

Who Determines the “Quality” in “Quality of Life”?

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QUALITY OF LIFE (QOL) is a concept frequently invoked in healthcare settings. In ethical deliberations, it is a weighty consideration when determining the appropriateness of an intervention or whether certain risks are justified. However, it can be challenging to unpack the meaning of this phrase and how the concept ought to factor into care decisions in a real-world clinical context. QOL, understood individually, is inextricably bound up with preferences, values, way of life, and personal projects. Understanding what’s best for a particular patient requires an understanding of what QOL subjectively means for that individual.

To illustrate this point, let’s consider two real-life cases. (Details have been changed to protect patient privacy.)

LAURA is a 62-year-old woman with multiple chronic health problems, most notably Type 2 diabetes. She was brought to the hospital with a blood infection due to extensive necrotizing fasciitis. This tissue infection can spread quickly resulting in limb loss and eventual death if not treated aggressively with multistage surgical cleanout and excision of dead tissue, in addition to weeks of antibiotic therapy.

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VIRTUAL BIOETHICS WORKSHOP

**Beyond the Basics:
Problem-Solving Unique Cases**

We were pleased to host our bioethics education workshop for the 17th consecutive year, the third to be held virtually. This year's workshop focused on helping participants refine their analytical skills to resolve complex patient situations. We will report back on this event.



ROOTS *of* BIOETHICS



We're busy planning the next session of our Roots of Bioethics seminar. Please stay up to date via Ethical Times, our website, or by contacting us directly. We'll email an announcement to our education list when we confirm a date.

Quality of Life

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To have a chance at recovery, Laura requires prolonged hospitalization, including multiple surgeries. Success is far from guaranteed and the prognosis remains guarded. As the weeks progress, providers begin to ask questions: "What are we doing to this patient? Are we just causing her to suffer?" Complicating these views is that from what Laura says and how she presents herself, it appears that she's content with prolonged hospitalization, happy to simply be eating meals and watching TV. In conversations with providers, she repeatedly expresses that she's doing all right and looking forward to recovering and ambulating again with the help of a wheelchair. Laura always greets providers with a big smile.

ROGER is a 75-year-old man also with multiple chronic health problems, most notably Parkinson's disease and dysphagia requiring tube feeds to reduce the risk of recurrent lung infections. Roger is in and out of the hospital every month or two for repeat episodes of respiratory failure, most likely due to progression of his Parkinson's disease.

Over several months, with each hospitalization, Roger is able to reestablish his baseline level of functioning and return to the nursing home where he's lived for many years. However, over time, the intervals between hospitalizations grows progressively shorter, indicating that the patient is on a likely irreversible trajectory of decline. Providers are asking, "What is being accomplished here?" and "Are we really benefiting this patient when he's just going to end up back in the hospital in a month or two?"

Roger says that he enjoys life at the nursing home, where he socializes with staff and enjoys frequent family visits. Although he's bedbound and contending with the burden of repeat hospitalizations, Roger maintains that he has activities that make his life worth living. He repeatedly expresses that he wishes to go on living despite the "horrible" experience of frequent ICU stays and repeat intubations.


WHAT'S ACCEPTABLE?

On the face of it, both Laura and Roger have a QOL that many might say is unacceptable. This is exemplified by the fact that both patients have providers who, with the best intentions, raise serious concerns about putting Laura and Roger through unnecessary suffering for the sake of a QOL deemed unacceptably poor by the providers themselves. Laura will be hospital dependent for a prolonged period, and Roger requires support at a nursing facility and will never be able to safely eat by mouth again. Both patients have limited mobility and will be subjected to uncomfortable and invasive treatments to prolong their life.

However, both Laura and Roger repeatedly endorse that they want to continue living. And in both cases it's clear that their motivation isn't because they fear death or possess a great capacity for suffering. Rather, it's because they actually appreciate the activities they're still able to enjoy. Both patients are a testament to the fact that each individual is different and people have varying abilities to adapt to physical impairment. These patients' experiences underscore that QOL is a fundamentally subjective judgment.

The most important factor in determining whether a patient's QOL is acceptable is to listen to the patient. They are the expert on their own QOL. It's important, however, to bear in mind that what a patient is willing to endure does not override fundamental professional responsibilities, such as the duty to only offer treatments judged to be more beneficial than harmful. Shared decision making is a balancing act between what is appropriately offered based on medical indications and what is appropriate to offer based on what the patient shares with their providers regarding their goals and treatment preferences.

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INDIVIDUAL AND SUBJECTIVE

Eventually, when Roger's condition progressed to the point that he couldn't remain outside the hospital for longer than a week or two and thus couldn't return to his former quality of life, he and his family decided to transition him to comfort-focused care. They deemed it preferable to let him go peacefully rather than prolong his life in a state that would be intolerable to him: inevitably being nonverbal with a tracheostomy and placed in an unfamiliar facility far from family.

Laura's condition deteriorated to the point that she was too sick to meaningfully interact with others or relate to her environment. She lost the ability to appreciate what she was watching on TV. Her smile also disappeared. Laura could no longer participate in her own medical decision making and had no one to help make decisions on her behalf. Her providers determined (in line with hospital policy) that a DNAR (Do Not Attempt Resuscitation) code status was most appropriate for Laura and that she wouldn't benefit from ICU-level care if her condition deteriorated. Laura ultimately experienced an arrest and passed away in the hospital.

Although both patients died while in an irreversible trajectory

of decline, both cases show the importance of QOL judgments in guiding appropriate treatment and demonstrating respect for the patient by including them in a genuine shared decision-making process. Laura and Roger also demonstrate that QOL judgments are deeply subjective and that assumptions regarding a patient's quality of life should, when possible, always be verified against the patient's own report.

QOL is a solid example of "one size does not fit all." To overlook this distinctive feature is to ignore the variety and multifarious sources of joy and meaning that can add value to an individual's life. Acknowledging and understanding the diverse elements that make a patient's life worth living can prompt providers to better see the patient as a whole person and to resist the impulse to view others' lives through the lens of a provider's own values and preferences. QOL is an individual and essentially subjective metric. A life with immense physical challenges may be perfectly acceptable to one patient and wholly unacceptable to another, depending on the values and preferences of the individual. And one needn't be writing treatises or running marathons to have a meaningful life; sometimes kind words and entertaining TV programs are enough.



Commentary

WILLIAM S. ANDERECK, M.D., FACP

Dr. Gipe's article on Quality of Life (QOL) reflects the difficulties clinical ethicists face when the term comes up in ethical deliberations. I contend that the confusion around the concept of QOL lies in our failure to properly appreciate the word *quality*. Wittgenstein called philosophy "the battle against the bewitchment of our intelligence by means of language." The English language leaves much room for bewitchment, and our use of the word *quality* is one such example.

In common usage the word has two distinct and frequently interchanged connotations. The first is quality in terms of **excellence**: this one is better than that one. The second frames quality in terms of **essence** – what makes something what it is.

Right now, in my garden, we are growing peaches. There is an essence to a peach. It is round, fuzzy, soft when ripe, and abundant on well-maintained trees. Beyond the basic essence of being a peach, however, there are innumerable peach orchards, and some peaches are demonstrably tastier than others. Even peaches have a hierarchy of excellence called quality.

Quality's two connotations apply separately in clinical settings. Dr. Gipe's patient Roger could determine what was and was not beneficial to him. He was the arbiter of excellence in terms of his QOL.

When the patient Laura, however, was no longer able to relate to her surroundings or appreciate the benefit of continued aggressive medical interventions, that gave rise to the question of essence, what it means to be a person. Although philosophers and theologians may disagree as to when essence appears, there is agreement that personhood extends beyond physical existence to include a person's values, desires, and social relationships. Persons can relate to their surroundings in some way. The bar to "relating" may be low, but it needs to exist. Those unable to relate in any way, and thus unable to appreciate the benefits of therapy, focus the discussion on essence.

When debate centers around a patient's capacity for personhood (essence), medical opinion, based on experience and science, has a stronger voice than in the context of quality as an excellence. That voice has charted the path in developing policies to address situations where medical treatment can no longer provide appreciable benefit.

Understanding the different connotations of quality and its relationship to essence and excellence can help avoid bewitchment while identifying appropriate sources for decision-making in these difficult cases.

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