

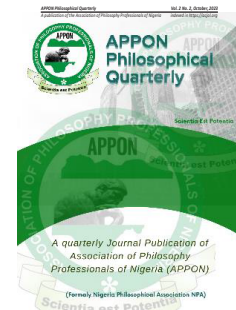
INFORMED CONSENT AND THE CHALLENGES OF DECISION MAKING IN MEDICAL BIOETHICS

Akpa Matthew Ikechukwu

Department of Philosophy,
Religion and Peace Studies,
Ebonyi State University, Abakaliki
Email: akpikchukwu@gmail.com
Phone Number: 07036677695



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Abstract

Every profession is embedded with a hard tasking subject which could make or mar the human effort. Medical profession is one of those professions faced with numerous challenges that stand to glorify man's effort or ruin it into mud. Informed consent as a medico-ethical discourse has given an unwavering challenges to medical practitioners because of insubordinate nature of some patients who fail to adhere and succumb to medical advice. Most often, consent may be difficult to obtain in the treatment of a minor, a person who has not reached the age of maturity. In some states, courts recognize two types of minors as being capable of informed consent. Mature minors are considered to possess sufficient understanding of treatment they are to receive and its consequences despite their chronological age. Emancipated minors have the legal capacity of an adult as indicated by age, maturity, intelligence, training, experience, economic independence, and freedom from parental control. In some states, someone who is married or in the military is an emancipated minor. However, to ensure that the problem or challenges of informed consent are avoided, there is need for the Doctor to have a regular contact with his client and to ensure that proper consent is obtained, it usually better to be put in writing.

Key Words: Decision, Informed, Doctor, Altruism and Consent

Introduction

One thing is to be informed, another is to take decision based on the information gathered. The issue of informed consent is a very serious one in medical practices as most information shared to the patients are not taken serious based on age or other

situations. Many a times, patients quash the information gathered and take a decision which they think will be beneficial to themselves other than the advice of the health practitioner. For instance, a 50 years old man was diagnose of cancer of the colon, when the

information was shared to him by his hospital adviser he left without going back for treatment. After three weeks, his doctor wrote to him informing him of the consequences of his health situation, he ignored the later and never visited the hospital for treatment. When the situation was deteriorated and got worst, he was taken to the hospital and was informed that his condition cannot be handled. Hearing this however, he sued Dr. James, his personal doctor to court for not persuading him to take his medication serious. After juridical debate, the court ruled in favour of Doctor James after reading and listening to all the evidences tendered which contained the conversations of the doctor. Few weeks later, the man died of prolonged cancer of the colon.

On the same vain, a young boy of 10 years was examined, diagnosed and recommended for blood transfusion. Due to the fact that he is too tender and cannot decide by himself, the attention of his parents were sought but they declined the recommendation because of their religious believe and church tradition / doctrine. However, the child died of loose of blood some months later. This caused a great commotion and condemnation by people who heard about it. It actually created a serious travail between the hospital practitioners and the society. So, the question now is, what would have the health practitioners do? Should they have treated the boy as recommended by the people? So, decision making in medical

profession has been a very serious problem especially in the side of health care practitioners.

The Concept of Informed Consent

Informed consent is the mutual agreement between a physician and his client to start or not a medical treatment. Before starting a medical treatment or diagnostics to a patient, he or she ought to have known of the type of disease which he or she is been treated upon. It is the duty and right of the patient to decide if the medical treatment be administered or not. Informed consent can also be viewed as “a legal condition whereby a person can be said to has given consent based upon an appreciation and understanding of the fact and implication of an action”.¹ For effectiveness and legal adoption of informed consent, the individual need to be rational and also be in the state of mind. He needs to be in possession of relevant facts and also of his reasoning faculties, such that such person will not be mentally impaired or retarded. Mental impairment are of different type; they could be impairment of illness, intoxication, insufficient sleep (where a person may not understand the decision of the physician because such person is induced by sleep) and other forms of diseases.

The question of informed consent is not left for medical doctors or nurses alone, all health care employees are involved in the consent process with the clients they serve. Although the health care provider

¹ Ekwutos, C. M. (2008). Bioethics: History and Contemporary Issues. Nigeria: Rex Charles and Patrick Ltd. 37-38

has the primary responsibility to inform the client of proposed treatment and to obtain consent for a procedure, clients commonly ask questions of health care employees. Consequently, everyone must understand all aspects of consent. Consent is the voluntary affirmation by a client to allow touching, examination, or treatment by medically authorized personnel.² Consent allows clients to determine what will be done with their bodies. Without consent, intentional touching can be considered a criminal offense.

Consent is authorization given by implications of a client's behavior, a medical contract, or by law.³ Consent is obtained through word or action. Consent may be given orally, expressed by nonverbal behavior, or expressed in writing. In the western world, some state laws mandate that written consent is necessary for any invasive procedure. Further, some states may find health employees liable for failing to give information to clients and obtaining their consent while some have no legal backing on informed consent. Health professionals also may be legally liable when offering information and for obtaining informed consent from clients. For instance;

1. A client calls complaining of a persistent, productive cough. When the receptionist makes the appointment with the physician, the client has given consent for examination, which may include

throat examination and culture.

2. When a physician requires a blood test for diagnosis and the client comes to the laboratory with a rolled-up sleeve, implied consent is being given.
3. A client is scheduled for an office surgical procedure and signs an appropriate consent form. This action constitutes a medical contract between the client and the physician. Written consent has been obtained.
4. If a client who comes to the office suddenly stops breathing during the physician's examination, the physician will take immediate action to restore breathing and preserve life. Consent is implied by law in an emergency situation when a client is unable to give consent. An emergency is said to exist when the client is in immediate danger and action is necessary to save a life or prevent further damage. Integral to consent is the client's belief that the health care professional to whom consent is given has the knowledge, skill, and ability to perform such tasks. In the examples above, the client has a right to expect that the physician has the ability to determine the need for a throat culture, perform the required surgery, and administer emergency treatment. Likewise, the client can expect the laboratory technician to

² Leo, B. Doctrine of Informed Consent in Marcia, A. L and Carol, D.T. (Eds) (2002). Medical Law Ethics and Bioethics for Health Profession, 6th edition, Philadelphia: F.A Davis Company.

³ Faden, R. and Beauchamp, T. (1986). A History and Theory of Informed Consent. New York: Oxford University Press.

know proper venipuncture technique.

Ideally, consent is informed, with the client understanding all facets of the consent. Clients who are a party to consent usually are informed or have sufficient understanding of the circumstances surrounding their consent. Uninformed consent occurs when the client gives permission but does not understand or comprehend what has been consented to. Because of the many occasions arising in the ambulatory health care setting that involve complicated medical procedures that are often difficult for clients to understand, informed consent is important to give the provider permission to act. To ensure that proper consent is obtained, it is usually put in writing. Specific guidelines generally are established in each state's doctrine of informed consent.

Conditions of Informed Consent

Theorists break down informed consent into components believed to be necessary to the concept. Typically, they maintain that an informed consent exists if and only if; (1) the patient is competent to decide, (2) she gets an adequate disclosure of information, (3) she understands the information, (4) she decides about the treatment voluntarily, and (5) she consents to the treatment.⁵ This analysis seems straightforward enough, but complications (and controversy) ensue when we try to specify precisely what these conditions entail and to apply them to real-life cases. As it pertains to informed consent, competence is very roughly the ability to render decisions

about medical interventions. Individuals who are incompetent in this sense cannot give their informed consent, in which case the burden of decision-making falls to a surrogate (often a court-appointed guardian or a proxy selected through the patient's advance directive). Most of the time, however, people are presumed to be competent unless there are good reasons to think otherwise. Patients are often judged incompetent in cases of mental retardation, dementia, psychosis, alcoholism, and minority (being underage). But they may also be thought incompetent in less clear-cut situations when they are overwhelmed by fear or pain, for instance.

In addition, they are sometimes considered incompetent because they lack only one or two particular mental capacities for example, the ability to communicate a decision, to understand the implications of a choice, to provide reasons, to explain decision-making, or to understand disclosed information. Still, incompetence is not necessarily total, or global; it may be specific to particular aspects of life. A woman who has been legally declared incompetent to handle her personal finances may be fully competent to give her informed consent. A man who has been involuntarily institutionalized for mental illness may still be able to make decisions regarding his medical treatment. Sometimes a court will formally determine someone to be incompetent. But in most cases, the judicial system never gets involved, and the task of making informal determinations of incompetence goes to physicians (often in

consultation with the patient's family).

So, given their informed consent, competent patients must receive an adequate disclosure of information from physicians but what is an adequate disclosure? What kind and amount of information are sufficient? The ethical doctrine of informed consent says that disclosure is adequate if it allows patients to weigh intelligently the risks and benefits of available choices. But how to achieve this ideal in practice is not obvious. Early court decisions suggested that physicians should be the arbiters of adequate disclosure (the physician-based standard); later rulings insisted that adequate disclosure is whatever satisfies the information needs of a hypothetically reasonable person (the patient-based standard); and others called for a subjective standard in which disclosure is supposed to be based on the information needs of a particular patient. But a purely physician-based standard for disclosure would ignore the patient's needs for information relevant to her own personal decisions. The kind of disclosure suitable for a hypothetically reasonable person would probably be very difficult to determine and might, like the physician-based standard, impose disclosure criteria that have little to do with the information requirements of a particular patient. And an entirely subjective standard naively assumes that patients can always decide for themselves what facts they do and do not need to evaluate treatment options. Some courts have combined these standards, but no configuration of requirements has been entirely true to the

spirit of informed consent.

Despite these difficulties, courts and legislatures have generally mandated the disclosure of several pieces of important information: 1. The nature of the procedure (for example, whether it is a test or treatment, whether it is invasive, and how long it will take to perform). 2. The risks of the procedure (what kind of risks are involved, their seriousness, their probability of occurring, and when they might happen). 3. The alternatives to the proposed procedure including the option of no treatment (includes information on the options' nature, risks, and benefits). 4. The expected benefits of the proposed treatment including their extent and their likelihood of being achieved. Physicians are not obligated to provide disclosure in all situations; the duty of physicians to obtain informed consent has exceptions.

Disclosure is often dispensed with in emergencies when stopping to obtain consent could seriously harm the patient. As suggested earlier, informed consent is not required when a patient is incompetent. Neither is it obligatory in cases of waiver, the patient's voluntary and deliberate giving up of the right to informed consent. It is an exercise in autonomous choice, the choice not to choose or decide. Authority to decide medical issues is turned over to the physician or surrogates.

Models of Decision Making

Decision-making capacity or competence (in its legal term) is conventionally defined as the ability to perform a task.

However, bringing it into medical term, it means to make decisions about one's medical care, or about taking part in biomedical research.⁴ Patients with decision-making capacity, it is widely agreed, generally have the right to make their own health-care decisions, even decisions that others believe are contrary to the patient's interests. However, as a result of illness, disability, or immaturity, some patients do not have the mental abilities required to make these decisions. If given the opportunity, many of these patients would make decisions that are risky, dangerous, or which they simply would not otherwise make if they were thinking soundly. Assessments of competence (or capacity) protect incompetent patients from the consequences of such decisions, while also protecting the rights of competent patients to make decisions for themselves.

Most writers agree that what is most important for judging competence is how patients reach their decisions, rather than what they decide. Merely because a patient reaches a conclusion that his physician regards as unreasonable, for instance, refusing effective treatment for a life-threatening illness, or deciding to enroll in a risky research protocol does not mean that the patient is incompetent. Since different patients have different values and needs, they may reach different

conclusions even when presented with the same choice. While it is a matter of debate exactly what mental abilities are necessary for competence, many standards require that a patient have a relatively stable set of goals and values; be capable of understanding the consequences of the decision, including its risks and benefits; be able to reason about the relevant information and communicate a choice; and be able to appreciate how the decision will affect them personally.⁵ Often patients are clearly not competent, but their families and physicians must still make decisions for them.⁶ For these patients, a hierarchy of decision-making standards has evolved, based largely on commonly held notions of respect for persons.

First, when patients have expressed any wishes about the treatment in question while competent (through an advance directive, for example), their surrogate decision-makers should abide by those wishes.

Second, when incompetent persons have not expressed any such wishes, surrogates should rely on the "substituted judgment" standard, according to which decisions are reached according to what patients would have decided if they were able, based on the patients' values, goals, and desires.

⁴ Dunn, L. B., Nowrangi, M. A., Palmer, B. W., Jeste D. V., and Saks, E. R. (2006). Assessing decisional capacity for clinical research or treatment: a review of instruments. *American Journal of Psychiatry* 163: 1323-34.

⁵ Ibid

⁶ Grisso, T. and Appelbaum, P. S. (1995). The MacArthur treatment competence study. I. Mental illness and competence to consent to treatment. *Law and Human Behavior* 19: 105-25.

Finally, in the event that a patient has never been competent, a small child, for example, the surrogate must make decisions based on the "best interest standard." What the interests of a patient are is often unclear or controversial, but they are generally understood to include, at a minimum, certain basic interests such as avoiding pain and disability and having conscious life extended.

Challenges of Decision Making

Decision making is very difficult especially when and where it involves minors who cannot possibly decide by themselves. Some of the challenges of decision making are discussed below;

i. Issue of Irrationality

Some patients understand all the important aspects of their decision, including its risks and benefits, yet still make decisions that seem irrational.⁷ Sometimes these decisions are irrational even from the perspective of the patient's own goals and desires. For example, an apparently competent diabetic patient being asked to consent to the amputation of a gangrenous toe might refuse, even if avoiding death is more important to him than avoiding the amputation, and even if he realizes that his refusal is threatening his life. What are we to make of such a

choice? Doctors and nurses, not to mention family members, are understandably reluctant to abide by a patient's decision when that decision is irrational, especially if it is also self-destructive. Yet irrationality is a part of ordinary life. At times we all deceive ourselves, take poor risks, make impulsive decisions, act out of fear or anxiety, downplay future risks or benefits in favour of present ones, and otherwise behave in ways that seem unreasonable, idiosyncratic, or odd. Should an irrational decision be given the same degree of respect as a rational decision?

A related problem revolves around the question of which mental abilities are relevant to competence. Severely depressed patients may be capable of reasoning and deliberating about a decision, yet make very poor decisions, at least partly because of their depression.⁸ They may understand the risks of their decision, for instance, yet simply not care about them. Is a severely depressed person who wishes to die competent to refuse life-saving treatment? Similarly, people with addictions may want to resist a desire and understand that giving in to the desire is contrary to their own self-interest, yet still find the desire extraordinarily difficult to resist.⁹

⁷ President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research (1982). *Making Health Care Decisions: The Ethical and Legal Implications of Informed Consent in the Patient-Practitioner Relationship*. Washington: US Government Printing Office.

⁸ Brock, D. W. and Wartman, S. A. (1990). When competent patients make irrational choices. *New England Journal of Medicine* 322: 1595-9.

⁹ Elliott, C. (1997). Caring about risks: are severely depressed patients competent to consent to research? *Archives of General Psychiatry* 54: 113-16.

ii. The problem of personal identity

The standard way of making decisions for incompetent but previously competent patients has come to be the patient's previously expressed wishes. Yet many neurologically damaged or demented patients are not, in some sense, the same persons they were before the damage or dementia. This is especially obvious for patients who are permanently vegetative, where the patient's higher brain functions are absent, but it is also true for patients with other types of cerebral damage, such as stroke or trauma. The patient's personality and values may have changed dramatically; his memory of his past life may be impaired; his intellectual and other mental abilities may be severely damaged. When this broad gap in identity separates the patient's current and past selves, it becomes a matter for debate how much weight should be given to the wishes, values or desires of the patient as he was in the past. Should the patient's previously expressed wishes prevail even when they seem to run squarely against his current interests?

Sometimes we may have reason to think that the person would have changed his mind if he could be made aware of subsequent events and developments, for example, a man in a persistent vegetative state from traumatic injury who, before his injury, had never been sick in his life, who had expressed a lifelong wish to have his life extended as long as possible

regardless of the circumstances, but whose family feels would have changed his mind if he had ever been in a hospital intensive care unit. At other times the patient's wishes and values in the past may directly contradict his present wishes and values.¹⁰ Take, for example, a writer who has devoted her life to matters of the mind, and for whom the mental deterioration associated with Alzheimer's disease has always seemed the cruelest way for a life to end. She has told her son that if her mental faculties were to deteriorate, she would rather have euthanasia. What she regards as most humiliating of all is the lack of awareness of one's condition that dementia brings. Yet when her mental faculties eventually deteriorate, she seems perfectly content with her life. She has no memory of her earlier wishes, and as far as anyone can determine, she would not now want her life to end. What value should we place on the wishes and values of a patient's previous self, and what should we place on those of the current self?¹¹

iii. The problem of involuntary "altruism"

In most pediatric hospitals, medical decisions for a child are meant to serve that child's best interests. Yet some medical interventions are clearly not in the child's interests, and in fact are designed for other purposes. For example, surgeons often transplant kidneys or bone marrow from children too young to consent, usually matched siblings of the transplant

¹⁰. Dresser, R. (1995). Dworkin on dementia: elegant theory, questionable policy. *Hastings Center Report* 25/6: 328.

¹¹. Nelson, J. L. (1995). Critical interests and sources of familial decision-making authority for incapacitated patients. *Journal of Law, Medicine and Ethics* 23: 143-8.

recipient. Unlike the conventional medical interventions for which parents are asked to consent on behalf of a child, transplantation from child donors exposes children to risks that are not balanced by commensurate benefits or at least not beneficial to them personally.¹² This problem parallels a problem in certain types of clinical research, where children undergo risks or discomforts not for their own benefit, but to generate scientific knowledge that may eventually benefit others.

For example, Phase 1 cancer trials are designed to test the safety and toxicity of new regimens for the treatment of cancer. The subjects in Phase 1 pediatric cancer trials are usually children whose cancer has a very poor prognosis and for whom standard therapy has not been effective. These trials are not designed to test the effectiveness of the new therapy, and the chance that children enrolled in the trials will experience any therapeutic benefit is relatively small. As with parents of living organ donors, parents of potential subjects in clinical research that has a poor risk–benefit ratio are asked to expose their child to risks, harms, or discomforts for the sake of someone (or something) other than themselves. When competent adults take risks or undergo harms for the sake of others, we ordinarily consider their actions not morally obligatory, but altruistic or supererogatory, that is beyond the call of duty. Certainly they are not things that an adult should be forced to do.

Yet if this is true, on what grounds can we justify such interventions on young children? Many of the justifications given in the past have a notably ad hoc feel about them.

iv. The problem of the moral imagination

Deciding what kinds of medical care an incompetent patient ought to receive often means trying to decide what kind of care would be in the patient's interests. How aggressively one should treat a newborn with severe 'spina bi?da'; whether a mentally retarded adolescent with cancer should undergo a burdensome course of chemotherapy with uncertain efficacy; determining the point at which a patient with schizophrenia should be treated against his will; deciding whether to treat pneumonia in a child with cerebral palsy and profound neurological impairment: understanding the interests of such patients requires a kind of imaginative leap.

Like anthropologists who must try to understand cultures vastly different from their own, health-care workers must try to understand patients whose lives differ dramatically from theirs by virtue of illness or disability. Imaginatively sharing another person's particular, subjective point of view, however, requires imagining a logical impossibility. It asks the question: what would it be like for me, if I were someone else? The most problematic cases arise when we must

¹² Dwyer, J. and Vig, E. (1995). Rethinking transplantation between siblings. *Hastings Center Report* 24/5: 7-12.

imagine what life is like for a person whose mental life appears radically different from our own, as a result of mental retardation, mental disability, or mental illness. This kind of imaginative leap requires us to imagine what it would be like not to have the mental abilities that we have, including those by virtue of which we are able to imagine.

Adam Smith thought that in imagining what the experience of the mentally impaired is like, a person is tempted to “imagine what he himself would feel if he were reduced to the same unhappy situation, and what is perhaps impossible, regard it with his present reason and judgment”.¹³ There are at least two serious dangers to this sort of exercise. One danger comes with trying to imagine the experience of the permanently unconscious, such as anencephalic children or permanently vegetative persons. This is the danger of imagining, in Nagel's words, that “there is something that it is like” to be permanently unconscious, and making a misguided judgment as to the permanently unconscious person's quality of life.

v. The problem of asymmetrical relationships

One serious criticism of the “best interests” standard theory of decision-making for children is that by focusing solely on the child it overlooks the role of the family.¹⁴ This can leave us with a kind of misplaced individualism, as if the only

ethically important considerations are those that have to do with the child himself, intrinsic abilities like his intellect, his awareness, his physical abilities, and so on. But this is an odd way to look at children, since what is most striking about children is not their intrinsic abilities but their dependence. Children exist in relationships of dependence on their families, and with time those relationships become deeper and richer and more complex.

It seems ungainly to try to consider children's interests apart from the interests of their families because their interests are bound up together. This is more than simply saying that parents are best placed to judge the interests of their child; it is saying that very often their interests are the same. It would not be exaggerating to say that very often the worst thing that could happen to parents would be for something to happen to their children. Because of these kinds of questions, bioethics has begun to pay more attention to families, and has tried to locate our ethical thinking about children within the parent-child relationship. Some writers have argued that what is morally important about children cannot be reduced solely to their intrinsic capacities, but instead needs also to take account somehow of their relationships with others. What matters morally about children is connected to the fact that they are loved by their parents, and what we value about human beings is not just their

¹³. Smith, A. (1982). *The Theory of Moral Sentiments*. Indianapolis, IN: Liberty Press.

¹⁴. Nelson, J. L. and Nelson, H. L. (1995). *The Patient in the Family: An Ethics of Medicine and Families*. New York: Routledge.

intellect but also their capacity for these deep human relationships. But with some children for instance, those who are left with profound neurological damage from traumatic and anoxic brain injury, these relationships are often completely asymmetrical.

vi. The problem of meaning and the profoundly damaged child

These are not necessarily a matter of choice for us, or not entirely: they are the framework of tradition and culture within which our choices are made. Part of this framework concerns understandings about what might be called the meaning and significance of life: questions about the way in which we make sense of our lives, what gives our lives significance, beliefs about how one ought to live, stories that we tell ourselves about successful lives and failed ones.¹⁵ Different cultures and eras have answered these kinds of questions in different ways, of course, and many individuals will answer them differently even within contemporary African culture. Yet some widely shared Western views may call into question the meaning of the life of a person with profound neurological damage.

These questions present deep problems for decisions about the conditions under which such lives should be prolonged. He then calls this emphasis on family and work the “affirmation of ordinary life.” Moreover, this view locates meaning at least in part within the individual himself. That is, we ordinarily think that the

meaning of our lives has something to do with us as individuals and the choices we make with discovering and following a calling, with looking inward and finding one's own special character or talents, with developing a relationship with God and so on. What is important to realize, however, is that this kind of life is inaccessible to many people with profound neurological damage.

If a person is incapable of appreciating and sustaining the emotional bonds of family, and incapable of finding meaning through work, she will not be able to live the kind of life that is widely regarded in our culture as meaningful. It could be otherwise, of course for example, in a culture in which meaning is found through occupying one's place in the natural order of things, or in which all life is seen as glorifying God, or in any number of other cosmologies.

Conclusion

Challenge is an inevitable phenomenon that always abounds in all professions, what matters most are the procedures used in handling it. In this work, we have discussed certain challenges which health care practitioners experience at the course of discharging their duties. Ideally, consent is informed, with the client understanding all facets of the issue. Clients who are a party to consent usually are informed or have sufficient understanding of the circumstances surrounding their consent. Uninformed consent occurs when the client gives

¹⁵ Taylor, C. (1989). *Sources of the Self*. Cambridge, MA: Harvard University Press.

permission but does not understand or comprehend what has been consented to. Because of the many occasions arising in the ambulatory health care setting that involve complicated medical procedures that are often difficult for clients to understand, informed consent is important to give the provider permission to act. To ensure that proper consent is obtained, it usually is put in writing. Specific guidelines generally are established in each state's doctrine of informed consent. Informed consent is a client's right to know and understand before agreeing to a procedure.¹⁶ It is the physician's sole responsibility to obtain consent from the client, even if other staff assist in the process. Consent should be obtained in writing because written consent implies an intentional and deliberate decision.

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