

# Alzheimer's Disease and the Quality of Life

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The concept of quality of life plays a controversial role in the care of patients with Alzheimer's disease. In general, the notion of one's quality of life is something that should be defined by the person to whom it applies. When others make a judgment of quality of life they are exercising power (because quality of life judgments have consequences for caregiving services), and they may be imposing a value or set of values that the patient does not share. Hence, improper or inappropriate quality of life assessments may both harm and wrong a person. To harm is to hurt or to violate a person's interests. To wrong a person is to treat that person like an object or a thing; it is to fail to recognize and acknowledge the humanity of the person.

In the case of dementia (and many other disabling impairments as well), the person is particularly vulnerable to both harm and wrong. Unfortunately, the misuse of the notion of quality of life is probably quite widespread in situations of Alzheimer's disease, because dementing illness undermines precisely those qualities that in American culture are seen as making an individual distinctively human—coherent communication, memory, social orientation, and behavioral self-control. And yet, as dangerous as it is, we cannot entirely avoid using the notion of quality of life when talking about Alzheimer's. We may avoid using the words, but we cannot avoid the idea. It is particularly important that we get this idea straight and use it appropriately. In this chapter I sort through the various meanings of the notion of quality of

life, and discuss how to use it ethically and appropriately for the benefit, not the detriment, of Alzheimer's patients, caregivers, and families.

## FOUR MEANINGS OF QUALITY OF LIFE

Some people refuse to use the term quality of life at all because to them it means that we are trying to evaluate something that is presumptuous or wrong for us to evaluate. Another version of this worry is that the idea of quality of life necessarily turns into a judgment about the value human life. (This mistaken line of reasoning goes something like this: "A life of very poor quality is not worth living. If a life is not worth living, then it has no value.") The term quality of life seems to suggest that life is not intrinsically worthy of respect, but can have greater or lesser value according to its circumstances. (Cohen, 1983)

These are powerful and plausible worries, but I think there is a way that the concept of quality of life can be used to enhance, rather than detract from, ethics. It is not only possible but essential to distinguish quality of life from the value or worth of life. Properly understood, the notion of quality of life can be used to enhance respect for them as human beings, as members of our common moral community. And it can be used to strengthen the case for social reform and improvements in Alzheimer's disease caregiving systems on the basis of social justice and equity. In order to use the notion of quality of life appropriately and for these ends rather than inappropriately, we need to become more precise about what the concept means. I think there are four different senses in which the term is used.

### *Quality of life as a property of the individual*

First, the notion of quality of life is used to refer to some characteristic or state of being of the individual person. A quality of life (whether good or poor) is something one has or possesses, much as one has a physical characteristic or a personality trait. Moreover, it is a temporary characteristic that can change over time, or it is a characteristic than can be compensated for or ameliorated by some artificial device or by special training—and for this reason quality of life is not an essential component of one's identity or self-esteem. As such it has no straightforward moral significance. A poor quality of life (due to ill health, loss of a job, breakdown of personal relationships, or the like) is not necessarily a sign of a person's moral failing, and it says nothing about the intrinsic value of life as such, or even about the moral value of that particular

life at that particular time. Those who suffer are not generally thought to be less deserving on that account of others' care and concern. On the contrary, morality teaches that they are more deserving.

### ***Quality of life as a goal of care***

A second common meaning of quality of life defines it as a goal of care. The moral point of our dealings with another (whether the situation be health care or some other form of relationship) is to sustain and improve the quality of life. In this sense, quality of life becomes a benchmark to guide human activity and a concept of assessment and evaluation, not of the person, but of the care he or she receives. Notice that the evaluation here is directed primarily at the caregiver and the caregiving process, not at the recipient of care, who partakes of the quality of life achieved but is not judged by it. Moreover, the quality of life that the person enjoys may be thought of as an interaction, so to speak, between the person and her surrounding circumstances, including other people. Thus understood as a goal or outcome of care, an improved quality of life may be a change (for the better) in the person's symptoms or perceptions; or it may be a change in the person's relationship with his environment. Medical cure, symptom relief, psychological happiness, or social empowerment may all be goals of care as comprehended by the concept of quality of life.

### ***Quality of life as a social situation***

Next, quality of life refers to the quality of the interaction between an individual and his social and physical environment. Here a certain quality of life is not a property of the individual per se, but a function of that individual's form of life, his way of being in the world. Once again, a low assessment of a person's quality of life in this sense does not suggest a negative evaluation of the person or his worth; only a negative evaluation of his circumstances. Instead it implies a critical evaluation of the person's environment and can be used to find ways in which that environment could be enhanced or improved. There are some kinds of cognitive function that persons with Alzheimer's disease can no longer perform, but the capacities for stimulation, response, and enjoyment that they do still have can be enriched by a good environment or can be starved by a poor one. Quality of life is less about what the person with Alzheimer's has lost and more about how to make the environment support the capabilities he or she still has. Far from rejecting human dignity as a moral touchstone, the concept of quality of life in this sense can be used as

a critical champion of dignity, attacking circumstances that undermine it and supporting change in the person's surrounding conditions that will respect it. Quality of life, high or low, does not reside in people, but in the space of interactions between and among people.

### ***Quality of life as the moral worth of a life***

Finally, it must be acknowledged that the term quality of life is sometimes, perhaps often, used to refer to the moral worth or value of a person and his or her life. Pushed to its logical extreme, this understanding of the quality of life takes us to the infamous Nazi concept of "life unworthy of life," (*lebensunwertes Leben*), which was used to rationalize everything from active euthanasia of those with disabilities to the genocidal death camps. (Lifton, 1986)

It is this last sense of the concept of quality of life, and this last sense only, that makes the concept prone to abuse and morally dangerous. How can a life of very poor quality possibly be respected or judged to have moral value? If the notion of "quality" refers to the moral worth of life, then the notion would seem incompatible with the idea of life's intrinsic value, and it would lead us, perhaps illicitly and improperly, into the realm of instrumental value only. But the notion of quality can be understood differently, and the implications are then reversed. The notion of quality may mark the gap between the *actual* circumstances and the *possible* circumstances of an intrinsically valuable life. I need not say that Beethoven is merely a means to the end of making great music (and thus value him only instrumentally) in order to say that he would be better off with access to a piano than he would be without access to one. Nor do I have to deny his intrinsic worth (or indeed make any judgment about his moral worth whatever) if I were to make the (admittedly much more controversial) quality of life judgment that Beethoven was better off when he could hear than he was after he became deaf.

An account of moral worth is based on an underlying account of humanness or the human person; an account, that is, of what it is to be human. The concept of quality of life, on the other hand, is based on an account of a person's inherent capacities and external circumstances. Quality of life may tell us something about the experience, but not the moral worth of humanness, or it may tell us something about *becoming (more fully) human*, but never about the value of *being human*.

In the end, the concept of quality of life must be judged by how it is used. In the hands of those who want to deny services or rights of individuals

who purportedly experience a life of low quality, the concept is dangerous. However, the concept may also be used by those who seek a way to assess individual need and the quality of care and services so that more effective and humane care can be provided, and so that more human benefit will result from these services.

## PHILOSOPHICAL THEORIES OF QUALITY OF LIFE

Philosophical discussions of the meaning of quality of life fall into three main types: (1) sensation (or “hedonic”) theories, (2) reasonable preference theories, and (3) theories of human flourishing. (Brock, 1993; McCormick, 1978; Scanlon, 1993)

### *Sensation theories*

This version identifies quality of life with states of awareness, consciousness, or experience of the individual. Happiness or pleasure are the constituents of a good quality of life; pain and unhappiness define a poor quality of life. This allows for considerable individual variation in assessing good quality of life because different things make different people happy, but it also allows for some kind of common measuring rod because there are seemingly universal negative states of pain or suffering or unhappiness that all (normal) persons avoid.

The trouble with this theory seems simple once you think of it. Imagine a person locked in a cell with an electrode implanted in a pleasure center of the brain. All he does is press a button and experiences pleasure all the time. No freedom, no friends, just pleasant sensation. This theory holds that such a person would be experiencing the highest quality of life. Most of us, I imagine, would see this as a stunted, pathetic way to live.

An interesting question, when applying this type of theory to the case of Alzheimer's disease, is whether it is necessary for the person to realize he is happy in order to be happy. If the pleasure or happiness in question requires some form of self-awareness (not only being happy, but being happy to be happy), then at some point in the course of Alzheimer's, when that capacity is lost, this theory will provide only a negative assessment of the patient's quality of life. It will load the dice against Alzheimer's disease. But surely we want that to remain an open question, subject to empirical research, and not a closed question settled in advance by the very definition we give to the notion of quality of life.

### ***Reasonable preference theories***

The second type of theory defines quality of life in terms of the actual satisfaction or realization of a person's rational desires or preferences. This is a much more objective theory than the sensation account in that a person need not be aware that his preferences are being fulfilled (or need not take pleasure in that knowledge) in order for the quality of his life to be good, it just must be the case that they are. For example, if I arrive in Chicago during a snowstorm to attend a political meeting that furthers the cause of justice, my quality of life is enhanced (because my rational desire for justice is furthered) even though subjectively I may feel cold, miserable, homesick, and bored by longwinded speeches. If I skip the meeting and go to a beach in the Virgin Islands instead, my pleasurable experience may be enhanced, but my quality of life will be diminished. The underlying appeal of theories of this type is the notion that individuals have a good life when the objective state of the world conforms to what they rationally desire.

### ***Theories of human flourishing***

This type of philosophical theory attempts to base our understanding of the good life on an account of those functions, capacities, and excellences that are most fully and constitutively human. To the extent that we attain and master those capacities, and to the extent that we negate those conditions that would stunt or undermine those capacities, we flourish as human beings. Theories of this type also usually have a developmental component built into them, for those most fully human capacities are ones that are not mastered at birth or automatically expressed by instinct, but must be developed and nurtured by education, interaction with others, and practice over the course of a life time. To the extent, then, that the individual continues to grow and develop throughout her life, the quality of life is enhanced thereby.

This account emphasizes the human capacity to express and to experience meaning in social relationships of intimacy, friendship, and cooperation; the capacity to use reason and to develop and follow a life-plan of self-fulfillment and self-realization; the capacity for independence and self-reliance; and the human need for an appropriate social and cultural environment that provides the individual with various types of resources—material, symbolic, spiritual—necessary to live a developmentally human life and to meet both basic and secondary needs.

These brief sketches scarcely do justice to theories that are in fact very elaborate and complex. But perhaps enough of a flavor of these three common approaches to the concept of quality of life comes through to draw a few conclusions.

For understandable reasons perhaps, in the literature on quality of life and dementia the most commonly adopted philosophical perspective is the sensation or hedonic account. It may seem that only this type of theory is compatible with the radically diminished cognitive capacity in Alzheimer's disease and other dementias. Or it may be that this type of theory seems most congenial to the value relativism and the subjective approach Americans are most comfortable with in dealing with such a sensitive and potentially discriminatory concept as the quality of life, especially when applied to this most vulnerable population.

I believe that we should not limit ourselves to this understanding of quality of life in Alzheimer's disease or other dementias. The main problem with this theory is its tacit conceptual bias. In discussions of quality of life in dementia, the relative strengths and weaknesses of these three types of philosophical theory have not been explicitly discussed, and the sensation approach has been adopted without sufficient critical analysis.

The concept of quality of life is misused, in my judgment, when it becomes a floor below which no significant societal expenditure of resources is required, and below which personal caregiving efforts may be reduced to the decent minimum. A much better way to think about quality of life is to see it as a ceiling, a potential level of functional capacity and capacity for relationship, toward which caregiving efforts should be designed to strive. The height of this ceiling will not be the same for everyone, and quality of life is not a test that you fail if you do not reach a certain height. But the important point is that quality of life should be used as a teleological concept—setting a goal to reach and a process to reach it, rather than as a prioritizing concept—setting a rank ordering for the allocation of scarce resources. In discussions of Alzheimer's disease, when we focus too much on the hedonic elements of pleasant sensation and immediate experience, this very point about how quality of life notions are used in policy analysis tends not to be raised at all. Since we assume the ceiling is inevitably going to be so low, we turn our attention to not “wasting” resources on those who have already fallen below the floor.

Future work on the quality of life with dementia needs to adopt a more synthetic and eclectic conceptual approach, drawing on the resources offered by each of the main types of philosophical theory of quality of life. Life lived with dementia, even well into its later stages, can be explicated by drawing on conceptions of rational desire and even human flourishing, and it need not be assessed only in the most directly sensate, hedonic terms. If we try to work with broader and richer notions of quality of life, as Lawton, for example, has done, we will in fact be rewarded with more insightful findings that will be helpful in guiding public policy and clinical practice. (Lawton, 1991; Lawton, 1995; Burgener, 1998; Albert et al, 1996; Russell, 1996) But I also argue for this broader approach because I believe the consequences of adhering to the sensation approach exclusively, are unacceptable.

## **A LIFE GREATER THAN ITS SENSATIONS**

When we use only hedonic notions of quality of life as our lens to view life lived with dementia, we run the risk of too quickly closing off aspects of meaning making and moral personhood from persons with Alzheimer's disease. Alzheimer's does not, until perhaps very, very late, close off the possibility of meaning-making activity by a person supported by the right types of interpersonal relationships and caring systems. This activity cannot be reduced to feelings or sensations alone; it taps a circuit of two-way communication and experience between human beings that goes beyond unilateral sensation or sensate experience. Of course, communication here does not mean verbal or even semiotic communication, for the capacity to manipulate previously learned semiotic systems may be lost with Alzheimer's patients. But touch, gesture, facial expression, posture, eye contact, even control of body movements to permit prolonged physical closeness, like sitting together, can conceivably be media of semantic agency, and these are much slower to be lost than memory, speech, functional capacities for activities of daily living and self-care, and the rest.

By "moral personhood" I mean that respect and acknowledgment of the individual as a member of the human moral community is ethically required. Each moral person (the caregiver, say) has an obligation to maintain and sustain relationships with other moral persons (the Alzheimer's patient). If I am a moral person, I cannot rightfully be ignored, abandoned, exiled from the space of connection between selves that we call the moral community. If we



come to the too-easy conclusion that Alzheimer's patients have lost moral personhood—have lost this status, this claim on our attention and response—then it will be all the easier to turn aside from these connections and all the easier to tolerate institutions and caregiving systems that fail to fashion, mend, and create those connections and relationships.

Is this not precisely what we do so often with demented patients now in our health care institutions? Isn't this what our lack of social support to Alzheimer's families makes so difficult to achieve even in the home setting? In asking these rhetorical questions, I do not mean to say that when Alzheimer's patients are seen as lacking in moral personhood they are necessarily neglected, abused, or abandoned. But I do claim that the moral basis of our care giving changes. It is one thing to give care and protection out of a sense of pity, or charity, or professional duty, or even love; it is another to maintain a relationship and connection with the other for as long as possible out of a sense of the moral importance of that connection *per se*.

Caring and caregiving, after all, are not only about meeting an individual's needs or making him comfortable; they are about the recognition of the person of the other, the one being cared for, and they are about the recognition of the caregiver's own personhood therein also. I have just said the recognition of the person of the other; I should also say that caregiving and quality of life are about the preserving, conserving, sustaining, nurturing, and eliciting of that personhood as well.

We can now return to our discussion of quality of life. When we define quality of life in exclusively hedonic terms—especially when we conceptualize happiness or pleasure in terms of direct sensation rather than the secondary interpretation or mediation of first order sensation—we effectively leave no room for semantic agency and moral personhood, whereas these ideas are at work to some extent in rational desire theories and figure very largely indeed in human flourishing theories. If we thought that an Alzheimer's patient had the capacity for semantic agency or moral personhood, why would we ever be content to say that she has a good quality of life if her pleasurable sensations outnumber her painful ones? Surely we would look at the surrounding conditions that the patient is living in and ask, how can the range of her exercise of (remaining) capacity for semantic agency be enhanced and facilitated? How could caregivers be given a better opportunity to mend and maintain those relationships and interactions appropriate to the recognition and honoring of

moral personhood? Pleasant sensations or feelings will come through the exercise of semantic agency and with the recognition of moral personhood, to be sure, but they, not the feelings per se, are the sum and substance of her quality of life. (Tragically, with Alzheimer's disease we may actually have to choose between happiness and agency, for to slow the progress of the disease in its early or middle stages and to extend the period of capacity and agency is also to extend the suffering that accompanies the awareness of ongoing and impending loss. Hedonic conceptions of quality of life would not necessarily view drugs that have this effect as beneficial.)

There is another reason why relying solely on sensation or hedonic conceptions of quality of life is a bad idea. The notion of quality of life is a tool for health policy makers to use in assessing the quality of health services. For Alzheimer's disease, this means mainly long-term care, rehabilitative, and palliative care. The hedonic conception of quality of life sets the bar too low for policy makers. We need more than safe, comfortable warehouses for persons with advanced Alzheimer's. We need to demand caregiving environments that provide some measure of rehabilitation in terms of the human relationships, modes of interaction and communication, and the sustaining of semantic agency moral personhood (making meaning, and being treated with respect). (Solomon & Jennings, 1998)

As my generation ages into the first few decades of the next century, I do not want to send a message to young policy makers that it is enough merely to provide a shelter where I can be kept pleasantly senile, as important as comfort and safety are. If Alzheimer's disease is destined to be the last chapter in the story of my life, I want those pages to have more of a plot, and more of a character than that. I can't bring that about by myself now, no matter how much I save or how much long-term care insurance I buy; and I won't be able to protect my own quality of life interests then. But the people and the institutions that care for me could do so. Will they have the wherewithal (the resources and the social investment) and the will (the proper understanding of the goals of care) to do so? The answer to that question will determine the quality of life ahead for millions of persons with Alzheimer's disease. ■

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