# CULTURAL DIFFERENCES IN ADVANCE DIRECTIVES RELATING TO END OF LIFE DECISION MAKING

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### **Abstract**

This paper offers an examination of end of life decision making in Western and African cultures. While Western medical practice focuses on individual rights, autonomy and self-determination, African societies emphasize communitarian values. It argues that "advance directives" in Western medical practice put so much emphasis on the autonomy of the patient that as a result, they are inconsistent with African traditional morality. The paper further argues that contrary to Western medical practice, the African practice of making decisions on behalf of an incompetent patient is based on African conception of death and dying and African communal values. The paper concludes by stressing that in spite of the value of "advance directives" in Western medical practice, they can be criticized based on the problems of precedent autonomy and atomistic individualism respectively.

#### Introduction

Making end of life decisions for patients who have lost the capacity to make their own decisions pose one of the most difficult ethical challenges for physicians and family members. In an attempt to extend patient autonomy, Western medical practice "relies on living wills, a formal document written by a competent person that is designed to guide medical treatment in the event of future incapacity" (Quill, 1993: 177). Besides, medical practice relies on patient's surrogates to make end of life treatment decisions and are instructed to use the substituted judgment standard, which directs them to make the treatment decision that the patient

would have made if he or she were capacitated (Shalowitz, et. al 2006). This paper examines the roles advance directives play in end of life decision making. It argues that, in spite of the value of advance directives in end of life decision making in Western medical practice, advance directives prove themselves to be inconsistent with African communitarian values particularly in their adherence to the autonomy of persons. It further argues that, the Western practice of relying on advance directives in end of life decision making is too individualistic and, as a result, undermines African communal values relating to end of life decision making. The paper underscores the fact that African conceptions of death and dying, and African communal values justify making decision for an incompetent patient at the end of life in many African societies. It concludes by stressing the problems of precedent autonomy, atomistic individualism and other practical problems which prevent the acceptance of advance directives in many African societies.

### **Advance Directives in Western Medical Practice**

Advance directives are "formal documents that are completed when one has full mental capacity, and are intended to guide medical treatment in case one loses the ability to speak for oneself in the future" (Quill, 1993: 177). Public interest in cases involving patients who are unable to make decisions in end of life care has grown since 1976 when Karen Ann Quinlan's parents obtained permission from the court to remove their daughter's respirator. Ms. Quinlan survived for ten years in a persistent vegetative state, not needing a respirator, but receiving nutrition through a feeding tube (McCarrick, 2008). Another event which shows an increased interest in establishing some measures for decision making in case the patient becomes incompetent is the Cruzan case. This is illustrated below:

In 1983, Nancy Cruzan was severely injured in a car accident. With the help of extensive, invasive medical measures, including the initial use of cardiopulmonary resuscitation, Ms. Cruzan survived. Unfortunately, she emerged from the process with severe brain damage, incapable of higher brain functions and unaware of her surroundings. Since she could not eat, a permanent feeding tube was surgically placed into her stomach to mechanically, provide hydration and nutrition. Because the rest of her body survived the accident, she could be sustained indefinitely in this state as 24 Prajñavigas the feeding tubes were continued. Her parents hoped she would

get better and waited for four years before reluctantly accepting that she would not recover. Then, out of love for their daughter and respect for what they felt would be her wishes, her parents formally petitioned the courts to allow removal of the feeding tube. They based the petition partially on their daughter's statement that she would not want to go on living if she could not be "at least half way normal" (Quill, 1993: 180).

In spite of her parents' petition, the court did not permit life support to be removed unless there is "clear and convincing" evidence that the patient had formed that wish. The court said that if Nancy had executed a formal living will that would have provided the necessary proof but that the informal causal statements her family and friends remembered did not (Dworkin, 1993). Eventually, family and friends were able to collect and present enough evidence about Nancy's statements and wishes before her accident to meet a "clear and convincing" legal standard that she would not want this life- sustaining treatment, given her persistent vegetative state. The court subsequently ruled that her feeding tube be removed and she died thereafter.

A more recent account that calls for the necessity of completing a living will when competent is that of Terri Schiavo. Her story is illustrated below:

"Terri Schiavo was an American woman who suffered brain damage and became dependent on a feeding tube. She collapsed in her house on February 25, 1990 and experienced respiratory and cardiac arrest, resulting in extensive brain damage, a diagnosis of persistent vegetative state and fifteen years of institutionalization. In 1998, Michael Schiavo, her husband and guardian petitioned the Pinellas county circuit court to remove her feeding tube. Robert and Mary Schindler, her parents opposed this arguing she was conscious. The court determined that Schiavo would not want to continue life-prolonging measures"

The controversy surrounding Shiavo's case continued for seven years and drew the attention of pro-life groups, disability groups and the media both at national and international levels. Terri's case also became more problematic because of the absence of a living will. Although it was confirmed by the court and also physicians in charge of Terri's treatment that she is indeed in a permanent vegetative state, the judge who was

appointed as the second guardian doubted Michael's (her husband) petition which according to the judge "might have been influenced by the potential to inherit what remained of Terri Schiavo's estate". Other lawyers also raised the issue of conflict of interests despite the fact that there was no possibility of improvement in Terri's condition. Even factors such as Terri's religious background came into play where it was interpreted that she would not have wanted to violate the Catholic Church's teachings on euthanasia. The feeding tubes were later removed in 2005 when it was found that Schiavo was in a persistent vegetative state and that she had made reliable oral declarations that she would have wanted the feeding tube removed

The stories of Nancy, Quinlan and that of Terri Schiavo serve to explain the importance of writing advance directive when competent. The ordeal of the victims and their family members in the above examples would have been more persuasive if there is adequate knowledge about the need to complete formal advance directive. To prevent apprehension about future treatment if one becomes terminally or critically ill and incompetent to communicate, it is often recommended that people should execute written advance directives, often known as living wills. Advance directives guarantee legal protection to the physician who is to execute its content.

Another goal of advance directives is to help persons plan their own treatment decisions while capable and competent. As a result, it offers a medium of extending the patient's autonomy and self-determination into the future. According to Mishkin (1986), advance directives do not create rights but allow one to exercise the fundamental right to make choices in health care. Brock describes this fundamental right as the right to self-determination stressing that "self-determination, as it bears on treatment decision making, is the interest of ordinary persons in making significant decisions about their lives for themselves, according to their own values or conception of a good life" (Brock, 2001: 232).

DeGrazia identified two types of advance directives: instructional directives which is also commonly known as living wills and proxy directives. While instructional directives "give instructions for what sorts of medical interventions to provide or withhold from the patient, proxy directives designate a surrogate decision maker to stand in for the patient if

he is incompetent" (DeGrazia, 2005: 161).

Living Wills: These are documents stipulating that specified medical procedures should not be used to keep the signer alive in certain specified circumstances. Living wills arose as a response to the decision making problem which often occurs when the question is whether to forgo the medical interventions sustaining the life of someone who is no longer able to make his or her own decisions known (Beauchamp and Childress, 2001). Because health care providers and relatives of patients find it difficult to withhold further interventions or withdraw those medical interventions which have been commenced, Lius Kutner, a Chicago attorney active in a right to die organization in 1967 drafted what he called a 'living will' (Capron, 2001). Kutner's living will allows a person to give instructions about end of life care. Without a living will, an incompetent patient runs the risk of having his/her treatment guided by the values of the physician or family members than by the patient's own values and wishes.

Living wills serve several purposes. First, by executing a living will, a person could lift the burden of decision-making off the shoulders of anxious relatives and physicians. Second, if the wishes expressed in the living will are honored, a person could in effect participate in treatment decision-making even after he or she has lost competence. And finally, the existence of living wills and the recent interest being shown in them help to educate people about the necessity of writing living wills, and educate the physician about the public's sense that life-prolonging treatments of patients who are incompetent is not always regarded as good (Capron, 2001: 263).

Although living wills help to extend the autonomy of an incompetent patient, a major problem often associated with this decision procedure is that the variations of illness associated with incompetence are myriad, so it would be impossible to anticipate and account for all possibilities. Also, the form forces respondents to make decisions in advance about highly technical interventions that they may not know about. Thus patients might refuse treatments that would have enhanced their overall goals, and they might request treatments that interfere with their goals (Quill, 1993). These problems can be reduced if each individual tailors his /her living will to his/her own personal philosophy about potentially losing

capacity in the future. Hence the ideal living will is clear and direct about a patient's treatment goals and objectives, and specifies the type of existence such patient values or views as intolerable, so that physicians can continue to help patients meet their unique needs when they become incompetent.

The criticism that it is impossible to anticipate the type of illness that will befall a person should he/she become incompetent in the future calls for the need to name a proxy. The advantage of naming a proxy stems from the realization of the limitations of living wills.

Health Care Proxy or Surrogate Decision Maker: Designated surrogate decision makers are authorized to make decisions for incompetent patients. Decision makers typically make substituted judgments or apply the best interest standard without any judicial proceeding. Ordinarily, courts are involved only where there are significant uncertainties about what the law requires in the situation at hand (DeGrazia, 2005: 161). Beauchamp and Childress (2001) have identified the capacities of a surrogate. They include "the ability to make reasoned judgment (competence), adequate knowledge and information, emotional stability and a commitment to the incompetent patient's interest that is free of conflict of interest" (Beauchamp, and Childress, 2001: 154). A surrogate who satisfies these four criteria should use the standards of substituted judgment and the patient's best interests in making decisions for the incompetent patient. These standards are also appealed to by courts in cases where an incompetent patient had not completed an advance directive while competent (DeGrazia, 2005: 161).

A) The substituted judgment standard: This standard permits a family member or another appropriate surrogate to determine what the patient would have wanted in the present circumstances (DeGrazia, 2005: 161). The central idea of the substituted judgment standard is that decisions about treatment belong to the incompetent patient by virtue of his right of autonomy. The patient in this regard has the right to decide but is incompetent to exercise it, and it would be unfair to deprive an incompetent patient of his right to decide just because he is no longer competent. This standard requires the surrogate to make the decision the incompetent

patient would have made if competent. The surrogate's attempt at answering the question 'what would the patient want in this circumstance?' rather than 'what do you want for the patient?' portrays the substituted judgment standard as the appropriate standard which reaffirms the incompetent patient's autonomy. This standard according to Beauchamp and Childress "helps us understand what we should do for once competent patients whose relevant prior preferences can be discerned; so interpreted, it translates into a pure autonomy standard that respects previous autonomous choices" (Beauchamp, and Childress, 2001: 100).

B) The best interest standard: If there is no reasonably clear basis for determining what the patient would have wanted, the law turns to the doctrine of best interests: treatment decisions are to be determined by what appears to be in the patient's best interests (DeGrazia, 2005, 161). This standard requires the surrogate to determine the highest net benefit among the available options, assign different weights to interests the patient has in each option and subtract inherent risks or costs. The surrogate should maximize benefit through a comparative assessment that locates the highest net benefit. The well-being of another is protected by this standard. This is done by assessing the risks and benefits associated with various treatment options, by considering pain and suffering for the incompetent patient, and by evaluating the possibility of the patient being restored or the eventuality of loss of functioning (Beauchamp, and Childress, 2001: 102). The need to assess the quality of life of the incompetent patient along with his/her best interests is the focus of this standard. Hence surrogates applying the best interest standard should consider the formerly autonomous patient's preferences, values and perspectives as they affect the incompetent patient's interpretation of quality of life, direct benefit and so on. Since quality of life judgments are comparative ways of expressing a person's worth, surrogates employing the best interest standard should focus on the value of life for the person who must live it rather than on the value the person's life has for other persons.

A major criticism against the surrogate form of advance directive is the likelihood of the surrogate imposing his values and beliefs on those of the incompetent patient while trying to decide for the patient. Nevertheless, because a living will has the shortcoming of not being able to

anticipate all possible future circumstances, surrogate decision making has been suggested as more flexible not only because it can cover a broader range of health care decisions but also because it is more responsive to changing medical circumstances.

Physicians should endeavor to respond to the directive of those who have clearly expressed their wishes that they would not want to live under conditions of incompetence. This can be done by treating them as conservatively as possible, avoiding all life-extending treatment and doing everything within their power to minimize their discomfort, maximize their dignity, and facilitate an easy death (Quill., 1993). For those who have expressed such wishes in their advanced directive, all treatments in all settings would be directed exclusively toward enhancing comfort and dignity and explicitly not to prolong life. The goal would be to make death as humane, dignified and as easy as possible, using medical intervention to ease the way.

In spite of the roles of living wills and surrogate decision-makers in Western medical practice, Beauchamp and Childress (2001) have examined some likely problems of advance directives in general. First, very few people take the initiative to complete advance directive forms. Also, even when a patient designate a surrogate when competent, such surrogate may not be available when needed, may be incompetent to make good decisions for the patient or may have conflicts of interest particularly if he/she stands to gain from the decision he is about to make. Again, some state laws often severely restrict the use of advance directives. For exam, "advance directives have legal effect in some states if and only if the patient is terminally ill and death is imminent. But decisions must be made in some cases when death is not imminent or the medical condition cannot appropriately be described as terminal illness" (Beauchamp, and Childress, 2001: 153).

Furthermore, advance directives provide no basis for physicians to overturn instructions of the patient as contained in the advance directive that may turn out not to be in the patient's best medical interests although the patient could not have reasonably anticipated these circumstances while competent. Finally, some patients do not have an adequate understanding of the range of decisions a physician or a surrogate might be called upon to make and cannot foresee clinical situations and possible future experi-

ences with an adequate understanding. For instance, how can anyone really know what he or she would want done in medical cases such as cancer, stroke or heart attack five or ten years before it occurs? Perhaps new treatments might be developed which were not in existence when the advance directive was drafted.

Apart from the problems highlighted above, a major problem often associated with writing advance directives is that of precedent autonomy; this is the problem of trying to reconcile the incompetent patient's earlier self with his present self. When a patient loses his/her status as an agent capable of guiding his/her actions, how can his/her earlier autonomously chosen values be allowed to continue to govern what happens to him despite his/her current inability to appreciate these values? Would autonomy require that such patient's earlier wishes be respected now by those in charge of the incompetent patient's care? It is important to note that many of the arguments often put forward to justify the authority of advance directives are derived from the moral principle of autonomy. Hence the need to examine the principle of autonomy as it relates to advance directives in end of life decision making.

### Autonomy

Advance directives are meant to extend and reaffirm the autonomy of the competent patient to the future in case of incapacity. According to Beauchamp and Childress (2001), the term autonomy when applied to individuals implies self-governance, liberty rights, privacy, individual choice, freedom of the will, causing one's own behavior, and being one's own person (Beauchamp and Childress, 2001: 58). The autonomous individual acts freely in accordance with a self-chosen plan while a person of diminished autonomy is controlled by others or incapable of deliberating or acting on the basis of his or her desires and plans (Beauchamp, and Childress, 2001).

Almost all theories of autonomy agree that liberty and agency are essential for autonomy. In these two senses, the traits of the autonomous person which include capacities of self-governance, such as understanding, reasoning, deliberating and independent choosing are taken into ac-

count. Autonomous actions are analyzed in terms of choosers who act intentionally, with understanding, and without controlling influence that determine their action. To respect an "autonomous agent therefore is to acknowledge that person's right to hold views, to make choices, and to take actions based on personal values and beliefs" (Beauchamp, and Childress, 2001: 59). Respect, on this account, involves acknowledging decision-making rights and enabling persons to act autonomously, whereas disrespect for autonomy involve attitudes and actions that ignore, insult or demean others' rights of autonomy. Respecting the autonomy of an incompetent patient involves taking the contents of his advance directive seriously which often reflects his interest in directing his life according to his conception of a good life.

In contemporary ethics, Immanuel Kant (1959) and John Stuart Mill's (1977) interpretation of respect for autonomy have contributed to the subject of autonomy. For Kant (1959), respect for autonomy flows from the recognition that all persons have unconditional worth, each having the capacity to determine his or her own moral destiny. To violate a person's autonomy is to treat that person merely as a means, that is, in accordance with others' goals without regard to that person's own goals. Mill's (1977) concern is with the individuality of autonomous agents. According to him, society should permit individuals to develop in relation to their convictions as long as they do not interfere with a like expression of freedom by others; but he also insists that we sometimes are obligated to seek to persuade others when they hold false or ill-conceived views (Mill, 1977: chps1, 111). These two conceptions are in support of respect for autonomy: Mill emphasizes not interfering with and actively strengthening autonomous expression while Kant stresses a moral imperative of respectful treatment of persons as ends in themselves. If Mill's account is plausible, then respecting an incompetent patient's advance directive requires not interfering with his wishes as stated in the advance directives. John Harris describes the main idea of autonomy in the following ways:

"The point of autonomy, the point of choosing and having the freedom to choose between competing conceptions of how and indeed why, to live, is simply that it is only thus that our lives become in any real sense our own. The value of our lives is the value we give to our lives. And we do

this, so far as this is possible at all, by shaping our lives for ourselves. Our own choices, decisions and preferences help to make us what we are, for each helps us to confirm and modify our own character and enable us to develop and to understand ourselves. So autonomy, as the ability and the freedom to make the choices that shape our lives, is quite crucial in giving to each life its own special and peculiar value" (Harris, 1995: 11).

The implication of the above is that competent patients have the capacity to make free and informed choices about whether to live or end their lives and this can be expressed through an advance directive which has to be respected in order to guarantee and extend the autonomy of the patient in case he becomes incompetent. It will be unfair to fail to respect an incompetent patient's choice (in his advance directive) on the grounds of incompetence. Since competent patients generally have the right to make their own health-care decisions, even decisions that others believe are contrary to the patient's interests (Elliot, 2001), such choices can be extended to the future through an advance directive.

When applied to patients in end of life decision making, the moral consideration of autonomy gives rise not only to the problem of precedent autonomy but also to that of atomistic individualism. I will first sketch the problem of precedent autonomy in advance directives then after that of atomistic individualism.

### The Problem of Precedent Autonomy and Advance Directives

The need to extend the incompetent patient's right of self-determination into the future raises theoretical problems. The tendency in bioethics has been to view the rights of incompetent individuals as an extension of the rights of competent individuals. This has created the problem of precedent autonomy. Because cases of permanent incompetence feature former preferences, bioethics speak of a special kind of autonomy known as precedent autonomy. John K. Davis (2007) defines precedent autonomy to comprise acts of self-determination under conditions where the agent's earlier preference becomes a former preference, during at least part of the time for which it was meant to be satisfied because the patient lost the competence to reaffirm it. Some bioethicists (for example Buchanan and

Brock, 1990; Dworkin, 1993) hold that a competent person's right to autonomy requires that his past decisions about how he is to be treated if he becomes incompetent be respected even if they contradict the desires he has at a later point.

The above position held by Buchanan and Brock (1990) and also Dworkin (1993) raises the question of whether respect for autonomy implies respect for precedent autonomy. The principle of respect for autonomy requires respecting the preferences formed earlier by a now incapacitated patient, such as those expressed in an advance directive. The concept of precedent which concerns just such preferences is problematic because it is not clear that we can still attribute to a now incapacitated patient a preference which that patient never disaffirmed but can no longer understand. Davis (2002) opines that if we cannot make such attribution, then perhaps we should not respect precedent autonomy- after all, how can one respect patients' autonomy by giving patients what they no longer want, even if they never disaffirmed those wants? (Davis, J.K 2002).

Realizing that a person's values and treatment preferences can change over time and advance directives are not always updated to reflect such changes, this gives room to doubt the authority of advance directives. Hence it was held that just as a patient's current choice has less moral weight when the patient is uninformed about the issue in question, so the moral authority of advance directive is weakened to the extent that patient did not understand or foresee the medical issues that would later arise (President commission, 1983: 182-183). In a similar vein, Robertson (1991) opines that following the earlier preferences or promoting the earlier interests may harm the now incompetent patient. According to Robertson,

In most medical cases, when a patient's treatment preference conflicts with his or her current welfare interests, medical ethics tells us to respect the preference --- so long as the patient is choosing autonomously. However, in most cases, the patient has that preference when the treatment is given; this may not be true when the preference was formed before the patient became incompetent and unable to comprehend that preference (Robertson, 1992: 7)

Robertson's main argument is that the focus should be on incom-

petent patient's needs and interests as they now exist and not view them as retaining interests and values which because of their incompetence, no longer apply. This I think is because treatment options might change between the time the directive was executed and the time it must be followed.

Despite the apparent absurdity of respecting incompetent patient's autonomy by giving them what they no longer prefer but have never disaffirmed, some bioethicists conceive of the problem of precedent autonomy as no problem at all. Buchanan and Brock (1990), for instance, explain that a person can exercise self-determination not only by accepting or rejecting treatment that is now offered but also by making decisions that will influence what is to happen in the future, when the person becomes incompetent. Consequently, following an advance directive can be viewed as a case of respecting self-determination even if the individual has no self-determination to respect at the same time the advance directive is carried out (Buchanan and Brock, 1990: 98-99).

Similarly, Dworkin (1993: 228) explains that "if we refuse to respect an incompetent patient's autonomy, - if we refuse to respect her past decisions, though made when she was competent, because they do not match her present, incompetent wishes-then we are violating her autonomy on the integrity view" (Dworkin, 1993: 228). He makes a distinction between the evidentiary view of autonomy and the integrity view of autonomy. The evidentiary view holds that "we should respect the decisions people make for themselves, even when we regard these decisions as imprudent, because each person generally knows what is in his own best interest better than anyone else" (Dworkin, 1993: 223). The integrity view of autonomy on the other hand holds that "people often make choices that reflect weakness, indecision, caprice, or plain irrationality-that some people otherwise fanatical about their health continue to smoke, for example" (Dworkin, 1993: 224). Accepting the integrity-based view of the importance of autonomy, recognizes that any judgment about whether incapacitated patients have a right to autonomy will turn on the degree of their general capacity to lead a life the way they want.

To be plausible, an integrity view of autonomy must distinguish between the general point or value of autonomy and its consequences for a particular person on a particular occasion. Since autonomy encourages and protects people's general capacity to lead their lives out of a distinctive sense of their own character (a sense of what is important to and for them), then one principal value of that capacity is realized only when a life does in fact display an overall integrity and authenticity (Dworkin, 1993: 224). But the right to autonomy protects and encourages the capacity in any event, by allowing people who have it to choose how far and in what form they will seek to realize that aim. If the integrity view of autonomy is recognized, then a competent person making a living will providing for his treatment if he becomes incompetent is making the kind of judgment that autonomy, on the integrity view, most respects: "a judgment about the overall shape of the kind of life he wants to have led" (Dworkin, 1993: 226).

Naturally, many competent people who are concerned about the end of their lives express fear about how they might be treated if they become incompetent. A competent patient for instance may be anxious to ensure that his life is not unnecessarily prolonged by medical treatment because the character of his whole life would be compromised if this is done. He therefore takes the initiative of completing an advance directive when competent asking not to be kept alive in a hopeless medical condition or when permanently vegetative. Since it is obvious that this patient dreads unconsciousness, if such patient's past request is to be respected, then his wishes not to be kept alive when unconscious as contained in his advance directive should also be respected.

It goes without saying that patients are incompetent if they are unable, whether permanently or temporarily, to make decisions about their medical care. Competence has been defined as the ability to perform a task (Culver, and Gert, 1982: p.123). It depends not only on a person's abilities but also on how that person's abilities match the particular decision-making task he or she confronts. Patients are competent if they are able to understand the available information about their conditions, to consider with medical advise the risks, benefits and burdens of different treatments or courses of action, and thus to make informed decisions (Walton committee, 1994: paragraph 24).

Pointedly, many bioethicist discuss the problem of precedent autonomy in terms of personal identity, invoking a theory of personal identity provided by bioethicists such as DeGrazia (2005). DeGrazia (2005) at-

tempts to address issues relating to the authority of advance directives. He explains that in some cases, the authority of advance directives is sometimes challenged on grounds of partial competence when completing the directives or that even if fully competent, the patient may not have foreseen the sort of circumstances he now finds himself. If he had, "he would have decided differently about the present case than a literal reading of his directive suggests" (DeGrazia, 2005: 164). The assumption that one can write some of one's narrative in advance and include sections that will, or may, occur when one can no longer appreciate one's own narrative creates the someone else problem. DeGrazia describes the problem of precedent autonomy as the someone else problem because it creates identity problem. According to DeGrazia (2005), the someone else problem is the problem that the person who wrote the advance directive is not the individual to whom it will apply. This constitutes a problem for the authority of advance directives because the advance directive one completes is supposed to authorize certain decisions regarding one's own future medical treatment, not someone else's (DeGrazia, 1999: 373-91).

Advance directives have been criticized even by Western critics based on the someone else problem. Central to this criticism is the claim that the authority of advance directive is weakened by the fact that in cases where a patient undergoes massive psychological and mental change, the individual who exists after such change is not only literally a distinct individual from the person who completed the directive, he is also no longer psychologically connected to the life of the person who completed the directive (DeGrazia, 1999: 373). If this is the case, then it creates the someone else problem and there is good reason to question the authority of the directive which is supposed to apply to the individual who completed it, not to someone else.

Since the someone else problem also gives rise to the identity problem, DeGrazia attempts to resolve this problem by making a distinction between the numerical sense of identity and the narrative sense. Numerical identity tries to address the question of whether person X at time T1 is the same person at time T2. The basic idea according to DeGrazia is "whether "A1-at-sixty-five" and "A1-at-seventy-five" are the same individual or numerically distinct individuals" (DeGrazia, 2005: 165). On the other hand, a person's narrative identity involves his self-conception, his

self-told story about his own life and what is of importance to him. It orders events and facts about a person, "highlights certain features and people, and organizes what is highlighted into a more or less coherent story of one's life and character" (DeGrazia, 2005).

In an attempt to further respond to the someone else problem, DeGrazia explains that the someone else problem can be effectively dissolved by appealing to person essentialism. This is the view that "A1-atsixty-five is essentially a person and therefore cannot exist at any time without being a person at that time" (DeGrazia, 2005: 167). Also, DeGrazia holds that a person can claim that "numerical identity confers authority on the directive she is now completing ("after all, it would be me"), while the disruption of narrative identity ("I wouldn't be myself") justifies a decision now to forgo life supports at that later time" (DeGrazia, 2005: 176). In both instances, there are strong moral reasons in favour of respecting autonomy which also extends to favouring the authority of advance directive. In other words, these two concerns about numerical and narrative identity "do not undermine the presumptive authority of advance directives" (DeGrazia, 2005: 188). In these two forms of identity, what matters to everybody about their existence is "the ability to continue our lives as persons with unfolding narratives and, if possible, self-creation" (DeGrazia, 2005: 173). One's significant decisions stem from the story as told up to that point and project into the future in a way that expresses one's values and priorities" (DeGrazia, 2005: 179-180). Therefore, one can autonomously make decisions for oneself in future times of nonautonomy if one has self-regarding intentions that extend beyond the time when one has explicit narrative-telling capacity.

Degrazia (2005) tried to make a case for the authority of advance directives by arguing that the author of an advance directive and the vegetative individual to whom it applies are numerically identical. She drew on Dworkin's (1986) argument that appeal to precedent autonomy must assume that "it is correct to regard a vegetative patient as a person who has become vegetative - that is, that the competent and incompetent stages of life are stages in a single life, that the competent and incompetent selves are parts of the same person" (Dworkin, 1986: 4). The central idea is that even when one is no longer autonomous, as long as one still exists, his autonomous self-regarding wishes can be respected. Hence, in order to

justify a strong presumption favouring the authority of advance directives, appeals to precedent autonomy depend on the assumption of numerical identity and narrative identity. Since a person's narrative identity involves his self-conception, his self-told story about his own life and what is of importance to him, DeGrazia (2005) is of the opinion that one can autonomously make decisions for oneself in future times of nonautonomy if one has self-regarding intentions that extend beyond the time when one has explicit narrative-telling capacity.

Another way to vindicate precedent autonomy and the associated preferences going by DeGrazia's account is to prioritize the ethical principle of respect for autonomy over that of beneficence. In contemporary moral thinking, when beneficence and respect for autonomy conflict, consideration is often given to respect for autonomy which allows the individual to make self-regarding choices even where others doubt that a particular choice serves his best interests. If beneficence gives way to respect for autonomy when the agent is capable of autonomous decision-making, since the persistent vegetative patient's recent preferences cannot be autonomously formed, respecting autonomy requires respecting precedent autonomy whenever the relevant, previously expressed preferences are known as specified in the advance directive (DeGrazia, 2005: 182). In this way, earlier autonomous preferences will be allowed to trump current nonautonomous preferences, consistent with the doctrine of precedent autonomy.

The implication of the above is that both numerical and narrative identity are necessary conditions for advance directives to carry authority. These two identity approaches also "concur that precedent autonomy establishes the presumptive authority of advance directives" (DeGrazia, 2005: 186). And if this is the case, then DeGrazia (2005) sums up her argument in this way: "precedent autonomy can extend to states of permanent unconsciousness so long as one is still alive and therefore still exists. Whether because living, permanently unconscious former persons can have interests, or because precedent autonomy can extend to times when one lacks interests so long as one still exists, I am inclined to accept the claim that precedent autonomy and narrative identity can extend to PVS or permanent coma" (DeGrazia, 2005: 199).

Because of the problem of atomistic individualism which many

communitarians attribute to advance directives, advance directives have been criticized as too individualistic for communitarian societies such as Africa. Atomistic individualism is "the idea that the isolated individual is the only fundamental reality and that the individual is the natural atom in artificial social composite (Sanchez-Gonzalez, 1997: 287). It views the individual as inventing himself rather than discovering himself within a social setting hence it abstracts the individual from the details of his social circumstances. Since African societies are famously communalistic, the importance of advance directives is not acknowledged by these societies. This is due to a major feature often attributed to advance directives by communitarians; that of atomistic individualism.

For many communitarians, the society is ontologically prior to the individual and the polis is that which makes man, as human being possible (Kymlicka, W., 2002). As a result advance directive is viewed as too individualistic. This is because the individual is not an isolated being but somebody who is brought up from the beginning with a sense of belonging, solidarity and relatedness with others. This is the basis of solidarity; a system of reciprocity in which each individual has obligations to a larger set of other individuals. This explains why African tradition does not recognize the roles of advance directives in end of life decision making for an incompetent patient but relies on social norms which dictate that decisions at the end of life reside with the family or community as the case may be. It is in line with this that Callahan (1994) sees the need to address this cultural dilemma---"a dilemma about the good society and whether such a society should leave crucial life and death decisions in the hands of individuals or let them be decided, at least in great part, by commonly shared cultural notions of what is and is not fitting, embodying such notions in ordinary medical practice" (Callahan, 1994: 866-867).

## **African Conceptions of Death and Dying**

African culture recognizes a difference between the physical person who dies and is buried and the non-physical person who lives on. This is quite unlike the Western dualism that separates 'physical' from 'spiritual'<sup>3</sup>. In Africa, when a person dies, his /her whole person continues to

live on not some part of him. It is the whole person who continues to live in a spirit world, receiving a new body identical to the earthly body, but with enhanced powers to move about as an ancestor. This can be attributed to the African belief that life does not end with death, but continue in another realm. Hence the concept of 'life' and 'death' are not mutually exclusive and there are no clear dividing lines between them<sup>4</sup>.

Although death is dreaded by many, it is perceived in African culture as the beginning of a person's deeper relationship with the whole of creation, the complementing of life and the beginning of communication between the visible and invisible worlds<sup>5</sup>. According to African conception of death and dying, the goal of life is to become an ancestor (people who have died but who continue to live in the community and communicate with families) after death and this cannot be achieved if a person asks for an unnatural death through an advance directive. This accounts for the traditional African explanation that anybody who dies a natural death must be given a correct and proper funeral which is often supported by a number of religious ceremonies. If this is not done, then this implies that the person did not die a natural death and may become a wandering ghost, unable to live peacefully after death and therefore a danger to those who remain alive. It can be argued here that the proper death rites are more a guarantee of protection for the living than to secure a safe passage for the dead

An African person prefers a slow and lingering death not through the aid of a machine but a natural prolongation of the dying process so that he/she could make their peace, say farewell to friends, relatives and give final instructions to immediate relatives. Among many African people is the widespread belief that those who die unnatural death as requested and contained in an advance directive are not admitted to the spirit world and are therefore refused proper burial. Sometimes their bodies are subjected to actions that would make such burial impossible; such as burning, chopping up and feeding them to hyenas. To be cut off from the community of the ancestors (people who have died but who continue to live in the community and communicate with families) going by the African belief system is an equivalent of hell<sup>6</sup>.

Africans, like others, resist the daily contemplation of death; often people do not write their living will. Unlike the Western world, Africans

do not tend to set aside money for their funerals while still alive. They do not make preparation towards their dying just as they do not make preparation for the future in case they become incompetent. They prefer not to think about it at all and rather leave the burden to their living family members. This death-denying attitude is attributed to the way Africans conceive of death. Though there exist this consolation of an afterlife and its connection with present life, traditional Africans hold a belief in the sanctity of life and fear of death for it is an enemy to life? Fear of death lead many to use fetish charms for self-protection, though death is invisible, it can be held at bay as many Africans believe because life is to be preserved at all cost.

Thus, an average African would not be inclined to discontinue life-sustaining treatment once it has commenced. Likewise, Africans do not favor any artificial means of terminating life, this is viewed as sacrilegious. In any event, such decisions would be arrived at through family concensus<sup>8</sup>. It would be offensive to other family members and extended relatives if one of them decides to write an advance directive without at least considering what others thought and felt. This is evident in the South African guidelines to assist doctors confronted with living wills where it was specifically stated that "it is the responsibility of a patient to ensure that the existence of an advance directive is known to his family and to those who may be asked to comply with its provisions"<sup>9</sup>. This communitarian spirit accounts for a major reason why the roles of advance directive is not acknowledged among Africans and its value not recognized.

### **African Communal Values**

The defining characteristic of African societies is communitarian. Communitarianism emphasizes the value of specifically communal and public goods and conceives of values as primarily rooted in communal practices<sup>10</sup>. Communitarians argue that the community rather than the individual, the state or the nation is the ultimate originator of values and in their analysis of human rights, group or communal rights rather than individual rights are emphasized. Accordingly, for the survival and the preser-

vation of the community and hence its members' personal lives, it would be perfectly justifiable for some individual rights and acts to be restricted or even banned especially those right claims of individuals whose actions are not in harmony with the ways of society and are considered to pose a threat to the maintenance of the good of the community at large<sup>11</sup>.

A communitarian ethos is embraced by many African societies as a solution to the alienation and disintegration of ethical values and social institutions in modern life. Many African scholars claim that the roots of a communitarian ethos go back to indigenous African societies with a social structure which was communitarian in character. Leopold Senghor (1964) for example explains that Negro African society is communal because it is a communion of souls rather than an aggregate of individuals. Negro African societies put more stress on the group than on the individual, more on solidarity than on the activity and needs of the individual, more on the communion of persons than in their autonomy (Senghor, 1964: 34). This attitude of Negro African societies explains why an advance directive which emphasizes the autonomy of the incompetent patient is not valued.

Senghor's emphasis on the communal nature of Africans is similar to that of Julius Nyerere who advocates *Ujamma* (African solidarity) as the ideal of social solidarity where people agree to subordinate their individual interests to the interest of the common objective of the collective. Nyerere maintains that *Ujamma* emphasizes "the Africanness of the politics we intend to follow----it brings to the mind of our people the idea of mutual involvement in the family and regards all human beings as members of this ever extending familyhood" (Nyerere, 1968: 2). This African communal attitude has been attributed to cultural upbringing. Putting more emphasis on this, Chukwudum Okolo (1985) explains that the African, through cultural upbringing is not individualistic and "there is no question of rugged individualism in outlook and life-style so characteristic of the European or the American" (Okolo, 1985: 397). Human persons are intrinsically communal beings embedded in a context of social relationships and have common values, interests and goals. Giving support to this view, Ifeanyi Menkiti (1984) asserts the ontological primacy of the community over the reality of the individual's life. He maintains that it is the community which defines the person as person, not some isolated static quality of rationality, will or memory (Menkiti, 1984: 172 and 179).

In essence therefore, the African understanding of human community plays a crucial role in the individual's acquisition of full personhood. This also implies that the individual is submerged in community and that community interests and its continued existence takes preference above the will and interests of the individual. One can infer from Menkiti's argument that the individual must of necessity be subject to the normative power of the community and is thus not seen as the primary reference point for moral actions. Rather, his/her moral status is linked to the fact that the cultural community is the primary context or social space within which he or she is regarded as a moral agent (Menkiti, 1984: 172 and 179). In order words, the importance of individual human rights is denied in terms of the priority of group rights. Therefore, the moral self develops within a social context where culture and history play vital roles.

The above analyses by African scholars serve to explain why advance directives are not valued in African culture. Allowing this will amount to emphasizing the autonomy and right to self-determination of the individual at the expense of the society and communal values; this, according to African communal thought system, is not acceptable.

There are other practical barriers to completing advance directives in African societies. A major problem militating against the completion of advance directive documents in Africa is lack of awareness on the part of many about the need to complete one. Very few percentage of the population in many African societies has thought it wise to complete a living will or formally select someone to serve as their health care proxy. Even those who strongly belief in the 'right to die' lack this awareness therefore making it difficult for physicians to handle cases of incompetent patients who did not make their wishes known while competent through completing an advance directive or nominating a health care proxy . Even those that are aware find it difficult to understand the forms and concepts of advance directives. The consequence of this is the misunderstanding of vital information about their preferred treatment option.

Another problem is that of fear of death and the grief that often accompanies the acknowledgment of an advance directive. Although many Africans may be fascinated, fearful, or preoccupied by the possibility of suffering unnecessarily before death, it is very difficult to think about death in personal terms (Quill., 1993). For some Africans who have strong feel-

ings and a clearly articulate vision about what they would want in case they become incompetent, it still takes months or even years to actually sign an advance directive form and have it witnessed. It is difficult to come to terms with one's own death because the possibility of one's death seemed real after an advance directive has been signed. For the very ill patient whose quality of life is deteriorating and for another who is gradually losing his competence, "the completion of an advance directive is often the sad acknowledgment of an unwanted but inevitable future" (Quill, 1993: 197).

Furthermore, lack of physician initiative is also a barrier to issuing advance directives in many African societies (Emanuel et.al 1991). Many physicians in African countries lack the initiative to discuss the necessity of completing an advance directive with their patients. This breakdown in communication consequently results in patients misunderstanding their options to refuse or withdraw treatment or to choose palliative care in completing an advance directive.

Lastly, African belief system makes it difficult to value the roles of advance directives in end of life decision making or even complete an advance directive form. Many Africans believe that a person does not have control over his destiny hence should not determine the course of his life; this should be left in the hands of God. Hence whoever decides to prolong his/her life or shorten it by signing an advance directive is interfering with the work of God and this is unacceptable in many African societies. For many Africans, nature should be allowed to take its course. This belief makes it difficult for even the educated ones to complete an advance directive or choose a health care proxy.

Thus far, this paper has examined the roles of advance directives in end of life decision making. It argued that while Western medical practice focuses on autonomy and self-determination in end of life decision making, African tradition emphasizes communal values according to which decision at the end of life for an incompetent patient has to be arrived at through family consensus. The paper also examined the rationale behind this practice by highlighting African conception of death and dying and African communal values. The paper further argued that advance directives are not valued in African culture due to the problem of precedent autonomy and that of atomistic individualism. The paper showed that there

are other practical barriers that militate against the completion of advance directive in many African societies.

### Endnotes

<sup>1</sup>Terri Schiavo, from wikipedia, the free Encyclopedia, Online .Available at : http://en.wikipedia.org/wiki/Terri\_Schiavo. [Accessed, 18th April 2008]

<sup>2</sup>Ibid.

<sup>3</sup>"African Religions: The African concept of death, African concept of the Afterlife. In Encyclopedia of Death and Dying". Online. Available: http://www.deathreference. Com/A-Bi/African-Religious.html. [Accessed, 22<sup>nd</sup> April, 2008].

<sup>4</sup>Ibid.

<sup>5</sup>Ibid.

<sup>6</sup>ibid.

<sup>7</sup>Onyewuchi, G.O. "Death and Dying in the African context." Chickenbones: A journal for literary and Artistic African-American themes. Online. Available: http://www.nathanielturner.com/deathanddyingafrican.htm. [Accessed, 25<sup>th</sup> April, 2008]

<sup>8</sup>Ibid.

<sup>9</sup>Guidelines for medical practitioners on living wills prepared by the South African Medical Association. Online. Available: http://www.livingwill.co.za/guidelines.htm. [Accessed, 25<sup>th</sup> April, 2008].

<sup>10</sup>On a communitarian Ethos, Equality and Human Rights in Africa, International Humanist and Ethical Union, The World Union of Humanist Organization. Online. Available: http://www.iheu.org/modules/news/-IK. [Accessed, 25<sup>th</sup> April, 2008].

11ibid.

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