nonsense.

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