

Virtual Mentor

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Journal Discussion

Quality of Life and the Problem with QALY Researchers: Comments on 2 Papers

by Tom Koch, PhD

In 2 distinct papers published in different journals, Menzel et al [1] and Ubel et al [2] confront the same, seemingly “paradoxical” problem [3]. As Menzel and his colleagues put it: “Chronically ill and disabled patients generally rate the values of their lives in a given health state more highly than do hypothetical patients imagining themselves to be in such states” [4]. Stated declaratively, the issue is that people who live with difference perceive their life quality as better than mundane folk and most academics believe is possible. Both authors seek, using a QALY-style (quality-adjusted life year) test, first to document the perceived difference, and then to understand the phenomenon. Menzel attempts to explain the perception of persons of difference through consideration of the adaptive process by which people accommodate to their altered states. Ubel takes a different but not incompatible approach, using the construction of a “focusing illusion” [2] to explain the judgments of mundane respondents.

The real question, implicit in Ubel’s paper and explicit in Menzel’s, is whether ethicists, lawyers, physicians, or policy analysts can accept the seemingly counterintuitive notion, advanced by persons of difference, that a physically or cognitively restricted life is as potentially full, fruitful, and worthy as a life without these obstacles. It is not that these generally healthy people dismiss the self-reported valuations of persons of difference. It is, however, that to the mundane public and, one assumes, members of the authorial teams themselves, the result is counterintuitive. Menzel, after all, describes the set of persons of difference as “thoroughly deprived” [6]. How can one credit a positively self-reported life quality by persons whose life context is thus described?

From the perspective of difference—I abjure use of “disability” as both inadequate and prejudicial—the real problem is with assumptions inherent in the researchers’ questions and the methodology employed in their work that result in a presumably unintentional lack of respect. With what are undoubtedly the best of intentions, the motive themes of these papers and the general methodology employed limit the usefulness of the papers’ conclusions and call into question the paradigms both research teams employ.

I would argue that predictive quality-of-life instruments impose a range of assumptions, typically implicit, that are not credible [7]. The first assumption is that a simplistic medical model with the descriptions of physical conditions can serve as a linear predictor of life quality for those living with that condition. But a wealth of

literature insists that such a medical model serves neither to address the complexity of the lived life or the life quality that may result from difference [8]. For example, research of social worker Young and colleagues, involved with patients with ALS (Lou Gherig's disease), offers one sample from a broad, if largely non-quantitative, literature [10].

Both Ubel and Menzel's teams impose a version of the simple medical model using QALY-style, health-related quality-of-life (HRQoL) instruments that ask mundane persons to make prospective judgments about life quality expected from different physical states. There is, however, no simple equivalence between changed physical condition and a resulting life quality [8]. Irrespective of a person's physical state, life quality is a complex outcome based on a daunting range of factors including but not limited to: age, education, employment, expectations and goals (familial, personally, and professional), experience, family structure, income, and social support. For persons of difference, the latter includes accessibility to the urban environment (curb cuts, transportation services, etc.), social and financial support if needed, as well as counselling and outreach services as appropriate.

To assume that the life quality for persons of difference can be predicted based solely on a single clinically defined difference is to suggest that any single, limiting condition solely defines the quality of our lives. It also assumes that persons with no understanding of life lived in a given health state can adequately predict what their life quality might be in that state. Further, to make even a moderately educated guess would require that subjects have some first-hand knowledge of the life that results, both its richness and its challenges. Most do not, and, thus, they judge out of ignorance [7].

In this vein, Ubel et al [2] consider a "focusing illusion" in which mundane people are assumed to "overestimate" the emotional impact of events by "disproportionately focusing on the narrow domains influenced by the events" [2]. When asked about blindness, most people will think as sighted persons about being unable to see; asked about paraplegia, people respond as ambulatory persons talking about being unable to walk. In other words, when faced with questions about states they have never been in, mundane people answer from the only perspective they have.

Ubel et al then argue that the goal of HRQoL "measurements should be to reduce this source of discrepancies" without suggesting how this reduction might occur [12]. While recognizing that patients and the public may not view HRQoL measures in the same way, Ubel assumes that this is a modest difficulty [12]. These "discrepancies" are, in fact, a fundamental flaw of the instrument that is built into the model and contributes to the arrogant assumption that mundane folks can judge complex states on the basis of a simple catalogue of physical differences.

Rather than looking at why people overestimate the impact of health events they have not experienced, Menzel et al, seek instead to explain the higher-than-expected life quality reported by persons of difference. To do so, they describe 8 modes by which persons of difference are assumed to adapt to their "damaged" circumstances. This

means that to understand a future quality of life in a specific circumstance, one must first consider which modes of adaptation he or she would follow. No QALY can do that. Hence, Menzel's study undermines rather than explains the QALY approach.

Certainly, people—mundane and distinguished alike—adapt to changes along the life course [13]. Unfortunately, Menzel does not draw upon the extensive and pertinent experiential literature, written by persons of difference or those who live with them [7, 8]. With great specificity recent literature documents the experiences of formerly mundane persons who have developed sensory limits (eg, blindness, deafness), mobility disorders (eg, paraplegia or quadriplegia), and severely limited neurophysical states [14]. A secondary literature describes the experiences of family members who live with and care for those persons and who reflect upon their own life quality within families of difference [8, 15, 16].

Across this range of writings and literatures, the message is simply profound and damningly complex. Life changes and people change with it [13]. Adaptation is a part of a process, individual and social—by which everyone accommodates to changes across the life course. Learning to live with difference is a subset of a more fundamental process with its specific challenges and boons as hard to perceive as the reality of a successful 20-year marriage is to a dating teenager. Why some are better able to change than others is a subject of our communal ignorance, one that extends into the greater realms of psychology and philosophy.

On the basis of the broader literature, professional experience with the families of hundreds of persons accommodating to changing realities, and my own psychophysical experience, I believe that there is much to learn about the human condition from persons of difference. These lessons cannot be reduced to a QALY-style questionnaire, however. They will not be discovered by assuming that lessons come easily to those unprepared to delve beyond the simple categorization of physical states as if they expressed a lived reality. The first lesson of difference, one that needs to be incorporated into research paradigms and the mind of the general public alike, is that life quality is not a simple outcome. Understanding that would inform the future research of these authorial teams and the work they hope in the future to present.

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