

Virtual Mentor

Ethics Journal of the American Medical Association
May 2006, Volume 8, Number 5: 319-322.

Journal Discussion

Coping Mechanisms and Quality of Life

by Helen Harrison

Kothari S. Clinical [mis]judgments of quality of life after disability. *J Clin Ethics*. 2004;15:300-307.

Much of the practice of law and medicine is predicated on the notion that disabilities impose real and significant harm. If a lawyer were to claim in court that the victim of an assault, rendered brain damaged and paralyzed, had the same quality of life as everyone else and, therefore, had suffered no injury, not a jury in the world would take that assertion seriously.

However, in his article “Clinical [Mis]judgments of Quality of Life After Disability” [1] Sunil Kothari notes that severely disabled individuals, including people with quadriplegia who require assisted ventilation, report a quality of life (QOL) that is nearly identical to the self-reported QOL of health care professionals [1]. Kothari also found that health care professionals and the public ascribe significantly lower QOL scores to people with severe disabilities than those with disabilities report for themselves. He fears that public and professional underestimation of the QOL enjoyed by the disabled may have significant clinical implications.

In “Making Lemonade: A Parent’s View of Quality of Life Studies,” [2] I have argued that the QOL self-reports of people coping with disability are inflated by the same mechanisms that allow them to put a brave face on adversity (in public at least). I refer to these coping mechanisms as “making lemonade” from the saying, “When life hands you a lemon, make lemonade.” Sadly, the private realities of lives lived with disability often differ substantially from the stoic facades.

My interest in quality-of-life issues began 3 decades ago when my son was born prematurely with severe disabilities. I was able to observe the emotional dynamics of altered QOL not only in my own family but also in the hundreds of parents, prematurely born children, and adults with disabilities that I met in support organizations, interviewed for books and articles [2-5], and studied as a parent advisor to researchers investigating outcomes and QOL of prematurely born children [6].

Those of us affected by disability quickly come to realize that others want to believe we are managing well, so we offer reassurances, hoping also to reassure *ourselves* that there are compensations for even the most devastating afflictions. We do not want to be

pitied or devalued, and so we assert our personal worth whenever it is questioned—for example, in QOL interviews. The more uncomfortable the questioning, the more defiantly optimistic our assertions tend to become.

My experience and observations are reinforced in a study by Saroj Saigal that evaluated QOL for a group of Canadian teenagers who had been born weighing less than 1000 grams (known in medical terms as extremely low birth weight or ELBW) [7]. Although 86 percent of these teens had functional limitations [8], 61 percent gave themselves perfect QOL scores compared to the 49 percent perfect QOL scores from normal birth weight control group [7]. In a personal communication, Saigal stated that perfect QOL scores were reported by ELBW adolescents who were blind, nonambulatory, and otherwise severely impaired. Were these teens honestly and fully describing their lives or were they “making lemonade”?

To examine this question, it helps to look at other responses from the teens with ELBW that could be objectively verified. For example, although 58 percent of them were experiencing severe educational difficulties (they were either in special education or had failed a grade in the previous 2 years) only 6 percent self-reported “below average academic performance” [9, 10]. By comparison, 9 percent of the control group admitted academic difficulties, a figure close to the objectively determined percentage (10 percent) [9, 10].

In virtually every area of functioning, the teens born at extremely low weights underreported medically diagnosed disabling conditions [2, 11]. According to these adolescents, more of them were free of impairment than the physicians who treated them or the general population of Canada [7, 12].

A recent study by Allin et al, “Personality in Young Adults Born Preterm,” confirms the tendency of prematurely born individuals to deny disability and answer questions in ways they think will make them appear more socially acceptable [13]. Adult stroke victims have also been found to rate their functional levels significantly higher than more objective medical assessments [14].

QOL is a subjective concept, much like “happiness” and “self-esteem,” and it may thus be considered immune to objective investigation. But the results of recent studies seem to defy common sense to a degree that calls into question the meaning of the concepts and the methodologies by which they are rated [15, 16].

Flaws in methodology may help explain the counterintuitive results of QOL studies. Researchers have described the “Hawthorne effect” in which “compliant patients have a remarkably intuitive ability to sense what is wanted of them—and they provide it” [17]. This may be especially true when the researchers also provide the subjects with medical care. One study found that subjects who were unable or unwilling to make positive QOL statements often declined to be interviewed, another fact that would contribute to biased results [18]; others have shown that the presence of an interviewer inhibits subjects from disclosing pain that they admit to in more private settings [19]. Physicians investigating QOL after treatment for complex congenital heart disease noted that

optimism during structured interviews differed from anecdotal information exchanged in less formal situations [20]. Formal characterization of QOL has also been shown to diminish over time in the same subject without any change in function [21].

QOL studies provide fascinating insights into the human psyche, but they must be supplemented by data on actual functioning, observations from others close to the patient, and in-depth, free-form interviews administered over time. Saigal et al in their 1996 QOL study urged that “a great deal of caution be exercised” regarding possible clinical application of the high QOL scores reported by teens born at extremely low weight [7]. I agree.

As a parent and a patient, I want to hear the facts about conditions and proposed treatments, not QOL reports that may be drenched in lemonade. To quote Carolyn Daniels, social worker to the teens with ELBW described above, “it is a mistake to confuse coping mechanisms with quality of life” [2].

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Helen Harrison, co-author of The Premature Baby Book and author of "The Principles for Family-Centered Neonatal Care," is the mother of a 30-year-old prematurely born son.

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