
My Quality is Not Low!

by Douglas McNair

Proponents of Quality of Life assessment often link QOL with contentment, a fact that may result in interference of the rights of people with disabilities. Instead, the voice of the client, his or her caregivers, and of society at large need to be listened to and respected.

"To accuse another of having weak kidneys, lungs, or heart, is not a crime, but saying he has a weak brain is. To be considered stupid and to be told so is more painful than being called gluttonous, mendacious, violent, lascivious, lazy, cowardly. Every weakness, every vice, has found its defenders, its rhetoric, its ennoblement and exaltation, but stupidity hasn't."

—Primo Levi

Other People's Trades, "The Irritable Chess-players" (1985; tr. 1989).

Measurement of "quality of life" (QOL) is increasingly performed in managed care programs, which usually treat QOL as an objective outcome or as one of a suite of quality indicators. QOL assessment involves the use of standardized questionnaires and survey instruments that aim to quantify, in a normative way that would be understood and accepted by the majority of the members of society, the 'quality' either as, or as amounts to, the desirability or tolerability of individuals' lives. Generally, QOL instruments include questions about functional capabilities and the ability to do the things one wants to do. But these questions are not value-neutral as their advocates tend to claim; the questions are emblematic of social norms regarding lives worth living, lives worth desiring or tolerating.

People who favor measures of quality of life generally agree that (1) QOL and subjective

contentment are not the same thing, even though there is statistically significant correlation between the two, and (2) individuals have a right to seek contentment in their own way, even though the situations that they seek or in which, lethargically, they remain would rate low according to QOL measurement criteria. Despite agreement on these aspects, advocates of QOL measurement nonetheless do often conflate QOL with contentment. This essay illustrates the notion that linking the two constructs may interfere with client rights, and recommends that good bioethics depends on good aesthetics, respecting the point of view of the client who is the subject of the care and measurement, the point of view of his social worker, and the points of view held in society at large.

Introduction: Kenny's Story

"The weak and the failures shall perish: first principle of our love of man. And they shall be given every possible assistance."
Nietzsche.

"Not so fast!" Kenny.

The care of people with mental retardation is realized in several types of institutions.

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Residential institutions accept persons with mental retardation who are unable to live independently and earn their own living, whose family is unavailable or unable to cope with the responsibilities of home care. Industrial workshop institutions accept persons who have some capacity for independence, occupying them at producing various utilitarian and decorative items or performing services such as packing or assembling mechanical parts. They come to the workshop from a home or family setting or a hostel; they work according to a schedule and under the supervision of a foreman; they receive meals and guidance and health care services while at the workshop; and at night they return home or to the hostel that is maintained by the workshop. An administrator helps them with financial matters, and free time and entertainment are supervised by a special educator.

Kenny — who has a recorded IQ of 60 and comparable deficits in adaptive behaviors — is seated at a folding table in the sheltered workshop, making wooden napkin holders shaped like geese. Several times each hour one of the other workers brings more pieces of scroll-sawed white pine for Kenny to sand smooth. The corrugated paper box that Kenny has filled with finished pieces is removed and a new, empty one is put in its place.

"In front of me. Kenny. I am forty-two. I have been [in places like this one] since 1968."

Kenny continues:

"People who say being contented is the same as quality of life are making a mistake. I want to have them come here or come home where I live with my parents. Then they would see I am contented even though I am mentally challenged and I don't have the objective measures of quality of life that they expect to see. I wonder about them, people whose quality of life is very high. They are very discontented with their lives sometimes, I think. Some of them even commit suicide.

"One reason why I am contented even though they say I have a 'low quality of life' could be that maybe I don't know how things might be better. I remember my grandpa [who had Alzheimer's

disease]. He was always in his chair at home, on the fringe of the rest of us. I think he wasn't really appreciated by people overall, and his life had been restricted in some way by his not knowing things anymore. But he had been a truck driver! He worked all his life. He knew lots of things. He knew about [had an image of] 'better'! But before he died he mostly used to like food and being in his chair, and he wanted to continue this life that would have, I guess, a low quality of life, according to some people, or low according to how he lived before.

"I'm as happy as Grandpa. This is not about forgetting or not thinking all the time about what is better. It's about having an idea [of 'better'] that changes or having different ideas. It's about not wanting bad enough to make it [an imagined 'better' situation] real. It's about disagreeing what 'better' means. I like it here. I like my friends. I like talking together and taking trips."

For Kenny and his grandpa, quality of life is about linking a lifestyle, including a sitting-in-a-chair life, to certain social relationships that the seeker values and that the quality of life measurements of the dominant culture do not value highly, linking them in such a way that the balance of values and pros and cons favors, for example, a relatively passive and dependent situation, where there are familiar and supportive caregivers and an absence of risk and fear and change. It is about linking these things, sometimes without any deliberation and without, at times, evidence of active desiring.

Penny's View: Act Consequentialism Lurks in Health Care Accountability

In addition to providing direct services to clients, Penny, Kenny's social worker for the past three years, is responsible for managing resource utilization within the state- and county-funded program of which Kenny's workshop is a part. Recently she has been directed to locate a different work situation for Kenny, with the objective of reducing the impact this workshop has on the county budget. Penny is doubtful that such a move is compatible with Kenny's best interests. She expresses her reactions in this way.

"I agree with Kenny. Many of us, at times, engage in speculating what's best; engage in kinds of speculation that conflate QOL and happiness. We think of ourselves as professionals and, as decision makers, we cite our altruistic intentions: we do this to explain or justify our interventions and our recommendations on behalf of our clients. People in human services sometimes push clients into independent living situations which may 'possibly,' but not 'certainly,' produce loneliness and anxiety, against the clients' and their families' wishes. It may place them at much higher risk of becoming victims of crime and abuse, having diminished access to care, and so on, and result in higher QOL, but lower contentment (Cwikel and Cnaan 1991; Reamer 1986; Schalock 1989).

"Discourse about developmentally challenged individuals sometimes resembles the debate on prenatal testing and what is the best decision regarding genetically challenged unborn fetuses or newly-born children. These conversations contain implied messages that certain individuals would be better off if never born ('wrongful life') or better off dead because they 'would have' low quality of life and 'would be' unhappy (Krajicek and Tompkins 1991). Discourse regarding societally devalued individuals who have dementia, like Kenny's grandfather, or who have metastatic cancer is commonly disposed toward withholding treatment that would not be withheld from others, or classifying certain treatment options as 'futile' that would not be judged futile in others, because these individuals 'have had' low quality of life and 'surely are or will be' unhappy if their lives are prolonged (Birren, et al. 1991; Rodgers and Bachman 1988). And in doing all of these things, we link QOL and happiness in a very peculiar way.

"I also agree with Kenny that he has a right to seek or to not seek whatever goals he can name. I agree that he even has a right not to be bullied into a process of identifying goals. Unfortunately, we have in Western societies a tendency to place high value upon goals and aspirations and desiring; we glorify independence and freedom and

the exercise of these. The notion of a 'dignity of risk' seems to outrank dignity that is conferred in other ways (Perske 1972; Slote 1989).

"In the definitions offered by some, QOL includes socioeconomic status, access to people willing to form and maintain positive relationships, and opportunities for personal development, for being productive, and for participating in social exchange. What we are really trying to do, I suppose, is discover a way to harmonize Kenny's wishes with those of others. His autonomy should be respected, up to the point at which it begins to interfere with others, collectively or individually."

According to Penny, accountability in mental health, as well as in other health care disciplines that are experiencing pressures of cost-containment and reform, is increasingly expressed as a kind of act-consequentialism, which says that, for each and every action opportunity, you should act so as to produce the best possible outcome. To be a good act-consequentialist you must continually (1) take into account all possible action opportunities; (2) compute which among the possible actions will produce the best outcome; (3) desire and actively intend the actions identified by (2); and (4) do those actions.

What is wrong with this notion of quality and accountability? Consequentialists are not required to always be right in their computations, so the problem is not about perfectly predicting the future, but instead is about the impossibility of trying to pick and perform the best action from those available. There are too many possibilities to discover and attend to a number, anyhow, that is so great and rapidly changing as to entail diverting such large amounts of attention as to be impractical (Foot 1985; Railton 1984).

In assessing Kenny's situation, Penny suggests that measurement-oriented, act-consequentialist notions of quality and accountability in health care are burdensome for busy providers. Moreover, they also are demanding for individuals like Kenny who may be developmentally unable to perform (1) and (2), and they are alienating and

devaluing of individuals like Kenny who cannot acknowledge (3) and (4) as duties.

The moral tension that Kenny feels in not wanting outcomes that others say he should want, and the moral tension that Penny feels in not acting to impose those outcomes on Kenny, both spring from the same source: not meeting the requirements of the act-consequentialism that today so permeates health care in the United States.

What is wrong with an act-consequentialist approach to health care generally, and to the care of developmentally disabled individuals specifically, is that it requires too much of everybody. Everybody who plays eventually loses. Supporters of the approach tend to be people who have never had to play the game, who have never been labeled as morally "bad" according to act-consequentialist rules.

Minimal Autonomy: Kenny's Preferred Way of Being

Kenny's case illustrates another way in which mental health ethics differs from bioethics as a whole. In many medical and surgical contexts, aesthetic considerations play a small role in decision making. However, givers and receivers of care in mental health contexts frequently find that ethics and aesthetics are closely intertwined. Conflicts regarding the aesthetics of human experience — the aesthetics of Kenny's life — versus the aesthetics of the goal-oriented, results-oriented, autonomy-oriented society to which he belongs translate directly into conflicts regarding rights and duties, a familiar idiom for traditional bioethics.

A different idiom, better suited to the realm of stories and aesthetics, is that of Heidegger (Heidegger 1927), who once proposed that all of human experience consists of narrative, and that in this natural narrative form human experience is hermeneutically meaningful. Heidegger's focus was ontology, the understanding of Being, and his main purpose was not to give a comprehensive account of the human experience of Being. His work, however, led him to believe that Being itself is structured aesthetically and is experienced

by humans through linguistic forms.

According to Heidegger, human experience is not the product of a knowing subject, separated from and detachedly observing Being. Instead, human Being is an aspect of the world's Being (Dasein) where the reality of Being reflects on itself. Human experience, for Heidegger, is a kind of "clearing" that is created by a part of Being (humanness, personhood) in which Being can reveal itself. No doubt Kenny inhabits a kind of Heideggerian clearing, every bit as much as each of us does.

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And every bit as much as Penny, who is responsible for planning safe and ethical interventions that may benefit Kenny. Of course, the object of inquiry and intervention for health care and the human disciplines is the human being, and, in order for these disciplines to function effectively as sources of utility and good, they must have knowledge that adequately represents the particular characteristics of individual human beings. To assemble such knowledge, formal science since the Enlightenment has been based on the notion that Reality, including real human beings, is ultimately comprised of objects whose actions and reactions are governed by stable laws. In this perspective, human existence has been considered simply one [abstract] object among others, a corrective to the revelatory notion that the nature of human existence was primarily spiritual and was governed by a relationship to God rather than to the laws of nature.

Yet, despite its merits and accomplishments, the Enlightenment definition of human existence is reductive. It takes objective time and space out of our original human experience of the world and removes sources of meaning, including the writ-

ing of our lives, stories, the production of our own narratives, from the account. It promotes in their stead, simplistic indices of human experience, such as QOL measures.

Developmentally Disabled Desiring

Bioethics has traditionally concerned itself with questions of autonomy, beneficence, non-maleficence, and so on, regarded primarily from the point of view of the provider. Penny comprehends these aspects of her professional role as social worker. Penny's struggle to harmonize Kenny's preferences with those of the society around him exemplifies the skills and dispositions of an ethical provider. She strives to help Kenny without regard to her own needs and interests, except perhaps her need to have self-respect, to live virtuously, to be "good."

Recently, bioethics increasingly has much to do with questions of right desires from the point of view of the consumer. There is the question of the relationship among an ethically good life, a psychologically healthy life, and a happy life. On almost every view, these three things — goodness, health, and happiness — are thought to be connected to issues of the wholeness or integratedness of personality (Taylor 1989), to personal and trait stability over time, and to accurate self-understanding and social understanding. In some ideal world, the three go hand-in-hand, but, in real life, this seldom happens; none of these is necessary nor sufficient for the others.

There are, for example, people whom we count as good who are, in some way, developmentally disadvantaged or psychologically disturbed. Some of these, like Kenny, are happy while others appear quite unhappy. More disturbing (Flanagan 1991; Williams 1985) are those who are contented but are self-absorbed or self-deceived, or constitutionally incapable of accurately understanding the needs of others, such that they are insensitive to the interests or suffering of other persons around them. By various measures they may be mentally "normal" or healthy, yet they behave in immoral ways.

Is Kenny such a person — an analogue of

Melville's "Bartleby"? Is the IQ 60 label accurate? Even if it were accurate at some point in the past, is it accurate now? Does the label entitle Kenny to rights and privileges that others who lack the label do not have? Does it entitle him to make perpetual claims on his parents, on his social workers, or on society?

I think the answer to each of these questions is, no. Although he has some impairments of reasoning and communicative skills, we have every reason to believe that Kenny's positive affect and sociability are connected with benevolence and other virtuous character traits. Stories such as his and Penny's cause us to feel critical of conceptions of moral goodness that place too much emphasis on action. We sense that such conceptions are incomplete insofar as they do not give proper moral weight to goodness of character, the foundation of good action.

But, on behalf of the act theorist and against the virtue ethicist, we have a further response. The emphasis on action to the exclusion of a theory of character is not so much based on the idea that moral action can be understood in purely behavioral terms as it is based on the idea that there can no more be one exact theory of morally good character than there can be exact agreement on what is aesthetically pleasing or morally desirable. This is not only because we disagree about what ways of being count as good; it is also due to the fact that, even where we have consensus about what is good and desirable, many different psychological states and mental processes can produce the object of the agreed-upon desiring. Our world is a pluralistic one, one that sustains a wide variety of morally good personalities and patterns of desiring.

Conclusion

As we enter the world of a person like Kenny, we become aware of how different his experience is from our own. We listen to him and come to suspect that he has an "internal clock" that is somehow different from our own, a bodily awareness of time's passing, which contributes to his perceptions of pleasure and pain, but which seldom

risers to conscious awareness (Husserl 1928; Ricoeur). That he has no temporal motivation or desires for plans and goals, however, does not mean that he has an impaired memory. It does not mean that he experiences life as a chaotic succession of "nows." It does not mean that he is less than a whole person or that he does not have "a story" (Flanagan 1991).

As Kenny confronts our world, he, too, is impressed with how different our experience is from his own. He cannot comprehend why others are so persistent in wanting to change his life. He asserts his preferences and his notion of good and pleasant and beautiful — his aesthetics — as his wish to "be" just as he is. He may be more "vegetative" than we would wish; his story may not be one that we would want for our own; but it is his. He vigorously defends his right to have it and to continue as the author of it: "My quality is not low!"

Bernard Williams has often argued (1) that having and striving to achieve certain personal goals, desiring and carrying out certain, personal projects, are necessary for a meaningful life; (2) that consequentialism and Kantianism in many cases require us to give up our personal projects and goals; and (3) that, therefore, something must be wrong with Kantianism and consequentialism. From cases like Kenny's we begin to grasp that (1) may be false but (3) still holds.

In situations such as Kenny's, dialogue between the affected parties, sufficiently extensive and sufficiently free from bias and coercion so as to be able to understand the narrative of each life, is an ethical means of resolving the aesthetic differences. Above all, providers should resist being misled into "binary" decisions by reductive, objective measures like QOL indices; misled into discounting the spiritual, psychosocial, and narrative aspects of the person; or misled into dismissing or marginalizing persons who very much need love and care. And if, instead of being a provider or other interested party, we find that we ourselves are Kenny, then we should hold out for a pluralistic accommodation and a greater degree of tolerance than is often extended to us, and strive

to understand and forgive those who would alienate us.

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