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# End-of-Life Decisions: Ethics, Cultural Norms, and Resource Management

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## Summary

The technological advances of medicine in recent decades have made it possible to extend the life of critically ill patients even in resource poor countries in Sub-Saharan Africa. Modern biomedical technology restores some patients to health but also allows others to live in a severely disabled stage and prolongs the dying process for others. The increasing role of technology in prolonging life in severely debilitated patients, with no possibility of restoring health, is on a collision course with moral norms in many societies. Patients have a limited say on when to initiate these complex treatments and when to stop them in the absence of advance directives or living wills. Such directives

may not be easily accommodated by African cultures where death is accepted as the will of God and rarely discussed until it arrives. To sustain the 'life' of a terminally ill individual with no chance of recovery on a machine at a high cost to an impoverished family and community could be considered socially unjustifiable. The right of the patient to decline treatment when the quality of life becomes untenable continues to meet resistance from religious doctrine and cultural objections. These deep ethical and philosophical questions with no easy answers may continue to haunt individuals, families, institutions and communities for generations to come.

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## Introduction

Managing terminally ill patients on life support has remained controversial and continues to be widely debated by philosophers, biomedical ethicists, medico-legal experts, politicians and communities. A moral principle recognized in biomedical ethics is to relieve the suffering of a patient as well as lessen or prevent harm (1). The question arises as to whether this principle applies to terminally ill patients hooked to life support machines and wish to shorten their suffering. In spite of constitutionally enshrined individual rights in civilized societies, religious doctrine and cultural norms often override individual decisions on how to end their lives when terminally sick. The modern African has also been caught in the crossroads of western religious doctrine and medico-legal laws that often come into conflict with traditional norms on how to manage death at the end of life.

End-of-life issues in African communities are resolved using accepted traditional cultural values of the tribe. An individual legal right to die as perceived in western biomedical ethics is alien to many African cultures but is often imposed through adopted colonial laws. The Scottish psychologist John Beloff (2) argues that if we conceive of the right to die as being like most other rights then we should, as in all these other cases, have a right to die and be able to call upon the resources of the community to help us fulfill that right. The complexity and di-

versity of human interpretations of ethical norms would render this logic rather simplistic and probably unrealistic. Health care workers continue to search for answers to questions like how long a brain-dead patient should be kept on a machine. How long should life support be continued in a terminally sick octogenarian? These questions, which touch on quality of life and allocation of resources, may prove difficult to resolve as we grapple with deeply rooted religious and sanctity of life philosophies. The present paper will analyze the role and ethics of contemporary health care decision making in the determination of death especially in resource poor countries.

## Historical Trends

When controversies associated with divisive public debates arise, there is usually a tendency to review historical perspectives to gain insights into the issues. The "right to die" has been debated extensively in the last four decades with court cases catalyzing intense media coverage and public debate (3). The Terri Chiavo and Nancy Cruzan highly publicized cases have challenged the public to re-examine their feelings about this emotionally packed issue. Paradoxically, the courts in developed countries like the United States have largely left questions about doctor assisted death and the right to die to the individual states as public opinion remains divided over these issues. The largely inherited post-colonial laws on biomedical

ethics in many sub-Saharan African countries have not performed any better than their western counterparts as evidenced in clinical practice today. A look at historical aspects of the right to die might put this issue in perspective.

In the controversy over the right to die, expert debate has turned back to ancient Greece and Rome. According to Gourevitch (4) many people in ancient Greece and Rome preferred voluntary death to endless agony, and the practice was actually encouraged by the doctors who provided patients with the poisons they demanded. A minority of doctors who belonged to the Hippocratic School pledging never to give a deadly drug to anybody when asked for it nor suggest such use opposed the practice (4). It is widely held that the ascent of Christianity with its belief in the sanctity of life strengthened the Hippocratic position on euthanasia—leading to the consistent opposition to euthanasia among European doctors in the middle ages. Both the proponents and opponents of euthanasia seem to have used these historical developments to base their arguments for 20th and 21st century debates on the right to die and euthanasia.

Basing debates about euthanasia on ancient Greece and Rome would be of limited relevance in helping to understand contemporary issues of euthanasia faced by modern societies. Ancient Greece and Rome were pagan societies with no well-developed medical professions, glorified slavery, and had cultural values that celebrated aristocratic virtues (4). These irreconcilable differences between modern and ancient cultures would minimize their usefulness in illuminating contemporary discussions on end-of-life issues. The proper historical context should perhaps dwell on discussions about euthanasia in the 19th and early 20th century Europe and the United States, as they would be in a position to shed light on current debates for and against euthanasia.

The question of involuntary euthanasia (in which the patient is killed against their wishes) featured prominently in the early part of 20th century Germany. A 1920 book written by a professor of psychiatry and a professor of law in Germany argued that patients who ask for “death assistance” should, under very carefully controlled conditions, be able to obtain it from a doctor” (5). This book helped support involuntary euthanasia by Nazi Germany during which the sick and disabled were subjected to widespread “mercy killing” at the outbreak of the second world war in 1939. In 1935, the Euthanasia Society of

England was formed by a group of prominent doctors to promote euthanasia (4,5). However, attempts to legalize it failed as the British House of Lords eventually rejected the bill in 1936. The defeat of the bill, the advent of the Second World War, the Nazi atrocities, as well as the role Nazi doctors played in genocide helped quell the debate on euthanasia but did not completely eliminate it. The United States, where individual right to autonomy is protected by the constitution, has featured prominently in this debate in the last 40 years as exemplified by media coverage of high profile court cases.

The deeply rooted bans on assisted suicide have been re-examined as a response to public interest and generally reaffirmed in recent years in the United States. In 1936, the Gallup organization asked Americans whether they favored “mercy deaths under government supervision for hopeless invalids”, 45% said they did not but 38% said they did (3, p.3). Notwithstanding these developments, patients and their families continue to demand increasing control over their health and finalization of life as this control comes increasingly under threat from modern biomedical technology (6, 3). Since death, in the developed world, is now most likely at the end of a long life, the views and values that older people express in relation to these issues have been considered and appropriate laws passed within the framework of existing biomedical ethics. End-of-Life issues are not salient in the policy making process in sub-Saharan African countries and hardly attract media attention.

## Critical Analysis

It is now possible to decide how one wants to die when the time comes within the prevailing legal statutes in most developed societies. Advance directives refer to statements given before decisional incapacity, regarding how an individual wants medical decisions to be made if he or she were to become incapacitated (7). However, the principle of basic human rights that protect specific liberties and interests of individuals stops here. The law, religious doctrine, and public opinion seem to have come to a crossroads on the issue of the termination of life by doctor assistance from patient requests. Tribal attitudes and accepted norms in handling end of life issues inevitably come into conflict with western religious doctrine in many communities in developing countries. The issue of euthanasia in all its forms remains alien in the African

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context, but delaying the death of terminally ill patients with the aid of modern life-support machines with no hope of returning them to former health and at great expense would probably appear pointless to the African mind.

Issues like whether to tube feed a dying terminally ill patient, or when to switch off the ventilator in a brain-dead patient, will continue to be debated for a long time to come. As Dickinson (3) eloquently states, "advance directives allow an individual to make decisions about care at the end of life, yet court cases and religious doctrine examine the individual's right to autonomous decision making in opposition to preserving the sanctity of life" (p. 5). Religious doctrine and cultural values will continue to influence the individual's right to self-determination in end-of-life issues. The judicial system, which should respect and uphold the individual's rights to self-autonomy, has a tendency to become indecisive in the face of adversity. The role of the doctor in end-of-life decisions will probably remain uncertain in the face of such adversity and the inability of the legal system and medical bioethics to provide a unified guidance.

The maxim, "primum non nocere" is often quoted in the delivery of health care. The maxim which means 'first do no harm' has perhaps inaccurately been conceived to be part of the Hippocratic Oath as it is not expressed explicitly in the oath per se (1). Two thousand years is a long time and historical facts inevitably become subject to intentional or inadvertent distortions in the process of passing on information. Nevertheless, the Hippocratic Oath irrespective of its origins has emerged as the pillar of medical ethics that ensures no harm is done to patients and that their welfare remains a priority in the delivery of health care services. Cartwright (8) posits that changes in medical technology that allows life to be extended beyond anything previously possible raise new and difficult challenges in health care decision making—especially when coupled with ageing populations. The interpretations and application of the principles of nonmaleficence (ensuring no harm) and beneficence (prioritizing patient welfare), seem to have generated much debate in the scholarly biomedical ethics literature as well as among the public.

The current controversies on nonmaleficence and beneficence can be illustrated by the concept of futile or pointless treatments. In medical practice, the notion of not causing harm is harnessed by the provision of due care

and should distinguish between optional and obligatory treatments (1). For example, the benefit of sustaining the life of a terminally ill patient with cancer could be brought into question. Robichaux and Clark (9) stated, "The transition from curative to end-of-life care in the intensive care unit is often fraught with ambiguity and anguish" (p.480). Questioning the goals of care and active resistance to the "technological imperative" becomes necessary as situations where the provision of all therapies and interventions are not anticipated to lead to an acceptable quality of life (9). Unreasonable demands are often placed on a critical care doctor or nurse to continue sustaining the life of an obviously terminal patient with advanced disease. It can be argued that such a questionable approach would not be ethically justifiable in resource poor healthcare environments where impoverished families have to often pay the intensive care bills.

Health care workers sometimes perform a resuscitative procedure not because it would improve the quality of life of the patient but because of concerns about actions that could conflict with accepted biomedical ethics. According to Beauchamp and Childress (1), biomedical ethics based on the principles of nonmaleficence and beneficence favor providing life sustenance to the sick and injured, occasionally violate patients' interests. What may often be ignored by this principle is that the burdens entailed by such treatments could far outweigh the benefits. It can be argued that the principle of nonmaleficence (ensuring no harm) is often violated by overzealous and unnecessary application of the principle of beneficence (prioritizing patient welfare).. This raises the question as to how non-beneficial and ineffectual medical treatments could be assessed in health care environments where advance directives are non-existent or not practiced due to cultural constraints.

Conversations on end-of life-issues should be conducted early in spite of their obvious discomfort to the family, patient, and doctor. Barriers to end-of life discussions have been attributed to health care professionals in the past, but recent evidence indicates patients often avoid discussions on the topic until circumstances dictate the necessity (10,11). The mental and physical incapacitation patients experience at the end of life prevents them from making important decisions about medical treatments. Such patients end up on unaffordable life support systems against the better judgment of the health care provider. To maintain control over their decisions on ter-

minal care, there is a need to encourage patients to document their preferences for treatments before they become incapacitated. Such documents, though often contested on cultural or religious grounds, would nevertheless ease decision making by the health care provider as well as immediate family members.

Most patients have an aversion to talking about impending death and discussions with a terminally ill patient on eminent death would be considered anathema in a traditional tribal setting. Yet, there is a need to make end-of-life conversations a routine in the early stages of an illness with a poor prognosis and encourage the documentation of a form of advance directives. In order to conduct such sensitive conversations with sick individuals and their families, special communication skills are needed. Doctors in training, who are often, delegated these unpleasant duties, lack competence in this key area. A trained counselor or the consultant in charge of the treatment facility would be more suitable for such an undertaking.

## Summary

Quality of life judgments in health care settings remain contentious and continue to fuel the debate on when to withhold or withdraw treatment—if at all. There is no doubt that the appropriate stewardship of resources is an important consideration when making decisions on costly, lengthy, or invasive procedures that do not restore patients to former health. The economic concept of cost-benefit analysis in medical care tends to generate heated debates because of moral objections to withholding care to save costs. Yet, it would be inappropriate in some circumstances especially in the midst of poverty to disregard the potential costs to the individual patient, family, and society.

The right of the patient to self-autonomy often comes into conflict with religious and cultural views on end-of-life decisions. Worries about the opinion of the church or community can cause families and proxies to balk at the last moment in carrying out explicitly expressed and documented advance directives. The wishes of the patient on how to end their lives when its quality becomes untenable are often ignored. Maintaining patient comfort in their final days is appropriate, keeping them alive for long periods of time with no hope of recovery through the use of biomedical technology may not. A doctor may want to keep a terminally ill patient alive in line with the principle of non-maleficence. However, that may not be what

the patient desires nor does it improve the quality of life.

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