

# Paternalism and the Utilization of Advance Care Directives

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## Abstract

The End-of-life period requires attention to total care of persons suffering from life-limiting or terminal illnesses. Rendering this type of care can alter the quality of life, though it is not expected to cure the fundamental underlying diseases or to arrest their progression.

Paternalism in medicine has become unpopular because it entails physicians telling patients what is, or is not good for them, without regards to the patient's own needs and interests. There is increasing awareness of the fact that patients have right to self-determination over how they are treated and the principle of respect for self-autonomy imposes on the attending physician and other health workers a duty to respect this right. During the end-of-life period, however, a patient may be incompetent and unable to exercise this right. Thus, there may be a need to plan in advance, by the making and utilization of advance care directives.

This article discusses patient care during the end-of-life period, the issue of advance care directives and paternalism in the light of some ethical theories and the role paternalism plays in its making and utilization of advance care directives.

**Keywords:** Paternalism; Care directives; Terminal illness; Kant's ethical theory

## Introduction

End-of-life care is one that requires attention to total care of the person during a life-limiting or terminal illness. This holistic care includes mental, physical, spiritual, emotional, and social care [1]. The end-of-life period is one in which holistic care, spiritual support for the patient and family, and adequate respite care and pain management can alter the quality of life but are not expected to cure the fundamental underlying disease or to arrest the progression towards death [1]. During this period, a gradual shift in emphasis from curative and life-prolonging therapies can relieve significant medical burdens and maintain a patient's dignity and comfort. Patients have right to self-determination over how they are treated and the principle of respect for self-autonomy imposes on us a duty to respect this right [2]. In the setting-of end-of-life care, however, a patient may be incompetent and unable to exercise this right. Thus, there may be a need to plan in advance.

In this article, the issue of advance care directives and the role paternalism plays shall be discussed, *vis-à-vis* its characteristics and effects on the physician-patient relationship, and the role it has to play in the making and utilization of advance directives.

## Advance Care Directives

Advance Care Directives are statements made in advance of an illness about the type and extent of treatment one would want, on the assumption that one may be incapable of participating in decision-making about treatment when the need arises [3]. They may be in written or oral forms and usually contain the names of persons to make decisions on one's behalf and instructions on what treatments should or should not be provided [3]. Forms of advance directives include a living will, durable power of attorney or health care proxy. They afford patients the opportunity to exercise their rights regarding their medical care in advance. The process of making advance directives provides individuals with the opportunity to determine their goals regarding health and medical treatment based on medical values, attitudes and beliefs surrounding health care, illness and death [4].

Advance Directives are legal documents that allow individuals to convey their decisions about end-of-life care ahead of time. They convey information about individual feelings towards care intended to sustain life. An advance care directive clarifies individual feelings and preferences regarding issues like dialysis, use of ventilators, need for or refusal of resuscitation if breathing ceases, tubal feeding, and organ or tissue donation [5]. Advance directives are the best possible assurances that decisions regarding a patient's future medical care will reflect his or her own wishes, in the event that the person in question is unable to voice these wishes [6]. An Advance Directive instructs others about a patient's care if the patient is unable to make decisions on his or her own. It only becomes effective under the circumstances delineated in the document. According to the Family Caregiver Alliance, an Advance Directive allows a patient to either appoint a health care proxy (agent), and/or prepare instructions for health care. The health care agent (also known as "Durable Power of Attorney for Health Care" or "attorney-in-fact"), will have the legal authority to make health care decisions for the patient if the patient is no longer able to speak for his or her self. This is typically a spouse, but can be another family member, close friend, or anyone else the patient feels will see that his or her wishes and expectations are met. The individual named will have authority to make decisions regarding artificial nutrition and hydration and any other measures that prolong life—or not. The Advance Directive also allows a patient to make specific written instructions for his or her future health care in the event of any situation in which he or she can no longer speak for himself or herself.

It is imperative at this point to mention however, that making and

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**Received** April 07, 2012; **Accepted** July 26, 2012; **Published** July 28, 2012

**Citation:** Ekore RI, Bolatito LA, Ekore J, Ajayi I (2012) Paternalism and the Utilization of Advance Care Directives. J Palliative Care Med 2:135. doi:[10.4172/2165-7386.1000135](https://doi.org/10.4172/2165-7386.1000135)

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utilizing advance directives, is not a problem-free and straightforward process. Beauchamp and Childress in their book [7], aptly described certain situations that may generate moral and practical problems for both families and healthcare professions in the end-of-life periods of patients. In summary, some of the situations include failure to compose or leave explicit instructions; unavailability, incompetence or conflict of interest on the part of a designated decision-maker when the need arises; failure of a patient who have changed their preferences about treatment to change their directives; severe restriction of the use of advance directives by some states; and lack of provision of any basis for health care professionals to overturn instructions that turn out not to be in the patient's best medical interest, even as the patient could not have reasonably anticipated this circumstance while competent.

The issue of advance directives has been gaining increasing popularity in this century, especially following some notable cases like those of Karen Ann Quinlan and others who were in persistent vegetative states and were on life support for so many years. There were, of course, associated financial, emotional and moral burdens in such cases and one is often forced to wonder on one hand the rationale behind using up scarce medical and financial resources to keep maintaining an individual who is in persistent vegetative state, or to treat a medical condition that is curable or at a terminal stage. On the other hand, one is also forced to wonder whether withholding any form of treatment at the request of the patient, in attempt to avoid medical futility, or wastage of scarce medical or financial, resources does not amount to a form of euthanasia. Does it also not amount to giving a sense of hopelessness? However, it appears unreasonable to attempt to give a treatment that would not amount to any change, whatsoever in the condition of the individual concerned but would only prolong pain and suffering. It also seems unreasonable to continue to consume scarce medical, financial and human resources on futile efforts. What appears reasonable is for an individual who has been diagnosed and informed of a terminal or potentially fatal medical condition to plan his/her line of medical management ahead of time. It would be very prudent of such a person, barring all unforeseen circumstances, to indicate his or her treatment preferences in case of any eventuality.

However, it is surprising that at this point in time, the level of awareness of, and the rate of utilization of advance directives is still virtually insignificant. Several factors may be responsible for this, some of which may border on patient-doctor relationship. On this ground, an attempt would be made to analyze the role paternalism may play in the utilization of advance directives.

## Paternalism

In the context of healthcare, this constitutes any action, decision; rule or policy made by a physician or other care-giver, without considering the patient's own beliefs and value systems and does not respect patient autonomy [2]. It involves attempting to impose one's own set of values on another person or group of people when one has the power to do so. It can be divided into two forms, namely weak paternalism and strong paternalism [2].

Weak paternalism refers to a situation in which the actor attempts to prevent conduct that is substantially non-voluntary or one that is done without full or adequate knowledge or understanding of the consequences by the person acting. At times, the doctor may temporarily intervene to determine whether an act was truly autonomous or not. An example of how the doctor tries to protect patients from non-voluntary harm can be by preventing harm to one under hypnosis or on drugs or even one who is under severe coercion, while an example of how the actor prevents conduct that is done without full knowledge

include giving life-saving therapy to a young child whose parents refuse such treatment. Lastly, an example of preventing conduct without full knowledge of the consequences include pushing someone from the path of an oncoming train or treating a patient who has taken an overdose of drugs but whose motives are not clear to us or whose motives are believed to be capricious, not thought out or temporary. Weak paternalism is a form of preventing persons from coming to non-understood harm. It involves protecting another from the results of misinformation or non-comprehension [8].

Strong paternalism, on the other hand, seeks to prevent harm to or act for the benefit of persons by liberty-limiting measures even when their contrary choices were not capricious, were well informed and voluntary. An example of this is forcing patients who are Jehovah's Witnesses to be transfused. It is done ostensibly to prevent harm or to bring about what is perceived to be the good of another—terms which, in this situation, are defined by the actor and not the recipient. In that it is by definition an act that only seeks to prevent harm or to benefit another, it is not self-interested but other-directed [9].

Traditional medical practice over many years was predominantly doctor-centered with the physician exhibiting a paternalistic relationship with the patient. This type of doctor-patient relationship was not in favour of the patient who, oftentimes had to unwillingly dance to the dictates of the physician. It oftentimes led to disaffection and mistrust on the part of the patient and eventually negatively affected the likelihood of utilization of certain services offered in the hospitals. Although there is an increasing trend towards abandonment of the doctor-centered approach to clinical consultations and the embracing of the patient-centered approach, and an increasing regard and respect for patient autonomy, an attempt is being made here to examine the role paternalism plays in the utilization of advance care directives which happens to be an emerging trend in health care.

## Paternalism in the Light of Some Ethical Theories

### Utilitarianism

This is an ethical theory which suggests that an act should be judged right or wrong according to the pleasure produced and the pain avoided. According to the principle of utility, the moral end that should be sought in all that we do is the greatest possible balance of good over evil [9]. John Stuart Mill and Jeremy Bentham are two notable philosophers who are advocates of utilitarianism. J.S Mill [10] formulated 'the Greatest Happiness Principle', which holds that 'actions are right in proportion as they tend to promote happiness, wrong as they tend to produce the reverse of happiness. By happiness is intended pleasure, and the absence of pain; by unhappiness, pain, and the privation of pleasure. Jeremy Bentham formulated a principle, which insists that the good for man is the attainment of pleasure and the absence of pain. Bentham was a hedonist who believed that individual happiness is based upon pleasure and pain: increased pleasure and decreased pain bring happiness while decreased pleasure and increased pain bring unhappiness. He believed that what is most in an individual's self-interest is to have pleasure rather than pain, and that the total happiness of the community is nothing but the sum of individual happiness of its members [11].

Thus, based on the utilitarian ethical theory as advocated by J.S. Mill, Jeremy Bentham and the like, paternalism in medical practice would be morally acceptable if it produces pleasure or reduces pain for the greatest number of people. According to this ethical theory, if a physician or health worker forces his or her own ideas on a patient, treats or carries out a procedure on a non-consenting patient, or

out-rightly disregards a patient's feeling, idea or wishes, it is morally acceptable so long as it is to the benefit of a greater number of people such as the patient's family or relatives, or the government at large. However, if paternalistic actions by physicians and other health workers result in pain or sadness for the patients, then it is morally wrong. For example, disregarding the wishes of a dying patient thereby causing displeasure for that patient is, according to utilitarian ethical theory, morally wrong.

The utilitarian ethical theory is, however, not without its own deficiencies. First and foremost, we cannot say for sure what the consequence of an action will turn out to be. That is, it will be difficult to predict whether an action will produce the greatest balance of good over evil. The utilitarian position also does not assign intrinsic rightness to an action. It only considers the consequence of an action and cannot say specifically what actions it would permit and what actions it would want us to desist from. Utilitarianism does not consider the intention of the agent.

Another problem with utilitarianism is that it permits the suffering of the few for the benefit of the majority [11]. One major advantage of utilitarianism in medical practice, however, is that it disciplines a physician to be cautious before taking or performing an action. The physician is constrained to act more cautiously by calculating the consequences of an intended action [11].

### Kant's Ethical Theory

Kant's ethical theory is a deontological theory as it focuses on the intrinsic nature of an action itself, rather than the consequences of the action. Kant's ethics can be subdivided into three categories, namely his concept of Goodwill, concept of Duty and concept of Categorical Imperative.

According to Immanuel Kant, goodwill is the only one thing that is good without qualification. Other things considered as good are not good unconditionally as their goodness can be bad when misused. For example, a physician can use his knowledge about the adverse effects of a drug to kill a patient. Therefore, the implication of Kant's concept of Goodwill in medical practice is that physicians and health workers are enjoined to always have goodwill in their dealings with their patients. It is only by doing so that any actions taken can always be justified.

As regards the concept of Duty, Kant distinguishes two types of duty, namely "acting for the sake of duty" and "acting according to duty". He regards the former as perfect duty and the latter as imperfect duty. To act for the sake of duty is to perform one's duty not because of the hope to gain anything from one's actions or because one just feels like doing it or one has a natural inclination to doing such things. Rather, it implies doing one's duty purely out of reverence for the moral law [11]. In other words, for an action to have moral value or to be morally praiseworthy, it must be done strictly for the sake of duty, or out of respect for the moral law.

Kant's ethics also distinguishes right from wrong actions by means of the principle of universalization, which is the first formulation of his Categorical Imperative. To know whether an intended action is morally right, the underlying principle of the action should be considered and universalized. The second formulation of Kant's Categorical Imperative is that we should always act to treat humanity as an end, and not as a means to an end. According to Kant, every rational creature possesses an autonomous self-legislative will. This, including the rationality they possess, enables them to make rules for themselves, direct their actions and consider the consequences of their actions. We must therefore, never undermine their self-respect or humiliate them for that would violate the requirement that we treat people with respect [1].

Applying Kant's ethics to the issue of advance care directives, it becomes obvious that physicians and other health workers owe patients a duty to first and foremost, inform them about living wills and encourage them to make one. For those who have made living wills or advance directives, there is a duty to treat them as rational, autonomous beings that are ends in themselves, by respecting and implementing every instruction contained in their advance directives, whenever the need arises. Of utmost importance is that physicians should ensure that all rules made and all issues handled in advance care directives are such that can be universally applied to each and every individual as the need arises.

### A Critique of Paternalism

Paternalism in medicine has become unpopular because it entails physicians telling patients what is good for them, without regards to the patient's own needs and interests [12]. Characterized as the antithesis of autonomy, it is widely thought not to have any role in medicine [13], and is often expressed in terms of a conflict between the principles of autonomy and beneficence because paternalistic physicians may intend to act in the patient's best interest without fully considering how their evaluation of those best interests may be modified by a fuller understanding of the patient's views [14].

According to Mills, in defense of Libertarian principles, "the only purpose for which power can be rightfully exercised over any member of a civilized community, against his will, is to prevent harm to others. His own good, either physical or moral, is not a sufficient warrant". Paternalistic approach to medicine could also be subject to abuse of the power entrusted to physicians by the unscrupulous.

Contrary to the idea of paternalism is that of patient autonomy. Autonomy, which literally means self-government, refers to independence or freedom of the will or of one's actions [15]. It refers to the capacity to be one's own person, to live one's life according to reasons and motives that are taken as one's own and not the product of manipulative or distorting external forces. Autonomy is said to be the aspect of the person that paternalism offends against [16]. Ike Odimegwu [17] in his article on the role of the state in economic development cited autonomy of being as one of the defining principles of personhood.

Immanuel Kant [18,19] in the second formula of his Categorical Imperative advocates that every human being be treated as an end in itself, and not as a means to an end. Furthermore, in the third formula of the Categorical Imperative (which is also known as the Autonomy Formula), he talks about the idea of the will of every rational being as a will that legislates universal law. The formula puts on display the source of our dignity and worth, our status as free rational agents who are the source of the authority behind the very moral law that binds us.

John Stuart Mill describes autonomy as one of the elements of well-being. This view allows one to adopt a generally consequentialist moral frame-work while paying heed to the importance of self-government to a fulfilling life. To what extent is it morally required to allow individuals to act in pursuit of their own aspirations? Does an individual with self-destructive aspirations thereby lose the right to autonomy generally enjoyed by others? Should freedom to act include freedom to follow a foolish or tragic course or events, or is it justifiable to override another's autonomy paternalistically, as well as for reason of social benefit? Does respect for a patient's autonomy require honesty on the part of the physician, even when deception seems medically prudent?

### The Problem of Paternalism in Medicine

In the hospital setting, the importance of patient autonomy cannot

be overemphasized. The right of patients to make decisions about their medical care without their health care provider trying to influence the decision is what patient autonomy entails. Health care providers are allowed to educate the patient but are not allowed to make decisions on their behalf [20]. Unless physicians and other healthcare professionals accept the fact that supporting or, at times, restoring a patient's autonomy is part of their responsibility, they may choose to treat against a patient's express wishes or attempt to delude patients by withholding or modifying information. According to Ryan Maboloc [21], "paternalism therefore is self-defeating because a life however good it might be does not have any meaning at all if the human person is dictated upon externally".

Respect for autonomy in health care obligates professionals in health care to disclose information, investigate a patient's illness and ensure understanding in order to foster adequate decision making. Discharging this obligation requires equipping them to overcome their sense of dependence and achieve as much control as possible and as they desire. It follows therefore that autonomy goes beyond respecting a person's choice; it extends to respecting the life choices that a person makes [22].

On the other hand, physicians, out of respect for an ill-conceived understanding of autonomy may allow patients, without further efforts, to pursue a course leading to disaster. That is, they may abandon patients to their possibly seriously deficient "autonomy". Unthinkingly and unfeelingly abandoning persons to their supposed autonomy is the flip side of paternalism.

One could argue that, even if a patient does not currently have the preference expressed in his or her advance directive, we should treat the patient in accord with the advance directive on the grounds that the patient really does want what he or she earlier wanted, but does not realize it because his or her mental capacity is impaired [23]. Abilities required for autonomy include rational reflectiveness, competencies in carrying out one's decisions, and the like vary across individuals. Hence, it is difficult to maintain that all autonomous beings have equal moral status or that their interests deserve the same weight in considering decisions that affect them [24].

## Conclusion

This article discussed the end-of-life period, the different types and forms of paternalism and the problems posed by paternalism in medical practice. In addition, autonomy (of individuals) was discussed and its important role in end-of-life care was emphasized.

Rejecting a paternalistic approach to medicine can lead to the redressing of an often unequal power balance, and the empowerment of patients who could otherwise be vulnerable, thus enabling self-determination and patient-centered decision making wherever possible [24].

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