

"The object of philosophy is the logical clarification of thoughts. Philosophy is not a theory but an activity."

— Ludwig Wittgenstein

Hot Topic

Quality of Life: Who Defines It?

The term "quality of life," often used in the field of bioethics and medical ethics, carries strong emotional aspects and deep meaning for different people. It is also a term that is used inappropriately, haphazardly, and without proper understanding of its implications. Quality of Life can be a way of protecting a patient's right to autonomy, or it can be used seemingly to morally justify unethical actions.

Founded in the principle of beneficence (the moral obligation to do good), quality of life centers on the significant element of beneficence that involves bringing satisfaction or happiness to others. Therefore, as Jonsen argues, "Quality of life, then, refers to that degree of satisfaction that people experience and value about their lives as a whole, and in its particular aspects, such as physical and psychological health" (Jonsen p. 111). Further extrapolating, Jonsen defines quality of life as "a state of satisfaction that expresses a value judgment: the experience of living, as a whole or in some aspect, is judged to be good or bad, better or worse" (p. 112).

The important aspect of this definition is that it focuses on the individual's perspective, their personal satisfaction/experience of their own physical, mental and social situation. Fundamentally, it is the patient who determines quality of life, not the provider. But the term is not exclusively to refer to patient autonomy. Difficulties arise when it is used in different situations.

Two Perspectives

There are two notable uses of the term "quality of life." One is the working definition above, which highlights the individual's perspective. The other may refer to an observer's evaluation of someone else's experience. These latter situations raise more challenging ethical issues, and the obligation towards beneficence defines how we attempt to respond to them.

The principle of beneficence conveys the importance of supporting and promoting good, with one way of defining this promotion seemingly to promote quality of life. In doing so, the principle supports prima facie rules of obligation that include but are not limited to "Prevent harm from occurring to other, and remove conditions that will cause harm to others" (Beauchamp and Childress, p. 204). But this falls into difficulties when "preventing harm" and "removing conditions that cause harm" are not shared between provider and patient. What might be considered a harm to the provider but not be seen as harm to the patient? And what if those harms are seen as interfering with quality of life, and steps being done to remove those harms come with their own potential costs and harms, thus meaning the patient and provider have different views on what is quality of life?

The Patient's Right

It is challenging, if not impossible, to quantify and absolutely define what constitutes harm and challenges, and failure to have universal standards means that neither patient nor provider will have to take priority over the other. This stance is supported by Susan Rubin stating, "Though there has been a movement to develop measurements for and indicators of quality of life, none of us can legitimately claim to know truly and authoritatively what another's quality of life is" (p. 51).

Of the prima facie rule of obligation listed by Beauchamp and Childress, the first one given is, “Protect and defend the right of others” (p. 204). While medical providers hold the obligation to beneficence, protecting patient rights is a powerful means of upholding beneficence. And patients hold the right to determine and define quality of life. Quality of life is an important conversational abstraction to more easily identify values, preferences and wishes; it is not an overpowering force that takes decision-making away from the patient. A patient holds the right to live a life that they find valuable, but only they should be able to define what a valuable life is because they are the only ones who will live it.

Bioethics in the News

[Is bioethics an honest profession? The jury's still out](#)

['Immunity Passports' Could Do More Harm Than Good](#)

[As Hospitals Walk Tightrope Of Patient Data-Sharing, One System Offers A New Balance](#)

[In Praise of Aphorisms](#)

[Do Vaccinations Violate Human Rights Under The Nuremberg Code?](#)

[The Journal of Health and Human Experience: Spring 2020 Edition: Vol. 6 No. 1](#)

Case Study

The patient is a 45-year old male with chronic cardiac issues. If the current standard continues, the patient is not expected to live past the next five years. It is recommended that the patient undergo a surgical procedure that will add several years to his life expectancy. The patient is an avid outdoorsman, and was told that he would have to limit his outdoorsmanship after the procedure. Patient declines the surgery stating that being outdoors and active defines his quality of life. He would rather die in five years than live fifty no doing so. An ethics consult was requested.

Ethical Musings

Quality of Life as Phenomenological Experience

As discussed earlier, quality of life is an important idea to help think through potential consequences and states of being that a patient may experience because of, or in avoidance of, particular medical procedures. As such, it is fairly strongly established within the medical ethics community that only the patient can define what is quality of life to themselves, and it is not the provider who can and/or should do so. The reason it is the patient's right to define what quality of life means to themselves is because only they can/will experience the life that results. An understanding of this brings to mind a school (or movement, there is debate on this) of philosophy called phenomenology.

As defined by the Stanford Encyclopedia of Philosophy, Phenomenology “is the study of structures of consciousness as experienced from the first-person point of view. The central structure of an experience is its intentionality, its being directed toward something, as it is an experience of or about some object.”

One key focus of Phenomenology is the concept of intentionality. Developed by Edmund Husserl, intentionality is a reflection of the experience of the acting agent, an experience that transcends defining objective truth statements that exist outside of the acting agent. The focus of the intentionality statement is the agent themselves. Intentional acts, and therefore intentional statements about intentional acts, have four aspects: who is performing, what this person is doing, what the act is about, and finally in what manner is the object of the act (EoP, vol 6, p. 144).

Experience Creates Truth Value

This is better explained through an example. Imagine the statement “Michael thought that a ghost was in his room”. This is a complete description of an intentional act. Michael is the one performing the act, Michael is thinking (thought), Michael is thinking about a ghost, and in what manner is Michael thinking about the ghost, he is thinking the ghost is in his room. Now contrast that to another statement, “I wrote and sent an email with my phone”. The major different between the two statement is the truth value of the second aspect (i.e., what this person is doing). If I do not have a phone, then the truth value of the statement “I wrote and sent an email with my phone” is false because it would make no logical sense to state, “I wrote and sent an email with my phone but I do not have a phone”.

But, with the perspective of Phenomenology and focusing on the individual, the truth value of the first statement, “Michael thought that a ghost was in his room” is not dependent on the truthfulness of the second aspect of intentional acts. If there was not in fact a ghost in Michael’s room, it does not change the truth value of the statement that Michael thought there was a ghost in his room. So, the statement “Michael thought that a ghost was in his room” can have a different truth value than the statement “There was a ghost in Michael’s room.” It does not change the truth value of the first sentence if there or was not a ghost. Michael’s experience of the event creates its own truth value.

The Patient’s Experience

Now, let’s relate this to the field of patient experience. Let us take the statement, “Michael is afraid and does not think the medicine is helping.” As medical professionals, many might think that Michael is wrong, that the medicine is helping, and his experience is too suggestive, misinformed, and therefore wrong. But that does not does not change the truth value of the phenomenological intentionality statement that Michael is experiencing. It is true that he is afraid and does not think the medicine will help. Medical professionals should apply thinking to the subject of quality of life. Let us use the statement, “Michael thinks that the surgery will not benefit him and give him quality of life”.

Just because the medical provider does not believe refraining from potentially aggressive treatment is upholding of quality of life does not mean that the true value from Michael’s experience is not true. And as discussed, quality of life should be determined by the patient because it is the phenomenological experience of the patient that defines the truth of the experience of the patient.