



# Health Care Ethics Informed Consent, Quality of Life, and Full Disclosure

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**Research Note**

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## Abstract

Health care ethics have taken an importance not appreciated in times past as a person's individual wishes are emphasized and respected more robustly in the 21st century. A patient has the individual right to decide his/her care and what steps can be taken (or not) based on their own beliefs, priorities, and wishes. It is imperative that clinicians and healthcare institutions, including all stakeholders, respect these right-including informed consent, a patient's wish for their specific quality of life, and their acceptance of not prolonging treatment. Informed disclosure continues to be the ethical standard that providers must follow to allow patients (perhaps after discussion with their families) to decide how to proceed in terms of their own healthcare. Attempts to minimize mortality are not the goal of healthcare, rather the drive should be to improve health outcomes by improving the quality of life remaining while ensuring that the patient has full knowledge of their condition, treatment options, and prognosis. Healthcare ethics demand that patients be equal partners with their medical providers in deciding the future of their healthcare and be not dissuaded from asking questions and demanding proper and accurate answers. This paper dwells on the most common aspects of healthcare ethical dilemmas and the proper mechanisms to deal with these issues.

**Keywords:** Ethics; Informed Consent; Quality of Life; Capacity and Competency; Full Disclosure

## Research Note

Quality of life fundamentally has to do with the satisfaction an individual feels in his life taken as a whole and the value they put to specific aspects of their existence, both mental and physical. This is a subjective evaluation by the individual on his perception of the quality of the things he has experienced in life and his overall gratification with it. In a bid to make this process more objective, researchers have tried to dissect this contentment into different areas: mobility, performances of actions of daily living, presence or absence of pain, and mental acuity [1]. Another approach to quality of life is the understanding that various components of our existence must be looked at: social responsibility

and roles, intellectual and physical functioning, emotional satisfaction, and the state of being well. The distinction must be emphasized that the quality of life differs from the concept of "sanctity of life"; a view, which abhors any practice, which may limit one's life existence by any, means whatsoever.

The ethical clinician must make all attempts to provide thorough, competent, and timely medical treatment (therapeutic or supportive) as this is the essential force to improve a patient's quality of life. In a team-based approach, both the provider and the patient must define what would improve the patient's quality of life and the subsequent treatment must be focused on that goal. This discussion must also explore the various treatment interventions available,

the risk-benefit ratio in following a therapeutic path, and the desired patient outcome.

The concept of Quality of life has recently gained steam due to various media reports of young people, with a terminal illness, electing an approach where they would rather hold off on experimental drugs with brutal side effects and end their days in family and comfort care. This concept is the subjective view of an individual on how they view and value their lives, their perception of their own happiness and satisfaction about their existence, and their desire to live in a preferred state. There has been a push into moving the Quality of life concept from the subjective to the objective arena using scales such as patient mobility, pain or absence of pain, social involvement in the community, and mental alertness [2].

An individual's quality of life can be shaped by their own personal view or evaluation or also by an observer. There is a subjective aspect inherent in this process of evaluation and all sides have their own validity. An observer could judge someone as having a poor quality of life due to the observer's own internal standard of what life should be like. Furthermore, consideration should be also given that the quality of life can be fluid at times, and the observer may bring in his or her own biases to this task. In cases where the individual is mentally incapacitated, it can be quite difficult to accurately identify the concept of the quality of life and this responsibility might be borne by a surrogate observer [3].

Discrepancies between a physician and their patient might occur due to multiple factors: lack of understanding about patient's values, bias, and discrimination (although unintentional), the introduction of social worth criteria into the quality of life judgments [1]. Biases can take various forms such as social, racial, economic class, lifestyle, gender, social worth, and all of these have to be explored to achieve an objective evaluation. Health care providers must show no bias towards challenging, antisocial, and malingerers and focus on the treatment regimen. Special care must also be addressed towards removing biases against folks with limited cognitive ability and developmentally disabled people [4].

Artificially administered nutrition and hydration is another area where it is ethically appropriate to withhold care if the certain standards are met: a) no therapeutic goal other than maintaining organic life is possible b) patient lacks mental capacity and this is irreversible and thus no patient preference can be elicited c) no prior preference for continued sustenance has been recorded and d) patient will not experience any pain or discomfort by stopping this intervention [1]. The United States Supreme Court has also

multiple times upheld the right of competent patients to withhold life-sustaining treatment; furthermore, even in the case of patients deemed incompetent, the Court has upheld the standard that treatment just for sustaining organic life can be withheld if there is clear and convincing evidence that the patient will never recover from a chronic vegetative state. These have taken the concept of the "best interests" of the patient, which also might mean that death might be in the best interest of patients in special cases.

The Principle of Double Effect emphasizes the need for palliative care including all comfort measures, especially pain control when treating dying patients, even if there is a risk of opiate medications causing respiratory depression [5]. Palliative sedation, which refers to the usage of painkillers, which might hasten death, has been long viewed as common and ethical. A controversial approach to death and dying has been physician-assisted dying. This process involves a patient, who is terminally ill, requesting their provider to prescribe a lethal drug. It is important to note that the physician does not administer the medication rather this is a patient-driven process. This is only legal in the states of Oregon and Washington currently and the statute does require a two-week wait period between the request and prescription and a psychiatric evaluation. Proponents of this statute state that fundamentally this is about respect to a patient's autonomy, this is an empathetic process as it relieves patients of pain and discomfort, an individual physician does have the right to refuse this request and this does not violate the Hippocratic Oath of "giving of poisons" as it is outdated.

Opponents argue that there is no difference, what they consider taking of life if the physicians administers the drugs or prescribe as the result is the same; it's just semantics, it directly contradicts the Hippocratic oath of not harming the patient, it undermines the inherent trust the public has in the medical profession, patients may be prone to make these decisions when their suffering, subjectively, seems to be worse for them, and finally, this could set up a dangerous precedent, a real slippery slope, where non-terminally ill patients but suffering from extreme pain could ask lethal medications. Physicians are encouraged to ensure that their patients are competent, made aware of all possible alternative interventions, continue to engage in two-way communication with the patients and their caregivers, and finally, realize that they can decline to participate in this decision-making process if they so desire. In pediatric cases, the Best Interest standard must be adhered to at all times as usually surrogates are involved in the decision making; a process which also takes into account parental right to control the child's medical treatment within the family values while balancing expected benefits [1].

The concept of Medical Futility encompasses clinical actions undertaken that play no useful role in attaining a specified goal for a given patient [6]. In other terms, it is virtually certain that a clinical action taken will fail in achieving a specified goal for the patient. The key here is that specified goals with the patient in mind must be objectively discussed in a joint patient/surrogate-provider discussion. The provider must ensure that the patient has access to all available treatment options, the risks-benefits of these alternatives, and the potential improvement or not these treatments can provide. In the article “Cases for Analysis”, it is imperative that the physician discuss objectively the clinical goals with the parents and if treating pneumonia would help reach that goal; if not, this is a case of medical futility. It appears that even if the pneumonia were treated, the patient will continue to be in a neurovegetative state, and without treatment, there is a possibility that the patient may die. Based on the information provided, it is highly unlikely that the patient would return to her pre-accident life. It is conceivable that the patient could recover somewhat although it is virtually certain that she would have lost most of her mental faculties; the definition of this new normal life, in this case, would once again have to refer to the goals set by the parents and the providers.

A definition of an undesirable life, by itself, can be very subjective as it considers one’s attitude, cultural values, and what one reasonable person may consider undesirable. If the pneumonia is treated, the patient, most likely, will continue to be in a deep coma, which could strain family relations due to caregiver fatigue, hamper financial resources of the family and affect hospital resources, which could be geared towards other patients with more potential to show therapeutic improvement. A frank and open discussion with the parents and providers has the potential to minimize any biases both parties may bring to the table: the concern the parents might have is that the best interest of their child is not the primary priority, the paternalistic attitude of the physician and the physicians concern that the parents are making an emotional decision not based on factual information [7]. Palliative plans could run the gamut from Do Not Resuscitate (DNR) for the patient all the way to transfer to hospice and ensure that the patient is comfortable and not in any pain. At this point, the patient and the family should be in surroundings conducive to letting the patient die soothingly. It can be challenging to limit an ethical solution based just on “Quality of Life” issues as one’s tolerance for specific circumstances may vary tremendously. Social support, financial resources, community help can influence the quality of life, parental involvement, and finally the attitude one possesses to deal with one’s limitations [6].

Patient Preferences fundamentally has to do with the autonomous choices a patient makes when faced with a

medical illness. The choices include everything from the type of care they receive, mode of treatment, and their choice of follow up. This preference is based on the fact that the patient is the most important person in the health care system and providers, hospitals and the whole system is there to provide timely diagnosis, medically indicated therapeutic regimens, and optimal treatment.

Several questions must be evaluated to assess if ethical principles are followed by which patients wish and desire are taken into account: a) Has the clinician provided the patient with the risks and benefits of the proposed treatment plan and after understanding this information, has the patient given consent b) Does the patient demonstrate sound clinical capacity (medical terminology) and competency (legal terminology); if not, does the patient exhibit incapacity to make medical decisions c) Has the patient made their preferences in regards to their medical treatment clear d) If physically or mentally incapacitated, does there exist proof of prior patient preferences e) If incapacitated, are there appropriate surrogates to make medical decisions for the patient in place f) Is the patient refusing or unable to cooperate with their medical treatment plan; if not, why? [1].

Patient Preferences need to be one of the most fundamental building blocks of the health care system. An involved patient partnership with their providers leads to better health outcomes and reduces medical disparities. The respect, which a provider or health system exhibits towards their patients, translates to optimal health and well-being for their patient. This is achieved by having a culture where patients are encouraged to provide their input into their medical treatment and the provider is supposed to give appropriate and timely feedback. The provider sees each patient as an individual with his or her unique characteristics and preferences. For example, a clinician could see multiple patients with asthma but they all could have various stages of the disease and their responses to standard medications could vary based on their personal and physical traits. It is also important for the patient to respect the provider’s knowledge of medicine, as this collaboration is a “two-way street”; an example would be the patient getting erroneous information from dubious websites regarding their condition and in this case deferring to the providers’ expertise.

In this age of defensive medicine, having open communication with patients also provides legal protection for clinicians as a patient satisfied with their provider is less prone to seek legal recourse in case of medical miscues. Finally, the psychological worth of having one’s autonomy respected can also help the patient be more adherent to provider treatment and follow up recommendations.

The process of informed consent involves a situation

where a patient seeks out a provider for medical help, is given the provider's professional opinion of what most likely the medical condition entails, optimal treatment options, side effects of therapy, alternative options, and risk and benefits of undergoing treatment. Ideally, the provider answers all the patient's questions in the most informed manner, and this leads to the patient understanding their condition and agreeing (or disagreeing) with the providers' recommendation. An educated patient often is collaborative with their providers and can weather any adverse effects more effectively. A provider using that patient-centered, joint decision-making subjective standard is using the more ethical approach to the informed control model.

The provider must also be candid in their scope of disclosure statement which should include a) the patients' current medical condition and the likelihood of disease progression with no treatment b) treatment regimens that would mitigate the patient's medical condition with likely side effects c) alternate interventions if any d) professional recommendation of the provider. The provider must make a thorough attempt to follow up on those patient's comprehension of the information provided as this leads to robust decision making. The patient's medical record must have documentation, which proves that informed consent was obtained most optimally, all alternatives were explored with the patient, and time was allotted for the patient to have any follow-up queries. The provider must take pains to ensure that technical lingo is minimized as much as possible to increase more transparency and trust between the patient and the health care system. Furthermore, all information conveyed to the patient must be truthful and follow all ethical norms.

The completeness of disclosure is a principle, which involves the provider paint the most accurate medical picture of the condition for which a patient is seeing them. It is not ethical to hold back information, alternate treatment strategies, and risk-benefits of clinical trials as it is up to the informed patient to make the best possible decision regarding their care. The provider here acts as a guide and helps the patient navigate this process. The patient also holds the right of refusal of information from their providers and this must always be respected. As long as the patient is made aware of that, they can change their mind at any time and communicate openly with their clinician. Disclosure of medical error, intentional or not, must always be reported to the patient and the health care system by the provider. Honest communication often reduces the risk of medical lawsuits if done promptly and apologetically. The patient must understand that there were changes in procedure due to the medical error the patient underwent, and their pain and suffering was not in vain.

The concept of decisional capacity involves a patient's capacity to accept or refuse care with the ability to comprehend relevant information and possible consequences of their actions. A seasoned clinician can decide on decisional capacity based on the conversation they have with a patient and the patient understanding the consequence of their treatment options [8]. An objective tool such as the MacArthur Competence Assessment can also help objectify this process. A sliding scale criterion may also be employed which considers the seriousness of the disease and the urgency of treatment. In my practice as a psychiatric physician assistant, I am often called to do decisional capacity evaluations and it is important to rule out organic causes causing changes in capacity. Capacity can be very fluid for example in the case of an alcoholic patient undergoing delirium tremens, which is different from a patient with progressive late-stage dementia. The United States Federal Courts have ruled multiple times in favor of patients who demonstrate both decisional capacity and competency to make medical decisions, which are not recommended by their clinicians. The patient's right to autonomy must be respected in such cases if all available information is presented to the patient. Refusals by patients due to religious and cultural diversity beliefs must also be respected and providers must take this worldview into context. The provider ethically cannot impose his beliefs on the patient and their fundamental right of autonomy must be adhered to; an example would be a Jehovah's Witness refusing life-saving blood transfusions. In this case, the ethical thing for the clinician would be to explore alternate medical interventions, which would lead to the patient getting medically better.

The concept of Advance planning is instrumental to help the patient inform their clinician on how they would like to be treated in the future if a medical issue arises and which person can speak for them if they are unable to do so. Legally there are documents such as durable power of attorney, living wills, and directives to physicians, which help, make this process easier to initiate and provides robust protection of the patient's rights when the need most arises. It is also vital that the patient has a surrogate in place to advocate for the patient and make his wishes be respected. The standard of "substituted judgment" is in effect when the patient's interest is already known and "the best interest standard" when the patient's preference remains unknown. In patients who fail to cooperate with medical recommendations, the clinician needs to explore the reasons for this failure, look for other opportunities/interventions to enhance compliance, evaluate if the failure to cooperate is voluntary or involuntary and all available information is relayed to the patient.

It is ethically permissible for a clinician to terminate treatment once due diligence is done on their part. In disruptive patients or patients who like to sign out against

medical advice, the common thread is the provider to once again ensure that the patient has the decisional capacity, has information available including the risks-benefits of their proposed course of action. It is not advisable to disrupt the care of multiple patients if one patient is uncooperative and caused disruption on a medical floor. These patients must be provided with follow up care referrals and other resources. Recently, the concept of complementary and alternative medicine has gained in popularity and the ethical provider must appreciate the fact that their patients might seek treatment from both them and alternate providers. This type of behavior on the part of patients must not be discouraged as this has both cultural and ethnic aspects.

Although pediatric patients are considered incompetent under American law, their concerns and rights must always be taken into consideration. There are legal provisions, which allow clinicians to provide care for children and young adults without their parental consent; examples would include drug abuse and venereal disease. Children 15 years or older who appear to demonstrate the capacity and comprehend informed consent, medical treatment for themselves, a medically justifiable decision can be deemed capable enough to receive medical care on their own from providers. Child protective services must be informed if any clinician seems a child to be physically or mentally unsafe with a parent who demonstrated incapacity due to psychiatric or other reasons.

One of the special cases in medicine is in dealing with these thorny topics in the context of patients with psychiatric disorders. It is unlikely that the patient who initially present to the psychiatric emergency rooms of hospitals in a disorganized and psychotic state really understand the concept of their condition due to the nature of his illness and thus true informed consent, which assumes comprehension of the medical condition and consequences of not following up with follow-up care, including medications, is unlikely. The patient needs to be evaluated by the psychiatrist regarding capacity as this can vary. If the patient is acutely psychotic, he or she does not have the capacity, but this is a decision, which can only be made from timely evaluation, not historical information. A medicated schizophrenic with good follow up care often does exhibit capacity.

One of the underlying themes of schizophrenia, other than hallucinations and delusions, is that it burdens the patient with very poor insight and judgment. As a psychiatric physician assistant for the last 14 years, I have often been witness to this phenomenon of medication non-compliance. It is the number one reason for the re-hospitalization of psychiatric patients. Typically, the patients get better on medications and then they feel that they do not need them because "I feel fine" discounting the fact that the medication is the reason they feel fine. Also, they are tired of the side

effects of these potent medicines, which often cause lethargy, and the feeling of their mind is clouded. After a couple of weeks of medication of refusing to follow up with their medical recommendations, they typically start exhibiting symptoms of schizophrenia which leads them back to the hospital [9].

The concept of patient preferences has to take into account if the patient is mentally competent to make valid decisions for them. In the throes of an acute psychotic disorder, they are unable to do so; consumed with auditory hallucinations that tell them to hurt themselves or others, delusional and paranoid thoughts, and underlying anxiety with poor insight. In this case, no prior preferences have been made, thus the concept of the patient's best interest must take center stage. I have seen multiple schizophrenic patients who are in their late 60's being cared for by their mothers who are in their 90's (no other family involved). It is almost as if the mother has willed herself to live just to make sure that her child is taken care of, a moving sight indeed. There is certainly no one more qualified at this stage than the patient's mother is to be the surrogate; however, if she is so emotionally invested in the patient that her judgment is faltering, a court-appointed lawyer can assume the surrogate role.

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