

Quality? Quantity? Quit Trying to Measure! Just Ask

Richard Taylor, PhD

RICHARD TAYLOR, PhD, is a retired psychologist who lives with and writes about Alzheimer's disease (AD). Richard has agreed to maintain frequent E-mail contact with *ALC* to provide us with a diary of his impressions, struggles, and conquests. Richard Taylor's reflections on AD follow.

How happy am I? What is the quality of my life? High or low, good or bad, poor or rich? Am I, can I ever be really happy?

That depends.

Depends on what?

Against what do you want me to measure my quality of life?

I have confirmed and reconfirmed dementia, probably of the Alzheimer's type. I live with its consequences every day. I'm still reasonably good at compensating and/or covering them up, but it is taking more of a toll on my energies and feelings. More and more my strategies are being overwhelmed by the disease, and other people are starting to know what I have known for quite a while now—my memory is increasingly unreliable and/or unavailable. My brain's executive function like "the old grey mare—ain't what it used to be."

How can I or anyone with the disease measure for themselves the quality of their own life? How can anyone who *does not* have the disease measure the quality of life of someone who *does* have the disease? One of us must have an unstable mind while the other one with a stable mind speculates as to



Richard Taylor, PhD, provides reflections on his battle with Dr. Alzheimer.

what is the structure of an unstable mind. Can an IBM operating system identify and diagnosis the status of a broken Apple operating system? And by the way, what makes the IBM believe it knows enough about itself to start branching out and looking at other operating systems? Doesn't it still crash too?

Professionals struggle with how to measure the disease, the pace of its progression, its consequences, and how these variables are influencing the "quality" of my life. If only they would ask me, I would tell them. If only they would define for me what quality of life is. In what increments is it measured? What is the best and what is the worst quality? Why is it important to them to measure my quality of life? I could give them a more informed answer to their questions: How is, or what is the quality of your life right now? Yesterday? A

week ago? Prior to the diagnosis? Compared to today?

I have long since ceased to measure myself against what I was or who I was. Right now I am me, and for me that is confusing enough to understand and appreciate. For a year or two, I kept looking over my shoulder at who I was (or remembered I was, or wanted to be), trying to measure my "decline." With each perceived decline, naturally came a decline in my quality of life. Annual neuropsychological tests were especially hard on me.

Look here, I lost 2 raw points on my score when compared to last year's score, and slipped 1 standard deviation there. What exactly did it mean? I wasn't sure, but I did know things must be getting worse. If they must, then they are! Probably even worse than measured too, I thought, as I carried "awfulizing" to its full extreme.

Why do others even want to know, measure, or track my quality of life? Can they do anything more about its decline if that is what they discover? Can they make good, "gooder"? It seems to me as if it is the wrong general question to ask—if you want to judge the impact of all the environmental manipulations you have made around me on me—if you want to measure the impact of all the drugs you have been prescribing for me to ingest—then ask me. I am still and always will be the best judge of my own quality of life.

Ask me! Give me some extra time if I need it. Be patient with me. Heavens know I am patient with you. Is there really one change in the color of paint on my walls, one change in how many and what kinds of vegetables I eat, one change in what pill, how big, how many I take that you honestly believe will have some measurable impact on my "quality of life?"

For me the quality of my life is defined and determined by:

- How much I feel loved by my family
- How much I feel I am giving myself to others
- How strongly and positively I feel about myself
- How much I enjoy right now, an hour ago, living in the here and now
- How little I live in yesterday to the exclusion of today and tomorrow
- How strongly I sense my own dignity, privacy, and honor
- How much I feel others honor me as a total person (not a diseased or incomplete person)

My quality of life is defined by my thoughts and feelings, not others' scales (pick a number from 1 to 10: how happy are you right now?). My quality of life is measured by how I feel about myself, others, and my relationships, not theories of self or stages of life. My answers to your questions do not fit well into data sets suitable for nonparametric and parametric statistical analyses.

What happens when you decide I can't decide for myself and/or I can't tell you what my quality of life is? Not so fast, please! I don't anticipate forever being able to fill out your forms and responding to your 3 pages of interview questions in a form of speech that I previously used, but please don't jump to the conclusion I can't know or communicate how I feel about myself. Isn't it your job to figure that out for your needs when you can't "read" me? First, perhaps more time and effort needs to be invested in discovering how you can communicate with me in the later stages. Who between us is best prepared to adapt to me and

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my ongoing attempts to understand my world—you or me?

For me this disease is not about stuff you can measure, or stuff you would really want to take your time to measure, much less worry about and devote an entire issue of a fine journal to exploring. This disease is not about pills, it is not about more information for my caregivers and it is not about filling out forms and making sure my paperwork is in order.

For me, this disease is about me, and I am confident each of the more than 25 million others living with this disease would offer the same answer. It's about how I feel about myself and how I feel about my relationships with other human beings. The quality of my life is not improved with a change from applesauce to fresh orange juice. It is improved by how I feel about the change, and the change in my feelings, my self-confidence, my sense of today.

My soul is bleeding to death

while others urge me to sign up for drug trials to find "the cure." My feelings are in such an uncontrollable state that I sometimes feel overwhelmed with dealing with them, while professionals want to know if I know who the President of the United States is. My sense of self and my sense of control over everything including my weakening sense of self sometimes bring me to tears. In the meantime, the organizations that I thought were formed to help people with this disease reorganize, refine, and rebrand themselves, and my government is placing all the dementia eggs in a basket labeled "RESEARCH." My government is betting that more eggs will mean that one will hatch with "the cure."

The quality of my life is defined between my ears. And the space between seems to be diminishing. The quality of my life is determined and measured against what's going on inside of me and outside of me, and both spheres of influences are becoming more and more cloudy, more and more limited, and frankly of less and less interest to me than was previously the case when I really cared what the Supreme Court ruled, who was the President, how funds donated in the name of people with Alzheimer's disease were spent.

I still care, but they seem to have less and less impact on how I feel. As I withdraw into myself (yes it begins very early on), as I lose more and more of the "old me," and I become someone different from who I was, not as easily understood by others and myself—perhaps my quality-of-life measures will simplify themselves and morph into applesauce and the colors of the plates from which I am fed. I hope not. I don't think so.

Always, the quality of my life is mine to determine, not necessarily yours to measure or understand.

If you really must know about the quality of my life right now, just ASK me! My answer won't be reliable, and it won't be valid. But it will be true for me. ALC