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Advance Directive in End of Life Decision-Making among the Yoruba of South-Western Nigeria

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Abstract

End-of-life decision making is value-laden within the context of culture and bioethics. Also, ethics committee role is difficult to understand on this, thus need for ethnomethodological perspective in an expanding bioethical age.

Anthropological approach was utilized to document Yoruba definition and perspective of death, cultural beliefs about end-of-life decision making, factors influencing it and ethics committee role. Interviews were conducted among selected Yoruba resident in Akinyele LGA, Oyo State, Nigeria. Content analytical approach was used for data analysis.

Yoruba culture, death is socially constructed having spiritual, physical and social significance. Relationship between the dying and significant others influences decision making. Hierarchy of authority informs implementing traditional advance directive. Socialization, gender, patriarchy, religious belief and tradition are major considerations in end-of-life decision making. Awareness, resource allocation and advocacy are important ethics committees' roles.

Further research into cultural diversity of end-of-life decision making will strengthen ethical practice in health care delivery.

Keywords

Advance Directive; End-of-Life Decision Making; Ethnomethodology; Ethics; Yoruba; Nigeria

Introduction

Increased capacity of health care professionals, armed with improved medical technologies, to sustain life even when there is no hope of recovery has created more need for an end of life decision making than ever^{1, 2}. With advancement in medical technology, the question of when to let patients die is a subject of debate among physicians, philosophers and theologians – “the dilemma of modern medicine”³ as well as patients and their relatives. For

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instance, it has been argued that “concurrent with the triumphant capacity to cure pneumococcal pneumonia and to treat diabetes mellitus has come the ability to prolong life of the dying and to maintain in a vegetative state the irreversibly comatose. Physicians applying their skills are endlessly haunted by the question of whether there are circumstances when their techniques should not be applied, whether there is ever a time to stop intervening⁴. This is an ethical issue bothering on end-of-life decision making in which we need to bridge the gap between increased technology and morality involved in using it appropriately. Therefore, “if we are to remain the masters of our technology and not become its slaves, we must never forget that the patient is in the middle of the apparatus that so often surrounds him... If the technical advance is not matched by an equal advance in ethical understanding and maintenance of standards, then the hospital becomes ‘a life-saving chamber of horrors’, and the doctor’s surgery a pharmaceutical supermarket”⁵.

It has been argued that what men value is closely connected with how they view the universe, with their “*Weltanschauung*” which affects biomedical because value as perceived in the field enters mightily into decision-making⁶. This will influence things like advance directive and value of life generally. End-of-life decision making is value-laden arising from the norms and values of the society. The subjective experiences of patients and their families, and the organizations and culture that provide end-of-life care, are complex social phenomena that are best examined using the approaches and methods of qualitative research⁷. However, there exist dearth of qualitative information on end-of-life issues especially in the Sub-Saharan Africa which will help give insight and understanding on the impact of the value system on its practice. Hence, it is difficult to understand what role ethics committees have played. A lacuna which this paper attempts to fill in the age of rapidly expanding bioethical knowledge globally. Thus, this paper discusses end-of-life decision making, defined as Advance Directive (AD) in this paper, in Africa in order to understand the role of ethics committees. The concept of AD is a process of giving advance directive on what to do when individuals are not conscious to make informed decision about his will or how to go about his treatment. This is a major bioethical problem that need to be understood cross-culturally. There is needs to clarify the distinction between western and African perspectives of the issue as a contribution to bioethical practice. To do this end, ethnomethodology analysis of the issue: cultural perspective of death and dying; issues in end-of-life decision making; factors influencing end-of-life decision making; social and cultural dynamics of end-of-life decision making were examined to chart a role for the ethics committee.

Why Ethnomethodological Analysis of the subject?

A large number of literature exist on end-of-life issues generally and decision making in particular but most of them are western oriented with few contributions from Africa. Even those from Africa tend to generalize as if African culture is a monolithic one. This gives wrong perspective of the issue in specific context and may cause confusion for ethics committees in reaching conclusion on some important issues. It has been argued that end-of-life researches and interventions have focused on patients and families. There are compelling reasons for studying the experience and care from community perspective⁸, this is because cultural factors influence patients’ reactions to serious illness and end-of-life treatment

care⁹. Since ethics committee practice is an evolving aspect of medical practice in Africa it needs this kind of information for developing framework that will enhance its activities.

The exact time of death for many intensive care unit patients or patients with terminal diseases is increasingly preceded by an end-of-life decision making. Such decisions are fraught with ethical, religious, moral, cultural, and legal difficulties¹⁰. The major questions include withdrawing of treatment, who should participate in such decision making, and what is the legal precedent. It has been argued that cultural variations exist and attitude to such issues are perhaps expected between continents, but key differences also exist on a more local basis^{9–13}. Cultures are not monolithic, and a range of potential responses to each issue is likely to occur in every ethnic group. Therefore, “careful examination of within-group variations, such as those attributed to acculturation differences, has not yet been applied to most studies of cultural diversity at the end-of-life. As the science in this area moves forward, we will be able to better understand not only differences between groups, but those within groups due to homogeneity nature of societies”¹⁴.

Ethnomethodologists start out with the assumption that social order is illusory. They believe that social life merely appears to be orderly; in reality, it is chaotic. For them, social order is constructed in the minds of social actors as society confronts the individual as a series of sense impressions and experiences which she or he must somehow organize into a coherent pattern¹⁴. Garfinkel suggests that the way individuals bring order to, or make sense of their social world is through a psychological process, which he calls “the documentary method”. This method firstly consists of selecting certain facts from a social situation, which seem to conform to a pattern and then making sense of these facts in terms of the pattern. Once the pattern has been established, it is used as a framework for interpreting new facts, which arise within the situation. This paper examined the pattern of end-of-life issue in Yoruba culture as a framework for interpreting this within the African cultural perspective. A similar approach had been used to understand the process of informed consent in Africa¹⁵.

Yoruba is one of the three major ethnic groups in Nigeria occupying the Southwestern part of the country and stretching to the neighbouring countries of Togo and Benin Republic. In this paper focus was on two issues, first, the culture-specific understanding of the subject matter and second, the issue of advance directive practice.

Methods

Study Design

The research employed an anthropological approach of descriptive design based on qualitative data collection technic.

Study Area

The study was conducted in Ibadan city, the capital of Oyo State, which is made up of 33 Local Government Areas (LGAs). Eleven of the 33 LGAs constitute Ibadan metropolis, which is further divided into core Ibadan (Urban) [five LGAs – Ibadan North, Ibadan Southwest (SW), Ibadan Northwest (NW), Ibadan Southeast (SE) and Ibadan Northeast (NE)], and outer Ibadan (Rural) [six LGAs – Lagelu, Ona-Ara, Egbeda, Akinyele, Ido and

Oluyole]. The study was carried out in Akinyele LGA purposively selected from the 11 LGAs that make up the larger Ibadan agglomeration. It has predominate Yoruba ethnic group with other ethnic groups constituting a substantial minority. Major religions are Christianity and Islam, but traditional religions also exist. Having appraised all the communities Moniya was purposively selected in the LGA because of the traditional nature of the community.

Data Collection

A total of 20 In-depth Informant Interviews (IDIs) were conducted in the study site among elderly male and female community members aged 60 years and above who are the custodian of traditions, and adult male and female community members aged between 20 and 40 years. Data was collected by trained interviewers with a strong background in social sciences in the local language of respondents at locations most convenient for them such as health facilities, compounds of dwelling places, the traditional head's place and workplaces, such as workshops. Responses were recorded electronically and manually with the consents of respondents. Data was transcribed verbatim. Field notes were collected to supplement the transcripts. Information elicited focused on interpretive phenomenology of Yoruba definition and perspective of death, cultural beliefs about end-of-life decision making, factor influencing end-of-life decision making and the role of ethics committees in end-of-life decision making. Each interview lasted between 30 and 60 minutes.

Data Analysis

The audio-recorded interviews were transcribed both in Yoruba and English, depending on the language which was used to conduct the interviews. Two of the research assistants and the authors ASJ and OOA listened to the recordings and checked the accuracy of the transcripts and translation. Content analysis was performed independently by the two authors. They analysed the transcripts and field notes for major issues and emerging themes. The responses from respondents were grouped together, coded and analysed according to themes, and where there was incongruence between the two authors, they re-read the transcripts and made necessary corrections. Both inductive and deductive methods were used to examine the respondents' perceptions – deductive reasoning was employed to draw conclusions from a combination of introduced and emerged themes. The findings were reported in narratives according to the themes and supported by relevant quotations.

Cultural Perspective of Death and Dying

Many factors including culture and ethnicity determine thoughts about death¹⁶. Most clinicians are brought up and trained in western culture and so the culture of the patients is not taken seriously and this often lead to poor interaction with patient and family¹⁷. Ethnicity is one's self-identified group and may include subgroups that share common values. Culture shapes choices for life support (e.g., resuscitation, feeding tubes) and preferences: to know a terminal diagnosis; to die at home, in the hospital, or in a hospice; and to promote quality during the last days.

Death is a complex issue in Africa, like any other culture, and usually not discussed¹⁸. It is mystified and involves many cultural practices. Death is person centred – the patient-but it affects many people. Patients whether at home or hospital are human beings whose whole mode of existence, in health and sickness, is relational. For instance in some cultures like the Zunis and Koreans, talking of death is taboo, because it might bring sadness or hasten the demise¹⁹. *Ifa*, a divination system and literary corpus among the Yoruba ethnic group of the South western Nigeria, see death is the first and ultimate evil and so sacrifice that is offered to avert death is always very expensive, rigorous and elaborate. Differences in beliefs, values, and the nature of traditional health care practices are of particular importance at the end of life. Clinicians need to respect culture and learn culturally competent strategies to explain a person's illness and health care²⁰.

In Yoruba culture, death is socially constructed being interpreted as “*Iku*” (*meaning: end of existence of a specific period of existence*). It has spiritual, physical and social significance. Yoruba's do not see death as the end of life. It is believed that there is transformation from one form of existence to another. The belief in an afterlife which is a continuation of this life, only in a different setting. Participation in this afterlife is conditional on the nature of one's life and the nature of one's death. However, there are exception in which others do fear death. They see it as the end of a life and beginning into an unknown life. The fears and attitude people have toward death are not instinctive, but rather learned through socialization and cultural vehicles including linguistics using such phrases as “*Iku ko gboogun, omo loogun iku*” (*meaning: death is incurable, to have one's own child is the panacea to death*), arts, and beliefs. This is expressed in the saying “*ai romo bi, opin isoro*” (*meaning: to be barren is the ultimate evil*). This explains the reason why Yoruba will do anything to make sure that he or she gives birth to children because, to be barren is to be conquered by death and it is the ultimate evil. And so a major prayer and desire of every Yoruba is to die and live children behind.

Olugbon lo lai fomo saye

Aresa lo lai fomo saye

Ori mi mo je n lo, lai fomo saye.

Olugbon (the king of *Igbon* town) died without a child

Aresa (the king of *Iresa* town) died without a child

My destiny, do not let me die without a child.

Generally, in Yoruba culture death is defined specifically as end of existence which has both physical and social significance. Data also showed that death is a transition process of joining the ancestors as indicated by a respondent who rendered this in poetically thus:

“ma j’ okun ma j’ ekolo, ohun ti won ba ti nje l’orun ni ki o maa ba won je”

[meaning: eat neither millipede nor worm but join them in whatever menu available in heaven][**Female, Elderly, Respondent 67 years, IDI**].

This is also obvious in burial rituals before and after death. Death is viewed as transition to the world beyond that is the world of ancestors which reinforces the belief in ancestor

worship. This suggests continuity of interaction and social relation spiritually. As a result, Yoruba people like other cultures in Africa believe in reincarnation which is the reason for naming some children at a particular period not far away from the death of elderly people either father or mother, grandfather or grandmother such names as “*Babatunde*” [*Return of the father*] or “*Yetunde*” [*Rebirth of the mother*] respectively while the death of young people especially children attract such names as “*Kokumo*” [*Die no more*], “*Kosoko*” [*No hoe for another burial*] and “*Rotimi*” [*Stay with me*] and so on. The distinction between the two is that the death of elderly people is acceptable and of value while that of young persons is not acceptable and considered as a loss.

Also, data showed that Yoruba perceive death as sacred in which the deceased will cease to interact with the living narrated in poetically by a respondent thus:

“...ewure jelejele, agunta jemojemo, alangba t’o nrin kiri lara ogiri” symbolizing spirit [Male, Elderly, Respondent 62 years, IDI].

Certain animals are associated with news about impending death e.g. owl and dog. Death is both perceived as personal and collective issue. Personal in the sense that it is about the deceased and collective in that it affects the relatives. The grief is also personal in terms of how close individuals are related the deceased and collective in the same manner. Hence, data revealed that post-death conceptions typically involve the integrity and continuity of one’s personal self. The ultimate goal is often an undifferentiated and impersonal oneness with the universe expressed in ancestor worship. In this context it believed that the deceased are alive to the concerns of the living especially one that involves aged parents as rendered by a respondent as follows “*Oku olomo kii sun*” (meaning: *deceased parents would always live to the concerns of their children even in death*).

The above is a popular Yoruba song about kings of *Igbon* and *Iresa* who ruled and died without anyone to assume their throne. It is considered a great loss to die without a child because it is thought to imply that the person’s whole being has been removed from existence; an existence which should have been substantiated if one had children. Therefore, in end of life decision scenarios, the participation of one’s offspring(s) is considered to be critical to the whole process. It is the children especially the first born that are called upon. A practice which is of reverence in the traditional African society and among the elitist who value Yoruba culture. In the foreign Yoruba society, the community, or any member of the extended family has no right to take decision on behalf of the children. Even when they are not around, it is important that people around wait for them. In the case of a person without a child, members of the family take decision on behalf of the sick person. In such instance it is important to have someone appointed as the decision maker for oneself should it happen that one cannot make decisions if some unforeseen and incapacitating health issues should suddenly arise. It helps to take the burden off the community and it also helps the appointed person to know what one’s preferences might be should the need arise that decisions have to be made.

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expressed in ancestor worship derived from a view “*Oku olomo kii sun*” (meaning: deceased person having surviving children plays guidance role at death).

Death is a transition process of joining the ancestors expressed: “*ma j’ okun ma j’ ekolo, ohun ti won ba ti nje l’orun ni ki o maa ba won je*” (meaning: eat neither millipede nor worm but join them in whatever menu is available in heaven). This is also obvious in rituals performed before and after death denoting unknown destination and expectations of continuity of social and spiritual interactions. The Yoruba also believe in reincarnation thus the giving of names like “*Babatunde*” (Daddy has returned) and “*Yetunde*” (Mummy has returned).

Death-*Ikú* according to Bolaji Idowu¹⁸ is the agent the Yoruba believe to be responsible, under commission from Olodumare (God), for killing and removing people from this earth. Hence he is known as *Òjísé Òrun* — Heaven’s Bailiff — and “dying” is described as a “debt” which everyone has to pay, sooner or later. This finality and inevitability is reflected in different adages: *Arùn l’a’wò, a kì ‘wo ikú* — “Sickness can be healed, not death”. An Odu recitation from the belief system of *Òrunmilà* says:

Ikú ibá gb’owó, Owó l’à bá san; Òjísé Òrun kì’gb’owó

If *Ikú* would accept ransom, it is ransom we would have paid; Heaven’s bailiff does not accept ransom¹⁸

The process of death is very important to the Yoruba like other African peoples. Death can take place anywhere any time. Where and how death takes place is important. Death at old age is cherished. It is eminently preferred that this should occur at home. Early death is abhorred and prolonged care encouraged. Peaceful death is also cherished, hence the prayer “*f’owo rori kú*” (meaning: have peaceful death); *ku somo lowo*: (meaning: to die while being held by one’s children). Yoruba culture is death-defying – contemplative and mystical sometimes expressed as a phenomenon of chain of reaction “*Iku awoku*” (meaning: recurrent death among relations); There are deaths that are considered unacceptable such deaths are called *iku buruku* tumultuous death or *iku igbona* (meaning: hot or excruciating death) *iku ojiji* (meaning: sudden death). To die of terminal or long illness is also abominable. It is believed that all these have implication on how the dead person will spend the afterlife.

These attitudes to death are significant in the taking of end of life decisions. For example, in any “bad death”, the dying person is preoccupied with the pains he or she is going through rather than taking decisions regarding property or other issues. This explains the reason why the Yoruba will like to die at home where he/she can pray and discuss with children and other family members. And so the Yoruba prays; *Olorun ma je a tajo gbe sajo* (meaning: May God not let us die on a journey or in a strange land). A terminally ill person will not want to die in a strange land and so he may ask that he be discharged from the hospital and carried to his home land even though the hospital may still want to continue to provide supportive treatments “in hospital” or the hospital is very far from his home.

Yoruba also consider it an abomination to die in the bush. A Yoruba person who is bitten by a snake in the forest and knows that he may die will want to be rushed home so that he does

not die in the bush. According to a Babalawo (Ifa priest), death is sacred and in fact, a corpse, in Yoruba is *oku*, it is not *per se* a dead body but a sacred body²¹, this is why it has to be handled carefully. In Yoruba land, to carry a corpse around from place to place is tantamount to desecration of the sacred body or sacrilege. Such a body is said to have suffered before burial hence they say *won fi oku e rare* (meaning: *the body was made to suffer*). Traditionally, Yoruba also use the term “bush” for “a place other than one’s home” – another town or city or country.

The sayings of a dying person are also held sacrosanct. Some elderly people may warn that their bodies should not be taken to the mortuary as this is a way of making the body to suffer. To sustain the sacredness of the body, it must be buried within two or three days. The sacredness of death is typified in how Yoruba bear names that are death related. Such names include; *Ikujunni lo* (meaning: *death is greater than man*); *Ikumuyi*: (meaning: *death has brought honour*), *Iku saan*, (meaning: *death is merciful*).

Talking about and planning for death is age specific. Whether to inform persons that they are dying depends on their age, nature of disease, duration of illness, disease burden, social aspect of the disease, quality of care and their role in the community. Family members and physicians are also important in the decision making process²². Aged persons and individuals suffering from prolonged incurable ailments may inform relatives about impending death but will still be hopeful of miraculous recovery. Hope plays significant role in illness experience²².

End-of-Life Decision Making

Though a ‘written will’ is a good resource for understanding patient’s wish, in most places in Africa, it is not yet a common practice and tradition prevails. International studies have shown the compelling nature of advance directive or living will on physicians^{23–27}.

In Nigeria, everything derives from communal values, the common good, the social goals, traditional practices, cooperative virtues and social relationship²⁸. Individuals do not exist in a vacuum but within a web of social and cultural relationships. This determines how the individual makes decisions on important issues. In this case, “community-wide agreements form the basis of acceptable moral rules...”²⁹. Respondents were of the view that individuals cannot make decision on their own but rely heavily on the advice of other members of the family. According to a respondent:

No one makes decision by him/herself in this place. Individual decision is the decision of others. Others that is the relative and the entire community where one is raised is affected by individual decisions. In other to ensure that there is orderliness in society individuals cooperate with others. **[Female, Elderly, Respondent, 63 years IDI].**

The trend has not change as observed from the responses of the younger generation where a respondent said thus:

In this culture, nobody makes decision without consulting family members. This is important because decisions are taking together. One cannot live in isolation. This is the tradition. **[Male, Adult, Respondent, 33 years IDI]**.

This suggests that community involvement in decision making is to enhance the quality of decisions in the interest of all so that the outcome would benefit the greatest number of people. The issue is not the individual but the community. Community is a society in which the individual participates in the beliefs, ceremonies, rituals and festivals of that community thus giving such individual sense of belonging³⁰. The community is the basis of existence for the individual. As a result, it is difficult to understand the individual independent of the community. Hence, advance directive is communally implemented. Data showed that the head of family known as “*Olori Ebi*” plays significant and leading role in advance directive with other members of the family contributing. However, males play more active roles in advance directive than females. According to a respondent:

Olori Ebi who is usually a male is the one to chair the meeting when there is need to make decision about end-of-life. Other family members will be present to make input. He will listen to everybody and moderate their discussion to arrive at decision on behalf of all. **[Female, Adult, Respondent, 38 years IDI]**.

The above view was corroborated by elderly male and female respondents. Generally, this practice is rooted in the patriarchy system.

Hierarchy of authority is the basis of implementing traditional advance directive in Yoruba culture like any other African societies. The elders constitute the apex of authority and their views are respected because respect is the basis of African ethics³¹. In fact, disclosure of bad news is usually organized and led by the elders who it is believed have the wisdom to break such news. End-of-Life decision is a major bad news which requires the attention of family members and relatives. This is because at death members of the immediate family of deceased person are answerable to the extended family about how and why their kinsman/woman died. This occurs in a major family meeting preceding funeral arrangement. Sometimes it can lead to dispute if neglect or abuse of the deceased is alleged. Such dispute is usually resolved in the traditional way with apologies and rituals before burial of the deceased can take place.

Cultural Beliefs about end-of-life decision making

Cultural issues in end-of-life have been well discussed in the literature^{32, 2, 28–29, 33}. In general, the stages in the process of dying are culturally determined: how the patient and loved ones feel about an impending death and what they do or do not do to prepare for it or fight against it are mostly determined by the cultural meanings attached to the cause of death. For instance, because chronic diseases like cancer often results in loss of hope, those who are diagnosed with it face not only typical end-of-life issues surrounding the degenerative illnesses and impending death but also issues specific to social aspects of the disease. These issues affect the grieving processes of their loved ones, who usually face the

impending decline and death of a partner, child, parent, or friend who has become a person living with cancer. Such reference on this illness experience is that of Arthur Kleinman in *Illness Narratives*³⁴ which explains that disease is what physicians diagnose but the symptoms experienced by the patient and shared by family is the illness experience. It is this illness experience that shapes the world of the individuals and gives meaning to ones existence as well.

Although, many factors are responsible for premature death, the leading cause of death in young people is accidents and trauma. Cancer, on the other hand, has a long clinical latency period. During the latency period death do not usually begin. Generally, many people cannot accept their diagnosis; hence, it is a period of denial for them. As a result they do not to tell friends, family, and others whereas they do come to terms with impending death within a short period in the final stages of the illness.

This view was captured in a respondents' opinion as indicated in the excerpt below:

Talking about and planning for death is a serious issue in our culture. For the dying to inform others that they are dying depends on several factors namely age of the sick person, duration of the illness, stigmatisation, disease burden, nature of disease and the role of the individual, family members and physicians. **[Male, Elderly, Respondent, 69 years IDI]**

In indigenous societies, there is a religious dimension to end of life decision making. It is believed that this cannot be made by man, but by God. God is believed to be the owner of life and death. To take the life of an individual even with his consent is considered a sacrilege. It is believed that it is not for the caregiver or family to take end of life decision even if the terminally ill person asked for it, no matter the amount of pain the individual might be going through. The stoic endurance of pain is itself an aspect of life that the sick person has to go through. The family and the sick person have to wait for *Olojo* (*God, the owner of one's appointed time of death*).

For adults, the period of transition from health to terminal illness involves continuing to live a normal life and wrapping up personal affairs – settlement of dispute, debts, disposal of properties and so on. For those with children, the process is complicated by the question of how and when to let a child know that their parent is dying. As the inevitability of decline and death becomes obvious, making a “good death” and providing for the future of children becomes increasingly important – some do hand over their families to close relatives. Respondents were of the view that there are some cultural beliefs about chronic infectious diseases like HIV, Lassa fever and Ebola virus. According to a respondent:

Many people are yet to come to terms with the fact about chronic infectious diseases because of their nature either because they are difficult to cure like Lassa fever or incurable like HIV and Ebola. **[Female, Adult, Respondent, 26 years IDI].**

This view was corroborated by elderly respondents who shared their concern about the stigma associated with such disease as they are taken into consideration while making marriage choices and in other relationships in society.

Factors Influencing End-of-Life Decision Making

Certain factors play prominent role in discussions of end-of-life decision making in Africa, Nigeria inclusive. For instance, beliefs about the meaning of life, death and the hereafter are a major consideration in Africa. It has been argued that culture fundamentally shapes how individuals make meaning of illness, suffering, and dying¹⁰. Africans perceive illness from four major areas namely natural, supernatural, preternatural^{31–32, 35}, and lately, hereditary³⁶. These perspectives play significant roles in decision making about choice of therapy and acceptance of diagnosis.

Although limited data exist on end-of-life decision making in Africa, studies among African-Americans showed that they are less likely as white patients to want discontinuity of treatment^{36–38}. The world view of the people of Africa promotes such factors as funerary rituals and strategies for body disposal, the physical and symbolic boundaries between the worlds of the living and the dead, the perceived role of the dead in the affairs of the living, the degree of social stigma attached to those dying, dead, or bereaved, death prevention and avoidance as a social goal, the death socialization for children (including death themes in children's stories and games) and their involvement in funerary rituals, the taboo status of the topic of death and dying in everyday discourse, the language used regarding death, and the nature and conception of death in the arts. Africans are ritualistic and they apply this to every aspect of life³⁹.

Perception of illness determines what decision will be made by patients and families. If a disease is perceived to be due to attack of an enemy, the patient and families will not be positive in end of life decision rather they will choose to go for alternative therapy. It is a common knowledge that medical practitioners in Africa who often share the worldview of their patients will sometimes tell them *e lo towo ile bo* (meaning: go and use the traditional therapy). This is a controversial referral system in western medical practice that has no official and ethical backing. This happens especially when the illness is said to be somatoform: a disease condition that has been found to be un-diagnosable^{40–41}.

Studies have shown that African American patients are more likely to want aggressive medical care at the end of life and are less likely to have Do Not-Resuscitate-Order (DNR) orders or Advanced Care Directives (ACDs) than European American patients^{42–43}. Although African-Americans represent 12.3% of the U.S. population, they comprise only 8% of patients enrolled in hospices³⁰. This suggests that people of African descent may perceive illness from the African worldview and may not surrender to death easily rather they may choose alternative therapy. This choice is influenced by the social and cultural milieu of the patient.

Social and Cultural Dynamics of End-of-Life Decision Making

To discuss end-of-life decision making in Nigeria, it is pertinent to understand the social and cultural dynamics of the issue⁴⁴. This can be understood within the context of kinship, family and marriage systems, socialization process, belief system, and political system, mode of production, ritual, and taboo and inheritance practices and cultural factors in end-

of-life decision making of which the patient is at the center of everything. Social institutions and cultural practices as a derivative of the social system (society) interact to influence the individual family members (kin group) and the health care system. The patient is at the center of decision making which most of the time produce negative outcomes. Figure 1 below shows how social institutions and cultural practices impact on kin group and the health care system producing an outcome for the patient. The figure shows the dynamics of social and cultural factors in end-of-life decision making of which the patient is at the center of everything.

Social institutions and cultural practices as a derivative of the social system (society) interact to influence the individual family members (kin group) and the health care system. Both the kin group and the health care system interact to make decision about patient's condition resulting in two outcomes of peaceful death or painful death. However, the process is not as simple in that both the cultural and social variables play a significant role in how the kin group and the health care system behave in end-of-life decision making. For instance, kinship is the organizing principle of society. It stipulates relationship, marriage choices and family patterns. It is the basis of economic, religious and political organization as well as social control. Therefore, it will be difficult to understand who should be involved in end-of-life decision making about a patient without understanding the kinship system. So also, cultural practices as earlier explained must be understood in relation to the individual patient. Rituals, for instance, provide some security and some supra-individual means for taking action against the fact for all that symbolically matters to humane⁴⁵.

A study among the Dinka people (an ethnic group inhabiting the Bahr el Ghazal region of the Nile basin in South Sudan) reports a ritual procedure associated with healing saying: "The patient is led to focus upon one among possibly many latent elements in his experience or the experience of his kin which give rise equally to bodily sickness and uneasy conscience. Confession, by the wrongful acts of the self are made present to it and to the community, is therefore often part of Dinka way of dealing with sickness. When the effective condition is imagined, both its grounds and reasons become manifest not only to the individual but also to those who care for him, and the individual's experience is represented in a form in which it can be publicly understood and shared"⁴⁶

The complexity of social existence needs to be understood in respect of individual patient to be able to provide adequate care. It has been argued that "misrepresentation caused by lack of cultural sensitivity and skills can lead to unwanted or inappropriate clinical outcomes and poor interaction with patients and their families at critical junctures as life comes to a close"⁹⁻¹⁰. Sometimes this can lead to litigation which may disrupt physician/patient relationship. Concluding their work, Meisel *et. al.*,⁴⁷ argued that legal myths about end-of-life care can undermine good care and ethical medical practice. For them, sometimes ethics, clinical judgment, and the law may conflict. Patients (or families) and physicians can find themselves considering clinical actions that are ethically appropriate, but raise legal concerns. They identified seven major legal myths regarding end-of-life care⁴⁸. However, they felt that many legal barriers to end-of-life care are more mythical than real, but that sometimes there is a grain of truth. Hence, they advised that physicians must know the law of the state in which they practice. This equally applies in Africa. Physician must understand

the social and cultural terrain of where they are working. This therefore, suggests a major role for ethics committee in order to ensure mutual relationship between physicians and patients (or families) for an enhanced successful transmission to end-of-life.

The Role of Ethics Committee

Although Africa is a political entity, the different countries within it follow their own practices and customs. It is important to, first of all, make it clear that most ethics committees in Africa are concerned only with research¹; they are not committees that one can call on when dealing with a dilemma in practice. A few hospitals in some countries are trying to put in place committees that can be consulted for clinical issues. In many hospitals, ethical dilemmas are addressed by ad hoc committees of hospital staff which are not formally inaugurated as clinical ethics committees. As a result, little or nothing is known about their activities despite their prevalence in Africa. No systematic information is available about their structure and function. However, there is no denial of the fact that ethical problems exist in the care of patients in Africa. In this context, there is need to establish ethics committee to respond to the needs of people needing end-of-life care. Ethics committee should put in place Standard Operating Procedure (SOP).

Physicians have always based their reputation on the doctor-patient relationship and therefore their concern is to ensure that patients are protected⁴⁹. According to Tschudin⁵⁰ “medical ethics has mainly been defined within the four principles of beneficence, non-maleficence, justice and autonomy, thus perhaps creating a climate of paternalism that has tended to exclude other views and other frameworks”. Being right in medical terms is one thing, but being right in moral terms is another. In Africa, Nigeria inclusive bioethics is an evolving field in the practice of medicine, it still takes the paternalistic posture. Studies^{51–53} have shown that two factors as critical problems are responsible for this. First the level of literacy is still low and as a result majority of the people do not understand their rights. Second, due to ignorance pervading the society physicians and other health workers see themselves as knowing everything with little regard for patient’s opinion. Third, the current practice of health care delivery in Africa does not give room for accountability for reasonableness in priority setting, meaning no opportunity is available for the public to make input to health care delivery.

As a result, health care delivery in most places is at variance with the needs of the patients and families leading to unmet needs of the public and communication breakdown. Fourth, medical education still follows the classical pattern in which doctors are given elitist training thereby making it difficult for them to work with rural people or communicate in local languages whereas language is a vehicle for expressing cultural norms and values. This hinders, to a great extent, physician/patient relationship and deprives the majority of people easy access to adequate health care delivery which is mostly urban based. Fifth, end-of-life decision making is not yet a major aspect of health care delivery in Africa due to lack of sophisticated life sustaining equipment. Even where there is equipment, they are faced with

¹For instance, the main objective of the Nigeria’s national ethics review system as contained in article 1.2 of the National Ethics and Operational Guidelines for Research of Human Subjects “is to promote ethics in scientific research, monitor and ensure compliance with the relevant legislations, regulations, ethical guidelines and standards.”

serious problem of resource allocation due to enormous number of patients in need of the service. Hence, distribution of such resources is unfair because most of the time allocation is based on favouritism or reserved for the powerful people in the society^{49, 51–53}. All these constitute a problem requiring the need for effective clinical ethics committee in Africa. Ethics committee should address strategies for resource allocation in the SOP.

It has been argued that “end-of-life issues have always been at the heart of the bioethics movement and have been the catalyst for most ethics committee consultations. Without exception, the early landmark cases that led to the creation of ethics committees were concerned with the proper care and appropriate treatment of seriously ill and dying patients”⁴⁷. However, most studies on ethics committees have found that, to a large extent, what triggers requests for consultations are ethical dilemma, autonomy, conflict and moral issues^{48–50, 54–55} whereas there is a lack of consensus regarding the need for ethics committee^{56–57}. It was argued that there should be agreement on standards for ‘auditing bioethical decisions’ which would help institutions better respond to ethical concerns and play important role in enhancing patient’s autonomy⁵⁸.

There is need to identify appropriate roles for ethics committee if it is to meet the need of the people. In doing this it should be realized that African ethics is communitarian in which community value is the first consideration which influences individual autonomy. Scholars like Wiredu Kwasi⁵⁹, Gyekye Kwame⁶⁰, Masolo Dismas⁶¹ stress the fact that traditional African culture is communitarian. A communitarian society is one in which individuality is regarded as a construct out of the community. This communitarianism fosters union between the community and the individual of which the individual derives their identity. That sense of belonging is very crucial for building trust in times of resolving conflicts in the community. As a result, ethics committee needs not only to play mediation role but also engage in policy issues that will enhance proper functioning of ethics committees as agent of change, advocacy and accountability. Hence, ethics committees should perform the following roles.

First, ethics committee should educate physicians and health workers on the need to focus on end-of-life issues as an aspect of care. It has, however, been suggested that there is a need to develop guidelines for ethics education⁶². The problem is that most health workers do not know how to manage end-of-life issues involved and therefore they pay lip service to it and grieve bereaved families more. Issues such as advance care directive practice should be understood and managed appropriately. This can only be possible if health workers are properly trained and made to understand the cultural issues involved in such issues.

Second, they need to engage the public in order to catalog the needs of the patients and families to be able to advocate for policy in this regard. Most of the time health care policies are at variance with the needs of the patients and families because nobody cares about what they really need as opposed to what is provided. Therefore, public engagement will fill the gap by eliciting information from the public about how they think end-of-life issues should be addressed in the hospitals. For instance, Breslin et. al.,⁶³ have demonstrated the role of top 10 ethical issues in Canada. Such exercise will be appropriate for prioritizing end-of-life issues in Africa.

Third, ethics committees in Africa need to address the issue of resource allocation so that there will be fairness in allocating the few available resources. There will be mandate guiding this resource allocation which would be enforced by the institutional authority. Ethics committee would ensure that relevant criteria are set out for allocating resources and that the criteria are acceptable to the stakeholders. It should also ensure that there is modality for modification of such criteria through feedback from the public and promote leadership for the enforcement of the procedure. This will enhance accountability for reasonableness in resource allocation and promote priority setting.

Fourth, ethics committees need to engage in advocacy to change the current medical curriculum in order to accommodate theoretical and practical ethical modules. This is still a major gap in medical education across the continent.

Finally, ethics committees should mediate in conflict and dilemma situations. Studies have shown that ethics consultation seems to be useful in resolving conflicts that may be inappropriately prolonging futile or perceived to be beneficial^{64–65}.

In summary, ethics committees should:

- Ensure that clinician receives cultural background and understanding of family and patient's explanatory model about illness, expectations about care, hopes for the future, and views regarding death
- Increase the visibility of the problem of end-of-life decision making.
- Conduct research on the status of end-of-life decision management both within the hospital and at the community in order to understand how cultural issues can be addressed.
- Promote the need for, and acceptance of, an acceptable advance care directive.
- Model the concept of an interdisciplinary approach to the problem of end-of-life decision making.
- Advance professional knowledge, beliefs, and competence in handling end-of-life issues.
- Ensure patient education regarding advance care directive to ensure the communitarian approach to care of patient and enhance the family role and to promote patient expectation for a peaceful death.
- Lead institutional efforts to understand and eliminate obstacles to successful practice of end-of-life decision making.

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Figure 1.
The Social Dynamics of End-of-Life Decision Making